

The focus on life-prolonging anticancer treatment hampers shared decision-making in people with advanced cancer: A qualitative embedded multiple-case study

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Abstract

Background: Implementing shared decision-making in oncology practice is often limited, particularly integrating the patient's context into decision-making. To improve this, we conducted a quality improvement project, *CONtext*. *CONtext* attempts to accomplish this by: (1) Integrating the patient's context into shared decision-making during consultation with the medical oncologist; (2) Actively involving the GP and case manager (a specialized oncology nurse), who often have knowledge about the patient's context, and; (3) Giving the person with advanced cancer a time-out period of up to 2 weeks to consider and discuss treatment options with others, including close family and friends.

Aim: To explore how persons with advanced cancer and their involved professionals experienced shared decision-making after the introduction of *CONtext*.

Design: A qualitative embedded multiple-case study using in-depth interviews analysed with inductive content analysis.

Participants: A purposive sample of 14 cases, each case consisting of a patient with advanced cancer and ideally their medical oncologist, case manager, and GP.

Results: Four themes were identified: shared decision-making is a dynamic and continuous process (1), in which the medical oncologist's treatment recommendation is central (2), fuelled by the patients' experience of not having a choice (3), and integrating the patient's context into shared decision-making was considered important but hampered (4), for example, by the association with the terminal phase.

Conclusions: The prevailing tendency among medical oncologists and persons with advanced cancer to prioritize life-prolonging anticancer treatments restricts the potential for shared decision-making. This undermines integrating individual context into decision-making, a critical aspect of the palliative care continuum.

Keywords

Shared decision-making, palliative care, medical oncology, communication, professional-patient relations, qualitative research

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Key Statements

What is already known about the topic?

- Shared decision-making is the preferred model for making complex medical decisions and has shown to be beneficial, for example, by improving patient satisfaction.
- Shared decision-making facilitates people with advanced cancer and professionals in complex medical decision-making.
- Despite its beneficial effects, implementation of shared decision-making, particularly the integration of the patient's context in decision-making, is limited in advanced cancer treatment, while this should be central within the palliative care continuum.

What this paper adds?

- Interviewees considered shared decision-making a dynamic and continuous process in which the medical oncologist's treatment recommendation is central; persons with advanced cancer experienced not having a choice.
- Most interviewees found integrating the patient's context into decision-making desirable. However, this is hampered by, for example, the association of discussing the patient's context with the terminal phase and the patient's insufficient awareness that talking about the patient's context with the medical oncologist is relevant.
- Medical oncologists and persons with advanced cancer tend to focus almost exclusively on life-prolonging anticancer treatment options. This hampers integrating the person's context into decision-making and, therefore, limits integrating oncology with palliative care.

Implications for practice, theory, or policy

- Palliative care professionals need to recognize how a strong focus on life-prolonging anticancer treatments among persons with advanced cancer and medical oncologists hinders integrating oncology with palliative care.
- Improving shared decision-making requires more exploration and intervention on a micro, meso, and macro level; the perspective and attitude of patients and healthcare professionals must change (micro); the collaboration between professionals must be addressed to the level of regional agreements (meso); and decartmentalization of healthcare and funding is necessary (macro).
- Patients, informal caregivers, healthcare professionals, scientists, and politicians should be actively involved in addressing this.

Background

People with advanced cancer often face complex medical decisions, needing to weigh the benefits and harms of anticancer treatment on their quality of life.¹⁻⁴ As these trade-offs are subjective and can significantly impact lives, understanding the person's context, as defined by Weiner⁵ (Box 1), is paramount.⁶ Shared decision-making has therefore gained momentum as a strategy to incorporate the person's context into medical decision-making.⁷ Shared decision-making has become even more relevant in recent years, as the expansion of treatment options for advanced cancer has increased the complexity of medical and shared decision-making.⁸ Nevertheless, studies show that the application of shared decision-making in daily oncology practice lags behind.⁹⁻¹² People with advanced cancer often participate less in decision-making than they would prefer, which may negatively impact their quality of life, even though they desire more say over decisions affecting it.^{1,13,14}

To improve shared decision-making for people with advanced cancer, we conducted a quality improvement project *CONtext* to combine patients' expertise of their

own context with medical oncologists' expertise on choices and treatment options. *CONtext* attempts to accomplish this by three core elements: (1) Integrating the patient's context into shared decision-making during consultation with the medical oncologist; (2) Involving the GP and case manager (a specialized oncology nurse), who often have a substantial knowledge about the patient's context,¹⁵⁻¹⁸ and; (3) Giving the person with advanced cancer a time-out period of up to 2 weeks (a time-out) to consider and discuss treatment options with others, including close family and friends. For a full description, see Box 1.

CONtext's design was guided by existing shared decision-making models, being mainly inspired by the exploration of the patient's context in the elements of "team talk" from Elwyn et al.⁷ and "preparation talk" from van de Pol et al.¹⁹ Since the onset of *CONtext*, many other decision-making models have been described to strengthen the likelihood of person-centred care,²⁰ including goal-based shared decision-making.²¹ *CONtext* had similar aims, for example, integrating the patients' context including goals, into decision-making. In addition to implementing *CONtext*, we aimed to understand how this

Box 1. The *CONtext*-method to improve implementation of shared decision-making.

CONtext, a quality improvement project, was conducted at the Medical Oncology department of the Radboudumc in Nijmegen, the Netherlands. The project was based on collaboration between: the Centre for Oncology; the Department of Medical Oncology; the Department of Anaesthesiology, Pain and Palliative Medicine; the Department of Primary and Community Care, and; the Department of Geriatrics. *CONtext* was financed by the National Health Care Institute.

CONtext's aim is to make patients and healthcare professionals aware of the inextricable linkage between the patient's context and medical choices and treatment options within shared decision-making. We used Weiner's definition of context⁵: "What is relevant to the immediate clinical problem from across the spectrum of a patient's life, including their cognitive abilities, emotional state, cultural background, spiritual beliefs, economic situation, access to care, social support, caretaker responsibilities, attitude to their illness, and relationship with healthcare providers."

CONtext targets all persons with advanced cancer and "no" as answer to the Surprise Question: Would I be surprised if this patient were to die in the next 12 months?.

CONtext is integrated into five healthcare chains with appointed case managers: gastroenterological oncology, gynaecological oncology, melanomas, urological oncology, and breast oncology.

CONtext introduces shared decision-making for those patients where a decision was needed for their cancer treatment. It explicitly focuses on the care process in the consultation room. It offers patients opportunities to discuss their context (including values and wishes) and decide on their treatment together with the medical oncologist (in training) and case manager. It also offers healthcare professionals the tools needed to optimize this conversation with their patients. Moreover, it gives patients time—up to 2 weeks—to consider and discuss treatment options with their GP and family and close friends. Medical oncologists contact the patient's GP and provide relevant content to assist the GP when having these discussions.

Medical oncologists (in training) and case managers participated in shared decision-making training courses. Almost all of them participated in two small-group workshops, and were then invited to join an eLearning course on shared decision-making developed by the National Cancer Patient Federation. Besides, practical observations from the consultation room with group feedback sessions were made by a member of the Support team "Radboudumc Person-centred Care of the Process Improvement and Implementation" advisory group.

The core elements of *CONtext* included:

- Discussing the choices and treatment options considering the patient's context in an outpatient consultation with the medical oncologist (in training) and case manager (team and option talk).
- Informing and inviting the GP, if agreed by the patient, to remain actively involved in the patient's care trajectory and to help their patient with decision-making.
- Striving for a time-out period of 2 weeks after the first consultation for the patient to consider and discuss treatment options with their GP and loved ones before making a medical decision. The case manager contacts the patient during these 2 weeks to support them in the shared decision-making process.
- Making the final decision about treatment in an outpatient consultation together with the medical oncologist (in training) and the case manager (decision talk).
- More information (in Dutch): <https://www.radboudumc.nl/centrum-voor-oncologie/context>

complex and multifaceted intervention could be further aligned with everyday oncology practice.

In this study, we therefore explored how people with advanced cancer, their medical oncologists, case managers, and GPs experienced shared decision-making after the introduction of *CONtext*.

Methods

Study design

We conducted a qualitative embedded multiple-case study.²² *CONtext* aims to improve the integration of patients' context into shared decision-making at a Dutch oncology outpatient clinic. The term "embedded" refers to the inclusion of multiple subunits within each case. Each case comprised multiple subunits, namely the person with advanced cancer and their medical oncologist, case manager, and GP. This embedded design allowed for data triangulation and provided a comprehensive view of the shared decision-making process. We included

multiple cases to compare and contrast experiences. This design enabled cross-case analysis, enriching the data, and offering a more comprehensive understanding of shared decision-making after the introduction of *CONtext* in oncology care. Reporting complied with the consolidated criteria for reporting qualitative research (COREQ).²³

Setting

The implementation of *CONtext* (2019–2020) occurred within the medical oncology department of a Dutch University Medical Center.

Study population

To gain comprehensive insights, we included people who participated in *CONtext* (see also Box 1). These were individuals diagnosed with advanced cancer (aged ≥ 18), and with "no" as answer to the Surprise Question. The origins of cancer included gastroenterological, gynaecological, melanoma, urological, and breast cancer. Moreover, these

individuals visited the oncology outpatient clinic to discuss their scan results and treatment decisions with their medical oncologist. Exclusion criteria were poor Dutch language fluency and an inability to answer interview questions. Additionally, of each participating patient we invited their respective medical oncologist, case manager, and GP to participate.

Sampling the case

Since we considered patient characteristics key determinants for case variety, case composition began with patient selection. To ensure diversity between cases, we purposively selected and invited patients based on personal characteristics such as age, gender, education level, and cancer type, as well as the variety of professionals involved in their care. To ensure that the data collected is sufficient and robust enough to adequately answer our research question and achieve the study's objective, we assessed information power in our study. This assessment considered factors such as study aim, sample specificity, use of established theory, quality of dialogue, and analysis strategy.²⁴ We estimated the need for 12 to 15 cases to ensure information power.

Sampling within the case

We invited each patient's medical oncologist, case manager, and GP to participate in interviews. Consequently, the maximum number of interviews could reach up to 60 (four subunits within each case \times 15 cases). However, the actual number of interviews may be lower than this maximum because some patients might share the same healthcare professionals, leading to multiple interviews with the same professional, and some healthcare professionals may decline participation.

Recruitment

Patients who met the inclusion criteria described under study population were eligible. Eligible patients were approached by their medical oncologist or case manager to grant permission for one of the researchers to contact them for an interview. Upon agreement, the researcher provided both verbal and written information about the study. One week later, the researcher contacted the patient to confirm participation and schedule the interview. To minimize recall bias, we aimed to include patients no later than 2 weeks after they made a treatment decision and to interview them within 6–12 weeks. Before the interview, the patient gave informed consent, including explicit permission for the researcher to invite their medical oncologist, case manager, and GP to participate. These professionals also gave informed consent before their interviews.

Study procedure and data collection

Between December 2019 and July 2020, we conducted in-depth interviews guided by a topic guide. We used in-depth interviews to explore participants' experiences with shared decision-making after the introduction of *CONtext*. This qualitative approach allowed us to gain a deeper understanding of their experiences. We developed an interview guide with open-ended questions. Topics were based on the *CONtext*-method's elements and initial implementation experiences with this procedure, relevant issues on shared decision-making extracted from the literature, and discussions within the research team. The key topics that the interview guide covered were: (1) Experiences with the decision-making process; (2) Participant's role in this process; (3) Roles of other actors in this process; (4) Expectations regarding the process vs. reality; (5) Knowledge and perceptions of the *CONtext*-method (see Supplemental File 1 for the complete interview guide).

When starting the interview, interviewees were informed about the background and occupation of the interviewers. DK, AS, and SM conducted in-depth interviews in Dutch. Initially, only professionals were given a choice between face-to-face and telephone interviews; patient interviews were face-to-face. Later, due to the COVID-19 pandemic, we only conducted telephone interviews with the remaining interviewees. Interviews were audiotaped, transcribed verbatim, and anonymized. We made field notes to isolate personal biases during and after each interview. Interview summaries were sent to the interviewees as a "member check."²⁵ At the end of each interview, we verified the demographic characteristics of all participants and the patients' medical information. Data were stored in Castor EDC.

Data collection ceased after including 14 cases, as we determined that we had achieved sufficient information power. This determination was based on preliminary results, which were discussed in weekly meetings involving DK, AS, DE, MP, and YE.

Data analysis

Analysis started after the first patient interview. DK and AS independently coded the first transcript, applying inductive content analysis, and aiming to minimize subjectivity by coding as closely as possible to the interviewees' words. Codes were compared and discussed until consensus was reached. If no consensus was reached, DE, MP, and YE were consulted. Subsequently, DK and AS coded the transcripts of the first patient's respective medical oncologist, case manager, and GP, discussing until consensus was reached and consulting the research team if necessary. They completed coding for the first case before commencing interviews for the second case. This

Table 1. Participants per case.

Subunit	Case number													
	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Patient	P01	P02	P03	P04	P05	P06	P07	P08	P09	P10	P11	P12	P13	P14
Medical oncologist	O01	O02	O03	O04	O05	O02	O06	O07	O01	O01	O05	O05	O08	O04
Case manager	C01	C02		C03	C04		C05			C01		C06	C07	
GP	G01	G02	G03	G04	G05	G06	G07		G08	G09	G10			

Reasons for incompleteness of cases were maternity leave ($N = 1$), lack of time ($N = 2$), lack of involvement ($N = 5$), unwillingness ($N = 1$), and unknown ($N = 1$).

iterative process of data analysis and interview planning allowed the interview guide to be updated regarding emerging themes and reflecting on preliminary results. This process continued until the first three cases were completed. DK and AS proceeded to conduct interviews for all cases. DE coded the remaining transcripts using the codes on which DK and AS achieved consensus. If new codes emerged, all transcripts were reviewed in relation to the new codes, ensuring ongoing refinement of the analysis. Over 6 months, DE, MP, and YE iteratively discussed codes in biweekly meetings. DE then grouped similar concepts into initial axial codes, further discussed with MP and YE until consensus was reached. Subsequently, during a 3-h research meeting, DE, MP, and YE categorized similar concepts into initial categories and themes, culminating in a preliminary codebook. This preliminary codebook was discussed with HS, KV, and EK until consensus was achieved on the final codebook. The entire inductive content analysis occurred at both the within-case and across-case levels.²⁶ ATLAS.ti (version 9.1.6) was used to support the coding process.

Additionally, based on the transcripts from each case, DE constructed an overview of the decision-making process, with a particular focus on the *CONtext*-method's application. This contribution aided both within-case and across-case analyses, allowing for an examination of how *CONtext* was implemented in each case and facilitating comparisons between cases.

Research team and reflexivity

Research team members had various backgrounds, including primary care, palliative care, and medical oncology (investigator triangulation), see Supplemental File 2. The researchers had no relationship with the interviewees prior to the study.

Ethical approval

The research ethics committee of Radboudumc concluded that this study was not subject to the Medical Research Involving Human Subjects Act (case number 2019-5825).

Results

All 14 invited patients agreed to participate. Some patients shared the same case manager and medical oncologist, resulting in these healthcare professionals being interviewed multiple times. Some case managers and GPs declined to participate. Consequently, not 4×14 , but 46 interviews with 14 patients, 8 medical oncologists, 7 case managers, and 10 GPs were conducted. Table 1 presents the participants per case, along with the reasons for incompleteness of cases. The median length of patient interviews was 36 min (range: 19–62). Table 2 provides the participants' characteristics. For medical oncologists, case managers, and GPs, the median interview lengths were 21 min (range: 10–41), 26 min (range: 12–30), and 18 min (range: 11–23), respectively. All interviewees approved the interview summaries.

Perceived application of the *CONtext*-method

The extent to which the *CONtext*-method was applied varied across cases and generally appeared to be limited (see Table 3 and Supplemental File 3 for detailed results). The treatments' impact on the patient's quality of life (considered part of the patient's context) was discussed in a few cases. In some cases, the case manager was present during the outpatient consultation with the medical oncologist. GPs were barely involved in the decision-making process. Only a few patients were stimulated to contact their GP regarding the upcoming decision moment. Many GPs were only informed after a patient had made a treatment decision. In a minority of cases, a time-out was offered. About half used this to consider and discuss the treatment options with others. Moreover, patients often needed to wait for diagnostic results or something similar. Thus, in such cases, an implicit time-out arose.

Experiences with the *CONtext*-method

From the interviews, we retrieved 234 codes, grouped into 78 axial codes, 21 categories, and 4 themes (Supplemental File 4).

Table 2. Characteristics of participants.

	Patients (N = 14)	Medical oncologists (N = 8)	Case managers (N = 7)	General practitioners (N = 10)
Gender, <i>female</i> ; N (%)	8 (57)	6 (75)	7 (100)	5 (50)
Age, in years; median (min-max)	61 (47–84)	47 (40–66)	42 (33–62)	42 (32–63)
Education level; ^a N (%)				
Lower	–	–	–	–
Medium	5 (36)	–	–	–
Higher	9 (64)	8 (100)	7 (100)	10 (100)
Marital status; N (%)				
Single	1 (7)	1 (13)	1 (14)	–
Together	10 (71)	7 (88)	6 (86)	9 (90)
Widowed	3 (21)	–	–	–
Unknown	–	–	–	1 (10)
Ethnicity, <i>Caucasian</i> ; N (%)	14 (100)	8 (100)	7 (100)	10 (100)
Primary cancer diagnoses; N (%)		NA	NA	NA
Breast	4 (29)			
Gastrointestinal	3 (21)			
Urological	3 (21)			
Melanoma	2 (14)			
Gynaecological	1 (7)			
Sarcoma	1 (7)			

NA: not applicable.

^aEducation level is categorized as: higher = university or higher professional education; medium = secondary education, and; lower = primary education or no education.

Theme 1: Shared decision-making is a dynamic and continuous process. Almost all patients and healthcare professionals considered shared decision-making a desirable concept and described it as a process that includes multiple conversations. They noted that discussing the choices, treatment options, and the patient's context was too much to be managed in one conversation. Additionally, several interviewees stated that treatments regularly needed reconsidering, as the patient's medical condition and context can change over time. Moreover, one medical oncologist reported that their role could also change over time, for example, to a more directive role.

As shared decision-making was experienced as a dynamic process, several interviewees considered that a time-out would facilitate decision-making, and many reported that it might help patients make a well-informed decision. One medical oncologist and one GP stated that not offering a time-out would be inhumane or even “*emotional blackmail*.” According to some case managers and medical oncologists, *CONtext* has led to them offering more conscious and frequent time-outs. However, some patients recommended that this should be more explicitly mentioned. “*On the way home, we had various questions because then my partner and I discussed it together (. . .) I wanted to let it sink in for a minute and discuss it the next day. I don't think it all fits in one conversation because you often get to hear something that frightens you, and then maybe you make a decision based on fear or other*

emotions. So then I think: let me first calmly think it through at home, so yes, maybe, I would like to have two conversations (. . .) So, in my opinion, the fact that you can think about it could be more emphasized.” (Patient case 4)

As shared decision-making was experienced as a continuous process, many interviewees indicated that continuity of care between healthcare professionals is needed, and that collaboration between primary and secondary care is necessary. Some interviewees reported that patients' contextual information could easily get lost in professional discontinuity. Consequently, many interviewees found that a transfer of this information to their GP would be essential. According to several GPs, this would support them in their (oncological) knowledge, like treatment options under consideration, possible complications, the medical phase the patient is in (curative/palliative/terminal), and the patient's experience with the shared decision-making process. Several GPs indicated that information transfer from the hospital could be improved. However, a number of GPs also indicated that the patient kept them sufficiently informed regarding the medical situation and decision-making.

Several medical oncologists considered themselves responsible for initiating and maintaining the shared decision-making process. They stated that it is their task to offer a time-out, involve the case manager preferably as early as possible, and inform or involve the GP.

Table 3. Overview of the perceived CONText-method's application^a.

Case; number, disease, gender, age	Outpatient consultation			Time out		Inviting and informing the general practitioner			
	Choices and treatment options considering the patient's context discussed with medical oncologist	Case manager present	Loved one(s) present	Offered	Used	Patient stimulated to involve the general practitioner in decision-making	General practitioner informed by phone	General practitioner informed by letter (after decision was made)	
1. Metastatic breast cancer, female, 60–70	+	-	+	-	±	-	-	+	
2. Metastatic melanoma, male, 80–90	+	+	+	+	+	?	-	+	
3. Metastatic synovial sarcoma, female, 50–60	?	-	+	+	-	-	-	+	
4. Metastatic bladder cancer, female, 50–60	?	+	+	-	-	-	+	+	
5. Metastatic colon cancer, male, 60–70	+	+	-	+	+	-	?	?	
6. Metastatic melanoma, female, 50–60	?	-	+	-	-	-	-	+	
7. Metastatic ovarian cancer, female, 60–70	-	-	-	-	±	?	-	+	
8. Metastatic breast cancer, female, 60–70	+	-	+	+	-	±	-	+	
9. Metastatic breast cancer, male, 70–80	+	-	?	-	±	-	-	+	
10. Metastatic breast cancer, female, 50–60	+	-	+	?	±	+	-	+	
11. Incurable gastric cancer (nonmetastatic), male, 70–80	+	-	+	?	±	-	?	+	
12. Metastatic rectal cancer, male, 40–50	+	-	+	+	+	-	-	+	
13. Metastatic bladder cancer, female, 40–50	?	+	+	-	-	?	-	-	
14. Metastatic prostate cancer, male, 60–70	?	-	+	-	-	?	-	?	

^aThe application of the CONText-method is according to the interviewees. Consequently, for some CONText-elements it is unclear if and how they were applied.

Theme 2: The medical oncologist's treatment recommendation is central in shared decision-making. Most patients, medical oncologists, and case managers reported that the treatment decision was made together. However, many interviewees commented on the term 'shared decision-making' like medical oncologist (case 3): "Shared decision-making is great, but that doesn't absolve us from giving advice. And occasionally it threatens to go on a bit with: these are the choices you have. Instead of saying: these are the choices, and for this one you can argue. . . , and for that one you argue. . . , and my preference is. . . ." A patient (case 9) described it as follows: "(. . .) 'this is what we decided together', I think that's going too far (. . .). I didn't experience it as it being shoved down your throat. I don't feel that way! You discuss things with each other, things are explained, and then you can agree with the explanation." Several medical oncologists and one GP agreed that the medical oncologist's recommendation is essential, for example, to prevent the patient from feeling responsible for the treatment decision. Several patients endorsed that they felt the medical oncologist's treatment recommendation was pivotal; the medical oncologist is the expert regarding cancer treatments. One medical oncologist (case 14) commented: "Yes, on the one hand, I'm the expert who comes up with treatment recommendations, and on the other hand, I'm also a coach to make someone's life as worthwhile as possible (. . .). The patient would like to know: how can I live as long as possible? But I also have conversations about what's important in life, and of course, I'm not the expert on that." One medical oncologist (case 6) struggled with patients relying on their treatment recommendation: "I do notice that I sometimes find it difficult because it relies heavily on my expertise. And, of course, it's also difficult to predict exactly how something will go. So, they have to make a choice that's not without uncertainties, based on the information from my side." Another reason why many interviewees found the medical oncologist's recommendation vital was that patients cannot always oversee the choices, treatment options, and consequences. Although the medical oncologist's treatment recommendation is central to decision-making, many interviewees considered it the task of the medical oncologist to facilitate a treatment decision in which the patient's context is integrated.

According to one medical oncologist and one case manager, *CONtext* has created more awareness regarding the case managers' added value in the decision-making process. Nevertheless, most patients and healthcare professionals specifically described the case managers' supportive roles within the disease process, such as providing patient psychosocial support and performing logistic tasks for both the patients and medical oncologists. Moreover, in the decision-making process, case managers can empower patients and support them in making well-informed treatment decisions that match

their context. They do this by, for example, discussing and integrating the patient's context in the decision: "(. . .) the case manager has gradually been able to get the patient to talk about this." (Medical oncologist case 4) Another medical oncologist (case 8) added: "But I also regularly see that patients tell the case manager things that they don't share with me. That's because they're afraid that this will immediately have all kinds of consequences for whether or not they can get treatment." Several patients and case managers emphasized that the case manager complements the medical oncologist: "I appreciate it when my medical oncologist is straight to the point, like 'this is it', he needs to cure my cancer. And the case manager brings in the social and emotional aspect during the conversation, which is, in itself, very pleasant. She's perfectly aware of how someone's feeling." (Patient case 4)

The GPs' roles ranged from passive to active involvement in decision-making. For example, many interviewees noted that it was vital that the GPs be aware of the oncological process, as they frequently take over end-of-life care. Moreover, according to the GPs, they can provide additional information regarding oncology treatments and support the patient to make their own decision. "What often happens, and I don't think all medical oncologists realize this, is that a patient comes to us with the question: 'Doctor, what should I do? Can you help me?' And that's where I can provide a bit of information." (GP case 3) For some medical oncologists, encouraging the patient was the only role for GPs: "But for me, it's difficult to ask a colleague for an opinion about something that they can hardly oversee. That colleague does indeed know the patient, and knows the rough principles of chemotherapy, but not those of immunotherapy or targeted therapy. And in this way, you make them partly responsible for a decision. So other than the GP being able to empower a patient to make an own decision, you can't expect much more." (Medical oncologist case 3) Several GPs were also reluctant to actively participate in decision-making: "I would never really give advice (. . .) I try to leave the choice to the patient. And if I think the patient isn't able to, then I'd rather consult the medical oncologist than I would steer them in one direction." (GP case 2) Interviewees frequently reported insufficient oncological knowledge of the GP as a reason for their limited role. A few medical oncologists even considered it risky to involve the GP: "Sometimes you also see that GPs, because they have an information deficit, support patients in decisions in the wrong way." (Medical oncologist case 8) However, one case manager (case 13) reported that the limited oncological expertise of the GP is subordinate: "Patients often say that the GP could give examples from practical experience, and that gives patients confidence. So, that is appreciated."

Although several interviewees were reluctant to involve GPs in decision-making, some medical oncologists considered them valuable in certain situations: "But a GP

does know the whole system and probably knows the patient longer. So, in the sense of whether to treat a patient, I think a GP is very valuable (. . .)" (Medical oncologist case 6) However, some GPs indicated that they didn't know the patients well. A case manager (case 7) added: "The medical oncologist isn't a GP who sees the patient once in a while. Making choices in life of what is important to the patient connects (read: the medical oncologist and patient)." Additionally, a few GPs and one medical oncologist (case 13) indicated that the GP might play a role in protecting the patient from overtreatment: "I think the GP can be well involved, certainly at the moment when we move towards the terminal phase and, for example, when the patient still insists on continuing treatment and I think: this is going too far. I think the GP can play a good role in protecting patients from treatments that won't benefit them. Then, it's important to have a good interaction between me and the GP, because you can bring that the same message) to the patient and that always helps from different perspectives." One GP also stated that patients may tell their GP more easily than the medical oncologist that they no longer want to be treated.

Finally, the GP is prominent in providing (proactive) palliative care. Most interviewees indicated that the GP primarily comes into the picture and thus takes on a more significant role when there are no more tumour-oriented interventions or the patient is terminal. One GP (case 4) mentioned this as a barrier to involvement during the decision-making process: "She (read: the patient) is a bit hesitant towards me . . . not to me as a person, but to me in the role of 'I only show up when it's over', and that's very confronting for her, she doesn't want that. In that sense, she avoids me a little bit."

Theme 3: Patients experience of not having a choice. Almost all patients felt they had no choice. Patients reported "doing nothing was not an option" and "I had no choice." Some patients experienced the option 'doing nothing' was not followed by an explanation: "And the possibility to stop that is something mentioned at the end of the conversation, like: 'You can also stop'. But by then, the conversation was nearly ended, and then, when I stood outside, I thought: 'Why stop? Is it not going to work?' (. . .) So that's something that could be discussed more in depth." (Patient case 4) One case manager argued that the term 'doing nothing' as an equal and considerable needs to be avoided. According to some case managers, CONtext created greater awareness in discussing no tumour-oriented treatment as a treatment option.

The sense of inequality in treatment options was fuelled by the feeling of having "to do something," as indicated by several patients. They wanted to give treatment a chance or feel they had done everything possible: "The sooner you address it (start therapy), the more there might be to save." (Patient case 8) and "It doesn't hurt to try." (Patient case 5) This patient also expressed that he

didn't understand why the medical oncologist suggested active surveillance: "Even if it (the cancer) doesn't grow, it still has to go away. So why not do it right away?" His medical oncologist reflected: "The only thing that struck me was that he seemed interested in active surveillance, but I think he was scared to run that risk. And I wonder if I could have given him more confidence; it may not have been a real risk. However, I had given him a week to think about it. But he made his decision. If I then had asked: 'Are you sure?' then I wouldn't be taking his decision seriously." However, this patients also said: "She (medical oncologist) said, take it easy, read the papers, and think about it. So I did. But I'd already made my decision."

Medical oncologists also mentioned the sense of inequality in treatment options. According to one medical oncologist (case 13): "I think the second option (stop anti-cancer treatment) isn't an option for her or not a very realistic option, given how she is in life and her age. I don't think that doing nothing is a very realistic option. She had a relatively good quality of life before and during treatment."

Due to their experience of not having a choice, many patients experienced no or less need for a time-out to consider and discuss treatment options with others. On the other hand, if patients did have equivalent treatment options, a few medical oncologists mentioned there was a need for a time-out: "In case where people really have a choice. If you say: 'Do you want to start with this or that treatment? Then they go home and think about it (. . .)" (Medical oncologist case 6)

Theme 4: Integrating the patient's context into shared decision-making is considered important but hampered. Almost all healthcare professionals considered integrating the patient's context into shared decision-making as something desirable: "You should regularly discuss the patient's context like you regularly perform CT scans or laboratory tests." (Medical oncologist case 4) However, discussing the patient's context was hampered by a number of barriers. Some patients associated this with the terminal phase: "They (medical oncologist and case manager) asked me if there were things that they needed to take into account. And then I thought, why? Am I almost at the end of life or . . .?" (Patient case 5) Some patients considered it only relevant at this final stage: "No, we haven't discussed my quality of life, but that wasn't an issue at the time. We hoped that the treatment would work, and then I'd have had a chance to live a long life. So it didn't have to be discussed." (Patient case 6) Moreover, some interviewees mentioned that the patient's context was assumed or implicitly discussed with the medical oncologist: "No, they (the patients' context) are not discussed, but I think my medical oncologist knows how I feel about it. He knows me by now." (Patient case 4) Furthermore, some patients preferably would discuss it with family and close friends or other professionals rather than with the medical oncologist. Lastly, one medical oncologist (case 8)

mentioned: *"Lately, we've both been very focused on the symptoms, they were predominant (. . .) So, all other goals became unachievable (. . .) If we didn't get the symptoms under control, there was no context."*

Many interviewees mentioned that the patient's contextual factors affected the decision itself and the application of *CONtext*, with healthcare professionals mainly mentioning the latter. Reported contextual factors included the patient's medical situation, cognitive ability, personality, and personal situation. For example: *"If you have a vulnerable patient or a complicated home situation with, for example, young children or a vulnerable partner or not involved at all, then I'm more likely to invite the GP to participate in the decision-making process."* (Medical oncologist case 9) Due to the strong influence of the patient's contextual factors, several healthcare professionals indicated that *CONtext* should be tailored to each patient. *"It (CONtext) doesn't have to be a 'one size fits all'. For example, sometimes a time out consultation is needed, sometimes not."* (Medical oncologist case 5) A case manager (case 5) agreed but stressed being careful about making assumptions: *"With some patients, you think it (a time-out) is unnecessary, but then it turns out they would still prefer it."*

According to many healthcare professionals, *CONtext* positively impacted patient-centredness in shared decision-making. A positive effect on the patient included more informed and patient-centred decision-making. Furthermore, a single healthcare professional indicated that *CONtext* might positively impact the patient's quality of life and advance care planning: *"If you ask someone specifically, 'What's important to you in life?' And they say, 'I'd like to be in good shape and if I can't go mountain hiking, I don't want to do it anymore. In that sense, agreeing on a limited policy makes sense (. . .). It's always a difficult subject, and now the bridges are built earlier, and it's easier to discuss."* (Medical oncologist case 6) During interviews, a recurrent topic was that applying *CONtext* raised awareness about discussing and documenting the patient's context. *"It (CONtext) makes me better document my consideration instead of: options discussed, advantages and disadvantages mentioned, the patient chooses for this or that. Nowadays, I neatly document the evaluated context too."* (Medical oncologist case 3) Others mentioned positive effects including that discussing the patient's context gave meaning to their work and that it doesn't necessarily cost more time, and in the long term: *"It might even save time because if you don't end up doing this, you'll probably be playing catch-up."* (GP case 11)

Discussion

Main findings

In this qualitative embedded multiple-case study, we found that the focus on life-prolonging anticancer

treatment options hampered shared decision-making. The focus undermines the integration of the patient's context into decision-making, something of utmost importance in the palliative care continuum aimed at integrating oncology and palliative care. Most patients experienced having no choice; they considered discontinuation of tumour-oriented treatment not to be an option. Consequently, a time-out was frequently regarded as unnecessary. Moreover, many patients and healthcare professionals considered the medical oncologist's treatment recommendation as something central which defines the roles of others in the decision-making process. The case manager was assigned mainly supportive roles and involving the GP was considered unnecessary unless the patient was in a terminal phase. Additionally, discussing the patient's context was hampered, for example, by the association of discussing a patient's context with the terminal phase and a patient being insufficiently aware that talking about their context with the medical oncologist is relevant.

Strengths and limitations

A strength of our study is the use of a relatively unknown design, the qualitative embedded multiple-case study, to examine a diverse and multifaceted phenomenon—shared decision-making in patients with advanced cancer. This approach was successful in providing in-depth insights and achieving sufficient information power. Our results are credible due to their high (internal) validity, ensured by data source and investigator triangulation.²⁷ Data source triangulation involved including the different perspectives of patients, GPs (primary care), case managers, and medical oncologists (secondary care). Investigator triangulation included a research team from a range of relevant backgrounds, including primary care, palliative care, and medical oncology. Additionally, we conducted the interviews during the implementation of *CONtext*. This allowed the interviewees to share their specific experiences, which contributed to the richness of the data.

We acknowledge the following limitations. First, our findings are primarily derived from the across-case inductive content analysis. During our analysis, we noted that within-case analysis provided limited in-depth insights, which we attributed to the restricted application of the *CONtext*-method. However, the across-case analysis yielded substantial depth and understanding. The themes we identified extend beyond experiences with *CONtext*; they offer insights into how our interviewees perceived shared decision-making, particularly integrating the patient's context into decision-making, which is an acknowledged critical aspect of shared decision-making.^{7,11,19,21} Second, our study was conducted in a Dutch academic hospital therefore our results are likely only to be transferable to similar settings: developed

countries where persons with advanced cancer highly value autonomy, attention to personal wishes, and receiving care from skilled healthcare professionals.²⁸ However, perspectives may differ in non-academic care centres. Third, the perspectives of lower-educated patients and persons with a non-Caucasian background were underrepresented in this study. Moreover, we did not address the perspectives of family and close friends, although they are known to play an important role in shared decision-making.²⁹ Nevertheless, we represented their perspectives in a separate study.³⁰

What this study adds

Improving personalized patient decision-making by involving GPs has been advocated,^{31–33} and others have reported on the impact of offering a time-out to engage the GP.^{32,34,35} Perfors et al.³⁵ showed that although patients were motivated to have a time-out, planning it appeared challenging; most time-outs were planned after the decision had been made. They noted that logistic hurdles formed a possible barrier to implementing time-outs. In contrast, our findings suggest that implementing a time-out and involving the GP is mainly hampered by a focus on treatment. In line with our findings, bereaved family caregivers also mentioned life prolongation as the most important treatment aim, and they highly valued the medical oncologist's opinion. The focus on life prolongation and treatment and less on the patient's context may explain why family caregivers were satisfied with the marginal role of the GP through the entire disease process.

Our finding that patients lack choice is confirmed in a systematic review and meta-synthesis³⁶ where one of the themes identified was the "Overwhelming situation of 'no choice'." The authors emphasize that palliative cancer care professionals must prioritize cultivating awareness regarding available choices. We report that palliative care professionals should be aware that the focus on life-prolonging anticancer treatments hinders integrating the patient's context, which, in turn, hampers person-centred care, where oncology and palliative care are intertwined. We found that the integration of the patient's context into decision-making reaches a standstill: patients prefer to discuss their context with others than with the medical oncologist; medical oncologists make assumptions about the patient's context; and GPs are only given a prominent role in decision-making when the patient is terminal or is running out of tumour-oriented treatment options. Moreover, discussing the patients' context seems to be hampered by patients associating this with 'end of life'. To the best of our knowledge, we are the first to explicitly demonstrate this.

In 2003, Haes et al. described the medical oncologist's preference for tumour-oriented treatment, even in cases where evidence for life prolongation is lacking.³⁷ Despite

the increasing use of systemic therapy and the introduction of new drugs, survival for several tumour types has barely improved.⁸ Perhaps unsurprisingly, the debate on whether to prolong or end treatment and whether or not to reimburse non-curative cancer treatments with limited proven effect on survival is ongoing. In 2012, Baszanger³⁸ described the debate on the tangled relationship(s) between innovation, "cure," death, and the symptoms and subjective experiences of sufferers.

To date, interventions, including ours, have not achieved sufficient integration of the patient's context into decision-making. We hypothesize that an intervention on a micro, meso, and macro level is needed. Our findings suggest that a cultural change on all levels is necessary. In the Netherlands, a campaign to change public opinions, "*Incurable. Not without care*" (*Dutch: Ongeneeslijk. Niet uitbehandeld*)³⁹ may be a step in the right direction. However, this alone is unlikely to be sufficient. Research is needed on how to kickstart a cultural change, including stakeholders ranging from patients and healthcare professionals to insurers and politicians.

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Author contributions

Conception/Design: DE, MvG, EK, HS, KV, YE, and MP. Provision of participants: EK, FPvA. Data acquisition: DK, AS. Data analysis: DE, DK, AS. Data interpretation: DE, MvG, EK, DK, AS, HS, KV, YE, and MP. Manuscript writing: DE. Critical revision of manuscripts and final approval: all authors. All authors have participated sufficiently in the work to take public responsibility for the appropriate content.

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Ethical approval and informed consent

The research ethics committee of Radboudumc concluded that this study was not subject to the Medical Research Involving Human Subjects Act (case number 2019-5825). Prior to the interviews, all interviewees gave informed consent.

Data management and sharing

Data are available upon reasonable request via the corresponding author.

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Supplemental material

Supplemental material for this article is available online.

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