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Research Paper

Older patients' experiences with and attitudes towards an oncogeriatric pathway: A qualitative study

Anna Uit den Boogaard [a,*], Dide de Jongh [a], Marjan J.T. van den Elst [a], Stella Trompet [a], Janneke M. de Man-van Ginkel [b], Johanneke E.A. Portielje [c], Yvette Meuleman [d], Simon P. Mooijaart [a,e], Nienke A. de Glas [c], Frederiek van den Bos [a]

[a] Department of Internal Medicine, Section Gerontology and Geriatrics, Leiden University Medical Center, the Netherlands
[b] Nursing Science, Department of Internal Medicine, Section Gerontology and Geriatrics, Leiden University Medical Center, the Netherlands
[c] Department of Internal Medicine, Section Medical Oncology, Leiden University Medical Center, the Netherlands
[d] Department of Clinical Epidemiology, Leiden University Medical Center, the Netherlands
[e] LUMC Center for Medicine for Older People, Leiden University Medical Center, the Netherlands

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ABSTRACT

Introduction: To tailor treatment for older patients with cancer, an oncogeriatric care pathway has been developed in the Leiden University Medical Center. In this care pathway a geriatric assessment is performed and preferences concerning cancer treatment options are discussed. This study aimed to explore patient experiences with and attitudes towards this pathway.

Materials and Methods: A qualitative study was performed using an exploratory descriptive approach. Individual face-to-face semi-structured interviews were conducted with older patients (≥70 years) who had followed the oncogeriatric care pathway in the six months prior to the interview. The interviews were audio-recorded and transcribed verbatim. The transcripts were analyzed inductively using thematic analysis.

Results: After interviews with 14 patients with a median age of 80 years, three main themes were identified. (1) *Patients' positive experiences with the oncogeriatric pathway*: Patients appreciated the attitudes of the healthcare professionals and felt heard and understood. (2) *Unmet information needs about the oncogeriatric care pathway:* Patients experienced a lack of information about the aim and process. (3) *Incomplete information for decision-making:* Most patients were satisfied with decision-making process. However, treatment decisions had often been made before oncogeriatric consultation. No explicit naming and explaining of different available treatment options had been provided, nor had risk of physical or cognitive decline during and after treatment been addressed.

Discussion: Older patients had predominately positive attitudes towards the oncogeriatric care pathway. Most patients were satisfied with the treatment decision. Providing information on the aim and process of the care pathway, available treatment options, and treatment-related risks of cognitive and physical decline may further improve the oncogeriatric care pathway and the decision-making process.

1. Introduction

In 2022, more than two-thirds of Dutch patients newly diagnosed with cancer were older than 65 years [1]. Older patients have a higher risk of negative treatment outcomes after intensive cancer treatments such as surgery or chemotherapy [2,3]. A geriatric assessment (GA) [4] can help evaluate the vulnerability of older patients and includes assessment of cognitive, functional, somatic, and social domains. Combining information derived from GA and cancer-related information including treatment options and expected outcomes [5] may optimize shared decision-making (SDM) [6]. GA has already been shown to improve treatment outcomes, including reduction of toxicity and improved quality of life (QOL) [7–9]. In addition to commonly studied clinical outcomes such as complications and survival, patient-reported

* Corresponding author at: Department of Internal Medicine, Section Gerontology and Geriatrics, Leiden University Medical Center, PO Box 9600, 2300 RC Leiden, the Netherlands.
E-mail address: a.uit_den_boogaard@lumc.nl (A. Uit den Boogaard).

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outcomes, such as loss of independence and QOL, may be of great importance to older patients [10,11]. Furthermore, integrating a GA into oncology care improves patient and caregiver satisfaction and communication about aging-related concerns [11].

Assessment of frailty, multimorbidity, and thoughts and wishes towards treatment options are essential in the decision-making process. In the Leiden University Medical Center (LUMC), these assessments are merged into an oncogeriatric care pathway that is implemented in standard care for all patients with cancer aged 70 years or older [12,13]. This pathway combines a GA with the exploration of patients' values and expectations and integrates geriatric interventions into cancer care [14]. In several hospitals in the Netherlands this kind of oncogeriatric care pathway has already been implemented specifically in colorectal surgery care [15]. However, patient preferences and needs in relation to such oncogeriatric care pathways have not been studied before. Therefore, this study aimed to explore the experiences with and attitudes towards an oncogeriatric care pathway among older patients with cancer.

2. Methods

2.1. Study Design and Patient Selection

In this qualitative study using an exploratory descriptive approach, individual face-to-face semi-structured interviews were conducted in October and November 2019. Patients were aged 70 years or older and had followed the oncogeriatric care pathway in the six months prior to the interview. They were recruited from the Triaging Elderly Needing Treatment (TENT) study (approved by the Medical Ethics Committee of the LUMC, P15.150). The TENT study is a prospective cohort study embedded in routine oncogeriatric care. Participants aged 70 years or older with a new diagnosis of cancer who are candidates for intensive cancer treatment, such as chemotherapy, surgery or chemoradiation are included. More details on the design and rationale of the TENT study have been described previously [13]. For this sub-study within the TENT study, the Medical Ethics Review Committee (METC) of the LUMC issued a waiver for formal ethics approval [16]. All patients gave written informed consent for participation in this study, including use of their anonymized data from electronic health records and audio-recording of the interviews. When informal caregivers or family members participated in the interviews, they gave verbal consent for the interview to be audio-recorded and for the use of their data for analysis. The Consolidated Criteria for Reporting Qualitative studies (COREQ) checklist was used for reporting the results [17].

In total, 50 participants in the TENT-study were approached by telephone and received verbal and written information about this study. When patients could not remember the visit to the oncogeriatric care pathway or when diagnosed with cognitive impairment, they were considered unable to consent and therefore ineligible for participation. No other in- or exclusion criteria were applied.

2.2. The Oncogeriatric Care Pathway

Patients were screened for frailty by their referring cancer specialist using the Geriatric 8 (G8) [18] and the 6 Cognitive Impairment Test (6CIT) [19]. A flowchart of the oncogeriatric care pathway is shown in the Supplementary File 1. When screening demonstrated risk of frailty (G8 $\leq$ 14 or 6CIT >7), patients were referred to the oncogeriatric care pathway for a GA. Depending on patient characteristics, cancer type and characteristics, and treatment options the GA was performed by a nurse practitioner specialized in geriatrics or a geriatrician [13]. In addition, patient life goals and preferences regarding treatment options were explored. The results of this consultation were discussed by the nurse practitioner or geriatrician in the multidisciplinary oncology team meeting. After this meeting, the referring oncologist and patient participated in SDM to decide on the best suitable individual treatment and geriatric interventions were initiated if indicated.

2.3. Interview and Data Collection

Interviews took place at participant's homes and informal caregivers or family members were welcome to participate. All interviews were audio-recorded with recording equipment (Olympus Vn-541PC). The aim of the interview had been explained in the patient information folder and was again provided at the start of the interview. The interviews were conducted, and data was analyzed by two researchers, AUB (BA in Nursing, MSc Nurse practitioner) and DJ (BA Health and Life Science, MSc Vitality and Aging), who were supervised by a third researcher (NG, MD, Postdoc, Fellow Medical Oncology). A semi-structured interview topic list was developed (AUB, DJ, NG) based on the research questions and clinical experience and was discussed with a researcher with experience in conducting qualitive studies and interviewing (YM, PhD, Medical Psychologist). The interview was not pilot tested, but there was consultation between the two interviewers immediately after conducting an interview. The interview consisted of open-ended questions and answers were further explored by using additional questions and probes. A concise version of the topic guide is shown in Box 1 and contains questions about perspectives, attitudes, needs, experiences, and life goals, and decision-making and was translated from the Dutch version. At the end of the interview, patients were asked for their input on how to improve the oncogeriatric care pathway provided in the LUMC.

The interviews were conducted in Dutch until data saturation was reached and no additional information or themes could be observed in the data [20]. Based on previous studies [21,22] it was expected that data saturation would be reached after approximately 10–15 interviews. Data saturation was assessed and discussed by the research team at different time points during the study until agreement was reached that no new themes had been brought up.

2.4. Analysis

All interviews were transcribed verbatim by two researchers (AUB and DJ). The transcribed interviews were not returned to the patient for comments or corrections. After each interview, the first impressions, ideas and themes were discussed in a debriefing session between the interviewers. Data was saved on a secured server, and an audit trail with detailed information about the research process was kept. The qualitative data analysis software Atlas.ti (ATLAS, Berlin V) was used to facilitate data organization and analysis. Data were analyzed inductively using thematic analysis by both researchers (AUB and DJ) following all six steps of Braun and Clarke [23]. After familiarizing ourselves with the transcribed interviews, initial codes were generated, and themes were sought, reviewed, and defined. More specifically, initial coding was done by AUB and DJ separately, and results were discussed with three other researchers FB (MD, PhD, Internist Geriatrician), YM, and NG to align coding strategy and judge consistency of interpretation. The analysis phases hereafter (i.e., combining different codes into themes; reviewing, comparing, and organizing themes; refining and defining themes) were conducted in the same manner, led by AUB and DJ and in close collaboration with the multidisciplinary research team. During the entire process, reflexivity was taken into account and interpretations were iteratively reviewed among the team and critically discussed until consensus was reached.

Finally, the findings were written up and illustrative quotes were selected and translated from Dutch to English using back-translation [24].

Demographic and clinical data (age, disease type, treatment options, education level, and living situation) were obtained from patients' electronic health records. Descriptive statistics of the patients' characteristics were conducted using IBM SPSS Statistics (version 25) and were presented as mean (standard deviation; SD), median (interquartile range; IQR) or numbers (proportion) where appropriate.

Box 1
Concise version of the topic guide.

Topic 1. Experiences with the oncogeriatric consultation

- How did you feel when you were referred?
- What was your experience with the consultation?
- In retrospect, would you have wanted parts of the consultation to be different?
- Were parts of the consultation less pleasant for you?
- What did you think of the duration of the consultation?
- Did you understand everything that happened during the consultation?
- What do you think older patients expect when invited for this consultation?
- What did you think of the care that you received in the oncogeriatric pathway?
- Would you recommend this oncogeriatric care pathway to other older patients, and if so, why?
- Do you think this care pathway improves care for older patients?

Topic 2. Treatment choice and decision and the added value of the oncogeriatric consultation

- Which were the treatment choices given to you before visiting the oncogeriatric outpatient clinic?
- How did you experience choosing a treatment?
- Did the oncogeriatric consultation give you new insights about your own health?
- Did the oncogeriatric consultation give you new insights about treatment risks?
- Were your wishes and goals in life, your medical history and personal health problems discussed?

Topic 3. Impact of cancer treatment on outcomes

- What were your life goals before this consultation?
- Have your daily activities changed after cancer treatment?
- Have you taken your daily activities into account when you had to make a treatment decision?
- What makes you happy every day?
- Did that change after the cancer treatment?
- Were there any factors in life that stood in the way of a specific treatment?
- What kind of decline after treatment would have been unacceptable for you
- What were your expectations about cognitive or functional decline after treatment?
- What did you consider to be the best treatment outcome after you had made a treatment decision?
- What did you hope for after treatment?

3. Results

3.1. Interview and Sample Characteristics

Sixteen out of 48 invited older patients with cancer (33%) gave informed consent to participate in this study. Of these patients, 14 patients (87.5%) were included in this interview study and two (12.5%) patients declined in a later stage. Of the 32 patients (67%) that did not give informed consent, six patients (18.8%) could not remember the appointment, 16 patients (50%) said they were too occupied with the hospital visits and did not have the time and energy for the interview. Ten patients (31.2%) could not be reached by telephone and attempts to reach them were put on hold in case more interviews were needed. In total, 14 patients who had followed the oncogeriatric care pathway were interviewed. They had a median age of 80 years (IQR 74–83) and the majority (57%) were female. Two (14%) participants had a higher education level, nine (63%) had middle, and three (21%) had lower education [25]. In six interviews (43%) a family member was present and participated in the interview. Five of these six family members had also been present during the visit at the outpatient clinic. The mean duration of the interviews was 47.9 min (SD 13.6), and all topics on the topic list were explored in all interviews. To gain more insight into patient's experiences and attitudes, we started with the questions on the topic list, and formulated additional questions when clarification was needed.

Three patients (21%) had ovarian cancer, three patients (21%) had esophageal cancer, three patients (21%) had stomach cancer and five patients (37%) had other types of cancers. Thirteen of the referring specialists were surgical oncologists and one was a medical oncologist. Eleven patients (79%) were treated with curative intent, seven (63.6%) of whom had a surgical treatment. The other patients had chemotherapy, radiation therapy, or a combination of these.

3.2. Oncogeriatric Pathway Characteristics

Six patients (43%) had a consultation with a nurse practitioner specialized in geriatrics and eight (57%) had a consultation with a nurse practitioner and a geriatrician or oncologist. For six patients (43%), the treatment decision had already been made prior to the oncogeriatric consultation and referral was aimed at the initiation of supportive geriatric interventions such as delirium prevention or prevention of functional decline during and after treatment. For eight patients (57%) no treatment decision had been made prior to the oncogeriatric consultation and GA contributed to the assessment of individual treatment goals and appropriateness of the available treatment options.

3.3. Themes

All generated data was used for the analysis and we identified three main themes: (1) patients' positive experiences with the oncogeriatric pathway, (2) unmet information needs about the oncogeriatric care pathway, and (3) incomplete information for decision-making. The themes and corresponding subthemes are described below, illustrated with quotes (Table 1).

Table 1
Overview of themes and subthemes with corresponding quotes.

Theme	Subtheme	Quotes
Patients' positive experiences with the oncogeriatric pathway	Appreciated the attitudes of the professionals	- *It was nice that there was so much focus on what was important to me. That was very positive and pleasant. I was impressed by the personal treatment. You get the feeling that they care about you. They represent my wishes regarding treatment (female, aged 82).* - *They have more time and patience, and they also have a listening ear (female, aged 81).*
	Clear conclusion of the consultation	- *I felt less anxious about the operation because of the conclusion of my functioning they gave me (male aged 78).*
Unmet information needs about the oncogeriatric care pathway	Lack of information on the aim of the referral	- *To be honest, the appointment surprised me a little, it overwhelmed me. You don't know what will come (male, aged 85).*
	Unmet information needs about the content of the appointment	- *Beforehand, I was nervous. You get the feeling the geriatrician will look at what is wrong with your cognition (female, aged 93).* - *I thought I was here for information about the chemotherapy (female, aged 86).*
Incomplete information for decision-making	Personal treatment goals and choices	- *I want to be healthy again, I want to become 90 (male, aged 72).* - *I told the nurse practitioner that If I become dependent on others, that will be my endpoint. That is a no go (female, aged 74).* - *When I learned I had a colon cancer, all I could think about was "it has to go". I want it out of me (female, aged 75).* - *If I do nothing, it's the end of the story, if I do the surgery there is also a risk that it is the end but there is always the other option (male, aged 84).*
	Treatment decision with unknown consequences	- *No, I wasn't thinking about decline. I said to myself "what will come, will come" (female, aged 86).* - *I didn't think about functional or cognitive decline at all, but I didn't want to lose my fitness, if you ask me now (male, aged 77).* - *I felt there was a choice and the way the referring physician talks to you makes you feel they still see the toughest treatment as an option for you (female, aged 93).*

3.3.1. Theme 1. Patients' Positive Experiences with the Oncogeriatric Pathway

All patients appreciated the attitudes of the healthcare professionals participating in the oncogeriatric care pathway. They felt heard, seen and well understood, and this was often related to the experienced patience and time taken by the healthcare professionals. To give some examples: one patient perceived more understanding from the oncogeriatric team than from previous consultations with other specialists. Another patient stated that this specific consultation could benefit younger patients too. In addition, patients anticipated reduced fear for future treatment because of the indisputable conclusion of the oncogeriatric consultation, that brought more clarity about their functioning in relation to treatment.

3.3.2. Theme 2. Unmet Information Needs about the Oncogeriatric Care Pathway

Most patients expressed that they did not know the aim of the appointment prior to the consultation. In their opinion, there was a lack of information from the referring doctor and there was no information provided with the appointment letter. Some patients said they did not need information prior to the appointment, but most would have appreciated more information. Due to the lack of information, some patients were afraid that the appointment would be a test for cancer treatment approval or about cognitive functioning or dementia.

3.3.3. Theme 3. Incomplete Information for Decision-making

In most patients the treatment decision had already been made prior to the oncogeriatric consultation and referral for GA was initiated to enable tailored geriatric interventions. Most patients felt that they had had a choice between treatment options. This did not differ between patients for whom the treatment decision had or had not been made before the oncogeriatric consultation. Some said that it had been easy to choose, either due to their fitness, or because they felt the responsibility to take the treatment opportunity offered to them. Other patients said that it had been difficult to choose because they felt they did not know enough about treatment options and the risk of complications to make the right choice. Others could not choose because they had heard conflicting stories about treatments. A few patients felt they had not had a real choice because doing nothing was not an option for them. Some patients stated that the GA did not contribute to the treatment decision.

The majority of the patients expressed that they had not taken potential functional or cognitive decline during or after treatment into account when deciding on treatment. Some patients mentioned that they had thought about cognitive or functional decline without realizing what the consequence could be. This had not been discussed with the referring doctor. The majority of the patients reported that living longer was the most important treatment goal, followed by remaining independent or being cured of cancer.

4. Discussion

This qualitative study explored patients' perspectives and attitudes towards an oncogeriatric care pathway. Patients had positive experiences with healthcare professionals' attitudes and felt heard, seen, and understood. However, they reported lack of information in different stages of the oncogeriatric care pathway, for example regarding the reason for referral prior to the appointment. Most patients felt confident about the treatment choice and decision made, although they had not been aware of the multiple other available treatment options and the potentially negative impact of the treatment on QOL and their cognitive and functional abilities when making the treatment decision.

Although (inter)national guidelines recommend implementation of a GA in cancer care for older patients [26,27], patients' attitudes towards and experiences with following an oncogeriatric care pathway are understudied. The results of this interview study provide insights from the perspective of patients.

Previous qualitative studies in older patients with chronic kidney disease [28] and older patients in the emergency department [29] also concluded that patients had a positive attitude towards introduction of a GA in the routine care for older patients and that they experienced it as standard part of care.

This study shows that, prior to referral, patients should be better informed about the fact that a GA empowers personalized treatment decisions and is aimed to improve patient related outcomes but is not meant to be an examination for therapy approval nor a screening for dementia. When patients know that the information derived from a GA contributes to the decision-making process, they can prepare for the consultation and obtain optimal information from the medical team to enable the most suitable individual treatment decision. Therefore, providing information about the aim and content of the oncogeriatric care pathway before referral is considered important and could reduce anxiety for the consultation and improve patient-centered care [11]. Hamaker et al. showed that one-third of older patients with cancer starting treatment in a usual care pathway without specific oncogeriatric involvement also experienced an information deficit on the practicalities of the treatment, self-care at home and prognosis and side-effects [30]. Another study showed that when a patient had a GA followed by a tailored GA summary with recommendations for their oncologist, patients were more satisfied with communication about aging-related concerns [11].

Most people expressed living longer as the most important treatment goal and independence in daily living as another important treatment goal. Our interviews showed that patients were unaware of the association between treatment-related functional or cognitive decline and consequent loss of independence and QOL; this warrants attention during the treatment decision process. As highlighted on the factsheet of the Dutch Cancer Federation [31], paying attention to the consequences of treatment by professionals is appreciated by patients and yields high scores on healthcare provider ratings.

Although information about different treatment options and their impact on patient-related outcomes such as independence and QOL was not mentioned as part of the treatment process, most patients were satisfied about the decision-making process. They felt that they had a say in treatment choice and participated in some form of SDM.

This study gives us unique information about patient experiences and attitudes regarding an oncogeriatric care pathway. Insights into the perspectives of patients is essential to further improve such pathways. Some recommendations made by patients can be easily implemented and may benefit future patients significantly. For example, more information about the content and the aim of the oncogeriatric care pathway prior to the visit may increase the input of patients during the consultation. This information may give patients time to prepare their thoughts on individual treatment goals.

However, our findings should be interpreted in the light of some limitations related to the generalizability and potential for bias. Generalizability could have been improved by also including participants of the oncogeriatric care pathway who opted for supportive palliative treatment. Patients who gave informed consent may potentially be relatively healthier and have a more positive attitude towards their healthcare. Selection bias may have occurred because patients were excluded who could not remember following this care pathway. Recall bias might have been an issue for some patients as time had passed since they underwent the assessment. This is a common problem in qualitative research and this study should be interpretated in light of this [32]. For future studies it would be advised to consider a shorter time span between oncogeriatric consultation and the interview. Finally, despite the high level of clinical experiences in the research team, knowledge on this topic could lead to tainted preconceptions and influence the research reflexivity. Because the nurse practitioner of the care pathway participated in the interviewing, participants may have been more hesitant to express negative experiences or perspectives. However, we propose that the time between the visit to the outpatient clinic and the interview (about 5.5 months) was enough to minimize any potential impact.

More information about patient experiences with oncogeriatric care pathways is needed. Further studies could focus more on patient wishes and goals in relationship to treatment options, decisions, outcomes, and decisional regret. Also of interest would be patients' experiences with and attitudes towards the oncogeriatric care pathway and their treatment choices when information from this study is implemented. The thoughts and preferences from the surgical and medical oncologist towards this care pathway would also be beneficial and could provide further input for a Plan-Do-Check-Act cycle to improve care for older patients with cancer.

Older patients had predominately positive attitudes towards the oncogeriatric care pathway. Most patients were satisfied with the treatment decision. Providing information on the aim and process of the care pathway, available treatment options, and treatment-related risks of cognitive and physical decline may further improve the oncogeriatric care pathway and the decision-making process.

Author Contributions

AUB, DJ and NG: designed the study. AUB, and DJ: collected data and performed analyses. YM: advised on analyses. AUB: drafted the paper. FB, JMG, YM, JP: advised during drafting process. FB, JMG, YM, JP, NG, DJ and SPM: revision for important intellectual content. All authors gave final approval of the current version of the article.

Declaration of Competing Interest

The authors declare no conflict of interest.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jgo.2024.101745.

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