



Experiences of older patients with cancer from the radiotherapy pathway – A qualitative study

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ABSTRACT

Purpose: To explore and describe experiences of older patients with cancer throughout their radiotherapy treatment, from diagnosis until follow-up after treatment.

Methods: Individual interviews were conducted to explore different phases of radiotherapy. Interviews were recorded and transcribed verbatim. Inductive content analysis was applied. Each interview was coded separately. Then to the codes were analyzed further, and an overall theme was developed.

Results: Twelve older patients with cancer, (7 male, 5 female) aged ≥ 65 related their experiences from radiotherapy treatment. A main theme describes the essence of their experiences; *Understanding "just enough"*. The theme comprises five main categories: *Understandable, adapted information is crucial for trusting health services; Previous experiences influence patients' perception and understanding; Involvement of next of kin is crucial to patients' comprehension; Professional treatment decisions and well-organized treatment determines satisfaction and Experiences of cooperation and coordination of services affects dependability.*

Conclusions: Findings from this study describe how understanding "just enough" – not too much nor too little – may assist older patients with cancer in participating in treatment decisions, preventing false beliefs, feeling reassured during treatment and in navigating the complex health care system. Next of kin are important assets for older patients with cancer in understanding "just enough". Cancer nurses may map comprehension of information, as well as reveal patients' previous experiences.

1. Introduction

Due to an aging population, the number of older patients with cancer is increasing, with two thirds of patients with cancer being ≥ 65 years (Cancer Registry of Norway, 2019; Hurria et al., 2014; Ornstein et al., 2020; Pilleron et al., 2019). An increasing number of older patients with cancer and diverse needs will require substantial health care resources for years to come. User involvement in the improvement and development of services has been advocated for years (Freeman et al., 2012; Ministry of Health and Care Services, 2016). Knowledge about experiences of older patients with cancer and their particular needs through

the radiotherapy pathway is essential for the development of adapted health services. Thus, exploring experiences of radiotherapy of older patients with cancer is crucial in identifying and accommodating their needs.

Radiotherapy is a main treatment modality in cancer, and may be given with curative or palliative intent. Typically, most radiotherapy treatments are scheduled as daily doses over several days or weeks, as outpatient care. Short- and long-term side effects occur in both curative and palliative settings, and can have substantial negative impact on quality of life and function of older patients (Bayman et al., 2010; Cleland et al., 2012). Comorbidities, cognitive problems, lack of social

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support, hearing difficulties, functional deficits, increased risk of falling and reduced nutritional status are some of the challenges facing older patients, even before embarking on the radiotherapy pathway (Puts et al., 2012; Wildiers et al., 2014). These frequently co-existing problems may affect the feasibility of daily travel or staying away from home, as well as their well-being and tolerance of treatment (Ministry of Health and Care Services, 2009; Wildiers et al., 2014). Long distances between treatment facilities and patients' homes are also burdensome, separating patients from family and friends (Ambroggi et al., 2015; Fjose et al., 2016).

Multi-professional involvement is essential in cancer care for older patients. The Norwegian health care system comprises specialist health care in hospitals and primary health care, which includes general practitioners (GP), cancer nurses, nursing homes and home health services. This organization is a complex system, where the distribution of tasks and responsibilities within and across sectors is not always clear to the patient (Ministry of Health and Care Services, 2009). In addition, managing older patients' complex needs requires contribution from a variety of health care professionals and collaboration across sectors (Syse et al., 2012). Participation from next of kin is also frequently needed for patient support (Andersen et al., 2018).

The World Health Organization focus on "Ensuring healthy lives and promot[ing] well-being for all at all ages" (United Nations, 2020). The complex health care of older patients may result in a correspondingly complex treatment pathway (Grimsom, 2013). Although older patients' care and treatment needs seem distinct, regular challenges concerning over- and under-treatment and unmet needs are reported (Puts et al., 2012; Syse et al., 2012; Wildiers et al., 2014).

Information needs are reported to be one of the most common unmet needs amongst older patients with cancer, and are elevated among patients recently referred to radiotherapy, further affected by e.g. gender and age (Puts et al., 2012; Smets et al., 2013; Smith et al., 2017). Patients' reported satisfaction with the information they receive, decrease with age. Additionally, low education levels – more frequent in older patients – had a negative effect on patient satisfaction (Jimenez-Jimenez et al., 2018). Patients want to stay informed of their situation, including bad news (Matsuyama et al., 2013). A Norwegian study of older cancer patients reports that patients have little access to information about their illness and its consequences and complications - as well as advice on nutrition and physical activity (Guldhav et al., 2017). This may lead to an increased symptom burden or additional worry for patients. As older patients with cancer are a heterogeneous group, Jimenez-Jimenez et al. (2018) suggests tailoring information to patients' needs.

A review of patients' self-reported information needs throughout the cancer trajectory shows that information needs vary both among patients and throughout treatment, and points out a gap in knowledge about patients' information needs (Fletcher et al., 2017). Studies rarely focus on the entire experience of radiotherapy, from diagnosis until treatment is completed, and there is a lack of descriptions from patients' perspectives (Egestad, 2013). We have not found studies of experiences

from older patients with cancer before, during and after radiotherapy. This study aimed to explore and describe the experiences of older patients with cancer receiving radiotherapy before, during and after treatment.

2. Design and methods

Exploring and describing the patients' experiences calls for a qualitative approach, comprehending and promoting the patients' voices. This study has a qualitative, explorative descriptive design, with in-depth individual interviews. Qualitative interviews aim to increase knowledge about the experiences of participants in relation to a particular phenomenon. In this study, the phenomenon explored is *experiences from undergoing radiotherapy*, made explicit by the research question:

What characterizes the experiences of older patients with cancer before, during and after radiotherapy?

We report according to the COREQ checklist for qualitative studies (Tong et al., 2007).

2.1. Recruitment and setting

As previous research describing experiences of older patients with cancer before, during and after radiotherapy is sparse, we aimed to explore a wide range of patient experiences. Therefore, the inclusion- and exclusion criteria (see Table 1) aimed to obtain heterogeneity in the sample. Participants were recruited through purposive sampling from two treatment facilities in Norway: one at a larger university hospital and the other at a smaller local hospital with a catchment area covering one of Norway's eleven counties. Diversity in gender, age and aim of treatment was requested from the researchers in the recruitment process. Through the patient record system, project nurses identified eligible patients by the end of their treatment. If there were uncertainties concerning eligibility, they consulted the treating oncologist. They also approached patients and informed about the project. Patients who consented to participate had their contact information shared with researchers. Researchers contacted participants two weeks after completing radiotherapy to schedule interviews.

We aimed to recruit 12–16 participants. In accordance with exploration of experiences through individual interviews (Braun and Clarke, 2013), we considered the material obtained sufficient for analysis after 12 interviews.

2.2. Data collection

One interview per participant was scheduled. These were conducted between December 2018 and July 2019, mainly in participants' homes or at researchers' offices, with one participant being interviewed in a rehabilitation facility. All participants had completed radiotherapy 4–6 weeks prior to their interview. Five participants requested their next of

Table 1
Inclusion and exclusion criteria.

Inclusion criteria:	
Treatment facilities	Local hospital University hospital
Age	≥65 years
Gender	Men and women
Medical care	Any cancer diagnosis AND Nearing end of Radiotherapy
Scope of treatment	≥5 fractions
Aim of treatment	Curative and Palliative
Prognosis	Life expectancy >6 months*
Language	Norwegian, written and spoken
Consent	Must be competent to give consent to participation
Exclusion criteria:	Patients who – based on an overall assessment of their health condition – were considered too fragile or ill to participate*

*evaluated by a physician and/or registered nurse at the radiotherapy ward.

kin's presence during the interviews, to assist them if needed.

An interview guide was used, focusing on the person's experiences associated with:

- i. The period before radiotherapy started
- ii. The period during radiotherapy at the hospital
- iii. Everyday life after treatment was completed, including follow-up from the municipal health care services and from the hospital

Distributing interviews between researchers was deemed advantageous, as interviews were conducted in two different hospital regions. Two researchers conducted seven interviews with participants from the local hospital (GE and ØK) and two researchers the remaining from the university hospital (LM and BE). All four researchers who conducted the interviews are co-authors of this report. Interview duration averaged 37 min. All interviews were audio recorded and transcribed verbatim. Transcripts were not returned to participants. The first author entered the project after the interviews were conducted, as a PhD Fellow (from October 2019).

2.3. Data analysis

Inductive content analysis was conducted (Elo and Kyngäs, 2008; Elo et al., 2014). The first author performed the analysis, guided by GE. All co-authors were involved throughout the process, and there was a consensus regarding themes. Throughout the entire analysis, we aimed

Table 2
Excerpt from analysis from open coding to grouped codes (sub-categories) in step two.

Assortment of Codes from Open Coding of Interview P1	Grouping (Sub-Category)
1.1 Uncertainty of the meaning of blood test results (uncertainty of the meaning of test results)	2.1 Uncertainty for the patient is a consequence of vague treatment plans in an early phase
1.2 Physician doubting what can/should be done based on test results	
1.3 Perceives something is not right (but does not know what)	
1.4 Annoyed with diffuse answer regarding further treatment	

Table 3
The abstraction process from sub-categories, to main categories, to the main theme.

Sub-Categories	Main Categories	Main Theme
Uncertainty for the patient is a consequence of vague treatment plans in an early phase Experiences of having received information and understanding the need for radiotherapy It is crucial to communicate information in an understandable manner and everyday language Being informed and updated on your health condition, and possible side effects due to radiotherapy treatment, is significant	Understandable, adapted information is crucial for trusting health services	Understanding "just enough"
Previous experiences with cancer or illness influence patients' response to the current situation A need to not assume the worst	Previous experiences influence patients' perception and understanding	
Next of kin involvement throughout the treatment on the patients' initiative Experiences of insufficient involvement and information of the next of kin Experiences of competently included and cared for next of kin	Involvement of next of kin is crucial to patients' comprehension	
Emphasizing the importance of treatment decisions being left with health care professionals Patients' satisfaction with the course of treatment and care at the hospital	Professional treatment decisions and well-organized treatment determines satisfaction	
Uncertainties in patients from inadequate coordination and distribution of responsibilities between municipalities and the hospital The experience of reassurance from an established contact with home health care	Experiences of cooperation and coordination of services affects dependability	

to reflect the participants' experiences as truthfully as possible. Thus, we report both commonalities as well as unique experiences held by single participants.

Inductive content analysis can be organized in three phases: Preparations, organization and reporting (Elo and Kyngäs, 2008). During the **preparation phase**, all the transcripts were read to obtain a "sense of whole". Thereafter, meaning units were identified in each separate interview. If one meaning unit contained several meanings, multiple codes were assigned to cover all aspects of the statement.

The **organization phase** comprised five steps, starting with *open coding* (step I). To get an overall impression, each interview was read separately. Then, the meaning units of each separate interview were openly coded using Microsoft Word. Meaning units in each interview interpreted to have similar meaning were given the same codes. All twelve interviews were coded separately, resulting in 491 codes (ranging from 31 to 55 codes per interview). We assembled a *coding sheet* (step II) with the 491 codes from all twelve interviews. Thereafter, we *grouped the codes* (step III) into sub-categories (see Table 2).

We generated sub-categories from codes with similar meaning, and grouped them by their common denominators. *Generic categorization* (step IV) involved further analysis and abstraction of the contents, where the different sub-categories were named. Further *abstracting* the contents (step V) by analyzing the 14 sub-categories resulted in five generic main categories. Main categories were labeled with the intent to preserve participants' own descriptions.

The reporting phase involved abstracting a theme from the main categories. Thus, the *theme* describes the participants' overall experience before, during and after radiotherapy.

2.4. Ethical considerations

This study was approved by the Data Protection Official (DPO) at the hospital in question 9.26.18, and reported to the Regional Ethics Committee (REC no. 2018/1068), but the study did not require approval as no individual health data was collected. Participants provided written consent to participate in the study, as well as verbal consent to recordings at the time of the interviews.

Interviewing older patients with cancer, particularly palliative patients, calls for special ethical concern. Interviews were conducted by experienced researchers in the homes of participants if desired, to ease any possible strain. Interviews were scheduled according to

participants' wishes. Next of kin participated upon request.

3. Results

The final sample comprises 12 participants; seven males, five females, aged 66–80 (average 73). Nine participants had received treatment with a curative intent, and three were in a palliative setting. The treatment regimen ranged from five to 35 daily fractions. An additional four patients consented to participate, but died before their scheduled interviews. Beyond these, due to the specifics of the recruitment process, it is not possible to verify how many patients were approached in total.

A number, P1–P12, represents participants to identify their individual statements.

The interview guide was organized to reflect three phases of treatment, in accordance with the aim of the study. However, the analysis revealed that participants viewed their experiences with the treatment pathway as a continuous process. The categories presented disclose the experiences of older patients related to the overall theme. Five main categories represent the main theme: *Understanding "just enough"*. Table 3 provides an overview of these categories.

3.1. Understandable, adapted information is crucial for trusting health services

Patients' experiences of the importance of information as well as how health care personnel disseminate information was significant.

Uncertainty for the patient is a consequence of undecided treatment plans in an early phase. Waiting for test results and not being sure if their symptoms would be taken seriously caused multiple participants to feel uncertain or even lacking trust in health care personnel. However, when test results were received, and the physician made final treatment decisions, patients felt reassured. One participant described being frustrated with his physician, as the physician was not able to give a definite response as to which treatment to schedule.

[...] the doctor telephoned, "I have doubts about what to do", he said. P1 [curative]

Ten participants talked about experiences of receiving information and understanding the need for radiotherapy. They found it reassuring when their physicians informed them about courses of treatment, despite the situation being severe.

That you have a person you feel you can trust, who gives you the information you seek. Even if it is good or bad. P9 [palliative]

Written information was administered prior to treatment, as well as a printed radiotherapy schedule. An informational assembly was also held. Most participants concluded that they acquired the information necessary in their situation; exceptions were one curative and one palliative patient.

Information communicated in an understandable manner and everyday language is crucial. Excessive use of medical language, as well as unclear information about side effects, made participants worried. When asking questions, some received unclear answers.

Not all doctors are equally skilled at informing. There is something called "speaking clearly". P5 [palliative]

Participants referred to many physicians as overly busy. However, when the participants felt they had the physician's full attention during their appointment, they felt reassured. Several participants asserted they had not received advice on preparatory actions prior to treatment. However, others described how they prepared for treatment, suggesting they had been adequately informed.

There are so many things that are said, so much going on, that even though you are alert and functioning, I feel there are things that I fail to notice. P7 [curative]

Participants had received contact information for the radiotherapy ward. Although being encouraged to contact health care personnel, none had done so. When questions about their treatment or health condition arose, participants were uncertain with whom to inquire.

I actually got enough time [for my appointment], but I feel that as you get older you have more things to ask, and you don't know where it belongs. P4 [curative]

3.2. Previous experiences influence patients' perception and understanding

Participants applied their previous experiences with illness to their current situation. Ten participants referred to narratives about how their previous experiences with cancer or illness could influence their response to the current situation. Narratives even dealt with close relations, or fellow patients. The subject of the experience was of little importance, but the impression left by these narratives played a crucial role in contextualizing their current situation.

It seemed that prior positive experiences made participants take a more positive outlook on their current situation. Furthermore, prior bad experiences also affected participants as they received information, treatment and experienced side effects.

[...] My mother had cancer. [...] So I've been deliberating for a long time. Will I get hysterical if I get this diagnosis? P8 [palliative]

All but one participant expressed a need to not assume the worst. Some coping strategies were hands-on, like chewing food thoroughly. Awaiting results after examinations, and not jumping to conclusions, was also a way of coping. Participants coped by learning to accept the situation, and maintaining a positive attitude. Most participants had a positive attitude towards their treatment and its outcome, and tried to go about their lives as usual.

If you do not try to be a bit happy, then your situation worsens. P8 [palliative]

3.3. Involvement of next of kin is crucial to patient's comprehension

Involvement of next of kin was crucial in coping throughout the radiotherapy. All but one participant talked about how they involved their next of kin throughout the treatment on their own initiative. Involvement of next of kin included transportation and helping to remember information, as well as next of kin providing reassurance and companionship during treatment. Next of kin are highly important in participants' everyday lives, and it appeared natural that they participate at the informational assembly, consultations and in the waiting room.

When I am there to receive my tests results and such, I'm a wreck, you know. Therefore, she is with me. [...] I am so scared, so nervous. But she [next of kin] can perceive topics of importance. P2 [curative]

In addition, three participants expressed insufficient involvement and information of next of kin explicitly, and felt their spouse or family member did not receive sufficient care. Some described how their children and grandchildren were insufficiently informed, resulting in a lack of support from them or loss of mutual understanding of the situation. This was a negative experience, which caused an additional strain on

these participants.

Six participants described how they experienced their next of kin competently involved and cared for. The next of kin were recommended – or at least allowed to – participate in consultations as well as ask questions.

My daughter goes with me to every doctor's appointment and to the cancer ward [...]they say she can ask as well, about everything. P2 [curative]

3.4. Professional treatment decisions and well-organized treatment determines satisfaction

The skill and expertise of health care professionals at the hospital provided a basis for trust throughout treatment. The importance of treatment decisions being made by health care professionals was emphasized. Most participants trusted and respected their physicians, and their recommendations concerning treatment. Some were involved in decisions regarding treatment, especially when there were multiple treatment options, or when receiving palliative care. However, some described feeling unsure when left with treatment decisions.

[...]Now you can go home and "google" about this, and then decide if you should have radiotherapy. [...]A doctor should not say such a thing. P3 [curative]

All participants described satisfaction with the course of treatment and care at the hospital. They considered hospital staff highly skilled at their jobs. Most participated in the planning of their radiation times. Having their opinions acknowledged seemed meaningful and positive. However, in contrast, one participant expressed dissatisfaction at not being able to affect the times of treatment.

[...]You just had to take the appointment you received, I think. Because it was pretty crowded down there. P8 [palliative]

The treatment was expeditious, according to most, with little or no delay. The informational assembly was a helpful experience, letting participants meet people in situations similar to their own. The presence of volunteers in the ward was a positive contribution to the participants' well-being, as they provided a friendly atmosphere and made the participants feel like "ordinary people".

3.5. Experiences of cooperation and coordination of services affects dependability

Coordination of services varied in quality between different hospital wards and between the hospital and municipal health care. Well-functioning cooperation reassured participants, while indistinct coordination led to worry.

Most participants were concerned whether their GP was informed about their treatment and health condition. However, those who had seen their GP regularly, found that they were informed about their current health status. Two stated not being happy with their GP's follow-up, preferring follow-up from the hospital.

I have a feeling that my general practitioner doesn't know what is going on. P6 [curative]

The participants felt that seeing multiple physicians led to worries that each of the physicians were concerned solely with their own areas of expertise, and that their treatment lacked cohesion.

[...]I think I've seen, not to exaggerate, I've seen fifteen-twenty doctors. [...]It's ridiculously many. P7 [curative]

A single participant explicitly stated that seeing the same two physicians throughout treatment provided a feeling of familiarity.

Discharge involved unpredictable arrangements with municipal

health care. One participant was to receive rehabilitation at a facility, but this was not resolved until the day of discharge. Others described physiotherapy at home, home rehabilitation and follow-ups, but these issues were not resolved with participants before discharge and led to uncertainty.

- Will you receive services from the municipality for further rehabilitation at home?

- I don't know if I am eligible. I'm unsure. P11 [curative]

Some participants had read that a nutritionist or a coordinator would be available after discharge, but these were not available when participants inquired. Eight participants described that they were encouraged to contact home health care or the cancer nurse in their municipality if necessary. The hospital had provided them with a phone number, but the participants were reluctant to make contact.

The experience of support from an established contact with home health care was apparent. Participants who received services from home health care, continued to do so during treatment, and viewed this as reassuring as these personnel also provided information about rest, activity, and nutrition.

Participants found the cancer nurses in the municipal health care to be someone to talk to, for support and guidance. Two participants had regular appointments with the cancer nurse in their municipality, and found this helpful.

I felt she really had plenty of time, and she took care of me, and I am sure she also had a busy schedule, but I didn't notice. P4 [curative]

4. Discussion

In this qualitative study, we have aimed to describe the experiences of older patients with cancer before, during and after radiotherapy. The main theme – Needing to understand "just enough" – refer to participants' needs related to their understanding: the need to be well-informed, and the need to prevent information overload.

This study indicates a need to pay special attention to older patients' information needs. Most participants were content with the information they had received. In spite of this, all three palliative patients found information about treatment unclear in an early phase, suggesting they were uncertain regarding what to expect. Information provided to patients must be relevant, trustworthy, structured, objective and concrete, as well as easy to understand (Andersen et al., 2018; Nordsveen and Andershed, 2015; Smith et al., 2017; Tärnhuvud et al., 2007; van Ee et al., 2019).

Assessing patients' information needs and tailoring information to the individual creates an opportunity to facilitate proper support for older patients with cancer (Jimenez-Jimenez et al., 2018; van Weert et al., 2013), and make sure each patient receives appropriate information; "just enough". However, one study argues that tailored information may have little effect, as poor tailoring was not associated with worse patient reported outcomes (Douma et al., 2012). Some reasons given for this are challenges with understanding patients' individual needs, or quality of information being more important than quantity. This brings up the concern of how and when to inform patients. Providing the right information at the right time is a key factor in enabling patients to cope (Fjose et al., 2018; Mills and Davidson, 2002).

Exploring previous experiences seemed to aid participants in understanding "just enough". A majority of participants mentioned previous experiences with cancer or other illnesses, and impressions from these experiences influenced their current situation. The effect of one's own – or significant others' – previous treatment experiences is described in a review of factors influencing older adults' decision making (Puts et al., 2015). When receiving information, negative experiences may be a source of uncertainty. Positive experiences may strengthen confidence. However, they may also produce false

expectations in the current situation.

Dreading their prognosis appears to be a commonly held concern by participants. Understanding “just enough” proposes a balance between knowing all details, and deficient knowledge and understanding. Several other studies also found that patients worry about their prognosis (Egestad, 2013; van Weert et al., 2013). This supports our findings where all participants expressed the desire to be informed of their condition in an understandable manner. Considering this, one study points out how the use of complex language is common among oncologists (Chou et al., 2017). This may hinder conversation about patients’ treatment, as well as discussion regarding their prognosis, as information is not perceived correctly by the patient. Several studies point out how older patients may suffer insecurities or have inaccurate beliefs about the effects of their treatment (Chen et al., 2013; Egestad, 2013; Golden et al., 2017), and understandable information is key in preventing false beliefs (Chen et al., 2013). While some patients understand the difference between curative and palliative treatment intents (Smith et al., 2017), this is not the case for all (Chen et al., 2013). If a patient does not realize that treatment has palliative intent, consequences could be severe. The patient might either falsely hope for recovery, or they are unknowingly robbed of the opportunity to conclude their life.

A great asset to older patients with cancer appears to be their next of kin, as they participate alongside patients during their treatment, provide practical as well as emotional support, and help patients to remember and understand “just enough”. Difficulties in absorbing and retaining information is a known challenge for many patients with cancer (Skalla et al., 2004). During their treatment, participants experienced little encouragement to include their next of kin. Former studies support the deficient inclusion of next of kin, but the responsibilities of health care professionals are apparent: The next of kin must be secured as an important resource (Balducci and Fossa, 2013) and given more professional attention (Osse et al., 2006). Being close to a patient with severe illness like cancer, families may require support or health care themselves (Ministry of Health and Care Services, 2020). A number of studies have pointed out both the practical and emotional support provided by informal caregivers (Andersen et al., 2018; Hjörleifsdóttir et al., 2008; Mills and Davidson, 2002; van Ee et al., 2019). A huge reliance on family caregivers among older adults is of great importance (Kahana et al., 2016; Ornstein et al., 2020), and support from spouses is described as equally or even more helpful than professional help (Hjörleifsdóttir et al., 2008). This demonstrates that next of kin are important resources in supporting the increasing number of older patients with cancer.

Understanding “just enough” also factors into decision-making. Some participants expressed a wish for physicians to make treatment decisions for them. This is consistent with former findings indicating that older patients tend to have greater faith in health care professionals (Kahana et al., 2016; Mills and Davidson, 2002) and that the most consistent determinant in accepting or declining treatment is physicians’ recommendations (Puts et al., 2015; Smith et al., 2017; van Ee et al., 2019). This may cause the patient to become passive in treatment decisions (Kahana et al., 2016), which demands special awareness from health care professionals. A great support in understanding the experiences and preferences of each patient may be interaction with a cancer nurse. Through revealing previous experiences of patients, cancer nurses can help patients understand “just enough” to partake in treatment decisions, or even allow for patients to withdraw from participating in decision-making.

The balance between being sufficiently informed and intimidated seems paper-thin. One participant described how she dreaded the side effects presented to her. When informing patients about possible side effects of their treatment, it is important to keep in mind that while most want to be informed (Freeman et al., 2012), this does not mean that everyone does (Skalla et al., 2004; van Ee et al., 2019). Understanding “just enough” may assist patients in being prepared, but excessive information can lead to feelings of worry. Thus, some information may not

benefit the patient (Halkett et al., 2009). Nuances in the information provided, and greater attention paid to what patients perceive, may offer the chance to rectify misunderstandings. In this study, patients who were in contact with home health services or a municipal cancer nurse found these encounters to be a great support, also in understanding “just enough”. This is supported by others, who reported that access to a cancer nurse led to increased access to information (Guldhav et al., 2017).

Uncertainty caused by not understanding a complex health care system and lacking knowledge of the division of tasks shines through in experiences of older patients with cancer. This has also been described by others: Not all patients and next of kin are aware, or well informed, about what care home health services may provide (Nordsveen and Andershed, 2015). Some studies describe how patients are given a contact telephone number if they need to contact health services during their treatment (Andersen et al., 2018; Tomlinson et al., 2014). In our study, this was also the case, but none of the participants made such contact with any of their health care providers. This may be due to frequent contact with radiotherapy wards during treatment, and the fact that uncertainty decreases over time, as according to both qualitative and quantitative findings (Astrup et al., 2015; Hsien et al., 2013). However, participants were also left to contact home health services themselves after treatment was completed. This may suggest that health care professionals transfer accountability to patients. Health care personnel should provide guidance in understanding the health care system to enable patients to identify any instance where they are not provided with the appropriate care, in order to procure the care they require, particularly with older patients with cancer.

This study shows the crucial importance of good cooperation and coordination, as the complex treatment pathway through the Norwegian health care system may lead to feelings of worry for older patients. And, patients’ feelings of worry may be appropriate. Frustration with services due to lack of continuity is also described elsewhere (Fjose et al., 2018; Smith et al., 2017). Inadequate information about comorbidities and patients’ abilities during transfers from hospital to municipal health service, increases risk of errors (Grimsmo, 2013). Thus, it is important for specialist care and municipality care to cooperate, and to communicate their mutual understanding to patients. A cancer nurse offers the chance to facilitate cooperation and communication.

4.1. Methodical considerations

Sample heterogeneity is considered one of this study’s strengths. The material contains rich depictions and varied experiences, and is considered saturated and a sufficient sample (Malterud et al., 2016). Field notes were not taken during- or after interviews. However, we consider no essential information was lost because of this. Dividing the interview guide into three parts – corresponding to phases of treatment – may have hindered participants wishing to convey their narratives freely. Participants did not relay their stories chronologically, in contrast to the construct made by the researchers. However, this may have been necessary to ensure experiences from all phases of treatment. The interview guide was not revised, as no pilot test was conducted. When four researchers collected data, having a detailed interview guide may contribute to equal conduction of all interviews. This makes the thorough interview guide a strength. Five of the participants attended their interview accompanied by their next of kin, who commented or asked clarifying questions to help participants retell their story. As the analysis shows, these significant others are important assets as they accompanied participants throughout treatment. Participants did not provide feedback on findings.

4.2. Implications for practice

Clinical judgement of health care personnel is important in assisting patients in understanding “just enough”. Although demanding, the

situation of each individual patient needs consideration. The needs of patients with cancer change across the cancer continuum (Puts et al., 2012), and service must reflect the needs and preferences of patients and their informal caregivers (Freeman et al., 2012). This makes knowledge of their needs and preferences crucial.

The health care system's complexity may cause unnecessary challenges for patients. A cancer nurse – if involved throughout treatment – may map the comprehension of information, as well as reveal patients' previous experiences.

5. Conclusions

This study describes experiences of older patients with cancer before, during and after radiotherapy. The findings indicate there is still potential for improvement in radiotherapy for older patients, as patients need to understand “just enough” throughout treatment. Understanding “just enough” – not too much nor too little – may assist in preventing false beliefs in treatment effects and consequences. Next of kin can assist patients in understanding “just enough” through assimilating information, and they are important assets for patients. Additionally, health care personnel must display their familiarity with patients' illness, in order to make patients feel reassured throughout radiotherapy. Also, understanding “just enough” enables older patients to participate in treatment decisions, helps them both to feel reassured during treatment, and navigate the complex health care system.

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CRedit authorship contribution statement

May Ingvild Volungholen Sollid: Conceptualization, Formal analysis, Writing – original draft. **Øyvind Kirkevold:** Conceptualization, Validation, Investigation, Writing – review & editing, Supervision, Project administration. **Marit Slaaen:** Conceptualization, Methodology, Validation, Writing – review & editing, Funding acquisition. **Bente Ervik:** Validation, Investigation, Writing – review & editing. **Line Melby:** Validation, Investigation, Writing – review & editing. **Grethe Eilertsen:** Formal analysis, Conceptualization, Methodology, Investigation, Writing – review & editing, Supervision, Project administration.

Declaration of competing interest

The authors have no conflicts of interest to disclose.

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