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Research article

What matters to you? – Free-text comments in a questionnaire from patients undergoing radiotherapy



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ABSTRACT

Background: Most cancer patients undergo external radiotherapy (RT) at some stage during their treatment trajectory and RT is often associated with unfamiliar procedures in a highly technical environment. The purpose of this study was to explore how patients experience RT and the related processes, as described in free-text comments in a large Swedish survey with questionnaires including items on psychosocial climate and treatment environment.

Methods: The data consisted of free-text comments from one open-ended question: “Is there anything else you want us to know” and were analysed using qualitative content analysis.

Results: Of 825 returned questionnaires, 261 contained free-text comments from patients (32%). The hand-written, free-text comments reflected the patients’ experience of the RT process and were abstracted into the four major categories with sub-categories: experiencing the high-tech RT environment, understanding the RT procedures and side effects, dealing with daily life during RT, and the nurses’ role and performance. The categories reflect the patients’ experiences and emphasize how important it is to evaluate what really matters to the patients when changing procedures, practices, and how to minimize disturbances in the patients’ daily lives.

Conclusion: The main conclusions from this study are that the involvement of patients in choosing daily appointment times, providing good information during the RT process to make the patients feel safe, experience and attitude of the staff and respect for the patient’s autonomy are highly ranked values for patients. An implementation of person-centred care may help relieve many of these problems.

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Introduction

About 50% of all cancer patients undergo external radiotherapy (RT) at some stage during their treatment trajectory [1]. The short (10–20 min), daily RT sessions range in number and most patients undergo adjuvant and/or curative RT during three to eight weeks. There are different ways to schedule the daily treatment time, in some departments patients are scheduled on specific time-slots and some departments use a “drop-in” system where patients can choose their own time during the day of treatment. RT is often associated with unfamiliar procedures in a highly technical envi-

ronment and play a major part in the patient’s experience of the treatment [2]. The patients often have to undress, lie still on a treatment couch and be alone in the RT room behind a closed door, whilst being monitored by staff through a surveillance camera. For certain types of RT, immobilization devices that restrain the patients on the treatment couch are needed to prevent patient movement during treatment [2].

The RT environment may affect the patients in various ways. Feelings of claustrophobia and anxiety are not uncommon [2–5]. Most patients also suffer from some form of RT-related toxicity, which often impact on the overall experience. The acute side effects normally appear after 10 days of RT and continue to increase during the treatment and up to 90 days after end of RT. These side effects vary in nature and intensity due to both treatment- and patient-related factors and arise in tissues with a

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high cell turnover rate, for example gastrointestinal mucosa, skin and bone marrow [6,7]. Acute radiation skin reactions is one of the most common side effects and affects up to 95% of the patients receiving RT [6,7].

Because of the extreme and unfamiliar environment, giving adequate information to patients undergoing RT and their families is important. Studies have shown that a major part of person-centred care (PCC) involves giving the patients the opportunity to be actively involved and to feel as if they are partners in the decision making process [8,9]. To achieve this, the RT staff needs to inform and invite patients and their families to be active participants in the RT-related processes.

In Sweden, in contrast to many other countries, registered nurses, who have one-year post-graduate specific oncology and RT education (RT nurses), deliver RT to cancer patients. In many other countries RT technicians, radiation therapists or radiographers perform these tasks. The education and training of RT nurses includes both radiotherapy technology and specialist cancer nursing, which includes providing education, information and counselling to the patients [10].

Including an open-ended question in questionnaires is common practice to invite patients to add, in their own words, further information [11]. A study by Riiskjear et al., has shown that using comments from patient surveys seems to be a promising way to collect data from patients. The free-text comments can be a valuable addition to the use of patient-reported outcome measures (PROMs) and may provide deeper insights into the data and add the patients' perception to quality improvement [12–14]. The aim of this study was to describe patient experiences of RT from free-text comments in a large Swedish survey.

Methods

Study design

In this study we used a qualitative descriptive design [15]. The data were derived from a larger project, development and validation of a questionnaire to measure patients' experience of external RT treatment [16].

Participants

Before inclusion, the participants received verbal and written information concerning the study aim, voluntary participation, and assurance of confidentiality. After informed consent was obtained, the anonymously completed questionnaires were collected in a sealed box on the RT units. Ethical approval was obtained from the Regional Ethical Review Board in Umeå, Sweden (Dnr 2014/40–31).

Participants were recruited from eight RT units in Sweden in May 2014. Adult outpatients scheduled to receive curative, adjuvant or palliative external-beam RT were eligible to participate. Exclusion criteria were: incapacitating psychosis or cognitive disabilities, <18 years of age, and insufficient Swedish language skills. The nurses and/or receptionists at the RT units distributed the questionnaires.

Data collection

The data consisted of free-text comments from this questionnaire analysed with qualitative content analysis. At the end of the questionnaire the patients were given the possibility to answer one open-ended question: "Is there anything else you want us to know?"

A total of 937 questionnaires were distributed and 825 were returned, representing a response rate of 88%. Out of 825 returned

questionnaires, 261 contained free-text comments from patients (32%).

Sample characteristics

The sample consisted of 38 % men and 62% women with a mean age of 63 years. The most common treatment-sites were chest (43%), abdomen (26%) and H&N (13%). Two percent of the patients had just completed their first RT session, 56% had completed 2–15 sessions, and 42% had completed 16 or more sessions (Table 1).

Analysis

A qualitative content analysis with an inductive approach was conducted [17,18]. The first step was familiarisation with the data by transcribing the handwritten free-text comments to an electronic document, and reading each comment several times to obtain a sense of the whole [19]. For the second step, meaning units, e.g. comments relevant for the study aim, were imported into OpenCode 4.03 (ICT Services and System Development and Division of Epidemiology and Global Health (2013), a tool for coding qualitative data generated from text. The meaning units were labelled with a code capturing its core. In the third step, codes with similar meanings were organised into subcategories based on how they were related and linked. Finally categories were abstracted from the subcategories' inter-relationships. For trustworthiness reasons, peer debriefing was employed throughout the analysis to enhance credibility [20]. The codes and categories were discussed and negotiated between the authors (KO, UÖ and LS) until consensus was reached. Examples of meaning units, codes, subcategories and categories are given in Table 2.

Results

The hand-written, free-text comments (1–161 words long) reflected the patients' experience of the RT process and were analysed into four major categories with sub-categories (Table 3).

Experiences in the high-tech RT-environment

This category describes the patients' experiences from the environment at the RT unit and comprises two subcategories.

Table 1
Patient characteristics (n = 825).

Characteristic	All respondents n = 825 (68.3)	Free-text n = 261 (31.6)
<i>Patient related characteristics</i>		
Age (years) Mean (standard deviation)	64.6 (11.6)	63.1 (11.6)
Gender		
Male	348 (42.2)	98 (37.5)
Female	444 (53.8)	163 (62.5)
Data missing	33 (4)	0 (0)
Completed RT sessions		
Treatment 1	38 (4.6)	6 (2.3)
Treatment 2–15	456 (55.3)	145 (55.6)
Treatments ≥16	286 (34.7)	110 (42.1)
Data missing	45 (5.5)	0 (0)
Treatment Area		
Brain, Head and Neck	123 (14.9)	34 (13.0)
Chest/Thorax	297 (36)	111 (42.5)
Pelvis/Abdomen	240 (29.1)	69 (26.4)
Other	105 (12.7)	43 (16.5)
Data missing	60 (7.2)	4 (1.5)

Table 2
Examples of meaning units, codes, sub-categories and categories.

Meaning units	Codes	Sub-categories	Category
The temperature in the treatment room is a bit too cold – but I can handle it. The treatment is delivered in a completely unnatural position. It's hard to be completely relaxed when your back hurts	Cold in the treatment room It's an unnatural position to lay in Hard to be completely relaxed	An uncomfortable experience enhanced by environmental details	Experiencing the high-tech RT-environment
Excellent staff that makes you feel safe The nurses are wonderful, without them I hadn't experienced the situation as well as I do today. And they (the staff) always take time to answer questions	The staff makes you feel safe The staff encounters contribute to a better experience The staff takes time for me	The atmosphere at the RT unit is due to encounters with the staff	

Table 3
Overview of categories and sub-categories.

Category	Sub-category
Experiencing the high-tech RT-environment	An uncomfortable experience influenced by environmental details The staff encounters contribute to the atmosphere at the RT unit
Understanding the RT procedures and side effects	A need to understand what RT is and does Better information improves my understanding of the RT process
The nurses' role and performance	The nurses care for me with compassion The nurses are professional and improve my experience
Dealing with daily life during RT	Involvement in scheduling my RT appointments Waiting for the daily RT session is frustrating The disease and treatment affect my life

An uncomfortable experience influenced by environmental details. In this sub-category, patients' described how they experienced the physical and the psychological environment in the treatment room and how they felt during treatment. Some patients described a negative reaction to the RT environment and that the environment negatively affected the working staff. Some patients described the treatment room as cold, while others described the feeling of being almost naked and exposed during treatment.

"I experience the temperature in the treatment room as a bit chilly. Nobody has asked me if I freeze. I am undressed during treatment"
[54-year old woman]

Some patients described details during the RT that improved their experience, such as artwork on the ceiling or the possibility to listen to music during treatment. In contrast, some patients described environmental factors that caused discomfort, such as hard treatment couches, sharp lighting or disturbing noise from the RT equipment.

The staff encounters contribute to the atmosphere at the RT unit. Some patients described how the attitudes and responses from the nurses and other staff made them feel welcome, comfortable and safe.

"It is a good place to come to when being treated for cancer. You feel safe even when you are feeling sick"
[65-year old woman]

Some patients described encounters that did not meet their expectations.

"I feel the nurses are stressed and don't have time to answer questions".
[57-year old woman]

Understanding the RT procedures and side effects

This category describes the patients' need for information and support during their RT experience and comprises two subcategories.

A need to understand what RT is and does. The patients described a need for more technical information about RT and how it works. Some patients even expressed that they did not know the rationale for why they were undergoing RT. Others were worried about risks or side effects and wanted explanations in case something unexpected happened.

"I would have appreciated if the staff told me what happened and explained why the treatment patterns sometimes deviate from the normal procedure. That would make me less worried. It is important to announce when leaving the treatment room and when they return."

[22-year old woman]

Some patients asked about management of skin changes and other side effects during RT. Some wanted more information on how RT impacts their body.

"I would like to receive information about what happens when my RT is over – for how long do the side effects, for example diarrhea, continue?"
[74-year old woman]

Better information improves my understanding of the RT process. Some patients described that they needed and received information from several sources such as nurses, family members and/or friends. Some were satisfied with the RT information and that their questions were answered appropriately.

"If more information was needed during the treatment process, as it was in my case, I asked and received a clear and good answer. There is a lot of information provided during your first appointment, and you can't grasp it all and remember it."
[71-year old man]

Other patients described the need for more continuous and repeated information during the treatment, and also gave suggestions for improvements, e.g. better written information with clarifying illustrations that explained the principles of RT. The improved written information was believed to be helpful for both patients and their significant others. Another suggestion was to improve the information about the waiting times for the daily sessions; one patient proposed an information screen in the waiting area with regular updates.

The nurses' role and performance

This category describes patients' relationship with the nursing staff, and comprises two subcategories.

Level of compassionate care from nursing staff. Some patients described the RT nurses as compassionate, patient and having good bedside manners.

“I’m so grateful for their patience and with the precision they work, and how they take care of me.

[58-year old man]

However, some patients described negative experiences related to the nurses being stressed and lacking understanding for the patients’ difficult and vulnerable situations. That could result in poor clinical communication.

“I feel that the nurses are stressed and don’t have time to answer questions” [57-year old woman]

The nurses are professional and improve my experience. Here the patients describe the nurses as professional, knowledgably and thorough in their work. These skills are described to improve on both the clinical information exchange and the safety.

“I think that the staff is fantastic, I feel calm and safe during my treatments. They inform me well. They do everything they can to make practical things work as smoothly as possible” [63-year old woman]

Dealing with daily life during RT

This category describes how the patients’ daily lives were impacted by the visits to the RT units and comprises three subcategories.

Involvement in scheduling my RT appointment. Some patients described how the RT appointments disturbed their daily lives, especially if they could not influence the scheduling. More personal influence on the scheduling was a common suggestion to improve the RT experience and to help patients manage their daily lives. One patient even stated that not being able to alter the appointment times was an invasion of his/her integrity that could have been avoided. Even here, some patients gave practical suggestions to improve the booking process and to make it more individualised. One suggestion was to place a computer in the waiting area, or a web-solution, that allows the patients to reserve their daily sessions, as they preferred. Some RT units offered “drop-in” appointments, during parts of or, the whole day in order to give patients the opportunity to choose their own appointment times. This model was described as a very good solution that allowed flexibility and involvement. However, in some cases this routine generated long waiting times that negatively affect the patients’ daily lives.

“I experience that there is a certain amount of fuss to get an appointment during the hours I prefer, I’m a single mum. Finally I got the appointments I asked for, but is very tiring to explain and nag every week when they provide us with next week’s schedule” [41-year old woman]

Waiting for the daily RT session is frustrating, when there is waiting times. Some patients described how frustrating it was to wait for treatment if the waiting time was long in the case of drop-in appointments or if there were delays. One patient described that she even considered quitting the treatment due to the long waiting times and the negative effects this had on her daily life. She found it inhuman to wait for hours each day. However, other patients described little or no waiting time, or even being treated before the scheduled appointment, and that this

had a positive impact on their RT experience. A 60-year old woman summarises her negative experience from a RT unit with drop-in appointments:

“I would absolutely have preferred to have set appointments instead of drop-in. It is impossible to predict the waiting time and plan for other appointments during the day. Today, for an example, there were 10 patients before me in the queue, yesterday it was two at the same hour. The time for treatment is negligible in comparison to the waiting time.” [60-year old woman]

The disease and treatment affect my life. Some patients described how the side-effects made them worried and tired. Some described how the uncertainty with the appointment times made it difficult to combine treatment, working and other activities such as physical activities. Other patients explained how they had succeeded to combine the RT session and other daily activities.

“I’m not the only person that works during treatment, and I get stressed by not being able to plan my days better. I’m told that exercising is important, but having RT, leaving and picking up the children at daycare, and working as well, you don’t have any time left. If I had a set time every day, I could have been able to plan my days better” [39-year old woman]

Discussion

These findings represent an attempt to explore patients’ experiences of the RT process, as described in their own written texts. The results comprise descriptions related to the patients’ experiences of the high-tech RT environment, understanding procedures, effects from RT, contact with the nurses and dealing with daily life during RT.

We found that the high-tech RT environment could contribute to feelings of worry and discomfort but encounters with staff could also contribute to more positive experiences and make patients feel safe. That an RT unit is an unfamiliar environment that causes worry has been reported earlier [21]. Furthermore, patients describing a higher person-centred psychosocial climate at RT units report lower levels of situational anxiety [5].

Providing good information about treatment and procedures, as well as appropriate communication, are of particular relevance for patients undergoing RT [22,23]. This was confirmed in the current study where patients described a need to understand the RT process, technical issues, and what happens in the body. The patients also described the need for more continuous and repeated information during the RT process. Douma et al [24] found that patients’ need for information decrease over time. The patients in the present study also gave several suggestions on how to improve the information, e.g. improved written information with clarifying illustrations. A previous report supports the use of preparatory information and education to improve outcomes in cancer patients undergoing RT and chemotherapy [25]. Our findings indicate that there are potential benefits of repeating information during the patients’ RT to increase their knowledge and understanding. The information may be more beneficial if it is individualized, presented in multiple formats, and provides both procedural and information regarding side-effects during the treatment.

Our study showed that the RT nurses influence patients’ experiences both by how they interact with the patients and how they perform the treatment. This agrees with findings that encounters with radiation therapists have a significant influence on the patients’ experiences [26]. Previous studies have shown that nurses’ guidance and support can improve the perceived quality of care [10,23,26–29]. Patients in our study also described nurses being *compassionate*. Compassion has been defined as “a virtuous

response that seeks to address the suffering and needs of a person through relational understanding and action” [30]. Compassion has been highlighted as a core dimension of quality care and related to PCC [30]. Our findings agree with the findings of Halkett et al [31] who concluded that the radiation therapists play a central role in enabling patients to achieve a sense of *emotional comfort*. Patients achieved this sense of comfort by forming relationships with radiation therapists and by gaining information.

RT services must find ways to give patients better possibilities to impact their care. One of the most important issues raised in this study is related to the daily appointments. The fact that many patients report little or no possibilities to impact this important factor, is a great concern. Several patients offered suggestions for improvements that could be implemented relatively easily, and hopefully these improvements would improve the patient involvement and patient experience. Not having enough impact on the daily RT appointments makes daily life more difficult, as described by other authors [32]. Some RT units had implemented drop-in appointment as an attempt to better meet these needs, and this strategy was experienced as both positive and negative. We have little information on the implementation process of this strategy, and we found no formal evaluation. Ekman et al. [8] state that when PCC is introduced the team, including the patient, should evaluate all aspects of management, taking in account treatment options that are suited to the patient’s lifestyle, preferences, beliefs, values and health issues”.

Limitations

There is an ongoing discussion about the value of free-text comments in questionnaires [33]. One of the challenges with using open-ended questions can be the analysis of the data due to the lack of structure or design, where the data are not purposefully or systematically collected [33]. In our study we conducted a rigorous analysis following the steps of qualitative content analysis [18,20]. Furthermore, all authors discussed codes and categories both for trustworthiness reasons [20] but also to guarantee methodological expertise throughout the whole analysis [33].

It has also been argued that respondents may not be representative of the population surveyed, and it may be difficult to estimate how many participants will take the opportunity to write comments [13,34–36]. In this study with a qualitative design, the sampling is a matter of judgement of the quality of data and its relevance for the study aim [37]. The thirty two percent of patients who answered the questionnaire and took the opportunity to write free-text comments could be criticized for not being representative for the population. Respondents that write comments can be more articulate than those who do not, or have a critical or negative comment to make [38]. The reason why many respondents did not respond to the open-ended question could be lack of time, or finding it difficult to express themselves in writing, or simply not having anything more to add. It is important for the reader to consider the transferability of the results instead of its generalization [39]. However, we argue that our results give an insight into aspects of patient experiences from RT, and these insights can improve our understanding and knowledge. Other authors [14,40] have also concluded that open-ended questions helped capture a broader picture of patient experiences than closed-ended questions may.

Conclusion

The main conclusions from this study are that the involvement of patients in choosing daily appointment times, providing good information during the RT process to make the patients feel safe,

experience and attitude of the staff and respect for the patient’s autonomy are highly ranked values for patients. An implementation of person-centred care may help relieve many of these problems.

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Declaration of Competing Interest

None of the authors report a conflict.

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