

## Original Article

# A survey of prostate cancer patients' perceptions of the support they receive during radical radiotherapy: is there room for improvement?

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## Abstract

**Aim:** The aim of this study was to ascertain prostate cancer patients' perceptions of the quality of physical and emotional support they receive as standard during their course of radiotherapy treatment.

**Method:** Semi-structured interviews were conducted on 13 patients undergoing radical radiotherapy treatment for prostate cancer. Interviews were conducted between fractions 32 and 37 and data were analysed using the Giorgi method.

**Results:** A number of themes emerged from the data including, interestingly, the value of patients' place on the 'waiting room support' with 46% finding this to be a positive aspect of their experience. On the whole, patients felt well supported during their treatment by both radiographers and fellow patients. However, the results highlighted areas for further improvements, particularly around bowel and bladder preparation.

**Conclusions:** This small single-centre study has highlighted the importance of good quality, timely information provision. Although patients were, for the most part very happy with the services they were being provided with, areas in need of development were also highlighted. If a more structured review process is to be further investigated then the role of the 'review radiographer' should be considered as part of this. The potential benefits of patient peer support is also worthy of further exploration.

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**Keywords:** patient support; prostate cancer; radiotherapy; radiotherapy side effects

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## BACKGROUND AND PURPOSE

Patients undergoing a radical course of prostate radiotherapy in the United Kingdom are routinely treated over seven and a half weeks (Monday to Friday).<sup>1</sup> This, along with associated side effects of radiotherapy can have a significant

impact on quality of life.<sup>2</sup> Short-term side effects such as diarrhoea, radiation cystitis, frequency and nocturia affect sleep and wellbeing, and can interfere with social activities, making the patient feel isolated and increasing anxiety.<sup>3</sup> Long-term side effects such as erectile dysfunction can affect personal relationships.<sup>4</sup>

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During a patient's radiotherapy treatment it is important that they are supported holistically by

treatment staff in order to minimise stress and anxiety, and adequately deal with the associated side effects,<sup>5</sup> however, the pressures of a busy radiotherapy treatment unit often mean that the support provided is insufficient.<sup>5</sup>

There is consensus within the literature that information and support play a huge role in reducing stress and anxiety and improving the patient's journey as a whole.<sup>2,5-10</sup> Cancer patients have individual and diverse needs that need to be taken into account when developing a support structure. Dubois and Loiselle<sup>8</sup> reported that the information and support needs of cancer patients often went unmet, with patients frequently reporting dissatisfaction with this aspect of care. This view is supported by Owens et al.,<sup>11</sup> who found that coping strategies for dealing with the cancer journey were severely affected when patients were not adequately supported during treatment, both physically and mentally. Current practice at the host department is such that patients only undergo a review if it is deemed necessary by the supervising clinician, or a medical need arises during treatment meaning the individual patient needs additional support. If these reviews occur then it is often to purely provide medication for side effects.

## METHODS AND MATERIALS

In total, 13 prostate cancer patients, undergoing a course of radical radiotherapy, participated in one-to-one semi-structured interviews. The sample was recruited and interviewed over 2 months.

### Sampling

Convenience sampling was used to establish the sample, and participants were recruited on a voluntary basis.

The reasoning behind choosing 13 participants as a sample size is that the radiotherapy department treats at least this many prostate patients at any given time.

A sample size of 10–13 is supported by the work of Bowen et al.<sup>12</sup> It was considered that at this sample size it would be unlikely that any new themes would emerge from the gathered data, therefore making it unnecessary to subject more

patients to interviews unnecessarily. This is known as 'saturation', a notion derived from Glaser and Strauss's<sup>13</sup> Grounded Theory.

Potential participants were approached by the researcher during their radiotherapy appointments, between treatment fractions 6 and 10. This time point was decided upon as it was felt that the patient had gained some experience of radiotherapy and would have begun to 'settle' into treatment. Potential participants were given an information sheet to explain the study and its potential benefits to future patients.

All patients approached agreed to take part in the study.

### Inclusion and exclusion criteria

#### *Inclusion criteria*

- Patients having radical radiotherapy to the prostate.
- They were between fractions 6 and 10 at the selection dates.

#### *Exclusion criteria*

- Patients who had not yet reached fraction 6.
- Patients who had undergone brachytherapy before undergoing external beam radiotherapy.
- Patients involved in other trials.
- Non-English speakers.

It was felt that it was beyond the scope of this study to explore the quality of life issues of patients who had undergone brachytherapy, as these patients have undergone an invasive procedure, which could be responsible for side effects and any quality of life issues. This study focusses specifically on external beam radiotherapy effects and experiences, and inclusion of these patients could potentially impact the validity of the results. However, this group of patients may be of relevance during future research.

### Interviews

Interviews were conducted between treatment fractions 32 and 37, in order to give participants sufficient time to decide if they want to

**Table 1.** Question/prompt sheet

Questions	Prompts
Do you feel that you were given the right amount of information before you started radiotherapy treatment?	By consultant At planning On day 1 of treatment Was there anything that you feel could have been better explained regarding treatment, side effect, outcomes, any other issues?
How were you feeling in yourself when your treatment started?	Tired, stressed, emotional, urinary problems sleep problems, bowel problems, bloating, skin problems, pain and any other co-morbidity
How were you feeling after 2 weeks of treatment?	Tired, stressed, emotional, urinary problems sleep problems, bowel problems, bloating, skin problems, pain and any other co-morbidity
How are you feeling now?	Tired, stressed, emotional, urinary problems sleep problems, bowel problems, bloating, skin problems, pain and any other co-morbidity
Do you feel comfortable discussing any of these problems during you treatment appointment with the radiographers?	Why?
Would you prefer to discuss any problems in a separate review appointment?	Why?
Who would you like to have that appointment with	Doctor, nurse, radiographer Why?
How often would you like to have had a separate review appointment?	Weekly, after 2 weeks, as and when, not at all
What are you overall thoughts about your radiotherapy experience?	Good, bad, significant

participate to, and also for them to have experienced the majority of their course of treatment, including any side effects/issues which they may experience during treatment.

The interview was recorded, allowing the researcher to facilitate a more conversational style interview.<sup>14</sup> The interview was semi-structured, with the interviewer using a prompt sheet to guide the interview, allowing the participant to expand on their answers and speak freely about their experiences, generating important qualitative data.

The questionnaire was devised by the researcher and then quality checked by a sample of radiographers who have clinical experience in dealing with the information and support needs of this category of patients. Open-ended questions were used with additional prompt words available to the researcher if required (see Table 1).

### Data analysis

Due to the qualitative nature of the data gathered and the fact that the primary aim was to find out

patients' perceptions of the support they were receiving, the phenomenological approach was considered the most appropriate.<sup>15</sup> Phenomenology is a philosophical theory of the way humans experience consciousness, developed by Husserl in 1962.<sup>13</sup> This approach focusses on individuals' interpretations of their lived experiences and the ways in which they express them.<sup>14</sup>

The data were analysed using the Giorgi method of analysis,<sup>15</sup> which is a descriptive form of phenomenology. The rationale being that it provides a more structured analysis framework, subsequently enabling a more accurate analysis be undertaken by reviewing interview transcripts to look for emergent themes in respondent's opinions, and these themes were used to evaluate the outcome of the study.

Giorgi emphasises that quality, rather than quantity of data is important, and advocated a three-stage analysis method. Stage one involves reading through all of the data, to get a 'sense of meaning'. Stage two involves looking for 'meaning units' or common themes, expressed

by the patients, and stage three involves further investigation of these themes, to fully understand meaning.<sup>12</sup>

The interview recordings were kept securely within the radiotherapy department until they were transcribed by the researcher. Recordings were then deleted and paper transcripts will be kept securely within the department for 7 years, (as per National Research Ethics Service (NRES) guidelines) for the purposes of audit, in a locked filing cabinet, securing anonymity. To further preserve anonymity, only the researcher transcribed the interviews, and was privy to any personal data.

### **Ethics**

The use of informed consent in this study provides a sound ethical base.<sup>16</sup> Participants were given an information sheet, which emphasised anonymity, the right to withdraw and the researchers contact details.<sup>16,17</sup> Written consent was also obtained before each interview commenced.

These measures aimed to minimise any anxiety that the patients may have suffered during the study.

## **RESULTS**

In total, 13 patients participated in semi-structured interviews between fractions 32 and 37 of their course of radical radiotherapy for prostate cancer. Following analysis of the data, a number of common themes emerged.

### **Happy with the support received**

All patients responded positively when asked about how they perceived the quality of support they received from the radiographers during treatment sessions. No participant admitted to feeling rushed at all when discussing any issues, treatment related or not, and felt that all problems and questions were dealt with effectively and in a timely manner. In all, 9/13 (69%) patients at the point of interview had experienced a range of different treatment-related side effects and felt that the radiographers were able to deal with these appropriately. The remaining four patients admitted to not discussing certain side effects with the radiographers, as they felt that the

information that they had received on the first day of treatment, during the 'first day chat' (also with a radiographer) had provided them with enough information to manage and cope with side effects on their own.

When asked about whether they had felt any anxiety or stress during the treatment, all but one of the participants had not. Two admitted to being apprehensive on the first day, the 'fear of the unknown', however, they felt that the first treatment experience set them at ease. One participant felt that his side effects were causing him some stress, as he was experiencing sporadic bouts of diarrhoea and problems with sleeping, leading to a perceived loss of control. However, he could not fault the support and advice he had been given, it was managing the side effect in the context of his day-to-day life, which he found stressful.

### **The waiting room 'support group'**

In all, 6/13 (46%) participants admitted finding their experience in the waiting room a positive one. Similar treatment sites are block booked in the radiotherapy department, to facilitate efficiency on the treatment unit, and this in turn leads to groups of the same prostate cancer patients attending at the same time each day. This means that they often sit together in the waiting room, allowing them to build relationships. This was mentioned repeatedly during the interviews, and it was always discussed in a positive light. It seemed patients took great comfort in the support they could give each other. One participant even said he looked forward to coming daily to see everyone, and referred to it as his 'little social club'.

### **On-treatment review**

In all, 10/13 (76%) felt that they would not have benefited from an on-treatment review, mostly saying that they had felt supported well enough during treatment sessions. Two stated that they would have liked to have had a review with a radiographer towards the end of treatment, as side effects were beginning to become an issue. One patient who did not feel the need for review actually stated that he thought it may cause more stress than benefit as it would involve additional time in the department, causing issues with travelling.

Reasons for wanting a radiographer to perform these reviews were that the patients felt that as they were seeing them daily, they were the ones who most understood what the patient was going through, as opposed to a doctor or a nurse. The third patient felt he would have liked a review with the consultant he was being treated under, 'just to wrap everything up and advise on the next steps'. He did, however, acknowledge the workload of the consultants was high and that this may not be possible, in that case he would have been happy with a radiographer conducting this review.

### **Information and support before treatment**

There were mixed responses from the patients regarding the information and support they had received prior attending for treatments. In all, 9/13 (69%) participants said that they had been well briefed by the consultant during their consenting appointment, and the presence of a Macmillan nurse was often commented on and praised. One patient who had been referred from a smaller local hospital commented that he had not received any written information, however, two other patients commented on how much written information they had been given, one stating that it was slightly too much. One patient had also had his treatment plan changed a number of times due to co-morbidities, and he felt that these changes had not been fully explained to him.

### **Bowel and bladder preparation**

The one criticism of radiographer treatment support was that some participants were unsure of their bowel and bladder preparation. This issue was raised by 4/13 (31%) of the participants. At the researchers institution prostate cancer patients are treated with a full bladder and an empty rectum, which involves the patient using a daily enema and drinking a measured volume of water to a timed schedule.

## **DISCUSSION**

### **Information and support**

Information and support of the cancer patients is discussed extensively within the literature. Dubois and Loisel<sup>8</sup> reported that the adequate

provision of information and support greatly reduced stress and anxiety among newly diagnosed cancer patients. They did, however, find that some patients reported poor support in face-to-face situations, from health-care professionals, stressing the need for health professionals to be well timed in the adequate and timely provision of information.

McParland<sup>9</sup> also supports the notion that high-quality information and support is very important when dealing with a cancer diagnosis, describing it as the 'cornerstone of holistic care'. His study specifically focussed on prostate cancer patients, and found that they expressed a need for considerable amounts of information, often at different stages of their journey, and the provision of this was key to reducing anxiety and enhancing the decision-making process.

### **Social support: waiting room 'support group'**

It was interesting that participants discussed the support that they received in the waiting room from other patients. This point was raised several times, unprompted by the interviewer, showing that it is a common area of important support which patients benefit from, out-with the clinical context. Participants all viewed this support in a very positive light, being able to share common experiences, and explain things to each other in, perhaps a more understandable, or lay manner. It was also commented upon that the newer patients very much appreciated the support of the more experienced patients, setting them very much at ease.

Queenan et al.<sup>18</sup> suggested that social support can play a vital role in improving the cancer patient's quality of life, underlining the importance of the patients studied developing supportive friendships with each other in the waiting room. Zhou et al.<sup>10</sup> also support this view, suggesting that good social support improves coping strategies, and can act as a 'buffer' to the treatment process. They found that positive social support was greatly associated with reduced anxiety and higher emotional wellbeing. When asked about stress and anxiety levels, participants all denied experiencing any to a great degree,



other than first day anxiety, and the stress of coping with some side effects. On this basis, it could be argued that the social support patients receive in the waiting room plays a significant role in reducing stress and anxiety, therefore improving quality of life.

Both of these studies discussed patients' social support in their day-to-day lives, not specifically from others in a similar situation; however, it is felt that the shared experience of cancer diagnosis and radiotherapy treatment can only serve to enhance the support, which patients are able to give to each other.

### **On-treatment review**

Patients had mixed reviews on whether they felt they needed a review appointment during treatment. In the most part, patients said that they did not need this service, however, it could be argued that as they have never had such an appointment, it is not something that they feel that they have missed out on. It is also encouraging from the above discussion that patients do seem to feel well supported, both from their peers, and by treatment staff. Despite these findings, it is important to recognise that the literature does support the implementation of such a service, and that extra patient support can only ever be a good thing. It is felt that although only three patients admitted to wanting extra support, the views of those patients are still valid, particularly as these views are supported by much of the existing literature.<sup>4,5,19,20</sup>

Lees<sup>5</sup> discusses how having a separate regular review appointment is in the patients best interests, so any treatment-related problems can be dealt with effectively. She also discussed that due to the increasing workload of oncologists, more and more often, radiographers were undertaking this role and supports the implementation of these posts. Cameron<sup>19</sup> supported this view, concluding that radiographers have the necessary skill base to undertake such a role. However, there is little evidence surrounding the radiographer review role, and what exists is somewhat ambiguous.<sup>19</sup> Often it is based on assumption rather than empirical evidence,<sup>11</sup> however, Ellis et al.<sup>20</sup> do discuss how radiographer led review

services are becoming more prevalent, feeling that they are ideally placed to provide such a service, due to their ability to build relationships with patients, and their extensive knowledge of radiotherapy treatments and side effects.<sup>5</sup> Radiographers will routinely inquire about side effects and general wellbeing; however, as discussed by Ellis et al.,<sup>20</sup> they are limited by time constraints to provide the best possible support. The literature also stresses the importance of utilising the experience and support of the multi-disciplinary team.<sup>6</sup> It is therefore imperative that more is done in this area to ascertain who should review patients and at what time points to provide the best possible patient care.

### **Bowel and bladder preparation**

It is also important to note that participants highlighted that they struggled with understanding how and why they needed to do bowel and bladder preparation. This information is given to the patient at least twice before treatment commences, which may indicate that they are suffering higher levels of stress regarding the treatment than they are admitting, leading to them not absorbing all the information they are being given. A way of minimising this could be to actively involve family members or friends who have come to support the patients, to facilitate better retention of information.<sup>20</sup> Another reason for this lack of understanding may be that the patient does not fully understand the rationale behind the treatment preparation, and the importance of it. Patients often find aspects of the preparation difficult or uncomfortable, and therefore may not comply. It may be that the radiographers, in a bid to not overwhelm the patient, are not discussing the reasons for the preparation in enough detail, so the patient does not fully understand the importance of it.<sup>20</sup>

This preparation is important in ensuring the accuracy of radiotherapy, however, it seems that despite patients being informed about this verbally and in written form, it is still an issue. One patient commented that he did not know WHY he was doing the preparation, which may indicate that it is necessary to provide more of a scientific reasoning rather than just instruction on HOW.

## CONCLUSION

This small single-centre study has highlighted the importance of good quality, timely information provision. Although patients were, for the most part, very happy with the services they were being provided with, some issues were still raised showing areas in need of development. This study also shows that the prostate cancer patients' needs are very multifaceted and interlinking, for example, good patient support being complemented by good peer support.

It is hoped that the findings from this study will support the further enhancement of an already well-run service, further developing patient support and information provision, particularly in the area of bladder and bowel preparation, as this has an important role to play in treatment accuracy. There is also a need for further exploration of the role of the radiographer in facilitating and leading this review process as well as the value of 'waiting room support', and how as health-care professionals we can utilise effectively the benefits of this aspect of patient/peer support. The literature has shown that the needs of the cancer patient are individual and ever changing, and as a profession, radiographers need to respond and adapt to those needs effectively.

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## Ethical Statement

The authors assert that all procedures contributing to this work comply with the ethical standards of the National Research and Ethics Service guidelines on human experimentation, and with the Helsinki Declaration of 1975, as

revised in 2008. Ethical approval was gained from the National Research and Ethics Service.

## Conflicts of Interest

The author declares that there are no conflicts of interest.

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