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A review of the results from a patient experience survey of the palliative radiotherapy bone metastases service

Sarah Jayne Griffiths

The Radiotherapy Department, Bristol Cancer Institute, Bristol Hematology and Oncology Centre, Horfield Road, Bristol, BS2 8ED, UK

Original Article

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Author for correspondence:
Sarah Jayne Griffiths, The Radiotherapy Department, Bristol Cancer Institute, Bristol Hematology and Oncology Centre, Horfield Road, Bristol, BS2 8ED, UK.
E-mail: Sarah.Griffiths@UHBW.nhs.UK

Abstract

Introduction: A patient experience survey was undertaken as part of the role of the Macmillan Consultant Therapy Radiographer for the bone and brain metastases patients to inform future development of the service.
Method: A questionnaire was developed and approved by the Trust's local Questionnaire, Interview and Survey Group to survey the experiences and satisfaction of the service including the informed consent process, radiotherapy appointments and overall experience and satisfaction. The survey used qualitative and quantitative methods, including Likert Scales and free comment boxes. The responses were analysed by counting the frequency of each response and identifying any themes in free text responses.
Results: Most patients were satisfied with the consent process with 1/36 patients reporting a lack of understandable information and 4/36 wanting more side effect information. The option of plan and treat was a preference of 53% of patients due to travelling back and forth to the centre; however, only 6% stated that they wanted two separate appointments. Ninety-four percent of patients felt that they had complete confidence and trust in the professional who consented them and 86% did not feel fully involved in the decision-making process. Overall, the service was rated as 10/10 by 61% of patients ($n = 36$).
Conclusions: The patients surveyed were satisfied with their experience of the Palliative Radiotherapy Service; however, it needs to be developed further to meet the needs and expectations of the service users.

Introduction

Skeletal metastases cause pain in 60–84%[1] of cancer patients with advanced disease, and palliative radiotherapy can have a significant impact on alleviation of this symptom. Trials of uncomplicated bone metastases show that 75–95% of patients will have a response with 50–60% having partial relief and 25–40% a total response.[2]

Rapid access to treatment can reduce distress and unnecessary symptom burden[3] and improve quality of life[4]; however, patients were facing delays in referral for treatment due to two factors within the department. A shortage of Clinical Oncologists (CO) nationwide in the UK resulting in vacant posts[5] and depending on the timings of outpatient clinics and the CO's planning session for palliative work, patients were waiting up to 7 days following their initial clinic appointment, before being planned and up to 28 days to be treated with an average time of 13 days (data collated for the Macmillan Application from MosaiQ). Within this waiting time, patients' symptoms could have changed, and further assessment and intervention may be required.

A Macmillan Consultant Therapy Radiographer (MCTR) was introduced into the pathway to reduce the average time that patients waited for treatment and to enhance the experience and satisfaction for this group of patients. The MCTR has responsibility for the entire pathway including patient assessment, informed consent, radiotherapy planning and prescribing, on-treatment review including the prescribing of supportive medication and telephone follow-up.

The job description for the post specifies the requirement for yearly patient and carer satisfaction surveys to identify areas for improvement in routines and practice to develop the service. Collecting patient-reported experience measures through regular surveys provides the impetus for service improvement that will meet the needs and preferences of the patient.[6,7]

Method

A questionnaire was developed and sent to the Proposal for Questionnaire, Interview and Survey Group (QIS) within the Trust in August 2020 to be reviewed and with minor amendments was accepted in September 2020 (see Appendix 1).

The MCTR wanted to assess the opinion of the service provided to ascertain the experience and satisfaction levels about the quality of care and communication, both verbally and written, between patient/carer and the service throughout the pathway from consent/referral to treatment. The questionnaire was divided into three sections to facilitate this:

- Consent for radiotherapy.
- Radiotherapy appointments.
- Overall experience and satisfaction.

The survey used both quantitative and qualitative methods to 'help gain broader perspectives than would be achieved by using one predominant method alone'.[8] A Likert Scale was used as it easily understood, there is an increased rate of response and the data collected are easy to quantify when analysed.[9] A 3-point Likert Scale was used as it allowed the respondents a choice including one option that was neither positive nor negative. The final question in the survey for the overall experience and satisfaction of the service used a 1–10 scale as it provides more options; however, a study in Norway found that a 5-point scale was better suited for a patient experience questionnaire.[10] Closed responses were used for questions where there was only the possibility of a yes or no response. Free comment sections allowed respondents to write comments or explain their responses in their own words about their satisfaction and experiences of the service.

Convenience sampling was used for ease and efficiency. Patients receiving emergency or urgent treatment were excluded. All participants were provided with an information sheet explaining the evaluation, contact details for the MCTR and a questionnaire. Consent was implied by the patient/carer completing the questionnaire and returning it in a sealed envelope to the radiotherapy reception desk. Anonymity and confidentiality were preserved by assigning each questionnaire with a number identifier.

Patients with bone metastases in October/November 2020 (abandoned due to COVID-19) and September/October 2021 were invited to complete a questionnaire to assess satisfaction and experience of the palliative radiotherapy treatment pathway. Out of 50, 36 questionnaires were completed in 2021 and returned which was a response rate of 72%.

Results

Consent for radiotherapy

The MCTR consented the highest number of patients ($n = 23$).

One patient felt that they did not receive enough understandable information when they were consented by a CO.

Information about the possible side-effects of treatment was not adequate as reported by four patients of which the MCTR consented 1 and CO the remaining 3.

All the patients felt able to ask questions and there was just 1 who only partially understood the answers they were given.

Out of 36, 32 patients received an information leaflet.

Patients/carers were given the opportunity to explain any reason why they had responded no to any of the consent section questions. The four patients who did not receive an information leaflet commented with the following response:

- No leaflet, previous radiotherapy.
- No leaflet already had one.
- No leaflet, quite possibly had one – I have had quite a few leaflets.
- No leaflet, it was very short notice.

The one patient who did not receive a leaflet was seen by the MCTR.

Radiotherapy appointments

One patient felt that they had waited too long for their appointments.

Fifty-three percent of patients would have liked plan and treat on the same day and the reasons given for that choice were

- Save extra travel.
- Did have the scan on the same day as treatment.
- Did have treatment same day.
- Transport.
- Travelling to Bristol is an inconvenience.
- It would make the process quicker, as all done in a single visit.
- Convenience of travel.
- To help with transportation.
- Reduces stress, no need for second journey and parking fees.
- Only 1 trip to BHOC from South Gloucester instead of 2.
- Because of the travel distance, time, availability and parking, it makes a total of 8 hours for x2 appointments.
- Just because the journey to and from hospital is quite painful so fewer journeys the better.
- Just to save another trip to the hospital.
- More convenient.
- No return journey.
- Save travelling to the unit twice.
- Would have reduced number of visits to the hospital required.

The patients who wanted treatment on another day gave reasons of 'just personal preference' and 'it would have been too much'.

The remaining 15 patients had no preference to when they had radiotherapy and 4 gave reasons why. This included 'I just needed the best treatment for me,' 'at this time any appointment is a bonus,' 'useful to allow a bit of processing time' and 'based on the most convenient time for the team' (Chart 1).

Thirty-two patients received advice about how to deal with their pain. The remaining 4 chose 'not applicable'.

Eight patients responded 'no' to the question 'Did you receive contact details for the Macmillan Consultant Radiographer and the Radiotherapy Aftercare Service?'

Overall experience and satisfaction

The patients were asked about their levels of confidence and trust in their CO/MCTR and how involved they felt with the decision making process about treatment and care (Table 1).

Table 2 shows the percentage response rate to overall satisfaction with the service.

Patients were given the opportunity to add any additional comments that they may have:

- Great treatment during these challenging and difficult times. Thank you all.
- I am grateful to being seen so quickly from having a MRI in the same week.
- Very helpful.
- Thanks to the NHS for everything you are doing.
- I would just like to say that the operation was carried out in a very professional manner with every part being explained during the course of the visit to radiotherapy department, quite a painless operation!

Table 1. Percentage response rates

	Yes, completely	Yes, to some extent	No
Did you have confidence and trust in the Doctor/Consultant Radiographer that you saw?	94%	6%	
Did you feel involved in decisions about your care and treatment?	86%	14%	

Table 2. Percentage response rates to patient's overall satisfaction using a Likert Scale

How would you rate your overall experience of the Palliative Radiotherapy Service at Bristol Cancer Institute?									
1	2	3	4	5	6	7	8	9	10
				3%		6%	13%	17%	61%

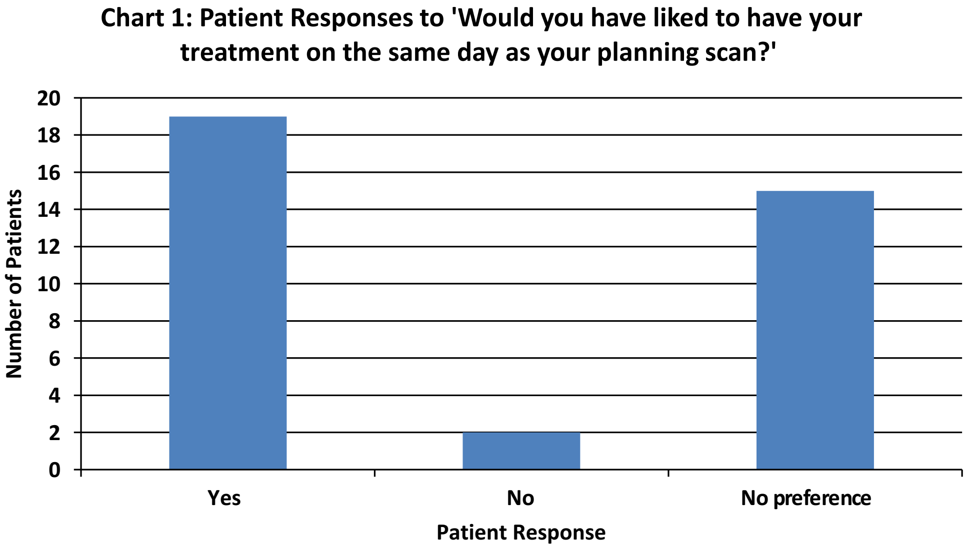

Chart 1. Patient responses to 'Would you have liked to have your treatment on the same day as your planning scan?'

- Excellent. Thank you!
- Excellent service as always, staff fantastic.
- Helpful pleasant, grounded people to be around thank you.
- Excellent care by all staff.
- Very good.

Most patients rated the service as 10/10. Of the patients who rated 7, 8 and 9 only one patient left a comment – 'I would just like to say that the operation was carried out in a very professional manner with every part being explained during the course of the visit to radiotherapy department, quite a painless operation!' and gave a score of 9/10.

Discussion

The questionnaire was approved in September 2020 and the data collection started the following month. However, this coincided with the second wave of COVID-19 in England,[11] so the survey was halted as per Trust guidelines until September 2021 when data collection resumed. There was an excellent response rate[12] to the survey, and overall, the patients were very satisfied with the service provided.

Consent for radiotherapy

The MCTR consented most of the patients due to the increasing numbers of direct referrals from the local Hospices, General Practitioners, Acute Oncology, Medical Oncology, Haematology and Multidisciplinary Teams. These patients attend an informed consent and radiotherapy planning session and do not attend a clinic appointment with a CO prior to their referral for radiotherapy, thus streamlining the service.

The one patient felt that they did not receive enough understandable information when they were consented by a CO did ask questions and agreed that they were given answers that they understood. The MCTR has assumed that initially the respondent did not comprehend and needed to ask questions to clarify for a full understanding.

Inadequate side-effect information was reported by four patients; however, they all received an information booklet and said that they had had their questions answered. However, the MCTR is unable to clarify whether the information was still inadequate after the questions were asked and a leaflet provided due to anonymity.

All patients felt that they were able to ask questions; however, the patient who felt they did not understand the answers given was consented by the MCTR. The respondent reported that they had received enough information about the treatment and side-effects but not in a way that was understandable. Informed consent requires a patient to make an informed decision to proceed with treatment with enough information in an understandable way regarding the purpose, efficacy, side effects, risks and benefits.[13] This raises the question as to whether this patient was appropriately consented; however, the MCTR will always ask patients if they have understood everything that has been explained/discussed at various stages of the process. This includes after the rationale and benefits of treatment, after the potential side effects and risks, after the management of the treatment toxicities and after answering any questions. This patient may have been too embarrassed to ask further questions or did not want to appear stupid not to have understood.[14]

The Teach-Back Method allows clarification of understanding[14] and a change in wording from 'have you understood' to 'I want to check that I have explained this clearly so can you tell me what we have discussed today?' by the MCTR should address this issue.

The nature of the caseload of the MCTR means that many patients are consented more than once for treatment to bone metastases, so some do not require a leaflet as they already have received one previously which was the case for two patients.

Patients receive or are signposted to many information leaflets during their treatment pathway, and many cannot remember what they have or have not received. One patient responded that they were unsure as they had had a few leaflets. The MCRT has no method of clarifying this for the survey results.

The MCTR consented the patient that did not receive written information as the treatment was 'short notice'. Emergency and urgent patients were excluded from the survey, so the assumption is that they required treatment outside of these two categories but as soon as possible. The reason why they did not get a leaflet cannot be identified though one possibility is that it was inside the treatment packet but not given to the patient as the normal practice of the MCTR is to either give the patient one at consent or place one in the wallet while the patient has their planning scan.

Due to the anonymity of the evaluation, the patient who felt waited too long for treatment cannot be quantified or any issues with their pathway identified. A study in Australia found that waiting times caused concern across the entire treatment pathway and was experienced by 31% of patients while waiting to start their radiotherapy after the decision had been made to proceed.[15] Unfortunately, any concerns that this patient may have had cannot be identified and discussed with them.

The survey responses support the need for a formal consent/planning/treatment clinic where the entire process can be done in 1 day for those patients who prefer one visit to the department. The most common theme for this type of service was to reduce the number of journeys required, thereby reducing costs for the patients. Innovative models for the provision of palliative radiotherapy can meet more than just the symptom management needs of these patients.[2]

The four patients who did not receive information regarding treatment of any pain flare after treatment all ticked the 'not applicable' box. The MCTR has assumed that these patients were either post-operative following prophylactic orthopaedic pinning or receiving treatment for local disease control which was not causing any pain.

Twenty-nine percent patients on completion of treatment did not receive details of support and advice for the 2 weeks after treatment completion. Departmental procedure states that all patients on completion of treatment should receive details of the Radiotherapy Aftercare Service which is manned by the On Treatment Review Team (OTRT), Monday to Friday, 8 am until 6 pm and their Specialist Therapy Radiographer (STR) if applicable.[16] Patients who are on any form of active treatment within the centre are also able to contact Acute Oncology Service (AOS) 24 hours a day if required and patients are given their contact number in the outpatient clinic. Acute Oncology allows access to expert advice; however, as demand for this service increases and workforce shortages impact service provision[17] patients need to have an alternative source of information, advice and support. The OTRT and STR are experts in treatment-related toxicity during and after radiotherapy so ideally should be the first point of call during their open hours for patients. This will also have the added benefit of relieving some pressure on the AOS; however, patients need to have the necessary contact details on their last day of treatment. The MCTR will ensure that all treatment machines have the necessary information to give to the patients on their last fraction.

Overall experience and satisfaction

A literature review found that patients will have a high level of trust in a doctor who has good communication and interpersonal skills.[18] Two patients indicated that they had trust and confidence in the CO/MCTR 'to a certain extent'. Further analysis of the responses of these patients showed that both felt that they did not receive enough information about side-effects and one about treatment. They also scored the service 5/10 and 7/10, respectively. The MCTR assumes that the lack of information contributed to these responses; however, whether it was communication or interpersonal skills which was the issue cannot be determined.

Patients being involved in decisions about their treatment improve patient experience.[19] Four patients felt that they were not fully involved though 3 out of 4 did not answer negatively for any of the previous questions and scored the service between 8 and 10/10. The fourth patient had indicated a lack of confidence and trust already and had scored the service 5/10. Again, the opportunity to discuss these results with these patients would enhance the survey results and inform practice.

Patient surveys provide patient feedback to manage patient experience and satisfaction and allow healthcare providers to improve services. All the additional comments were positive with the department and its staff being described as 'excellent'.

Conclusion

The survey results were positive; however, there are still areas of improvement and development. The service needs to adapt to meet patients' needs and preferences. The introduction of palliative planning clinics will enhance patient experience and satisfaction by allowing patient choice in how their care is given.

The survey must be repeated as per the MCTR's job description; however, amendments need to be made to produce richer data for analysis to enhance practice and patient satisfaction and experience. Corner et al.[20] stated that patient experience surveys need the option for a qualitative response to quantitative feedback. Patient feedback on their perceptions of their participation in the consent process including what is sufficient information and what would elicit total confidence in the person taking informed consent would help inform and improve the process within the department. The MCTR has made assumptions while analysing the data, whereas the option for the respondent to explain an answer to some questions will provide clarification on the patient's reason for their answer.

Supplementary Material. To view supplementary material for this article, please visit https://doi.org/10.1017/S1460396922000425.

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