

Original Article

An evaluation of support of patients with prostate cancer during and beyond radiotherapy treatment. A local perspective on future provision

Alison Mary Ormerod¹, Anne J. Jessop²

¹Northamptonshire Centre for Oncology, Northampton General Hospital, Northampton, Northants, UK, ²Faculty of Health and Wellbeing, Sheffield Hallam University, Sheffield, UK

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Abstract

Purpose: This study was designed to evaluate whether radiographer-led on-treatment review clinics are meeting the wider needs of prostate patients receiving radiotherapy.

Methods: Semi-structured interviews were used to elicit patient and staff perspectives. Interviews are used extensively in qualitative research to produce a breadth and depth of insight into participants' experiences and opinions. Seven patients and two radiographers participated in individual audio-taped interviews. Thematic analysis of the data identified some key themes and their perceived importance within the review service for both patients and staff.

Results: Semi-structured interviews were used to elicit patient and staff views. Several themes emerged from patient and radiographer perspectives. Radiographers and patients both expressed overall satisfaction with the service. Strengths included staff communication, relaxed environment, individualised support, regular information spread throughout the review pathway and consistency in managing acute side effects. Weaknesses included information and communication gaps at the beginning and end of treatment, information inconsistency between staff groups, gaps in specialist knowledge and a possible gap in skills where staff could train as supplementary prescribers.

Conclusion: Interviews produced an in-depth view of patient and staff experiences. Staff and patients identified both strengths and areas for improvement within the local service. Study findings support review radiographers in sourcing additional specialist training and a closer collaboration with other staff groups, which will further develop the service. As a next step, triangulation of research methods with questionnaires could be used to evaluate whether this small sample of patients is characteristic of prostate patients in general.

Keywords: interviews; living beyond cancer treatment; patient information; prostate cancer; review clinic

Correspondence to: A. M. Ormerod, Oncology & Haematology Department, Queen Alexandra Hospital, Cosham, Hants PO6 3LY, UK. Tel: +0 239 228 6000, ext 4467. E-mail: alison.ormerod@porthosp.nhs.uk

BACKGROUND

In 2010, 40,975 men were diagnosed with prostate cancer. It is the second most common cancer in men. Low and intermediate risk prostate cancer 5-year survival is reaching 98% for low and intermediate risk and 67% for high risk or locally advanced prostate cancer.¹ Consequently, many men are living with cancer beyond treatment.

The National Institute of Clinical Excellence (NICE) acknowledge uncertainties and controversies still exist in international guidelines regarding active treatment options.² Treatment choice often depends on local specialist experience, treatment provision and patient preference. Correspondingly, patients with prostate cancer may have more complex choices than most cancer diagnoses and increased anxiety levels.²

Mc Parland³ suggests information has an important psychosocial function, reducing anxiety, assisting decision-making and diagnosis acceptance. NICE emphasise the importance of adult patients understanding their diagnoses² yet studies show that many patients do not report being well informed or do not understand the complex information.^{3–5}

On-treatment review clinics

The Calman–Hine Report called for transformation of cancer services delivering nationwide equality of treatment and recognising the importance of patient quality of life.⁶ The Royal College of Radiologists⁷ called for innovation in the way oncology professionals worked together in order to deliver a better and friendlier patient experience.⁷

‘Improving Outcomes’ placed patient experience and quality of life on the national agenda alongside equality of access for treatment and best clinical practice.⁸ The concept of working within a multi-disciplinary team is well established within radiography professional guidance^{9,10} leading to development of radiographer-led on-treatment review clinics within the local radiotherapy department.

National Radiotherapy Advisory Group observed that implementation of advanced practitioner roles within radiotherapy practice has

‘demonstrated the potential to drive efficiency, reduce waiting times’ and most importantly ‘refocus radiotherapy services around the needs of patients’.¹¹ Radiotherapy radiographers while primarily technical are increasingly providing vital emotional support and information giving.^{12,13} Halkett and Kristjanson¹⁴ reported breast cancer patients strongly associated radiotherapy radiographers with emotional care and comfort.

The aim of this service evaluation was to investigate both patients and staff perceptions of on-treatment review clinics in meeting patients’ needs during and at the completion of radiotherapy treatment.

Objectives were identifying the most important issues for patients and staff and appraising relevant literature to identify ways the local on-treatment review service can better inform and prepare patients for life beyond treatment.

Local on-treatment reviews are based on the following facets of patient care.

Information giving

Surveys show UK cancer patients desire a high level of information.⁵ Hendry’s¹⁵ focus groups also put lack of information top of their agenda for improvement. Prostate patients report they need verbal information initially, supported with written material, and repetition at intervals in order to process it all.³ Douma et al.¹⁶ found certain groups, male gender, religious and poor health literacy, all scored lower for initiating or receiving information. The 2010, UK cancer survey revealed only 66% prostate cancer patients reporting adequate written information at the start of their cancer journey and 21% said their information conflicted. This improved by the end of treatment with 82% reporting sufficient information and 92% had key workers. However, worryingly only 59% felt their families got all the information they needed.⁴

Clinical assessment of acute side effects

Acute side effects from radiotherapy are assessed in on-treatment review using the Radiation Therapy Oncology Group (RTOG) acute morbidity scoring system extensively used in clinical

trials to grade severity of radiation side effects.¹⁷ Good communication and clinical skills are key to using this tool effectively and elicit information in order to assess patients accurately.

Holistic support

Douma et al.¹⁶ found information needs decrease over time where patients' receive regular support. In addition, Donohue¹⁸ identified a 'shift theory' that describes how patients' information needs develop over time. Initial focus is on diagnosis and survival but gradually there is a shift towards quality of life, chronic side effects and relational issues.

Life beyond treatment

Jaeger et al.¹⁹ report that Oncologists deliver treatment information but are less likely to talk about self-help groups or recovery after treatment. Donohue¹⁸ recommends active promotion of support groups since men often need encouragement to seek information at the end of treatment.

National Cancer Survivorship Initiative²⁰ state that 'critical to good information-giving at the end of treatment is an individualised approach, family involvement and understanding patients' wider social and psychological concerns'.

Qualitative methodology

Qualitative phenomenal research methods were chosen for this study. Phenomenology focuses on an 'intervention' viewed through participant's narratives.²¹ Semi-structured interviews were chosen to capture an in-depth picture of patients' and staff experiences.²² Patient 'stories' are powerful, inspiring and motivating health carers to drive service improvements.^{23,24}

METHOD

A convenience sample was used of all prostate cancer patients completing treatment within a calendar month. A verbal invitation with written information was given during treatment and consent obtained before the interviews. A quiet room without disturbances and ability to pause audio-recording meant issues such as acute radiotherapy symptoms did not affect patients' participation. Interviews were scheduled at the patients or staff convenience, within the local

hospital radiotherapy department. Partners were not included since many patients attend radiotherapy alone.

Data analysis

Dialogue was manually transcribed and categorised using the four facets of patient care above. Sections of dialogue were compared and smaller themes emerged. Thematic analysis was used to test the results. Methods of 'using established categories' and 'extracting categories from the data' were used to reduce the danger of distorting data to fit pre-determined categories.²² Attridge-Stirling's²⁵ 'thematic networks' formed a basis for processing data analysis to recombine categories extracted from data. The two different methods produced slightly different emphasis but the themes considered important by the staff and patients were broadly similar.

Findings

Mean age of patients was 68.7 years referred from three different local hospitals. Seven patients accepted interviews and one declined 'it's not my kind of thing'. Five out of seven patients received intensity-modulated radiotherapy (IMRT), one out of seven received short-course IMRT with brachytherapy boost and one out of seven IMRT following prostatectomy (RADICALS trial). All patients also received neo-adjuvant hormone therapy.

Both radiographers have completed an MSC Module to underpin their advanced practice.

Two main themes emerged from the interview data.

Theme	Subjects discussed
Information giving	Verbal, written, internet, friends, family Specialist information and referral (holistic care) Information at the end of treatment
Clinical assessment of symptoms	Acute side effects during treatment What to expect while recovering from acute side effects and details of possible chronic side effects. Contact details of the Urology Clinical Nurse Specialist (CNS) as ongoing key worker

General comments

Both staff felt review clinics were ‘well received’.

Information and symptom management is ‘fairly consistent between reviewers which is the most important focus’.

Radiographer-led reviews are ‘much more relaxed’.

The environment is ‘less structured’ than the doctors who are ‘rushed, sometimes overwhelmed’.

Patients’ agreed ‘I was well looked after, the girls are marvellous’.

All seven patients reported satisfaction with review clinics.

‘from the outset ... gave me the information ... any time just mention and I can see the doctor, well it puts your mind at rest’ (1).

‘helpful, positive, any questions I had were dealt with’ (2).

(I was told) ‘what side effects I might expect, to reinforce the information that I had’ (3).

‘She was lovely, it was so relaxed, we didn’t feel rushed and she put our minds at rest’ (5).

Both staff and patients rated highly the value of more time with less structure. Langen et al.²⁶ suggests good support can also contribute to better compliance with medication and advice.²⁶

Information giving

Information in all its forms was the most important theme from the data.

Four out of seven patients reported accessing ‘a lot of information’. Of these two out of seven had initially chosen active surveillance and one out of seven a prostatectomy before radiotherapy.

P5 comments ‘there is so much information around that it confuses you’.

Staff1 had recognised this concern ‘patients don’t really take in information at the start, there is a need for repetition and reaffirming’.

Staff2 ‘need for consistent information and assessment’.

Mc Parland³ agrees emphasising the need for repetition and different formats of information.

Others lacked information. Two out of seven had successfully accessed the Urology CNS for additional support. One out of seven felt he had missed information ‘I wish I’d asked more questions’.

Two out of seven had not understood the purpose of daily imaging during treatment.

P5 reported review clinics were not always explained before the first visit.

‘I didn’t know what the reviews were for, patients’ are asking each other ‘what are they for, who is doing them?’.

I thought ‘I would be reviewed by a doctor’, however ‘once I had been, I understood’.

Two out of seven patients expressed concerns regarding information omissions at planning and treatment commencement. Although information had been clarified during first review they felt that this caused ‘anxiety and should not have been necessary’.

Inconsistencies included ‘dietary and topical cream advice’ (P5) and being warned about daily enemas; ‘this could have been a barrier to treatment’ (P3).

Six out of seven patients said they were satisfied with information given during and at the end of treatment.

‘I was well prepared, no surprises’ (3).

French found patient narratives were powerful motivators validating staff training in consistent local information, particularly for new staff, the results being reflected in subsequent patient

satisfaction surveys.²⁴ A feature of advanced practice is the development of seamless support for patients by improving communication and information giving within the local service.¹³

Clinical assessment

Staff felt their assessment chart (based on RTOG¹⁷) worked well;

‘gives structure to the review and promotes good communication and transfer of information’.

‘sometimes I sit writing up the assessment and give patients a relaxed silence, if you aren’t looking at them it can take the pressure off’.

‘because it was written about it in the first review, I could see side-effects progressing’.

‘we do have a proforma and I go through that but I do find I come from it at different angles depending on the person’.

‘patients’ know you are taking them seriously’

All patients said that they were aware of the possible side effects but six of seven had not experienced any that required medication or referral. Only one had required referral for a prescription. Interestingly, he felt his first review unnecessary ‘I felt a fraud, I had no symptoms’. Retrospectively he recognised the first review set a baseline for assessment and as he deteriorated his referral for a prescription ‘was actioned immediately’.

Staff1 commented ‘I tend to lean towards small changes in diet and fluid intake, to see if side-effects can be managed by the patient before going into medication’ and was of the opinion that many prostate cancer patients are keen to avoid medication.

Staff 2 conversely expressed frustration ‘we can’t give the drugs most of them need’ and sometimes there is ‘nothing in the notes, no annotation’ after referral to a Doctor. This lack of communication sometimes resulted in difficulties following up referrals.

P4 received verbal information during review clinics but wished for written information ‘like

the ones in urology for flow measurements, so you can measure exactly how your side-effects are progressing’. However, he had not expressed this wish during any review clinics.

Both staff recognised the importance of psychological and sexual issues among prostate cancer patients;

‘sometimes the side-effect are not the thing that affects the patient’.

‘gentle probing often opens the doors to other issues’.

but no patients commented on these issues during interviews.

Owens et al.²⁷ reported that it was difficult for patients to ‘disentangle radiotherapy from the overall cancer journey’ and therefore the staff are rightly identifying a need for further specialist training and information in order to facilitate these delicate discussions and be able to refer patients appropriately.

Holistic support

Family and friends were important sources of support. Six out of seven patients had supportive partners, five out of seven of whom had partners who attended all the reviews and the patients felt their partners had all their questions answered. Three out of seven patients said that they viewed themselves as a ‘team’ and ‘two pairs of ears were better than one’. Echelin and Rees²⁸ suggests partners can have an important role as advocates helping to identify knowledge gaps.

Two out of seven patients said their families had independently accessed information on the internet.

Both staff thought partners or family members are more likely to read information given to patients. Two out of seven patients’ daughters had sourced information and encouraged them to read it. One of the seven said his wife read the information booklet because he was happy with an initial consultation letter giving diagnosis and referral decisions.

Echelin and Rees's²⁸ wider study agrees partners are more likely to access information than prostate cancer patients. It was interesting to note that neither of the patients whose wives had previously had radiotherapy reported being more informed than the other patients.

P4 revealed he had discouraged his wife from finding information on the internet despite feeling in retrospect 'I missed out at the beginning by not asking questions'. His wife did not attend review clinics and he had realised 'my wife asks the questions when she is with me'. He also said that his family looked to him for answers that he felt unable to give but had not sought the information to give them. He had not acknowledged these psychosocial tensions during the reviews, and only reflected upon this during the interview. However, extent of family involvement is a patient choice.⁴ Mc Parland recommends signposting additional sources of information for both patient and family.¹⁸

Staff2 recalled 'problems if partners are at cross purposes with the patient' and suggested that sometimes it was more effective to see the patient on their own.

Patients rated peer support very highly and five out of seven patients had independently forged relationships in the waiting room. The friendships provided a means of support, competitiveness and information giving.

Two patients used the term 'colleague' and none used 'patient'.

'a nice little group' (P4).

'like old friends' (P1).

'and talking to the other guys, that was good as well' (P3).

'there is a general air of we are all in the same boat' (P2).

The Urology CNS was an important source of information and support for most patients. Five out of seven patients had very positive interactions with their CNS and three of seven

described a 'long-standing relationship'. P2 had not met his CNS but had 'a great relationship with my GP'. All the patients confirmed they had contact details at the end of treatment and would be confident to use them.

Living beyond treatment

All patients' priority at the end of treatment was to 'know how it's gone'.

All patients stated having their follow-up appointment arranged and verbal information about side effects after treatment had 'put my mind at rest'. In contrast to literature suggesting a shift in concerns,¹⁸ in this study all patients appeared remain focussed on their survival and questions regarding quality of life at this stage were not commonly raised.

Both staff recognised 'long-term side-effects don't seem real at this time'.

Staff were less confident at the end of treatment although on reflection they both recognised their own training needs.

'to be fair I don't know what the CNS gives them' (Staff1).

'at the end we haven't quite got the information to give them ... all have different journeys' (Staff2).

Mc Parland³ identified 'end of treatment' can be a time of short-fall in care. Department of Health have identified information and support at the end of treatment as an integral part of the radiotherapy pathway and improving patients' longer term quality of life.²⁹ National Cancer Survivorship Initiative²⁰ has produced a pro forma for a written summary letter and a strong recommendation that their use could improve continuity of care. However, it is not yet used locally.

Despite all patients enjoying support and camaraderie during treatment, only one of the seven patients was positive about attending a support group after treatment finished. Interestingly he was the only patient living alone.

Generally the responses from both staff

‘whether they want to take support further, I am not sure’ (Staff2)

and patients was not positive.

‘I find the idea depressing’

‘I am not a clubbable person’

‘It’s not something I am personally interested in’ (P3).

Nevertheless, National Cancer Survivorship Initiative strongly recommend all patients are aware of support groups, which can provide a social and information function in the local area²⁰ and suggest patient education and support events should be offered. This warrants further investigation to ascertain what best meets the needs of local patients.

CONCLUSION

This service evaluation suggests a generally high level of satisfaction. The use of semi-structured interviews revealed an in-depth study of the staff and patient views. The patient interviews have given an in-depth set of ‘patient stories’ which studies show can help to create a framework for service improvement. The evaluation shows that there are certain points where information giving is falling short.

At the beginning of treatment patients are sometimes lacking or given conflicting information and there is a need for radiographer training to ensure consistency, which the review radiographers are well placed to give.

Staff identified their need to work more closely with other specialist services such as the sexual dysfunction clinic and psychologist to deliver a more holistic service to patients and improve information and support for patients beyond treatment. Further studies are recommended to assess the needs of local patients beyond the end of treatment and to evaluate at what point the patients concerns shift away from survival to addressing the quality of their post treatment experience.

The end of treatment is identified by staff and in literature as a significant event in the patient journey. Signposting a wider source of information, including the in-house information service is vital at the beginning and end of treatment. Staff have shown that they are already cognisance of this and motivated to create more multi-disciplinary links thus improving their own knowledge and service pathway.

Recommendations

Further study is recommended to evaluate how patients concerns shift from survival to quality of their post treatment life.

A future service evaluation should be scheduled to assess how service developments impact on needs of local patients beyond the end of treatment.

Owing to the small sample it is recommended that this study be regarded as a preliminary to a wider study. The use of questionnaires to survey a more diverse sample over a longer period of time would be an effective way to triangulate data, and test the validity and credibility of the findings.

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Conflicts of Interest

The researcher was also a review radiographer conducting prostate patients review clinics and also a colleague of the other staff. This is a limitation of the study but was considered appropriate for the aims of a service evaluation. The study was conducted as part of the researcher’s MSc Dissertation.

Ethical Standards

The authors assert that all procedures contributing to this work comply with the ethical standards

of the relevant national guidelines on human experimentation (United Kingdom) and with the Helsinki Declaration of 1975, as revised in 2008, and has been approved by the institutional committees (Northampton General Hospital Trust and Sheffield Hallam University).

Written ethics approval for a 'Service Evaluation' was received from the Research & Development Department, Northampton General Hospital Trust, Northampton and Sheffield Hallam University. Local stakeholder approval was given by the Clinical Oncologist, Urology Specialist Nurses and Review Radiographers.

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