

## Original Article

# How was it for you? Men, prostate cancer and radiotherapy

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## Abstract

This paper explores the views of men who have experienced external beam radiotherapy as part of their treatment for prostate cancer. Using three focus groups, the study aimed to explore men's experience of radiotherapy. However it soon became clear that it is not possible to disentangle the experience of radiotherapy from that of the whole cancer journey. Four themes emerged from qualitative analysis of the data, namely, making decisions (feeling prepared and informed), the experience of radiotherapy, side effects of treatment and sources of support.

The findings indicate that health care professionals involved in radiotherapy treatment delivery need to understand and maintain sensitivity to the physical and emotional impact of the men's experience prior to radiotherapy in addition to those experienced during radiotherapy. In order to raise awareness and understanding of whole experience from the men's perspective, it is suggested that feedback of patient experience should become an integral part of radiotherapy department activity.

This paper is an extract from a wider study that explores the experience of men undergoing brachytherapy and external beam radiotherapy.

## Keywords

Prostate cancer; men's experience; external beam radiotherapy

## INTRODUCTION

The demands on therapy radiographers are diverse and multifaceted as it is one of the few professions, which combines highly technical and caring roles. As radiotherapy becomes more complex, balancing treatment delivery with supporting and caring for patients' needs in such a technical environment requires great skill and expertise in itself. There is some recognition of this within the profession in the form of specialised posts, developed with a clear remit for either one or the other. The reality is that the majority of radiographers on treatment

units are relentlessly juggling technical and supportive care skills to provide the best possible service for patients. Though it is acknowledged that the technical complexity of radiotherapy places great demands upon radiographers, they continue to be seen as the professionals ideally positioned, not only to deliver the radiotherapy but also support and build relationships with patients.<sup>1,2</sup>

Whilst protocols are available to underpin the technical aspects of radiotherapy, there is often little information available to assist the patient care aspects of the service. The ability to effectively support patients has to be underpinned with a basic understanding of the patient's whole experience of cancer. Whilst there is a plethora of data on the physical impact of cancer treatment,<sup>3,4</sup> the reality of the experience and its impact on people

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The study was supported by a grant from Leeds Staff Initiatives Fund.

is far less frequently reported. Furthermore of the limited literature available, the majority focuses on the effects on women as opposed to men. But there is a growing realisation that men's health has had neither the research nor the funding in comparison with women's health.<sup>5</sup> Prostate cancer is one of the principal cancers in men, with over 21,000 new cases diagnosed each year and over 10,000 men dying from this disease annually in the UK.<sup>6</sup> Despite this, there is little empirical data (in particular qualitative data) to underpin service development and therefore service provision is often based on assumptions rather than evidence.

## AIMS

This study aimed to explore the experiences of men with prostate cancer as part of a needs based analysis into the services offered to men undergoing brachytherapy and external beam radiotherapy. This paper focuses on the men who underwent external beam radiotherapy in order to enhance radiotherapy workers understanding and consider if the services currently provided are meeting the men's needs.

## RESEARCH DESIGN

The investigation took the form of a descriptive qualitative approach using focus groups. The discussions were structured using a question framework derived from current literature and the professional expertise of the researchers. The study was funded through a local staff initiative fund.

## RATIONALE

Focus groups have been employed as a means of determining people's thoughts about services they have experienced since the 1940's.<sup>7,8</sup> Whilst it has been highlighted that the influence of group culture can interfere with individual's expression,<sup>8</sup> focus groups are acknowledged as a reliable method of obtaining a rich source of consensus data on complex issues.<sup>9-11</sup>

## SAMPLE AND RECRUITMENT

Potential recruitments were identified from current follow up clinics and their medical records

**Table 1.** Selection criteria

Inclusion criteria	Exclusion criteria
Treatment by radiotherapy for localised, primary cancer of the prostate gland	Men who have experienced complications either due to their cancer or from the radiotherapy
Men of any age	Men who cannot speak English fluently
Men of any culture	
Men who saw the consultant within a normal time period	

examined against the sampling criteria (Table 1). Suitable candidates were then approached in the Outpatient department as they attended for follow up appointment. It was necessary to recruit some by telephone as the recruiting researcher was unable to attend every clinic.

The sample consisted of 17 men (age ranges 58–79 years). All participants had completed a course of external beam radiotherapy for prostate cancer within the last 6–8 weeks. The men were recruited by one of the researchers and this researcher did not attend the focus groups. After three focus group discussions it felt that no new issues were being generated and so recruitment was halted.

All participants were provided with written information about the study and signed consent form was obtained. Anonymity for patients was assured and a follow up process was observed with a letter of acknowledgement and provision of a contact number for those requiring it. The study was granted full medical ethics approval by the local research ethics committee.

## DATA COLLECTION

Three focus groups were recruited. Two groups had 6 men and one was made up of 5 men which is regarded as an adequate number for data collection.<sup>9</sup> The discussions were conducted on the site where the men had undergone their radiotherapy. The intention had been to hold the groups off site but the men expressed a preference to return to the hospital, as they were confident of the location and parking.

An experienced male facilitator unknown to the men led each group. It was decided that a

**Table 2.** Key headings for questions

1. Recognition of symptoms
2. Impact of diagnosis
3. Knowledge and Information
4. Support during radiotherapy
5. Life after treatment

male would facilitate the discussions, as it was perceived that the men would feel more comfortable discussing potentially sensitive issues in a single sex group. In addition the facilitator was independent of the hospital as it was felt this would encourage the men to speak more freely about their experiences.

The focus groups lasted one and a half-hours and were recorded by audiotape. The tapes were transcribed and all patients' names coded. All the tapes pertaining to the study were destroyed following transcription. To enhance the transcriptions and assist in the data analysis, an independent social researcher was contracted to attend the focus groups and record field notes.

The men were invited to contact the research team, the hospital, or their GP if fresh issues arose for them as a result of the study. Letters were sent to all the men's GP's to inform them of the study. The research team structured a question schedule based upon current literature and needs analysis. Each focus group used the same question framework that covered key areas of interest (Table 2).

## ANALYSIS

Analysis of the transcripts took the form of a standard qualitative thematic analysis along with preconceived coding based around questions asked.<sup>8</sup> To enhance validity of the findings, independent analysis by all three researchers was undertaken. The data was further discussed and refined. The resultant themes were then cross-checked with the social researcher who had recorded field notes. Four themes were uncovered, which were common to most of the men. This paper will discuss these themes with specific reference to the men who underwent external beam radiotherapy.

## THE FINDINGS

The four emergent themes were:

1. Making decisions and feeling prepared and informed.
2. The experience of having radiotherapy.
3. Side effects of treatment.
4. Sources of support.

### 1. Making decisions: feeling prepared and informed

Prostate cancer is one of the few cancers where disease management presents patients with complex and controversial options for treatment.<sup>12</sup> Consequently choices have to be made by each individual. Whilst the men in this study revealed very different experiences in reaching the decision to opt for radiotherapy, the importance of the amount and factual content of information was seen as hugely important by most men.

Involving patients in making choices about treatment options is not new and studies have demonstrated that many cancer patients wish to share decision making with their clinician.<sup>13,14</sup> However, in order to do this, it is crucial that patients have sufficient detailed information about the options. If this is not achieved, in addition to increased anxiety, the lack of understanding about the merits of different treatments has been highlighted as an important factor contributing to the development and utilisation of effective coping strategies.<sup>15</sup> Whilst variation in the range of information and questions provided by clinicians has been recorded,<sup>16</sup> in the case of prostate patients it is perhaps the lack of multidisciplinary approach to information provision that is of more concern.<sup>17</sup> For early stage prostate cancer, most men can have a choice of four options namely brachytherapy, external beam radiotherapy, surgery or watch and wait. For some men in the focus groups it was clear that they did not want to be involved in the decision making implying that there were issues of competence in decision making. For example,

*E1#2 "I let my doctor make it (the decision) for me. I am a builder, I build houses."*

However, for the majority of men, being involved in the decision making process was important to

them but for most seeking good information was difficult. The role of the doctor with whom they discussed their treatment options was repeatedly a source of frustration to the men.

*E1#3 "I seen a young doctor and all she knew about was surgery. She didn't know about any other treatments. My wife ... was asking questions about brachytherapy. The young lady ... said you probably know more about than I do. You know it was such an important period... I felt we needed more."*

Overwhelmingly the men recognised that the professional background of the doctor discussing the treatment options had influenced the conversation.

*E1#6 "He was pushing me into surgery because he is a surgeon."*

In addition, it was the speed with which they felt compelled to make a decision with little information that the men found difficult.

*E1#1 "He told me I had cancer. I was expecting a little more information, but it was "make your mind up time", which came as a bit of a shock."*

*E3#2 "He (the urologist) said, you have two options available, you can have an operation to have the prostate removed or you can have radiotherapy. But he never explained what radiotherapy was about and I got no leaflets and I had to make a decision then."*

Despite research repeatedly demonstrating that people feel more in control when they are informed and understand what is expected,<sup>12,18,19</sup> the lack of written information was a recurrent theme. The men clearly wanted better information provision to help decision making at a critical time in the cancer journey.

*E3#2 "They didn't give me any leaflets or booklets or anything so I sort of had to make a decision but I had nothing to base it on... When they said radiotherapy I was sort of thinking of chemotherapy, I thought I was going to end up like Roy Castle."*

The exception to this came from the few who had undergone consultation with both the urologist and the clinical oncologist. These men had experienced a much fuller explanation of the

options. However even with this approach, some received conflicting information from health professionals, which, in itself can induce confusion and loss of confidence in the treatment team.<sup>18</sup> This was echoed on two occasions firstly, when a GP told one man he thought he had made the wrong decision and another occasion when one of the men made a choice and was advised otherwise.

For many of the men, radiotherapy as opposed to surgery was chosen as the lesser of the two evils rather than by a well informed decision which suggests that the information provision and its reinforcement has to continue even when the treatment option has been decided. The reasons for this are two fold. Firstly, being informed has been evidenced as a significant theme overarching most others in a study of patients undergoing radiotherapy.<sup>18</sup> Secondly, as this study suggests, arriving at a decision to have radiotherapy does not ensure that all information needs have been met.

## **2. The experience of having radiotherapy**

There is dearth literature on the experience of undergoing radiotherapy itself. Research around radiotherapy tends to follow either a quantitative medical model searching for objective knowledge or follow a qualitative paradigm in attempting to examine the individual's experience in terms of side effects and psychosocial needs. The experience of radiotherapy treatment itself remains relatively unexplored.<sup>18</sup> In the focus group discussions the majority of men spoke fondly of their experience of radiotherapy, expressing an affinity for the hospital, the staff and even individual treatment units.

*E1#1 "The only snag I had, and I had to rectify was when I first went in for radiotherapy, they were playing this head banging music, so I went home and made them a CD of lovely piano music..." "Music to have radiotherapy to"... "Do you mind playing this for us older men".*

In studies examining women's experience of radiotherapy<sup>1,18</sup> fear of the machines and isolation when the radiographers left the room were recorded. This contrasts sharply to the experience

of the men who repeatedly used joviality and trivia in recalling their experience of radiotherapy and especially the machines themselves. When asked if there was anything difficult about going in for the treatment one of the men, E3#3 said:

*“No, it was a laugh . . . you walk in and take your trousers off, march across a room and lay on this bed and pull your trunks down. The nurse is there, adjusts you, and pushes you back.”*

This is not an uncommon reaction from men. Playing down feelings about treatment and its implications have been described by Boehmer and Clark<sup>20</sup> where men adopted a fatalistic attitude. Such a phenomenon was expressed by one of the men:

*E2#4 “...since I’ve had cancer I have just accepted it and thought well that’s it. What’s happened happened, but she (his wife) was very worried about a thing like that”*

Whilst for some men this may genuinely be the stance adopted, for others trivializing the impact of the experience may erect a barrier to communication, either between patient and professional or more importantly between patient and carers. This can become significant, as this form of protective buffering<sup>20</sup> can result in lack of communication that can indicate a risk of poor adjustment to illness. To this effect it has been written that men who have received radiotherapy to the prostate report more unmet needs in care and support than those choosing other treatment options for prostate cancer.<sup>21</sup> It could be argued that needs increase due to the extended period of time over which external beam radiotherapy treatment is delivered. However the duration of radiotherapy also optimises the opportunity for health care professionals to interact with patients and identify needs.

### 3. Side effects of treatment

As stated, much of the literature about radiotherapy side effects relates to the physical impact rather than the individual’s experience of living with the impact of the treatment.<sup>3,4</sup> Whilst acknowledging that understanding and managing patients’ side effects is important, patients are not simply a vehicle for the toxicity of radiotherapy but people who have had their lives turned upside down by their experience of cancer.<sup>22</sup>

In the focus groups, the men remained factual in their description of a whole range of radiotherapy side effects, again using humour to deflect the gravity of the situations.

*E2#3 “I started to have some explosive moments if you like before the end of the third week of treatment.”*

Researcher “What do you mean by explosive?”

*E2#3 “Blame it on the dog next door.”*

*E2#5 “I had wind once it must have been about 200 mph, (laughter) well it felt like it, it didn’t half hurt my backside.”*

*E2#6 “You’d only seconds to get to the toilet... I couldn’t distinguish a trump from a motion.”*

Such dialogue supports the stance suggested by Bohemer,<sup>20</sup> that men are capable of expressing factual physical changes but unwilling or unable to communicate about the feelings regarding these changes. This may be concurrent with what society accepts as the norm for male gender role. For example, strong, silent type showing no emotion.<sup>14</sup> Surprisingly then, the predominant and recurrent theme concerning side effects was the emotional impact of hormone treatment. As one man said,

*E3#4 “I’m watching Lassie on the television, you know the dog and I’m crying because the dog had been hurt. My emotions are shot at the moment, I could cry for England so easy. The least little thing upsets me.”*

Emotional lability was a problem experienced by many of the men and described as humiliating. For some it was especially hard to understand as they felt they had not been forewarned of this by the hospital as a potential side effect.

*E1#2 “Because I haven’t had it explained at the hospital, no one has told me at the hospital that I would have this effect (emotional). Haemorrhoids and all that business but no one ever mentioned the emotional side of the treatment.”*

For these men, hearing that other men were experiencing similar feelings gave them reassurance.

The physical side effects of hormone therapy such as gynaecomastia, hair loss, and loss of libido also represented a difficult part of the men's experience of treatment. Hot flushes were the major problem for many of the men and were also a side effect some men felt they did not receive much support in.

*E1#6 "but the hot flushes wake you up at night. ...every time you say to a woman I'm having a hot flush, she says "now you know what we suffer."*

It is clear that the side effects of prostate cancer treatment are complex and multiple. The effects of radiotherapy form only part of an entangled matrix of each individual experience. Therefore understanding the whole experience of cancer, its treatment and the potential effects of therapies is imperative for those engaged in the care of these patients.

#### 4. Sources of support

It emerged that the supportive needs of the men in the groups were very individual and variable. Many of the men made it clear that close family and friends were their main source of support.

*E1#2 "The best support I have is my wife and family. That's the support I want initially."*

That men prefer to utilise a tight network of family and the clinician for support and information is not uncommon.<sup>19</sup> For some using this network was vital but in addition, having a contact point outside of this was important. However this contact was viewed very much as a one way, practical lifeline for information only if a problem arose.

*E1#5 "With regards to support you don't want no intruding in your life do you? You want them there when you want them. You don't want them ringing up saying, "how are you today, have you been to the toilet lately?" You don't want that but at the same time you think, I have a bit of a tinkle, I know I'll phone so and so".*

In contrast, some men did find support beyond their family and doctor.

*E1#5 "The greatest support that I find is meeting people of my own age that have had prostate cancer".*

Finding support from others was echoed when the men were sharing their experiences about side effects. Several of the men stated a feeling of great comfort in hearing that other men's experiences were similar.

In discussing the supportive needs of men with prostate cancer, the issue of gender needs consideration. Gender differences are frequently recorded in the literature, for example, that men are less willing to seek support<sup>23</sup> whilst women prefer to share emotions whereas men prefer to share information.<sup>14</sup> Though it may be accepted that such gender difference occur,<sup>14,19,23</sup> care should be taken not to apply the stereotyped norm of gender to all men. The reasons for this are threefold. Firstly not all men are engendered to the cultural stereotype of masculinity.<sup>24</sup> Secondly gender is not static and is constantly being constructed and reconstructed.<sup>23</sup> Finally, some hold the view that major life events, like a diagnosis of prostate cancer impacts on gender identity and associated emotional responses.<sup>25,26</sup> For these reasons, men should be seen as individuals and assessed as such which as Malterud<sup>24</sup> points out, requires skilful listening to hear that persons needs.

#### DISCUSSION

Modernisation of cancer services has involved health care professionals looking at processes involved in the whole of the patient's pathway. It would seem that this philosophy should be as rigorously applied to understanding the patient's interpretation of the experience of cancer and its treatment. Increasingly, radiotherapy is only one element of multi-modality treatment regimes used in cancer treatment. Whilst protocols in radiotherapy are in abundance to define treatment process, developing the resources to enhance understanding of the impact of the whole experience on the patient is paramount if care is not to be left trailing behind technological advances.

The purpose of this study had been to identify the experience of men undergoing radiotherapy for prostate cancer in order to identify potential service improvements. As such, it was envisaged that the focus group discussions would primarily be centered on the radiotherapy experience. However, the reality is, radiotherapy only forms a

part of each individual's cancer story and isolating the radiotherapy experience proved not only difficult but also inappropriate. How men present for radiotherapy is a product of their previous experience and this should not be disregarded. It is vitally important to understand the men's individual experience of prostate cancer and its treatment to assist identification of the individual's preference with respect to the provision of information and support. The protracted duration of radiotherapy treatment provides healthcare professionals in the radiotherapy department the ideal opportunity to gain insight into the individual's experience, as the best form of information, psychosocial and other support is that identified by the patients themselves.

It has been clearly shown that there are men with prostate cancer who present for radiotherapy have not had their information needs fully met or even addressed. Radiotherapy workers need to maintain awareness that there are differing pathways to a treatment decision, some of which may not have been well supported and informed. For those arriving at Radiotherapy as the lesser of the evils, there may be fears and misconceptions that need exploring to reduce anxieties. If information needs are not met, the men's coping strategies may be affected<sup>15</sup> and men may experience a loss of control due to the inextricable link between the two.<sup>18</sup>

In prostate cancer treatment, the side effects can be complex. There is interplay between some of the effects of radiotherapy and hormone therapy on men's sexual, physical and emotional well-being. For this reason care should be taken not to consider radiotherapy and its effects in isolation from the effects of other therapies. Consequently knowledge and understanding of the whole experience of prostate cancer treatment is required.

Health care systems contribute greatly to the institutional and structural influence of gender and health.<sup>23</sup> There is an increasing awareness that health care professionals contribute to the notion of men as healthy and women as the sicker gender,<sup>23</sup> in need of more attention and support. This may explain the disproportionate research and funding in breast cancer as compared with prostate cancer. In terms of support for men with

prostate cancer it would be worthwhile examining more closely the influence of gender on the choices men make about supportive care. As health care professionals, there is a need to reflect upon our personal constructs of men and masculinity to challenge whether these may be communication barriers that lead to evasion of opportunities and environments for men to talk.

Whilst some see radiographers as ideally positioned to support and care for patients,<sup>1,2</sup> concern has been expressed from a nursing perspective. Wells,<sup>22</sup> highlighted that large numbers of patients pass through the radiotherapy department every day without seeing a nurse and that many have needs that are not being met. But every person who passes through the radiotherapy department for treatment sees a radiographer every time. As workload and treatment complexity continues on an upward spiral, it can be difficult to retain focus on each patient as an individual who is living through the experience of cancer. To ensure we continue to address the needs of patients during radiation treatment, it is essential that we encourage routine integration of patient experiences into radiotherapy departments. Gathering patient feedback either by questionnaire or verbally will enhance understanding and sensitivity of the issues faced by patients.

## RECOMMENDATIONS FOR FURTHER RESEARCH

This study showed the men to be very open and candid in sharing their experiences of radiotherapy. Whilst there is evidence to support the use of an independent, male facilitator when exploring men's experience of hospital treatment, some questions arise regarding the data collected. Firstly the data generated covered the men's experience from diagnosis to life after treatment which questions whether someone with experience of radiotherapy would have guided the discussion differently to gather more data about radiotherapy treatment itself. Secondly, the impact of a young healthy male facilitating a group of older, ill men has not been considered. It is therefore recommended that a similar study be conducted using a female facilitator, familiar with radiotherapy treatment for prostate cancer.

## Acknowledgements

To all the men who gave their time and agreed to share their experiences. Also, to Lorraine Cooper for her invaluable contribution at the outset of the study.

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