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# Assessing the information and support needs of radical prostate cancer patients and acceptability of a group based treatment review: A questionnaire and qualitative interview study

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## **Abstract**

### **Aims**

Current literature suggests the information and support needs of oncology patients undergoing radical radiotherapy to the prostate often remain unmet and can impact quality of life. We aimed to explore the effectiveness of delivery and opportunities for service improvement, including a group based treatment review.

### **Methods:**

Sixty prostate patients completing radical radiotherapy (mean age 70, range 47-79) in a UK cancer-centre completed a self-designed questionnaire assessing information and support. To explore views on a group-based-treatment-review, 11% took part in a semi-structured interview. Descriptive data were computed and interviews transcribed and analysed thematically.

### **Results:**

Eighty-seven percent were satisfied with information and support when delivered by radiographers. However, 26% were only '*sometimes*' able to complete bladder-filling, suggesting information regarding treatment delays would improve this. 49% preferred both Doctor and Urology nurse reviews whereas 26% preferred nurse only. 70% stated their '*concerns were always addressed*' by a nurse and 49% by a Doctor. Interviews revealed that a group review was generally acceptable with peer support an influencing factor.

**Findings:**

Overall patients felt their needs were being met. Suggestions for improvement (more information on preparation, side effects and delays) will be implemented locally. Future work will explore the feasibility of group reviews in patients undergoing radical radiotherapy to the prostate.

**Financial support**

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**Conflicts of interest**

None

**Background**

Prostate cancer (PC) is the most common male cancer and radical radiotherapy (RRT) is a key treatment option available for localised and locally advanced disease (1). Recent advances such as intensity-modulated radiation therapy, fractionated delivery regimens and volumetric modulated arc therapy (2-3) aim to reduce toxicity. However, both late and acute symptoms and side effects can still occur and impact on quality of life (QOL) (4,5). Therefore, robust plans to ensure patients' supportive needs are met both during treatment and beyond need to be implemented (6,7).

To enable patient coping it is important to offer both information and support (IAS) however, often these needs are left unmet (8-10) particularly regarding information about treatment, psychological, sexual issues and logistics of the health care setting (11,12).

Patients were more likely to feel their needs were unmet where they had limited access to health professionals (HP's) both during and after treatment (12). Certainly, in a large Finnish sample half of the patients undergoing treatments for PC were dissatisfied with their IAS and if inadequate at baseline a significant predictor of QOL at 5 years (13). Recommendations to improve supportive care suggest that a comprehensive understanding of individual patient need along with staff training may ultimately facilitate decision making between health professionals (HP's) and patients (9) and a key role for the nurse specialist is recommended to facilitate this (12).

However, with limited resources it is challenging to meet the IAS needs of patients and sustain them over time (14). One way to encourage patients to share experiences and coping skills is through group support (8).

A conversational group support for men with PC proved successful (15) in that men felt supported and were positive about airing concerns (including impotence) this ultimately resulted in a greater understanding of PC and its side effects. Indeed, an end of treatment group psycho-educational intervention in breast cancer (BC) patients to address IAS and psychosocial needs found it effective resulting in patients reporting enhanced knowledge (16). A recent pilot study in Leeds Teaching Hospitals Trust (LTHT) radiotherapy (RT) department in BC patients found no significant differences in QOL between patients assigned to an individual or a group based treatment review (GBTR) (17) suggesting this may be a credible alternative for some patients to improve patient satisfaction and compliance.

In order to deliver changes in practice to meet patient IAS needs government initiatives and publications have stressed the need for practitioners to review service delivery to take account of patient needs, make timely and information accessible to enable informed decision making with HPs (1, 18, 19).

The majority of studies report unmet IAS around diagnosis or follow up (8,9 & 13) with less focus during treatment. However, addressing key needs and enabling signposting to relevant services during treatment (when patients are in close contact with HPs), could bridge the gap between diagnosis and follow up. Here we explore the IAS provision in patients undergoing treatment within the LTHT RT department from their individual review with a doctor or UN specialist. Further, as there is limited research on group support for patients undergoing RRT for PC and with literature suggesting this could be beneficial for patients the aims of this service evaluation project are to:

- Establish the effectiveness of the current service in relation to patient's information and support needs including their individual treatment review.
- To identify opportunities for service improvement and in particular the value of GBTR.

## Method

### Participants and recruitment

A convenience sample of eligible patients who had PC, treated with RRT (+/- concomitant chemotherapy, hormone therapy and surgery) and completing treatment were recruited. Exclusion criteria deemed patients should not exhibit overt psychopathology or serious cognitive dysfunction. Using a cross sectional design 68 patients were approached and 60 agreed to take part (mean age 70 range 47-79). For patient RT fractions see Table 1. Patients were identified through Mosaic® (Elekta, Stockholm, Sweden) the department's radiation management system and recruited between June to August 2015 and asked two weeks prior to completing RT if they would like to take part. Information sheets were given and informed consent obtained. Of those who agreed to be interviewed a convenience sample was selected. See Figure 1 for data collection and recruitment flow chart.

### Materials

#### Questionnaire

A 16-item questionnaire was constructed following guidelines (20) to explore patient experiences of RT and their IAS needs (including treatment review and enema and bladder filling). The questionnaire comprised mainly closed-response questions e.g. *Do you feel there was any additional information you required prior to your initial appointment? YES/NO*, a free text box underneath each question enabled patients to expand on their answers.

### Procedure

#### Research governance and ethics

The study was deemed service evaluation not requiring NHS ethical approval (21), however Trust Research and Development department was obtained alongside Sheffield Hallam University ethics committee approval. The authors assert that this work complies with ethical standards of the Helsinki Declaration of 1975, (revised in 2008), the data protection act (22) and good clinical practice guidelines (23).

#### Self-reported questionnaire

Typically, questionnaires were completed in a quiet area of the RT department or at home and posted back in a pre-paid envelope.

### Semi-structured Interview

Patients (n=11) were interviewed on their final day of treatment in a private room in the RT department. Interviews were audio-recorded, took approximately 30-45mins and were subsequently transcribed. Patient anonymity was maintained by allocating study numbers to participants and supplying pseudonyms, HPs were referred to by letters e.g. doctor/nurse X/Y/Z. See table 2 for interview schedule.

## **Analysis**

### Self-reported questionnaire

Descriptive data (frequencies and percentages) were computed using IBM SPSS v20 and qualitative data forming the free text comments (FTC) e.g. *'please explain your answer'*, were categorized according to the questions.

### Semi-Structured Interview

Thematic framework analysis was applied to the interview data (see table 3) (24). Two researchers individually identified a thematic framework enabling indexing, coding and charting of data. Interpretation of coding was discussed and where differences occurred these were resolved via consensus to ensure inter-rater reliability.

## **Results**

The topics emerging from the proportional data and FTC (table 4) include satisfaction with information provision prior to and during treatment; bladder filling and enema procedures (including reasons for non-compliance) and Individual treatment reviews including patient preference for health professional, timing of appointments and whether concerns were addressed. Please see figure 2 (a-f) for summary of these data.

### Information provision

In general, 87% of patients felt they were given the 'right amount' of information ranging from 90-93% for bowel preparation and bladder filling respectively. Eighty two percent of patients felt that the IAS given by treatment radiographers was 'very good' (Figure 2c). Overall 10% of patients stated they needed extra information this was particularly true prior to commencing RT (15%) (Figure 2a). Most patients (77%) did not require any additional support from the doctor or UN however 6% required more

information for the enema procedure suggesting verbal emphasis from the HCP would be useful see table 4.

### Bladder and enema procedure

Twenty percent of patients described occasions where they did not use the enema due to them having a natural bowel movement and 26 % said they only 'sometimes' managed to follow the procedure and 2% never managed (Figure 2b). Treatment delays were the most common reason for not being able to maintain a full bladder and patients suggested improved communication could obviate this in future.

### Individual Review

The doctor and UN were seen as having very similar roles (table 4) and 49% of patients preferred to be reviewed by both. Twenty six percent of patients preferred to see the UN and 3% the doctor (Figure 2 d). Seventy nine percent of patients thought scheduled appointments were 'about right' for the UN and 64 % for the doctor. With 10 and 7% stated they needed more appointments with the doctor and UN respectively (21% stated they didn't see a doctor). Seventy percent of participants '*a/ways*' felt their concerns were addressed by the UN and 49% with the doctor (Figures 2e and 2f). A small number (5%) felt their concerns were '*never*' addressed by the doctor and 3% felt the same about the UN (table 4). However, the overall experience with the doctor and/or UN was either 'Very Good' (62%) or 'good' (23%).

### **Semi structured interviews**

Here emergent themes and subthemes are presented (figure 3) and illustrated with supporting quotes (table 5). The mean age of patients was 70 (range 60-80) and 60% were in receipt of hormone therapy.

### **Summary of themes**

#### Issues and concerns

These were generally related to information provision, physical problems, medication, logistics of the department and survivorship. Some patients felt they would benefit from more information about how RT works, and the rationale for prepping procedures (bladder filling and enema) and suggested this information could be presented visually.

## **Advantages**

### Peer support

One of the main potential advantages of GBTR was that peer support could inform and alleviate patient issues or concerns.

### Talking and Listening to others

Patients felt it would be beneficial to know what other patients are going through and to learn from others experience. A GBTR could give patients the opportunity to access information, ideas or questions they may have been too afraid (or had forgotten) to ask.

## **Practicalities**

Timing Some patients thought it would be useful at the beginning of treatment however, others thought it most beneficial in the middle.

### Partner or carer involvement

Several patients recognized that relatives or carers may need to be involved for practical reasons alternatively others were less positive suggesting this would make them feel inhibited.

### Number of participants

Proposed numbers ranged from 2-3 to 6 which was seen as the ideal.

## **Disadvantages**

### Privacy and independence

Some patients felt they and (potentially others) would not attend a GBTR citing concerns around confidentiality and privacy and others felt they wouldn't attend because of their strong sense of self-reliance and independence.

### Taboo subjects

Patients highlighted that some subjects would not be amenable to a GBTR including sex life/impotence and bodily functions including diarrhoea. However, it was also acknowledged it would be difficult to discuss these issues individually.

### Domination by others

There were concerns from patients that a GBTR had the potential to become dominated by others and that careful facilitation could avoid this.



## Discussion

This study explored the effectiveness of the IAS for men receiving RRT to the prostate, and opportunities for service improvement, in particular the value of GBTR.

The majority of patients felt they received the right amount of information prior to their initial appointment although as in previous research some would have appreciated more information on diet and side-effects (15, 25). Our findings suggest that prior to commencing RT more detailed and varied information should be delivered via a variety of means including the internet, audio tapes and orientation visits to increase retention and satisfaction (4, 26). However, we acknowledge not all patients can take in information prior to treatment due to anxiety over treatment and diagnosis (40) and therefore IAS should be accessible throughout the treatment trajectory. A recent pilot study recommends the use of videos or VERT (Virtual environment of a radiotherapy treatment room) to enable a flexible way to deliver IAS (27).

Some patients did not use enema procedures (against department protocol) and had bladder-filling problems due to treatment delays. Indeed, the interviews highlighted the need for the staff to communicate better about treatment disruption and preparation procedure. Indeed, conflicting information can result in loss of confidence in the treatment team (28).

Around half of patients were happy to be reviewed by either the doctor and/or UN, however the majority stated their concerns were addressed by the UN consistent with literature showing the significant impact of the UN role in RT treatment review (25, 29 & 30). Less than half of patients reported their concerns were 'always' addressed by the Doctor reflecting current research (25). The overall patient experience with radiographers was very high in comparison to the doctor and UN reflecting previous findings (25). Perhaps the rapport built over time with radiographers by frequent visits is better than a time limited appointment which can inhibit help seeking behavior and disempower patients (31 & 25). These findings suggest a coordinated approach from all members of the multi-disciplinary team (MDT) is needed to deliver comprehensive IAS to patients.

Generally, patients were positive about a GBTR with peer support seen as factor a major factor to enable patients to come to terms with their situation in line with previous research (15). However as in previous research (4) not all our patients were

certain, most patients felt difficult or embarrassing experiences should not be discussed in contrast to previous research where these issues had been successfully discussed in a group situation (15). Another suggested disadvantage was the potential for individuals to dominate so other voices may not be heard; indeed, strong leadership is recommended for group facilitation (32, 15). Views were mixed in terms of whether relatives or significant others should be included, the timing of the sessions and the optimum number of participants. Earlier research has stated groups of 6 or more are of limited value to patients (29).

The study was a cross sectional snapshot of local service provision thus the findings may not be generalizable to other departments. Similarly, the interviews formed a small sample not necessarily representative of others with PC. For future use the questionnaire will be adapted to give options to state whether they saw the Doctor or UN as this may have influenced results.

## **Conclusion**

This study has highlighted the need to co-ordinate approaches with members of the MDT particularly radiographers and the UN) to deliver IAS to patients. In terms of RT practice this could include using a variety of means to advise patients on the rationale for treatment preparation and ensuring treatment delays are cascaded efficiently. Future work will develop a pilot study working with patients and staff to explore the feasibility and acceptability of a GBTR including stratifying patients on need, preference and suitability. Other options include embracing new technologies to augment patients IAS needs. Patients with low level concerns could be signposted to an electronic patient reported outcome (ePROM) self-management system (eRAPID) which is being piloted in the LTHT RT department (33, 34).

## **Acknowledgements**

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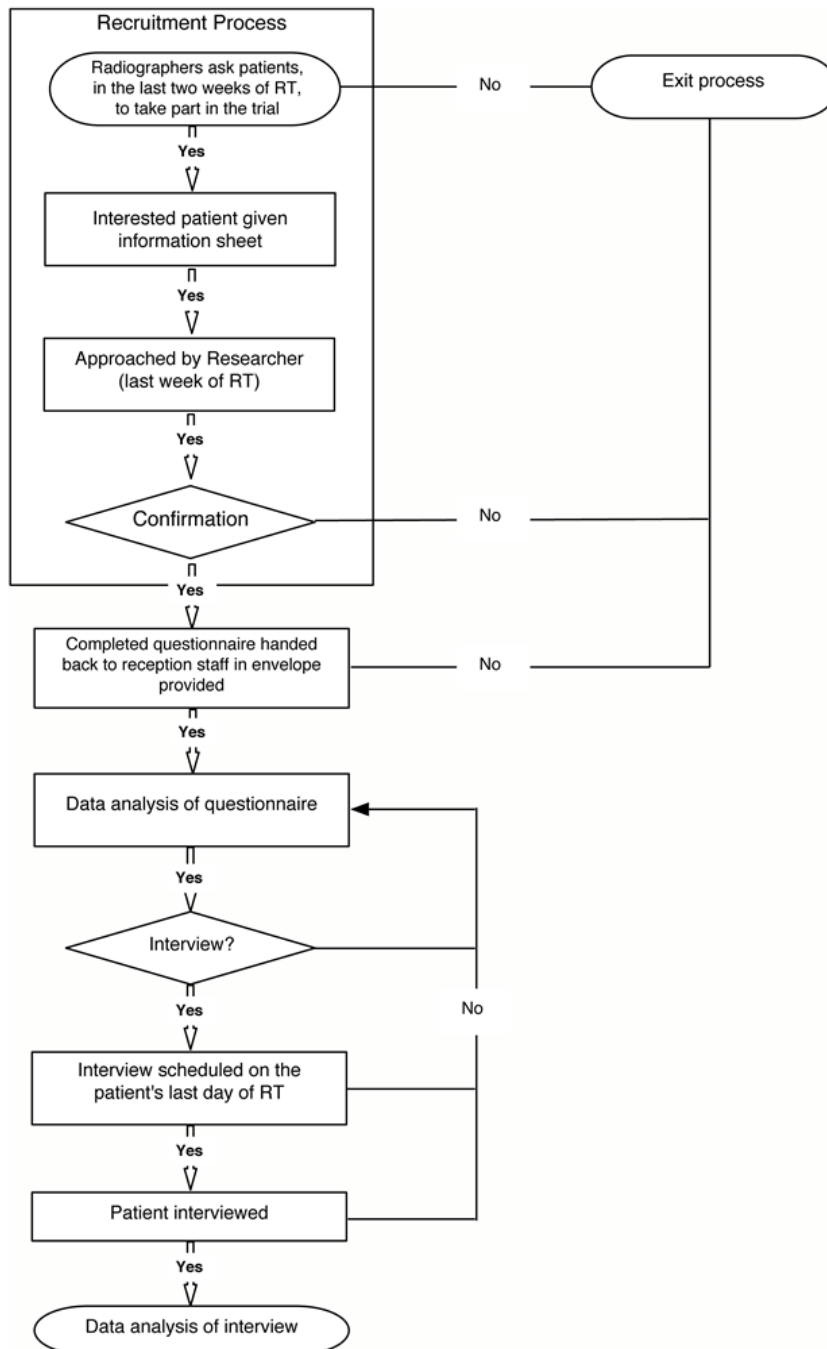


Figure 1: Recruitment and data collection flow chart

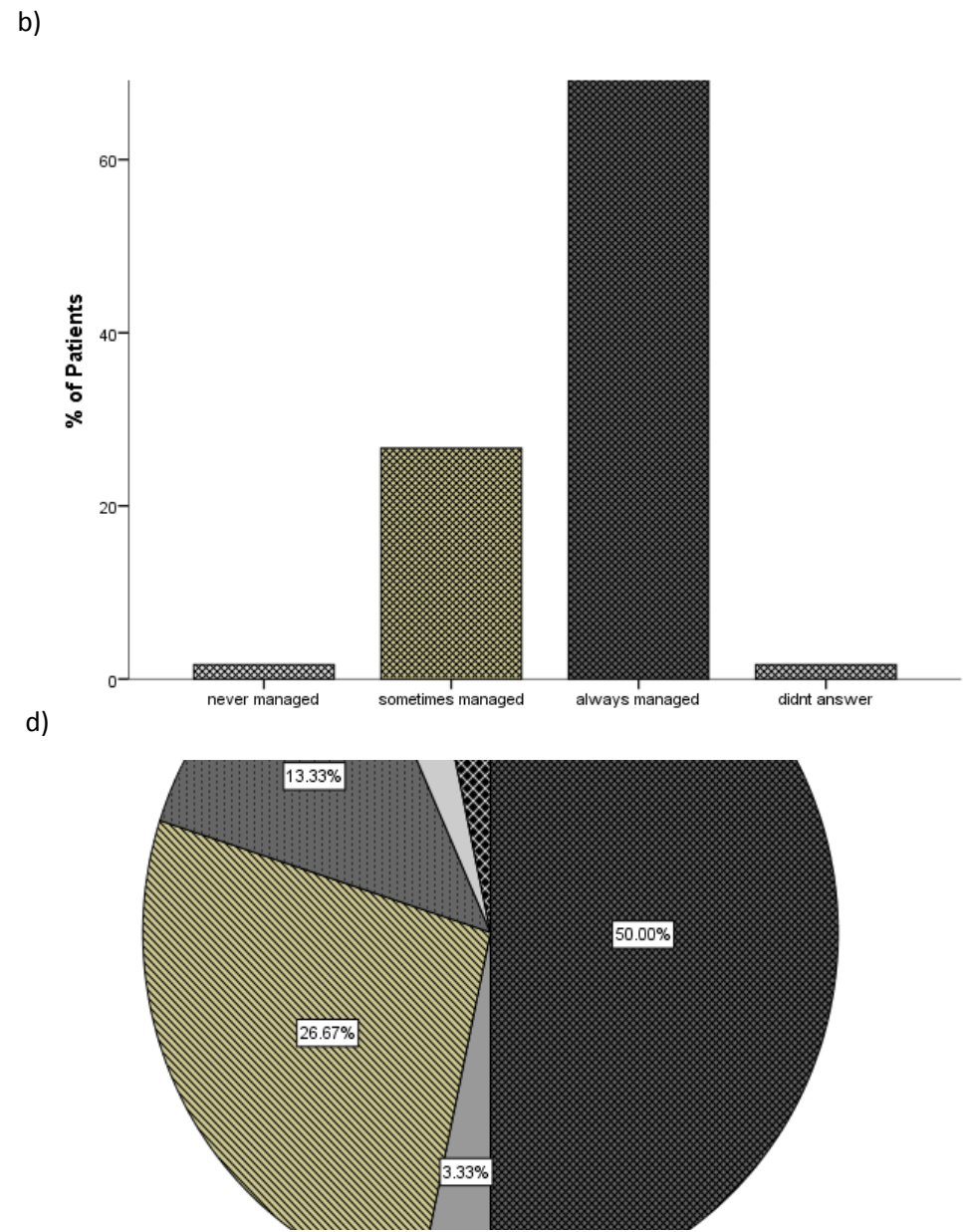
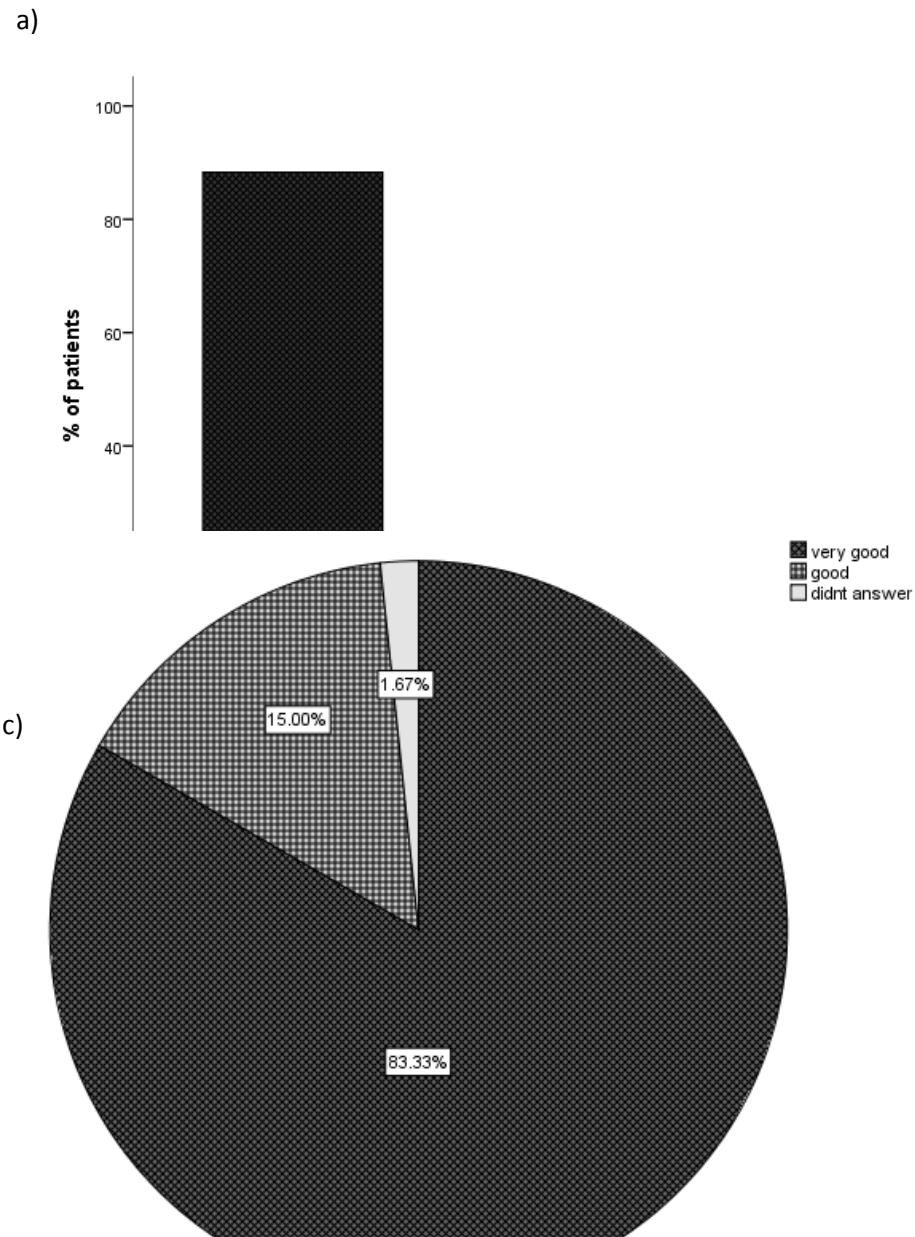


Figure 2a: The proportion of patients who felt they got the right or too little information on symptoms and side effects prior to treatment.

Figure 2b: The proportion of patients who managed bladder filling by following the procedure

e)

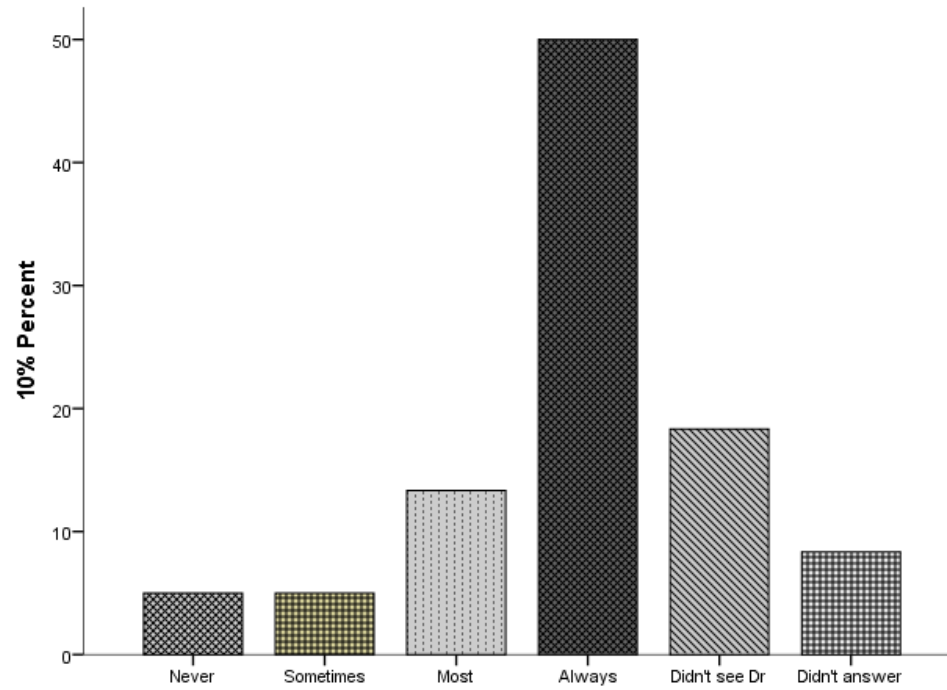


Figure 2e: The Extent to which Patient Concerns Were Addressed by the doctor

f)

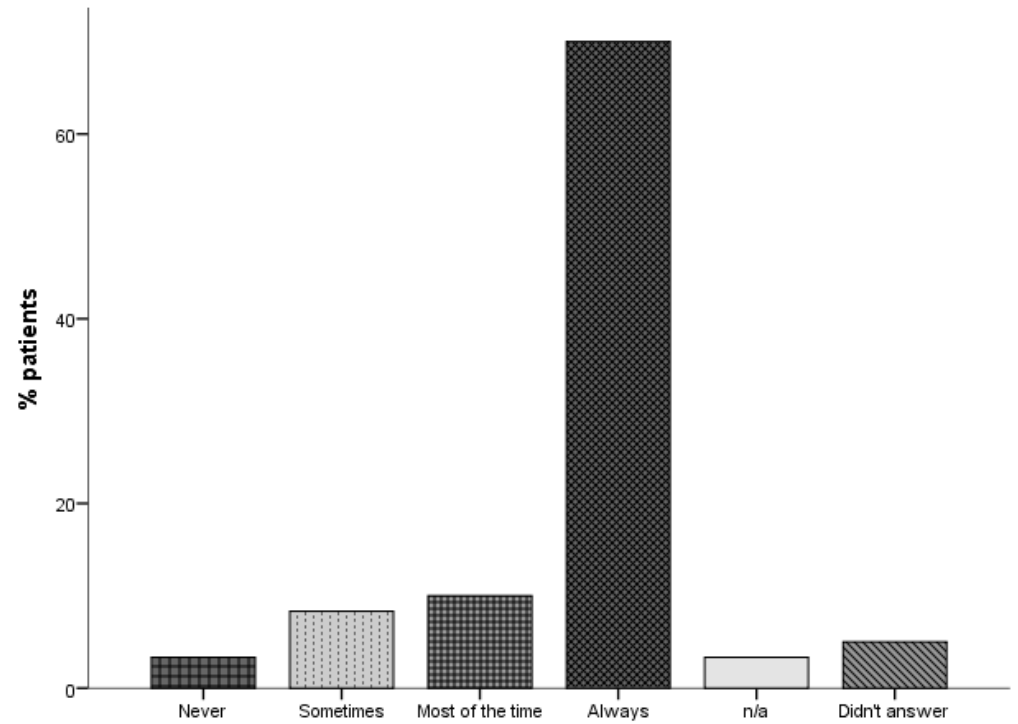


Figure 2f: The Extent to which Concerns Were Addressed by the Urology nurse



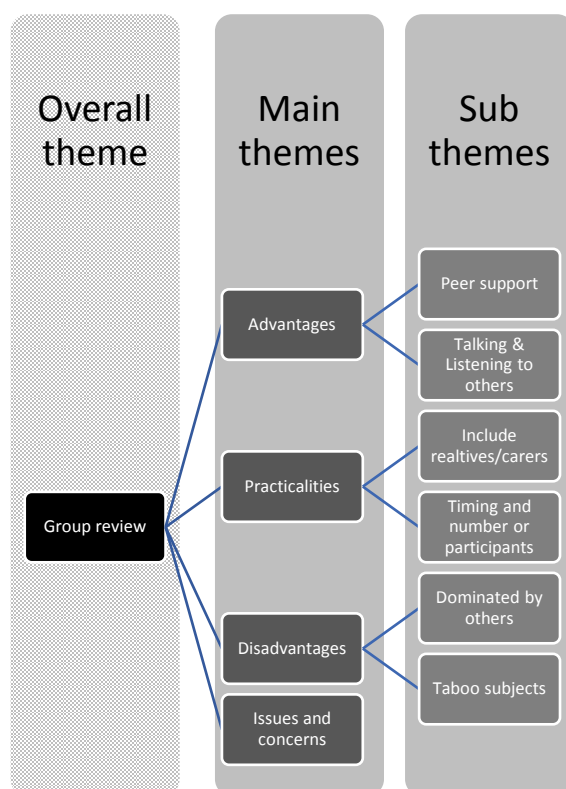


Figure 3: Overall themes, main and subordinate themes from the thematic framework analysis

Table 1: Treatment details of participants (N=60)

<b>Number of RT Fractionations</b>	<b>n</b>	<b>%</b>	<b>Hormone treatment</b>	<b>%</b>
15	5	8	38	63.3
20	7	12	22	36.3
37	48	80		
<b>Total</b>	<b>60</b>	<b>100</b>	<b>60</b>	<b>100</b>

Table 2: Semi-structured interview schedule

<b>How have you found your treatment in the radiotherapy department?</b>
<b>With your individual review, we usually ask about how your treatment is going and discuss your side effects. Are there any other issues apart from these that have affected you during your treatment?</b>
<b>Thinking back during your treatment at what stage/time would a review of your concerns and issues be most appropriate?</b>
<b>Are there particular issues that would be acceptable for you to discuss in a group review?</b>
<b>Are there any issues which you think you would definitely not like to discuss in a group?</b>
<b>Do you think it would be helpful to know that others are having the same concerns and worries as you?</b>
<b>Do you think it is possible you may get support from other patients attending the group review?</b>
<b>How many patients would be the maximum you think would be appropriate for a group review?</b>
<b>Can you think of any advantages of a group review?</b>
<b>Can you think of any disadvantages of a group review?</b>
<b>Do you think relatives/carers should be invited to participate in the group review?</b>
<b>If you were asked to day about taking part in a group review how would you feel about this?</b>
<b>Are there any other ways in which you would you improve the service for patients having Radiotherapy Treatment?</b>
<b>Do you have any other comments you would like to make before we close the interview?</b>

Table 3: Stages Of thematic 'Framework' Analysis (24)

<b>Stages</b>	<b>Methods undertaken</b>
<b><i>Familiarisation</i></b>	Preliminary ideas and notes were made from the transcribing the raw data
<b><i>Identifying a thematic framework</i></b>	Based on the aims of the study and questions asked during the interview of emergent themes a framework was identified
<b><i>Indexing</i></b>	The themes were numbered and the data was coded if it related to a theme
<b><i>Charting</i></b>	The indexed data relating to the theme/subtheme was charted using participant numbers to identify the patients
<b><i>Mapping and Interpretation</i></b>	The chart text was summarised and interpreted in relation to the aims and themes emerged and used to support the findings of the study

Table 4: Free text comments from the self-report questionnaire

<b>Themes</b>	<b>Free text comments</b>
Information prior to treatment	<p><i>'a bit more information about side effects would have been helpful. I hadn't been told to expect blood in my urine/stools, so when that occurred I was anxious and made an appointment to see nurse. Only to be told it is quite normal otherwise fine' (Pt 7).</i></p> <p><i>it took me a little time to work out the logistics of each visit e.g. when to start the enema, at what stage to check in, how to find out if the machine was running late (critical if you are filling up with water). I suggest a check list for the radiographer doing the initial briefing, to ensure nothing is missed and an additional information sheet for patients' (Pt 10).</i></p> <p><i>the reason in detail why certain foods/drinks were to be excluded (for example: acidic drinks causing painful urine problems)' (Pt 38).</i></p> <p><i>'How many delays in treatment (possible machine breakdowns) at main reception' (P 61).</i></p>
Bladder and enema procedure	<p><i>'most people do not read brochures, such as procedure of usage' (Pt 39).</i></p> <p><i>'when I had bowel movement naturally upon arriving at the hospital' (Pt 8).</i></p> <p><i>warning system needs to be improved in terms of delays-i.e. when to start filling bladder (I did struggle at times when machine was running late" (Pt 25).</i></p>
Individual review procedure	<p><i>"radiotherapy is a vital-probably in some cases life-saving treatment. I very much welcomed seeing the doctor and urology nurse" (Pt 5).</i></p> <p><i>"The nurse and the doctor were interchangeable, I felt both directly dealt professionally with my case" (Pt 14)</i></p> <p><i>"Information given by the nurse towards end of treatment gave answers to many questions to answers that arose during treatment" (Pt 6)</i></p> <p><i>"Any questions that I had were adequately answered by the nurse and on the only occasion I needed recourse to a doctor, that was effected efficiently" (Pt 8).</i></p> <p><i>"I feel the doctor would have a better understanding of the side effects I experienced" (p 6)</i></p> <p><i>"the doctor gave clear information given with a caring attitude" (Pt 1)</i></p> <p><i>she was excellent, explained things clearly for me to understand" (Pt 2)</i></p> <p><i>"The urology nurse was absolutely excellent. she was prepared to listen-was very knowledgeable and was prepared to listen whilst ever you had doubts" (Pt 5)</i></p> <p><i>"difficulty passing water at night in particular final week, could have done with a talk and help" (Pt 19)</i></p>

Table 2: Semi-structured interview schedule

<b>How have you found your treatment in the radiotherapy department?</b>
<b>With your individual review, we usually ask about how your treatment is going and discuss your side effects. Are there any other issues apart from these that have affected you during your treatment?</b>
<b>Thinking back during your treatment at what stage/time would a review of your concerns and issues be most appropriate?</b>
<b>Are there particular issues that would be acceptable for you to discuss in a group review?</b>
<b>Are there any issues which you think you would definitely not like to discuss in a group?</b>
<b>Do you think it would be helpful to know that others are having the same concerns and worries as you?</b>
<b>Do you think it is possible you may get support from other patients attending the group review?</b>
<b>How many patients would be the maximum you think would be appropriate for a group review?</b>
<b>Can you think of any advantages of a group review?</b>
<b>Can you think of any disadvantages of a group review?</b>
<b>Do you think relatives/carers should be invited to participate in the group review?</b>
<b>If you were asked to day about taking part in a group review how would you feel about this?</b>
<b>Are there any other ways in which you would you improve the service for patients having Radiotherapy Treatment?</b>
<b>Do you have any other comments you would like to make before we close the interview?</b>

Table 5: Themes, subthemes and selected quotes form the semi-structured interviews

<b>Theme &amp; subthemes</b>	<b>Selected quotes</b>
<b>Issues and concerns</b>	<i>“some people didn’t really seem to know what was really going on, which I thought was poor” (Pt 52)</i>
Worries around the future	<i>“I think sometimes you don’t really know what your letting yourself in for at the beginning” (Pt 34)</i>
Physical problems	<i>the 64 thousand dollar question is what happens next and how long have we got” (Pt 58)</i>
Logistics in the department	<i>“probably the drugs I’m taking for me bladder affect me more than anything else</i>
Information about how the machines work	<i>I need to talk to him just about these two tablets” (Pt 34)</i>
	<i>“I would say struggling a little bit as to what are the procedures so I think that mainly a slight clarification is required for some people as to exactly what they should be doing, when they should be going to the main desk, when they should be going to the desk where the machine is” (Pt 37)</i>
	<i>“knowing that you need a full bladder and an empty bowel is of course necessary, but to know why they are needed would be useful” (Pt 32).</i>
	<i>“I think maybe a short video of exactly explaining the procedures might be a good idea, you know a 10-15minute video. I mean there is a bit of a danger that there is so much information on the internet these days that you could actually try and gleam that information yourself but it may not be the right information” (Pt 37)</i>

## **Advantages**

Peer support

*“Erm, yeah as I say I think I would do because we are all in the same boat” (Pt 32)*

*“I think generally I think patients would get support from other people, yes. I think that would be a good thing” (Pt 37)*

*“am I the only one going through this?” (Pt 55)*

*“rapport, I think that makes you more relaxed and I think it sort of erm helps the stress” (Pt 34)*

Talking and listening  
with others

*“this gets covered a little bit by us chatting to other people in the room you know and especially in our case where there’s a few of us coming on the bus” (Pt 52).*

*“hearing other patients talking together I realise that some want to discuss it and hear what others have to say” (Pt 55)*

*“including one or even two people who have had previous treatment would be beneficial” (Pt 32).*

*“some people might just bottle up and say nothing”, “you can get your questions answered without asking them really if other people have asked that question” (Pt 34)*

*err yes you can get your questions answered without asking them really if other people have asked that question that can tick one of your boxes can’t it erm so that’s a positive yes, and of course it triggers off questions in your own mind to throw in” (Pt 58)*

## **Practicalities**

Timing of the GBTR

*“I think initially would have been the best time” (Pt 61)*

*“If you had any concerns, I think early on really so you’re not blundering along a bit” (Pt 32)*

*“I suppose if I’d got any issues of concerns it would be in the early stages but I haven’t had any so” (Pt 34)*

*“well any time really. I suppose you would want it somewhere around half way” (Pt 55)*

*“about half way through and that seemed to be the reasonable thing to do” (Pt 58)*

Partner/carers involvement in GBTR- positive	<p><i>“if the person who is attending wants someone with them then yeah, it’s not a problem, so long as people respect other people’s sort of points of views (Pt 34)</i></p> <p><i>“one fellow out there X (mentions patients name) I think his wife has to come with him because I don’t want to say he is forget to say he is forgetful but I don’t think he quite understand things straight away” (Pt 37)</i></p>
Partner/carers involvement in GBTR-negative	<p><i>“again, really awkward cos I’m not in that situation you know. I really feel it would very much depend on particular individual circumstances (Pt 52)</i></p> <p><i>Not really no, not in my case” (Pt 55)</i></p> <p><i>“Well I wouldn’t say so, I think just the patients should be participating personally” (Pt 61)</i></p>
Number of participants	<p><i>“2 or 3, I soon think the individual can get his point across better and listen” (Pt 55)</i></p> <p><i>“probably ½ a dozen, otherwise it might just get a bit too big and too long and drawn out” (Pt 34)</i></p> <p><i>“ well you don’t want too many do you.....ooooh half a dozen”(Pt 52)</i></p> <p><i>“Yeah I think it’s got to be a small amount because you, if you have a larger circle of people you get less of a say and people will keep quiet as I found in my lifetime. Maybe three or four maximum yeah” (Pt 61)</i></p>



**Disadvantages**

*"I'm sure people would rather have the one-to-one" (Pt 52).*

Confidentiality and privacy

*"erm I think it could get quite personal and erm quite emotional particularly if you're on the hormone treatment" (Pt 58)*

*"there's things I like to talk about but not to other people cos personally I'm a private person" (Pt 32).*

Self-reliance and independence

*I would say but my answer might not be open in a group discussion, I may dodge and I may feel reluctant to participate so it all depends on what the questions are and who the people are and how good the leader is" (Pt 58)*

*"I'm quite happy to be independent", I would ask somebody like yourself if I had a problem" (Pt 55).*

Taboo subjects

*your sex life and your impotence" (Pt 32)*

*"some people might be a little bit cautious about saying something because you're talking about your bowels, you're talking about this you're talking about that, you're talking about things which you don't normally talk about" (Pt 37)*

Domination by others

*"if you have a group of patients you start to get cross contamination of ideas and someone brings something up and things start wondering off the track that you actually want to talk about and so I prefer the individual" (Pt 32)*

*"you could end up not getting out of the room, it could it could go wild (laughs) and then you would need to be very skillful to sort of shut the thing down and have everybody feeling as though they were ok. It's a much more*

*traitorous path then dealing with one person” (Pt 58)*