

Men's experience of virtual simulation to aid patient education for radiation treatment to the prostate

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Abstract

Prostate cancer affects more than 3000 New Zealand men each year. Many of these men receive a complex type of radiation treatment which requires patients to have a full bladder and empty rectum to aid in the accuracy of treatment delivery and minimise side effects. These concepts can be difficult to explain and current patient education involves verbal and written materials.

A 3D immersive teaching tool Virtual Environment Radiotherapy Training system (VERT) can visually simulate and demonstrate how radiation treatment is delivered to the prostate. There is sufficient evidence to support VERT as a useful teaching tool in the academic environment however; using VERT for one-on-one patient education is a novel approach.

This qualitative, pilot study set out to explore men's experience of VERT when it was incorporated into education sessions for prostate radiation treatment. More specifically, how VERT shaped the men's understanding of how radiation treatment is delivered; why a full bladder and empty rectum is required; and their initial treatment experience. Data collection involved semi-structured interviews one week after the participants had experienced the VERT education and received their first week of radiation treatment.

Interpretative phenomenological analysis (IPA) was used to offer insight into the men's experience of the VERT education session. The findings strongly suggest VERT education enhances patient understanding of radiation treatment through visual learning. There is a preference to have the VERT education delivered sometime near the first treatment appointment and VERT has the potential to support men through engagement, information sharing and encouraging peer support. There is a role for visual tools such as VERT to be included as part of patient education sessions for radiation treatment to the prostate.

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Table of Contents

Abstract	ii
Acknowledgements	iii
Table of Contents	iv
List of Tables	vi
List of Figures	vi
1 Introduction	1
1.1 Prostate cancer in New Zealand	1
1.2 Treatment options for prostate cancer	1
1.3 Radiation treatment for prostate cancer	2
1.4 The impact of diagnosis and the importance of information	3
1.5 Virtual Environment for Radiotherapy Training (VERT).....	4
1.6 Clinical relevance	5
1.7 Aims of the study.....	6
2 Methodology.....	7
2.1 Setting.....	7
2.2 VERT presentation	8
2.3 Study design.....	8
2.3.1 Standard patient information procedure at WBCC	8
2.3.2 VERT pilot study design	9
2.3.3 Ethics and consultation.....	10
2.4 Sampling	12
2.4.1 Inclusion and exclusion criteria	12
2.4.2 Participant numbers	12
2.5 Participant recruitment.....	13
2.6 Data collection	13
2.6.1 Interview process.....	13
2.6.2 Additional data	14
2.6.3 Bias.....	15
2.7 Data analysis	15
2.7.1 Transcription of interviews.....	15

2.7.2	Analysis of transcripts.....	15
2.8	Rigor and trustworthiness.....	18
2.8.1	Prolonged engagement	18
2.8.2	Reflexivity	19
2.8.3	Triangulation and member checking.....	19
2.8.4	Transparency and audits trail	21
3	Findings.....	22
3.1	Summary of participants.....	22
3.2	Summary of major themes.....	22
3.3	Major themes explored individually	24
3.3.1	VERT education enhances patient understanding of radiation treatment	24
3.3.2	Timely delivery of the VERT education.....	29
3.3.3	Supporting role of VERT in addressing men’s masculinities.....	31
4	Discussion	40
4.1	Support for visual learning to be part of patient education	40
4.2	Improved understanding of radiation treatment	40
4.3	Addressing patient information needs.....	41
4.4	Aid with health literacy barriers	42
4.5	The impact of not feeling informed about treatment options.....	43
4.6	Supporting masculinities by encouraging men’s engagement using VERT	44
4.7	Study limitations	46
4.8	Conclusions	48
4.9	Further research suggestions	48
	References	50
	Appendix A: Screenshots from VERT education session.....	58
	Appendix B: Participant information sheet	61
	Appendix C: Participant consent form.....	68
	Appendix D: Interview schedule	71

List of Tables

TABLE 3.1: TABLE OF MAJOR THEMES AND SUPPORTIVE SUBTHEMES	22
TABLE 3.2: PATIENT DIAGNOSIS, TREATMENT & DEMOGRAPHIC INFORMATION	23

List of Figures

FIGURE 2.1 FLOW DIAGRAM OF STUDY OUTLINE	11
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1 Introduction

1.1 Prostate cancer in New Zealand

Prostate cancer is the most commonly diagnosed non-cutaneous malignancy in New Zealand. More than 3000 New Zealand men are diagnosed with prostate cancer every year and around 600 men die from this disease, making it the third most common cause of cancer death in men behind lung and colorectal cancer (Ministry of Health, 2015). Prostate cancer most commonly occurs in men aged between 65-74 years and rarely occurs in men younger than 50 years (Ministry of Health, 2013a).

There are significant inequalities for prostate cancer outcomes in New Zealand. Most notable are the inequalities between survival and death rates for Māori and non-Māori men. In 2011, Māori men were about 18 percent less likely to be diagnosed with prostate cancer than non-Māori men, but were 37 percent more likely to die from the disease once diagnosed (Prostate Cancer Working Group and Ministry of Health, 2015). There are also disparities for prostate cancer outcomes between men who live in rural or low-decile communities compared with men who live in higher decile communities. The reasons for these inequalities are not well understood but may be related to differences in appropriate health information as well as access to diagnostic and treatment services (Prostate Cancer Working Group and Ministry of Health, 2015).

1.2 Treatment options for prostate cancer

A variety of methods can be used to actively treat prostate cancer with curative intent and include surgery, brachytherapy and radiation treatment (radiation therapy). Surgery involves the removal of the prostate and the seminal vesicles and is known as a prostatectomy. Brachytherapy is when radiation treatment is given internally and involves the temporary or permanent insertion of a radiation source directly into the prostate gland whilst the patient is under general anaesthetic. Radiation treatment uses a linear accelerator to deliver ionising radiation directed from outside the body at the tumour and permanently damages or destroys cancer cells.

Treatment selection can depend on the stage and grade of the disease as well as other factors such as the age, co-morbidities, symptoms, lifestyle and personal preference

(Ministry of Health, 2013a). Generally, there is no conclusive evidence that either surgery, brachytherapy or radiation treatment is superior in terms of disease-free survival and changes in quality of life (Kibel et al., 2012). All three treatment options offer similar survival benefits and can cause temporary and permanent changes to bladder and bowel function as well as sexual function (Ferrer et al., 2008; Hamdy et al., 2016). Therefore, the Ministry of Health Prostate Cancer Taskforce (2013a) recommends patients should be informed of the advantages, disadvantages and potential complications associated with all suitable treatment options and men should consult with both types of specialists before making a decision about treatment.

1.3 Radiation treatment for prostate cancer

Radiation can be used to treat patients in low, intermediate and high risk groups for prostate cancer (Ministry of Health, 2013a). The aim of radiation treatment is to deliver high doses of radiation directly to the tumour or target area, whilst minimising dose to surrounding tissues. For prostate cancer treatment, the target usually involves the prostate gland and seminal vesicles whilst trying to reduce dose to the nearby rectum, bladder and other healthy tissues (Brady, Heilmann, Molls, & Nieder, 2011). Both the bladder and rectum sit adjacent to the prostate and depending on their fullness each day; they can change the position of the prostate and seminal vesicles. Prostate displacement can be reduced if a constant and reproducible organ filling is maintained for both the rectum and bladder (Graf et al., 2012). For this reason, patients are asked to have a full bladder and empty rectum each day for radiation treatment, as it reduces the variation in the prostate position. Also, significant differences in rectal and bladder volume can increase the risk of toxicities the patient may experience (Becker-Schiebe, Abaci, Ahmad, & Hoffmann, 2016; Sripadam et al., 2009). Therefore, achieving a similar bladder and rectum size each day can improve the accuracy of treatment delivery and decrease the acute side effects a patient may experience.

Image-guided radiation therapy (IGRT) is when imaging technology is used daily to verify the position of the prostate before radiation treatment is delivered. Daily IGRT involves using static x-ray images to localise the prostate by tracking fiducial markers

that are inserted within the prostate gland, or performing a cone-beam scan of the pelvis which allows visualisation of the prostate, bladder and rectum (Hayden et al., 2010). Intensity-modulated radiation therapy (IMRT) or volumetric modulated arc therapy (VMAT) is a complex, highly localised type of radiation treatment that has excellent clinical results, improving tumour control rates and decreases dose to surrounding organs such as the rectum and bladder (Wolff et al., 2009). Currently IMRT or VMAT radiation are the gold standard treatments for prostate cancer in all New Zealand radiation therapy departments in conjunction with daily image guidance (Ministry of Health, 2014).

For IMRT or VMAT radiation therapy to be delivered accurately to the prostate, it is imperative patients can adhere to the requirement of filling their bladder and emptying their rectum prior to treatment to minimise prostate and organ variation. Graf et al. (2012) and McNair et al. (2014) found providing patients with specific instructions can help to achieve a consistent bladder and rectum size which reduces the variation during treatment and helps improve outcomes for the patient. The importance of this process is difficult to explain and a lack of understanding can make it challenging for patients to achieve these instructions. Lack of adherence may result in a decision by staff not to treat and the patient will be asked to reattempt to fill their bladder and empty their rectum before continuing. For some men, the pressure associated with meeting these requirements on a daily basis can lead to feelings of increased stress and anxiety about receiving radiation (Appleton et al., 2015).

1.4 The impact of diagnosis and the importance of information

Coping with a cancer diagnosis and navigating the different treatment options can be a difficult and distressing time for patients (Dunn, Steginga, Rose, Scott, & Allison, 2004). Communicating effectively and providing suitable information and education are important approaches to alleviate patient anxiety and stress (Stark & House, 2000). A systematic review of the literature shows once diagnosed with cancer, patients are primarily interested in information related to available treatment options and expected treatment side effects (Rutten, Arora, Bakos, Aziz, & Rowland, 2005). Radiation therapy and its use of complex technology and specific bladder and

rectal filling requirements for prostate treatment, can add to the challenge of providing effective information.

A patient's negative mood is often highest before treatment commences, indicating that psychological preparation is important before radiation begins (Dunn et al., 2004). Previous research has demonstrated that patients who are well informed about their disease are less likely to be anxious and emotionally distressed, and more inclined to cooperate with treatment instructions (Long, 2001). Bolderston (2008) identified effective patient education as a useful strategy to alleviate stress and anxiety in cancer patients because it increases their sense of control. A study by Skalla, Bakitas, Furstenberg, Ahles, & Henderson (2004) reported patients can feel overwhelmed by too much information, and the material provided should address the individual's needs and be presented in a format they can understand.

Effective methods of providing information to cancer patients and their families, should include a variety of sources such as written materials as well as audio-visual aids (McPherson, Higginson, & Hearn, 2001). The New Zealand Ministry of Health, (2010a) recommends the use of personalised, audio-visual material because it can foster improved patient outcomes by; enhancing a person's knowledge, recall, symptom management and level of satisfaction of health care services. The use of audio-visual teaching resources can complement written and verbal information especially where there are language or literacy barriers (Dunn et al., 2004). This is important for New Zealand as health literacy rates are low, particularly among Māori who live in rural areas (Ministry of Health, 2010b). In a recent study that evaluated using multimedia resources to educate men who were to receive radiation for prostate cancer, participants reported they felt better informed and prepared for treatment after viewing a customised video (Dawdy et al., 2016). This suggests using a range of tailored education resources according to the patients' learning requirements, can optimise their understanding, adherence and preparedness for treatment.

1.5 Virtual Environment for Radiotherapy Training (VERT)

Virtual Environment for Radiotherapy Training (VERT) is a 3D immersive simulation system originally designed as an educational tool to assist with the training of

radiation therapy students in the United Kingdom (James & Dumbleton, 2013). VERT can simulate the entire radiation treatment environment and process, demonstrate virtual patients and provide visualisation of internal anatomy and dose (Phillips, Ward, & Beavis, 2005). A study by Bridge, Appleyard, Ward, Philips and Beavis (2007) reported that the majority of students who interacted with VERT perceived an improvement in their understanding of key concepts of radiation therapy. There is further evidence to suggest VERT can facilitate understanding through the simulation of technical processes within the radiation treatment environment (Leong, 2015). A recent trial conducted in Australia also concluded VERT helped students understand the radiation treatment process, aiding their preparedness for the clinical environment (Bridge et al., 2016).

Departments in Switzerland, Denmark and the United Kingdom have investigated whether VERT is a suitable tool for patient education. When VERT was used for patient education in a group environment, participants reported high levels of satisfaction, decreased anxiety and an increase in their knowledge of radiation therapy (Boejen, Bloch-Larsen, Poulsen, & Seiersen, 2011). Another study by Stewart-Lord, Brown, Noor, Cook and Jallow (2016) demonstrated men with prostate cancer responded positively to VERT when it was used for group patient education. In particular, it helped them understand the importance of bladder and rectum preparation for radiation treatment and this improved compliance with achieving these instructions.

VERT is currently used at the University of Otago, Department of Radiation Therapy in Wellington, to teach clinical skills, conceptual knowledge as well as demonstrate complex treatment techniques to radiation therapy students (Montgomerie, Kane, Leong, & Mudie, 2016). At present, VERT is not used in any New Zealand cancer centres for patient education.

1.6 Clinical relevance

A review of the literature shows there is sufficient evidence supporting the successful use of VERT as a teaching tool for radiation therapy students (James & Dumbleton, 2013). However, there are limited publications on the use of VERT for patient education, particularly in a one-on-one setting using qualitative methods. Visual

learning is one of the three basic learning styles that incorporates ideas, concepts, data, and information associated with images and techniques (Pashler, Mcdaniel, Rohrer, & Bjork, 2009). Audio-visual tools can enhance learning through visual demonstration and has the ability to overcome communication and literacy barriers by offering an alternative source of information to verbal and written materials (Skalla et al., 2004).

The research described in this thesis will add to the literature by exploring how male adult patients experience VERT when it is incorporated into one-on-one education sessions for prostate radiation treatment. This group of patients has been selected, as prostate cancer is commonly treated in New Zealand using complex radiation techniques and patients are asked to adhere to specific bladder and rectum filling instructions. By interviewing participants about their experience of VERT and how it has shaped their understanding of radiation and initial treatment experience, further research can be developed using the data collected in this pilot study.

VERT can visually simulate any type of radiation treatment, meaning there is potential to design different patient education presentations for other sites treated with radiation such as breast, lung and bowel. With the increasing complexity of radiation therapy and the use of high end technology, comes the challenge of effectively explaining the treatment process to patients. The unique ability of VERT to visually represent such complex ideas can complement this growing area of radiation therapy, helping patients feel fully informed and engaged with their treatment.

1.7 Aims of the study

This preliminary, qualitative research sets out to explore how male adult patients experience VERT when it is incorporated into one-on-one education sessions for prostate radiation treatment. More specifically, it will explore each patient's experience of VERT and how it has shaped their:

- perceived understanding of how radiation treatment is delivered,
- understanding of why a full bladder and empty rectum are required for radiation treatment,
- initial treatment experience.

2 Methodology

Interpretive phenomenological analysis (IPA) is a qualitative approach that seeks to explore, understand and communicate the lived experience and perspective of the participant (Larkin, Watts, & Clifton, 2006). IPA's theoretical underpinnings come from Heideggerian phenomenology which is concerned with the way things appear to individuals in their experience and context, and hermeneutics which is concerned with text interpretation (Smith, Flowers, & Larkin, 2009).

IPA methodology has been used to analyse the data and uses a combination of interpretative, phenomenological and idiographic components. The phenomenological requirement is to understand the individual's perspective and give voice to their thoughts and emotions; and the interpretive requirement is to contextualise and make sense of the participants' lived experiences (Larkin et al., 2006). The idiographic requirement refers to an in-depth analysis of single cases and examining individual perspectives in their contexts before producing general statements (Pietkiewicz, Smith, Pietkiewicz, & Smith, 2014). This means IPA is an inductive approach that tries to understand what an experience is like from the participant's perspective and interpret how the person made sense of it. As I was interested in the participants' experiences of the VERT education session, how they made sense of what they were shown and what it meant for their initial treatment experience, IPA was a suitable analytical method for this project.

2.1 Setting

The research site was the radiation treatment department in the Wellington Blood and Cancer Centre (WBCC). This department was selected because it employs the researcher (AF) as a radiation therapist, which allowed clinical access to patients who receive radiation treatment for prostate cancer. Because of my clinical role with WBCC, there were already established relationships with the oncologists, team leader and clinical staff. I also had an important awareness and understanding of the department's processes and was able to design the research to have minimal impact on the department's workflow and resources. Interviews were scheduled around pre-existing appointments at WBCC, reducing the impact this study may have had on the participants' time.

2.2 VERT presentation

Prior to the study commencing, a pre-designed VERT education presentation was developed by AF (Appendix A). This VERT presentation provided a 3D interactive, audio-visual representation of the radiation treatment process and visually demonstrated:

- the treatment room environment and how radiation is delivered to the target,
- an explanation of what the treatment process would involve for the patient,
- why it is important for the patient to have a full bladder and empty rectum for treatment.

The VERT presentation was reviewed by multiple groups to check its suitability for the study. These groups included radiation oncologists, radiation therapists, nurses, a member of the Māori Health Development Group, lay people as well as two male patients already receiving radiation treatment for prostate cancer. Their feedback was used to help shape the final VERT presentation that was used for this study.

2.3 Study design

2.3.1 Standard patient information procedure at WBCC

The following is a summary of the standard information procedure for all men receiving VMAT radiation for prostate cancer at the WBCC:

- Referral to a radiation oncologist and consent obtained to undergo radiation treatment.
- Sent written information on the planning CT scan procedure with bladder and rectum filling requirements, as well as given a follow up phone call to check their understanding of this information.
- Attend the planning CT scan appointment which includes a 20 minute pre CT education session with a radiation therapist and involves standard verbal and written materials.
- Attend their first treatment appointment which includes a 20 minute pre-treatment education session with a radiation therapist and involves standard verbal and written materials.

- Attend subsequent treatment appointments and receive weekly reviews by their radiation oncologist or registrar.
- Attend follow up appointment with their radiation oncologist 6-8 weeks after completing radiation treatment.

Standard written and verbal information includes:

- Two booklets, one explaining why a full bladder and empty rectum are required for treatment, instructions on how to achieve these and suggested changes to diet to minimise gas. The other explaining possible treatment side effects, management and support services available.
- A printed schedule of treatment appointments.
- A verbal explanation of the CT scan and treatment procedure as well as an orientation of the department such as where to get changed and where to wait.
- A discussion to check their understanding of how to prepare the bladder and rectum for treatment and their understanding of expected side effects and management.

2.3.2 VERT pilot study design

The standard WBCC patient education procedure was followed, except that the VERT presentation was also included at the time of the pre-treatment education session. The VERT presentation took approximately 10 minutes to deliver and was presented to the participant in addition to the standard verbal and written information normally provided. The entire VERT education session took around 35 minutes to complete. Participants were asked to come to the radiation department one hour before their first radiation treatment appointment. This allowed sufficient time for the education session to take place as well as time to prepare their bladder and rectum for treatment. After the education session was finished, each participant went on to receive their first radiation treatment.

Once the participant had received approximately 5 radiation treatments (1 week), a semi-structured interview was conducted. This allowed the participant sufficient time to reflect on their experience of VERT and how it shaped their perceived

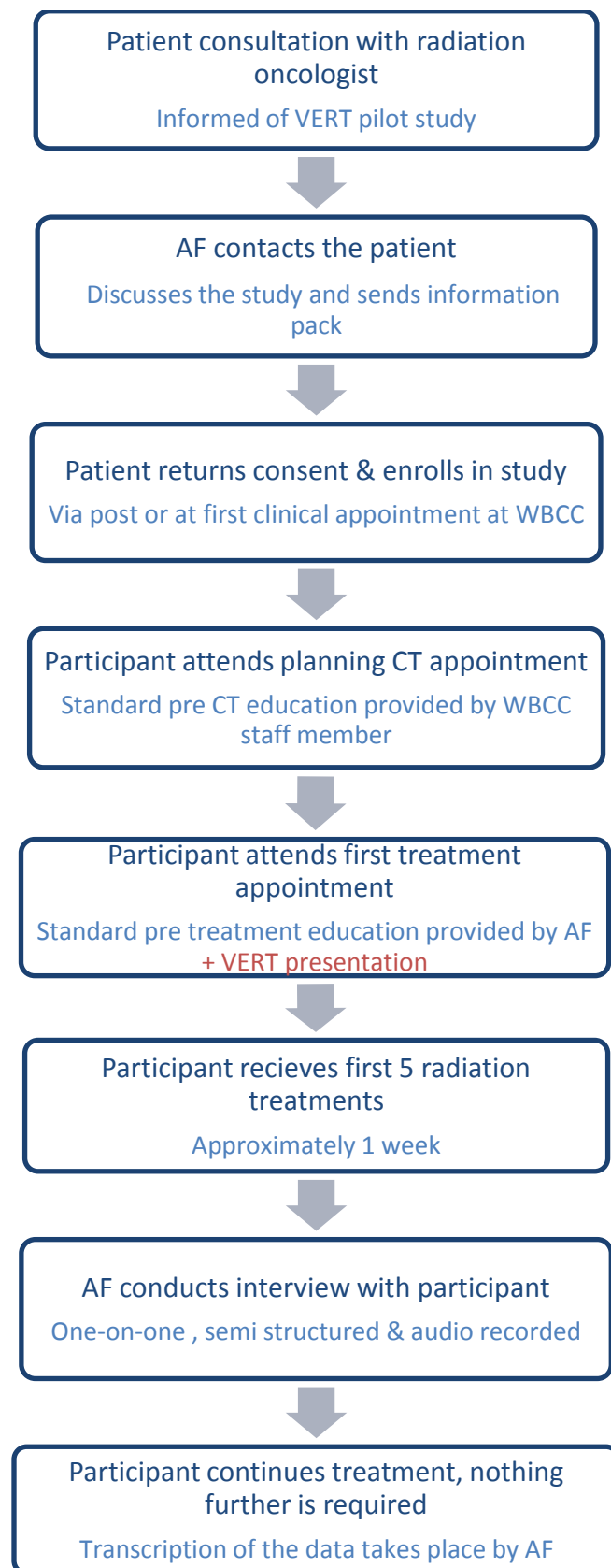
understanding of how radiation treatment is delivered and their initial treatment experience.

The data collected from the interviews was transcribed and analysed using IPA in order to understand the men's experience and their ascribed meaning of VERT. All stages including the VERT education, interview and interview transcription for each participant were performed by AF. A summary of this process can be seen in the flow diagram 2.1.

2.3.3 Ethics and consultation

The University of Otago Human Ethics Committee (Health) approved the study prior to commencement (protocol number: H15/049). A locality agreement was signed with Capital and Coast District Health Board (CCDHB) and consultation was also sort with the Research Advisory Group Māori (RAG-M) and the Ngāi Tahu Research Consultation committee.

Figure 2.1 Flow diagram of study outline



2.4 Sampling

This research was focused on the education of male patients who were to receive radiation treatment for prostate cancer. This was a very specific part of the population; therefore purposive sampling was used to recruit participants who would represent a perspective on this research topic (Smith et al., 2009). Specifically, men who were to receive VMAT radiation treatment at WBCC for prostate cancer were informed of the study by their radiation oncologist at consultation.

2.4.1 Inclusion and exclusion criteria

To be eligible to take part in this study, the participant had to meet the following criteria:

- confirmed diagnosis of prostate cancer,
- offered a course of VMAT radiation treatment at WBCC,
- had NOT received any previous external beam radiation treatment,
- able to speak a reasonable level of English to participate in an interview.

Receiving a course of previous brachytherapy treatment was not an exclusion criterion as the education and treatment procedure is completely different to external beam radiation treatment. Brachytherapy enables the delivery of high dose radiation to the prostate in a single treatment and reduces the total number of external beam radiation treatments a patient will require (Challapalli, Jones, Harvey, Hellawell, & Mangar, 2012). Patients who are suitable for brachytherapy may be offered this treatment before receiving a course of VMAT radiation treatment at WBCC. Similarly, men who had received previous surgery to remove the prostate were not excluded as VMAT radiation treatment can still be offered where there is a high risk of recurrence due to positive surgical margins or a rising prostate specific antigen (PSA) level in the blood post surgery (Ministry of Health, 2013a).

2.4.2 Participant numbers

A total of nine participants were recruited into the study. IPA studies are typically conducted with relatively small sample sizes because it requires the close examination of each individual transcript in detail, to discover the perceptions and understandings of the participants' experiences (Smith et al., 2009). IPA researchers should focus on depth rather than breadth in their studies and less than 10

participants is recommended (Reid, Flowers, & Larkin, 2005). Data saturation is when more sampling will not lead to more information related to the research question and often occurs more quickly in small sample sizes such as in this study (Morse, 1995).

2.5 Participant recruitment

Patients with prostate cancer, who attended their routine radiation treatment referral and met the inclusion criteria, were given an information sheet summarising the study and the contact details of the researcher by their oncologist (Appendix B). If the patient was interested in the study, the oncologist asked for verbal consent for the researcher to contact them. If they agreed, the patient received a phone call explaining the VERT system, the aims of the study and what participation in the study would involve. Patients were reassured that participation was entirely voluntary and that their treatment and standard of education and care would not be compromised in any way should they choose not to participate. During this time, patients had the opportunity to ask questions and were encouraged to discuss the study with their family or support person.

If the patient expressed an interest in participating, an information pack containing a participant information sheet and consent form (Appendix C) with a prepaid envelope was sent to the patient's address. One week later, patients received a follow-up call to ask whether they had any further questions about the study.

If patients were willing to participate, they were asked to complete and return their consent form using the supplied prepaid envelope. Alternatively, they were able to complete the consent form when they attended their first clinical appointment at WBBC.

2.6 Data collection

2.6.1 Interview process

In-depth, semi-structured phenomenological interviews were used to collect rich data and gain insight into the participants' experiences of the VERT education session. They also explored what VERT meant for them in terms of their understanding of radiation delivery and initial treatment experience (see attached

interview schedule in the Appendix D). Questions and prompts were used to encourage participants to describe their experience in detail and to capture both the obvious and hidden meaning of their lived experiences (Pietkiewicz, & Smith, 2014). The interview schedule was adapted slightly as interviews between participants progressed, enabling emergent themes and meanings to be clarified and validated by subsequent participants (Van Manen, 2014).

Data collection involved the audio-recording of in-depth, face-to-face, one-on-one conversational style interviews with the participants. Interview times were scheduled round existing treatment appointments, ranging between 30-60 minutes. Participants were given a choice of the interview taking place in a clinic room at WBCC or in an office outside, but still within walking distance of the department. They were able to view the interview schedule prior to the interview taking place and consent was obtained to make observational notes during the process. All of the men were offered the opportunity to review their own transcripts before data analysis began, or review a summary of the main results at the conclusion of the study.

While this study was considered low risk, it was recognised that discussing the men's cancer journey may potentially trigger some negative memories and possibly cause some emotional distress. During the interviews, participants were closely monitored for signs of distress such as agitation or withdrawal. Plans were in place to stop the interview if necessary and refer the person to appropriate support services such as their oncologist, general practitioner or the oncology counselor. At the conclusion of the interview, each person was provided with my contact details should they wish to add anything else to their interview. One participant did ask for a short additional interview, as he found he had more to say after he went home and reflected on the initial interview.

2.6.2 Additional data

With the participant's consent, some demographic information was also collected without identifying them. These details help contextualise the person and can be related back to their experience and social context, as well as demonstrates the transferability of the data (Smith et al., 2009). This information included age, staging

of prostate cancer, radiation treatment prescription and other treatments, ethnic background, marital status and employment situation.

2.6.3 Bias

It is important to acknowledge the researcher is associated with the research process, therefore her behaviour and relationship with the participants may impact on their responses and the study's findings (Krefting, 1991). To standardise the process and minimise potential bias, I carried out all of the steps associated with this research project; delivery of the VERT education sessions, conduction of the interviews, production of the transcriptions and data analysis. By performing all of these roles, it was possible the participants could have wanted to please me by providing answers they believed I wanted to hear, rather than their genuine opinions. This was minimised by maintaining transparency, ensuring confidentiality and encouraging the men to provide their answers honestly, without feeling pressured. This was stipulated in the participant information sheet and they were also reminded at the beginning of the interview that it was important to provide their honest experience of the VERT education session. They were also reassured that their honesty would not negatively impact on their treatment or care in anyway.

2.7 Data analysis

2.7.1 Transcription of interviews

I transcribed each interview, and by doing so, became immersed in the data. This process involved listening carefully to each interview and accurately recording everything that was spoken by me and the participant. This included prosodic features such as significant pauses, hesitations, emphasis as well as notable non-verbal sounds such as laughter. Every line was numbered to aid in the organisation of the transcripts and helped identify specific lines when coding the data.

2.7.2 Analysis of transcripts

1. Close reading and creating initial exploratory comments

The transcripts were examined case by case using a systematic, qualitative analysis approach. Pietkiewicz et al. (2014) recommends reading and re-reading transcripts closely and re-listening to the audio recording to help the researcher engage with the

data and recall the atmosphere of the interview. By doing this, it was possible to focus on the content and linguistic features of the interview transcript and make initial exploratory notes in the margin. Distinctive phrases as well as important responses and explanations offered by the participant were highlighted to produce a comprehensive set of notes (Smith et al., 2009). These notes included descriptive comments such as key events and experiences for the person, linguistics comments which noted the choice of language or the way something was said, such as metaphors, as well as conceptual comments which try to understand the context of the participant's perspective (Smith et al., 2009). Conceptual comments were developed using the contextual information provided by the participant to help understand their point of view and how they made sense of their VERT education experience. During this process, it was important to acknowledge that the assumptions and experiences of the researcher might influence how the participants' responses were interpreted, therefore any preconceptions or judgements needed to be suspended (Biggerstaff & Thompson, 2008). This is known as bracketing and it occurs when the researcher deliberately separates their own beliefs throughout the analysis (Chan, Fung, & Chien, 2013).

To achieve this, a reflective diary and discussions with supervisors were used to critically examine and self-reflect on how my personal characteristics, social background, assumptions and values may have affected the research process. Specifically, this includes my sex (female), age (30 years), New Zealand European ethnicity and role as a medical professional and how these attributes may have affected my rapport with men aged between 55-75 years, of varying social backgrounds and ethnicities who are undergoing treatment for prostate cancer.

2. Developing emergent themes

The second stage of IPA involves working predominately with the initial exploratory comments generated for each transcript and transforming these notes into emergent themes (Pietkiewicz et al., 2014). Themes that best captured the essence of what the participant said were highlighted and grouped together based on connections and patterns within the exploratory notes. The themes were broken up into 3 sections: (i) discussion related to their VERT education experience, (ii) discussion related to their preferred way to learn information, and (iii) other themes that seemed specifically

important to each participant, such as their cancer experience and treatment decision making process; preconceptions of radiation treatment; emotions experienced since diagnosis; or concern about treatment outcomes. Themes were colour coded to aid in the organisation of the data. Verbal accounts from the original transcripts that supported the emergent themes were grouped together to reflect the participants' lived experience and demonstrate how this theme was developed.

3. Forming clustering themes

The third stage requires making connections between emerging themes, grouping these together into clusters or concepts and giving each cluster a descriptive label known as a 'super-ordinate' theme (Biggerstaff & Thompson, 2008). The super-ordinate theme emerges at a higher level and provides a structure of how themes fit together and allows the most interesting and important aspects of the participant's interview to come through (Smith et al., 2009). Pietkiewicz et al. (2014) suggests some themes may be discarded at this point if they do not fit well with the emerging structure or they have weak evidential support. Cluster themes were generated by arranging emergent themes into groups according to relevance or relationships with each other, to arrive at a super-ordinate theme. These cluster themes were collated into a table supported by the original accounts from the interviews. In keeping with IPA's idiographic commitment, emerging ideas and themes from the previous case needed to be bracketed whilst the next case was analysed so the individuality between each case was not lost (Smith et al., 2009). This process was repeated and applied to each transcript until a set of cluster themes were produced for all nine participants.

4. Developing major themes

The fourth stage was to create a master list of the major themes that highlighted the key features and concerns identified by all of the participants (Biggerstaff & Thompson, 2008). These major themes not only represent commonalities across all the participants' accounts but also accommodate the individuality and variance in the data set (Reid et al., 2005). For sample sizes greater than six, Smith et al. (2009) suggests measuring the recurrence of themes across multiple cases and a super-ordinate theme could be classified as recurrent if it is present in at least half of the participant interviews. This final stage of data analysis involved evaluating the cluster

themes for all participants and organising them into groups based on patterns or relationships to develop major themes. Recurrence of key themes was also used to help identify the most important super-ordinate themes, suggesting a hierarchical relationship between them. For example, some themes such as preference for visual learning occurred in all cases, suggesting this was of high importance for all the men. Working closely with the super-ordinate themes and the supporting transcript extracts, a final results table consisting of three major themes was produced and reviewed with the research supervisors.

2.8 Rigor and trustworthiness

To successfully present and defend a study's design and interpretation of the data, rigor and trustworthiness must be assured. The model by Guba (1981) to test rigor is relevant for qualitative studies and involves exploring (a) truth value or credibility, (b) applicability or transferability, (c) consistency or reliability, and (d) neutrality or confirmability. These four criteria offer researchers a strategy to increase rigor and trustworthiness in their study designs and also provide readers a way of assessing the value of qualitative findings (Krefting, 1991). The following outlines the techniques used throughout this study's research process to ensure these four criteria have been achieved.

2.8.1 Prolonged engagement

Credibility requires sufficient engagement with the phenomena and respondents; allowing the researcher to check perspectives and encourages participants to become more comfortable with the research process (Krefting, 1991). Lincoln and Guba (1985) termed this prolonged engagement. Allowing this extended period of interaction to occur between the researcher and participant can increase rapport and participants may volunteer different or more thoughtful information as a consequence (Krefting, 1991). For this study, I met with all participants at their first clinical appointment so we were acquainted with each other. Prior to the interview starting, time was spent making small talk to establish rapport and to help the participant feel more relaxed. Information on the participant information sheet was reiterated to check their understanding and reconfirmed their consent to take part. At the conclusion of the interview, the participant was provided with my contact

details and told they could make contact should they wish to add more to their interview.

2.8.2 Reflexivity

While a close relationship between researcher and participant is important, it is possible this can become too entwined and the researcher may have difficulty separating her experiences and expectations from the participant, affecting the interpretation of the data (Krefting, 1991). Reflexivity is a useful strategy to help reduce this. I was aware of my part in the research process and acknowledge this may have affected the participants' responses. In addition to this, my own background, perceptions and knowledge would influence the interpretative process (Finlay & Ballinger, 2006). As the researcher, I was interested in the participant's perspective of the VERT education and the meaning this had on their initial treatment experience. However, I am also a radiation therapist and have expert knowledge and understanding of radiation treatment and VERT; therefore I needed to juggle the influence of these two roles and made every effort to suspend my assumptions. This was managed by using a research diary to reflect my thoughts, feelings, questions and frustrations during the research process and help identify any biases and assumptions, as well as having critical discussions with my supervisors. An example of this was when a participant became slightly emotional when discussing his cancer journey. At the same time, a person close to me was going through their own challenging cancer experience and I needed to acknowledge my own emotion and take steps to ensure my initial reaction did not influence the interpretative process.

2.8.3 Triangulation and member checking

Triangulation involves using different sources, methods and different investigators to cross check the data and interpretation (Schwandt, Lincoln, & Guba, 2007). It is a powerful strategy for enhancing the quality and integrity of the research (Krefting, 1991). For this study, I did not feel equipped to adequately interpret the Samoan participants' transcripts because I have minimal experience with Samoan culture, especially with Samoan men over the age of 65 years. There was also a slight language barrier as English was the Samoan men's second language and at times during the interview it became challenging to understand each other. For these reasons, consultation was sought with the Pacific Health Unit at CCDHB to enlist a

person of Samoan ethnicity to provide a cultural lens to some of the terminology from the interviews and check my interpretation of the data. This cross checking process helped identify some misunderstandings and misinterpretations and also offered essential insight to Samoan culture and perspectives. An example of this was the term 'Samoaness' used by a participant to explain how the views of some Samoan people generally from an older generation, can affect the way important health information is provided to the community due to the stigmas and taboos associated with it. Consultation was also sought with a member of the Māori Health Development Group to cross check aspects of the Māori participant's interview transcription to ensure cultural sensitivity was achieved.

Member checking is the process of continuously testing the researcher's interpretation of the data and conclusions with participants (Lincoln & Guba, 1985). This strategy involves disclosing research information to participants to ensure their perspective has been accurately translated into data and decreases the chances of misinterpretation (Krefting, 1991). As this research is interested in men's experiences of the VERT education, member checking occurred with the men taking part in the study. Emerging themes were tested on subsequent participants during their interviews to cross check ideas. This was done carefully as it was important not to reveal any identifying information about other participants and also not influence the current participant's perspective. Sentences such as 'another participant brought up this idea, do you have any thoughts of your own around this?' were used to achieve this. An example of an emergent theme that developed into a major theme through member checking and discussions was the potential supportive role VERT has in addressing men's masculinities.

Participants were invited to review their own transcripts or a summary of the major themes at the conclusion of the study. Peer examination was also utilised by asking a male academic colleague who had some background in qualitative research but was not involved in this study, to check the interpretation of the data had not been 'feminised' or 'medicalised'.

2.8.4 Transparency and audits trail

Transparency has been achieved by providing relevant, contextual information about participants so readers can evaluate its transferability to persons in similar contexts. The research process and methodology includes a concise commentary of the data demonstrating the interpretation process. Emerging and major themes are supported by evidence from the original transcripts which have been presented in the results section.

3 Findings

3.1 Summary of participants

Nine men took part in this study. The average age was 68 years, which is comparable to Ministry of Health (2013) data which reports prostate cancer most commonly occurs in men over the age of 65 years. All participants were categorised with intermediate or high risk disease and received one of three treatment options:

- a) previous prostatectomy followed by radiation
- b) previous brachytherapy followed by radiation
- c) radiation treatment only

Of the nine participants, six identified their ethnicity as New Zealand European, two as Samoan and one as Māori. A full summary of the participants' diagnostic, treatment and demographic information can be viewed in Table 3.2.

3.2 Summary of major themes

Close analysis of the interview transcriptions using IPA methodology generated the major themes for this study (Table 3.1). These themes represent the views for all nine men and are arranged in a hierarchical order with the most important sub-ordinate themes at the top.

Table 3.1: Table of major themes and supportive subthemes

VERT education enhances patient understanding of radiation treatment <ul style="list-style-type: none"> • Visualisation helped patients understand and feel prepared for treatment • Preference for visual learning to be part of patient education • Explained how radiation treatment is delivered and the technology involved • Improved understanding of why a full bladder and empty rectum are required
Timely delivery of the VERT education <ul style="list-style-type: none"> • Prefer to receive VERT education close to first radiation treatment appointment • Repetition of the VERT education would reinforce the information
Supporting role of VERT in addressing men's masculinities <ul style="list-style-type: none"> • The impact of not feeling fully informed on personal autonomy • Taboos associated with prostate cancer and a lack of open discussion • VERT to engage men, initiate information sharing and encourage peer support

Table 3.2: Patient diagnosis, treatment & demographic information

Identifier code	P1	P2	P3	P4	P5	P6	P7	P8	P9
Diagnosis: Risk category & staging	High T2c N0 M0	Intermediate T1C N0 M0	High T2b/T3a N0 M0	High T2b/T3a N0 M0	High T4 N0 M0	High T3 N0 M0	High T3 N0 M0	Intermediate T2 N0 M0	Intermediate T2a N0 M0
Target site	Prostate bed	Prostate and seminal vesicles	Prostate and seminal vesicles	Prostate and seminal vesicles	Prostate bed	Prostate and seminal vesicles	Prostate bed	Prostate and seminal vesicles	Prostate and seminal vesicles
Previous brachytherapy or surgery	Prostatectomy	None	Brachytherapy	Brachytherapy	Prostatectomy	Brachytherapy	Prostatectomy	None	None
VMAT prescription	64Gy in 32#	74Gy in 37#	46Gy in 23#	46Gy in 23#	64Gy in 32#	46Gy in 23#	64Gy in 32#	74Gy in 37#	74Gy in 37#
Age	66	75	68	74	69	68	66	66	56
Ethnicity	New Zealand European	New Zealand European	New Zealand European	New Zealand European	New Zealand European	Samoan	New Zealand European	Samoan	Māori
Marital status	Divorced	Married	Married	Married	Married	Married	Married	Separated	Married
Highest level of education	University Entrance	5 th form school certificate	University Diploma	6 th form school certificate	5 th form school certificate	6 th form school certificate	5 th form school certificate	Left high school at 18 yrs	Graduate of Emergency Services
Employment Status	Retired (Information Technology)	Retired (Theatre production)	Retired (Sheep farmer/ vineyard owner)	Retired (Electrician)	Retired (Mechanic)	Retired (Gardener)	Part time (Online company)	Factory worker	Emergency Services
Home location	Wellington	Marlborough	Marlborough	Wairarapa	Wellington	Wellington	Wellington	Wellington	Wellington

= number of total treatment fractions

3.3 Major themes explored individually

3.3.1 VERT education enhances patient understanding of radiation treatment

This dominant major theme was generated from the accounts of all nine participants and primarily answered the research question - how do male patients experience VERT when it is incorporated into education sessions for prostate radiation treatment? The development of this major theme can be seen through the analysis of the following four subthemes.

Visualisation helped patients understand and feel prepared for treatment

All participants strongly expressed their positive experience of the VERT education and identified that it was the visual aspect of the VERT presentation that clearly explained the treatment process and thus enhanced their understanding:

I thought it was excellent because the first time I walked into that room, I could see where I was going to be and umm how it all worked...so I guess that gave me a very good understanding, pictorial or visual understanding, whatever it is understanding, I thought that was great (P7)

Most men felt the treatment process simulated by VERT was very similar to their real treatment experience:

It connected, it linked, what you showed there is exactly what I saw in the linear room (P9)

When I saw the video and when I went into the room it was exactly like what I had seen in the video so you know, I thought this is it (P5)

Receiving this explanation prior to their first radiation appointment helped them feel more comfortable and prepared for treatment as they knew what to expect:

I think the visual presentation made a big difference to your understanding of what lay ahead of you (P3)

It's bad enough coming in here and you don't know what is going to happen to you but if you have got an idea of when you go into a room, that helps (P5)

Participant 2 particularly emphasised the importance of seeing VERT prior to receiving his first treatment appointment as he mentioned the relief he experienced numerous times which decreased his anxiety about receiving radiation treatment:

I didn't realise just how much relief I got after seeing it (VERT) and what the process was (P2)

He seemed almost surprised at the positive effect the VERT education had on his attitude and his initial treatment experience.

Preference for visual learning to be part of patient education

The value of visual learning was acknowledged by all nine participants. For many, visual learning was their preferred way to acquire information and identified one of the main benefits of VERT was its ability to convey information in a different way compared with written materials:

Yes I must say the information that comes out from you people at the hospital and also from the Cancer Society, there is all sorts of brochures and things and you read through and read through but it's different when you actually physically see it on screen and have it explained to you like that, it's definitely a better tool I think (P3)

This implies visual education tools are viewed as another useful and important way of explaining information and could be used alongside written materials:

Well in this day and age I think you can read it, but I think, what I got out of that was the visual, umm, it's all very well to read it and listen, listen to somebody go on about it, but it's... it's the visual, umm that at the end of the day for me, was the most important thing (P2)

Participant 5 pointed out the speed and ease associated with visual tools. For explaining certain types of information such as how radiation is delivered to the prostate, visual education tools may be the most suitable choice:

I think if people can see things they comprehend, really, really fast (P5)

He related visual learning back to his occupation of being a mechanic and how reading about a process does not always explain it:

I'm a motor mechanic you know, if I give you something on a diff I would confuse you too you know, here you read this and you wouldn't know it. They talk a different language doctors umm but hey it's like anything, they just know it and you don't (P5)

Participant 2 agreed that visual learning is a fast and simple way to communicate information and uses the example of the way children are taught to illustrate this:

Visual learning I mean that's how little kindergarten kids learn is visual, there is no difference is there? He learns visually and even when you are an adult you still learn far quicker by visually seeing it (P2)

The men of Māori and Samoan ethnicity identified the importance of visual learning to aid in the understanding of health information, especially when the information is complex. They stressed some of the challenges with reading comprehension and explicitly stated they found information presented visually much easier to comprehend compared with written information:

When I saw that video on the screen, it's made it easier to understand and to know where, where the treatment is going (P6)

I thought it was absolutely brilliant and I got more from that than any of my readings to tell you the truth umm it's nice to have little pictures there but when you have got words underneath it I sort of umm, I'm not silly and I know the relationship between the words and the pictures but for it to actually sink in I've got to see it, I've got to see a visual movement of somebody actually going through the process (P9)

Both Samoan participants discussed the difficulty they had with understanding health information in a written format as English was their second language and they found information presented visually much easier to understand:

Because I learnt this one, it's easier to learn if I see the picture, than the words because I can't understand all the words but when I see, the one you show me, I understand (P8)

These men relied on family members to translate the health information they received and it is likely some of that information was misunderstood or missed completely:

My daughter explained to me

So you needed someone to help you understand the information? (AF)

Yeah I understand some...but not the whole lot (P8)

Participant 8 explained how important the local Samoan radio station was for him and others to learn health information. It was through hearing reminders on this radio station to have his prostate checked every year that he went to his doctor and asked for an examination. He attributed his own prostate cancer diagnosis to these

messages because they were spoken in Samoan and he was able to understand and take responsibility for his own health checks:

Yes, it is easier because they are talking in my own language, and they explain everything (P8)

Through these accounts it can be inferred the majority of participants considered visual learning to be valuable and visual simulation tools such as VERT can aid in patient education. Information such as how radiation is delivered to the prostate and the simulation of the treatment process lends itself well to a visual demonstration. For patients with communication barriers such as English as a second language, visual tools are a fast and effective way of communicating important information, aiding health literacy. There is a desire from these men to have visual learning incorporated into patient education to support and consolidate written and verbal information.

Explained how radiation treatment is delivered and the technology involved

Over half the men reported the VERT education increased their understanding of the technology used to accurately locate and treat the prostate. Some felt they developed a new sense of appreciation for the precision involved in treatment delivery:

I think it's the technology, shall I put it that way. You started to appreciate or understand the technology that I was about to go under (P2)

One person attributed this new understanding to increasing his confidence and trust in the safety of treatment:

It helped to build my confidence and trust because I thought it's really targeted, it's precise and that's fine, I'm happy to proceed with it (P4)

Participants 5 and 7 were able to relay the information they had learnt from the VERT education back to family and friends, indicating how much they understood of what they had been shown with VERT and what this new insight meant for them:

Hey you know the video was brilliant, I think the video was probably the best thing I have bloody [sic]...I've done...umm yeah no, it just helped me out a lot you know...Because I said to my brother Jeff, I said 'oh no this machine now can shut off dose part way and then come back on again' (P5)

I said to my wife and family and some friends yesterday that that actually explained how (P7)

Being able to understand the technology used to accurately deliver radiation seemed to resonate with many participants. This increased awareness seemed to give most men peace of mind and provide reassurance in the safety and efficacy of treatment.

Improved understanding of why a full bladder and empty rectum are required

Most participants believed their understanding of why a full bladder and empty rectum was needed for radiation treatment was improved after experiencing the VERT education. Being able to visualise the location of the bladder and rectum in relation to the prostate was a useful and effective way of conveying this important information:

Well that was vital because I realised that if you didn't have a full bladder and it's sitting too close to the prostate because it moves, you could cause unnecessary burning or damage or whatever you like to call it and also with the bowel not being empty yeah I understood that, I think that it is really vital to know those things (P4)

For the Samoan men, this visual representation was particularly important as the written information describing this process was often difficult for them to understand. Being able to physically view the bladder and see how filling it stretches it up and away from the prostate aided their understanding of why these instructions are required for treatment:

Yeah, yeah I remember, there are 2 things, when I drink the water it help, to make it not touch or something like that...that's why I know to drink the water, I understand what you tried to explain about that (P8)

To understand illness and disease in Samoan culture, it is important for the person to visualise the problem. For these two Samoan men, the visual aspect of the VERT education and being able to view internal organs such as the prostate, bladder and rectum was hugely beneficial for their understanding of prostate cancer and how radiation treatment is delivered:

Oh, that video...I saw with my own eyes, mine is, I, when I looked at video oh I understand what is very hard, the teaching you do that is very hard yeah (P6)

Yeah, I understand what you showed me on that (P8)

Some attributed their improved understanding of bladder and rectum filling requirements to an increase in motivation to achieve these instructions. This new knowledge seemed to empower the participant by involving them in their treatment process and giving them a sense of responsibility:

Because the bladder is lifted up and the bowel is empty, and before I thought oh ok wonder what this is all about but I think how you put it it's to my advantage, immediately made me want to do it (P7)

A clear voice can be heard through all nine accounts that the VERT education enhanced the participants' understanding of radiation treatment through visual learning. VERT effectively demonstrated how radiation is delivered to the prostate, why a full bladder and empty rectum are required and this increased understanding helped these men feel more prepared for treatment.

3.3.2 Timely delivery of the VERT education

During the interviews, participants were asked if they had any suggestions on how the education process could be done differently to improve their VERT experience. One major reoccurring theme was the timely delivery of the VERT education and this related to when VERT was delivered and how often.

Prefer to receive VERT education close to first radiation treatment appointment

The majority of participants wanted to receive the VERT education close to their first radiation treatment appointment so the information was fresh in their mind. Some preferred to receive it on their first day of treatment, just as they had experienced during the study. Others could see the advantage of having the VERT education a week or two earlier to allow time for processing and suggested their planning CT appointment as another suitable option:

Well for myself, it was good to have it kind of close to the treatment...I really did because it was very fresh in your mind and it all just fell into place, so to me that was good. Some people may like it a lot sooner and then some people would just fret and worry but...people are built differently aren't they (P4)

I would have been quite happy to have spent 20 mins or quarter of an hour after the CT scan, to have a look and do that (P5)

Most men recognised the preferred timing of the VERT education would vary between patients as people's need for information is different. Ultimately, most participants felt experiencing the VERT education at some stage was important regardless if it occurred weeks earlier or on the day of their first treatment, as long as it occurred sometime near their first radiation treatment appointment:

Couple of days before, something like that...even just before treatment its better than not having it altogether is what I really think (P3)

Repetition of the VERT education would reinforce the information

Some participants emphasised they had received a significant amount of information since being diagnosed. This can be overwhelming and there is a risk the information can be misunderstood or forgotten:

You don't want to bombard people with too much information because if you hear something you don't want to hear your mind plays on it and then you miss things which people are saying further down the track and all of sudden you think umm hell I've forgotten what the hell she said in the first place (P5)

You do get a lot of information and you only...digest certain parts of it, I think you only digest the bits you want to know, or want to hear (P1)

Interestingly, participants 1 and 5 were both receiving radiation treatment because their prostate cancer had reoccurred after surgery. They alluded specifically to learning bad or unexpected news which can limit a person's ability to process and understand further information which may be a reflection of their own experience.

With regards to the VERT education, some highlighted that repetition could be a useful way of reinforcing the information and increase understanding. Taking away written information allows the person to read and re-read the information at their leisure therefore, providing patients with the same opportunity to repeat the VERT education could be important for learning and understanding:

Yeah and I'm probably the sort of person who would read through this brochure and then a week later I might read it through again and I think oh yeah and then just scan it again just to try and reinforce what's happening

Yeah so that repeat of information is useful? (AF)

Yeah, especially when it's something...totally different, totally out of your normal experience (P1)

Two participants suggested making use of online resources and have the VERT education available in a video format which patients could re-watch. This would provide greater access and would allow those who require repetition for reinforcement, the ability to do this whenever it suited them:

You can go online, download, see it and watch it umm good idea...Yeah, you're probably so familiar with it now you can see it in your sleep but I only saw it once and you know that was a week ago, and I've since had all this stuff happening (P7)

Both of these men had backgrounds in information technology and were likely to be very comfortable with using online media. Participant 7 even suggested using online applications like WhatsApp or Skype to facilitate online education and group discussions but reflected that this may not be suitable for everyone:

Well if you're confident you don't mind in a group situation but other people, the majority aren't, so that would be actually taking your technology on video to a WhatsApp, Skype or whatever the application is and there are a few of them around

That's a really interesting idea (AF)

Maybe...I guess the only down side to that would be most of the people are going to be my age and some of them aren't digitally ah...connected yet but I think as time goes by (P7)

While this is beyond the scope of this study, it is important to note repetition is a key part of observational learning. Re-reviewing VERT would aid in retention and this should be considered with future developments.

3.3.3 Supporting role of VERT in addressing men's masculinities

When discussing the participants' initial treatment experience, a number of themes were expressed that impacted on their masculinities. These included not feeling completely informed about all available treatment options and the impact this had on personal autonomy and ability to make informed decisions. Also, the taboos that

surround prostate cancer which make it difficult for men to talk about and the role of the VERT education to initiate conversations with men, encourage information sharing and provide peer support.

The impact of not feeling fully informed on personal autonomy

Over half of the participants discussed their personal experience with treatment decision making. Two of these men were receiving radiation treatment due to recurrent disease and both commented on how vulnerable they felt after being told they had prostate cancer and were unsure of which treatment option to choose. They wanted direction from the specialist; however they felt alone when making their treatment choice:

The only 2 options for me were operation or radiation and I said well, I don't know what do you recommend and he said I can't recommend anything to you and I thought...at that stage I felt completely cast adrift (P1)

When discussing their initial decision to have surgery, they reflected talking to a radiation oncologist as well as the surgeon could have been beneficial although it may not have changed their outcome:

Yes he did say I could talk to a, the radiotherapy specialist or his colleague but...umm he also said he's a surgeon and he would recommend surgery and I guess I hadn't had any contact with the radiology people so, on reflection I probably should have asked to speak to the radiology person umm but, whether the outcome would have been any different, who knows (P7)

Both men pointed out that while they were told radiation treatment was an alternative option to surgery, an appointment with a radiation oncologist was not made for them automatically. Participant 7 felt it shouldn't be his responsibility to arrange this consultation, and appointments with both types of specialists should be routine to ensure patients feel fully informed of all their treatment options:

I guess maybe it should have been compulsory rather than an option, because you know I'm coming in here totally, haven't been in the place, never been in the hospital in my life before so I didn't know how all the different departments work...and I don't think I should be expected too (P7)

Participant 3 shared this view and felt it was through luck rather than standard process that he was given the opportunity to speak with a radiation oncologist. Despite not feeling totally comfortable with surgery, he would have proceeded as he felt like it was his only option. A nurse recognised he was reluctant to undergo surgery and suggested he consult with a visiting radiation oncologist to discuss all of his treatment options. After receiving the information from both specialists, he chose radiation over surgery:

It really was lucky that she sort of, you know said, said that otherwise I was sort of 90% going to have surgery and then after speaking to the radiation oncologist you know who sort of umm got rid of all those myths about the damage it was going to do to you and was absolutely confident that you guys could cure it umm I sort of went that way (P3)

Participant 9 also came away from his initial consultation feeling convinced surgery was his only option and that the surgeon was biased towards him having surgery:

We came away; my wife and I both came away from that interview or that consultation believing that was our only option

The surgery? (AF)

The surgery yes umm he...umm he later on admitted that there is a bias to have it removed because that's what he does, that's what he is a specialist at...and umm when I went back, when I left there umm we were pretty convinced that we were going to do radical surgery (P9)

He was also reluctant to have this procedure as he was concerned about potential side effects on his lifestyle, implying sexual function, and wanted to explore brachytherapy. He initiated a consultation with a radiation oncologist in the private sector at his own cost which eventually led to him choosing external beam radiation treatment over surgery:

No I wasn't convinced actually, I found it quite, I do and I still do umm the way he described his side effects and umm the...invasive, very invasive and I just don't, that just didn't suit me, didn't suit my lifestyle and my wife was in agreeance with that umm...from there I spoke to two of my friends who had the brachytherapy (P9)

These accounts illustrate some of the challenges men face with treatment selection after being diagnosed with prostate cancer. Some men felt that by not being

automatically provided with the opportunity to consult with both types of specialists, they did not have all the available information on suitable treatment options, which added to their distress. These participants thought a referral to a surgeon and radiation oncologist, prior to making their treatment decision, would improve the way this information is provided, minimise bias from the specialist and preserve their personal autonomy to make an informed decision regarding their treatment.

Taboos associated with prostate cancer and a lack of open discussion

Some participants highlighted the taboo nature of prostate cancer and the difficulty men experience when discussing the impact it has had on their lives and masculinity. Most felt reasonably well despite having cancer, and were having difficulty coming to terms with needing treatment. For participant 4, his diagnosis came as a shock as he thought prostate cancer wouldn't happen to him:

I probably wouldn't want to know because all these things happen to other people you see I mean even, even for myself to be honest you know that there is a lot of people who get prostate cancer blah blah blah but that won't happen to me kind of thing, I mean you don't say that but just in your mind you go well I hope that doesn't happen, I'll be alright and then you know something bad gets you and you think whoa, it does happen to me as well as other people (P4)

He also explained he has not told many people about his diagnosis as he feels it is a private and personal matter and does not want his extended family or friends to know he is receiving treatment for prostate cancer:

My wife doesn't actually agree with me, she says you should be able to tell everybody and I said no, I don't want anybody knowing, my children know and she knows of course and a couple of trusted friends but nobody else and I don't talk about it because I don't want to talk about it and I wouldn't go out and tell everybody I know I've got prostate cancer! (P4)

This response could be reflective of his background being a male in a conservative, rural community where men's health is not discussed openly. However, he would be comfortable sharing his experience of other medical procedures such as a knee or cataract surgery indicating, in his opinion, prostate cancer is not socially acceptable to talk about due to its relationship with sexual function:

You don't talk, you don't talk I mean I, for example I had both my knees replaced, I'm happy to let anybody know because I use to limp like you wouldn't believe and that was fine, but to talk about your prostate is something you, that I personally don't want to do it, I mean...no if you know what I mean it's different isn't it? And I've got to have a cataract operation as I have got cataracts in one eye and I know it's there and it's got to come out and I'm happy to let people know that I have got to have my cataract done tomorrow or when it happens and I'm fine but this, to me is, is private and personal (P4)

Participant 2 experienced feelings of shame and embarrassment with having to undergo treatment for prostate cancer:

Well I mean I would be embarrassed to come in and say oh look I'm sorry but I've got a full...bowel down there I would be embarrassed by that so, if it had to happen it would happen, but I would be embarrassed (P2)

He attributed this to the male ego and the way it challenges masculinity when asked to discuss parts of their anatomy that is considered private and associated with sexuality:

The male ego thing doesn't want to talk about that part of their anatomy (P2)

Participant 8 invited men within his Samoan community over to his house and shared his health information with them. He implied Samoan men can experience shame when confronting health issues, especially matters that involve sensitive areas of the body that are related to sexuality, and therefore can be reluctant to talk about it:

Yeah, oh I got some big group coming to my house every Saturday...I share everything with them, I say don't be ashamed to go see the doctor because that's your future for your kids and your grandchildren (P8)

Participant 9 felt guilty when he compared himself to other patients he had met since coming to the radiation department and noticed how unwell they were due to treatment toxicities and yet he was feeling fine. This sense of disparity made him feel fraudulent and unworthy of receiving the same kind of support as others:

It feels like I'm parking under false pretences because I see all these other people that have scarfs around their heads and they are far more advanced than me and a lady I was talking to the other day who is having chemo and radiation and I'm thinking there is so much pain

and you are going through a lot at the moment and here I am just walking around good as gold (P9)

Many were focused on the treatment results and it became clear some were worried about the successfulness of radiation treatment and being cured of prostate cancer. Some of these comments were made in humour indicated by laughter but seemed to illustrate uncertainty:

I suppose yeah, so umm yeah I am just hoping the treatment is going to work (laughs) (P1)

Participant 2 compared the lack of openness that surrounds prostate cancer with the high level of public awareness that breast cancer has in the media and believed prostate cancer needs the same spotlight to improve public awareness and encourage men to speak more openly:

All of that needs to be much more open, I mean women with breast cancer I think that's a lot more open now than it ever was (P2)

The perception from these participants is that there is a lack of openness and social acceptability for men to discuss prostate cancer compared with other medical conditions. For some, prostate cancer is considered a sensitive and private issue and its connection with sexual function and sexuality makes it a taboo topic. Feelings of shame, embarrassment and guilt have also acted as barriers to these men feeling comfortable to being open about their diagnosis and the impact it is having on their lives.

VERT to engage men, initiate information sharing and encourage peer support

Being able to share information and learn from their peers was important for some men in this study. This seems to go against traditional masculine perceptions that men prefer not to talk about their feelings and do not want support. Participant 2 indicated this attitude contradicts the male ego but for some men, support is what they need and want:

Right but they don't talk about the men's problems, is that the male ego getting in the way? But it is...it needs to be spoken about and you need to come out and say come and learn about it, come and understand what is going on with your body, understand what your friend is going through you know (P2)

The benefit of peer support was evident for participant 1 who is a member of the Cancer Society support group PALS 'Prostate Awareness is a Life Saver'. He talks positively of the peer support he has received since being diagnosed with prostate cancer three years ago:

Yeah I think it's good, it's a good way of meeting other people with umm, prostate cancer or who have recovered from prostate cancer and umm, find your...we just talk and generally chat and we've got an email group now which if we find a useful article on...treatment or hospital treatments, we'll you know, circulate it around...it's a very useful thing and I would recommend it to anyone with you know, prostate cancer (P1)

Participant 9 felt unsure about the potential side effects of radiation and wanted to speak to another male who had experienced treatment. He approached the Cancer Society who arranged for a previous patient to contact him which he found helpful:

I said to her I don't know anyone, I know someone with brachy, I know someone that's had radical but I don't know anyone that's had radiation and I'm not sure what the effects will be and she said she will get someone to ring me that's actually been through radiation (P9)

Participant 8 explained how the Samoan radio station uses technology to overcome cultural barriers and provide access to information. They use humour to break down stigmas associated with sensitive topics such as prostate cancer and tell people not to be ashamed to talk to their doctor. This makes information more widely accessible within his community and reduces the 'Samoaness' interfering with the sharing of important health information:

Because the Samoaness always comes to interfere with it (P8)

Participant 2 could see a role for visual tools to help communicate health information and may facilitate with informing the public about different treatment options for cancer such as radiation:

There's probably a lot of things in the community and I am just going to say this, health wise that would probably help enormously if there was more of that sort of visual teaching done rather than handing you a pamphlet, which is ok and, and what you can find out on the net is ok but that (VERT) actually gave you insight into the technology a little bit behind it, or the machine or the rest of it. There are lots of things in the health system I think you could

change, if they were able to give you more visual you know...I think the fact that you actually saw it, it just clicked (P2)

One person suggested seeing VERT with the oncologist when making a choice between radiation and surgery could have been a useful way to learn how the treatment works, and may have helped with making an informed decision:

Yeah, well it was just so simple, I mean you could have it on the umm, you know have it when you have your interview with the oncologist or whatever they could perhaps pull it up and show it to you then I guess (P3)

Some men thought having the VERT education delivered in a small group environment rather than a one-on-one setting would be beneficial. This was considered more practical and may encourage other men who are going through a similar cancer experience to meet and provide support to each other during treatment:

It would actually bring that little group together too, because I've only meet one other person that is going through the same process as me but I know there are a couple of others I've bumped into that maybe ah if umm are starting at the same time, perhaps that could actually help as well umm that they start a little support group or like this one guy, him and I just sit there and have a little natty every now and again but I've never meet him before (P9)

The VERT education may also create a safe learning environment where men feel comfortable to be more open about their experience and learn from each other:

Because you might find that some guy asks a question who's quite able to ask and confident to ask and there's some guy sitting there who might want to ask (P7)

Some felt including their support person in these discussions was important and would help them understand what they are going through and share in their experience:

It probably would have helped for my wife to have seen it because then she would understand what I go through each day because she doesn't although I try and tell her or whatever, but you know she doesn't understand (P2)

A group VERT education session may also foster new connections, support networks and a sense of community whilst receiving radiation treatment:

Knowing that you're not alone in this (P9)

Through these accounts it can be inferred men are open to receiving support. Visual teaching tools such as VERT are an effective way of engaging men to learn about radiation treatment and it has the ability to open up conversations about their diagnosis. Providing this education to small groups of men who are receiving a similar treatment for prostate cancer can support men's masculinities by informing them how radiation is delivered accurately, and potentially create a safe environment where they feel more comfortable to share their experiences. This in turn may open up lines of communication, initiate information sharing and encourage peer support among patients.

4 Discussion

The study findings have illustrated how men experience VERT when it is incorporated into education sessions for prostate radiation treatment. It also raised other important themes related to men's experiences of prostate cancer.

4.1 Support for visual learning to be part of patient education

All nine participants responded positively to their VERT experience and its ability to convey information visually. Most thought it was the visual demonstration that helped them understand the treatment process and how radiation is delivered accurately to the prostate. Visual learning is considered a useful and effective way to present information, and visual aids can stimulate learning and help the observer make sense of the process (Russell, 2006). Skalla et al. (2004) identified most patients want timely information that is personalised to their situation and in a format that they can understand, and suggests interactive multimedia technology and virtual programmes are an innovative way to engage and educate patients. This may explain why these men had such a positive reaction to their VERT education experience and attributed their enhanced understanding to visual learning.

The men in this study also accredited their improved understanding of why a full bladder and empty rectum are required for treatment to the VERT education. Having these instructions explained effectively, helped them feel informed and prepared for treatment. These results are supported by a similar study conducted in the United Kingdom which explored prostate patient's perception of VERT using questionnaires. Those respondents also reported high levels of satisfaction with VERT as it helped them understand the importance of adhering to the bladder and rectum preparation instructions which resulted in improved compliance and participants feeling more prepared for radiation treatment (Stewart-Lord et al., 2016).

4.2 Improved understanding of radiation treatment

The results showcase VERT's ability to effectively explain how radiation is delivered precisely to the prostate and these participants reported a new sense of appreciation for the technology and accuracy involved. Some men found this reassuring and believed VERT could be used to help address some of the misconceptions and

misunderstandings people may have about radiation treatment. An Australian study that reviewed the information needs of woman with breast cancer, also reported the need for more logistical information on how radiation therapy is delivered safely to the target (Halkett et al., 2010). Some participants in this study felt there is insufficient information on radiation treatment in the public domain and people's preconceptions of radiation treatment can be based on outdated experiences of other patients. An American publication also identified the influence anecdotal cancer experiences of other people can have on men's understanding of treatment options available for prostate cancer, and this can impact on treatment selection (Denberg, Melhado, & Steiner, 2006).

These results indicate the perceived information available to the public explaining the technological advancement of radiation treatment is limited, and some people's attitudes towards radiation treatment are based on the experiences of others. In 2015, an initiative from the Faculty of Radiation Oncology of Royal Australian and New Zealand College of Radiologists (RANZAR) called Radiation Oncology Targeting Cancer Campaign was launched. The aim of the Campaign was to increase awareness of radiation treatment as an effective, safe and sophisticated treatment option for cancer (The Royal Australian and New Zealand College of Radiologists, 2015). They have a dedicated website and utilise social media networks such as Twitter to promote themselves. This Campaign recognised there was a lack of suitable, up to date, public information in both Australia and New Zealand on radiation treatment and promotes general practitioner education evenings to help increase awareness within the community and reduce common misconceptions. As suggested by one participant, visual tools such as VERT could be used as a teaching aid and be incorporated alongside these education evenings to visually demonstrate how radiation treatment is delivered accurately, particularly in rural settings where access to radiation treatment departments is limited.

4.3 Addressing patient information needs

A comprehensive literature review of cancer-related patient education by Chelf et al. (2001) found patients want the maximum amount of information about their illness and the preferred timing and degree of information varies from person to person. There is also a risk patients can feel overwhelmed with large volumes of information

and may forget what they are told therefore, supplementing oral information with written material, enables patients to revisit the information and help with their recollection (McPherson et al., 2001). With this in mind, it is unsurprising some of the participants wanted to repeat the VERT education to reinforce the information they were given and suggested the use of online applications as a way of providing access to VERT outside of the department. While these suggestions are beyond the scope of this study, they do propose other useful ways visual tools and online applications can be utilised to improve accessibility to information, and warrant further investigation.

4.4 Aid with health literacy barriers

Health literacy is the degree to which individuals have the capacity to obtain, process and understand basic health information required for making appropriate health decisions (Kickbusch, Walt, & Maog, 2005). On average, New Zealanders have poor health literacy skills, with both Māori and non-Māori males and females all scoring below the minimum required score for individuals to meet the complex demands of everyday life (Ministry of Health, 2010b). The health literacy of Pacific peoples is also lower than other ethnic groups and factors that may contribute to this are lower socio-economic status and language difficulties (Statistics New Zealand and the Ministry of Pacific Island Affairs, 2010).

The accounts from the two Samoan participants illustrate the different literacy capabilities of patients, especially for ethnic groups where English is not their first language. Also, both men were employed in roles that generally do not require high levels of education (gardener and factory worker) and may be indicative of their socio-economic level. These men relied on family members to translate and explain some of the health information they received.

Traditional communication strategies have been shown to be less effective among people who face barriers related to literacy, culture, or language (Kreps & Neuhauser, 2008). The reading level of patient-education materials is often beyond some patients' abilities and some, simply cannot understand printed information. For these reasons, the New Zealand Ministry of Health Strategy Future Direction (2016) focuses on improving health literacy by making health information accessible and

recommends the integration of alternative communication methods such as digital technologies. The incorporation of VERT into education sessions for prostate radiation treatment aligns well with these strategies and is particularly important, as there are significant inequities in survival between Māori and non-Māori for prostate cancer in New Zealand (Ministry of Health, 2013a).

4.5 The impact of not feeling informed about treatment options

Some participants acknowledged the challenges they experienced when deciding which treatment to undergo for prostate cancer. Studies show that surgery, brachytherapy and radiation offer similar oncologic outcomes for localised prostate cancer and therefore the treatment decision making involves the patient weighing up the risks of potential side effects and personal preference (Hamdy et al., 2016; Kibel et al., 2012; Kupelian et al., 2004). A longitudinal, quality of life study by Zelefsky et al. (2016) concluded treatment selection can be informed by the importance a patient places on sexual dysfunction against ongoing urinary problems and bowel irritation. These are the most likely side effects a man could experience after receiving any of these three treatments and their significance on a person's quality of life will vary between patients.

In New Zealand, men suspected of prostate cancer are referred to urology services for a biopsy (Ministry of Health, 2013a). As the surgeon performs the biopsy, it often means they initially discuss the results and treatment options with patients and become the gatekeepers of the referral pathway. While the Ministry of Health (2013a) recommends patients should be offered the opportunity to discuss their treatment options with an urologist and radiation oncologist, the men in this study have highlighted this does not always happen. As a consequence, these men do not feel fully informed about all their treatment options and believe it should not be their responsibility to request these appointments, especially as they trust the specialist's clinical judgment. This is important, as previous studies conducted in the United States have illustrated how the consulting physician's perception can bias a patient's treatment selection. When investigators asked urologists and radiation oncologists how they would treat patients with localised prostate cancer, both specialists overwhelmingly recommended the therapy they themselves deliver (Fowler, Jr et al., 2000). In a more recent study, Jang (2010) identified urologists varied widely in the

proportion of their patients who were also evaluated by radiation oncologists, suggesting that referral patterns may be influenced by factors such as geographic access to radiation oncologists or the personal viewpoints of the urologist. Due to these potential speciality biases, both of these studies and the New Zealand Ministry of Health (2013a) recommend a multidisciplinary consultation to ensure men receive a balanced perspective on the risks and benefits of all available treatments. The accounts from these men illustrate how a lack of information can impact on their personal autonomy to make an informed decision regarding their treatment management, which can add to their distress during what is already a stressful time.

4.6 Supporting masculinities by encouraging men's engagement using VERT

Masculinity is the qualities and behaviours traditionally associated with men. Connell (2005) defines masculinity as a social construct which can vary across time, culture and the individual. Characteristics associated with hegemonic masculinity include stoicism, assertiveness, physical strength, independence and emotional restraint. Courtenay (2003) discusses the challenges associated with masculinity as; men will often prefer to face risk or physical discomfort rather than display traits that are perceived to be feminine such as vulnerability, dependence and weakness. Women are considered to be comfortable with vulnerability and their emotions and are more likely to employ health-promotion behaviour such as seeking support (Evans, Frank, Oliffe, & Gregory, 2011). These differences in coping strategies may explain why there are such large disparities in health between men and women. In New Zealand, men's life expectancy is almost 4 years less than women's and this is largely due to men having a greater incidence and mortality from heart disease as well as lung cancer and suicide (Ministry of Health, 2013b). This disparity in health between men and women is similar in western societies across the world. In 2000, the World Health Organisation acknowledged the lack of understanding of the role masculinities play in the health promoting and coping behaviours of men, and this needs to be viewed with a gender lens (Evans et al., 2011).

The men in this study discussed how their diagnosis of prostate cancer had impacted on their masculinities. For example, one participant who was under the age of 60 years reported feelings of unworthiness for the care and support he had received

since starting treatment. These feelings may have been related to his age, altruistic nature and occupation within emergency services. His personal identity and masculine qualities such as being a well, strong and courageous male who provides help and service to others, was challenged when he found himself on the receiving end of care and support. Others expressed feelings of shame and embarrassment and for men who often pride themselves on being strong and healthy; being diagnosed with a life threatening illness and its association with weakness and vulnerability may go against their sense of masculinity. Their way of dealing with these emotions was to keep silent as they did not want anybody to know what they were experiencing and wanted to avoid showing perceived emasculating behaviours such as seeking support and sexual impotence. A study by Kelly (2008) who also interviewed men with prostate cancer, reported similar findings of emotional isolation particularly because of the stigma associated with prostate cancer the effects treatment can have on their bodies such as incontinence and sexual dysfunction. This was also comparable with two of the men in this study who disclosed they had not told many people about their diagnosis as it was a personal and private matter, and its relationship with sexuality was very difficult for them to name and discuss.

The physical and emotional consequences of prostate cancer on masculinity, identity and self-worth have been highlighted in other studies as well. Men interviewed in focused groups after receiving prostatectomies for prostate cancer revealed how incontinence and impotence had affected their sense of self-worth (O'Shaughnessy & Laws, 2010). The respondents in Appleton et al. (2015) study, viewed changes to their sex drive and feminisation of the body after hormone treatment, particularly distressing. This loss of manhood impacted on their emotional state as well as their relationships with their spouses. Evans et al. (2011) identified the inability of men to sustain masculine ideals by keeping the body muscular, strong and resilient as they age, threatened their perception of masculinity. In addition to this, men with prostate cancer become aware of their own mortality and changes to their sexuality can represent deterioration and loss of vitality which adds to the complexity for providing health care to aging men (Evans et al., 2011).

All three of these studies recommended peer support as an effective way of supporting men's masculinities. This resonates with the findings of this research as peer learning and support was important to over half the participants. It was suggested that providing the VERT education in small groups of men who are to receive radiation treatment for prostate cancer, has the potential to create a safe environment where men can learn about radiation treatment together and know they are not alone in this experience. This may seem to go against traditional masculine behaviours such as reluctance to admit vulnerability and ask for help however Appleton et al. (2015) found peer support was commonly valued as an outlet for emotions and provided an opportunity for camaraderie and a sense of belonging. These researchers also highlighted the importance of including spouses and family members to be part of these conversations which was also raised by some of the men included in this study.

The challenge with supporting men and their masculinities can be with initiating the conversation. Heron-Speirs (2014) suggested providing information in a way that protects the dignity and vulnerability of men. This study has demonstrated VERT is a highly engaging piece of visual technology that men are keen to interact with and have a positive response too. VERT could be utilised as a tool to attract men into small group education sessions on radiation treatment for prostate cancer which may foster other conversations about treatment side effects, coping mechanisms and encourage peer support. This supporting role of VERT may help in addressing some of the known impacts prostate cancer can have on men's masculinities and help break down the stigmas associated with it. Therefore, making prostate cancer more socially acceptable and comfortable for men to talk about and share their experiences with health professionals and each other.

4.7 Study limitations

The participants were self-selected therefore, the men's experience captured in the study were from people who felt comfortable to participate in a research project and were willing to share their points of view in an interview. This may mean men who find talking about their treatment experience difficult were unlikely to be included and therefore their views have not been represented in this sample.

Also, the men were recruited from only one cancer centre in New Zealand and local factors may have affected their experience. This limitation was minimised by including men who were from Marlborough, Wellington and Wairarapa and of different backgrounds and ethnicities.

The role of the researcher also needs to be acknowledged as a limitation. It is possible the position of power I had as a health professional with expert knowledge of prostate radiation treatment and VERT could have affected how the men responded in this study. Equally, my role as a radiation therapist who is experienced in communicating and developing rapport with patients may have created an environment where the men in this study felt comfortable to disclose their personal experience without feeling judged. Also, my age, gender, background and perceptions would influence the interpretation of the transcripts and this was managed using a reflective diary, discussions with the research supervisor and utilising triangulation and member checking processes.

I minimised coercion by never being involved in the delivery of the participant's radiation treatment. Prior to the study, WBCC staff who may be involved with the participants' treatment were educated about coercion and were asked not to pressure participants to disclose their experience of VERT and provide the same standard of patient care, regardless of whether the patient was part of the study or not.

The limitations of phenomenology methodology should also be acknowledged. Norlyk and Harder (2010) argue studies should include methodological keywords such as bracketing, as well as articulation of the investigated phenomenon and how an open attitude was maintained throughout the research process. IPA research is only as good as the data it is derived from and the researcher must demonstrate sensitivity to context which can be achieved through existing literature or material provided by the participant (Smith et al., 2009). Findings should always be related back to relevant literature in the discussion section, therefore IPA studies often include themes in the discussion which were not referenced in the introduction (Smith et al., 2009). An example in this study was the emergent theme on masculinities and the supporting role of VERT.

4.8 Conclusions

The men in this study attributed the VERT education to enhancing their understanding of radiation treatment and the technology involved. Visualisation of the process helped them feel prepared for treatment and improved their understanding of why a full bladder and empty rectum are required. There is a preference to have VERT education delivered sometime near the first treatment appointment.

Prostate cancer can negatively impact on men's masculinities such as lack of autonomy, shame, embarrassment, vulnerability and sexuality. This can be difficult for men to talk about and a lack of information can add to their distress. VERT effectively engages men with discussing radiation treatment and this has the potential to initiate further information sharing and encourage peer support. There is a role for visual tools such as VERT to be included in patient education sessions for radiation treatment to the prostate.

4.9 Further research suggestions

While this study has concluded there is role for VERT to be incorporated into patient education sessions for prostate radiation treatment, it has also highlighted other areas that require further investigation and include:

- Evaluate the use of VERT for patient education in small groups who are to receive similar radiation treatment such as, men with prostate cancer or women with breast cancer, from a peer support perspective.
- Include VERT as part of education sessions for other health professionals such as surgeons and general practitioners to raise awareness of radiation as a safe and effective treatment for cancer.
- Take VERT to rural settings around New Zealand to aid in the education of patients who need to travel to urban centres to receive radiation treatment.
- Develop and evaluate an online application that provides the VERT education in a video format that patients can access at any time to reinforce the information.

- Quantify patients' adherence of preparation instructions after receiving the VERT education by physically measuring bladder and rectal filling on cone beam CT data.
- Create and evaluate VERT education sessions specifically for advanced, hypofractionated radiation techniques such as stereotactic body radiation therapy for lung cancer where target accuracy and patient compliance are vitally important.

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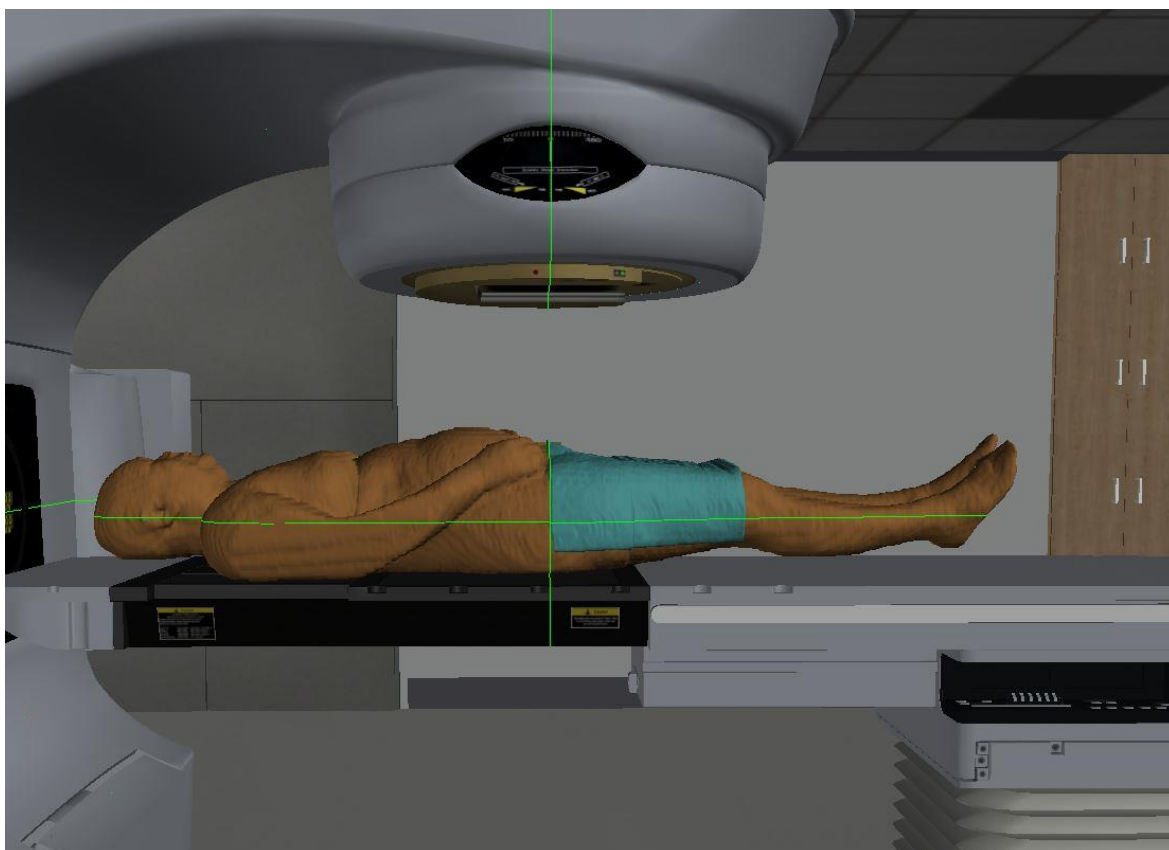
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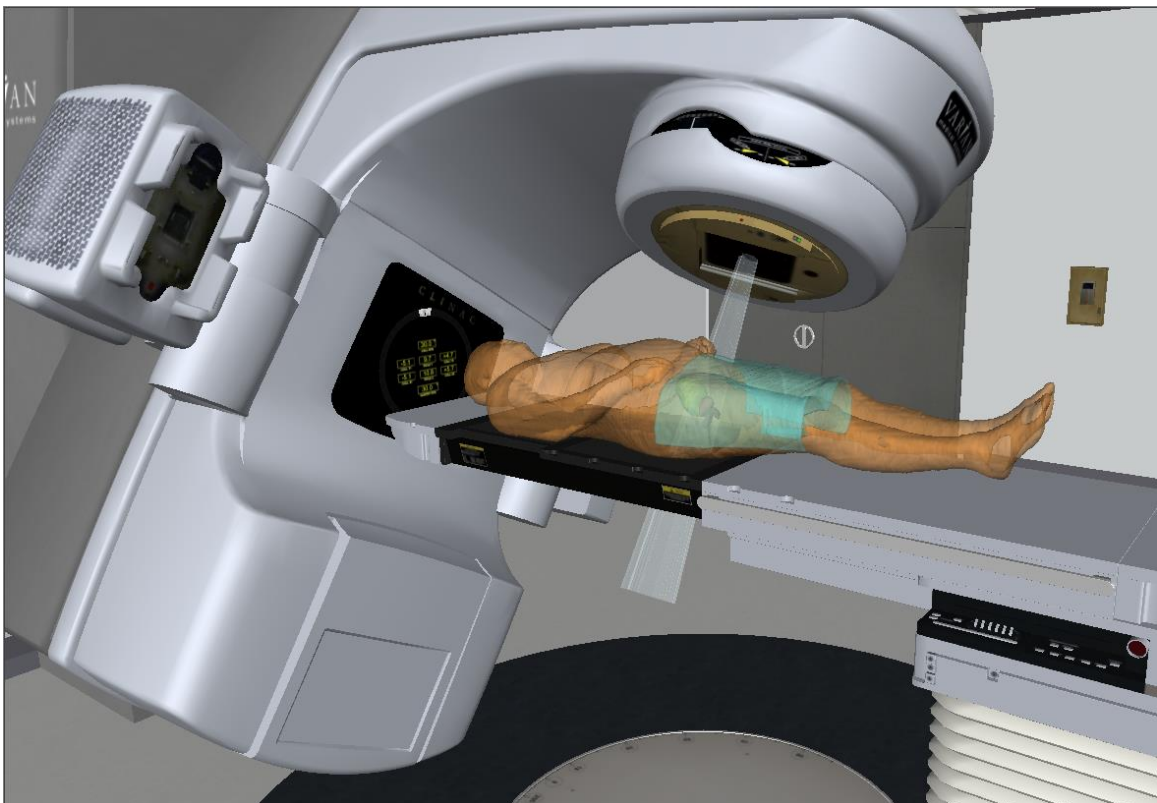
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Appendix A: Screenshots from VERT education session





Appendix B: Participant information sheet



Participant Information Sheet

Study title:	Men's experience of virtual simulation to aid patient education for radiation treatment to the prostate	
Principal investigator:	Patries Herst Department of Radiation Therapy Associate Professor	Contact phone number: 04 806 1753

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. If you decide not to take part there will be no disadvantage to you and we thank you for considering our request.

You are invited to take part in this study that explores the use of a new patient education tool called VERT.

What is VERT? (Virtual Environmental Radiotherapy Training System)

VERT is a 3D visual teaching tool that is being used to help train radiation therapy students. VERT can simulate the radiation treatment room and visually show what the

treatment process will involve. VERT can also show the inside of a patient's body and how the radiation treatment is delivered to the prostate (image below).



Why are we doing the study?

Many patients with prostate cancer are treated with radiation therapy. Because of the location of the prostate, nearby organs, such as the bladder and rectum (final section of the bowel) also receive some amount of radiation. We are interested in patients being treated for prostate cancer because there are some specific bladder and bowel filling instructions that you need to follow to have your treatment. We think including VERT in your education session may help you understand why this is important.

We are interested in finding out about your experience of the VERT education session and would like to know if it has assisted:

- your understanding of how radiation therapy works
- your understanding of why a full bladder and empty rectum are required for your radiation treatment
- your initial radiation treatment experience

Knowing this information will help us decide if including VERT into patient education sessions is helpful and would benefit other patients.

During the VERT education session, you will be given the same written and verbal information that is normally given, the **only difference** is VERT will be included in your education session. It will provide a visual demonstration of what is being explained.

Who is funding this study?

This project has been funded by the Cancer Society, New Zealand and is supported by the Capital and Coast District Health Board and the University of Otago.

Who are we seeking to participate in the project?

We would like to invite patients who are going to receive a course of radiation treatment for prostate cancer at the Wellington Blood and Cancer Centre and have not received radiation treatment before.

This interview will be in English so as long as you feel comfortable with this we would like to include you in this study.

If you participate, what will you be asked to do?

There are two parts to the study:

Part 1 – Patient Education on Day One

On your first day of treatment you will be asked to come to the department an hour before your treatment appointment. During this time you will be given the information patients are usually provided with, as well as the VERT presentation. You will then go on to have your first treatment. Once your treatment has finished you will be able to go home. The education takes about 45 minutes.

Part 2 – An Interview

After you have received five treatments, an appointment will be arranged for you to have an interview with the researcher. This can be scheduled around your treatment appointment to make it easier for you to attend. The researcher will ask you about your experience of the VERT education and how you found your initial treatment experience. It is important that you are honest about your experience of the VERT education session, as we are interested in how you found it. The interview will take about an hour.

Are there any costs to me for doing the study?

There is no cost for you to take part in this study nor is any financial compensation offered.

Who is conducting this study?

The current study is an exploratory pilot study run by the Department of Radiation Therapy at the University of Otago, Wellington but located at the Wellington Blood and Cancer Centre.

This research study is done as part of a postgraduate research honours degree. The research student is a qualified radiation therapist who works at WBCC. She will provide the VERT education sessions for all participants as well as conduct the interviews. The researcher will not be involved in giving your radiation treatment.

Is there any risk of discomfort or harm from participation?

This pilot study is unlikely to cause you harm. However, talking about your cancer journey may trigger some negative memories and possibly cause some emotional distress.

If this happens, the VERT education session and/or interview will stop. Your immediate needs will be assessed and you can be referred to appropriate services if required.

What information will be collected, and how will it be used?

The only health information collected will be your diagnosis and treatment prescription. Interviews about your experience of VERT will be audio recorded and then transcribed by the researcher.

All your information and data will be de-identified by removing any identifying information, such as your name, NHI number, and date of birth, and will be given a specific participant number which is known only to the researcher and supervisors.

All health information, interview data and recordings will be kept in a secure locked cabinet at the Department of Radiation Therapy, University of Otago Wellington under the specific participant number without name, initials and date of birth. Electronic data will be backed up regularly and stored on a password-protected computer known only to the researcher.

If you wish, your interview transcripts will be available for you to review before data analysis or you can review a summary of the main results at the end of the study. You will not be identified in any thesis or publications.

Who will have access to my data?

Only the researcher and supervisors will have access to your data. From time to time the ethics committee and auditing committee may require access as part of ongoing review of the study; however, your data will be anonymous so that you cannot be identified in any way.

If you agree to participate, can you withdraw later?

All participation in this study is entirely voluntary (your choice) and even if you decide to take part now and change your mind later, you are free to withdraw at any time, without giving a reason. Whether you decide to participate in the study or not, your current or future healthcare will not be affected in any way.

Any questions?

If you have any questions now or in the future, please feel free to contact either:

Alannah Flockton Radiation Therapist Wellington Blood & Cancer Centre	Contact phone number: 04 806 2007
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This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Appendix C: Participant consent form



Men's experience of virtual simulation to aid patient education for radiation treatment to the prostate

Principal Investigator: Associate Professor Patries Herst

Email: patries.herst@otago.ac.nz Phone: 04 806 1753

CONSENT FORM FOR PARTICIPANTS

Following signature and return to the research team this form will be stored in a secure place for ten years.

Name of participant:.....

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time without it affecting my current and future healthcare in any way.

6. I know that the interview will explore my experience of the VERT education session and how it has shaped my understanding of radiation therapy and my initial treatment experience. If the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s), and /or may withdraw from the project without it affecting my current and future healthcare in any way.
7. I understand the nature and size of the risks of discomfort or harm which are explained in the Information Sheet.
8. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least ten years.
9. I know that I can review my interview transcripts before data analysis or review a summary of the main results at the end of the study.
10. I understand that the results of the project may be published and be available in the University of Otago Library. I understand that any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study
11. I know that there is no remuneration offered for this study, and that no commercial use will be made of the data.

Signature of participant:

Date:

Appendix D: Interview schedule

1. Tell me what you understood about radiation therapy before you came to this department to begin your treatment

- Types of sources did you learn this information from?
- Oncologist/specialist/GP, media, internet, WBCC patient DVD, friends/family, written materials from the cancer society etc)
- Preferred way to learn information?

2. Tell me about your experience of the VERT education

- Reaction to the VERT presentation?
- Can you tell me what was it about the VERT presentation that made you feel this way?
- Can you give an example?
- Was this useful/helpful?

3. Tell me about your understanding of radiation therapy after seeing the VERT education

- Do you think your knowledge or understanding of radiation therapy has changed after you saw the VERT education session?
- Can you tell me what was it about the VERT presentation that made you feel this way?
- Can you give an example?
- Was this useful/helpful?

4. Did the VERT education help you understand why you are asked to have a full bladder and empty rectum for treatment?

- Has that information been helpful for following and complying with those instructions?
- Can you tell me what was it about the VERT presentation that made you feel this way?
- Can you give an example?
- Was this useful/helpful?

5. Tell me about your initial radiation treatment experience

- Can you tell me what contributed to this?
- Do you think VERT presentation influence your initial treatment experience?
- Can you tell me what was it about the VERT presentation that made you feel this way?
- Can you give an example?
- Was this useful/helpful?

6. After experiencing the VERT education, is there any changes or things you would have liked to have seen done differently?

- Can you give examples? E.g. content, timing, presentation style?
- Do you have an opinion on when seeing this VERT presentation would have been of most benefit to you?
- Would you recommend the VERT presentation to a friend who was to receive the same type of radiation treatment?
- Can you tell me what was it about the VERT presentation that made you feel this way?