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# **Original Article**

"Living with radiotherapy": the experiences of women with breast cancer

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## Abstract

The research attempts to gain a greater understanding of the experience of radiotherapy from the viewpoint of the female patient with breast cancer. A qualitative, phenomenological approach was employed using semi-structured interviews undertaken in the patient's home approximately two weeks after completion of their treatment course. Data analysis resulted in the description of five important categories of experience for the women. Discussion concludes that it is paramount for all health care professionals and therapy radiographers in particular to undertake and promote this type of research in order for them to establish and maintain a true sense of empathy and understanding with their patients. It also helps health care professionals maintain a sense of the importance of the 'whole experience' for those in their care. This type of enquiry provides a valuable and yet all too rare insight into aspects of attending for radiotherapy which would otherwise remain buried beneath the bustle of a busy radiotherapy department.

This article is an edited version of a Master's dissertation and as such can only convey the essence of the original work.

## **Keywords**

Experience; qualitative; phenomenology; breast cancer; radiotherapy

# INTRODUCTION

The role of the Therapeutic Radiographer constitutes a unique and complex relationship with the cancer patient. One of the attractive features of this role, which, in my experience, is often cited by radiographers describing their work, is the extent to which we feel we can build a relationship with our patients. However, it is important that we as therapy radiographers question how effectively we achieve this, in an attempt to gain a greater understanding of our patients' experiences.

The trend towards employment of Macmillan funded radiographers is a clear indication that the current limitations of the role of the Therapeutic Radiographer compromise holistic care. Can we ever really understand what it feels like, from the patients perspective, to undergo radiotherapy and can we enhance our own practice by increasing our awareness of the treatment as experienced by the patient? This research project was developed against the background of these difficult questions which are rarely explored in current literature.

Whilst there is a wealth of published literature pertaining to the issue of breast cancer in general, there is relatively little which explores the experiences of patients receiving treatment modalities other than in relation to physiological morbidity. There is a notable lack of information relating to the lived experiences of such treatment side effects for instance. Rosser¹ suggests that this limited approach reflects the prevalence of the "clinical model reality" which determines which issues are

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legitimate to explore and which concentrates on a social and culture-free view of health. Indeed, radiography literature in particular is notably bereft of such qualitative enquiry per se.

This project was also driven by a desire to find out more about how patients cope after completion of their radiotherapy. This again, is an aspect of our patients experience which therapy radiographers in particular are rarely privileged to share. The aim of the research was thus to investigate the experiences of women with breast cancer following external beam radiotherapy.

# **METHOD**

#### Rationale

The research strategy employed was a qualitative phenomenological approach which attempts to describe the lived experiences of the participants. Since the nature of the research was to examine the feelings and experiences of women undergoing radiotherapy a qualitative approach is the most valid in order to gain the depth of insight into their experience. Streubert and Carpenter<sup>2</sup> emphasise the value and contributions which qualitative approaches offer:

"Qualitative research offers the opportunity to focus on finding answers to questions that centre on social experience, how it is created and how it gives meaning to human life" (p.2)

Phenomenology is a qualitative method which examines lived experiences and which seeks to discover the meanings of those experiences for the participants. It attempts to capture what is real for them, without preconceptions, since it is their construction of reality which shapes their experience.<sup>2</sup> Lincoln and Guba<sup>3</sup> further develop the notion that there are many versions of reality but the reality constructed by the individual being studied is the most meaningful. It is the construction of reality by patients attending for radiotherapy which is central to this study.

# Sample

The women were selected on a convenience basis i.e. all those eligible for inclusion during the study period were approached and asked to participate. There were no strict criteria regarding radiotherapy technique or whether they had received chemotherapy in addition to radiotherapy since the aim of the

study was to gain a broad view on patient experience and was not specifically related to the type of treatment they received. Exclusion criteria included:

- Previous radiotherapy (since prior experience would have created an influence).
- Those women whose treatment was administered by the researcher (since this may have affected the researcher's interpretation of events and may have prevented the participant from honest responses).

The final sample consisted of thirteen women all of whom had undergone surgery prior to radiotherapy, three having mastectomy and the rest tumour excision only. Two of the women were receiving a concurrent course of chemotherapy, four had already completed a chemotherapy regime prior to commencing radiotherapy and the remaining seven were receiving radiotherapy as the sole post-surgical intervention.

All the women were requested to participate by the researcher, given a full verbal explanation and written information sheet as well as signing a consent form as directed by the local ethics committee who approved the project.

For the purposes of the study and the subsequent reports all women were assigned pseudonyms and were assured anonymity.

## DATA COLLECTION

Data collection was by means of audio-taped semi-structured interviews conducted in the patients homes on average 9 days after completion of radiotherapy. The decision to interview the patients at home was taken to avoid the influences and constraints of the clinical environment which may have sullied the data. It also established my role as a researcher as opposed to a health professional though it is debatable how separate and distinct these roles can be.<sup>4</sup>

All interviews were transcribed verbatim by the researcher and during the data collection stage a reflexive journal was also kept to enable the researcher to enrich the taped data with observations and instantaneous reactions which would not be captured by the tape. This is an important element of qualitative methods and is invaluable during the data analysis stage where immersion into the data is required.

The interview format was loosely based around a pre-determined framework but allowed opportunity for digression and spontaneous self-expression as appropriate. There were six fundamental areas of questioning covered in all interviews:

- 1. Describe how you felt when you were first told you needed radiotherapy
- 2. Describe your feelings on your first attendance in the department
- 3. How did you feel attending daily for the course of radiotherapy?
- 4. How did you feel upon completion of the radiotherapy?
- 5. How would you describe the period since finishing your treatment?
- 6. What were the main sources of support during the radiotherapy?

This interview schedule facilitated a logical progression through the radiotherapy experience in a reflexive sense. It also allowed the women to put their experiences into the context of having breast cancer.

#### DATA ANALYSIS

Data analysis employed the phenomenological framework as proposed by Hycner.<sup>5</sup> This proved to be a relatively straightforward, step-by-step method of analysing data for the researcher who was relatively inexperienced in this type of enquiry. Although a straightforward method of data analysis, Hycner's approach does involve many stages, which serves to increase the rigour of the study. Rigour in qualitative work is a controversial issue and Hycner argues that validity can be enhanced by checking findings in published literature and with the participants themselves. Denzin and Lincoln<sup>6</sup> further suggest that a reflexive style of data presentation is the key to allowing the reader to assess validity and to ensure that the essence of the phenomena under scrutiny has been captured – which is crucial to the success of this type of study.

The result of data analysis was that five themes of experience emerged which were common to most of the women and which health professionals need to be aware of and respond appropriately to.

#### **FINDINGS**

The five main themes which emerged from the data were as follows:

- 1. The enormity of the initial response to radiotherapy
- 2. Uncertainty, antithesis and developing coping strategies
- 3. Treatment side-effects and gender role dysfunction
- 4. The value and nature of support
- 5. The legacy of the experience

# 1. The enormity of the initial response to radiotherapy

The women offered a range of descriptions of their initial feelings towards radiotherapy most of which involved descriptions of fear and anxiety:

"Oh I was terrified, really terrified. I was just frightened" (Diane).

Much of this fear was clearly present during the initial visit for radiotherapy:

"I think that was the worst bit, just walking in at first and seeing the machine and thinking 'Oh My God'" (Barbara).

Many of the women talked of this fear being closely related to "not knowing" i.e. the unfamiliarity of the whole situation. Mischel and Braden<sup>7</sup> note this fear in other patients experiencing novel medical encounters. This fear of course is compounded by the relatively poor knowledge and misunderstanding of such a specialised intervention as radiotherapy amongst the lay population – a situation which our profession needs to continue to address.

Additionally, for some women, attending for radiotherapy also represented a reinforcement of their having to come to terms with facing malignant disease, so radiotherapy became not a specific medical intervention but an integral element of the cancer experience:

"I was frightened of being left on my own but I think it was that it had come to me that I had got cancer of the breast" (Diane).

"... now I can put it out of my mind and get on with my life. I couldn't do that during the treatment because I was going to hospital every day. . . . It was just being reminded everyday that you've got cancer." (Christine). The notion that receiving active treatment contributes to forcing women to face the malignant nature of their disease can be found in earlier studies which suggest that this phenomenon is a real cause of psychological morbidity amongst breast cancer patients.<sup>8</sup>

Simultaneously however, several of the women welcomed the thought of commencing radiotherapy and rationalised receiving their treatment as the onset of a welcome battle in the war against their disease.

"I think I just wanted to have the radiotherapy as soon as possible once I found out it was a malignant growth – I just wanted to get something done as quickly as possible" (Christine).

Other women who largely welcomed the onset of radiotherapy were those who had either had chemotherapy and saw radiotherapy as less aggressive treatment or those who had researched chemotherapy and decided it was a worse alternative:

"I wasn't bothered about the radiotherapy, I thought I'll get through it – what I didn't want was the chemotherapy. That would have upset me if I'd had to have chemotherapy" (Frances).

Fallowfield and Clark<sup>9</sup> corroborate this fear of chemotherapy and suggest that it has the worst reputation of all treatment modalities for breast cancer because of its perceived side effects.

# 2. Uncertainty, antithesis and developing coping strategies

Many of the women talked of the antitheses and contradictions they faced during their radiotherapy, one of these being the carcinogenic properties associated with radiation:

"They say if you get a lot of radiation it causes cancer – it doesn't make sense to me to treat it with that" (Sarah).

Christman<sup>10</sup> concludes that uncertainty about treatment with radiation is associated with psychosocial adjustment problems and indeed throughout the interviews many women asked technical questions which they had clearly not explored either prior to or whilst attending for radiotherapy.

For some of the women antithesis came in the form of finding support and hope amongst other patients whilst simultaneously facing up to the fact that some patients who were not doing so well could represent their own futures:

"that feeling of a common experience is comforting. . . The down side is, of course, that some people don't do so well. There's one lady there undergoing treatment for spinal mets and it's not so good for her so there's always a feeling that that could be me" (Debbie).

One of the strange contradictions described by the women was that whilst simultaneously talking of fear and anxiety they also seemed to enjoy aspects of the experience:

"to tell the truth I've enjoyed going for my treatment -I know that sounds odd. . . but honest I did enjoy going, the people made it, they were so friendly and welcoming" (Dawn).

Cancer is a disease characterised by such contradictions. It is also rife with uncertainty which is characterised by lack of clarity. It is this lack of clarity which made uncertain events experienced by the women stressful:

"I was offered a trial involving chemo. I didn't like being offered that. . . I didn't really want to choose. You want to be told – you're putting your life in other people's hands and you need to have faith that they can tell you what is best for you" (Christine).

"I read in a BACUP book that when you are premenopausal... I should be expecting chemotherapy so it actually had a negative effect and when I wasn't offered chemotherapy I thought I'm not getting all I need here. I got rid of that idea and I thought the doctor knows what he's doing and then blow me if the Sunday Times didn't do a health feature on breast cancer and they quoted exactly the same sentence." (Sally).

The majority of the women were also facing up to experiences of relatives and friends who had suffered cancer, many of whom had died:

"It's all about learning to live with a disease that you know may come back and recur. . . it's really different, it's feeling isolated from those around you. . . something has happened so traumatic in your life" (Debbie).

"I still have doubts like 'is there any of these cells floating round somewhere else?' And well it's like a niggling feeling" (Barbara).

'Uncertainty', according to Christman<sup>10</sup> is: "a cognitive appraisal of an event for which the outcome is unclear" (p.17).

The outcomes of such a complex disease as cancer, not to mention the variety of treatment

approaches, creates multiple uncertainties for patients many of which may remain with them for the rest of their lives. In response to these demanding uncertainties, the women described a variety of coping strategies – some behavioural:

"the first week you are white knuckle riding (holding tightly onto the equipment). . . eventually I began to count the seconds and I kept saying to myself 'don't squeeze your hands', but I always did" (Sally).

#### Others novel:

"I was born Catholic and I just said 'Our Father', three 'Hail Mary's' and a 'Glory Be' and it was all over!" (Carol).

And the majority adopted a specific attitude towards the whole experience:

"I think a lot of it is in the mind – you've got to think positive all the time – I've done that" (Grace).

Radley<sup>11</sup> describes such emotion based coping strategies as means of reducing the devastation of confronting serious disease but it is also the case that such strategies do not always sustain the individual throughout their entire experience. It is important for health professionals to note that from time to time these coping and defence mechanisms can be threatened and it is often difficult to reassert the coping strategy:

"You're just about coping. . . and then you read something else like I read a booklet that told you how cancer could spread and then you think 'My God it could be in my blood'!" (Christine).

Some women were surprised by how well they had coped and dealt with the entire experience:

"I was quite surprised really – I thought I would have gone to pieces. . . strange how I reacted because I always thought 'God I'd hit the bottle if it was me' In fact I've surprised myself in the way I've coped with it" (Christine).

For some of the women however, these coping strategies had not been very successful. This was the case for one lady, Dawn, who had remained stoical throughout her treatment but during the interview those coping mechanism clearly broke down:

"I thought I was alright but obviously I'm not (cries) The thing is, while I was having treatment I was fine and I don't know why I'm feeling like this now" (cries again)

Similarly, Diane had steeled herself psychologically for her treatment visits but her composure was shed in the security of her own home:

"I was alright while I was there saying 'Good Morning' to everyone and 'thank you very much' and then I came home and went to pieces – I just cried and cried."

It is clearly paramount for health professionals and particularly radiographers to understand the complex nature of coping strategies and to continue to develop skills which enable them to assess the individuals preferred manner of coping and also to recognise the signs of breakdown.

# 3. Treatment side-effects and gender role dysfunction

Since the entire sample constituted females it was impossible to deduce that many of the issues raised by the interviews are free of gender values. However, a distinct theme did emerge which indicated that women did view their experience of radiotherapy within the context of their normal gender roles without prompting by the researcher. Although some women experienced uncomfortable skin reactions this did not represent serious concern for the majority. Fatigue, however, did. Not solely because of it's physical effect but primarily because it restricted and interfered with normal functioning within their gender roles and the consequence of this was that the women became frustrated and self critical:

"It really got to me that I couldn't Hoover up... Now I look back I think it was silly, I'd got to Hoover up and get the polish out and I kept thinking Christmas was coming – it's daft isn't it?" (Diane).

"I'm having to look after my grandchildren so my daughter can work and it's all getting too much — I'm stuck in the house and it's scruffy and it's all getting on top of me (cries). . . I feel guilty".

"Why?"

"Because I've never been one for lying around and I can see there's all these jobs to be done" (Dawn).

Radley<sup>11</sup> suggests that the home has a different symbolic representation for men and women during illness – for men it is a sanctuary from the workplace which allows him to enact the sick role whilst for women the home also represents a place of work. Consequently, she must cope with the "special burden of her sickplace also becoming. . . a visible testament to a whole series of unfinished and undone household tasks" (p.129)

Christine equated her ability to return to these household tasks (which many of us may regard as

relatively unimportant tasks) as an affirmation of her return to normality:

"All the things I've neglected in the house I feel I can tackle now – I've done the curtains and I feel I want to get my life back to normal now"

Fatigue is a well documented side effect of radiotherapy<sup>12,13</sup> and there are indications that fatigue can be prevalent in some women for up to a year after completion of radiotherapy.<sup>9</sup> Fatigue is also an important treatment consequence of chemotherapy.<sup>14</sup> Clearly for the women experiencing such side effects it was not solely a physical manifestation of the cancer treatment but also became a threat to their 'normal' gender role compromising their place within the family and the social context. Such positions within society are essential for the maintenance of self-esteem and the radiotherapy side-effects must be acknowledged as creating not only physical dysfunction but also psychosocial dysfunction.

# 4. The value and nature of support

A crucial element to the women's experience was the nature of the support they had received around the time of their radiotherapy and there was a clear indication from most that they could not have endured the experience in the absence of such networks.

The sharing of experience with other patients was noted and the sense of camaraderie in the waiting room environment was cited by many:

"Even the men, they're all there for the same thing – they all get talking" (Diane).

"I think for some it's the only opportunity they've got to explore things (in the waiting room)" (Debbie).

The sense of the common experience seems to bond patients but conversely may serve to isolate or exclude significant others. This is of course where 'normal' family relationships are affected and where support may be required for those close to the patient.

"Sometimes I feel I want to go there (a support group). . I want to be with them rather than my own family because I know that they really know and understand what I'm feeling and going through" (Debbie).

In addition to the support network it provides, the waiting room also served as a valuable source of clinical reassurance and there is much evidence in the literature which shows that in chronic illness, the patient quickly becomes what is termed the 'lay expert' and develops skills in managing and recognising symptoms. Consequently they also become skilled in participating in the 'clinical system' and the balance of their relationship with health professionals, in particular, doctors, changes.<sup>15</sup>

"I suppose it's comforting to hear that other patients were having the same feelings as I was, the aches and pains or whatever. We helped each other in a way" (Carol).

Other patients can be both a support and a source of distress for the woman attending for radiotherapy:

"It is often uncomfortable that waiting room – it's something about the atmosphere I suppose it's just the nature of the treatment and the anxiety that's around" (Debbie).

Fallowfield et al<sup>9</sup> explores this notion of other patients acting as reminders to the individual of their diseased status.

All of the women clearly valued support but they definitely did not appreciate an over sympathetic approach and this included not only friends and relatives but also the approach of health professionals:

"She deals with you as if you are eighty or ninety – you know I don't want that. . . she was all 'are you alright Pet' and 'yes Pet' and I don't want that" (Grace).

Indeed when the women described successful clinical encounters with any health professional it was invariably the result of a very delicate balance:

"They're caring – but not over caring" (Frances).

Achieving a successful balance in support is a very difficult feat and one which must reflect the needs of the individual. It does, however, require a great deal of skill, intuition and commitment on the part of significant others and health professionals alike.

## 5. The legacy of the experience

For the majority of the women the end of the course of radiotherapy signalled the opportunity to return to a state of normality, albeit an adjusted state of normality which was the result of their experience.

"During the treatment life is not normal – how can it be normal. . . there is a sense that you are out of the real world and you can't get back in until the treatment is finished" (Debbie). For some women the last day of treatment was a real triumph and for others there was some reticence and further uncertainty:

"I really was on a high. . . it was as if I'd done a big achievement" (Barbara).

"It's a bit of an anti-climax in a way. . . I got through by convincing myself that next March it would all be over and I'd be feeling myself and I'd be back to normal but it's not quite like that" (Carol).

"It has both a positive and a negative side. I can't wait to finish my treatment so I can start my life again. . . but it feels quite safe that while ever I'm going there people are aware of what's happening to me" (Debbie).

Fallowfield et al<sup>9</sup> recognise the occurrence of such feelings of insecurity at the end of active intervention and note that some patients see it as a relaxing of the clinical surveillance of their disease and worry that non-attendance on a regular basis may allow their disease to progress unnoticed. This perhaps gives some indication of the importance of post radiotherapy support mechanisms.

All of the women talked openly about how the experience of having cancer and it's subsequent treatments had radically altered their values and outlook on life in general and they felt that not only had it had an impact upon them during this traumatic period but would also leave an indelible effect upon their lives i.e. they would return to normality but a different normality, one with radically altered values, reassessment of priorities and changed aspirations:

"I feel I've got a peculiar calmness that I can draw on now. . . I don't worry about the things that before I would be knotted up about. . . I feel a better person – that's a stupid thing to say" (Sally).

"I think we (my husband) have both learned a lot more about each other. . . it's funny but I would say it's done us the world of good" (Barbara).

Many of the women felt that they had gained something as a result of the trauma they had faced and thus did not view the experience as entirely negative. One lady, Christine, talked of the possibility of using her experiences to help others facing the same predicament. 'Making a contribution' in this way is not widely recognised in the literature although some authors do acknowledge that it occurs. <sup>16</sup> The potential value of such a contribution is clear as many of the

women talked of the uniqueness of their experience and feeling that others who have not been through the trauma could not achieve true understanding.

#### DISCUSSION

In summarising the findings of this study it would be true to say that they are characterised by commonality and yet a uniqueness emerges which is as individual the women themselves. as Overwhelmingly, the themes described have an inherent similarity in that they all relate to the notion of change. Initially, women face changing lifestyles, new and unfamiliar clinical situations forcing changed routines. On a deeper level they face changed values and perceptions of their life patterns and perhaps radically changed views of their own mortality. This culminates at the end of the clinical intervention in a changed outlook and the acknowledgement that they could not experience such a traumatic experience as breast cancer and radiotherapy without submitting to or adapting to its enormity. Adaptation brings an acceptance that a return to normality will not mean a return to a pre-diagnosis concept of normality but a new and 'different' normality which will shape the rest of their lives.

The participants in this study expressed many important feelings and emotions and raised several issues of importance to radiographers. There is a clear value in health professionals gaining a greater understanding of these issues and the reasons for their importance to the patient. We are all too familiar with literature exploring the physical side-effects caused by radiotherapy, for instance, but there is little data available to describe how these side effects impact upon the activities of daily life, family and social relationships of those in our care.

The lived experiences of women with breast cancer have significant implications for therapeutic radiographers who play a key role in the treatment of cancer and the support of the patient. Much of the literature currently available in Oncology which informs our practice is based upon quantitative or 'clinical model' approaches. Our professional research background has emerged with a strongly positivist bias and there is a relatively weak research base founded on 'real

world' approaches.<sup>17</sup> This is clearly a detrimental imbalance for our professional development.

This type of enquiry allows us to truly explore our health services from the perspective of our patients and this is indeed an enlightening experience.

Politically, the climate is such that we are being encouraged to develop patient centred services and to avoid gaps in care which have all too often been seen in the field of oncology. 18 Thus, it is imperative that we give credence to the voices of those at the 'sharp end' of the service. In Sheffield, we are attempting to respond to some of the needs of our patients by expanding supportive services. Many of the women in this study acknowledged the initial fear and uncertainties around their referral and their lack of knowledge of radiotherapy as a treatment modality. Monthly Client Information sessions have now been running for some time in Sheffield where patients referred for radiotherapy are invited to attend the department (along with friends and relatives) one evening prior to their first attendance. The radiographers then offer tours around the department in small groups to explain the equipment and to attempt to demystify the treatment, as well as becoming a recognisable face when the patient attends for treatment. These sessions are extremely popular and as such are a testament to the need for explanatory and educational schemes to help our patients overcome the fear and anxiety that the notion of 'Radiotherapy' can and does instil. It also allows them to ask questions to increase their understanding of a treatment modality not widely understood by the general public. Furthermore, the sharing of this experience with relatives may promote the support mechanism they may need to provide when the patient commences their radiotherapy.

There are many issues which are very relevant to our patients which qualitative research methods could assist us to explore more fully. Furthermore, radiographers are ideally placed, given the appropriate encouragement and support, to undertake such studies. This type of exploration could radically improve our practice by heightening our sensitivity to some of the issues raised and facilitating our acknowledgement that the traumas experienced by our patients often have a profound and pervading effect upon their behaviour, attitudes and lifestyle.

Finally it is pertinent for all health professionals to be constantly reminded by this type of study that our patients may be undergoing traumas that we ourselves may one day face as Debbie so poignantly reminds us:

"The line is very thin between being a cancer patient and not being one, being a member of staff and not being one"

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