

## *A Different Thing Altogether: An Idiographic Case Study of Breast Cancer in Men Using Interpretative Phenomenological Analysis*

Sarah J. Butterworth, & Elizabeth Sparkes

### **Abstract**

**Background:** Around 300 men are diagnosed annually with breast cancer in the UK. In comparison to the wealth of information on breast cancer in women there is a paucity of literature regarding the psychological consequences of being a man with breast cancer. Due to the small incidence and strong identity as a female-specific disease having breast cancer as a man may be an incongruent and unexpected experience.

**Methods:** A case study was undertaken with a 55 year old man in the early recovery phase of breast cancer. An in-depth semi-structured interview was conducted using an interpretative phenomenological analysis (IPA, Smith 1996) approach to gain insight into the participant's lived experience of breast cancer.

**Results:** Four superordinate themes were generated from the data: the Impact of the Cancer; Factors that influenced coping; Changing Identity: retaining masculinity despite limitations; and Feeling fortunate and a need for awareness.

**Conclusion:** Acquiring further information on breast cancer in men allows services to be better positioned to help the recovery process by: offering suitable information, being aware of male psychological distress, increasing patient autonomy, normalising the experience to reduce exclusion, and promoting support outlets.

**Keywords:** qualitative, breast cancer, men, interpretative phenomenological analysis.

### **Introduction**

Breast cancer is a disease rarely found in men and accounts for less than 1% of all breast cancers in the UK; with around 300 men diagnosed annually compared to 45,500 women (Cancer Research UK, 2010) but with some evidence indicating an increase in the incidence rate (Ying, Agrawal & Cheung, 2005; Contractor et al, 2008). Whilst the symptoms and treatment of breast cancer are similar in both sexes, male breast cancer has biological differences, including a more aggressive clinical behaviour, a higher propensity to metastasise (Crinchlow & Galt, 1990) and a poorer prognosis (Ravandi-Kashani & Hayes, 1998).

As well as a different clinical presentation, breast cancer in men also has a different psychological course. Male breast cancer constitutes a unique lived experience for a man that is unparalleled in other disease profiles because of its strong relationship with gender (Donovan & Flynn, 2007). This gendered view of the illness can lead to feelings of shame surrounding the disease. This has implications for how men accept and cope with their diagnosis; influences their disclosure (France et al 2000; Iredale et al, 2006); creates feelings of foolishness and embarrassment (France et al, 2000; Naymark, 2006; Bohn, 2008); and is also upheld by

the medical profession leading to further feelings of exclusion (Donovan & Flynn). In addition to the perceived shame some men feel in their typically 'female' diagnosis there may also be a change in appearance following mastectomy which can have a profound effect on some men in terms of changing their perception of self, self esteem and sense of masculinity (Donovan & Flynn).

The often reported shock of diagnosis across existing qualitative studies suggests that there is still a lack of awareness amongst men that breast cancer is not a female-only disease. The lack of inclusion in breast cancer awareness campaigns and the limited information available has implications for men's help seeking behaviour, diagnosis, treatment and prognosis. Help seeking behaviour amongst men differs across studies; with earlier studies citing significant delays in seeking help after the emergence of symptoms, sometimes up to two years (France et al, 2000) but with later studies finding little or no delay in contacting services (Williams et al, 2003; Iredale et al, 2006). The difference in male and female support needs also deserves further investigation. The question of cancer support groups has previously generated mixed results across studies with some men believing male support would be beneficial (France et al, 2000; Williams et al, 2003) whilst others considered it 'not something men talk about' (France et al, 2000; Pituskin et al, 2006; Pituskin et al, 2007). Some men were happy to talk to other women with breast cancer (France et al), whilst others felt that a man 'imposing' on these groups may censor women's discussions (Naymark, 2006). Consequently many men wanting support find it difficult to obtain as they feel uncomfortable approaching mixed groups but find there are few other men with breast cancer to approach that wish to discuss it.

There is a paucity of literature about the psychological consequences of being a man with breast cancer which is often acknowledged in comparison to the extensive research into breast cancer in women. Qualitative research in this area is valuable as there is little existing evidence on the experience and needs of men with breast cancer on which to base the health care of this group. Discovering the needs of this group is necessary as there is evidence that the incidence of male breast cancer is rising in the UK (Contractor et al, 2008). The aim of the present study was to conduct an Interpretative Phenomenological Analysis (IPA; Smith, 1996) to further explore these identified themes. Employing an IPA approach offers an insight into a person's idiographic experience and allows us to gain a fuller picture of how a man with breast cancer conceptualises the issues he may face and assigns meaning to his experience.

### **Method**

IPA investigates the life world of the individual and attempts to understand how events are experienced and given meaning by the person through a process of interpretation by the researcher (de Visser & Smith, 2006).

#### ***Participant***

The participant is referred to throughout as Henry. At the time of interview Henry was a 55 year old retired gentleman living with his partner. Henry was diagnosed with breast cancer in early 2010; he had a positive prognosis and completed treatment in four months; three months prior to interview. Henry responded to an advertisement for research participants on the Macmillan Cancer Support Community Forum website.

#### ***Procedure***

The case study reported here is based on an interview with a man who had experienced breast cancer. Ethical approval was granted from Coventry University. After responding to an advertisement the participant was contacted by telephone and emailed full and complete information about the study before the interview. A semi-structured interview schedule allowed the participant to discuss freely any aspects of the breast cancer experience and to elaborate on chosen topics rather than to follow directive questions. The interview began with open questions which led to a discussion of the journey from discovery of cancer to its successful treatment. Later more detailed questions were used regarding the provision of information and overall

awareness of breast cancer. The interview was recorded and transcribed verbatim, producing 70 minutes of data. All names and identifying features of location were replaced with pseudonyms.

### ***Analytic Process***

IPA is Phenomenological, Interpretative and Idiographic. It is phenomenological in that it is concerned with the subjective meanings people ascribe to experiences, Interpretative as it recognises a double hermeneutic as the researcher interprets the participants interpretation of events (de Visser & Smith, 2006) and Idiographic as it values the case in its own right. The transcript was read in full and the recording listened to several times to gain familiarity with the interview content. Following the work of Smith, Flowers & Larkin (2009) notes were made on the transcript of what the participant talked about, understood and thought about his experience. These initial thoughts were broken down into descriptive, linguistic and conceptual comments. This together with an iterative approach allowed themes to form and these themes were checked with a second researcher. Through the process of abstraction, numeration and contextualization four superordinate themes were established that encapsulate Henry's lived experience of Breast Cancer: (1) Impact of the cancer; (2) Factors that influenced coping; (3) Changing Identity: retaining masculinity despite limitations; (4) Feeling fortunate and a need for awareness.

### **Results**

The superordinate themes that were generated from the data were those of: the impact of the cancer; factors that influenced coping; changing identity: retaining masculinity despite limitations; and feeling fortunate and a need for awareness. First the analysis showed how Henry made sense of his cancer diagnosis and his subsequent emotions of shock and psychological distress, an altered sense of time, and feelings of helplessness. Secondly he gives meaning to the factors involved in his recovery and his ability to cope, such as the relationship he had with professionals, feelings of exclusion, the gender differences between men and women's experiences, and dealing with other's reactions. Thirdly the transformation of the self is examined including the restrictions cancer imposes, the potential threat to masculinity, body image and the perception of the new self. The last theme considers how Henry felt that he had only been successfully diagnosed and survived due to luck rather than knowledge of the disease.

### **Impact of the cancer**

#### ***The shock of diagnosis***

Henry's breast cancer journey began by discovering a lump under his nipple which he checked for after unintentionally watching a TV news extract on breast cancer in men. He recalled discussing the lump with his partner and several health professionals with an element of calmness, and received a response that it was unlikely to be anything of concern: 'I don't think it's anything either' (GP) and 'it doesn't look like a cancer to me' (sonographer). This tentative reassurance appeared to minimise any concerns Henry had, which led to a greater sense of shock when, conversely the consultant disagreed with past professionals and ordered further investigations. As the sense of reassurance broke down there was a clear change of tone in the situation with new emerging feelings of uncertainty:

up until then, I'd thought – it's nothing...then they're doing biopsies and suddenly you think - this could be *something*...

Having initially assigned little meaning to the lump, the possibility of having cancer left Henry waiting apprehensively. Two weeks later he received a cancer diagnosis which led to feelings of shock, acute anxiety, and fear:

the shock kicks in and er, it's a little unreal, and it feels like it's happening to someone else (laughs) it's a very odd feeling..And then you have, all the bad feelings start to come - I'm gonna die. I'm only 55 and I'm gonna die.

The impact of the diagnosis left Henry with a sudden awareness of his mortality; his thoughts turned to what he may lose; the loss of his future, his old age; and his life expectancy.

Henry described intense anxiety, a preoccupation with his prognosis and both physical and mental exhaustion following his diagnosis. He reported absorption in thoughts of cancer mortality rates and recollection of a friend who had died of leukaemia; perhaps reminding him that cancer does kill people; people like him, people he knows. When describing this he used the phrase ‘and all this plays upon your mind’ which gave a strong impression of being consumed by negative thoughts:

You really start thinking the worst things. In the middle of the night generally, is, you know you’re lying half awake and the bad thoughts come in the early hours of the morning.

This passage shows how the psychological impact of knowing he has cancer occupied his thoughts as well as invading his body. There is a sense of isolation, of time dragging, with negative thoughts relentlessly playing upon his mind. He illustrated how the anxiety of waiting affected his wellbeing:

those two weeks were pretty awful, I didn’t sleep a great deal, I didn’t eat a great deal, I was off my food, ... You start thinking about making wills.

The anxiety of waiting was not limited to the diagnosis but to all investigations throughout the cancer journey: the bone scan, the lymph node test; the radiotherapy. This constant state of deprived sleep, little food and high anxiety led to feelings of exhaustion. He described this as cumulative and a combination of the stress, the operation and the post-operative radiotherapy. He described how this exhaustion impacted on his lifestyle and that it only started to withdraw gradually three months after the radiotherapy was completed.

### ***Altered perceptions of time***

The way time is experienced initially is with a sense of urgency. This pressing need for the cancer to be removed quickly is contrasted with the repeated waiting between various investigations. There is a clear sense of time dragging against his desire for it to be fast:

So that was the two weeks that seemed to stretch forever, every day seemed like an eternity. And you just want to get in, get it done and get it over with - pull it out, you know, get it out of me!!

The language in the last sentence of the extract emphasises his desperation to have the cancer removed from his body and from his life. The anxiety of waiting for the numerous investigations is repeated and emphasised throughout the interview. These time periods are described as ‘awful weeks’ and are full of apprehension and fear. This is again accompanied by ruminations about negative prognosis and a sense of having limited time. Despite the promptness of the mastectomy and radiotherapy treatment Henry still experienced a delay in feeling fully recovered. He described an exhaustion ‘that seemed to go on for weeks and weeks and weeks.’ This long-term exhaustion was experienced as frustrating initially and something that altered his pre-morbid lifestyle ‘I was going to bed at 9 o’clock, I used to be a night animal out until 2 or 3 o’clock in the morning’. However, it appears that he later adapted his lifestyle and accepted this change as a residual implication of his illness.

### ***Feelings of Helplessness and wanting to regain some control***

Henry’s diagnosis, treatment and recovery generated feelings of shock, fear and anxiety. He described a need to satisfy questions such as the cause of his cancer and gave a sense that he felt ill-equipped to deal with the disease. An ignorance of breast cancer in men coupled with little available information may have led to a secondary appraisal of his situation as one where he had insufficient resources to cope. This led to feelings of helplessness which left him feeling vulnerable and unable to contribute an opinion. To rectify this Henry consulted online research as a way of increasing his knowledge, resources and regaining feelings of autonomy. The appraisal processes is shown to play a significant role in psychological adjustment to breast cancer in women (Gallagher, Parle & Cairns, 2002) and so recovery from breast cancer may be aided by identifying low self-efficacy and addressing any deficits in knowledge or resource the person has so they feel more able to cope.

He mentioned that healthcare information on breast cancer was insufficient and preferred relying on his own research, which he began from the first stage of diagnosis and throughout his experience. Later, it appeared that acquiring this knowledge allowed Henry to feel more in control of his situation and he was able to assert his opinion more confidently. He spoke of his response to a bad reaction he had to one medication:

I looked online and saw these particular [drug name] do cause some people problems and then I thought 'Ah', the light went on and I thought – 'Ah ha, that's what it is'. And so I told the doctor I'm not taking them, I said I'm stopping these, that's that.

The impact of the cancer clearly had a great psychological impact on Henry. Thoughts and feelings of shock, fear, anxiety, rumination, frustration and exhaustion all created a feeling of vulnerability in the absence of knowledge to reassure himself or offer support. Once able to access information from his own inquiry Henry appeared to feel more equipped, less helpless, and more able to cope with his disease.

### **Factors that influenced coping**

#### ***Relationship with professionals***

Various professionals and their approaches contributed differently to the process of coping. When talking about the female nurses at the clinic and radiography centre Henry spoke about their manner in terms of compassion and understanding, 'they're all very nice and er they remember your name and you know'. These staff members appear to have contributed positively and given Henry a sense of being cared for. Conversely, when talking about his consultant he valued his approach because 'he didn't beat about the bush' and was direct and informative. He denied feeling afraid of the impending operation because of this direct manner:

I found Mr [consultant] to be very...trustable. You know sometimes you can tell with folk, he was an old-school man, I think he was about the same age as me, er, and I liked his no-nonsense attitude, you know, tell it straight and how it is, you know, not covering anything up.

There is a sense that Henry feels that the consultant is akin to him and knew how to meet his needs in this way. These different relationships with professionals, whether due to a difference in gender or profession, contributed positively to the experience of coping with cancer.

#### ***Feeling Excluded***

One feeling the breast cancer experience gave to Henry was that of exclusion. Exclusion was sensed from men and women, from healthcare services and online communities. In the public domain Henry acknowledged a lack of inclusion for men with breast cancer and described how only women have an awareness of breast cancer due to campaigns and information:

people have sponsored walks and they have all these things that are all geared to women, there is very, very little that is geared to men. Er, information is rare to find, all of the online material is at women. And on the breast cancer care site there is one little bit in referral that says *for men*.

This suggests men are excluded from the start and subsequently throughout their experience. Henry experienced services and information provision in a similar way; finding that the majority of information was female-orientated with only a basic body of information for men. These limited resources led Henry to understand breast cancer in men as 'just an addendum to what happens to women' which gave the impression of feeling neglected by professionals. This was emphasized again when asking staff for male patient contacts:

She said 'if I come across anybody I'll put you in touch'. But, she hasn't so, it's really, like I said, they only get about one a year.

Henry was keen to make contact with another man with breast cancer for support but the facility was not available. This demonstrates that whilst the support provisions are different for men and women they are not

equally different, and that men's need for support is often overlooked. Henry also tried to make contact via website cancer communities and remembered receiving supportive comments from some female members but did not feel women shared his experience:

It's nice for folk to do, but there is, I would quite like to talk to another man that's had the same experience, 'well did you have to have this and did you do that'

This again highlights that although the presentation and treatment is exactly the same for both sexes the experience of breast cancer is understood to be very different. There seems to be feelings of neglect here by the other males; as Henry attempted to contact others to share his experience of the disease he received no response from other men. Henry also recalled feeling directly excluded by the women on one breast cancer site:

a woman who said 'you shouldn't be posting on the *women's* bit' and I said 'well I didn't' and she said 'I'm terribly sorry, you didn't did you' it was like you can't just go on

This woman's territorial response gave Henry further feelings of rejection, of being pushed out and made to feel unwelcome.

Henry spoke about exclusion in terms of attending breast cancer support groups. He felt 'you're not encouraged to go to any of the women's [groups]' by health professionals. It is perhaps significant that he calls them 'women's groups' rather than breast cancer groups, which illustrates how strongly associated the disease is with gender. Henry felt excluded within a community with many sufferers as he was not encouraged to gain support from them. His perception of these groups if he had tried was 'that you'd be unwelcome'. He appears to be in 'no man's land'; excluded from the exclusive female breast cancer group and equally excluded when trying to find support from men.

### ***Gender Comparison: It's different for men***

As well as the difference in health promotion and information provision there were other perceived differences between the male and female experience of breast cancer. Henry felt there was a gender difference in the values men and women placed on their appearance post-mastectomy, 'a woman will feel different about it than I feel about it'. He felt women would place more value on their appearance than he did:

For a woman yes it can be, it's kind of a, it's like it's attached to sexuality - undermines your self confidence and er, a different thing altogether - whereas I didn't have that. My only worries were about dying! (laughs)

He stressed that whilst he would not look any different to others a woman's changed appearance would be noticeable 'women can look lopsided' and this would have an emotional impact on their self-esteem and sense of sexuality. He stressed several times that these experience are 'a different thing' between men and women with no commonality. The difference between the sexes was again reflected in the literature provision as Henry was offered a 'separate booklet for men'. This suggests that male and female experiences of breast cancer are so different that they need a separate booklet and a separate understanding with not enough commonality to make a combined resource.

A clear disparity in numbers made both the support-groups and online support forums female-orientated. Henry appeared to consider himself invasive if he did attend the women's groups and downplayed his need for support:

lots of women in these groups they can show each other there scars and they can do all that kind of stuff, but whereas if I was there, I do understand, it would be difficult. I'm lucky in that I'm quite a strong character, I'm quite, I know a few people that would benefit from support groups, not everybody's me, I'm pretty good, I can carry on alright, but there would be people that would really need some therapy, emotional support and psychological support and it really isn't there, not at the moment.

As well as comparing himself to women he compares himself to other men. He denied his need for support and cites his disposition as a protective factor, but believes that other men without this may need support, and almost separates his experience from theirs.

### ***Dealing with other people's reactions to cancer***

Henry appeared to acknowledge his own stigma around having cancer. When describing first going to a breast cancer unit he remembers feeling uneasy 'Although it doesn't hurt, it's going to a cancer unit...'. It seemed that by going he was placing himself in the role of a cancer patient and this was painful to acknowledge. Although the reaction from others was largely positive he received some less-supportive responses, which he interpreted as stigma surrounding cancer:

Some people didn't know what to say, they find it awkward, some people really do find discussing things like cancer quite hard, and of course there's always been that connotation of death. Cancer, I mean I know it's not now, but people from my age and generation, if you've got cancer you're generally dying. So people they, one guy in particular kept away from me.

This shows how stigma surrounding cancer and how people experience it are shaped by society. The reason for the friend's perceived avoidance is unknown; it may be due to social awkwardness as Henry suggested, perhaps from a fear of cancer or other reasons. Interpreting this as deliberate avoidance may have hindered Henry's recovery process and may have even reinforced his own thoughts about the disease.

Henry felt a need to tell people what was happening in his life and in a very public way; 'I told everybody. Erm, I thought - I want to get this out'. He told all of his friends, posted a message on his social-networking site, told a woman he met walking the dog, told all his friends at his local social club and following treatment the MC at the club announced to everyone that he was clear of cancer. This was also enforced by his wanting to wear a t-shirt declaring that he had survived breast cancer. This public exposure may have been a way of coping with his disease, reducing any insecurities and not 'hiding away'; it could also have been about reasserting masculinity and dispelling the myth that it is a female-only disease; or about raising awareness amongst others. He described having good friends and neighbours that helped him after his operation and when describing his relationship with his partner he declared 'you go through it together' and that cancer 'brought us a lot closer'. He supposed this would be similar for females with breast cancer, 'whether they have a supportive husband or not', so this was one part of the experience that he thought both sexes shared; the support of those close to you.

### **Changing Identity: retaining masculinity despite limitations**

Henry's life and the way he makes sense of it changes throughout the cancer experience. There is a distinct point after the moment of diagnosis when Henry recalled that 'then everything changed'. Although he does not specify what changed, there is a sense of loss, of re-evaluation and of the beginning of something else; a different life than he is used to.

After his treatment there was a physical change in his body and the impact of surgery reduced his arm strength and movement: dressing himself became difficult; he gave up hobbies with a repetitive nature such as gardening or painting; he was in a constant level of discomfort; and his social life changed as he retired to bed hours earlier because of the physical exhaustion. Although the cancer experience affected several areas of his life he remained positive and described himself as able to adjust to new challenges 'you adapt to a different way of life. I learnt to shave left handed.' As well as physical challenges Henry has had to cope with a change in his appearance. He minimised the impact of the scar, the loss of nipple and asserted that he was unconcerned with the change:

I'm used to having scars I've got scars all over the place. Scars here, scars there, scars everywhere.

He denied that he wanted the nipple tattoo and reasoned that ‘I just think it would be a bit silly (laughs)...I’ve never had a tattoo and I don’t want to start now’ perhaps indicating that this would be a further change to his body that he did not wish to make.

A subject closely linked to the changes in body image was the concept of masculinity and how physical appearance can reaffirm or refute a masculine identity. When speaking of the change in his body Henry minimised the importance he places on appearance:

I don’t worry about how I look, I don’t think, you cannot tell. You know, I don’t go walking about without a shirt on very often so, er, you know, when I’m going swimming in [destination] I shall probably tell them it’s a war wound you know (laughs)

Despite denying the importance of aesthetic appearance Henry feels the need to give a masculine explanation, and also uses humour, perhaps suggesting he might not be completely comfortable with his new appearance and disclosing he has a mastectomy scar. Although Henry dismissed pain as a factor the difference in physical strength did seem to threaten his sense of self as a strong male and he had to adapt to this new self that was weaker than previously:

You’re told to gentle that arm really, which is very difficult, because I’m right handed.

And I’ve been a strong man. And I’m used to being able to do things.

This suggests that Henry sees the cancer as causing him to become a weaker man which has brought with it feelings of frustration, reduced masculinity and being less capable. Although he feels his strength has reduced he denied that having breast cancer affected his sense of masculinity. He makes social comparisons with other male breast cancer patients and positions himself as someone who can talk candidly without feeling this threat to masculinity:

It might be easier to say they have testicular cancer or bowel cancer or any other type of cancer but breast cancer they find that difficult I think – because of the connotation.

This clarifies that it is not sharing the diagnosis of cancer per se that is the difficult or perhaps shameful for men but the specificity of *breast* cancer. Henry expected some men would be reluctant to discuss breast cancer openly on on-line forums because of this stigma:

It’s seen as a female disease and they wouldn’t like that. You know, some men’s masculinity would be affected by it. And they might feel that discussing it would lower that as well, that it might have detrimental effects on how others would view them...Doesn’t bother me, but some men it would

This highlights the importance of a man’s social context; what others know about him and how others perceive him and his masculinity. It seems that one’s masculinity may be at stake by simply having breast cancer as it is seen as something typically female and that it is not masculine to have a ‘woman’s disease’ or to discuss it. By differentiating himself from men who would feel their masculinity was vulnerable Henry may also be asserting his own masculinity by stating that he did not feel threatened but secure and unchangeable.

A transformation of the self occurred as all these difficulties (a change in lifestyle, capability, body image and masculinity) were seen by Henry as challenges to overcome; his ability to see change as positive being attributed to his temperament and life-view. His perception of himself was that of a ‘strong character’, who will ‘make the best of life’ which he emphasised throughout the interview. His position progressed throughout his cancer journey from someone who was afraid of the disease and uncomfortable being associated with it, to someone that sought support from others, was keen to wear a breast cancer t-shirt and take part in research to generate awareness of the disease. The cancer did indeed change his life and he recounts post-traumatic growth after the experience:

This has been life changing again because you realise that the material things in life are really quite irrelevant; money means nothing, cars, houses, nothing at all, the one thing that really matters is your health. If you’re going to live or if you’re going to die. So I



think for me be more, to enjoy my life more, to make everyday count, and to do something different every week, go somewhere you've never been, experience something you haven't done before. Because life really is a fragile thing that can snap at any moment. Erm, you don't often think about it but when you've had cancer you do (laughs) and it brings into sharp focus what you really must concentrate on.

The cancer has been interpreted as something that has reminded him of the fragility of life, his own mortality and that life is time-limited. This has caused him to re-evaluate what is important in life and prompted him to fulfil his life in ways that he might not have done if he had not had the cancer experience and the threatened loss of life. It seems that not only has his sense of the world changed but also his sense of himself within it.

### **Feeling fortunate and a need for awareness**

Throughout the interview Henry mentions luck as a mediator in his cancer experience. He is aware that it was not his initiative that led to the discovery, early detection and early treatment of breast cancer but the coincidence of watching a serendipitous news clip 'pure luck that I saw it' which prompted him to check 'I consider myself to be very lucky'. He also described luck in other areas of his recovery; the luck of meeting new people who coincidentally had breast cancer 'it's just pure luck, chance, life's strange the coincidences it throws up'; the luck of having such a supportive partner; and the luck that he has a positive disposition to assist him with coping. He contrasts his good fortune with that of other men diagnosed with breast cancer late because of a general lack of public awareness:

There really does need to be more exposure. To try and save some of those 80 men a year that are dying. To get them to check, to get them to have a look. It's pretty easy. Unless they know that the possibility exists, that many men don't know, then, then they'll continue to wait too long and erm, and die.

Henry described his prior knowledge of breast cancer 'I'd never ever, considered it, I didn't ever know men could get breast cancer.' He stressed throughout that men are unaware of the disease and stated he was happy to help with research to create more awareness. Recognizing that his discovery, treatment, prognosis and support were due to chance Henry was keen to see change in the public health breast cancer campaigns to include men.

### **Discussion**

This study offers a close analysis of an individual journey through diagnosis, treatment and early recovery of breast cancer. It presents an opportunity to learn from and raise awareness of this relatively uncommon experience of being a man with breast cancer. Henry's experience of diagnosis appears to be similar to other men across the existing qualitative studies who often report a reaction of shock to the diagnosis of breast cancer (Iredale et al, 2006) suggesting that there is still a lack of awareness amongst men. Henry was fortunate in his experience of services, however, small comments by health professionals intended to offer reassurance may have actually amplified his shock and anxiety as they were incorrect. By offering these comments Henry was led into a false sense of security which may have contributed to his distress. This highlights the need for health professionals to perhaps use a disclaimer if they are offering such reassurance.

The altered perception of time, anxiety and exhaustion experienced reflects the psychological distress waiting for investigations and treatment creates which can lead to further health complaints. Henry found out later from discussion with his consultant that this was a 'normal response' but this information may have been more beneficial if offered beforehand. It is important that men's psychological health is not overlooked in this way and one recommendation might be the provision of some brief psycho-education comprising of information and coping together with signposting to support agencies if required.

Henry's experience generated feelings of helplessness and vulnerability which were partly created by his lack of knowledge regarding breast cancer in men. Much research into the psychological impact of breast

cancer in men cites information offered by services as either unavailable, less than satisfactory and often geared towards women (Williams et al, 2003; Iredale et al, 2006; Naymark, 2006). Henry was given a male specific booklet but felt this was not very helpful and he preferred to investigate breast cancer via internet resources.

Communication and information are considered important in helping people to cope with cancer as the diagnosis may invoke uncertainty, fear, and loss that can be alleviated by information (Leydon et al, 2000). Henry appeared to use research and knowledge to inform himself, enable himself to actively participate in treatment discussions which may have reduced feelings of helplessness. This is similar to research by Bohn (2008) who found that lack of information and knowledge can dramatically affect a man's sense of autonomy and sense of self and create feelings of helplessness and anxiety. More significantly, some men in the Bohn study reported that a lack of knowledge decreased their ability to make informed decisions and if they had access to information they may have made different decisions regarding their treatment. The charity *Breast Cancer Care* created a booklet aimed specifically at men with breast cancer 'Men with Breast Cancer' which was published in 2005 (updated in 2009). It is interesting to see that the information needs of men are still similar to ten years ago despite this publication. After gaining information Henry's confidence developed and he felt more able to assert his opinion. This suggests that being informed may reduce feelings of anxiety and promote autonomy and so it may be useful to direct men to external resources to investigate further. Henry's experience also showed that information was not well absorbed when given directly after diagnosis, so timing is another consideration.

Coping consists of cognitive and behavioural efforts to manage psychological stress which can change over time and between situations (Lazarus, 1993). Coping has been described as both a personality characteristic and a process. Henry cites his personality trait of a 'sunny disposition' as a mechanism for coping with difficulties and this could also be considered *positive reappraisal*; an often stable coping method across situations in which the individual grows as a positive way following adversity (Folkman and Lazarus, 1988). At times it is also possible to see his coping as a process in which he consciously manages stress 'you adapt to a different way of life. I learnt to shave left handed.' Other people also influenced coping, such as Henry's relationship with professionals. He reported feeling supported by both the compassionate nurses and the 'direct' consultant. Past research indicates that men cope with a diagnosis in a different, more practical way than women (France et al, 2000; Williams et al, 2003) which has also been acknowledged by health professionals who have described men as stoic and concerned with practical issues; leading them to treat men in a more matter-of-fact way compared to women with breast cancer (Williams et al, 2003). This was reflected in this case study by the consultant's approach to Henry with his 'no nonsense attitude' which reduced Henry's fear and anxiety. Had Henry been female the approach may have been different. This demonstrates the importance of social influences and reinforces the gendering of male and female patient roles. The fact that Henry felt supported by both direct and compassionate communication and sought the support of an online group shows that men do not always follow the stereotype documented in the literature; indeed support needs may differ between individuals and within individuals at different times and so support and communication should be personalised to the individual rather than their sex.

One unmet need was that of support. Henry felt directly excluded by both men and women, by the health promotion of breast cancer and by support groups and online communities. The rationale for a support group is to give emotional, informational and practical support, as well as a sense of comradeship (Iredale, 2006). Henry indicated that he wanted to be part of a group but felt discouraged by professionals to approach one and his own perception was that he would be unwelcome. If male-only groups were available many men would not feel comfortable talking to other men with breast cancer (France et al, 2000; Pituskin et al, 2006; Pituskin et al, 2007) which may partly explain Henry's difficulty in finding men to converse with on online cancer communities. There appears to be a lack of support for men with breast cancer and reluctance to

integrate them into existing networks. This double deficit leaves men like Henry with no support from support groups that are perceived as 'exclusively' women due to a fear of approaching them and no support from men because of the perceived masculine attitude towards the discussion of health and emotional needs.

Research suggests that men have a tendency to seek information and knowledge about their illness from a support group setting, whilst women prioritise intimacy, confidential discussion and shared emotion (Krizek et al, 1999). Changing the theme of support groups to one of information giving may improve uptake (Iredale et al, 2006) and make this a more 'acceptable' outlet for men to gain support. There is also a need to educate the female members of the breast cancer support groups, both attendance groups and online, that breast cancer is not exclusive and to welcome men as part of it. As it stands there is another double deficit for men; they are less likely to benefit from the extensive research and support services women utilise and any clinical treatment approach is a modification of that designed for women without consideration of men's different psychological needs.

The gender comparison Henry made between male and female experiences of breast cancer reflected his belief that the sexes held a completely separate understanding of the disease with little shared experience of value placed on body image, emotional impact of mastectomy and the information and support available. This again emphasises that although physically the presentation and treatment of breast cancer is similar regardless of sex, psychologically the journey through and meaning of breast cancer may be considered different by some men and women and support should be tailored to individual need.

Some men on internet forums have argued that there is no male or female breast cancer, there is only breast cancer (hence the term throughout *men with breast cancer* rather than *male breast cancer*). As women have the breasts women seem to have claimed breast cancer in terms of health promotion, which leaves men further excluded from what is an already gendered illness. Indeed, it has been suggested that organisations continue to contribute to the image of gender specificity through constantly portraying women as the only people affected breast cancer by using female images, pink merchandise and excluding men from some fundraising events (Piasecki, 2009). There appears to be an important discrepancy within male breast cancer; men are in need of inclusion in awareness campaigns to reduce initial delays in detection of breast cancer, however, this research suggests that men identify their needs as separate from women's for the remainder of the breast cancer journey. As services it is difficult to know whether to integrate knowledge and understanding of breast cancer as one disease or if the separate experience of men and women call for a separation of the two with separate booklets, websites, sponsored walks, promotion campaigns and support groups. What men want in this regard deserves further research attention.

When recalling the reaction from others Henry cited a great deal of support from friends and his partner which is consistent with previous research (France et al, 2000; Williams 2003; Iredale et al, 2006; Bohn, 2008). Henry reported experiencing stigma in relation to the overall diagnosis of cancer; he was uncomfortable being associated with it and also received some negative reactions from others because of it. Stigma surrounding breast cancer in men is evident in the existing literature and some men report feeling foolish (Naymark, 2006) or embarrassment by their 'female' disease (France et al, 2000; Bohn, 2008). Whilst Henry denied feeling this way himself he did suppose that many men would feel this sense of shame and as such feel unable to discuss their disease. This stigma affected his experience as he felt unable to join existing support groups and did not benefit from this socialisation.

Attitudes of health professionals also contribute to the image of men with breast cancer. Naymark (2006) comments that professionals that treat men with breast cancer differently maintain the stigma around the disease; they perpetuate the stereotype that men are expected to cope with cancer without assistance. In this study this may have been replicated as health professionals did not promote the support groups available to

Henry which they may have done with female sufferers. This lack of support may lead to men feeling further isolated from the breast cancer community, which could contribute to feelings of shame, influence their psychological wellbeing and capacity to cope which could ultimately affect their engagement with treatment regimes. There is a clear need to educate staff around the need to integrate men into a breast cancer community to assist their recovery and reduce feelings of isolation. Reducing the stigma around male breast cancer in staff and other support group members will enable men to feel more comfortable disclosing to others and benefitting from their support.

One often underestimated effect of breast cancer is the insecurities men acquire post-mastectomy and body image transformation was an evident theme in this case study as it has been in past literature. Henry minimised the impact of the scar and denied that it affected his overall body image. He opted not to have the tattoo of the nipple as felt it was 'silly' which may reflect the minimal importance he attaches to appearance or decline any further changes to his body. Henry also believed that women would feel a much greater need for reconstruction as the presence of the scar would affect their self-esteem and perceived sexuality, which was similar to what men expected in studies by Iredale et al (2006) and Bohn (2008).

In past studies developing a feminised illness within a masculine body presented significant distress in some men and clearly affected their own perceived masculinity (Donovan & Flynn, 2007). Many males likely associate their chest with pride, strength, and masculinity (Robinson, Metoyer & Bhayani 2008) and a mastectomy can alter a man's appearance in both the shape of the chest, the scar and also their upper body strength. This may further serve to reinforce a perceived loss of masculinity coupled with a 'feminised' disease. Again Henry denied feeling his masculinity was threatened by his change of appearance but he did suggest that the lost upper body strength had affected his sense of self; 'I've been a strong man' indicating that strength was part of a past identity and his new self, post-mastectomy has a reduced strength and ability. He made social comparisons with other male breast cancer patients and believed others may feel this threat to masculinity because they do not have a typically 'male' cancer which would also prevent them from receiving support from online community forums because they feel ashamed of their diagnosis and feel that having a 'female disease' and discussing it emotionally would seriously damage how others perceived their masculinity. If this shame and stigma does prevent men from talking about breast cancer then awareness of breast cancer in men is further reduced and so it will remain a gendered disease. Conversely, Donovan & Flynn (2007) described some men as 'coming out' and declaring their diagnosis as it empowered them and reasserted a sense of masculinity by proving that it is not a woman's disease, which may also be part of Henry's reason for announcing it publically.

Some men downplayed the significance of their scar stating that they should not be 'shirtless at their age anyway' (Bohn, 2008) which Henry again echoed. Similarly, in past studies some men asserted the mastectomy scar as a masculine feature; and joked that it could be passed off as a battle scar (France et al, 2000) or a shark bite (Iredale et al, 2006) and in Henry's case 'a war wound'. Placing the scar in this context minimises its importance and allows a masculine identity to remain. It is important to note that a past study has found that men denied any threat to masculinity or embarrassment when completing an initial paper survey but that this theme did emerge during interviews (Iredale et al, 2006). This highlights the continued need for in-depth qualitative interviews to identify salient features about a person's experience.

The association of breast cancer with women appears to have lead to an erroneous conclusion by men that they are not at risk of the disease (France et al, 2000); this is demonstrated in the shocked reaction to diagnosis and lack of knowledge among male sufferers across studies (France). Henry mentions luck of watching a TV news clip as the reason he discovered cancer early and survived; this may suggest TV as an appropriate media for health promotion campaigns targeting men. It is also noteworthy that there was no

delay in help seeking once symptoms were discovered but any delay would have been due to a lack of awareness.

### **Limitations & Further research**

This study focused on one participant and so was unable to explore the different experiences or differences in meaning-making between individuals. Larger studies are needed to ascertain if these reported experiences are unique to the individual or universal. Interpretative Phenomenological Analysis (IPA) is a research methodology oriented towards exploring and understanding the experience of a particular phenomenon; in this case breast cancer in men. An IPA case study was appropriate because of the small incidence of breast cancer in this population and because it is concerned with individual experience and meaning. Care has been taken throughout to distinguish between the interpretation of the participant and the interpretation of the researcher; however one limitation is that it cannot be discounted that the authors' expectations or experience may have influenced interpretation.

The majority of existing qualitative studies focus on men with positive outcomes and in the recovery phase of their illness at the time of interview. Further research should include men recently diagnosed and those with breast metastases to gain a more representative sample. It would be beneficial to the evidence base to conduct qualitative studies with men from various ethnic and cultural backgrounds to compare their experience of the disease with the research published largely in the West. Another limitation is that the study is retrospective and this may influence recollection of factors such as coping. From a process prospective coping changes over time and in accordance with the situation in which it occurs, therefore, a patient retrospectively describing how they coped with cancer may report differently to the time when they were dealing with threat of the disease. Future prospective studies are therefore needed to explore the experiences of men as they advance through every stage of their diagnosis, treatment and care so we may learn how attitudes, coping strategies and development of meaning change over time. There is also a need to further investigate how men with breast cancer wish to be integrated or not within the existing breast cancer community.

### **Conclusion**

Considerable work is still needed to raise the profile of breast cancer in men amongst healthcare professionals and the public. Awareness is needed to encourage help-seeking, improve patient care, encourage self-exam, increase support options for sufferers and improve outcomes for this group. This research also suggests that awareness amongst the public may help to reduce the stigma felt by men in having what is thought of as a 'female disease.' Research into this area is invaluable so we can better inform services and to help the cancer recovery process by: offering suitable information, being aware of how staff approaches may influence psychological distress, increasing patient autonomy, normalising the experience and reducing exclusion, and promoting support networks.

### **Acknowledgements**

I would like to thank the participant Henry for offering his time to this research and Macmillan Cancer Support for allowing me to advertise my research on the Macmillan community forum.

### **References**

- Bohn, M (2008). Assignment of meaning in the male breast cancer experience: a phenomenological study, *PhD Publication*, 1-108.
- Cancer Research UK, 2010. Breast Cancer in Men, available at [www.cancerhelp.org.uk/type/breast-cancer/about/types/breast-cancer-in-men](http://www.cancerhelp.org.uk/type/breast-cancer/about/types/breast-cancer-in-men) (accessed 01.06.2010.)
- Contractor, K.B.,Kaur, K.,Rodrigues, G. Kulkarni, D., &Singhal, H. (2008). Male breast cancer: is the scenario changing, *World Journal of Surgical Oncology*, 6 (58): doi:10.1186/1477-7819-6-58.

- Crichlow, R.W. & Galt, S.W. (1990). Male breast cancer, *Surg Clin North Am*, 70 (5), 1165–77.
- Donovan, T. & Flynn, M. (2007). What makes a man a man? The lived experience of male breast cancer, *Cancer Nurs*, 30 (6), 464-470.
- Folkman, S. & Lazarus, R. (1988) Manual for the Ways of Coping Questionnaire, Palo Alto, CA, *Consulting Psychologists Press*.
- France L., Michie S., Barrett-Lee P., Brain K., Harper P., & Gray J. (2000). Male cancer: A qualitative study of male breast cancer, *The Breast*, 343-348: doi: 10.1054/brst.2000.0173.
- Gallagher, J., Parle, M. & Cairns, D. (2002) Appraisal and psychological distress six months after diagnosis of breast cancer, *British Journal of Health Psychology*, 7 (3), 365–376, DOI: 10.1348/135910702760213733
- Iredale, R., Brain, K., Williams, B., France, E., Gray, J. (2006). The experiences of men with breast cancer in the United Kingdom, *Eur J Cancer*, 42 (3), 334-41: doi:10.1016/j.ejca.2005.09.027.
- Iredale, R., Williams, B., Brain, K., France, E. & Gray J. (2007). Men's health. The information needs of men with breast cancer, *British Journal of Nursing*, 16 (9), 540-544.
- Krizek, J.D., Roberts, C. & Ragan, R., et al. (1999). Gender and cancer support group participation, *Cancer Practice*, 7 (2), 86-92.
- Lazarus, R. (1993) Coping theory and research: past, present and future, *Psychosomatic Medicine* 55; 234-247.
- Leydon, G., Boulton, M., Moynihan, C., Jones, A., Mossman, J. Boudioni, M. & McPherson, K (2000) Cancer patients' information needs and information seeking behaviour: in depth interview study, *BMJ*, 320, 320:909 doi: <http://dx.doi.org/10.1136/bmj.320.7239.909>
- Naymark, P. (2006). Male breast cancer: incompatible and incomparable, *Journal of Men's Health & Gender*, 160-165.
- Piasecki, C. (2009). Men get breast cancer too! *Nursing Standard*, 23 (26), 33-34.
- Pituskin, E., K., Williams, Au, H. & Martin-McDonald, B. (2007). Experiences of men with breast cancer: A qualitative study, *Journal of Men's Health & Gender*, 4 (1), 44-51.
- Pituskin, E., Martin-McDonald, K., Williams, B. & Au, H. (2006). The experience of a sample of Canadian men with breast cancer, *Oncol Nurs Forum*, 44-51.
- Ravandi-Kashani F, Hayes TG. (1998). Male breast cancer: a review of the literature. *Euro J Cancer*, 34 (9), 1341–7.
- Robinson, J.D., Metoyer, K.P. & Bhayani, N (2008). Breast cancer in men: A need for psychological intervention, *Journal of Clinical Psychology in Medical Settings*, 15, 134–139: doi 10.1007/s10880-008-9106-y.
- Smith, J.A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology, *Psychology & Health*, 11 (2), 261-271 doi: 10.1080/08870449608400256.
- de Visser, R., & Smith, J.A. (2006). Mister in between: A case study of masculine identity and health-related behaviour. *Journal of Health Psychology*, 11, 685-695: doi: 10.1177/13591053060666624.
- Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*, SAGE: London.
- Williams, B.G., Iredale, R., Brain, K., France, E., Barrett-Lee, P., & Gray, J. (2003). Experiences of men with breast cancer: an exploratory focus group study, *Br J Cancer*, 1384-1386: doi:10.1038/sj.bjc.6601305.
- Ying, M., Agrawal, A. & Cheung, K. (2005). The 'other half' of breast cancer: A review of male breast cancer, *Journal of men's health and gender*, 406 (2), 406-413.