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Background

Breast cancer continues to be a major public health problem globally.^{1,2} Current emphasis is on early detection and treatment. Early diagnosis of symptomatic cancer is linked to longer survival and more favourable outcomes for women.^{3,4} Furthermore, optimal outcomes for breast cancer treatment are linked to a shorter time interval between self-discovery of a breast change and presentation to a health care professional (HCP) i.e. help seeking behaviour (HSB).⁵ From hereon in HSB will refer to a woman's initial presentation of breast symptoms to a HCP, usually the General Practitioner (GP).

Many women undergoing diagnostic investigations for a breast lump fear malignancy, and view such an outcome as being a direct confrontation with their mortality.⁶ One of the main barriers to HSB is the fear and worry associated with a cancer diagnosis.^{7, 8-11} A qualitative study¹² reported that women delayed help seeking because of their beliefs about the consequences of cancer, for example, where a loved one died having experienced a long or painful death. In a cultural context, focus group interviews found that cancer was believed to be a 'time bomb' or 'death sentence', and a source of 'discrimination', amongst immigrant groups in the US.¹³ While discussing cancer in such terms may be socio-culturally unacceptable in Ireland, however, it is possible that similar beliefs underpin women's emotional responses to symptoms that are potentially cancer related, contributing to a time lapse in HSB.

A synthesis of qualitative studies on HSB¹⁴ reported that stigma, incurability and 'severe internalized fear of cancer' are part of the experience of women who self-discover a breast cancer symptom, although this fear is oftentimes not discussed. A study on decision-making¹⁵ at the time of women's (n=28) breast symptom discovery, found that all but one of the participants, spoke

about cancer as 'terrifying', 'ugly', 'extremely frightening'. Some women who delayed told 'stories that emphasized the pain of treatment and the inevitable death associated with a breast cancer diagnosis'.¹⁵ In contrast, some women who sought help promptly spoke about the suffering and needless breast loss that they associated with delayed diagnosis or misdiagnosis, and related positive stories of well-treated cancer and benign biopsies associated with early help seeking. An Irish study¹⁶ investigating women's (n=99) HSB following breast symptom discovery, reported that women were anxious, afraid, scared and unsure. Similar to previous research,¹⁷ women who were anxious sought help more promptly.¹⁶

It is reported that knowledge alone does not always guarantee that appropriate decision making around symptom appraisal will take place and application of a more holistic framework to promoting early help seeking, is recommended.¹⁸ Additionally, while knowledge of cancer is important, crucial beliefs and emotions remain underexplored¹⁹ and could provide insights into the gap that exists between knowledge and behaviour. Notably, despite having knowledge around breast cancer, one study reported that some women believed their breast symptoms to be 'normal changes'.²⁰

The need to further examine beliefs and emotional responses around symptom discovery and any possible link to engaging in the diagnostic process, is clear. As argued "it is necessary to move beyond description and explore broader issues that constitute the reality of women's lives and the meanings they attach to finding a breast symptom and how these impact on their decision to wait or seek help promptly at the onset of breast symptoms"¹⁶ (p 2028). The use of narratives of cancer survivors have been advocated to promote early presentation of cancer related symptoms.¹¹ Thus, the current analysis of data from women who have discovered a possible breast cancer symptom,

offers a novel insight into the meanings that women attach to their breast symptom discovery and their associated help seeking behavior.

Methods

A descriptive, cross sectional, correlational survey design was used to describe women's help seeking behaviour (HSB) and the associated influencing factors on self-discovery of a breast symptom. A researcher-developed questionnaire was used to collect information on women's demographics, breast symptom, social factors, emotional responses, knowledge and beliefs, health seeking habits, health service utilization and HSB, following breast symptom discovery. HSB was categorised as either prompt i.e. within one month (≤ 4 weeks) of symptom discovery or delayed i.e. more than one month (> 4 weeks) following symptom discovery.²¹

Data were analysed using descriptive and inferential statistics, findings of which are reported elsewhere.²¹ The final item on the questionnaire asked women if they wish to include any further comments on their experience of finding a breast symptom and their associated HSB. This paper reports on the comments received which were analysed using Discourse Analysis.²²

Sample

On receipt of ethical approval, data were collected from participants on their first visit to the breast clinic, by a nurse researcher during several visits to two breast clinics in the Republic of Ireland between August and December 2009. A convenience sample ($n = 449$) of women who met the inclusion criteria (of being over 18 years of age, with a self-discovered breast symptom and no previous history of breast cancer) participated in the study.²¹ Amongst these women, 37% ($n=167$) made written contributions to the final item on the questionnaire. Responses varied in length from

a short response comprising as few as 2 words, to a long response comprising 280 words. Thus, as researchers we were ethically obliged to analyse and present women's contributions.

Data Analysis

Data analysis began with the 167 hand-written contributions being typewritten into one document. A qualitative approach was chosen with a view to exploring the meaning of the contributions that these women choose to make at the particular time as they wait at a clinic. How these women make sense of and cope with their situation suggested that a social constructionist approach to understanding the meaning of their contributions would be appropriate. This commenced with an exploratory process of open coding of the data by a research psychologist. As the coding proceeded, memos were written to record observations and ideas. During discussions with the nurse researcher to evaluate the initial ideas for analysis, the content of the memos suggested that discourses were emerging from the data. The language being used in the participants' contributions suggested that these women were creating a metaphorical distance between those who will and will not be diagnosed with breast cancer. Consequently, in order to explore the social meaning of the women's experience, it was decided that Discourse Analysis²² would be an appropriate and useful approach to help gain a better understanding of women's written contributions.

Discourse Analysis aims to understand how and why people use language in order to construct identity, regarding themselves, other people, and their social worlds.³¹ It seeks to extract other meanings than what is foregrounded, thereby shedding light on how people actively participate in their world, and why.³¹ In this instance, the use of Discourse Analysis is to shed light on

how the participants understand what is happening, in its social context, how they respond actively to this situation, and what this enables them to achieve.

Analysis began with the responses being read through by the research psychologist. Notes on the emergent ideas concerning the analytic direction of the discourses were developed and rewritten iteratively. This analytic process was conducted in light of the literature, with repeated reading of participants' contributions, in order to gain insight into women's experience during the particular timeframe of data collection i.e. post symptom discovery and prior to first presentation to a consultant. During the analytic process, the content of the notes were expanded into a total of thirty memos. These memos document the analytic process, illustrating how codes were amalgamated, and expanded into discourses. The grouping of the contributions into four discourses, and how they are linked, is illustrated in the findings. Credibility of the findings was established through review of the women's responses in conjunction with the emerging discourses, with the nurse researcher.

Findings

Four linked discourses were identified: (1) 'Being and remaining normal', (2) 'Emotion', (3) 'Becoming and being abnormal' and (4) 'Rationality'. Women draw on, and link, these discourses in order to make sense of their experience, reconciling their knowledge with their emotional response to the situation. These discourses are presented and discussed in four sections, using exemplars to illustrate how they are interlinked.

1. Being and remaining normal

Participants are at the clinic, and are pre-diagnosis, hence there is a possibility that they can remain normal, which is the best outcome possible. This hope is illustrated by a discourse that constructs life as being normal, and the likelihood of it remaining so. In this way, the meaning of the clinic visit is downplayed, as is its significance; it is referred to as an intrusion into ordinary life. As such, the visit is something unusual, to be managed. Participants focus on the mundane, such as the nuisance of organising travel and babysitting, in order that they can attend the clinic. This signifies the clinic visit as an anomaly in a routine, an intrusive event into an ordinary life. Constructing the experience in this way means that the alternative possible outcome, a diagnosis of cancer, can be regarded as abstract. Thus, the possibility of illness is remote, a hypothetical future that participants make sense of by constructing it as a less significant discourse. The way of dealing with this possible outcome is to remain calm, at a distance from emotional responses. Previous medical history is also constructed as normal, for example, one participant mentions having mastitis, however, this is relatively normal compared with cancer. Similarly, another woman reflects:

“I previously have had a fibroadenoma so I suppose at the moment I feel it's the same sort of lump that I had last time but in a different breast so I suppose I am less anxious because I am hoping its just the same as I had previously. Hope I'm right.” (P312).

In the above exemplar, the clinic visit signifies the possibility of becoming abnormal. In addition, the sequencing of this woman's experience is drawn on to construct a timeline of being and remaining normal. This participant describes being normal in the past, and in the present, and she relies on this, hoping to continue to be normal in the future.

Similarly, another participant describes the experience of what is happening to her body, as being “her normal experience” (P5). However, what is normal to this woman is determined to be abnormal by her GP, and this transformation of her experience has brought her to the breast clinic.

Another extract from this woman’s contribution related:

"I found the symptom about a year and a half ago. I visited my GP and she said it was normal. I thought it would go away but it didn't. The next time I visited a different GP in the same clinic and she said she would send me to the breast clinic in [venue] just in case it was anything serious.[....]." (P5)

The reference to “anything serious” in the above extract implies cancer. This oblique way of referring to cancer is echoed by other participants. The symptom is an abstract idea that is mentioned, rather than something requiring prompt action. Even at this stage, when the women are in a clinic for evaluation of a breast symptom, the mundane tone is used. Some participants, downplayed their breast symptom to the extent that it does not even merit a visit to their primary health care provider, as illustrated in:

"When I discovered the symptom I didn't think it was anything serious and waited until I had to go and see my GP for another problem to mention it to her." (P12)

This participant mentioned the symptom to her GP, as a side issue, downplaying it to be of little significance. Some participants distance themselves from the possibility of cancer. There was a sense that the clinic is for, and about, other women, that it is not specifically for them, even that they ought not to participate in the research being conducted. The tone of the following contribution illustrates detachment from the clinic, and distances other people present:

"Sorry if my answers seem a bit random - it is only a cyst that I have so I couldn't really relate to all of them [the questions on the form] as my cyst isn't a serious condition." (P134)

Above, the language and tone construct a sense of the everyday, the casual nature of what is happening. The symptom is a trivial matter, and the questions on the form are, as she puts it, not 'really' applicable to her. Indeed, at this stage, it is possible that none of the women have cancer. While these women do have a breast symptom, their contributions are about being normal, and the hope of remaining normal despite what is happening to them. Entering the medical system, engaging in HSB, signifies a change in identity, from being 'normal' to becoming 'abnormal'. This shift is from being 'healthy' to becoming 'unhealthy', from being their normal self, to being a woman with cancer.

2. Emotion

While overt emotional responses to discovery of their breast symptom are infrequent in the participant contributions, those who do write explicitly about them refer to their horror and anguish. In one of the contributions where fear is explicitly referenced, it is constructed as something to be controlled and concealed. Here, this participant describes her struggle for control, with the aim of appearing normal:

"Panic, tried to act as if everything around me had to go on as normal and pretend that nothing was wrong. Haven't told anyone other than my partner and GP. Don't want to talk about fear of breaking down." (P201)

In the above exemplar, this woman chooses to pretend that what is normal continues, and she explains her choice in the context of being afraid of her own emotional reaction. She is trying to convince herself and others that nothing is wrong. The distress she is experiencing is with her

symptom discovery. This response, however, is compounded by anxiety and a desire to conceal her distress. This woman's contribution gives a vivid insight into her emotional turmoil.

Other participants also draw on the discourse of emotion. This can be juxtaposed with other discourses, such as being normal (discourse 1), or being rational (discourse 4) as illustrated in the following:

"Afraid after finding the lump and the knowledge of our local [name] clinic being closed added extra upset and anguish for me with the extra disruption of having to travel to [venue]. Finding a babysitter for 3 children for 4-6 hours, etc." (P399)

In her contribution, this participant writes about fear and her symptom, and then goes on to consider the disruption to her normal life that has occurred because of her symptom. What she achieves is being able to focus on logistical problems, rather than on the fear concerning her symptom, and the 'extra upset and anguish' are linked to what is normal, such as arranging travel and a babysitter. This achieves control of the emotional responses, by downplaying them, while foregrounding rational responses. In this way, participants diminish their fear, as illustrated in:

"The main reason I went to my GP was because finding a lump in the breast is not right and frightened me and also my mother died of cancer (not breast cancer). 'Prevention is better than cure'." (P38)

In the above contribution, the reference to being frightened is associated with the abnormality of the symptom, cancer and the death of this woman's mother. In contrast to this, everyday rational commonsense is present in the form of a proverb "prevention is better than cure." Similarly, another woman begins and ends her contribution with rationality, as follows:

"My GP was the first one I considered talking to. I have a lot of faith in her. She reassured me immediately and took the horror out of the equation." (P159)

Acting rationally is foregrounded, by talking to her GP. This woman refers to the horror of cancer and balances this emotional response with her rational response of choosing to contact her GP, and what doing so meant for her.

In the next extract, two distinct discourses are voiced, one of emotion and the other of rationality:

".....I think fear is a very big issue and I was amazed at how quickly it set in.....". (P263)

This participant addresses the extent of fear, and chooses to refer to fear in an impersonal way. As we have seen, there is a tension between being emotional and of being rational. The health care system is drawn on as being rational, and scientific. This is a socially approved discourse for illness, diagnosis, and treatment. The alternative discourse, the emotional response is marginalised and, as such, is presented as a disapproved discourse for illness, diagnosis and treatment. Participants know that delay in a diagnosis of cancer is linked to poorer outcome. Despite this knowledge, participants may choose to appear as though their emotional response is of less importance than being rational and in control. It is possible that the tension between these two discourses contributes to the time-interval between symptom discovery and HSB.

3. Becoming and remaining abnormal

This is about the abnormal identity that a potential diagnosis of breast cancer confers. There is a tension between being normal, and the potential consequences of the illness. Delay in engaging in HSB postpones the process of becoming abnormal, that is, a person who is ill with cancer. Seeking medical help serves to indicate a possible change of identity, and a further step toward the

possibility of becoming abnormal. In the particular context of this study, the abnormal are those who become cancer sufferers, and as such are subject to aggressive treatment, which may not provide a cure. The clinic visit is a seminal event where one of two possibilities becomes reality. One possibility is remaining normal, while the other is becoming abnormal together with a future of remaining abnormal. The future thus becomes uncertain for participants, and the following example from one woman's contribution explains what this means for her:

"Its probably nothing but I found myself putting on hold thoughts about the future." (P14)

The future here can mean having the illness, and being treated. It can also mean the absence of the anticipated normal life. There is the possibility of being ill with cancer, and the loss of identity. This is linked to emotion (discourse 2) discussed earlier. However, with abnormality, the status that cancer confers is explicit. There is, for instance, a possible truncated future, as one woman wrote:

"Scared that I might have breast cancer it is in the family I have two young children and a husband I am only 29 and the fear of having treatment and being sick and not being there for my family." (P12)

In this woman's exemplar, 'not being there' for her family, can relate to treatment for cancer, or perhaps death. The treatment for the illness is itself feared, as one woman remembers the treatment her mother underwent:

"[.....] going through aggressive chemotherapy and radiology for breast cancer" (P99)

Death is a possibility, and the illness of friends and family members illustrates how participants are aware of their own vulnerability. The contribution of another woman illustrates this:

“My brother died from cancer last year (throat/lungs). My sister has had breast cancer - both my brother and sister were ill at the same time. This has heightened my own awareness to my own health so I acted promptly when I had an unusual sensation/pain in my breast.” (P26)

The possibility of death is explicit for this woman and her choice is to seek help promptly, despite the consequences.

Another part of abnormality is the unpredictability of the illness. With breast cancer, there is a sense that one is powerless to avoid becoming ill. The risk of developing breast cancer increases with age, however, the young age of those who have died, or become ill with cancer, suggests an arbitrary quality. There is a sense that luck plays a part in not being diagnosed with cancer as apparent in:

“[....] An aunt of mine had very cystic breasts also and was in and out of hospital all the time but luckily for her they were all just cysts. [....].” (P115)

As we have seen above, women's young age, being a mother and wife, do not fit with the discourse of cancer sufferers being older. This illustrates how participants hope not to have their identity changed.

There is a tension between abnormality, described in this section, and rationality, discussed below. Rational knowledge means that speed is important in engaging in HSB, once a breast symptom has been identified. This means that delay exacerbates the outcome following diagnosis of breast cancer. Once the participant engages in HSB, by having their symptom medically checked for cancer, they have taken an irrevocable step, leading toward a changed identity. For example, one woman writes:

“Due to my aunt dying of breast cancer, this strongly encouraged me to attend GP”. (P101)

In this contribution, there is awareness that death is a possibility, yet, despite this, there is a time interval of two months for this participant, between self-discovery of her breast symptom and HSB. Participants are aware of the change in status from normal to becoming a cancer sufferer, and therefore becoming 'abnormal'.

4. Rationality

The fourth discourse is one of rationality: the knowledge that early detection benefits cancer outcome. Within this discourse, there is a particular reference to the phrase ‘get it checked’, which is often part of the participant contributions. For example:

“[.....] Stay at home and worry, come in and have it checked out. Hoping you are going to be sent home clear but hoping you are not taking up valuable time for someone else”. (P389)

and

“No point in leaving things to chance it was better to see the GP and get it checked”. (P390)

Below, one woman acknowledges her fear, and then voices the necessity of acting positively despite this, and rationality outweighs fear:

“No matter how much you're scared it's essential to get yourself checked.” (P49)

This participant did act, within a time interval of one week.

However, despite this knowledge a puzzle remains. One woman writes as follows:

"Wasn't going away so decided it was about time I got it checked" (P140)

Unlike the previous participant, the time interval (from symptom discovery to initial presentation to a HCP) is a less than optimal 12 weeks (3 months). Adopting a rational tone, there is also a sense of having entered into a health care system, thus the need to relate to that, as apparent in:

"There is an extensive waiting time between finding a breast symptom, visiting a GP and then actual referral to a specialist consultant. I was influenced by various factors including friends, family, media and common sense to visit the GP on finding a lump in my breast as I am aware that early diagnosis is key to beating breast cancer". (P262)

This contribution is calm; there is no sense of panic or fear, or loss of identity, as we have seen in earlier contributions. While this would seem to be an ideal response, the time interval here is also a non-optimal 12 weeks (3 months).

Another contribution illustrates rationality, with a similar time interval. One woman writes about her own response as being out of character for her, as she became emotional and imaginative in what the future might hold, her own death and funeral. The description she evokes is of a journey on which she is retrospectively reflecting. In the following extract, this participant speculates on being restored to being herself, and this is linked to the possibility of remaining well, if the diagnosis she receives is benign:

'[....] Finding Symptom: I was very surprised with my own reaction to the finding. I am usually a very optimistic person, practical and calm, but I cried my eyes out, gone through the chemo cycle, thought about the most negative outcome and even decided on a wicker coffin! I am now sitting here in the clinic and feel a sense of calm. Maybe I have come to my senses and have realised that this may all be a thing of nothing'. (P314)

The timeline between symptom discovery and HSB, for the above participant, is 12 weeks (3 months). Her contribution includes all of the four discourses: (1) being normal, represented by her usual self, who is optimistic, practical and calm; (2) emotion, represented by her tears; (3) abnormality, represented by illness and death; and finally (4) rationality, represented by her calm presence in the clinic. The discourses are present in what we can interpret as a temporal sequence. Interestingly, this participant identified herself as being a Nurse. This indicates that her rational knowledge about her symptom would be reliable, and yet there is a time interval that is maladaptive. This woman's contribution encapsulates the tension that exists between knowledge and action.

Discussion

Through the use of Discourse Analysis, this paper reveals that women can have varied cognitive and emotional responses to breast symptom discovery. Women appear to make sense of their breast symptom and rationalize their responses in the context of their everyday lives and their knowledge around breast cancer.

Women in this study are aware that delay in the diagnosis of breast cancer exacerbates the outcome of the illness. Despite this, women who choose to take the time necessary to present to their initial HCP, may be perceived as being in control of their emotions. The choice to reconcile an emotional response to a breast symptom, with the knowledge that prompt HSB is optimal, may account for some of the individual variability in the time interval illustrated by participants in this study. As the analysis above illustrates, while the rationality (discourse 4) of 'Get it checked' is familiar to women who have self-discovered a breast symptom, there is another discourse at play. Emotion (discourse 2) is downplayed, perhaps, sidelined. It is possible that the tension between these two

contributes to the time interval between symptom discovery and HSB, that is, between knowledge and taking action.

The analysis provides insight into the under-researched area between knowledge and behaviour, as called for by researchers¹⁹ who highlight the crucial role of beliefs and emotions. The exploration of the discourses, and how they relate to each other, also concurs with a study¹⁸ emphasising the need for a more holistic framework to promote early HSB.

With individual experience, each person's construction of cancer as an illness²³ will differ. Hence, the analysis highlights the need to acknowledge and support each individual's emotional reaction, which is part of the experience when a breast symptom is self-discovered. If women choose to sideline their emotional response, it is possible that this helps to manage the worry about becoming ill with cancer. This echoes findings of a recent grounded theory study on women awaiting diagnosis of breast cancer where participants described strategies for suppressing and managing their distress as a means of carrying on with their daily lives.²⁴ However, as previously highlighted, worry about symptom outcome¹¹ can be a barrier to help seeking. Providing support for women prior to diagnosis, could lessen anxiety, and in turn, promote a shorter time-interval between symptom discovery and HSB. Acknowledging, that each individual's response to finding a breast symptom is unique, supports the need for a more holistic approach encompassing emotional reactions. While use of terms such as "time bomb" and "death sentence"¹³ are absent from women's contributions in this study, the fear of a cancer diagnosis is evident. Therefore, rather than sidelining that cancer is something to be feared, it may be useful to disseminate knowledge of an expected emotional response to breast symptoms. As we have seen in the current analysis, such a response can in itself be an additional burden to women as they deal with their physical symptom(s). However, women's emotions may not be a priority for HCPs including physicians

who tend to focus more on the cancer diagnosis and treatment.²⁴ An awareness of the possibility of an emotional response as part of the dissemination of knowledge around breast cancer awareness may be effective in facilitating timely action by women, following self-discovery of a possible symptom of breast cancer. This has implications for future interventions for breast cancer awareness in women as recommended in a recent Cochrane Review.²⁵

Limitations

There are limitations to this paper. Firstly, it reports only on the analysis of open comments collected as part of a questionnaire in a larger quantitative study.²¹ One could argue that a qualitative study could have been embarked upon initially, conversely the need for a quantitative study to investigate women's help seeking behavior and the associated influencing factors was evident. However, the quantity and in depth nature of the contributions made by women in the open comments section of the questionnaire warranted further analysis and reporting. Discourse analysis²² provided the researchers with a means of making sense of women's contributions and their meaning in the context of awaiting a possible breast cancer diagnosis. In addition, it must be acknowledged that the data reported were collected in 2009. However, as data were collected at women's first presentation to the acute breast services, women's perspectives are captured at a time that is very close to their initial symptom discovery, limiting the likelihood of recall bias. In addition, while associated practices and treatment of breast cancer are likely to have changed, breast symptom discovery and the possibility of a breast cancer diagnosis will continue to be a reality for women. Therefore, insight into women's experience at this time will be of benefit to practitioners, researchers, policy makers and women themselves.

Conclusion

The data on which this study is based is uniquely placed to contribute to our understanding of the time from discovery of a breast symptom, almost up to the time of diagnosis. Delving into the discourses, as we have done, allows us to take a particular perspective, and gain insight into the tensions that exist for women at this time. This way of understanding offers a unique insight into the meanings that women attach to a breast symptom and its possible outcome. Through the revelation of the four linked discourses: 'Being and remaining normal'; 'Emotion'; 'Becoming and being abnormal' and 'Rationality', women's contributions provide a unique opportunity to broaden our understanding of what it means to experience the possibility of a diagnosis of breast cancer. This insight is valuable, as much of what we know to date about this experience has been learned from those who have been diagnosed and treated for breast cancer. This analysis contributes to raising breast cancer awareness with a view to shortening the time interval between self-discovery of a symptom and HSB. Findings are important for all HCPs involved in the assessment and diagnostic phase of women's breast symptom experience, as we need to be mindful of the emotions and fears that women experience no matter how assured and confident they choose to appear. Recognition of these tensions will help HCPs to understand and empathise more fully with women and other patients awaiting assessment of possible cancer symptoms.

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