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Original Article

A pilot study to evaluate and explore the information and support offered to male breast cancer patients by breast care nurses

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Abstract

The purpose of this pilot study was to explore with the breast care nurse specialist (BCNS) their perspectives on the information and support offered to male patients with breast cancer. The BCNS role is to provide the patient with both verbal and written information, and they are viewed as a key resource for the patients during their cancer journey.

A qualitative method was adopted that utilised semi-structured interviews with the BCNS. The questions were derived from reviewing the literature and the written information available for the male patients; identifying key areas to explore and then utilising open ended questions to collect the data in the interviews. After each interview the transcripts were analysed and coded and further questions were formulated.

The findings illustrate that although there is some gender specific information given, this is limited and often directs the patient to literature designed specifically for women. It is therefore recommended that a more comprehensive gender specific booklet be designed for men with breast cancer.

This article is an edited version of an undergraduate dissertation and as such can only convey the essence of the work.

Keywords

Male breast cancer; qualitative; information; support; breast care nurses

INTRODUCTION

Breast cancer is now the most common malignancy throughout the world with an annual incidence of 21,000 new cases in England and Wales with only 1% of these being male.¹ Male breast cancer is a rare disease; which can often present late, this coupled with men being unaware of the likelihood of malignant disease within their breast the prognosis is often poor. Due to a high annual incidence of 500,000–700,000 new females being diagnosed world wide there is now in existence a

wealth of information, screening, special clinics and professionals able to deal with a woman's needs.²

For male patients who have the same physical disease as their female counterparts, attending a predominantly female orientated clinic may result in them experiencing feelings of stigma and seclusion.

Ambiguity and the loss of control over the situation are feelings that all patients diagnosed with cancer may experience, so correct, timely information and good communication is of paramount importance. Evidence clearly suggests that accurate information and good communication

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is a key factor and has a positive influence on the patient's subsequent approach to their health.³

IMPORTANCE OF INFORMATION

The present government's central theme has been to modernise Britain's Health and Social Care policy. Fundamentally this has meant an ongoing political drive to remodel the National Health Service (NHS), with the aim of "giving the people of this country the best system of healthcare in the world". One of the key areas identified was the improvement in the access to accurate and appropriate information.

The NHS Cancer Plan³ reminds us that:

"Research shows that very many cancer patients continue to feel that they have not received as much information as they need from health professionals, and see this as a serious failure of NHS services."

NHS Centre for Review and Dissemination at the University of York⁴ further endorses this, by declaring:

"The most common complaints made by people with cancer are about poor communication and inadequate information."

The existing research, which looks specifically at the information given to male breast patient's is very limited, but it has highlighted that in some cases information was in fact, non-existent.⁵

It is arguable that due to the rarity of male breast cancer⁶ it is an area of medicine that has been subsequently neglected, this has resulted in very little information for both medical professionals and patients alike. This could have dire consequences with many males unaware that breast lumps and nipple changes can be evidence of a potentially fatal disease.⁷ The late presentation of this disease in men has been proven to be linked to a poor outcome and is one of the major influences on prognosis.⁸

Education and dissemination of key information to inform both the public and health care

professionals should perhaps be seen as a key factor in improving the diagnosis and support for this group of patients.⁹

It is a reality that the general public expect healthcare workers to meet all of their individual information and support needs, with a specific view to improving the quality, and reducing the subsequent disruption of their lives post diagnosis.¹⁰

The wider need for more research and development in the management of these patients and their disease is also highlighted by Ravandi-Kashani and Hayes¹¹ and Wang-Rodriguez et al.¹² who both reported gaps and limitations in the current evidence base. Both authors assert that the majority of current knowledge with reference to male breast cancer (in terms of biology, natural history and indeed the treatment strategies) has been extrapolated from its female biological counterpart.

It is not only the information about male breast cancer and its treatment, but also the information that patients are given both during and after the diagnosis that is often not gender specific. A qualitative study by France et al.⁵ involved six in-depth interviews with men, all of whom raised several issues, one being the "provision of information" relating specifically to the male patient's condition. In this study, it was clear that no male patients were given gender specific information, but they had received information sheets relating to care for women. The males in the study found this useful but limiting:

"The participants had read literature which had been acquired opportunistically from female friends who had themselves had breast cancer. They all found this information helpful but suggested that the provision of information about male breast cancer would have been more relevant."

One could argue that having only female literature to read will lead to feelings of a loss of masculinity, isolation and potentially the denial of the disease.⁹ It is also debatable that men are often reluctant to discuss health related matters or to approach health care professionals. It maybe a reality that with this group of patients there is a clear

need to be both innovative and creative to encourage patient interaction.¹³

The information any patient gets needs to be seen to be of relevance to them, making them feel reassured and allay any fears they have as anxiety can only increase the chances of patient non-compliance.¹⁴ There is a clear link between increased satisfaction with the information patients receive and the reduction of psychological distress.¹⁵ For all patients we must be mindful that the information provided is clear and accurate, as, alongside discussions with healthcare workers, it will help the patient to make informed decisions.¹⁶

Subsequently, this research was driven by the authors desire to explore this area further. The pilot study aimed to investigate exactly what information and support was available to the male patients at the peripheral clinics within the authors Hospital Trust. This would hopefully allow good practice to be identified, and explore possible areas where, information for the male patients could be improved.

LIMITATIONS OF THE STUDY

The application of a pilot study was undertaken due to restraints in place for the researcher in terms of the timescale for the research (and dissertation) and obtaining ethical approval from more than one hospital trust. These limitations will result in some degree of bias, as it only explored the views of the BCNS in one Hospital Trust. Nevertheless, this exploratory study is to be seen as a precursor for further investigation.

METHOD

The aim of the study was to ascertain what information and support is given specifically to male breast cancer patients at the peripheral clinics in one Hospital Trust.

The research questions were:

- What information and support is available from the BCNS?
- Is gender specific information given and if so how comprehensive is this?

- What experiences have the BCNS had when dealing with male patients?

Qualitative data was gathered by utilising semi-structured interviews with open-ended questions. The use of semi-structured interviews allowed both control and flexibility to be accomplished during the questioning, and after the first interview the researcher was able to examine the data and formulate further questions. Crookes and Davis¹⁷ promote that:

“Data collection and analysis are undertaken concurrently and consideration of the analysis of the data will then affect the type of data collected in the future.”

The interviews were transcribed, coded and analysed. The nurses were given copies of the transcriptions and allowed to feedback regarding accuracy thereby increasing construct validity.

The interview questions were initially derived from the literature review plus a review of the written information given to the male breast patients in the clinics. Emerging themes from the initial interviews were used to develop questions for the subsequent interviews.¹⁷

All the interviews began with background questions about the interviewee in an attempt to break the ice and establish the context within which the nurses practiced. These can be seen in the table below.

Topic area

Nurse experience
 Job role
 Experience with male breast patients
 Use of published information

DOCUMENTARY ANALYSIS

The author undertook a systematic review of the information given to the male breast cancer patients by the BCNS, looking for evidence of gender specific information, and how comprehensive that was.

The information given to patients can be seen in the table below.

Contents of information pack

Treating breast cancer – Breast Cancer Care
All about Macmillan – Macmillan cancer relief
Support information (here for you) Breast Cancer Care
Breast cancer and you coping with a diagnosis– Breast Cancer Care
The cancer guide – Macmillan cancer relief
Publication list – CancerBACUP
Male breast cancer – Breast Cancer Care fact sheet

Locally produced information

Breast care support group
BCNS services
Breast cancer in men fact sheet

FINDINGS AND DISCUSSION

The key themes and areas explored in the interviews were around communication, individual nurse characteristics and psychological issues. Both written and verbal information was covered in the communication area.

WRITTEN INFORMATION

The written information given to the male patients is the same as the female patients, the exception being that they are given an extra leaflet, the “Male Breast Cancer Fact sheet” produced by “Breast Cancer Care”. The BCNS were asked their opinions regarding the information they give to the male patients:

“Well in terms of the information I would give out, the male breast cancer sheet helps them with that, but otherwise it isn’t really tailored to them at all”. (Breast care nurse 1)

“We tend to use the information that breast cancer care produce, their information sheet on male breast cancer, I mean it gives a specific over view about basically causes, risk factor, making a diagnosis and sort of a little bit about treatment, but then refers them on to other information”. (Breast care nurse 2)

“Up until recently the males unfortunately did get the same literature as the ladies that are going through the system. We would point out to the patient, that’s the male patient of course that it is very female related and it does comment on that in the early introductions to the book that we give”. (Breast care nurse 3)

The breast care nurses stated they try to give out as much information and support available dependant on the patient’s needs. Where the male patient is concerned the BCNS acknowledged that gender specific information is very limited.

“Well, I would say that the vast majority of the things we are giving out probably does mention a woman as opposed to a man and that must be awful”. (Breast care nurse 1)

INFORMATION AVAILABLE SPECIFICALLY FOR MEN

The fact that patients receive the information sheet on male breast cancer¹⁸ clearly is good practice and is in contrast to some of the literature where no gender specific information is given at all.⁵

The fact sheet “male breast cancer”¹⁸ explains what the causes of breast cancer are, the symptoms, how diagnosis is made, and the different types of treatment available along with coping strategies. The bulk of this information will be of limited use to the patient at this stage in their journey, as they will have already have undergone the tests and received the diagnosis. It may be more appropriate for this leaflet to be given at a much earlier stage in the patient’s pathway.

The information contained within the fact sheet male breast cancer¹⁸ is brief but sound, however, it needs to be supplemented with extra information, so the patient is directed to read the female booklets:

“Although it is aimed at women, you might find it helpful to read our booklet Breast cancer and you: coping with the diagnosis.”

The booklet “Breast Cancer and you: coping with diagnosis” is well produced and comprehensive. It contains 32 quotes from female patients that give valuable accounts and insights into their perspectives and experiences; unfortunately there are none from their male counterparts.

The fact sheet male breast cancer¹⁸ has a section that deals with “Coping with breast cancer” it explains that everyone diagnosed with cancer will experience differing emotions and that this is common, with people coping and managing very

differently to the news of their diagnosis. It subsequently goes on to say:

“Many people find that they can get back some sense of control by finding out as much as possible about their condition and treatment.”

This is a dilemma for the reader as the fact sheet acknowledges that the information in it is limited and that the males must utilise female information leaflet to supplement this information. Finding supplementary information arguably is easy with the Internet, and this is now a popular and important source of information for patients and healthcare workers. Relying on the Internet as a basis for patient information has had mixed reviews in terms of how effective, accurate and useful the information can be. Concerns exist around the quality of information available to patients, and evidence suggests that sites need to be attached to “centres of excellence”.¹⁹

Although not available directly from the clinic, the Breast Cancer Care organisation advertises provide audio and video recordings for patients, but again this is female biased with no provision for for male breast cancer patients.

It was reassuring to see that the lack of written information has been acknowledged by one of the BCNS, who was in the process of producing a fact sheet “Breast Cancer in Men” (which, at the time of this research had not been distributed to patients). The author was able to review this, and it is very similar to the Breast Cancer Care fact sheet in its explanations. Although there is additional information on psychological support it still refers the man to information offered to women. One item of information in the fact sheet that the author found intriguing was that it offered support for the female partner of the male with the breast cancer. This, however, is not reflected in the information given to females; there is no mention of male partners being offered support. In principle, this is a very good initiative but leads the researcher to consider what the rationale behind this was?

NURSE CHARACTERISTICS

The interviewee’s had varied lengths of clinical experience as BCNS. This ranged from 9 months

to 14 years. It is not surprising therefore that due to the small percentage of patients who will present with male breast cancer the nurses experience of dealing with male breast cancer patients was very different. One had never seen a male breast patient at all, and the other two had seen two a year in their time as BCNS.

Aside from the written information given, it was evident that the BCNS tried to assess the needs of the individual patients and establish how much information they gave.

“I do think information is important and obviously some patients want a lot of information and other patients want a minimum amount of information and there again I think that is an important part of my job to assess how much information a patient wants and that may well change”. (Breast care nurse 2)

“I think information is very important especially written information as well as verbal information because when people are given the news that they have actually got cancer, when they hear that word they just shut off and anything else that’s said is just totally oblivion to them”. (Breast care nurse 3)

The development of material that can be taken away by patients and carers and reflected on later is vitally important as:

“Studies have shown that some patients only remember one tenth of what they were told during a consultation. Face to face communication needs to be backed up with high quality, accurate information that the patient can return to in their own time.”²³

The nurses were also very cognisant of the “female environment” that the breast clinic operates within. Being considerate of the impact that may have for the males they try to give them appointment times early or later in the day when there are fewer female patients about, and

“(We) don’t put them into the pink flowered capes that the ladies go into”. (Breast care nurse 1)

The BCNS deal with each patient individually and feel that no two patients are the same. Whether the patient is male or female they will all have different concerns and the BCNS demonstrate

empathy when dealing with these individuals, by trying to help them deal with these. They are theoretically available throughout the treatment pathway offering help and guidance the whole time. However, with the vast workload and amount of patients attending each clinic it can make it, in reality, difficult. The BCNS have to rely on patients contacting them for further information and support.

This could be exacerbated by all of the BCNS operating in rural locations that serve a diverse geographic area and large population. One BCN identified this as an issue and how it could impact on the quality of the service the patients receive:

“There’s only one post holder and although I can meet their needs if they tell me what they are, I can’t actively go out and find out whether people are coping or not, I have to rely on them coming to me”. (Breast care nurse 1)

The male patients appear to be reluctant to make further contact and it is noticeable to the BCNS that no male patients have attended the Breast Care Support Group sessions or made contact with any other support services. Empathic care towards these patients at the initial assessment is essential, encouraging them to make use of the services available to them.

*“Health professionals need to know how best to elicit patients’ need and readiness for information as well as their desire for involvement in decision making.”*⁴

All the BCNS stressed the importance of listening and dealing with patients as individuals:

“I think my job is to give the patient information and try to listen to what their concerns are and you deal with their concerns. So each woman is going to come along with completely different concerns, and so I just treat a man exactly as I would treat a woman, find out what the issues are and deal with them and help them to deal with them”. (Breast care nurse 3)

“I just treat a man exactly as I would treat a woman, find out what the issues are for them and then sort of deal with them and help them to deal with them”. (Breast care nurse 2)

PSYCHOLOGICAL ISSUES

Psychological issues exist for any patient diagnosed with cancer, irrespective of their gender, but this can be exacerbated and accentuated if there is limited information:

*“It is often very difficult to find information and support when you are diagnosed with a rare cancer. Men find that they experience many different emotions including anger, resentment, guilt, anxiety and fear.”*²⁰

Two of the BCNS acknowledged the possible psychological issues that men may experience from the diagnosis of breast cancer.

“I also think that often men can be quite embarrassed I think you know, because most people just associate breast cancer with women. So you know there are obviously lots of similarities but then there are obviously some areas that are specific to men”. (Breast care nurse 2)

“I think the biggest thing that a lot of men, suffer with is they’ve got a disease that is female orientated. In the group of people we have given the information to there’s been no real psychological problems with them, again we are looking at an older generation and I feel that if we were looking at a younger age group there would be a lot more psychological problems”. (Breast care nurse 3)

The BCNS clearly identified the potential distress caused to the male patient psychologically by being diagnosed with what is perceived as a female disease. It was an interesting comment and perspective from the BCN 3 regarding the generational issue that could arguably be transferred to any older patient group regardless of their disease. It is recognised that psychosocial support does reduce symptoms associated with psychological morbidity and could improve survival.²¹ It also acknowledged that healthcare workers involved in the patient’s treatment seem to be more effective than support organisations as they have direct access to clinical information relating to the patient.²¹ However, it is recognised that:

*“Some patients find it helpful to talk to someone who has had a similar experience to them.”*¹⁸

To facilitate this the patient can be put in touch with one of the male Breast Cancer Care volunteers available through the Breast Cancer Care organisation. Sharing experiences and forming some sort of social and support network can be valuable and the BCNS were aware of the option to refer patients to this service:

“We can get them in touch with help lines that will get them to speak to men who have had the disease”.
(Breast care nurse 1)

The literature does not always support the notion of support groups, and when some male breast cancer patients were interviewed and asked specifically about the concept of support groups, they were not overly enthusiastic.⁵ Mens experiences using fellow patients for support vary depending upon their personal situation and individual experiences, with a good experience reported as feeling emotionally supported as a result of attending these groups and in the worst case scenario’s some males felt very threatened.²² Fallowfield et al.²³ debate the value of support groups for some cohorts of patients, as they may find them a constant reminder of their disease. It is important as health care professional we are respectful of individual patient preferences, and acknowledge that support groups are not effective support mechanisms for all individuals. Patient empathy, and one to-one contact with a key individual can be construed as being important in developing a good relationship and building trust between the health care professional and the patient.

One of the BCNS felt that males and females both faced similar issues when undergoing the diagnosis and treatment for breast cancer.

“I think a lot of the issues surrounding breast cancer in men are quite similar to issues you know with women”. (Breast care nurse 2)

This attitude and opinion may explain the apparent dearth of patient information available locally and nationally that is designed specifically for men, as the perception maybe that the same information can be used for both genders. This, however, is questionable. Although the epidemiology

may be similar,⁵ men with breast cancer are often older, more likely to have hormone receptor positive disease and generally have a more aggressive approach to their diagnosis and subsequent treatment management.⁸ It would seem unwise (without further research) to assume that the issues are entirely similar for male and female patients. Gender specific issues have been investigated in previous research based on women’s experiences of breast cancer and radiotherapy. This concluded that there are gender specific issues that relate to women. These were around the women feeling there was a threat to their normal gender role and a compromise of their place within both the family and a social context.²⁴ Some research in Finland has already identified that social roles such as that of husband and father were put under strain whilst men underwent treatment for cancer.²²

It is acknowledged by the BCNS that the male patients may feel embarrassment because they have a disease that generally affects the female population. However, they have not come across any other real psychological issues and they believed the reason for this is that the majority of the male patients are of an older generation and less likely to “self-disclose”.

Interestingly, in one of the interviews, it was mentioned that the partners of men affected by breast cancer have sometimes requested counselling. It has been recognised in other studies that male patient’s partners have also expressed a desire for counselling.⁵ It may well be a validation of the gender differences in terms of the need to seek emotional support, but also the lack of desire for emotional support from the men²² perpetuates the belief that men do not like to self-disclose. What is of a concern is that the sense of isolation and potential lack of disclosure by the men may well be the reason that the nurses at the clinics have not identified psychological concerns. The impact of diagnosis may be something that will emerge over a period time and intervention and support could be needed when the patients are subsequently undergoing either radiotherapy or chemotherapy. It is imperative that all members of staff who deal with these patients, no matter where they meet the patient on their journey, are aware of the possible issues.

CONCLUSION

After having contact with the BCNS the author is in no doubt about their dedication to the role, their enthusiasm and their excellent communication and patient care skills. They all wanted to achieve the best outcome for the patients; ensuring patients were well informed about the treatment they would receive. However, it is debatable that the written information available for the male patients is adequate either locally or nationally. To allow male patients with breast cancer to have choice and affirm control over what happens to them and play an active role in their care after diagnosis, more gender specific information is needed. The information currently available clearly describes the patient pathway from being diagnosed through to being disease free, but is brief and often refers them to literature for women. There is also some concern around when, in the patient's journey, they are given the information to maximise its relevance.

The dearth of information available to the male patients at a local level has begun to be addressed. This information subsequently needs evaluating by users of the service. Input by previous patients is also viewed as beneficial as it will add to the clarity, development and relevance of the material to this group of patients.²⁵

The pilot study has potentially identified an area for further research at a national level where information and support available to men with breast cancer could be examined and benchmarked for good practice.

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