

Delivering Dignity through Empowered Leadership

Improving the treatment and care for
older women with breast cancer

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End of project report to the Burdett Trust for Nursing

Introduction

In August 2013 Breast Cancer Care was awarded £22,179 under the Burdett Trust for Nursing's Delivering Dignity through Empowered Leadership programme to deliver a portfolio of work designed to improve the treatment and care of older women with breast cancer. In particular this project aimed to raise awareness of body image, intimacy and sex issues that are often left unaddressed for older breast cancer patients.

Overview

While there is much good news about the half a million people living after a diagnosis of breast cancer in the UK today, the legacy of treatment and its side effects for a person can be huge. Treatments such as surgery, chemotherapy, radiotherapy and hormone drugs can leave a woman with many physical and emotional changes to deal with. These may include not being able to have children, loss of femininity, feelings of anxiety and depression, as well as not feeling sexy or sexually attractive.

The term 'body image' is used in relation to how we view our own bodies and how others view us. After a diagnosis of breast cancer, getting used to the changes that have taken place and adjusting to life after breast cancer can take time. Some people adapt very quickly to an altered body image, but for others it can affect their self-esteem and self-confidence for a considerable period of time and can have a major impact on all areas of their life.

Most women will have surgery as part of their breast cancer treatment and surgical scars or losing a breast will affect how a woman feels about herself. After surgery, the first time a woman looks at her body can be difficult and for many this doesn't get easier overnight. Some women describe feeling unfeminine or unattractive, lop-sided or incomplete. Some women feel that having a breast reconstruction helps to improve their confidence and self-esteem but it isn't the right solution for everyone. For some women, wearing a prosthesis is a temporary choice before they have reconstruction at a later date. Other women may choose not (or be unable) to have breast reconstruction and find wearing a prosthesis an effective long-term choice.

Some chemotherapy drugs will cause a person to lose the hair on their head as well as other hair such as eyebrows, eyelashes, underarm and body hair. Hair loss is almost always temporary and hair usually starts to grow back once chemotherapy has finished, sometimes sooner. When the hair grows back, the quality, texture and colour may be different from before and although in most cases it will eventually return to the colour and condition the transition from hair, to hair loss and regrowth can be both shocking and distressing.

Many women feel unprepared for the weight they gain during and after breast cancer treatment. This is often the result of some of the drugs which can increase appetite, being less active than usual when having treatment, or wanting to eat more than usual when anxious. While losing weight can take time there are some simple changes that people can make to the way they eat and exercise which in the long term can help to lose weight and keep it off.

Trying to come to terms with the side effects of treatment whether temporary or permanent can have a profound effect on the way a woman views her body. Yet many women fear that, compared to the life-threatening nature of their illness, body image issues are seen as trivial. Breast Cancer Care wants people talking about this issue, so that everyone understands that a change to your body image is not a small price to pay.

The context for older women with breast cancer

Although it is known that breast cancer risk increases with age (in the UK, 31% of breast cancers are diagnosed in women aged 70 and over), the standards of treatment for older people are largely based on clinical trial data drawn from younger patients. Breast Cancer Care recently published evidence demonstrating how standards of care vary considerably according to patient age and which showed strong evidence that older women tend to receive non-standard breast cancer management, including not being offered breast reconstruction (Improving outcomes and experiences for older women with breast cancer, Breast Cancer Care supported by Age UK, November 2011).

While any changes in body image can be an 'emotionally difficult experience' for the individual, undergoing physical changes to one's body can also affect 'feelings of integrity and wholeness' (Harcourt and Rumsey, 2006). For instance, if a woman is older, healthcare professionals may assume that she does not need to discuss sex and intimate relationships.

Breast Cancer Care's Equality and Diversity Strategy commits us to addressing inequalities in breast cancer and we try to address issues relevant to all patients. Issues faced by older patients are of particular interest to us; we think that every older woman with breast cancer should be treated as an individual. They should be given a personalised care plan as standard, taking into account any other medical conditions and personal preferences, including body image-related concerns which is often a hidden effect of breast cancer.

What we planned to do

In response to the lack of tailored information available, Breast Cancer Care set out to produce a policy report on body image, as well as review and reprint our booklet on how breast cancer may affect sexuality and wellbeing of patients and their partners. The booklet was planned for use with patients as well as healthcare professionals, while the policy report's aim was to influence healthcare professionals, service commissioners and planners, and cancer policymakers. Breast Cancer Care's Information Standard accredited publications are relied on by a large number of breast care nurses across the UK who use the resources to update and refresh their own knowledge, as well as a trusted source of information to hand over to people diagnosed with breast cancer.

By providing nurses with the latest information on how breast cancer can affect patients' sexuality, we aim to empower them to deliver better care and support for older patients. We will also help patients to approach the subject with healthcare professionals, notably including a patient prompt in the new booklet. This list of questions that patients may want to raise will help to treat sexuality issues as an important part of the management of breast cancer, and dignity of care of older people.

The key objectives of this work

- To raise awareness of issues around body image and sexuality for older women with breast cancer.
- To inform and influence healthcare professionals about the difficulties older women often face in dealing with these issues.

Your body, intimacy and sex booklet

Breast Cancer Care developed a specialist booklet that provides tailored information for women facing changes to the way they feel about their body after breast cancer and the impact this can have on sex and intimacy - Your body, intimacy and sex. The content of the booklet was written by Breast Cancer Care's Senior Clinical Nurse Specialist, Rachel Rawson, with editorial support from our Publishing team. A draft of the booklet also went out for input and feedback from our Breast Cancer Care Voices, and Service User Research Partnership volunteers (SURP), all of who have had a diagnosis of breast cancer and have used our services. Voices are people affected by breast cancer who participate in discussions on planned developments as well as existing services. We currently work with 624 active Voices across the UK. SURP are a group of service users, functioning at the 'partnership' level of user involvement. Members are equal partners on all research projects we work on with external partners, and have independently represented user involvement with Breast Cancer Care at academic conferences. Topics covered include potential impact of treatments for breast cancer on sexual health; professional help; and intimate relationships at the end of treatment.

As is the procedure with the production of all of Breast Cancer Care's patient information resources, the final draft was reviewed externally by experts in the field Dr Isabel White and Melanie Lockett. Isabel is a Clinical Research Fellow in Psychosexual Practice at the Royal Marsden NHS Foundation Trust, focussing on the needs of people living with post treatment sexual and relationship difficulties. Melanie is a British Association of Counselling and Psychotherapy senior accredited counsellor and supervisor, specialised in the field of cancer since 1987. Incorporating this feedback, the booklet layout was finalised and went to print for release in October 2013.

Regaining confidence, talking openly with partners, family and friends about how they feel, and accessing professional support when they need it can all help people reach a 'new normal' after breast cancer. Breast Cancer Care wants every patient to get the right support and information needed. Our newly updated booklet is especially for people facing the harsh reality of cancer and the impact that it has on their body, intimacy and sexual relationships.

To date a hard copy of the booklet has been received by 6,345 people while an electronic version has been downloaded 705 times. Further to the promotion and dissemination of Your body, intimacy and sex, we're delighted to announce that at the recent British Medical Association awards, our booklet was judged as 'highly commended' allowing us further opportunity to raise awareness of the booklet's availability among healthcare professionals who we aim to influence. For further details of this award please visit:

<http://bma.org.uk/about-the-bma/bma-library/patient-information-awards/pia-commended-resources>

Aim of the evaluation of the Your body, intimacy, and sex booklet

The aim of the evaluation was to explore patients' opinions about the Your body, intimacy and sex booklet.

Anticipated outcomes of the project

We hope that Your body, intimacy and sex will improve the management of older women's sexual wellbeing after a diagnosis of breast cancer. Our publications will provide older patients and their healthcare professional's access to comprehensive and accurate information on sexuality after breast cancer. The policy report will contribute to the booklet outcomes and dissemination.

Methods

The evaluation was completed through analysis of quantitative and qualitative data collected on paper and electronic evaluation forms. A monitoring questionnaire was included in each booklet, and an online version of the questionnaire was made available to those who were downloading the electronic version of the booklet.

Participation in the evaluation was open to anyone who had accessed and used the booklet and chose to complete a questionnaire. The questionnaire included a section exploring whether the booklet prompted or facilitated a discussion about sex, intimacy and relationships or any other related subject, with a healthcare professional.

We also specifically targeted members of our Voices via our Voices bulletin. We encouraged them to use the booklet with their healthcare professional and complete the questionnaire. Older members of Voices (aged 70 and over) were contacted separately to ensure that they had access to both paper and electronic versions of the booklet and to encourage them to complete a questionnaire as part of the evaluation.

The data collection period was from October 2013–September 2014. We chose Breast Cancer Awareness Month (October), during 2013, to launch the booklet and the questionnaire. This tied in with Breast Cancer Care's Body image campaign as well. The data collection period of a year was also chosen to allow circulation of the booklet across the whole of the country, in order to collect data from a geographical spread, allowing people enough time to read the booklet and potentially use it in an appointment with a healthcare professional.

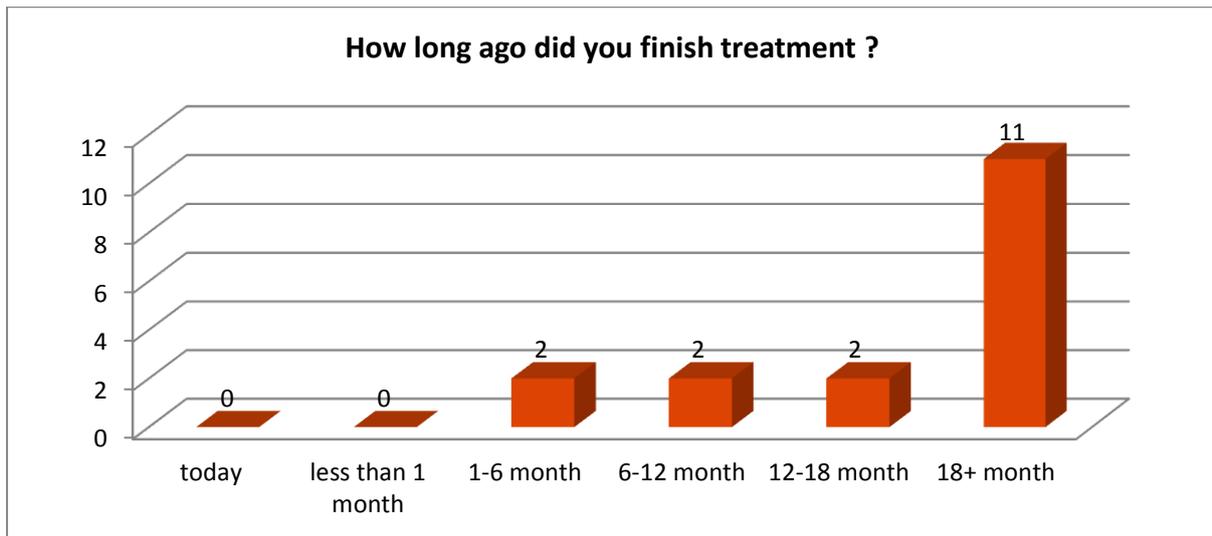
Results

A total of 25 questionnaires were analysed over the period of one year (October 2013-September 2014).

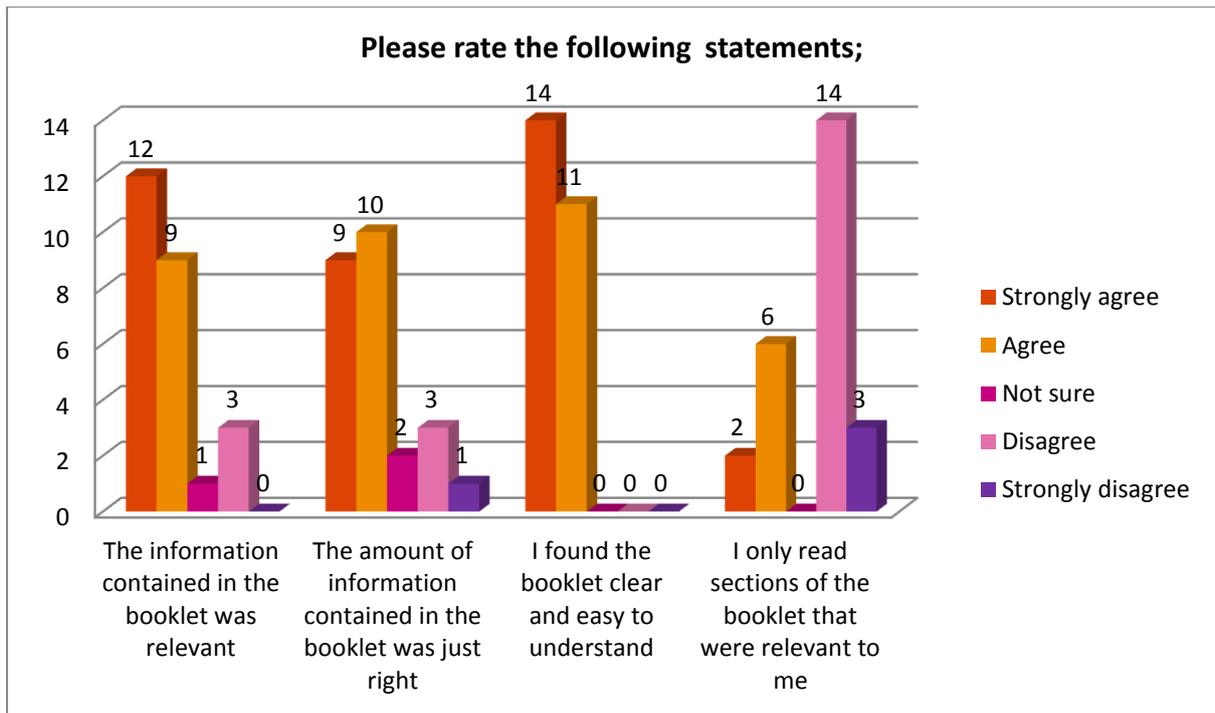
Sample demographics

Our sample consisted of 20 people who identified as English/British, 3 were Scottish, while 2 did not provide information about their ethnicity. Of 25 respondents, over half were between the age of 51 and 70 collectively.

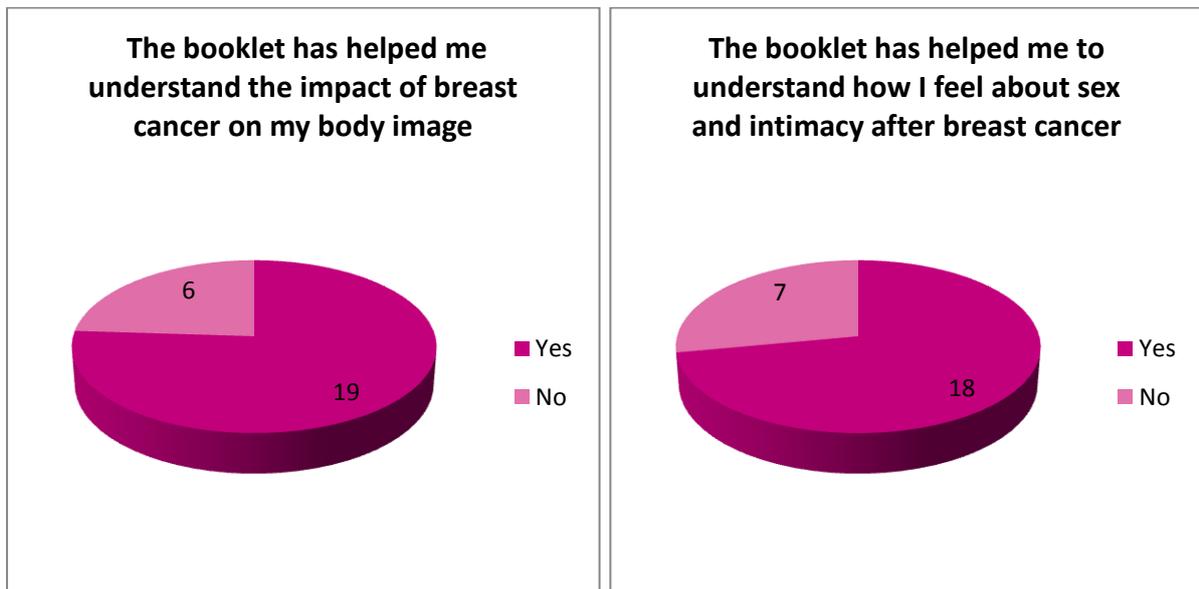
Our respondents were mostly post treatment (17 of 25), ranging from 1-6 months up to 18 months.



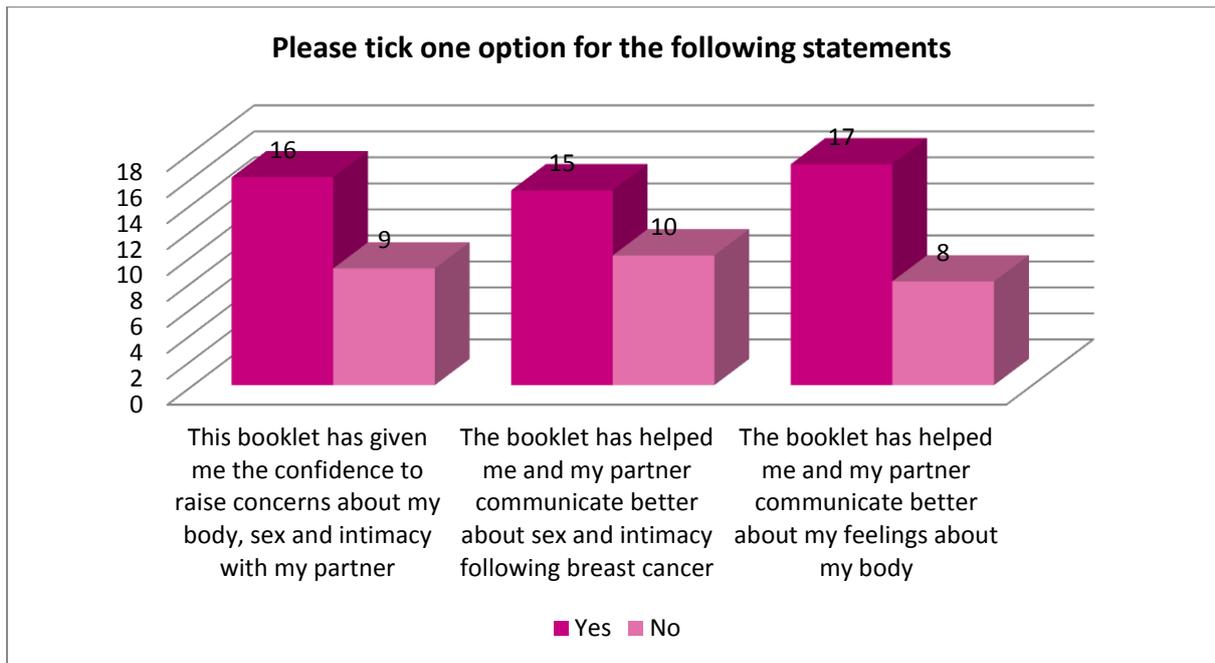
The questionnaire data illustrates that people rated the booklet positively on the whole; 21 of 25 either strongly agreed or agreed that the information in the booklet was relevant, 19 either strongly agreed or agreed that the amount of information was just right, 25 either strongly agreed or agreed that the booklet was clear and understandable. It was interesting to note that our respondents tended to read the whole booklet rather than reading the sections they only deemed relevant to themselves.



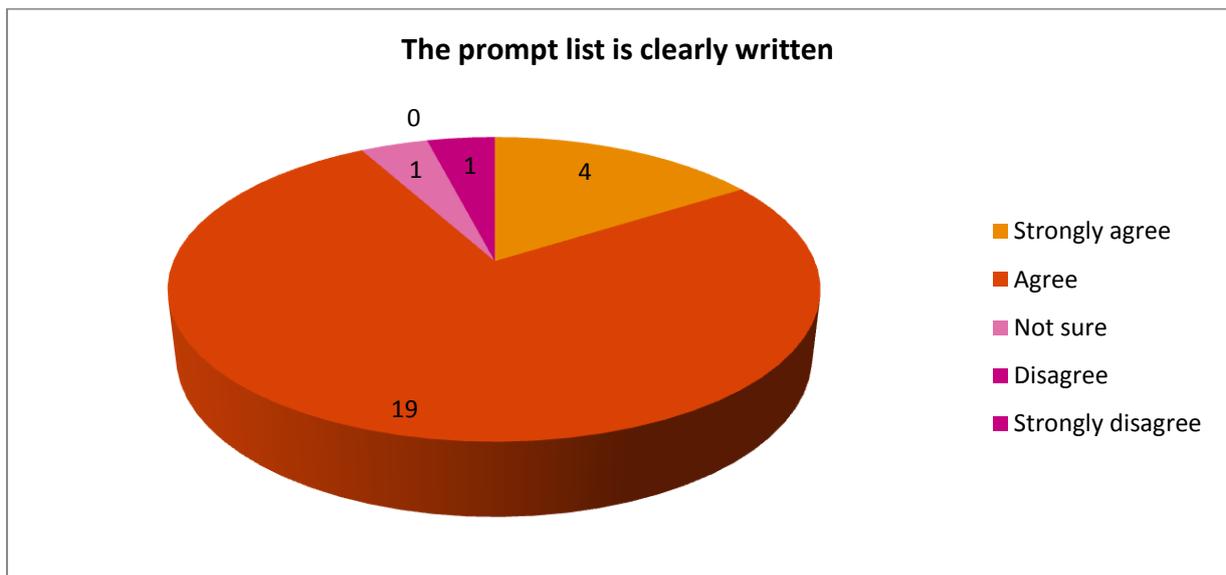
The booklet was successful in helping people to understand how their body image, intimacy and sex lives might be affected after breast cancer.



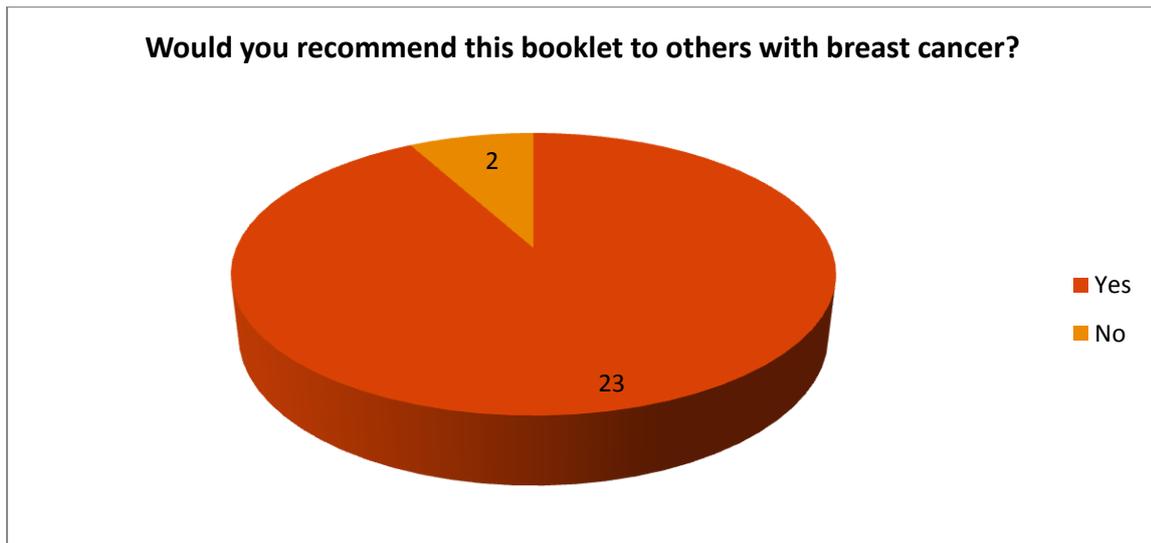
The questionnaire was designed to explore the perspectives of those currently single, and those in relationships. All of our sample were in relationships and reported that the booklet was on the whole positive in raising confidence to have discussions with their partners about sex and intimacy. It also appeared that the booklet was helpful in facilitating communication between couples about the emotional issues and about sex and intimacy.



Our findings indicate that the majority of our sample strongly agreed/agreed that the prompt list was written in clear language.



The final question asked was whether people would recommend the booklet to others, and the majority of respondents reported that they would.



Free text comments provided by respondents provided greater insight into why people would recommend the booklet to others. The feedback received fell broadly into the following themes:

- Clarity and content

‘The usual excellent, supportive, delicately written and factual guide that I have come to expect from Breast Cancer Care. Thank you from the future readers.’

‘A nice and easy to read guide, covering all the things I was concerned about. Good tips on how and when to look at your new body shape in a gradual way.’

‘Covers lots of info in an accessible way without being overwhelming.’

‘I found it very simple, concise and informative. A sensible, useful booklet.’

‘It tackles some of the questions we're afraid to ask...’

- I know I'm not the only one

‘It was good to know that my feelings about my body and the struggles with intimacy were normal and to know that I was not alone.’

‘...reading this booklet helps me feel less alone.’

‘It may make some women feel less isolated and it signposts where to go for help.’

- Accepting a new normal

‘Good ideas to help accept the new body and also how to get back into having an intimate relationship.’

- Facilitating communication

'I have been to my doctor many times regarding my lack of libido as I had a high sex drive prior to the change. Your booklet has helped me to talk to my husband regarding how I feel.'

Conclusion

The booklet was well received by respondents who reported that the content was well balanced and clear. From the findings it appears that the booklet facilitated communication between couples due to enhanced confidence about issues related to body image, sex and intimacy. The hope is that such discussions will not only enable greater acceptance and understanding between the couple, but also for the person facing the consequences of treatment, having to adjust to a 'new normal'.

Although our sample size is modest, it is perhaps indicative of the difficulties people face discussing issues related to body image, intimacy and sex. A lack of black and minority ethnic (BME) representation may also be indicative of religious or cultural beliefs about sex and discussions about sexual activities. However, the anonymity of receiving this vital information through a booklet is key to its success in being able to raise awareness of these complex issues. As such, it is understandable that we received a relatively low return of evaluation responses in relation to the 7,050 people that have received this publication to date (both electronically and hard copy) nevertheless, it is encouraging that the information contained in the booklet is being accessed by so many.

The booklet's influence on healthcare professionals

Our hope is that the work Breast Cancer Care has done to disseminate the contents of the booklet to healthcare professionals will also raise awareness and encourage nurses in practice to explore issues related to sex and intimacy, with all of their breast cancer patients.

Breast Cancer Care has raised awareness of sex and intimacy with healthcare professionals through the following channels.

- Regular blog posts (on the Breast Cancer Care website); for example
<http://bit.ly/1oBKFoC>
<http://bit.ly/11aL4Eq>
<http://bit.ly/1yprdve>
<http://bit.ly/1wKxhjM>
- Our annual conference for breast healthcare professionals was held in November 2013 and was attended by 200 delegates (including oncologists, breast care nurses and clinical nurse specialists). A copy of the booklet was provided to all of our delegates, as well as a stand promoting the Body image campaign.
- A specialist edition of our Nursing Network News (with a distribution to over 1,000 nurses).
- Presentations at nursing conferences by our Senior Clinical Nurse Specialist, Rachel Rawson.

My body, myself policy report

Diagnosis and treatments for breast cancer can bring changes related to a person's body image and sexuality, which in turn can have a devastating impact on intimate relationships.

The 'My body, myself' policy report was written by former Policy and Campaigns Manager Lizzie Magnusson, and Campaigns and Involvement Co-ordinator Emma Lavelle, with vital contribution from people affected by breast cancer, Breast Cancer Voices, and members of the Body Image Advisory Group.

Published in March 2014, the report offers an overview of the key issues involved in altered body image after breast cancer, with a particular focus on changes in sexual and self-identity, and the impact these changes can have on an intimate relationship, both existing and new. In the opening pages we share Jane's poignant 'letter to my body' about the changes to her intimate relationship after breast cancer treatments. She writes to her body:

'I find I cannot look at you in the mirror and my husband stays "asleep" while I get dressed and comes to bed after me.'

We involved lots of different people to make sure our recommendations for service improvement are practical and reflect what people affected by breast cancer told us, working with an advisory group and reference panel made up of professionals and people directly affected by both primary and secondary breast cancer to develop this report. To ensure that perspectives from diverse groups were reflected, we also gathered comments from BME healthcare organisations and experts.

Our recommendations

The My body, myself report centers on six statements that summarise the support wanted by people affected by breast cancer, followed by Breast Cancer Care's recommendation on each.

Overarching recommendation: national breast cancer clinical guidelines and national cancer policy/strategy documents should include recommendations for assessing and addressing needs and concerns about body image, intimacy and sex as an essential and integral part of breast cancer treatment and care.

1. I want to be treated as a whole person. I want issues relating to changes to my body, and concerns about intimacy and sex to be taken seriously, assessed and addressed as an essential and integral part of my treatment and ongoing care for primary or secondary breast cancer.
2. I want to be listened to as an individual. I do not want assumptions to be made about how I feel about my body, intimacy and sex based on my relationship status, age, gender, religious background, ethnicity, disability or sexual orientation.

Our recommendation: everyone diagnosed with breast cancer should have a holistic needs assessment that includes questions on altered body image, intimacy and sex.

3. I want to be able to access specialist information about altered body image, intimacy and sex throughout my breast cancer treatments and after treatment has ended. I want this information to include practical ideas. I may want this information in a language other than English.

Our recommendation: as guided by the outcomes of a holistic needs assessment, patients should be given specialist practical information or referred to reliable sources of information

created for people affected by breast cancer about changes to their body and self-image, and concerns about relationships, intimacy and sex.

4. I want to know about and be referred to services in the NHS and voluntary sector that offer support with altered body image, intimacy and sex. These services should be available to me regardless of where I live.

Our recommendation: each breast unit should establish referral pathways to relevant NHS and voluntary sector services that can offer support and information on the altered body image, intimacy and sexual issues raised through holistic needs assessments.

5. I may want to be able to get in touch with other people affected by breast cancer to talk about changes to my body and to share coping strategies.

Our recommendation: each breast unit should establish referral pathways to peer support services and peer support opportunities. This should include local voluntary organisations that are appropriate to their ethnic and cultural background.

6. I may want my partner to be involved in the support I receive about body image, intimacy and sex or to receive information specifically designed for partners.

Our recommendation: people affected by breast cancer and their partners should be offered or referred to specialist information or support services designed for partners.

Based on the report's recommendations, we are campaigning for altered body image and intimacy concerns to be consistently recognised as part of this holistic, person-centred approach to cancer policy and cancer care. Our aim is that support and information about altered body image, intimacy and sex are available to everyone, including older women affected by breast cancer as an essential and integral part of their cancer treatment and care.

Dissemination of the My body, myself policy report

So far we have disseminated the report to:

- all 12 Strategic Clinical Networks in England
- all members of our Nursing Network (over 1000 members)
- voluntary sector stakeholders (relevant leads at Relate, Macmillan etc.)
- our Breast Cancer Voices (currently just over 600 members, all of whom have been affected by breast cancer) with a view to them getting actively involved in campaigning on the recommendations of the report
- all 211 Clinical Commissioning Groups in England.

The report was highlighted at the Appearance Matters Conference in June 2014. Appearance Matters is a two-day international conference run by the Centre for Appearance Research at the University of the West of England. The conference highlights current research and good practice around psychology and appearance, including body image, and is attended by a range of professionals with an interest in body image issues. The event was a great opportunity to promote the My body, myself report and also talk with healthcare professionals who had previously not heard of Breast Cancer Care and our services.

Breast Cancer Care's recent Body image campaign won an award at this year's All-Party Parliamentary Group Body Image's Body Confidence Awards. The award ceremony took place on 16 October and we were delighted to be announced the winner of the 'Dove Self Esteem' category. These highlights of our wider Body image campaign work have helped us to further disseminate the availability of the My body, myself policy report as an integral aspect of the campaign.

Next steps

Building on the success of our initial wide-reaching dissemination of the report, our Policy and Campaigns team are now planning the next phase of implementing the report's recommendations. We'll be working with healthcare professionals, service commissioners and planners, and cancer policymakers to take our recommendations forward with the following planned activities.

- A 're-launch' of the report to kick-start the campaign.
- Hold roundtable events in England, Scotland and Wales to work with healthcare professionals to scope how we can implement the report's recommendations.
- Setting up pilot sites in a number of locations to work closely with healthcare professionals and people affected by breast cancer to carry forward implementation plans in their local area.
- Developing a campaigners' network to involve people affected by breast cancer in influencing change in their local area.

Summary

At the time of writing this report, 7,050 people, including healthcare professionals and breast cancer patients, have accessed the Your body, intimacy and sex booklet. The distribution of this booklet is enabling the Clinical team at Breast Cancer Care to engage with healthcare professionals on the topic of intimacy and sex after breast cancer so that they are better equipped to meet the needs of women who come to them with questions. Research shows that being able to access information around intimacy and sex after cancer treatment via anonymous channels is preferable, so the booklet is available through our website, our Helpline, as well as directly from healthcare professionals.

The My body, myself policy report has so far been positively received in our initial dissemination phase, as such we are confident in our planned activities and implementation phase. Our recently expanded Policy and Campaigns team are continuing to focus on planning next steps for taking forward the recommendations in the My body, myself report. Body image will continue to be a key campaign issue for us over the next few years.

The publication of the Your body, intimacy and sex booklet and the My body, myself policy report are enabling Breast Cancer Care to raise awareness of body image, intimacy, and sex issues. We know older women with breast cancer may have to deal with these issues but may not have it embedded in their care plan. We hope that these empowering resources continue to encourage a more open discussion between both women and their partners, and women and their healthcare professionals, so that they are able to access the support they need.

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