Altered body image, intimacy and breast cancer

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Dear Body

I wasn’t always happy with you. I wanted longer legs, a flatter tummy, firmer arms.

But recently we've been through a lot, you and I. We faced cancer, together.

We lost our right breast, our hair fell out. But we got through it. And now I've learned to love and accept you for what you are.

Not perfect. But beautifully imperfect. You are my body.

And I'm proud of you.
Is altered BI is an issue?

Breast Cancer Care carried out a poll from 23/08 to 09/09 2013 via Facebook and ‘Breast Cancer Voices,’ - 603 people responded

72 per cent of respondents (437) said they feel less confident about their bodies. Many felt it had lowered their self esteem, that they had experienced a ‘loss of self’ compared to what they felt before breast cancer or felt a combination of the two.
My body, myself

What do women want?

- treated as a whole person
- listened to as an individual
- access to specialist information
- referral to services that offer support
- talk to others about coping strategies
- involvement of partner

http://www.breastcancercare.org.uk/body-image-breast-cancer
Altered body image

What is body image?

Impact of surgery on body image

Impact of altered body image on relationships
What body image is not

- It's not **self esteem** or **quality of life** because this involves one’s relationships, career, values etc.

- **BUT** both of these can be influenced by body image and changes in body image do not always reflect self esteem and quality of life.

- So what is it....
It’s multifaceted

• Perceptions, thoughts and behaviours related to one’s physical appearance, attractiveness and competence as well as one’s perceived state of overall health, wholeness, functioning and sexuality

• It’s a highly subjective experience  
  Borquiren
So what influences body image?

Before age 6 – awareness of societal bias

**Gender role socialisation** physical appearance and behaviour

**Direct/indirect** Media, family, friends peers all reinforce cultural ideas of attractiveness and the role of a woman - societal approval

**Self objectification** constant comparison and perceiving a discrepancy between actual and ideal self plays a pivotal role in poorer BI
Beth Whaanga
Poor body image is associated with emotional distress
Cash et al 2004

Evidence suggests that there is an interaction between BI and age which predicts some aspects of emotional distress i.e. younger women more affected
Miller at al 2013
Adjustment after breast cancer to BI changes

The evidence suggests that:

• Not all patients will manifest the same body image issues
• Changes to body image because of breast cancer not only affect the person but also affect how others behave towards them
• **Constant reminder of disease**
• **Change accommodation** - The speed with which these changes happen can also be a factor
• **Sensory perceptions** - phantom sensations
• **External prosthesis**

Bolton, Lobben and Stern 2010
The potential to affect body image

• Surgery
  • Weight gain
  • Lymphoedema
  • Menopause – trouble shooting BC survivorship
  • Hair loss
Body image disturbances are…

Consistently associated with mental distress, anxiety, reduced physical health, sexual dysfunction and impaired QOL

A significant subset continue to report BI difficulties years later

Boruiren 2013
Body image and surgery

Impact of mastectomy lumpectomy reconstruction

Choosing reconstruction - expectation and reality what influences choice?

Young /Old
Younger women had a poorer BI compared to older women.
More pronounced in single women regardless of surgery.
Negative impact was strongest among young married women.

Helms et al 2008 literature review
lumpectomy
mastectomy
reconstruction
The numbers (UK data)

82% have surgery (90% under 50)

- 57% breast conserving surgery
- The remainder undergoing mastectomy with or without reconstruction
- 21% immediate reconstruction
- 11% opted for delayed reconstruction

National mastectomy and reconstruction audit 2009 (10% up)
Breast conserving surgery and body image

BI only minimally disturbed by WLE

Incidental finding:
Patient level of satisfaction was higher than that of the clinician

Lyngholm et al 2013
The psychological effect of mastectomy with or without BR

103 ♀ pre surgery, 6 and 12 months post

BI concerns across the study group improved significantly over the study

- 12 months post surgery younger women had less favourable BI (all surgery)
- Overall satisfaction scores delayed \[ \Rightarrow \] mastectomy

Immediate reconstruction

Harcourt et al 2002
Psychological functioning and mastectomy +- BR

Harcourt et al 2002

The psychological effect of mastectomy with or without breast reconstruction

HCP should not assume that immediate reconstruction necessarily offers greater improvements in psychological functioning.

Brunault et al 2013

There is a strong association with depression in long term BC survivors and patient perception of cosmetic outcome (non reconstruction)
Men’s experience of their partners mastectomy

Primary concern was their partners health BUT

- Described mourning the loss of their partners breast
- Questioned their ability to cope with altered BI
- Shift in level of intimacy-no longer seeing partner naked
- For some men very complex issues of not seeing the surgery/seeing the surgery/reaction to it/ partner not wanting to show. Men feeling distaste, unattractive, less feminine
- The majority of men reported that mastectomy had had a negative effect on their sexual relationship

Rowland and Metcalfe 2014 systematic review
Breast reconstruction who has it and why?
Lots of studies spanning the last 20 years overwhelmingly they seem to say that the driver for BR is young age, lower feelings of attractiveness, and sexual interest

- Mean age significantly lower (52vs 64)
- Higher education
- Employed
- Influenced by physicians opinion
- Sexually active

Fallbjork et al 2010
Breast reconstruction can recreate physical appearance but is unable to resolve women's physical perception of feeling abnormal or different.

Whilst those women undergoing BR had a better body image than those who had a mastectomy alone it is not always the panacea.

Body image problems occur despite satisfaction with shape and appearance.

Fang, Shu and Chang 2013
Meta analysis

Offering accurate and realistic information for women during decision making is key
Motivations, influences, predictors and impact
The motivation

155 ♀
63% 40-60, 54% African American
Most likely to be motivated by body image concerns NOT sexuality or femininity

♀ between 50-65 more likely to pursue BR

African American women were less likely to be offered/accept referrals

Women undergo reconstruction to ‘feel whole again’, get rid of external prosthesis, avoid mutilation and feel feminine again

Only 25% ♀ reported being concerned about partners satisfaction when making decisions

Women who chose not to have BR often cite additional surgery and complications for not going ahead

Duggal et al 2013
The predictors

- US SEER data base- over 52,000 cases
- The most likely predictors (immediate and delayed) are:
  - Younger age
  - White race
  - Lower stage disease
  - Urban living
The influences

• Influenced by clinician- pre op discussion re reconstruction  Duggal 2013
• The impact of age, phases of a woman’s life, prior body image  Fallbjork et al 2010
The impact

Pockai et al 2009
Meta analysis

Findings- breast reconstruction may impair QOL
Need for HCP improved QOL through pre op counselling

Sheehan J et al 2008
Looked at the occurrence of women experiencing regret associated with breast reconstruction.
Prior negative BI is associated with decision regret
So what is really important for the patients adjustment?

Immediate and delayed reconstruction

Cosmesis
- Feeling normal and looking normal –confidence and femininity

Relationship with surgeon
- Positive and negative feelings- difficulty telling surgeon of disappointment

Reconstruction as completion of cancer journey
- Patients felt they had completed the cancer journey positive whether cosmesis was good or poor

Beesley 2012 (audit)
In summary

All women are individuals

- Surgery does impact on BI particularly in relation to immediate reconstruction
- Assessing patient expectation
- Younger age
- It’s the patients view of the end result that is crucial – they maybe satisfied when the surgeon is not
- Importance for patients that the information given is realistic
Dear nice, young (usually), male (usually) breast cancer reconstruction surgeon,

Thank you for your help in making me healthy. But we’ve come to a tricky discussion, about the difference between seeing and feeling.

I don’t care what you can see; I care what I can feel. When I am dressed, and up and about and getting on with my life, the size and shape of my breast really isn’t a big deal. I’m a woman, in my middle age. I have body issues. That’s normal for me.

When you ask me to stand in front of you, both breasts bared, and compare my “new” breast to my “old” breast and ask if I want the old one reshaped, you are insulting me. You are insulting the part of me that has, brilliantly, not had cancer. I quite like the bit that’s not had cancer. No, I don’t want it cut up too. (I try to love the bit that has had cancer as well, because I figure that’s more sane. It’s tricky, but I try.)

http://www.theguardian.com/commentisfree/2014/nov/14/breast-reconstruction-surgeon-cancer?commentpage=1
Is lymphoedema significant?

Priorities for women with lymphoedema

Information and support around the condition featured highly

• **BUT** issues around body image featured highly
  – accepting appearance
  – hiding
  – clothes
  – self consciousness
  – avoiding social situations

Girgis et al 2011 BMJ

• lymphoedema altered relationship patterns and led to self isolation

Ridner et al 2013
Is weight gain significant?

‘Losing my hair was a big worry for me, but within a few months I also started to put on weight, a lot of weight, and I didn’t feel myself. It was after my secondary diagnosis that it started to have an even bigger impact on my body image.’
What causes weight gain?

Why women put on weight remains unclear **BUT**

- Imbalance between energy intake and energy expenditure

- Weight gain is common in all age groups +/- 5kgs and has been rigorously researched across all treatment modalities

- Weight gain tends to be central and is associated with muscle loss – (sarcopenic obesity) potential reduction in muscular strength and mobility

Women reported gaining between 1-5kgs on average

62% women were moderately to severely bothered by their weight gain

Demark-Wahnefried et al 2012 Cancer Partridge et al 2004
Preliminary evidence suggests that lifestyle change may also improve prognosis in individuals with early-stage cancers but much work still needs to be done to validate this and to determine which types of lifestyle change are most important.

Body image and intimacy

...and then she asked "What's the best form of birth control after 50?"
I said "Nudity"
So what does a woman think?

‘I had to lose my nipple after radiotherapy which I was ok with. What I didn’t realise was I wasn’t likely to be having sex again either. My husband had not wanted sex since my diagnosis. I cannot look at my body in the mirror and my husband stays ‘asleep’ while I get dressed and comes to bed after me.’
What we know is

• Surgery
• Lymphoedema
• Weight gain
• Menopause

And this affects intimacy
Intimacy is affected after breast cancer

1,011 women in the analyses, <70 years partnered
70% experienced sexual function problems
Panjari, Bell & Davis Jnl Sex Med 2011

Women with body image issues were 2.5 times more likely to report sexual function problems

Most of the sexual difficulties related to breast cancer can be managed-physical and psychological
Physical changes that can impact on intimacy

A lot of research around surgery and sexual function. Association with mastectomy BUT mixed results

In addition
Numbness in previously sensitive breasts/abdomen/loss of nipple
Chemotherapy associated with problems of arousal, lubrication, orgasm and sexual pain
Radiation associated with feeling medically ‘invaded’
Weight gain, hair loss............

Emilee et al 2010 Maturitas
Validating altered BI and it affects
Pre surgery -

Whole MDT approach

How do we manage expectation?

patient partner surgery

Assessment tool

partner

Women need to know that their issues are not unique and that they are valid

breast cancer care
Post surgery

**Validity**
Women need to know that there issues are not unique and that they are valid

**Immediate**
Encourage patients to confront surgical scars ASAP

**Survivorship phase**
Frame a question around hormone therapy... ‘many women tell us.. Is this so for you?’
Encourage patients to confront surgical scars ASAP

Reinforce that initially this will be difficult but lessens the more a person looks. This is a process called “habituation”. Advising patients to use a full length mirror, fully clothed, then working towards undressed. Encourage a patient to touch their scars so that they know what it feels like, if it is sensitive, numb, painful.

http://www.sda.uk.net/index.php
Know what’s available

Breast Cancer Care
- Someone like me
- Live chat
- Younger Women’s Forum
- Forums

Relate
- Singles, couples, sex relationships

College of sexual and relationship therapists (COSRT)
- http://www.cosrt.org.uk/tips.asp

Local
Set up pathways
Gynaecologist
Psychologist/psychiatrist/counsellor
Consider how a person wants to receive information on intimacy

Ussher et al 2012 (review)

Majority of respondents wanted to receive information about sexual well being nearly 2/3rds had not received it

- Written, booklets, websites
- Levels of satisfaction with information where high from BCN, helplines, and psychologists
- Talking to partners important coping strategy
It’s evident from the literature that…

… women who held greater investment in physical appearance exhibited greater difficulty post treatment and reported more body dissatisfaction and poorer mental health than those who held lower levels of investment.

Petronis 2003
Boquiren et al 2013
And finally

- Altered BI affects how a woman views herself, the relationships she has with others and her long term QOL

- We can’t change a woman's original body image perception but maybe we can validate her concerns and signpost

- Sexuality and intimacy are central to psychological well being and QOL and they make the experience of cancer more manageable. Emilee et al 2010
Thank you
Breast Cancer Care
Helpline
0808 800 6000