Psychosocial aspects of breast cancer

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• What is the psychosocial impact?

• Research at CAR, UWE:
  – Breast Reconstruction
  – Chemotherapy
Including:

- Impact of diagnosis (shock?)
- Impact of treatment
- Impact of genetic testing
- Impact of recurrence
- Decision making about treatment
- Impact on others
- Coping
- Beliefs about cancer
- Provision of supportive care
- Anxiety (~1/3 at some stage)
- Depressive symptoms
- Quality of life
- Cognitive functioning
- Relationships
- Social confidence
- Fears for the future
- Impact on roles & sense of self
- Feelings of uncertainty
- Existential questions
- Body image
Positive outcomes

• Priorities

• Change in perspective

• “Benefit-finding”
• Reactions aren’t unusual

• A usual reaction to an unusual situation

• Increased recognition over past 15 - 20yrs

• Increased provision of psychosocial support
Research at the Centre for Appearance Research, UWE:
Breast cancer & appearance:

- scarring
- loss of sensation
- swelling (lymphoedema)
- onset of menopausal symptoms
- hair loss
- weight gain or loss
- ulcers
- hormonal changes
- use of prosthesis
Changes can be:

- permanent (e.g. scarring)
- temporary (e.g. hair loss)
- changeable (e.g. breast reconstruction)
Impact of changes to appearance:

- adjustment to new body image
- loss of previous looks
- body is failing?
- body is out of control?
- signals recurrence or new cancer?
- act as vivid, constant reminders
Research areas to date:

• Breast reconstruction
• Partners’ experiences of reconstruction
• Nipple reconstruction
• Chemotherapy
• Ductal carcinoma in situ
Breast reconstruction:

- ~10% of women who undergo mastectomy
- assumed to offer psychological benefits

- 103 women:
- 46 electing breast reconstruction
- 57 undergoing mastectomy
Body Image according to surgical group (lower score preferable)

- Mastectomy immediate reconstruction
- Immediate reconstruction
- Delayed reconstruction

Mean Score

- Pre-surgery
- 6 months
- 12 months
Satisfaction with the results of surgery (scores range 0-100)
No one option is necessarily better than another

So, how do women decide?
A complex decision

• Reconstruction or not?
  – Which type?
  – When?
  – Nipple reconstruction?
Instant/immediate Decision-makers

I sort of accepted it without thinking about it. It was just the next step as far as I was concerned.
Information-seeking decision-makers

I wanted to seek out the information and get all the details. All surgery has risks but I wanted to know information about how long the operation would be, how my muscles would be compromised, how long it would take to get back to normal etc.
Indecisive decision-makers

Then the breast care nurse said well, if you’re not sure why don’t you just have the mastectomy with a prosthesis and then have the reconstruction later? Well I’ve got to be honest with you, but that really mixed me up. I hadn’t even thought about that, so my head was spinning again.
What influences the decision?

- one choice is more or less salient
- previous experience
- personal background e.g. occupation
- understanding of cancer & BR
- option to ‘wait & see’
- the hospital system & HCP
Summary:

• Complex decisions must be made soon after diagnosis

• some women find this decision particularly difficult

• cannot assume benefits of procedure over another
• it is a major commitment

• it can be psychologically beneficial for many women

• impacts on partners too

• not a panacea for the psychological impact of mastectomy

• support in decision-making is needed
Chemotherapy & Appearance

• 19 women due to start chemo
• mean age 44 (range 35-68 yrs)
• interviews pre- & post chemo
• photos during chemo
- Being identifiable as having cancer
  - *it’s obvious to everyone, it’s like a signal, ‘I’ve got cancer’ you know you can’t walk around anonymously any more in the world”*

- Dealing with the reactions of others

- Anticipating an altered appearance is a significant stressor

- “only temporary”?
Until now:

• Most research with White UK patients

• Current research: experiences of South Asian & Black women

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Summary:

- Appearance matters to patients
- Impact on appearance is diverse & enduring
- Still little research in some areas, e.g. men, radiotherapy, BME groups, DCIS
- Impact of new treatments need research
- Concerns evident before changes occur
- Issues for the provision of care
• Help patients prepare

• Ascertain pre-treatment expectations & fears about appearance

• Don’t assume or underestimate the impact of changes to appearance

• Clear referral routes for specialist support (e.g. Psychology services, support groups & organisations)
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http://hls.uwe.ac.uk/research/car.aspx


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