Who decides?: Women with severe and profound ID and mammography

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Incidence of Intellectual Disability (ID)

- The World Health Organisation (1997) Classification for people with intellectual disability (ID)
- UK population = 60.2 million (... Scotland 5.3 million)
- Approximately 1-2% of the population have ID (602,000 and 1,204,000 people).
- Scottish Government (2013) about 26,000 adults in Scotland have intellectual disabilities and require support.

Breast cancer in the UK and Scotland

- Breast cancer most prevalent form of cancer in women
  - 50,000 women diagnosed
  - 12,000 women dying from the disease each year in the UK

- In Scotland 4,232 women are diagnosed with breast cancer each year.

- Incidence of breast cancer in Scotland in women with ID is not known.

Breast cancer screening UK

- National Health Service Breast Cancer Screening Programme (NHSBCSP) commenced in 1988 and is nationally co-ordinated.
- It is free to all women registered with a GP aged 50–70 years in Scotland.
- Breast screening is organised by area and based on the postcode.
- Invitations to attend for breast screening are offered on a three-yearly basis in each postcode area.

Literature .....

- Focused on whether breast screening is appropriate for women with profound/severe ID due to issues about consent, sedation and distress
- Inappropriate to exclude these women because they have a right to health and screening
- Support from family/staff ...
  - training and knowledge seen as barriers
  - Rights of guardians
- Alternative means of screening suggested – e.g. ultrasound but not as effective
- Limited information about this group due to paucity of reporting in the literature

Lalor and Redmond (2009)

- Study of 90 women with ID
- 24 with severe/profound ID
- 15/24 of women with severe/profound ID had received invitations for breast screening.

- Of these:
  - 12 women had attempted the mammogram
  - Seven women with severe ID were successful.

This work...

- Part of a larger study looking at what influenced women with ID to go to breast screening.
- Was not specifically focused on severe/profound
- Findings presented look at views about women with severe/profound ID and breast screening

Methods

- Semi-structured interviews
  - Explored their role, discussing breast awareness, experience of breast screening

Participants:

- 3= family carers
  - Difficult to recruit
- 10= paid-carers

- 10 Allied professionals from health, education and social care
- 23 semi-structured interviews interrogated to see comments about working with severe/profound ID

- Thematic analysis used ...

Where to begin?

- Discussions about breast screening commenced with the arrival of the letter of invitation
  - intercepted by the supporter.

- Discussion difficult due to cognitive ability
- Accessible information available - often too complicated
- Some carers had not discussed breast screening with the women:

"I don't think I would personally know where to begin trying to explain breast screening to her." (Elaine, paid-carer)

Hierarchy of necessity

- Capacity to consent impaired the decision to attend
- Decisions made with community intellectual disability team who worked with the women:
  - GP, consultant in psychiatrist in ID, nurses, speech and language therapist, dietician, physiotherapist, occupational therapist.
- Decisions always made in the woman's best interest
- "*Hierarchy of necessity*"
  - Only go to breast screening if it was essential

Barriers

- Breast screening seen as inappropriate
  - GP wrote to carers to suggest one woman did not go.

    “he didn’t think it appropriate for her to go.”

- Sedation: used due to concerns for distress
  - Hierarchy of necessity

- Parental attitudes:
  - Carers reported parents often had negative perceptions about screening
  - Positive attitudes positive for breast screening in this study

Going for breast screening

- Observation of one woman with ID (Annie) and her carer (Fergi) going for breast screening
  - identified a number of problems:
- Despite notifying the breast screening centre about Annie having ID and making a double appointment - poor experience

  "Annie was manoeuvred into position by the mammographer who did not reassure or speak to her .... She began counting (her distress signal)"
- **Reasons suggested for poor experience**
- Mammographers were not used to working with this client group.
  - Time limit on screening session 6 minutes for each woman to be screened
  - Communication
  - Lack co-working with carer
  - Pressure to keep to time
  - Nervous about being observed.

Limitations

- This is a snap shot
- Small sample
- Not specifically focused on severe /profound ID

Conclusions

- Starts with the invitation
- Difficulty in discussing breast screening however some decisions are made as a team using ‘best interest’ as a guide
- Consent....
- Hierarchy of necessity for medical procedures – mammography not a priority?
- Breast surveillance in the intervening years?
- Experience during mammography – barrier
- Training/awareness for staff

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