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

Dr Diane Willis Edinburgh Napier University
School of Nursing, Midwifery and Social Care
Sighthill Campus
Edinburgh
Scotland

d.willis2@napier.ac.uk
Incidence of 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 snapshot

• 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