

Exploring family communication after receiving BRCA1/2 results: Early data from a family case

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Background

- Research investigating family communication about test results for BRCA1/2 genes - largely quantitative or limited to investigation with individuals undergoing testing
- Little known about how test information is communicated to other family members, received by them and how this impacts on decision-making, relationships and family life
- Need for more exploratory research tracing detailed content of communication and assessing impact of information
- Essential knowledge to ensure genetic services are achieving informed decision-making

Aims

To examine:

- **Flow of information** from genetic consultation through families
- How patients **decide** who to talk to about their test result and what they say
- Ways in which information content given is **changed** as it is transmitted to family members
- **Impact** of information on family members' thinking, emotions, behaviour and family relationships
- Influence of aspects of condition on communication in terms of **behavioural implications** for prevention
- Influence of **ethnicity** on communication

Method

- Clinicians recruit affected patients undergoing diagnostic genetic testing from genetics clinics at Guy's Hospital and the North East Thames Regional Genetics Service clinics
- Results consultations with participants where a genetic mutation is found are audio-recorded by clinicians
- One month later, interviews with participants are conducted
- Similar interviews are then conducted with relatives recruited by the index patients, with whom results have been shared
- All interviews are recorded, transcribed and analysed

Results consultation



Interview with index participant



Interview relative 1

Interview relative 2



Interview relative 3

Interview relative 4

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Analysis

Professional perspective: Quantitative analysis using **content analysis** - numerical description of data - content of information reaching relatives

Patient perspective: Qualitative analysis using **Interpretative Phenomenological Analysis**

- in depth case by case analysis of several family groups initially in order to develop framework - close examination of text & development of themes

Analysis within family, within ethnic group, across families, within condition

Results

Recruitment & data collection has been underway for **36** months. So far we have recorded:

- **139** Index participants recruited
- **45** results consultations
- **50** interviews with index patients
- **22** interviews with relatives
- **12** full family groups (10 BRCA1/2 positive; 2 BRCA1/2 unidentified)

Family case 1

Analysis of results consultation, interview & clinic letters with a 30 year old woman with breast cancer (BRCA1 carrier) & interviews with 2 of her sisters

Content analysis – Key information reached patient and some key information reached relatives but there were significant gaps eg. sisters not aware that BRCA1 mutation increases ovarian cancer risk.

Interpretative Phenomenological Analysis - Key themes:

1. Silence: reasons for not talking **within family**

- **Own distress:** 'I didn't tell her about, you know, me passing it to my children and things like that because, you know, I didn't want to believe I would do that...'
- **Protecting others:** '...people don't want to know, you know, they might be passing on something if they have it. It is really hard to tell somebody, you know, you could be passing this onto your children, it's not something you want to say with your mouth.'
- **Assumed knowledge:** 'She didn't really ask me questions about it because I felt she knew, you know, about it already.'
- **Emotive subject avoided:** 'It's been an issue, that, like everybody's not willing to talk about because we lost two of my mum's sisters to the breast cancer thing and it is a really hard thing, we know it's in the family but you know, like don't go there.'

2. Burden of family history

- **Family curse:** 'Well I think she feels the curse has come down from a generation, a generational curse or something like that so that's why I knew she knew it was in the genes. She felt it was a generational curse and we have to fight it, you know, she said that word fight it, pray about it, you know, and be strong in the faith, things like that...'

Next Steps

- Continue data collection using innovative recruitment procedure
- Continue analysis across family groups
- Draw out information re communication, lay beliefs & family dynamics
- Involve users, clinicians & academics in interpreting & disseminating results