How do women who are informed that they are at increased risk of breast cancer appraise their risk? A systematic review of qualitative research

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Background:

It is well known that women are inaccurate when estimating their breast cancer risk.[1] Provision of a clinically-derived risk estimate only modestly improves their accuracy.[2] Meaning that pre-existing risk appraisals are only weakly affected by numerical risk information, effecting women's risk reducing behaviours and informed decision making. Reasons for this discrepancy are largely unknown.

Aim:

To synthesize qualitative research exploring breast cancer risk appraisals in unaffected non-mutation carrier women who have been informed that they are at increased risk of the disease.

Methods:

Information sources
- 5 electronic databases.
- Reference lists & citations.

Eligibility criteria
- ✓ Women (>18 years old).
- ✓ Women (non-mutation carriers) who have received a clinically-derived risk estimate & are at increased risk.
- ✓ Qualitative and mixed methods studies.

Screening process
- Double screened; third author consulted when needed.

Data extraction
- Study & participant information.
- Author narrative & participant quotes.

Data synthesis
- Thematic synthesis.[3]

Quality assessment
- CASP checklist. [4]
- All studies included regardless of quality.

Results:

Analytical themes from 14 records reporting 12 studies

Theme 1: Breast cancer risk is not the only priority

- Family history of <u>other</u> diseases in the family can take precedence over breast cancer.
- Hierarchy of worry employed.
- Severity of breast cancer risk associated with engagement in preventative behaviours.

"I don't know which I would prefer cancer or the stroke. I think probably cancer because a stroke, I mean that just renders you, you know, not able to function pretty much in a lot of cases."

Theme 2: Congruency between personal risk appraisals and clinical estimates

- Women hold pre-existing appraisals and expectations of their risk.
- These appraisals are primarily informed by the strength of family history.
- Clinically-derived risk estimates reporting lower than expected risk are met with shock and dubiety.
- When expectations are met, women are satisfied with their results.

"… you're a little higher than average risk; that doesn't mean anything […] so I can't really say I really trust the number that they gave me, you know?"

Theme 3: Comparative predictors of breast cancer risk

- Comparisons between self and affected relative examined to determine possibility of developing breast cancer. These included:
  - Comparing breast size to the affected relative.
  - Age of onset in the affected relative – with passing that age having protective value.
  - Health and behavioural characteristics.

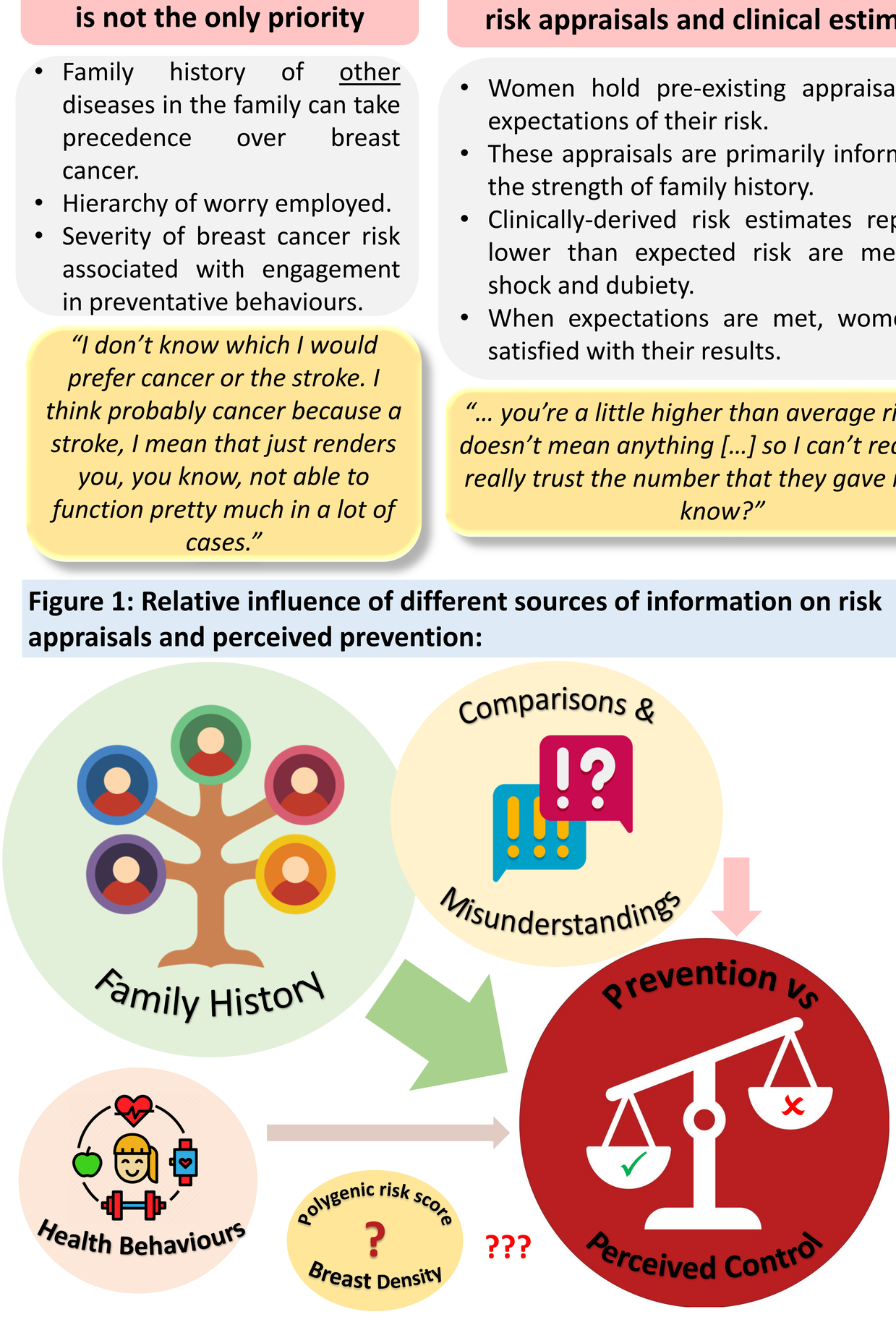
"…it's going to happen because I have the same breasts as my mom"

Theme 4: Living under a breast cancer cloud

- Women describe living in either a state of uncertainty or believing breast cancer is inevitable.
- This led to thoughts regarding whether breast cancer can be prevented or risk controlled.

"…it's the not knowing that drives you crazy, [rather] than the knowing. If you know, then you can deal with it a lot better than not knowing . . . they can't guarantee me [anything]."

Figure 1: Relative influence of different sources of information on risk appraisals and perceived prevention:



Conclusions & Implications:

Women hold stable appraisals of their breast cancer risk which appear to be mainly formed through their experiences of breast cancer in the family. To encourage more accurate risk appraisals healthcare professionals should consider:

- ➢ Eliciting personal risk appraisals to correct misunderstandings.
- ➢ Prevent misunderstandings occurring by presenting risk information in vivid and meaningful ways.
- ➢ Appreciate that preventative decisions are made in the context of other disease risk and illnesses.
- ➢ Routinely conveying non-familial sources of breast cancer, such as the influence of breast density and a polygenic risk score to facilitate more balanced risk appraisals.

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Funding: This work was supported by a Medical Research Council PhD studentship (MR/N013751/1) and the NIHR Manchester Biomedical Research Centre (IS-BRC-1215-20007).