ABSTRACT OF DISSERTATION

Measuring psychosocial consequences of false-positive screening results

Breast cancer as an example

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ABSTRACT

A systematic literature review of papers reporting quantitative studies on the consequences of false positive screening mammography (FPSM), where the psychometric properties of the most frequently used measures were scrutinised, showed that three questionnaires (the GHQ, the HADS and the STAI) should not be used to measure psychological consequences of any kind of cancer screening. The PCQ was found to be the most adequate questionnaire for capturing short-term psychosocial consequences of screening mammography.

The PCQ was translated and adapted into Danish. Content validity was ensured in focus group interviews with women who had previously received an FPSM. These interviews revealed that several areas were not covered by the PCQ. Therefore, fifteen new items were generated resulting in a new draft version of a questionnaire measuring negative psychosocial consequences of abnormal screening mammography (part 1). To cover the issues of long-term psychosocial consequences of FPSM thirteen items were generated (part 2).

Part 1 and part 2 were completed by women screened for breast cancer. Item Response Theories (the Rasch model) and Classical Test Theories were used to analyse data. The psychometric properties covering construct validity, concurrent validity, known group validity, dimensionality, additivity, specific objectivity, internal consistency and reliability were established. The analyses on part 1 showed six dimensions: anxiety, behavioural impact, sense of dejec- tion, impact on sleep, breast examination and sexuality. In part 2 four dimensions were identified. These were: impact on the women’s existential values, relationship with their social network, being less or more relaxed/calm, and less or more anxious about breast cancer/less or greater belief in not having breast cancer.

Given the inadequacy of the measurement identified in the review, any current conclusions about the psychosocial long-term consequences of FPSM must remain tentative.

Preliminary evidence for a valid and reliable condition-specific measure for women having an abnormal and FPSM has been established. This study shows that there are substantial negative psychosocial consequences associated with having an abnormal and FPSM.

Consequently, the number of women receiving FPSM should be kept to a minimum. Letters and folders posted at invitation to breast cancer screening should contain information on the negative psychosocial consequences arising from abnormal and FPSM.

The new understanding of psychosocial consequences of screening mammography revealed in this study contributes to the balance sheet of benefits and harm of breast cancer screening and should be included in the decision-making process of whether or not to implement breast screening.