

# Development of a Decision Aid to support the surgical decision making of young women diagnosed with early stage breast cancer

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## Introduction

Information is important for breast cancer patients. Receiving information at different stages of the cancer treatment pathway means increased patient involvement in decision-making, greater satisfaction with treatment choices and improved ability to cope during the phases of diagnosis, treatment, and post-treatment (Andersen, et al., 2009). Studies show that the desire for information and the type of information required varies throughout the course of the disease and is influenced by needs linked to patients' age (Peate, et al., 2011).

Decision aids are tools that help to convey disease and treatment information in an interactive way. They improve patient understanding, reduce uncertainty and lead to greater satisfaction with the decision made (O'Connor, Fiset et al. 1999; O'Brien, Whelan et al. 2009; Belkora, Volz et al. 2012). Presently, decision aids for breast cancer are aimed at wide age ranges. Our study indicate the need for the creation of a Decision Aid tailored for women aged 40 years and younger, as expressed through interviews and during focus groups of young breast cancer patients.

## Aims

Aim (1) To investigate what information young women diagnosed with breast cancer want to have to support their decision-making before, during and after receiving treatment for cancer.

Aim (2) To develop and test a surgical decision aid that will provide age relevant information aimed at helping young women better understand treatment choices and outcomes.

## Methods

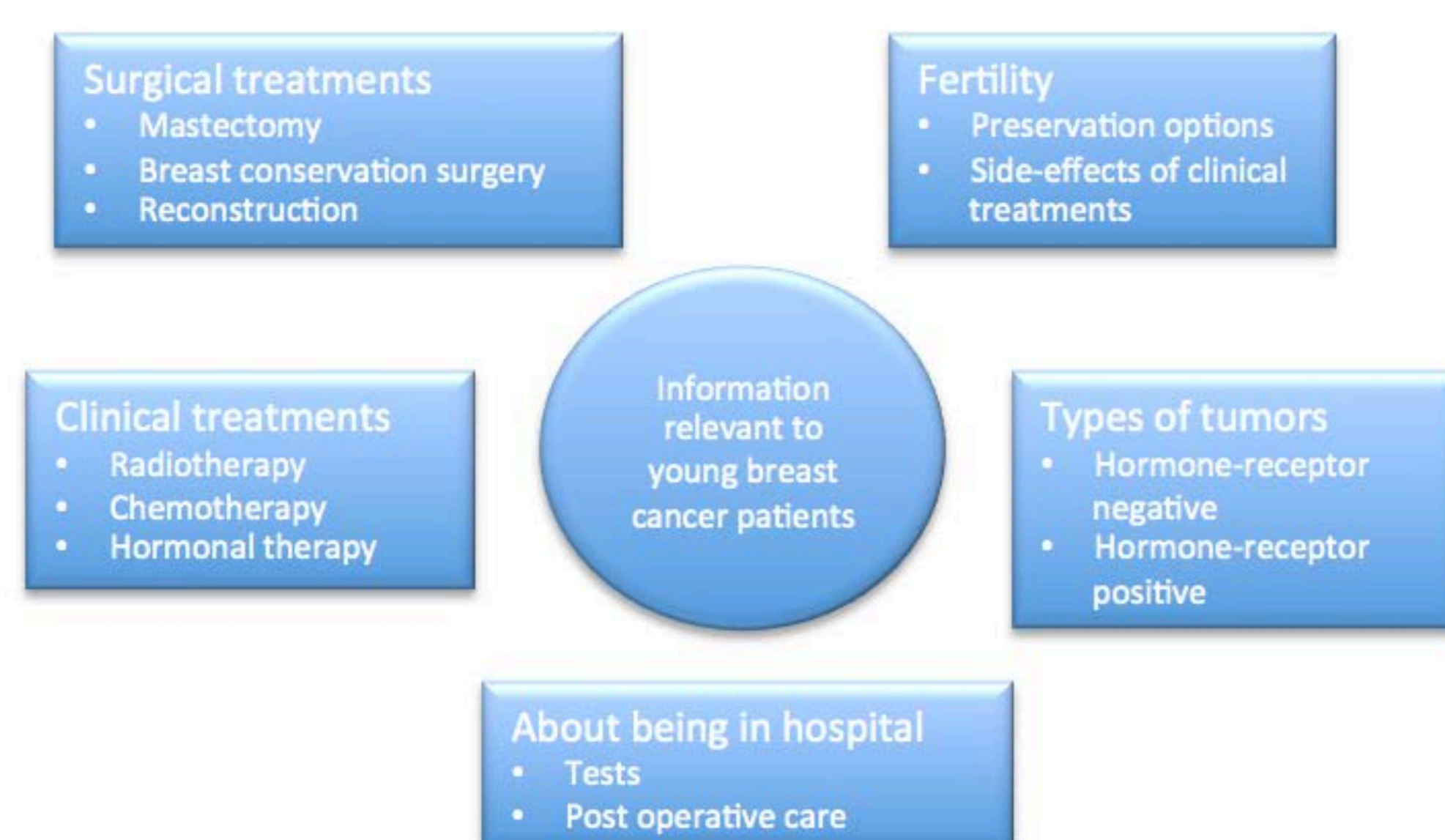
- Systematic review regarding information that young women with early onset breast cancer would like to know when potentially facing a surgical choice between mastectomy and breast conserving surgery.
- Twenty semi-structured interviews that explored the retrospective decision making experiences of women regarding their surgical treatment.
- Focus group discussion where the key information resulting from the analysis of the cohort data in Aim 1 and the key themes from the interviews around decision making were explored.

## Analysis

Transcripts from the interviews and focus groups was analysed using a framework approach. The findings provided a description and interpretation of women's experiences of making decisions about surgery and their views and recommendations for the type of information that could be most helpful to young women at the time of making a surgical decision.

## What do women want to know?

Analysis of the interview transcriptions showed five main categories of information that young women expressed to have needed or been relevant at the time of their surgical treatment. Each them subdivided in categories that reflected the depth and breadth of knowledge that women found to be useful to understand and follow their treatment.



## Next steps

The information that participants identified to be required throughout the trajectory of breast cancer treatment will be collated with quantitative data from the POSH longitudinal study following young women diagnosed with breast cancer. A prototype of a surgical decision aid to support young women is in preparation.

## Reasons for knowing

An important result to support the need of the decision aid was that eleven women discussed not having had enough information in a range of topics, from diagnosis to side effects of treatment in the short and long term, fertility preservation and/or options for reconstructive surgery.

*"But it would have been like nice to, time to you know think about potentially think about things, been given a bit of time to go away and say OK have a, we're going to run through a treatment plan in a bit, [...] but you know have a think about, I don't know, maybe have a list of things that they want the patient to consider" (Int9)*

A semantic analysis of the transcriptions showed that frequent terms included in women's stories were change of their future, family plans, self-image, and lifestyle.

able advanced affected after all amount around bad because  
been being benefits chance change chemo choice  
concern could couple cure day decided decision definitely determination  
did didn't die doing don't done drugs effects end explained far feel frightened  
from get give going good got had happen have hi i'd  
initially just kids knew know knowledge leave life like made mainly  
make mastectomy measures heeded obviously off other part place point  
possible reason right wanted say someone survival take  
tell ten they'd things think thought time treatment trying very view  
weigh well were what whatever when

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