

Needs and preferences of breast cancer patients in shared decision making regarding post-treatment surveillance supported by personalised risk information

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Background

Surveillance after breast cancer is currently equal for every curatively treated patient, but could be less intensive for low risk patients. Personalised risk estimations for locoregional recurrences (LRR) and second primary (SP) tumours can be used to guide shared decision- making (SDM) regarding personalized surveillance.

Purpose

- 1) To explore patients' experiences and wishes regarding information provision and decision-making about post-treatment surveillance after breast cancer.
- 2) To explore patients' perspectives on less intensive surveillance in case of a low risk of recurrence.

Methods

Semi-structured interviews with 23 women from seven Dutch teaching hospitals (Santeon hospitals).



Results

See figure for a summary of the main results.

Conclusion

- SDM about post-treatment surveillance does often not take place, but is desired.
- Not all patients feel ready for less intensive surveillance.
- Insight in personal recurrence risks and improved information provision may support more realistic attitudes and better allocated care and can improve patient satisfaction.
- Fear of recurrence should be addressed in SDM.

"I don't remember them mentioning anything about that. This is just how it went."

"I did not feel like I had a choice, but it seemed like a good proposal."

"I don't think you can leave it up to the patient alone, because she may have irrational thoughts or wishes that cannot be fulfilled. But the healthcare provider should lay the options side by side and ask: What do you prefer?"

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Current information provision

- Limited information provision
- Mostly related to practicalities
- Patients informed by range of HCPs*
- Mostly oral information
- Patients informed at range of moments

2

Current decision-making

- Hardly any SDM**: Patients uninformed about available options
- Patients satisfied with decision-making and organisation surveillance: High trust in HCPs

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Preferred decision-making

- Role-preference: Differing opinions, majority prefers SDM
- Prerequisites for SDM**
- Reflection time
 - Reconsiderable decision
 - Trust in HCP
 - Moment: after active primary treatment
 - HCP: with the NP*** or surgical oncologist

* HCP = Health Care Professional; **SDM = Shared Decision Making; *** NP = Nurse Practitioner; **** PtDA = Patient Decision Aid

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Information needs

- Nature and risks examinations
- Personalised risk for recurrences
- (Dis)advantages personalised surveillance
- Alarm signals metastasis / recurrences
- Overview of illness characteristics

Reasons for use PtDA**** (+)

- Allows patients to be well-informed
- Allows patients to participate in decision-making
- More time to discuss personal considerations
- Allows patients to think about all relevant aspects

Reasons against use PtDA (-)

- Can cause fear and insecurity
- Stressful for women who don't want to participate in decision making
- Implementation costs resources

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Use of personalised risk information

- Half of participants have received risk information
- Half of participants wants to be informed about personal risk for recurrences

Difficulties with use risk information

- Uncertainty risk prediction
- Risks feel impersonal
- Difficulties understanding risk
- Lack of guidance decision making
- Other important factors disregarded
- Bias due to recurrences in environment

"If the risk is demonstrable, then of course you have to anticipate it."

"And even if you only have a half percent chance that something will come back, that half percent must be filled by someone, right? There are people who fall into that half percent."

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Perspectives less intensive surveillance

Perceived advantages (+)

- Lower patient burden
- Lower use of resources / costs
- Regaining confidence in body faster

Perceived disadvantages (-)

- Later detection recurrences and consequences
- More unrest and worries
- Anticipated regret in case of recurrences

Pre-requisites

- Low-threshold access to care / contact HCP
- Knowledge and skills self-examination
- Possibility regular aftercare consultations

"You must be given sufficient information about the risks, and advantages and disadvantages of various options."

"You should ensure that care is accessible at times you have doubts, suspicions or are simply worried."

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If you have any questions or if you want to know more, please contact me!

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