

Strategies to support shared decision making in breast cancer

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Abstract

Shared decision making is a key component of patient-centred and evidence-based healthcare. Its integration into routine care is of interest to healthcare providers, consumers and policymakers who want to improve the quality of healthcare. The process of shared decision making enables healthcare providers and a patient with a condition that has more than one available clinically appropriate management strategy, to make a joint health decision. The decision takes into account the best available evidence, in conjunction with the patient's values and preferences and understanding of the benefits and harms of available options. There is unequivocal evidence that shared decision making improves the quality of healthcare decisions, reduces unwarranted variation in care, and improves patient outcomes. Despite these benefits, shared decision making has not been systematically adopted in clinical practice in Australia. Strategies exist that can help healthcare professionals who treat patients with breast cancer incorporate shared decision making into their practice. We review these strategies, including patient decision aids, patient navigators, decision coaches, and online risk calculators.

Patient-centred care is an important expectation of healthcare internationally. In 1988, the Picker/Commonwealth Program coined the term 'patient-centred care' to set an agenda for clinicians and healthcare systems to shift their attention from diseases back to the patient.¹ The patient's perspective is crucial to drive improvements in design and delivery of health services to enhance the quality of care by improved ability to meet patients' needs. The patient-centred care approach was further advocated by the Institute of Medicine, for improving the quality of US healthcare. They defined it as "care that is respectful of and responsive to individual patient preferences, needs, and values" and that ensures "that patient values guide all clinical decisions".² Breast cancer, with a wide array of both treatment options and patient preferences, is a key setting in which shared decision making can be applied.

Shared decision making (SDM), a process by which a healthcare choice is made jointly between the patient and one or more healthcare providers,³ is considered the crux of patient-centred care.^{4,5} SDM can facilitate patient-centred care, particularly given the increasing number of healthcare choices for treatment and disease management. Despite multiple benefits (box 1), SDM has not been systematically adopted in clinical practice in Australia.⁶ Studies report suboptimal levels of patient-involving behaviours in decision making, and a need for more healthcare providers to consistently facilitate patient involvement and adjust patient care to patient preferences.⁷

Box 1: Benefits of shared decision making of interest to healthcare providers and policy makers.

Shared decision making can:

- improve patient outcomes;⁸
- reduce overuse of options not clearly associated with benefits for all (e.g. breast cancer screening for some people);⁹
- enhance use of options clearly associated with benefits for the majority;¹⁰
- reduce unwarranted healthcare practice variations;¹¹ and
- promote the right of patients to be involved in decisions concerning their health.¹²

Involving patients in medical decision making can improve patients' quality of life, sense of control over illness, symptom relief and adherence to treatment, and decrease fatigue, depression and illness concerns.^{8,13} When patients are presented with multiple treatment options, they may experience uncertainty (known as decisional conflict) about which to choose. If patients are not supported to make these decisions, the consequence may be unresolved decisional conflict. Studies report patients with unresolved decisional conflict are more likely to change their mind, delay medical decisions, have regret after their treatment, depart from active treatment, and blame their treating clinicians for bad outcomes or sue their clinicians in cases of harms from treatment.^{14,15}

When decision support is needed

For decisions where a clear optimal treatment option is available, or there is a lack of equally beneficial alternatives, patient values and preferences may have little or no role. However, for most medical decisions where more than one treatment option is acceptable (e.g. treatment options for early-stage breast cancer), patient involvement in decision making is valuable for aligning decisions with individual values and preferences. For patients, some decisions are tougher than others. A decision between two or more options might involve a trade-off between associated risks versus the potential benefits, and the potential for regret if the intended outcome is not achieved. For example, patients might decide against post-operative chemotherapy for early-stage breast cancer due to concern about short and long-term toxicities, weighed against a modest incremental survival gain from that treatment. Patients will value benefits and harms of treatment differently and vary in how much risk, loss, regret or challenge to their personal life they prefer.

Through SDM, clinicians can help patients incorporate their values and preferences in making medical decisions that are best for them. When patients know they have options for the best treatment, screening test or diagnostic procedure, most prefer more active involvement in health decision making.¹ This interest is shared by patients worldwide, as demonstrated by the release of the Salzburg statement endorsing SDM by representatives from 18 countries.¹⁶

Major decision points in breast cancer

More than 16,000 Australians will be diagnosed with breast cancer in 2016.¹⁷ Due to improved treatment options, 89% will survive for more than five years.¹⁸ Treatment options for patients with breast cancer include surgery, radiotherapy, chemotherapy, endocrine therapy, biologic therapy and supportive care.¹⁹ Within each of these treatment modalities there can be a number of different options, each with benefits and harms that might be valued differently by individual patients.²⁰ Without involving patients in the decision, clinicians cannot confidently predict which option will be most suitable for that particular patient at that particular time.²¹

Major treatment decisions for breast cancer patients may include:

- *Surgical*: mastectomy or breast conserving surgery; axillary clearance or sentinel node biopsy; reconstruction surgery; contralateral prophylactic mastectomy.
- *Medical oncology*: chemotherapy; endocrine therapy; neoadjuvant chemotherapy.
- *Radiation oncology*: radiation to breast/chest wall, and/or nodal regions.

Many of these choices depend on decisions about other treatment modalities. For example, survival and recurrence rates are equivalent between breast conserving surgery and mastectomy, however this is only the case if breast irradiation follows breast conserving surgery.²² While most women with early stage breast cancer are cured of their cancer with one or more of these treatment modalities,¹⁸ receiving a diagnosis of a potentially life-threatening condition causes substantial distress for many patients and their support person(s).²³ This distress may impair their ability to be fully involved in their treatment decision-making.²⁴ However, women who were actively involved in treatment decisions for their breast cancer had higher physical and social functioning, and quality of life, and lower fatigue compared with those who took a passive role.²⁵ As such, strategies to support SDM in breast cancer patients are an important component of high quality multidisciplinary care. Box 2 presents a case study and highlights how decision support would benefit this patient.

Box 2: A case-based example of shared decision-making for breast cancer

Karen, a 39 year-old woman, is diagnosed with early-stage left breast cancer. She has an ultrasound and a core biopsy, showing a 30mm diameter, oestrogen, progesterone and HER2 negative (triple negative) tumour with at least one involved axillary lymph node. Her surgeon explains that with breast conserving surgery, the cosmetic outcome would not be optimal. Karen would like to retain her breast, but is also worried about the long-term effects of the radiotherapy that would be required after breast conserving surgery. Her mother was diagnosed with breast cancer at age 44, and she is concerned that she might carry a BRCA1/2 gene mutation that would predispose her to develop breast and/or ovarian cancer. Her surgeon refers her to a medical oncologist to consider pre-operative (neoadjuvant) chemotherapy, which would otherwise have been given after surgery, to shrink the tumour to facilitate breast conserving surgery. In addition, she could receive genetic testing prior to surgery, which if positive might cause her to have bilateral mastectomies and immediate reconstruction to reduce her risk of future new primary breast cancer. In order to prepare her for the discussion with the medical oncologist, the surgeon gives her a patient decision aid on neoadjuvant systemic therapy.

In this example, the patient has multiple decisions to make: decide between mastectomy and breast conserving surgery, whether to have radiotherapy and pre-operative chemotherapy, and whether to have genetic testing. The patient has preferences such as retaining her breast, but she also has worries about long-term treatment effects, so she would benefit from support to weigh up her values and preferences against possible treatment effects and her individual risk. There is also clinical information that she will need to understand to help her make an informed decision such as what her HER2 negative and involved axillary lymph node means for her individual risk. In addition, she has family history to consider.

Considering the likely suboptimal outcome with breast conserving surgery and that the patient has preferences but also evident decisional conflict around possible treatment effects versus risk reduction, this patient would definitely benefit from decision support. Decision coaching could help the patient consider her values and preferences and weigh up the harms and benefits of all possible treatment options. The patient decision aid will assist her in deciding whether to have pre-operative chemotherapy.

Strategies to facilitate SDM

Evidence summaries such as clinical practice guidelines and systematic reviews can be useful in supporting decision making, but these do not map well onto decision points in the consultation, nor do they promote patient interaction and discussion.²⁶ This is particularly apparent where the evidence is uncertain or where clinical equipoise exists and therefore benefits and harms need to be weighed up with patient preferences and clinical contexts to individualise decisions.²⁷ Strategies that facilitate adoption of SDM in clinical practice include: 1) patient-mediated interventions such as coaching patients and using patient decision aids, navigators, patient activation and printed educational materials;^{28,29} and 2) health professional-mediated interventions such as education, audit and feedback, and barriers assessment.³⁰ A systematic review of SDM interventions concluded that use of any one or multiple strategies was better than none at all, but no one intervention was clearly superior to the others.⁴

Decision support tools for breast cancer patients

Patient Decision Aids (PtDA)

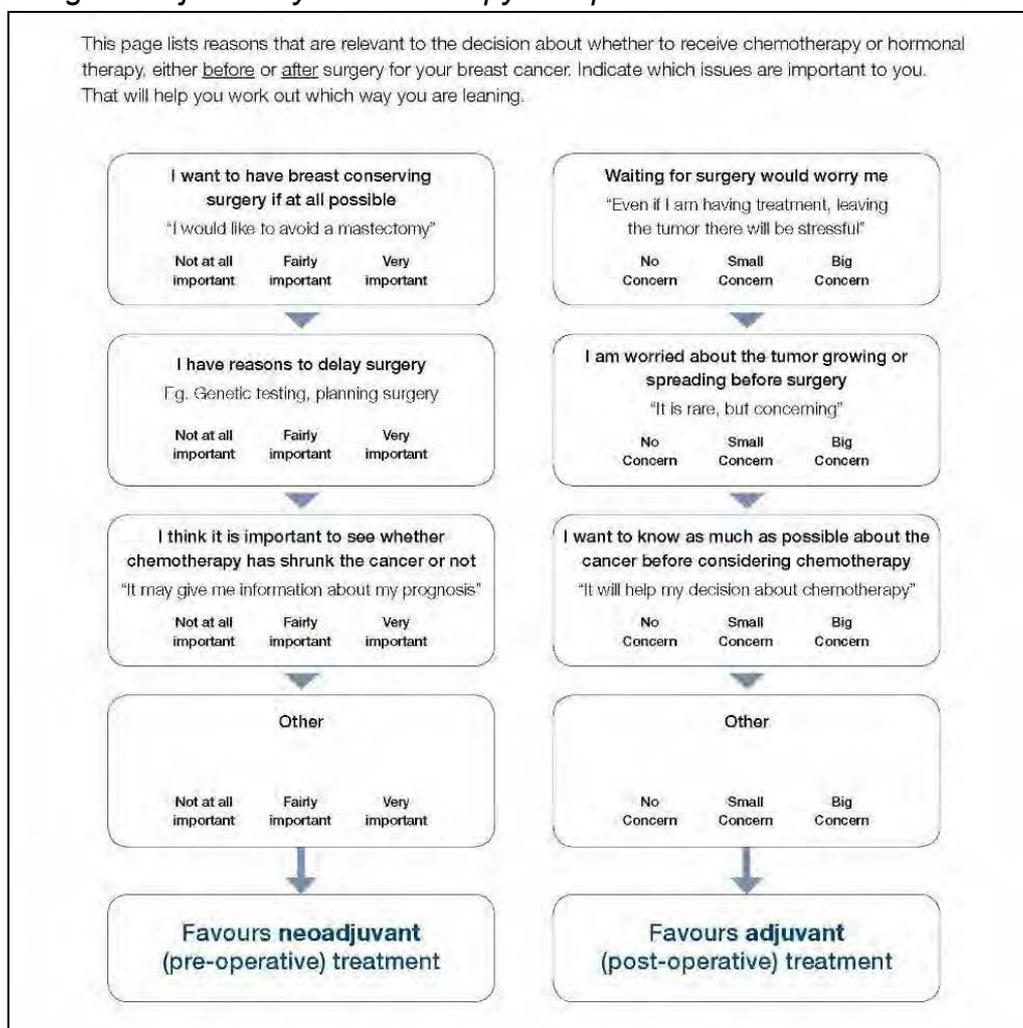
PtDAs are a proven method of implementing SDM principles into clinical practice. A PtDA is “a tool to help people participate in healthcare decisions with the goal of promoting deliberation between patients, healthcare providers and others about these options”.³¹ They are designed to raise patients’ awareness and understanding of treatment options, relevant clinical evidence and possible outcomes, and aid them in developing and communicating their preferences about these outcomes.¹³ They are not designed to convince a patient to choose a particular treatment, rather to clarify the decision for an individual.³²

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The core components that differentiate a PtDA from routine patient information are: presentation of two or more options; balanced, evidence-based content; inclusion of outcome probabilities for each option; and a values clarification exercise (figure 1).³³ A Cochrane review of PtDAs for treatment or screening decisions found PtDAs improve decision-related patient outcomes, including decisional conflict, knowledge, more accurate risk perceptions and expectations of possible benefits and harms; increase participation in decision-making; and help patients reach choices consistent with their values.¹³ Despite these benefits, PtDAs have had variable uptake, partly due to lack of widespread availability and physician awareness.

PtDAs have been developed for a wide variety of healthcare situations,¹³ including most major breast cancer decisions.³⁴ PtDAs have been found to improve breast cancer decision-related outcomes including: decreased decisional conflict, increased knowledge and decisional satisfaction. Notable gaps in the breast cancer PtDA literature include decisions about neoadjuvant systemic therapy and contralateral prophylactic mastectomy, however current studies are underway to fill these gaps.^{35, 36} A PtDA library is available at <https://decisionaid.ohri.ca/>, along with guidance for practitioners in the use and development of PtDAs.

Figure 1: Example of a values clarification exercise from a decision aid for women considering neoadjuvant systemic therapy for operable invasive breast cancer.³⁶



Patient navigators

A patient navigator is an appropriately trained former patient, consumer, volunteer or health professional whose role is to assist patients in receiving timely, quality care that is consistent with their values and preferences.³⁷ This practice has been widely adopted in cancer care. When cancer nurse coordinators have taken on navigator roles, their involvement was associated with better patient adherence to treatment and greater satisfaction with healthcare.^{38,39} However, not all studies have

shown improved decision-related outcomes as a result of patient navigators.⁴⁰ This approach appears particularly suited to patients considered vulnerable as a result of socioeconomic disadvantage, low health literacy, and/or belonging to a culturally or linguistically diverse group. Patient navigators have helped Latina and Black American breast cancer patients with decision-making and communication.^{41,42}

Decision coaches

A decision coach is a trained healthcare professional who is non-directive and provides support aimed to build patients' skills in: thinking about their options (deliberation); preparing for discussing the decision with their healthcare provider (communication); accessing support; and implementing the chosen option.^{4,28}

Decision coaching has application to breast care nursing practice. The role of a decision coach is to diagnose the problem and screen for decisional conflict, and provide options.²⁸ Specifically, a decision coach should: 1) assess and discuss individual patients' decisional needs and factors influencing decisional conflict; 2) provide decision support tailored to decisional needs and relevant information (e.g. options, benefits/harms); 3) assess understanding of the options and evidence, and clarify patients' values and preferred option; 4) monitor and facilitate progress in resolving needs and decision quality; and 5) screen for factors influencing implementation.⁴³

Coaching can be face-to-face or via the telephone, and used alone or in combination with a PtDA. Studies report when decision coaching was used alone or with a PtDA, patients were more knowledgeable, had higher perceived involvement and satisfaction in the decision making process, greater values-choice agreement, and reduced decisional conflict compared to usual care groups.²⁸ One study reported decision coaching, with and without use of a PtDA, reduced healthcare costs when compared with standard care.⁴⁴ Examples of healthcare professionals who have provided decision coaching are nurses, pharmacists, geneticists, health educators, psychologists, and social workers.

Online risk calculators

A key aspect of facilitating patient participation in decision making is availability of tailored information, presented in a comprehensible format, that describe outcome probabilities for available treatment options. Online risk calculators are available for predicting the benefit of adjuvant chemotherapy and/or endocrine therapy (Adjuvant!Online, Predict),^{45,46} sentinel/non-sentinel lymph node metastases,^{47,48} and the ductal carcinoma in situ recurrence (nomograms.mskcc.org).⁴⁹ These tools are designed for the clinician to use and interpret within the consultation, providing patients with details about individual risk. For example, [Predict](#) provides five and 10-year survival estimates based on clinical and pathological factors. It also shows the benefit of chemotherapy, endocrine therapy and trastuzumab, if indicated, as an absolute percentage point increment.⁴⁶ Once the patient understands the risks and benefits including survival outcomes, they can make a more informed decision in line with their own values and preferences.

Models for patient-engagement in decision making

SDM is an active process that begins with a decision to be made. Multiple models exist for patient engagement in SDM,^{27,30,50-52} however common features include: information exchange; decisional needs and decisional conflict assessment; empowering patients to process information and consider their values and preferences; and reaching agreement on the treatment to be implemented. In SDM, both parties exchange information: the clinician offers options and describes their risks and benefits, and the patient considers and shares their values and preferences. Through this process, both the patient and clinician have better understanding of the relevant factors and share responsibility in the decision made.²¹ In breast cancer, multiple health professionals must work together with the patient and each other to ensure that mutually satisfactory outcomes are achieved.³⁰

An important consideration is that patients will likely have different decision making styles. Preferences include leaving all control to the clinician, to full patient control, and anywhere in between. Preferred decision making style may change for different decisions and over the course of their illness.⁵³ This presents a challenge for clinicians for whom SDM is one of a number of competing

priorities for consultation time.²⁶ However, SDM can be effectively integrated into the clinical setting to enhance the quality of care.

Strategies for implementing SDM into practice

Strategies for advancing and implementing SDM into practice have been proposed, including: building SDM into existing healthcare delivery processes (e.g. clinical practice guidelines, clinical care pathways); engaging providers as partners throughout the SDM process and providing adequate training in SDM.⁵⁴ The Institute of Medicine made three recommendations for healthcare process redesign relating to SDM: 1) shared knowledge and free flow of information; 2) evidence-based decision making, whereby patients should “receive care based on the best available scientific knowledge” and that “care should not vary illogically from clinician to clinician;” and 3) the need for transparency, whereby information made available to patients allows them to make informed decisions when choosing among alternative healthcare choices.²

SDM is not dependent on the use of decision support tools, however tools exist to facilitate knowledge translation into practice. For example, PtDAs present knowledge in clear, concise, and user-friendly formats. A variety of approaches can be used concurrently and selected and tailored to individual healthcare settings. There are five steps for implementing PtDAs and decision support in health services from a systems perspective, based on the Knowledge to Action Framework:⁵⁵ 1) identify the decision; 2) find a PtDA or other decision support tool and consider their quality and relevance; 3) identify factors likely to influence their use (including policy) and explore ways to overcome these barriers;^{56,57} 4) select strategies to implement decision support (e.g. education and training in SDM, approaches to overcome barriers); and 5) monitor use of decision support tools, quality of decision support provided, and patient outcomes (e.g. informed values-based decisions, decisional conflict).⁵⁸

Conclusion

SDM is a process of interest to healthcare providers, consumers, and policymakers who want to integrate patient-centred concepts into standards of care to improve patient outcomes and evidence-based healthcare. This process is undertaken between healthcare providers and a patient with a condition with more than one clinically appropriate management strategy to help the patient decide among available options in accordance with their values and preferences. SDM is particularly relevant in breast cancer as there is unequivocal evidence that SDM improves the quality of healthcare decisions, reduces unwarranted variation in care, and improves patient outcomes. Despite these benefits, there remains room for improvement in the use of SDM in the Australian healthcare system. Healthcare providers and policy makers are supportive of SDM, but the challenge is how to effectively integrate and successfully implement SDM into existing healthcare processes. Although SDM can occur without decision support tools, tools now exist that effectively facilitate SDM in clinical practice.

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