How can we best respect patient autonomy in breast cancer treatment decisions?

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Practice points

- Decision-making in breast cancer can be complex for patients, as different therapies come with unique balances of risks and benefits.
- Patients are increasingly interested in participating in breast cancer decision-making, yet this can present challenges for physicians in ensuring patients receive evidence-based care.
- Shared decision-making aims to maximize patient autonomy by taking into account both the values and preferences of the patient as well as the medical expertise of the physician.
- Patient preferences for decisional roles in breast cancer treatment decision-making vary; a mismatch of a patient's desired and realized role in breast cancer treatment decision-making can result in patient distress.
- Currently, very few models exist to help physicians elicit the decision-making preferences of patients; there is a critical need for the development of tools in this domain.
- Increasing precision of personalized estimates of risks and benefits of different therapies for patients presents both opportunities and challenges to shared decision-making, as this complex information can be difficult for patients to fully understand.
- A number of decision aids exist to assist patients in making some breast cancer decisions, yet better tools are needed, particularly in the domains of chemotherapy, endocrine therapy and radiotherapy.
- Future efforts to maximize patient autonomy in breast cancer decision-making will need to account for the increasingly diverse nature of the patient population.
- Particular attention to understanding patients' preferences for decisional roles as well as their comprehension of complex treatment information is paramount.

SUMMARY Helping patients to maximize their autonomy in breast cancer decision-making is an important aspect of patient-centered care. Shared decision-making is a strategy that aims to maximize patient autonomy by integrating the values and preferences of the patient with the biomedical expertise of the physician. Application of this approach in breast cancer decision-making has not been uniform across cancer-specific interventions (e.g., surgery, chemotherapy), and in some circumstances may present challenges to evidence-based care delivery.

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SUMMARY (CONT.) Increasingly precise estimates of individual patients' risk of recurrence and commensurate predicted benefit from certain therapies hold significant promise in helping patients exercise autonomous decision-making for their breast cancer care, yet will also likely complicate decision-making for certain subgroups of patients.

KEYWORDS

• breast cancer • breast-conserving surgery • chemotherapy • endocrine therapy • genetic testing • mastectomy • patient autonomy • shared decision-making

Historical models of medical care were largely built around top-down decision-making by physicians, the assumption being that physicians were best suited to serve as decision-making agents for the welfare of their patients. Over the past three decades, however, emphasis on the role of the patient in medical care decision-making has grown significantly [1,2]. This trend toward greater patient involvement in medical decision-making is built on increasing understanding and respect for the unique values and preferences patients have for both medical interventions and health states [3].

Respecting patient autonomy in breast cancer decision-making can present challenges. Newly diagnosed women face numerous decisions related to their medical care, each with varying profiles of risk and benefit. These include decisions regarding locoregional treatment (i.e., surgery and radiation) and systemic treatment (i.e., chemotherapy and endocrine therapy). Depending on the situation, women may face additional decisions regarding evaluative testing, breast reconstruction or fertility preservation, among others.

Close to a quarter of a million women will be diagnosed with breast cancer in the USA within the next year [4]. Each of these women comes from a unique social and cultural background, and has diverse prior experiences with medical care and varying expectations for her role in treatment decision-making.

In this manuscript, we first provide an overview of the concept of autonomy and how it relates to medical decision-making, focusing on the shared decision-making model. We then discuss patient and provider perspectives on shared decision-making, and outline some challenges to and opportunities for maximizing patient autonomy in cancer care. Using four different breast cancer related decisions – surgery, chemotherapy, endocrine therapy and genetic testing – we discuss a number of key issues related to patient autonomy in breast cancer decision-making.

Ethical perspectives on patient autonomy in medical care decisions

• Patient autonomy

Broadly, patient autonomy is conceptualized as the patient's right to make informed decisions about their own care without undue influence or

manipulation from others [5]. Respect for autonomy derives from the deontological theories of Immanuel Kant, who expressed the importance of respecting fundamental human dignity for its own sake, rather than for the ends such behavior might accomplish. A central tenet of autonomy is that, given adequate information and personal freedom, individuals should be able to make decisions concordant with their own preferences and considered opinions [5].

In the context of cancer care decision-making, respect for patient autonomy can be challenging. Given the complex biology of a cancer diagnosis, the many treatment options available, and the rapidly changing science of oncology, even a well-informed patient likely lacks the scientific and biomedical expertise required to make evidence-based decisions about her condition. As a result, most patients must rely on physicians to provide the appropriate information necessary for them to make informed decisions about their care. However, the balance of responsibilities in medical decision-making between patients and physicians can vary considerably [6].

In their seminal work on models of physician–patient relationships, Emanuel and colleagues defined four broad archetypes of the patient–physician decisional relationship: the paternalistic model, wherein the physician makes medical decisions with little or no input from the patient, the informative model, wherein the physician provides all relevant medical information to the patient but does not actively participate in the decision-making process, and the interpretive model, wherein the physician elucidates patient values and subsequently provides medical care based on those values [7]. These three models, the authors argue, are limited either by overreliance on physician-led decision-making (the paternalistic model), by overreliance on patient-led decision-making (the informative model) or by lack of integration of the two (the interpretive model). Consequently, the ideal model of medical decision-making, the authors posit, is one that takes into account the unique and important contributions of both the physician and the patient – the physician for his or her medical expertise, and the patient for her values and preferences. Emanuel and colleagues call

this the deliberative model. While optimal in theory, this relational decision-making model has proven difficult to translate into practice, particularly in the context of cancer care.

• Patient-centered care & shared decision-making

Patient-centered care has been highlighted by IOM as a major priority area for improving the quality of cancer care [8]. A fundamental aspect of patient-centeredness is involvement of the patient in medical decision-making [9].

Currently, the most common form of what Emanuel and colleagues called the deliberative model of medical decision-making is known as shared decision-making (SDM). In medicine, SDM is a strategy to align the physician and the patient in a dynamic decision-making process. The primary goal of SDM is to support the patient in making a high-quality medical decision, defined as a decision that is both concordant with patient preferences and values and medically sound [10]. Operationally, in SDM, the physician ‘shares’ in the decision-making process through two main mechanisms. First, the physician communicates appropriate information to the patient about treatment options and risks and benefits of different therapies, ensuring that the level and form the information takes is understandable and culturally tailored to the patient. Second, the physician seeks to understand the values and preferences of the patient, both through direct inquiry and through helping to shape the patient’s understanding of relative preferences [11]. An important aspect of autonomy underlying this assertion is that patient autonomy is not achieved by simply allowing patients to choose a treatment out of a comprehensive list of treatment possibilities. Rather, patient autonomy is maximized when patients undergo an informed deliberation process along with their physician about their medical options. The nature of medical decision-making is as such that most patients lack the biomedical training required to critically evaluate the relative medical value of a list of possible medical treatments. As a result, key to maximizing patient autonomy, the physician must help the patient frame the decision in the context of medical evidence as well as in the values and preferences of the patient. Within this process, the physician must help the patient understand the relative medical importance of different values and preferences, advocating that some

values may be more worthy to consider than others (i.e., temporary hair loss versus considerable extension of life) [7]. Thus, in the context of patient autonomy, SDM can be considered a form of relational autonomy [12], as it is a mutually dynamic decision-making process aimed at maximizing the patient’s welfare.

Shared decision-making in practice

• Patient & physician perspectives on shared decision-making

Patients are increasingly interested in taking a more active role in medical decision-making. A recent systematic review documented an increase in the proportion of patients reporting a preference for SDM, from 50% of patients surveyed before 2000 to over 70% of patients surveyed in the past 15 years [3]. Patients vary, however, in their preferences for decisional roles [13]. Consequently, elucidating and respecting decisional preferences is a major component of maximizing patient autonomy in breast cancer [14,15].

Like patients, most physicians view patient participation in medical decision-making favorably [16]. That said, physicians report a number of important barriers to SDM including patient anxiety, misinformation, lack of willingness to participate in decision-making [17] and insufficient time with the patient [18,19].

• Aligning decision-making preferences

Multiple recent studies have found significant discordance between patients’ desired and perceived involvement in decision-making [6,20–24]. Breast cancer patients who report having ‘too much’ responsibility for treatment decisions also report more decisional regret than those who feel that their decision-making involvement met their preferences [25]. Furthermore, breast cancer treatment often involves multiple specialties and decision points, taking place over several months. Patient preferences for decisional roles may not remain stable within a single decision-making process [26] and/or may change over the course of treatment [27]. As a result, achieving concordance between patients’ desired and realized roles in breast cancer decision-making is critical. Yet research suggests that many physicians find it challenging to determine patient preferences in this regard [28].

• Communicating uncertainty

A foundational principle of SDM is that patients are well informed about the risks and benefits of

different treatment options, yet risk communication in this context can be difficult [29]. This is particularly true for decisions that must be made in the absence of clear-cut evidence [30]. The concept of uncertainty in treatment risks and benefits is often cumbersome for physicians to communicate, and difficult to patients to comprehend [31,32]. Prior research has shown that the levels of patient versus physician involvement in decision-making may vary by the level of evidence in favor of or against different treatment options, with SDM more likely in circumstances where there is strong evidence in favor of a particular treatment [33]. Physicians who perceive their patients to be averse to ambiguity may opt to forgo SDM [34], yet at times this may be in the best interest of the patient. Research has shown that physicians' communication of uncertainty about risks and benefits is associated with decisional dissatisfaction among some patients [35]. Unfortunately, to date, no formal tools are available to physicians to help identify patients who may be averse to ambiguity. Lack of sufficient support for physicians in the difficult task of communicating the uncertainty of treatment outcomes may pose a major obstacle to physician-initiated shared decision-making around treatment selection.

Patient numeracy, or the ability of the patient to understand and work with numbers, has been shown to vary by patient factors, such as age and race [36]. A number of studies have demonstrated that presentation of numeric risk information may be interpreted and understood differently by cancer patients with low numeracy [37,38]. This important variation in the ability of patients to comprehend numerical information related to risk, benefit and uncertainty of different treatments underscores the need for individualized approaches to assist patients in making informed decisions for care.

• Decision aids

Patient values and preferences have been shown to be associated with breast cancer treatment decision-making and are critical considerations in maximizing patient autonomy [39,40]. Most newly diagnosed women have never previously faced a breast cancer diagnosis, and therefore may have limited understanding of personal preferences within this entirely novel context. In response to this important need, patient-directed decision support tools, called decision aids, aim to help newly diagnosed women clarify their preferences and values associated

with potential cancer care treatment decisions. In addition, decision aids can provide individualized information about the patient's specific type of disease and the risks and personalized benefits of different courses of treatment (or nontreatment) [41]. While all decision aids are aimed at elucidating patient values and preferences related to medical decisions, their length and level of detail can vary considerably, as can their mode of delivery, from a brief tool administered within a clinical encounter to an online tool the patient uses in their own home. Use of decision aids has been shown to be associated with more values-concordant decision-making, greater participation in decision-making and improved patient-provider communication [41], indicating the key role patient-directed decision aids may have in maximizing patient autonomy in breast cancer decision-making.

Maximizing patient autonomy in breast cancer decisions

In the following section, we provide literature-driven commentary on a selection of issues related to patient autonomy in breast cancer decision-making. While many patients are confronted with a wide array of decisions related to their care, for the interest of this paper we focused on four major decision-making domains: decision-making for surgery, chemotherapy, radiotherapy and genetic testing.

• Methods for literature selection

This manuscript is intended to provide a summary of a selection of literature related to key decisions in breast cancer treatment (surgery, chemotherapy, radiotherapy, endocrine therapy and genetic testing) and is not intended as a full systematic review of the breast cancer decision-making literature. We acknowledge that there exists important literature related to this topic beyond that discussed in this paper, including a rich body of qualitative literature [42–45]. However, due to the broad scope of this paper, as well as the large quantity of existing literature related to decision-making in breast cancer, we chose to only include in our selection of studies those focused on these key decisions with quantitative outcomes published in the year 2000 or more recently. Literature was identified via searches on PubMed, as well as review of reference lists of included papers. Key search terms included 'autonomy', 'decision-making', 'shared decision-making' and 'patient-centered

decision-making' within the domain of breast cancer care; however, this list is by no means exhaustive.

Surgical decisions

• Overview

Following a new diagnosis of localized breast cancer, most women choose between two surgical procedures: breast-conserving surgery (BCS) or mastectomy. While numerous randomized trials and their meta-analyses [46,47] have established that these surgeries confer equivalent breast cancer-specific and overall survival, each comes with different risks and benefits. Despite this survival equivalence, use of mastectomy relative to BCS has been shown to vary considerably [48].

Among women eligible for BCS, the use of bilateral mastectomy (even among noncarriers of mutations such as *BRCA1/2*) has become increasingly common in the past 10 years [49–51]. A recent population-based study estimated that 12% of women with unilateral breast cancer had received bilateral mastectomy in 2011 [51]. Published evidence does not support a benefit of bilateral mastectomy compared with other surgical options for early breast cancer patients, and bilateral mastectomy carries a number of additional, sometimes serious, risks compared with BCS.

It is well documented that women with early-stage breast cancer often overestimate their risk of recurrence [52], as well as their risk of developing cancer in the contralateral breast [53]. Surveys of women following treatment for early-stage breast cancer suggest that a significant proportion of patients are not aware of the survival equivalence between BCS and unilateral mastectomy [54]. Among most women diagnosed with unilateral breast cancer, the risk of developing a future breast cancer in the opposite breast is low [55,56]. Despite this, many women who choose to remove their contralateral breast report doing so out of a desire to reduce their risk of a new primary breast cancer or to improve their survival [40].

One might, then, assume that this well-documented trend toward use of more (versus less) extensive surgery for localized breast cancer is largely a result of patient knowledge deficits regarding the risk of recurrence and/or the risk of a new primary breast cancer. Research shows, however, that use of mastectomy is greatest among patients with the highest educational

attainment [56]. Active patient involvement in surgical decision-making is also related to greater use of mastectomy versus BCS [57–59].

• Patient autonomy in surgical decision-making

Patient autonomy in breast cancer surgical decision-making – particularly in regards to bilateral mastectomy – has been a topic of considerable recent interest [60,61]. Of particular debate is whether patient involvement in surgical decision-making is a valuable independent measure of decision quality in breast cancer.

Increasing access to and transparency of recurrence risk information for women making breast cancer surgery decisions holds some promise in improving decision quality. However, information alone is likely insufficient in this context. Even when presented with personalized breast cancer risk estimates, many women view such statistics with skepticism, and may not believe that the estimates apply to them [62]. Reasons for this lack of understanding or acceptance of risk statistics by patients are not fully understood. Some have theorized that women may have pre-existing beliefs about their risk of recurrence that may bias them toward believing their risk is higher than personalized estimates suggest [62]. Women also may not believe a discrete risk calculation could comprehensively account for their unique circumstance and family history [62].

Patient-focused decision aids for breast cancer surgical decision-making have demonstrated some positive impact on patient-centered outcomes in this regard, including improving patient knowledge and decreasing decisional conflict [63,64]. Use of these tools has also been shown to be associated with higher patient uptake of BCS relative to mastectomy [65]. However, a recent review of the use of breast cancer surgical decision aids found that their utility was somewhat limited by physician knowledge deficits regarding the tools as well as inadequate clinical encounter time [63]. Future research on decision aids for breast cancer surgical decision-making will need to address both provider and systemic barriers to their use in clinical practice.

The recent marked increase in the proportion of women eligible for BCS who ultimately choose to undergo bilateral mastectomy presents a novel challenge to the notion of patient autonomy in surgical decision-making [60,66]. An emergent body of research seeks to better understand the potentially numerous forces that

underlie this trend [40]. Better understanding of women's decision-making rationale for or against different breast cancer surgeries may help physicians optimize the balance of patient preferences and medical evidence at play in surgical decision-making.

Chemotherapy decisions

• Overview

A quarter of a century ago, chemotherapy was a mainstay of front-line treatment for early-stage invasive breast cancer. While chemotherapy is still indicated for the majority of patients, in the past two decades, improved understanding of the relative efficacy of different treatment modalities based on tumor histologic subtypes has allowed medical oncologists to tailor adjuvant therapy based on patients' anticipated benefit.

Even among women with the same anticipated benefit from chemotherapy, there is wide variation in patient preferences for chemotherapy [67,68]. Patients' concerns about side effects related to chemotherapy may influence a physician's recommendations for a specific chemotherapy. For example, patients with a history of diabetic neuropathy may prefer to avoid the neuropathic side effects associated with taxanes, and may be less likely to receive these chemotherapy agents [69]. Such considerations may also factor into chemotherapy decisions among women whose job function depends on nerve function in the hands or feet, such as a surgeon or a bus driver. Hence, incorporation of a patient's preferences into chemotherapy decision-making is critical to maximizing her autonomy. As a result, the presentation by physicians of the projected risks and benefits associated with chemotherapy to individual patients is widely considered to be an important aspect of a patient-centered decision-making approach [70].

In recent years, the development of genomic risk profiles, such as OncotypeDX® (Genomic Health Inc, Redwood City, CA) and MammaPrint® (Agendia, Irvine, CA), have provided personalized estimates of the projected benefit from chemotherapy, specifically among women with early-stage hormone-receptor-positive breast cancer [71]. Since their recent introduction into clinical practice, use of these profiles has been associated with patient decision-making about chemotherapy [72].

More research is needed to determine whether there are differences in preference for presentation of recurrence risk information by patient characteristics. Further, much remains to be

determined about how physicians communicate the results of these tests, patients' understanding of the results, and the true impact on the exercise of autonomy in systemic therapy decisions.

• Patient autonomy in chemotherapy decision-making

Efforts to involve the patient in chemotherapy decision-making through use of personalized presentation of risk and benefits have demonstrated positive outcomes, including higher patient satisfaction with decision-making [73]. Yet many women find the presentation of genomic recurrence risk information confusing or difficult to understand [74–76]. The type of risk information presented (e.g., relative risk reduction of recurrence versus absolute survival benefit) about the potential personal benefit of chemotherapy is also associated with differing levels of chemotherapy uptake by patients [75]. As these tools are fairly new, the existing body of literature around ways of presenting this information is small and little is known about the acceptability of different presentation formats to patients. In one study, Brewer and colleagues (2012) found that the standard OncotypeDX risk recurrence presentation format was the least understandable or liked by a small sample of early-stage breast cancer patients [76]. Brewer and colleagues (2009) also examined the experiences of women whose genomic and standard recurrence risk profiles did not match and found that having a high standard risk of recurrence, regardless of the personalized genomic risk results, was associated with greater uptake of chemotherapy [77]. For this small yet important subset of women whose genomic and standard recurrence risk profiles do not match, conflicting information may actually complicate chemotherapy decision-making rather than clarify it [77].

Maximizing patient autonomy in chemotherapy decision-making thus requires more than presentation of numerical risks and benefits; there is an urgent need to personalize the presentation of recurrence risk information beyond what is offered by currently available tools. For patients with low health literacy, overreliance on genomic risk information may decrease patient autonomy by increasing decision-related confusion and distress [78,79].

Continued efforts to maximize patient autonomy in chemotherapy decision-making will need to focus on both the utility and limitations of genomic risk profiles in communicating salient

information about risks and benefits to patients. While use of these tools certainly holds great potential to improve the quality of chemotherapy decision-making among many patients, care must be taken to ensure there are not unintended negative consequences of their widespread use in clinical practice, particularly for patients with low health or numeric literacy.

Radiotherapy decisions

• Overview

Strong evidence from multiple randomized trials and their meta-analyses supports the use of radiotherapy in improving locoregional control and survival in patients undergoing lumpectomy, as well as node-positive patients undergoing mastectomy [80–82].

Previous research has shown substantial variation in the use of different radiotherapy protocols among eligible women, which is not fully explained by differences in patient preferences [83]. Specifically, there has been low uptake of less burdensome approaches to radiotherapy that have been identified as noninferior in selected patients with breast cancer who undergo BCS. For example, large trials [84,85] have established that a regimen of approximately 3 weeks of daily radiotherapy to the whole breast is as effective and not more toxic than the traditional approach of 5 weeks [86]. Despite this, existing evidence suggests that few women, even among the oldest elderly [87], are receiving shorter courses of treatment. Similarly, few elderly women are choosing to forgo radiotherapy [88], despite the results of a large randomized trial that revealed relatively modest benefits in terms of locoregional control and no difference in survival [89,90].

Worrisome evidence suggests that physician-level variation may reflect inadequate individualization of care. For example, prior research has shown that women were less likely to receive radiotherapy after mastectomy than after lumpectomy, adjusting for baseline preferences to avoid radiation, even when benefits were at least as substantial [83]. This lack of individualization may result from limitations in knowledge among referring surgeons [91].

• Patient autonomy in radiotherapy decision-making

Few decision aids have been developed to assist patients with radiotherapy decisions, and even physician-oriented decision aids to predict benefit are uncommon [92]. Together with the complexity

of information regarding various radiation options (including targets, dose, schedule and technique) that can have substantial implications for patient convenience and side-effect profile, this evidence suggests that radiotherapy decisions may be a particularly good research domain for those seeking to promote patient autonomy in breast cancer decision-making.

Endocrine therapy decisions

• Overview

For women whose breast tumors are responsive to estrogen or progesterone, adjuvant endocrine therapy is a major component of recommended care. Despite evidence that early discontinuation of endocrine therapy is associated with higher cancer-specific mortality [93], patient persistence on the drugs remains suboptimal [94,95].

Patient preferences for taking endocrine therapy vary [96]. While some women require a very small survival benefit to make hormone therapy ‘worth it’, others – particularly those facing bothersome side effects from hormone treatment – require more survival benefit in order to initiate or persist on the drugs [96–98]. Much like other aspects of breast cancer care, patient knowledge and beliefs about endocrine therapy are significantly associated with their use [99].

• Patient autonomy in endocrine therapy decision-making

Prior research has shown that patient persistence with endocrine therapy is related to patient-centered communication practices by their physicians [100,101]. Patients who perceive their physicians communicate with them better, and who feel as if they shared in the decision-making process about taking endocrine therapy, more often persist with the drugs. Yet in comparison to breast cancer surgery and chemotherapy, literature on specific interventions to improve shared decision-making in endocrine therapy is scant.

Given the high benefit of and low risk of endocrine therapy to women with hormone positive breast cancer, physicians may not often see this as an appropriate target for shared decision-making. However, patients may see the balance of risks and benefits associated with these drugs very differently than their physicians. Persistently high rates of endocrine therapy discontinuation point to the critical need for better patient-physician communication and shared decision-making in this domain. Finally, recently updated clinical guidelines supporting women’s persistence on

tamoxifen therapy for 10 years versus the previously recommended duration of 5 years [102] will undoubtedly present new challenges.

Genetic testing decisions

• Overview

Due to advances in genetic testing, physicians now know more than ever before about an individual patient's inherited risk for breast cancer (either for developing breast cancer at all, or for developing a new primary breast cancer), and can thus provide useful risk information to a growing proportion of women.

With this recent influx of genetic information has also come a corresponding rise in uncertainty, with variants of uncertain significance found more often as a function of the number of sequenced genes [55,103]. Complicating this situation, patients vary widely in their preferences for disclosure of genetic information following testing, as well as in their understanding of the clinical implications (or lack thereof) of their genetic testing results. Consequently, preserving patient autonomy in the setting of genetic testing can be complicated for physicians [104].

• Patient autonomy in genetic testing decision-making

Genetic testing decision-making can be extremely difficult for patients, as those with high-penetrance mutations (i.e., *BRCA1/2*, *TP53*, *PTEN*, *CDH1*, possibly *PALB2*) are faced with decisions about prophylactic removal of cancer-free organs. Yet even among mutation carriers, patient preferences for risk management are not uniform. Furthermore, results of genetic testing may have implications for family members who do not yet have a cancer diagnosis, and who are then faced with these decisions as well. Moreover, substantial international variation in patient decisions about prophylactic surgery by *BRCA1/2* mutation carriers [105] may reflect the importance of social and cultural context in decision-making.

In response to the need for patient-centered decision-making approaches in genetic testing decision-making, a number of decision aids have been developed and tested with patients and physicians. These have largely demonstrated positive results in terms of patient education [106,107], and appear to be both acceptable and feasible for patient and physicians, alike [96]. However, as we obtain less definitive, more subtle genetic information about a larger proportion of the population [55], there is a need for strategies to guide decisions

about primary cancer prevention and screening.

Discussion

In this paper, we provided a broad overview of some of the issues related to patient autonomy in four major domains of breast cancer treatment decision-making. The topics focused on for the purpose of this paper, and the selection of studies presented therein, were not intended to present an exhaustive list of possible breast cancer treatment decisions. Indeed, the number and scope of treatment decisions a woman may be confronted with around a single diagnosis of breast cancer may vary widely. Yet our assessment of this selected body of literature points to some important next steps in advancing patient autonomy in breast cancer treatment decision-making.

Issues related to patient autonomy in breast cancer care may differ considerably for different patient populations. Patient age is one such factor, as the evaluation of risks and benefits associated with different treatments may take on different meaning for very young women versus their older counterparts. Women of childbearing age often must consider risks associated with loss or delay of fertility as a result of different breast cancer treatments [108], while older women may need to consider the role of existing comorbidities in breast cancer treatment decisions [109]. Interventions to support patient autonomy and shared decision-making in such subpopulations of patients must meet the unique needs of women who may have little in common other than a breast cancer diagnosis.

To date, most interventions aimed at improving the quality of decision-making in cancer have focused on assessing and improving patient knowledge and understanding of the risks and benefits of different courses of action. However, physicians, too, are critical agents in the shared decision-making process. In the domain of decision aids, specifically, lack of physician knowledge and understanding of the potential importance of these tools in maximizing patient autonomy remains an impediment to their use [63]. Systemic barriers to physician participation in shared decision-making with patients, such as limited time with patients, will not be easily surmountable. That said, physician-directed interventions to support shared decision-making in clinical practice are needed [110]. Development of new decision support tools will need to strongly consider existing physician- and system-level barriers to their use in clinical practice.

Finally, in order to evaluate and improve decision-making processes, we must know how to measure them. Patient-reported measures of participation and satisfaction with decision-making are necessary but not independently sufficient. A number of instruments exist to measure shared decision-making in the clinical context [111]. As new diagnostic and prognostic technologies emerge, potentially complicating the decision-making landscape in breast cancer care, continued review and calibration of these instruments is imperative. Additionally, as decision aids are increasingly integrated into clinical practice, evaluation of their effectiveness in regards to patient autonomy is critical. Currently, the evidence base for decision aids in cancer care is somewhat limited, due in part to the heterogeneity of outcome measures and tools. In order to ensure the continued use and dissemination of high-quality patient-directed decision aids, the development of a standard set of measures related to their acceptability in clinical practice as well as patient-reported satisfaction measures related to their use is needed.

Conclusion & future perspective

The individualized nature of modern breast cancer care makes efforts to maximize patient autonomy in this condition a noble and important ideal. Shared decision-making holds significant promise in helping providers and patients achieve the optimal course of care, based on patient preferences and values, as well as up-to-date medical science.

However, like any new technology, the application of shared decision-making in breast cancer care may present some unforeseen challenges. In particular, careful consideration must be paid to possible unintended consequence of increasing distress or decisional conflict among certain patients for whom ‘sharing’ a medical decision with their doctor is not their preferred path.

Consequently, maximizing patient autonomy cannot be defined solely by involving patients in all breast cancer-related decision-making. Rather, we contend that autonomy is achieved when patients’ preferences for decisional roles are elicited and respected, and there is understanding that these roles may vary for different patients and for different decisions by the same patient. Currently, few tools exist for physicians to determine the decision-making preferences of their patients. There is a critical need for research in this area, and it is unlikely that a ‘one-size-fits-all’ approach will be sufficient for determining the decisional preferences of an increasingly diverse patient population.

Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending or royalties.

No writing assistance was utilized in the production of this manuscript.

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