

# A Review of Shared Decision-Making and Patient Decision Aids in Radiation Oncology

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Published online: 30 January 2017  
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**Abstract** Cancer treatment decisions are complex and may be challenging for patients, as multiple treatment options can often be reasonably considered. As a result, decisional support tools have been developed to assist patients in the decision-making process. A commonly used intervention to facilitate shared decision-making is a decision aid, which provides evidence-based outcomes information and guides patients towards choosing the treatment option that best aligns with their preferences and values. To ensure high quality, systematic frameworks and standards have been proposed for the development of an optimal aid for decision making. Studies have examined the impact of these tools on facilitating treatment decisions and improving decision-related outcomes. In radiation oncology, randomized controlled trials have demonstrated that decision aids have the potential to improve patient outcomes, including increased knowledge about treatment options and decreased decisional conflict with decision-making. This article provides an overview of the shared-decision making process and summarizes the development, validation, and implementation of decision aids as patient educational tools in radiation oncology. Finally, this article reviews the findings from decision aid studies in radiation oncology and offers

various strategies to effectively implement shared decision-making into clinical practice.

**Keywords** Shared decision-making · Patient decision aids · Radiation oncology

## Introduction

Frameworks of patient decision-making have evolved to support a more collaborative process in which the clinician and the patient make healthcare decisions together [1]. Specifically in oncology, treatment options can include varying combinations of chemotherapy, surgery, and radiation therapy, depending on the primary cancer, stage of disease, and other clinical factors. In many cases, a given cancer diagnosis can have multiple clinically appropriate treatment options. In these situations, it can be challenging for clinicians to communicate medical information effectively, and for patients to fully conceptualize the risks and benefits of the various treatment options within the context of their own personal values [2]. Thus, decisions related to cancer treatment can be difficult for patients to make, especially when the clinical evidence is limited or when the choices to be made are between two or more medically equivalent options.

Radiation therapy is a well-established treatment modality for cancer patients and can be used with curative or palliative intent. With recent advances in technology, imaging, and systemic agents, radiation therapy has also become increasingly complex [3]. As a result, multiple radiotherapy regimens that vary in dose, schedule, technique or modality can be recommended to a patient for a given diagnosis without one having clear superiority. In these “preference-sensitive” situations, the final decision involves weighing the benefit and harms with consideration of the patient’s values and preferences

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[4]. For example, once deciding on breast conservation therapy over mastectomy, women with early-stage breast cancer may have several different treatment options to choose from, including standard fractionated external beam radiotherapy (EBRT), hypofractionated EBRT, and accelerated partial breast radiation via interstitial brachytherapy or EBRT. Although these treatments options have similar medical effectiveness with respect to breast cancer cause-specific and overall survival, outcomes may differ in terms of recurrence patterns, side effects, cosmesis, convenience and cost; and, each of these factors may be valued differently by different patients [5]. In such clinical decisions of equipoise, or when patients feel uncertain about the best course of action, specialized tools can be used to support patients in the decision-making process.

Clinical decision-aids (DAs) are support tools that facilitate patient-driven decision-making, especially when equipoise exists among treatment options [6]. This article provides an overview of the shared-decision making process and discusses the steps involved in designing, validating, and testing a decision aid. We also evaluate the randomized controlled trials (RCTs) that have examined the use of DAs in radiation oncology. Finally, barriers and strategies for implementing SDM into oncology practice are discussed.

## Shared Decision-Making in Cancer Care

Evidence shows that increasing patients' involvement in medical decision-making can improve healthcare outcomes [4]. As a result, the "shared decision-making" (SDM) paradigm has become a key component of the patient-centered care movement and high quality healthcare. SDM is most useful for preference-sensitive situations in which there is inconclusive clinical evidence with respect to survival, potential benefits do not outweigh the possible harms, and there is variation in patients opinions about the desirability or undesirability of treatment options (Table 1) [1, 7–9]. It is suggested that SDM occurs when four criteria are met: "(1) that at least two participants—physician and patient—are involved; (2) that both parties share information; (3) that both parties take steps to build a consensus about the preferred treatment; and (4) that an agreement is reached on the treatment to implement" [10, 11]. It is the consideration of patient preferences as well as the

**Table 1** Reasons for a shared decision-making approach

Provide patient-centered care
Be responsive to patients' desire to be involved in the decision-making
Understand patient preferences and values regarding treatment options
Improve patient satisfaction with the decision-making process
Potentially improve patient health outcomes

shared process that distinguishes SDM from an informed decision-making model that provides information about outcomes [10]. Thus, SDM goes beyond "informed decision-making" and integrates patients' views, preferences, and values into a shared, dynamic, and complex process surrounding treatment decisions.

Radiation oncologists can utilize SDM to help patients understand their options, as well as elicit patients' preferences and values, especially when they are deciding between radiation therapy and other local treatment modalities, such as surgery, or when comparing different radiotherapy regimens with the same or similar efficacy [12]. Several studies have investigated how patients reach a decision when different radiotherapy regimens are offered for palliation of lung cancer and brain and bone metastases [2]. Szumacher et al. examined the decision-making and treatment preferences of patients with painful bone metastases who were given a choice between a longer and shorter palliative radiotherapy regimen (2000 cGy in five fractions vs. 800 cGy in one fraction); a decision board was utilized to help patients decide on their preferred palliative RT regimen [13]. Overall, patients preferred a collaborative approach with their physician and were more likely to choose a single fraction regimen out of convenience, despite a higher retreatment rate in the multifraction schedule.

## Patient Preferences in SDM Participation

Patients have variable preferences in their desired level of involvement in decision-making, with some choosing to be more active or passive participants than others. This is likely related to various factors, including gender, race/ethnicity, cancer type, prognosis, religion, education level, and level of medical knowledge or understanding. For instance, racial minority groups are more likely to include family members in their decision-making [14], whereas older patients commonly may choose a more passive role [15]. Cancer type can also influence patient preferences in decision making, as seen with breast cancer patients, who tend to play a more active role than patients with other types of cancer [16]. In a study of 1012 Canadian women with early stage breast cancer, 44% wanted to participate in a collaborative approach with their physician, and most woman wanted as much information as possible regarding their disease [17]. In fact, even those desiring a less active decision-making approach, not surprisingly, wanted as much information as possible regarding their diagnosis [6].

However, patients' preferred role in decision-making varies depending on the cancer type, as seen in a study of 57 men with prostate cancer. Fifty-eight percent preferred a passive approach despite wanting to be well-informed [18]. Regardless of one's preferred approach, patient preferences are sometimes misaligned with a physician's approach, and

it is estimated that only 34 to 42% of cancer patients ultimately achieve their desired involvement in making a treatment decision [19, 20]. Discord between patients' preferred involvement and their actual involvement can lead to lower patient satisfaction and higher decisional regret and reduced quality of life [2, 21, 22].

### Interventions to Improve Decision-Making

Evidence suggests that patients have difficulty understanding and retaining clinical data conveyed during a standard cancer consultation [6]. Various interventions have been shown to promote patient engagement, including information aids, communication training for patients and clinicians, techniques to reduce patient anxiety, and DAs. DAs can improve decision quality by (1) providing unbiased education about the condition, options, outcomes, and probabilities; (2) clarifying patients' preferences of the outcomes that matter most to them; and (3) guiding patients so that a decision can be made that best aligns with their informed values [4, 6]. Outcome information in a DA is typically presented with the aid of visual graphics, ranging from simple brochures or pamphlets, to more extensive personalized, interactive computer programs that incorporate patient-specific health information into a unique model [6]. Other formats include videotaped interventions, structured interviews, and decision boards; all of these tools can be administered before or after a patient's initial consultation.

Involving cancer patients in medical decision-making has several advantages [2–6]. A recent update of the Cochrane systematic review identified 55 randomized trials that focused on decisions regarding cancer screening, treatment, and genetic testing [23]. In general, DAs were found to consistently improve patient knowledge, lower decisional conflict, and result in choices that were aligned with patients' values. Other reviews in oncology have shown that DAs are associated with higher patient satisfaction with treatment and greater trust in providers without worsening patients' anxiety [1, 2, 4, 24, 25]. Ultimately, DAs can facilitate an individualized, patient-centered approach in which patients participate in achieving high quality decisions based on their informed values.

### The Development of a Quality Decision Aid

O'Connor is among the earliest authors to suggest a systematic model, termed the Ottawa Decision Framework, to guide the development of a decision aid [23, 25]. Based on expectancy value, decisional conflict, and social support theories, the framework suggests a five-step process: (1) identification of a need for the decision aid; (2) determination of the feasibility of developing a decision aid; (3) identification of the objectives of the decision aid; (4) selection of a decision framework to guide development

of the decision aid; and (5) selection of the methods with which to support decision making within the decision aid. This framework is especially applicable to decisions that require careful deliberation due to the "preference-sensitive" nature of the trade-offs among options [6]. Key features of other commonly used development processes include scoping and design, development of a prototype, "alpha" testing with patients and clinicians in an iterative process, "beta" testing in "real-life" conditions, and production of a final version for use and/or further evaluation [26].

The purpose of developing a decision aid can vary greatly from one-off use in research studies to broader real-life clinical settings. DAs are more than conventional educational materials—they present balanced personalized information so that patients can make informed and individualized judgments about the personal value of options. Well-developed decision aids are carefully designed, user-tested, and open to scrutiny with a well-documented and systematically applied development process. Thus, poor quality DAs may result from presentation biases, lack of citation from evidence based-treatment options, or lack of validated methods of patient DA development and testing [26]. As a result, The International Patient Decision Aid Standards (IPDAS) has developed a set of criteria to help researchers, patients and healthcare professionals evaluate the quality of decision aids [27].

### Trials Investigating the Use of DAs Related to Radiation Oncology

It is important to objectively evaluate whether DAs truly benefit the patient decision-making process, especially before incorporating it into clinical practice. Decision aid efficacy can be measured through validated instruments that assess patient knowledge, satisfaction, decision regret, decisional conflict, anxiety, and quality of life measures (Table 2) [6]. However, the optimal outcome for determining the quality and effectiveness of a DA has not been determined. Thus, it is common to measure the final treatment choice, decision quality, and health outcomes, including quality of life. Indicators of decision quality include knowledge of decision options and outcomes, alignment of the decision choice with values and preferences, increased decision satisfaction, decreased decision conflict, and decreased decisional regret. The decisional conflict scale (DCS) has been used in multiple studies and includes a 16-item scale [36]. The DCS assesses the level of "decisional conflict" that patients experience while making healthcare decisions, and it encompasses the following five subscales: (1) Informed, (2) Values Clarity, (3) Support, (4) Uncertainty, and (5) Effective Decisions. A commonly measured outcome is patient knowledge, which can be determined through a series of questions regarding the cancer diagnosis and the risks and benefits associated with each treatment

**Table 2** Randomized controlled trials of the use of decision aids in radiotherapy

Study	Year	Treatment options discussed	Intervention	Participants and setting	Outcome measures
<b>Prostate cancer</b>					
Auvinen [28]	2004	Watchful waiting, surgery, EBRT, hormonal therapy	Extensive consultation with urologist vs. standard information + usual care	210 men with prostate cancer at 4 major hospitals in Finland	Treatment choice
Davison [29]	2007	Watchful waiting, surgery, EBRT	Personalized treatment information + generic video + written information vs. generic video + written information	324 men with newly diagnosed prostate cancer (CaP) referred to patient education center in Canada	Decision-making involvement, decisional conflict, satisfaction with treatment choice
Hack [30]	2007	EBRT	Audiotaped consultation vs usual care	425 men with newly diagnosed CaP at 4 cancer centers in Canada	Knowledge, decisional satisfaction, quality of life
Berry [31]	2013	WW, surgery, EBRT, brachytherapy	Internet-based Personal Patient Profile-Prostate + usual education vs usual education	494 men with newly diagnosed CaP at 4 US institutions	Decisional conflict, treatment choice
<b>Breast cancer</b>					
Goel [32]	2001	Mastectomy, BCS	Audiotape and workbook vs control pamphlet	136 females with EBC in Canada	Knowledge, anxiety, decisional regret
Whelan [33]	2004	Mastectomy, Breast conservation therapy (BCT)	Decision board within standard consultation vs standard consultation	201 females with early breast cancer (EBC) in Ontario	Knowledge, decisional conflict, anxiety, decisional satisfaction
Lam [34]	2013	Mastectomy, BCS	Take home booklet vs standard booklet	276 women with EBC	Knowledge, decisional conflict, decision-making difficulties, decision regret
Hawley [35]	2016	Mastectomy, BCS, reconstruction	Online tool vs usual care	101 female with EBC	Knowledge, decision appraisal

option. Decision regret can be measured with a number of validated scales, including the Decision Regret Scale [37].

The majority of DA studies have been performed in patients with breast cancer and prostate cancer, probably because of the relatively high incidence, favorable outcomes, and the fact that multiple clinically comparable treatment options with vastly different treatment toxicities exist for both of these malignancies. Some RCTs have examined the efficacy of decision aids in facilitating patient health care decisions in radiation oncology (Table 3) [2, 6]. Whelan et al. conducted a randomized trial in patients with node-negative breast cancer following primary surgery (modified radical mastectomy or lumpectomy plus axillary dissection) who were candidates for adjuvant chemotherapy. This study compared the impact of a standard consultation supplemented with a validated decision board (DB) vs. a standard medical consultation alone [33]. Patients randomly assigned to use the DB demonstrated a significant improvement in knowledge regarding disease and treatment, as well as a higher satisfaction with the decision making process up to 12 months after the initial consultation. Additionally, patients exhibited no statistically significant

difference in anxiety, consultation duration, or treatment choice between the two arms. Patients randomly assigned to use the DB were more active participants in their medical decision making than those randomly assigned to the standard consultation. Furthermore, there was no difference in physicians’ satisfaction with the decision-making process with a DB.

The multitude of treatment options available for low-risk prostate cancer patients can lead to a complex decision-making scenario. In these situations, DAs have demonstrated promise in improving many parts of the decision-making process, such as increasing patients’ confidence in understanding and discussing treatment options with their physicians and family [38]. Auvinen et al. conducted a trial in which they randomized 210 prostate cancer patients in Finland to an intervention arm which involved greater patient participation (in-person consultation with urologists and a multidisciplinary team) in the choice of treatment following a structured procedure or a control arm, in which the standard approach was used [28]. The main outcome measured was the primary treatment chosen for prostate cancer which included watchful waiting,

**Table 3** Summary of reported randomized, controlled trial outcomes

Study	Knowledge	Involvement in decision-making	Decisional conflict	Anxiety	Treatment choice	Satisfaction
<b>Prostate cancer treatment</b>						
Auvinen, 2004 [28]	–	–	–	–	20% fewer men chose surgery in the intervention group	–
Davison, 2007 [29]	–	ND	ND	–	ND	ND (with treatment choice)
Hack, 2007 [30]	Increase	–	–	ND	–	Increase (decisional)
Berry, 2013 [31]	–	–	Decrease	–	ND	–
<b>Breast Cancer Treatment</b>						
Whelan 2004 [33]	Increase	Increase	Decrease	ND	Increase (BCT)	Increase (decisional)
Goel, 2001 [32]	ND	–	ND (trend towards lower)	ND	–	–
Hawley, 2016 [35]	ND (trend)	–	–	–	–	ND
Lam, 2013 [34]	ND	–	Decrease	Decrease (depression)	–	–

surgery, radiation therapy (external beam or brachytherapy), or hormonal therapy. Interestingly, 20% fewer men chose surgery in the intervention group vs the control group (63 vs 85%;  $P = 0.001$ ) although radical prostatectomy was the most commonly chosen form of treatment for operable prostate cancer in both arms of the trial. They also found that patients in the DA arm selected what their physician considered the treatment of choice less often than patients receiving usual care (58 vs 86%;  $P < 0.001$ ).

Another recent study demonstrated an association between SDM and patient satisfaction by administering a cross-sectional survey of patients during radiotherapy [39]. Participants included patients aged >18 years who were undergoing RT for a diagnosis of cancer with a Karnofsky performance status of >60. Patients were excluded if they were receiving palliative RT, had a known brain tumor or abnormal neurologic function. The perception of having control in treatment decisions was associated with increased satisfaction regardless of whether the patient desired control. Increased anxiety (44.0 vs 20.0%;  $P < 0.02$ ), depression (44.0 vs 15.0%;  $P < 0.01$ ), and fatigue (68.0 vs 32.9%;  $P < 0.01$ ) were also reported in patients who desired but did not perceive to have control over their treatments when compared with those who both desired and perceived control. Although no specific decision aid was studied, this study emphasizes the value of SDM and patient-perceived control during radiotherapy, particularly as it relates to patient satisfaction and psychological distress.

While many decision aids exist for early-stage cancer patients, DAs in palliative care are underrepresented despite their

use having significant potential benefits [2, 6]. Advanced cancer discussions are very complex, as patients grapple with prognosis, treatment goals, and trade-offs between benefits and toxicities. Additionally, advanced-stage cancer patients often have a greater need for emotional support and symptom control [40]. Brundage et al. developed a DA for locally advanced and metastatic non-small-cell lung cancer patients who were considering either chemotherapy and radiotherapy or radiotherapy alone [41]. The DA was followed by a structured interview to help clarify the trade-offs and patient values regarding survival outcomes. Participants were asked to indicate their strength of a treatment preference using a seven-point Likert scale. In this study, patients felt that the DA was useful in reaching a decision and that their treatment preference was stronger. Participants' stated treatment preferences were evenly divided between the two treatments with 31 (52%) preferring BSC and 28 (47%) preferring C+BSC. Their findings suggest that patients with advanced NSCLC should be offered more than one treatment option, and that a systematic process for educating patients and for eliciting their preferences is desirable, although their DA procedure was fairly labor intensive (1 h per patient). Another recently completed, but not yet published, prospective non-randomized cohort study will clarify the effectiveness and acceptability of an informative video geared towards patients who have been evaluated by a radiation oncologist for palliative radiation therapy during a hospitalization at Memorial Sloan-Kettering Cancer Center [42].

There is also an ongoing discussion regarding the radiotherapy approach to patients with brain metastases with whole

brain radiotherapy (WBRT) [2, 6]. Sze et al. described two parallel qualitative studies involving interviews, one for patients and one for caregivers [43]. Following interviews, all patients received WBRT. The authors found that hope, knowledge of WBRT, and current symptoms were major factors that influenced decision-making. While some studies have shown benefits of DAs in the palliative care setting, additional assessment of these tools in RCAs is needed. Future research may further our goal of improving the quality of decision-making and overall care in advanced-stage cancer patients through enhancing informed consent, decision satisfaction, better harmonizing of treatment decisions at the end of life with patient values, and potentially improving patient well-being [6, 33].

### Implementing SDM into Oncology Practice

There are several barriers to fully implementing SDM into clinical practice, and the widespread use of DAs has not been achieved in cancer care [26, 44]. Some explanations for this may include a lack of physician awareness and personalization to the individual patient, physician financial incentives, and specific situations where the patient or family prefer a more passive approach [44]. Additionally, the development of a decision aid is a time-intensive and financially costly task, and updating clinical information requires a significant demand on physician time [6, 45, 46]. Thus, the most common barriers to implementing DAs include time management, beliefs that patient characteristics or clinical situations are not conducive to SDM, the belief that patients prefer a “physician-driven” approach, and conflicting physician beliefs specific to each specialty [47]. For example, clinician perceptions of the available data regarding early-stage lung cancer treatment are variable, as recently shown in a binary-choice experiment between SBRT and surgery that revealed strong specialty biases, further underscoring the importance of SDM [12, 48]. Indeed, studies have suggested that not only do physicians have limited familiarity with SDM, but they also tend to engage in unidirectional information-giving without consideration of patients expectations or values regarding their treatment options [1, 49, 50]. Furthermore, patients themselves may feel overwhelmed or anxious about sharing the responsibility of medical decisions, or they may prefer to process their treatment options with friends and family. Thus, physicians and other healthcare providers need to learn the components and barriers together with their patients in order to effectively implement SDM into oncology practice.

Strategies for implementing SDM must address their patient, provider, and systems level. Successful implementation of patient decision aids into clinical practice requires access to the interventions, practitioners who are aware of and skilled in using them, and environmental structures that support their use [51]. Implementation steps used by oncologists include

eliciting patients’ preference; describing the available options, including the risks, benefits, and associated uncertainties and agreeing on a plan for next steps in the decision-making process [43, 51]. In addition, SDM has the potential to improve the value of cancer care, with potentially highlighting the appropriateness of less intensive treatment options and/or surveillance in appropriate conditions. The Informed Medical Decisions Foundation encourages the following six-step approach: [52]

1. Invite the patient to participate.
2. Present available treatment options.
3. Provide information on benefits and risks.
4. Assist patients in evaluating options based on their goals and concerns.
5. Facilitate deliberation and decision-making.
6. Implement SDM.

In general, a team approach that engages all clinical members can help facilitate the implementation of a DA. Nurses, patient navigators, and other clinical and research staff can play key roles in providing information, administering DAs, and helping patients prepare to meet with their provider. This can reduce the large time investment for physicians, improve the quality of patient decisions, and increase and improve communication. Providers can also reduce the strain on the clinical workflow by providing each patient with the level of support that is individualized for each patient. However, not all healthcare decisions require the same level of support, nor do all patients—even for the same decision. Other interventions include specialized communication, educational training workshops for physicians that emphasize the importance of SDM as a fundamental tenet of patient-centered care.

### Conclusions

Treatment decisions in cancer care are complex. As a result, research has focused on improving the treatment dialog process between patients and physicians through SDM, especially for preference-sensitive decisions. This review provides an update on the current role of SDM in radiation oncology, highlighting that communication should be individualized to suit the patient’s preferred decision-making style. A major research focus is the development and testing of DAs, which are designed to help patients make informed choices that match their preferences and values. As more DAs continue to be tested and employed in clinical practice, it is important to ensure that high quality tools are developed through an evidence-based framework. In radiation oncology, a number of DAs have been developed for patients considering the treatment modality and types of radiotherapy for curative intent of common malignancies, decisional support tools for palliative

cancer patients are still lacking. As viable treatment options emerge for other malignancies beyond breast and prostate cancer, and especially in the setting of increased lung cancer screening, there will be additional opportunities for decision support for these preference-sensitive malignancies [53]. At the University of Pennsylvania, efforts are underway to develop and validate a personalized, Web-based, electronic DA for patients with early-stage NSCLC choosing between SBRT and surgery, and these data will be used in a randomized trial with the primary end point of decisional conflict [12]. While this type of patient-centered approach is certainly beneficial, it must be noted that the research and decision aid developmental process requires a significant investment in multidisciplinary efforts, and it is critical that radiation oncologists be involved in the development of such tools.

Overall, studies in radiation oncology have shown that DAs can facilitate treatment decisions, improve patient knowledge regarding treatment options, decrease decisional conflict, and improve patient satisfaction with their decisions, although there is no clear data to show that they change decisions. Patient satisfaction is at center stage both in the clinical delivery and research of oncology care; the encouraging results from DA studies should give clinicians hope that there is a systematic approach available to improve patients' perception of their quality of care by increasing their involvement. Considerable effort and future research should be directed towards understanding how to effectively implement these tools to achieve meaningful benefits for patients and the highest quality cancer care.

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