Focusing on the "Person" in Personalized Medicine: The Future of Patient-Centered Care in Radiation Oncology

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Abstract

Numerous efforts in radiation oncology aim to improve the value of clinical care. To evaluate the success of these efforts, outcome measures must be well defined and incorporate the beliefs of the patients they affect. These outcomes have historically centered on rates of tumor control, overall survival, and adverse events as perceived and reported by providers. However, the future of patient-centered care in radiation oncology is increasingly focusing on the "person" in the population and the individual in the studies to more closely reflect the ideals of personalized medicine. Formally known as patient-centered outcomes, this metric encompasses parameters of patient satisfaction, engagement, and treatment compliance. Evaluations that investigate the safety and efficacy of treatments are increasingly soliciting participation from patients within a model of shared decision making that improves patients' knowledge, satisfaction, physical and emotional well-being, and trust in providers. Modern clinical trials that embrace this approach may even focus on patient-reported outcomes as the primary end point, as opposed to time-honored physician-reported events. The authors explore the growing role of patient-centered care, the incorporation of shared decision making, and the relevant body of existing and developing literature on this topic in radiation oncology. The authors report recent discoveries from this area of study and describe how they can not only support high-quality, high-value patient care but also enhance recruitment to clinical oncology trials, both of which are challenging to achieve in today's relatively resource-strapped environment.

Key Words: Radiation oncology, shared decision making, personalized care, decision aid, quality of life, patient-reported outcomes

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INTRODUCTION

What is personalized care in radiation oncology? Although molecular genomics have revolutionized medical oncologists' ability to distinguish which chemotherapy or targeted agent best suits any individual patient, defining the "personal" patient characteristics that drive decisions to use radiation, and, if so, what type and how much, remain ill defined at present. Radiation oncology historically has been a field rooted in patient-centered care, with an engrained drive to achieve optimal efficacy against the target, whether for cure or palliation, with minimal morbidity to patients. Although ostensibly this dual-sided but complementary drive has focused on technological innovation, the nontechnical advancements are equally if not perhaps more important to patient satisfaction, engagement, compliance, and ultimately outcomes. Shared decision making (SDM), with or without the use of clinical decision aids (DAs), holds the promise of providing the degree of personalization and patient-centered care for patients in their journey toward discovering the most appropriate radiation treatment plan, including whether radiation is at all appropriate or the modality used. In addition, outcomes research in radiation oncology is increasingly moving to a patient-centered era, with the incorporation of patient-reported adverse events as preeminent end points.

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SDM IN ONCOLOGY PERMITS PATIENT-CENTERED CARE

SDM, or the active involvement of patients in considering and ultimately deciding upon their treatment plans jointly with their health care providers, is not a new concept but rather was defined in the late 1990s by Charles et al [1]. Their revised framework, published in 1999, espoused the key hallmarks of SDM as a process that

> (1) explicitly identifies different analytic steps in the treatment decision-making process; (2) provides a dynamic view of treatment decision-making by recognizing that the approach adopted at the outset of a medical encounter may change as the interaction evolves; (3) identifies decision-making approaches which lie between the three predominant models (paternalistic, shared and informed); and (4) has practical applications for clinical practice, research and medical education.

Most importantly, the model identifies that patient preferences are taken into account, which previously was not formally recognized in the literature. The concept of SDM has been supported by many national organizations, including NRG Oncology, the American Society of Clinical Oncology, and the Patient-Centered Outcomes Research Institute, which have funded more than 71 comparative clinical effectiveness research studies focused on SDM [2].

Despite this formal definition, there is significant variability in the definition of SDM. The Informed Medical Decisions Foundation defines six steps of SDM, but the steps are broadly defined: invite the patient to participate, present options, provide information on benefits and risks, assist patients in evaluating options on the basis of their goals and concerns, facilitate deliberation and decision making, and implement SDM [3,4]. One group developed an oncology-specific SDM coding system, the Decision Analysis System for Oncology, in early-stage breast cancer, a topic for which there are ample data that patients wish to be actively involved in surgical choice yet are inadequately involved [5]. The investigators found it to be reliable and valid compared with other recognized SDM coding systems such as the OPTION and the Decision Support Analysis Tool [6].

Generally, SDM has been touted for its potential to create more informed patients and family members and to increase trust in the physician-patient relationship. Nonetheless, there have been barriers to physicians using SDM. A German group investigated these challenges using quantitative analysis and found that time and structural constraints and a lack of (multidisciplinary) communication were the most negative aspects of SDM [7].

For the past two decades, groups have investigated the use of SDM to improve patient-centered care [7]. However, few studies have examined SDM in radiation oncology specifically. Shabason et al [8] explored the association between SDM and patient satisfaction during radiotherapy. Interestingly, they found that only about one-third of patients experienced SDM or perceived control in treatment decisions and that these metrics correlated with patient satisfaction. In addition, anxiety, depression, and fatigue were greater in patients who desired but did not perceive control over their treatments.

PATIENT-CENTERED SDM MODELS IN RADIATION ONCOLOGY

SDM models have been conceptually developed, as outlined previously, yet the exact mechanism and features that distinguish them from typical office visits are still being defined. A detailed discussion about the risks and benefits of one treatment over another can constitute SDM, but the most formalized approach is the use of a DA, which can be presented as a printed handbook, a video, or an interactive electronic guide. Clear hallmarks of a DA include a detailed, personalized discussion of treatment options within the context of a patient's specific demographics, disease-related features, and personal beliefs to help prioritize the patient's values and goals. The International Patient Decision Aids Standards collaboration has helped define the required elements of a DA. Even in groups of physicians who believe they are using SDM, a minority are using DAs [9]. Like SDM as an overall concept, DAs in oncology also have been proved to promote higher quality decisions [10], patient knowledge, patient-provider communication, patient participation, and decisional satisfaction [11,12]. The largest barrier to routine DA implementation is the system-level support, staffing, and time needed to make DAs part of routine clinical care [11,13]. Embedding DAs into the electronic health record (EHR) has a multitude of potential benefits: (1) it reliably extracts all pertinent clinical information, (2) it prompts providers to offer the use of DAs, (3) it allows sharing of the DA results with the patient through a secure patient portal, and (4) it enables real-time clinical decision support for patients and providers on the basis of the DA results [4]. Despite these benefits, few EHRs are currently able to