

# Shared Decision Making in Neurocritical Care



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## KEYWORDS

- Shared decision making • Decision aid • Patient-centered care • Intensive care unit
- Neurocritical care

## KEY POINTS

- Shared decision making, an essential part of patient-centered care, is a collaborative process in which health care providers, patients, or surrogate decision makers make medical decisions together, taking into account the best scientific evidence available, while considering the patient's values, goals, and preferences.
- Shared decision making has been found to reduce decisional conflict and passivity and lead to more realistic expectations of treatments and outcomes.
- Decision aids are Shared decision making tools; high-quality decision aids should follow the 12 quality criteria set by the International Patient Decision Aids Standards Collaboration.
- Few decision aids exist currently in general intensive care units; no International Patient Decision Aids Standards-compliant decision aids exist for the neuro-intensive care unit.
- Research is currently underway to help develop International Patient Decision Aids Standards-compliant decision aids for the neuro-intensive care unit.

## INTRODUCTION

Shared decision making (SDM) has become a hot ticket item since the Institute of Medicine's 2001 report *Crossing the Quality Chasm*,<sup>1</sup> calling for the transition to patient-centered care, and the mandate for SDM by the Affordable Care Act in 2010.<sup>2</sup> SDM is defined as "a collaborative process involving both the physician and the patient or surrogate working together to make important decisions; it incorporates the beliefs, desires, and goals of patients and their families along with the expertise of the physician, and evidence based medicine to make the best health care decisions for the individual patient."<sup>3-5</sup> SDM is commonly

practiced using a decision aid (DA). A DA is a tool designed to help patients or their family members decide among treatment options.<sup>6</sup> These tools provide objective information about the options, including the option to do nothing and the likely consequences (harms and benefits) of each. DAs often include printed materials, videos, or interactive Web programs.<sup>6</sup>

Over the last 10 to 20 years, several areas of medicine, including orthopedics,<sup>7-9</sup> cancer care,<sup>8-10</sup> and other mainly outpatient-oriented fields, have adopted the use of DAs as a routine procedure to enable patient-centered decision making and to support difficult decisions.<sup>8,9</sup> However, few DAs exist in critical care,<sup>11,12</sup>

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despite the fact that choices in the intensive care unit (ICU), particularly the neuro-ICU, are often difficult and value laden and therefore may benefit from SDM.<sup>13</sup> Recently, a joint policy statement between the American College of Critical Care Medicine and the American Thoracic Society highlighted the urgent need for SDM in critical care and made recommendations for the application of SDM in the ICU.<sup>3</sup>

The scope of this article includes a general introduction to SDM, its history and the existing guidelines for the development of DAs, implementation barriers of SDM, and the effects of SDM on patient and surrogate decision-maker outcomes. Examples relating to decisions in the ICU and insights into the recent American College of Critical Care Medicine and the American Thoracic Society SDM recommendations will be provided. Finally, the ongoing SDM research in neurocritical care is discussed.

### ***History of Shared Decision Making***

The term *patient-centered care* was first coined in 1993. Using focus groups with recently discharged patients, family members, physicians, and nonphysician hospital staff, researchers funded by the Picker Foundation and Commonwealth Fund published the Seven Dimensions of Patient-Centered Care in the book *Through the Patient's Eyes*.<sup>14</sup> Access to Care was added as the eighth dimension soon thereafter (**Box 1**). The 2001 landmark report by the Institute of Medicine, *Crossing the Quality Chasm*,<sup>1</sup> urgently called for a change in the US Health Care System toward closure of the quality gap between the current state of a physician-centered system and a more patient-centered system concentrating on what really matters to patients (and their families). Patient-centered care was then mandated through the Affordable Care Act as a measure of quality care.<sup>2</sup> Per the Institute of Medicine, patient-centered care is “providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.”<sup>1</sup>

The term *shared decision making* was first used in 1982 in a report by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research on the Ethical and Legal Implications of Informed Consent in the Patient-Practitioner Relationship.<sup>15</sup> However, the concept of SDM remained rather poorly and loosely defined. Fifteen years later, in 1997, the report by Charles and colleagues<sup>16</sup> provided key characteristics and measures of SDM and provided greater

#### **Box 1**

##### **The 8 Picker principles of patient-centered care<sup>a</sup>**

Respect for patients' values, preferences, and expressed needs

Coordination and integration of care

Information, communication, and education

Physical comfort

Emotional support and alleviation of fear and anxiety

Involvement of family and friends

Transition and continuity

Access to care

<sup>a</sup>Seven principles of patient-centered care were derived by focus groups with recently discharged patients, family members, physicians and nonphysician hospital staff. The eighth principle, “access to care”, was added soon thereafter.

From Gerteis M, Edgman-Levitan S, Daley J, et al. *Through the patient's eyes: understanding and promoting patient-centered care*. 1st edition. Jossey-Bass; 1993; with permission.

conceptual clarity about SDM. The Federal Program Healthy People 2020 was launched in 2010 by the US Department of Health and Human Services and includes supporting SDM between patients and providers in their list of objectives.<sup>2,17</sup> The connection between SDM and patient-centered care was crisply summarized in the highly cited *New England Journal of Medicine* opinion article in 2012 “Shared Decision-Making—The Pinnacle of Patient-Centered Care”.<sup>18</sup>

### ***Shared Decision Making and Patient-Centered Care***

#### ***Essential elements of shared decision making***

One of the most important attributes of patient-centered care is the active engagement of the patient and a collateral decision-making process to reach the best decision for an individual patient. To achieve this, SDM is used. SDM involves a patient, or a surrogate decision maker in cases in which a patient lacks decision-making capacity, and a health care provider. The exchange of information takes place between both parties to describe the decision at hand, discuss available options (including the option of no treatment), their risks and benefits based on available evidence, pros and cons of each option, and, most importantly, the patient's values and preferences. **Fig. 1** shows the essential elements and steps of SDM. As a result, the patient (or his or her

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