Shared Decision Making in the Medical Encounter: Are We All Talking about the Same Thing?

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Shared Decision Making in the Medical Encounter: Are We All Talking about the Same Thing?

Nora Moumjid, PhD, Amiram Gafni, Pr, PhD, Alain Brémond, Pr, MD, Marie-Odile Carrère, Pr, PhD

***Objective**. This article aims to explore 1) whether after all the research done on shared decision making (SDM) in the medical encounter, a clear definition (or definitions) of SDM exists; 2) whether authors provide a definition of SDM when they use the term; 3) and whether authors are consistent, throughout a given paper, with respect to the research described and the definition they propose or cite. **Methods**. The authors searched different databases (Medline, HealthStar, Cinahl, Cancerlit, Sociological Abstracts, and Econlit) from 1997 to December 2004. The keywords used were* informed decision making *and* shared decision making as *these are the keywords more often encountered in the literature. The languages selected were English and French. **Results**. The 76 reported papers show that 1) several authors clearly define what they mean by SDM or by another closely related phrase, such as* informed shared decision making. *2) About a third of the papers reviewed (25/76) cite these authors although 8 of them do not use the term in a manner consistent with the definition cited. 3) Certain authors use the term* SDM *inconsistently with the definition they propose, and some use the terms* informed decision making *and* SDM *as if they were synonymous. 4) Twenty-one papers do not provide or cite any definition, or their use of the term (i.e., SDM) is not consistent with the definition they provide. **Conclusion**. Although several clear definitions of* shared decision making *have been proposed, they are cited by only about a third of the papers reviewed. In the other papers, authors refer to the term without specifying or citing a definition or use the term inconsistently with their definition. This is a problem because having a clear definition of the concept and following this definition are essential to guide and focus research. Authors should use the term consistently with the identified definition.* **Key words:** *shared decision making; informed decision making.* **(Med Decis Making 2007;27:539–546)**

Since the mid-1990s, an increasing number of papers, studying different aspects of shared decision making in the medical encounter, have been published by researchers from different areas (e.g., sociology, psychology, economics, medicine, ethics, etc.). The interest in shared decision making is so great that it has led "a number of prominent medical journals to publish articles heralding a 'paradigm shift' in which the concept of shared decision-making is said to be replacing the old notion that the 'doctor knows best.'"[1] In 1998, a new international journal, *Health Expectations*, was launched.[2] It is entirely devoted to studying the area of patient and public involvement in health care decision making. Also, in 1999, the *British Medical Journal*[3] published a special issue on patient partnership in recognition of the need to further study the "paradigm shift." It seems, therefore, that a new approach to treatment decision making is advocated, and it is suggested that the term *shared decision making* is used "as a deliberate contrast to emphasize the role of the patient."[4] This might lead one to believe that there is a clear definition or at least an agreement of what shared decision making is. However, reviewing the literature, it is not clear whether such an agreement exists. Terms such as *informed decision making*, *informed shared decision making*, *partnership*, *patient involvement*, *patient-centred care*, and *evidence-based patient choice* are used, it seems, as synonyms for shared decision making.

The purpose of this article is to find out whether, after all the research done in the area, a clear definition of shared decision making (SDM) has emerged. A clear definition of SDM can indeed guide and focus research, both by ensuring that all important

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aspects of shared decision making are measured, controlled, or varied in studies or by making sure that someone does not "invent" an additional feature and append it to the definition of the original term. On the contrary, if several names and definitions are proposed to describe a phenomenon, this might be confusing for the reader. If more than one definition exists, it is important to assess if authors clearly define the phenomenon and how close or different they are. This article consequently attempts to answer the above question and to determine if the use of the term by different authors in the literature is consistent with the definition chosen (i.e., cited or provided) or if the term is used without an attempt to clearly define it.

METHOD

We searched articles published between 1997 and December 2004, during which studies on SDM became more numerous. English and French articles were extracted from Medline, HealthStar, Cancerlit, Cinahl, Sociological Abstracts, and Econlit. *Shared decision making* and *informed decision making* were used as keywords as they are more often encountered than other terms previously mentioned. They were also used because they made article retrieval feasible as more than 870 additional articles were related to other terms. We also searched our personal files and scanned the bibliographies of articles identified by electronic search for additional references. In each article, we 1) searched for a clear definition of SDM or a reference clearly defining the term and 2) verified whether the term was used consistently with the definition proposed or cited.

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Address correspondence to Nora Moumjid, GRESAC (GATE, UMR 5824)—CNRS, Centre Léon Bérard, 28 Rue Laënnec, 69008, Lyon, France; e-mail: ferdjaou@lyon.fnclcc.fr.

The results are organized as follows. The first section presents authors who define SDM; it also tries to determine how close or how different their definitions are. The second section presents authors who cite other authors who have defined SDM. The third section analyzes whether the use of the term SDM is consistent with the proposed definition. The fourth section presents authors who do not provide a clear or any definition of SDM or who do not cite definitions given by others.

RESULTS

Of 85 papers identified, 76 are reported here; the other 9 could not be obtained despite direct request to the authors.

1. Authors Who Define SDM

Charles and others,[5,6] in papers published in 1997 and 1999, provided a definition of *shared treatment decision making* in the context of the physician-patient encounter. In SDM, "the *information exchange* is two ways. . . . The defining characteristic of *deliberation* . . . is its interactional nature" (i.e., between the physician and the patient or potential others), and "both parties work towards reaching an agreement and both parties have an investment in the ultimate *decision* made."[5] Thus, the definition emphasizes patient-physician shared participation in every step of the decision-making process.

In 1999, Coulter[7] proposed a definition of *shared decision making* based on articles by authors such as Szasz and Hollender[8] and Emanuel and Emanuel,[9] who were among the first authors to develop the concept of patient participation in medical decision making. Coulter's[7] definition can be perceived as a synthesis of these approaches and as very close to the definition by Charles and others[5,6] when she says,

> "In SDM, the intention is that patients and health professionals share both the process of decision-making and ownership of the decision made. Shared information about values and likely treatment outcomes is an essential prerequisite, but the process also depends on a commitment from both parties to engage in the decision-making process. The clinician has to be prepared to acknowledge the legitimacy of the patient's preferences and the patient has to accept shared responsibility for the treatment decision."[7]

Towle[10] in 1997 and Towle and Godolphin[11] in 1999 defined what they call *informed shared decision making:*

> "Models of doctor-patient encounters that result in increased involvement of patients and that are informed by good evidence have been termed, for example, "informed patient choice," but do not describe the interactive process clearly. We use the term informed shared decision-making to describe decisions that are shared by doctor and patient and informed by best evidence, not only about risks and benefits but also about patient-specific characteristics and values."[11]

The authors use the term *informed shared decision making* to describe a decision-making process in which both the physician and the patient are fully informed (i.e., their information on clinical data is founded on both evidence-based medicine and patient's personal characteristics) and where both actors have roles and responsibilities in the decision made (i.e., the decision is truly shared). For the authors, this last point is not sufficiently explicit in the sole term *informed patient choice* as it does not express the idea of sharing the decision. This definition is close to those of Charles and others[5,6] and Coulter.[7] The emphasis here is also placed on the information exchange between the physician and the patient and the involvement of both parties in the decision made.

In 1997 and in 1999, Braddock and others[12,13] published papers that attempt to characterize the informed consent process in routine, primary care office practice. The authors refer to SDM but prefer to speak of "informed decision making," which they define as "the product of a thoughtful dialogue between physician and patient leading to a decision."[12] Interestingly, some authors (Charles and others,[5,6] Gafni and others[14]) clearly discriminate between informed decision making and SDM. According to them, informed decision making is a process that implies that the physician's knowledge is transferred to the patient, who then has the knowledge and preferences necessary to make a decision. The patient is thus the sole decision maker, whereas in SDM, the physician and the patient mutually inform each other to reach a common agreement on the decision to implement. Both parties are actors in the decision-making process and in the decision made. Consequently, when McAlister[15] and Barry[16] speak of SDM, one may wonder whether they are refering to "shared responsibility"[5–7] or to "patient responsibility," as described by Braddock and others, whom they cite.

In 2001, Weston[17] described similarities between SDM and *patient-centered communication*, a clinical method for communicating with patients.[18] Weston suggests that there is a major similarity between one component of patient-centered care,[18] called finding common ground, and SDM, knowing that finding common ground consists of establishing a partnership with the patient to address his or her problem, then coming to a mutual agreement on how to manage it. Yet, for Wensing and others,[19] these 2 approaches are different: "Whereas 'common ground' can be conceived as an agreement in broad terms, and as a platform for moving forward, SDM specifies a set of principles [Charles and others[6]] and competencies [Elwyn and others[20]]." The difference with patient-centered care, therefore, lies in the detailed process of elucidating the exact nature of the problem and outlining the range of options that need to be legitimately considered. Interestingly, whereas Charles and others[5,6] give a definition only, Wensing and others[19] go further, describing how SDM should be achieved.

In 2001, Gatellari and others[21] described the concept of shared decision making and proposed a definition very similar to that of Charles and others[5,6] and Coulter,[7] without actually citing them. They described SDM as an approach where "doctors and patients are seen as equal partners and are required to exchange information and share their preferences for treatment in order to negotiate a mutually acceptable decision."[21]

In 2001, in a collective work titled *Evidence-Based Patient Choice: Inevitable or Impossible?*, some contributors analyzed SDM, but the editors of the book, Elwyn and Edwards,[22] used the term *evidence-based patient choice* introduced by Hope[23] in 1996 to designate "the use of evidence-based information as a way of enhancing people's choices when these people are patients."[22] Nonetheless, one might wonder whether the term itself (and its definition) emphasizes the idea of informed decision making rather than that of SDM, as defined by Charles and others[5,6] and Gafni and others.[14] In some other works,[24,25] the authors also evoke the concordant therapeutic alliance model, a type of encounter introduced by Dowell and Dowie[26] that resembles SDM in that the exploration phase should lead "to the step of agreeing on goals and negotiating control" and then an "agreement on action and future appraisal."[25]

Prendergast[27] in 2003 and also Bauchner[28] in 2001 extended the concept of SDM to the relation between doctor and family. Prendergast raises the sensitive issue of SDM with family members in the context of treatment withdrawal:

> First, ... we prefer to frame the interaction between surrogates and clinicians as a negotiation rather than one in which both parties compete to determine a decision.... Second, SDM means that, working together, the parties can make a better decision than can either party alone.... Finally, not every clinician is adept at communication and negotiation, but these are learnable skills.[27]

Without quoting or making reference to authors such as Charles and others,[5,6] Coulter,[7] Towle,[10] or Towle and Godolphin,[11] Prendergast proposes a similar definition that includes the patient's family and/or close friends rather than the patient alone.

In 2 papers commented on by Kaplan,[29] Sheridan and others[30] and Briss and others[31] present the US Preventive Services Task Force's (USPSTF's) definition of SDM, elaborated in collaboration with the Task Force on Community Preventive Services:

> SDM is a particular process of decision-making by the patient and clinician in which the patient: 1) understands the risk or seriousness of the disease or condition to be prevented; 2) understands the preventive service, including the risks, benefits, alternatives, and uncertainties; 3) has weighed his or her values regarding the potential benefits and harms associated with the service; and 4) has engaged in decision-making at a level at which he or she desires and feels comfortable.[30,31]

Sheridan and others underline that "this process has the goal of an informed *and* joint decision. Thus, although the definition focuses primarily on evidence for patient involvement, the process necessarily requires clinicians to reveal their clinical reasoning and biases to facilitate a truly joint decision."[30] Here, emphasis is placed on the patient's preference being considered in the decision-making process, whereas for Charles and others,[5,6] Coulter,[7] Towle,[10] and Towle and Godolphin,[11] both patient and physician must be engaged in the decision-making process and the decision made. This point is not so clear in the USPSTF definition, especially when it states that "the patient has engaged in decision-making at a level at which he or she desires and feels comfortable."[30,31] Nevertheless, scales such as those developed by Deber and others[32] can be used to measure the patient's degree of participation in the decision-making process.

2. Authors Who Cite Authors Who Define SDM

Articles by Charles and others[5,6] are the most frequently cited. However, a descriptive categorization of "use" could be as follows: a) Certain authors[19,24,33–37] mention Charles and others as part of their literature review but do not explicitly cite their definition. b) Others simply quote papers by Charles and others as the definition of what SDM is[1,38–42] or indicate that they use it to analyze SDM[43,44] and/or only certain steps of SDM as information exchange.[45] c) Some cite Charles and others but add new elements to their definition. For example, Frosch and Kaplan[46] speak of conditions to be fulfilled to reach a shared decision, but a few years later, they give no precise details of what SDM is really.[47] Gwyn and Elwyn[48] and Elwyn and others[20] add the notion of *equipoise*, stating that "a situation in which options are really options must exist in order for SDM to successfully take place and thereby justify the term."[48] Thus, SDM appears more feasible in situations of equipoise—that is, in situations where no professional consensus exists on the best treatment available—than in situations where the physician has a clear-cut vision of what must be done. Yet, for Steven,[49] "the 'SDM model' should be extended to allow participation in the formulation of treatment options. Therefore, it is potentially relevant to all consultations."

Papers by Towle,[10] Towle and Godolphin,[11] Coulter,[1,7] and the precursors of patient participation in medical decision making are also often cited, though less frequently than publications by Charles and others.[5,6] In 1999, Elwyn and others[33] were the first to test the feasibility of Towle and Godolphin's approach to teach informed shared decision making. They continued quoting Towle and Godolphin in some of their other works.[19,20] Ankum and others[36] also refer to Towle and Godolphin's definition, even if only quickly in the last sentence of their article. Authors such as Bauchner[28] and Mazur[43] cite Towle and Godolphin not with the aim of using their framework but only of mentioning what it is. Concerning Coulter[1,7] arguing in favor of SDM for several years,[50,51] her papers are frequently cited by authors such as Edwards and others,[52] Ankum and others,[36] Bauchner,[28] Emery,[53] Montgomery and others,[54] McAlister,[15] and Sculpher and others[41] to

let the reader understand the general state of mind that prevails in SDM as compared mainly to paternalism. Last, precursors of patient participation in medical decision making are also often quoted. For example, Coulter[1] cites the seminal work of Emanuel and Emanuel[9] when she speaks of SDM, and Charles and others[55] cite Hughes and Larson[56] and Eddy[57] when addressing partnership.

3. Is the Use of the Term SDM Consistent with the Definition Chosen?

Even if we observed that authors who quote Charles and others,[5,6] Coulter,[7] Towle,[10] and/or Towle and Godolphin[11] are actually consistent with the definition of SDM they propose, it seems that others are not, either within a given paper or from one paper to another.

In 2001, Woolf[58] stated that "the trend towards SDM is a welcome advance in helping patients make more informed choices," leading one to think that for the author, SDM is a situation where the patient only has to make decisions. But a few years before, Woolf[59] stated,

> In the special circumstance when the tradeoff between benefits and harms is a subjective 'close call,' when selecting the best choice turns on utilities . . . , a case can be made for seeking the patient's perspective rather than deciding for him or her. The intent is not to force patients to make decisions—they are free to decline the offer and defer to the clinician—but to give them the opportunity.

Several lines further down, he stated, "But there are problems with SDM. Chief among these is that many patients do not want to make decision about their care." Consequently, one may wonder whether for Woolf, SDM is a situation where the physician makes the decision when the patient does not want to.

Holmes-Rovner and others,[60] in an article titled "Implementing Shared Decision-Making in Routine Practice: Barriers and Opportunities," state that "hospitals were provided with a detailed background describing the theory of informed patient decision-making." Do they speak of SDM or of informed decision making, as defined by some authors (Charles and others,[5,6] Gafni and others[14])?

Members of the Foundation for Informed Decision-Making (Weinstein,[61] Chatterton[62]) and users of its Shared Decision-Making Program tools (videos and CD-ROMs)[63–66] primarily cite Kasper and others,[67] leading one to assume that these authors propose a definition of SDM. Yet Mulley and Wennberg, founders of the foundation and sometimes referred to as initiators of SDM, have not defined the concept of SDM in their paper.[67] We nonetheless found a definition on the foundation's Web site (Health Dialog)[68]:

> SDM means partnership with the provider to make the health care decision that is right for the patient. Patient's feelings and preferences play an important role in the patient's treatment decisions, because he with his family will live with the outcomes of that decision. The patient brings important knowledge about himself and his situation, and his doctor brings expertise and judgement based on evidence, training and experience.

Yet this definition does not specify whether the decision is actually shared by patients *and* physicians. Patients may thus be seen as sole decision makers. Consequently, SDM and informed decision making, as defined by Charles and others[5,6] and Gafni and others,[14] might be perceived here as identical. This possible confusion is enhanced by the names given to the foundation (Foundation for *Informed Decision-Making*) and the tools it develops (*Shared Decision-Making* Programs).

4. Authors Who Do Not Provide a Clear or Any Definition or Who Do Not Cite Definitions Given by Others

In 1998, Entwistle and others[69] defined *evidence-informed patient choice* as a

> decision about which health care intervention(s) or pattern of care a person will or will not receive; the person concerned is given research-based information about the effectiveness . . . of at least two alternative interventions; and the person concerned provides some input to the decision-making process (i.e., the decision is in some way shared between health professionals and the patient) . . . . There are basic moral obligations to provide individuals with information and choice about their health care. . . . Second type of argument is based on the assumption (or hope) that informed patient choice will have beneficial outcomes.

This definition is so broad, especially when the authors say that "the decision is in *some way* shared," that it might include physicians making the decisions. Montgomery and others[54] speak of SDM, but their reference to Coulter[1] when saying

that "cardiovascular risk assessment, utility assessment and decision analysis software is becoming increasingly easier to use, and may mean that individual decision analysis will be more common in the future" provides no precise definition.

Sowden and others[70] do not define SDM in their article on information, communication, and shared decision making with people who have cancer, although cancer is a field where SDM is extensively studied.[21,71] Coulter[7] and Charles and others[5] are quoted only to underline the results expected from SDM.

Durand-Zaleski[72] states that "SDM allows the patient to be informed and be part of the decision-making process.... SDM satisfies both the patient, whose preferences are taken into account, and the physician, who has to refer to validated knowledge," but does not further define the term.

Sieber and Kaplan[73] only underline that "SDM involving both patient and the provider is the logical extension of patient-oriented healthcare." Likewise, Benowitz[74] stresses the necessity of implementing SDM in cancer screening but does not define the term, whereas Mort[75] takes a stand in favor of informed decision making but does not define it either.

Last, as regards literature reviews on patient participation, none evokes the term SDM. Benbassat and others[76] and Guadagnoli and Ward[77] speak of general concepts such as patient autonomy, involvement, and self-determination but do not define them.

CONCLUSION

This literature review highlights several issues for those involved in research on shared decision making and those whose aim is to implement it in medical practice.

Several authors clearly define what they mean by *shared decision making* or another term closely related to it. This is essentially the case with Charles and others,[5,6] Coulter,[7] Towle,[10] and Towle and Godolphin,[11] whose definitions of the phenomenon are similar. As shown, the focus of their definitions is placed both on the information exchange between physician and patient and on the involvement of both parties in the decision made. About a third of the authors reviewed cite Charles and others,[5,6] Towle,[10] Towle and Godolphin,[11] and Coulter.[1,7]

Several authors seem to use the term *shared decision making* in an inconsistent manner with the definition they propose, and some use the terms *informed decision making* and *shared decision making* as if they were synonymous, thus leading to confusion. The conceptual difference between these 2 terms, however, has been described by some authors (Charles and others,[5,6] Gafni and others[14]). Last, about a third of the authors do not provide a clear definition as to what is informed decision making and what is shared decision making, nor do they provide a definition or quote authors who have provided one, thus leading to real confusion.

Authors can decide to provide their own definition if they find that the existing definitions are inadequate. However, not defining or citing a definition and not being consistent with one's own definition or the cited one is problematic, hence our call in this article for a clear definition and typology of the terms used.

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