# A systematic review of assessment instruments used in studies on shared decision making

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# Abstract

Shared decision making (SDM) is a model of communication processes that facilitate cooperative decision making between a patient and medical practitioner regarding treatment. The use of assessment instruments is an important way to gain insight into the practice of SDM. In order to fully utilize the various assessment tools available for use, it is important to not only reveal what instruments are used to measure SDM but also shed light on which aspects of SDM are captured by different instruments. However, the instruments currently used to measure SDM are unclear, as are the aspects of SDM processes each instrument reflects. So that, we reviewed assessment instruments used in studies on SDM with the aim of clarifying what aspects of SDM processes each instrument was intended to capture in this study. As a result, we identified 16 assessment instruments used in 115 articles concerning SDM as the main theme. The most commonly used instrument was the OPTION scale, followed by SDM-Q-9. Step 4 ("informing on the benefits and risks of the options") was covered by most instruments, followed by Step 5 ("investigation of the patient's understanding and expectations"). In the future, assessment instruments for SDM will likely be used primarily in areas in which there is considerable uncertainty about evidence, and where multiple options exist. When you assess SDM, it is necessary to be able to select the evaluation indicator that suits the purpose.

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#### 1. Introduction

Shared decision making (SDM) is a model of communication processes that facilitate cooperative decision making between a patient and medical practitioner regarding treatment.<sup>1,2</sup> Towle and Godolphin<sup>3</sup> systematically classified processes involved in SDM as a series of events; their model starts with partnership building between a patient and medical practitioner, followed by subsequent steps that include information provision on the part of the medical practitioner and confirmation of whether the information is appropriately transmitted to the patient, ultimately leading to cooperative decision-making with appropriate follow-up. Each of these processes is meaningful and should be implemented accordingly, as the effectiveness of SDM has been demonstrated in a number of studies.<sup>4-9</sup>

The use of assessment instruments is an important way to gain insight into the practice of SDM. Simon<sup>10</sup> and Scholl<sup>11</sup> investigated a variety of instruments used for the purpose of measuring SDM and identified 19 different instruments. They reported on the methods of measurement employed in each instrument, the

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purpose of their development, and the reliability and validity of each instrument. However, the instruments currently used to measure SDM are unclear, as are the aspects of SDM processes each instrument reflects. In order to fully utilize the various assessment tools available for use, it is important to not only reveal what instruments are used to measure SDM but also shed light on which aspects of SDM are taken by different instruments. If such an understanding could be gained (i.e., aspects of the SDM communication process model each instrument captures), then it would be possible to select an appropriate assessment instrument according to the specific purpose in various clinical settings. The use of assessment instruments may allow for visualization of the practice of SDM, which in turn will help determine optimal communication processes for patients and medical practitioners.

In this study, we reviewed assessment instruments used in studies on SDM with the aim of clarifying what aspects of SDM processes each instrument is intended to capture.

# 2. Methods

This review was conducted according to the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) statement.<sup>12</sup>

# 2-1. Information sources

The following databases were used: MEDLINE PubMed (1950 - present), Cochrane database (1992 - present), Web of Science (1990 - present), Physiotherapy Evidence Database (PEDro; 1999 - present), Occupational Therapy Systematic Evaluation of Evidence (OT seeker; 2003 - present), Cumulative Index to Nursing and Allied Health Literature (CINAHL; 1981 - present), and Ichushi-Web (Ichushi; 1977 - present). Database searches were conducted on March 31, 2016.

#### 2-2. Search term

In order to extract articles of which the main theme was SDM, searches were conducted for titles that included the search term, "shared decision making." This search term was decided through brainstorming among three medical caregivers (physician, physical therapist, and occupational therapist).

# 2-3. Selection criteria for articles

Among articles obtained from the databases, target articles were selected according to the following inclusion criteria: 1) full text is available; 2) written in either English or Japanese; 3) original paper (excluding reviews, review articles, case reports, letters, conference minutes, and commentaries); and 4) published in 1997 and thereafter, i.e., after the definition of SDM was established. Exclusion criteria were 1) no description is provided regarding the instrument used; 2) the instrument used is difficult to obtain; 3) had a unique design (e.g., review article); and 4) the instrument used was originally developed, 5)the studies that targeted students and medical practitioners such as therapists were excluded from the total count of articles.

# 2-4. Data collection and analysis

Selected articles were summarized in a table and reviewed individually by 2 evaluators (NK, SF). Contents reviewed included author, journal, and year of publication. Instruments used to assess the practice of SDM were extracted, and the number of articles in which these instruments were used, and the target of each instrument (respondents), were recorded.

In order to understand what aspects of SDM each instrument captured, content analysis was performed to examine whether questionnaire items of each instrument contained descriptions pertaining to 9 SDM steps (Table 1).<sup>13</sup> There are several concepts that define SDM, e.g., 4 elements proposed by Charles et al.,<sup>1</sup> 7 elements proposed by Towle et al.,<sup>3</sup> and 8 elements proposed by Elwyn et al.,<sup>4</sup> and 9 SDM steps proposed by Kriston L et al.,<sup>13</sup> Among these, we used the 9 steps that are considered most comprehensive. When opinions differed between the evaluators, discussions were repeated until a consensus was reached; if no consensus was reached, a final decision was made through discussions with a 3rd member.

We also analyzed the extracted instruments in terms of targeted diseases. In order to examine what disease area the instrument in each article was used in, we classified the articles based on descriptions within the articles. If there was no clear description of disease name (e.g.,), we excluded the article from the count for the number of diseases when the patient's disease is unknown, and so on.

#### 3. Results

In total, 1,346 articles were extracted from the database searches. Of these, 659 met the inclusion criteria. After applying the exclusion criteria, a total of 115 articles were eligible for analysis (Figure 1). Among these, 16 assessment instruments (scales) were identified (Figure 1).

Among the extracted articles, the most frequently used instrument was the Observing Patient Involvement in Decision Making (OPTION) scale<sup>2</sup> (42 studies), followed by the 9-item Shared Decision-Making Questionnaire (SDM-Q-9)<sup>13</sup> (20 studies), the Decisional Conflict Scale (DCS)<sup>15</sup> (16 studies), and the Control Preference Scale (CPS)<sup>16</sup> (10 studies). Fourteen of the 16 instruments are designed to be responded to by patients alone. The OPTION scale uses a sound recording of scenes of decision-making to obtain responses from a third party. The Shared Decision Making Questionnaire-physician version (SDM-Q-Doc)<sup>18</sup> uses responses of only medical practitioners.

Table 2 shows the results of assessment of SDM processes for each instrument. Among the extracted instruments, proportions of instruments with questionnaire items pertaining to each step of the SDM process are shown in Table 3. Of the 9 SDM steps, the most frequently included in the questionnaire items were Step 4 ("informing on the benefits and risks of the options") and Step 5 ("investigation of the patient's understanding and expectations") (81.3%). Step 6 ("identification of both partners' preferences") and Step 7 ("negotiation") were the second most frequently included steps (68.8%), followed by Step 3 ("presentation of treatment options") (56.3%). SDM-Q-9 covered 8 of the 9 steps, except for Step 9 ("arrangement for follow-up"). None of the instruments covered all 9 steps.

Table 4 shows disease areas in which the extracted instruments were used. Cancer was the most common disease area. In particular, SDM appeared to be prevalent in patients with breast cancer. Mental disorders represented the second most common disease area, followed by musculoskeletal disorders.

## 4. Discussion

In this study, we conducted a systematic literature review to extract assessment instruments concerning SDM in order to examine which aspects of SDM these instruments were intended to capture. Our review yielded 15 instruments, each of which was found to reflect different aspects of SDM.

Ten of the 15 instruments related to SDM matched those previously reported by Simon et al. 10 and Scholl et al. 11 The remaining 5 instruments were newly extracted in the present study and included SDM-Q-Doc, 18 Decisional Regret Scale, 26 Collaborate score, 25 Mappin'SDM, 24 and Man-Son-Hang scale. 28 Three of these (SDM-Q-Doc, Collaborate score, and Mappin'SDM) were developed after Scholl et al. published their review in 2011. With regard to the Decisional Regret Scale and Man-Son-Hang scale, which were developed prior to 2011 and had been used to measure regret and satisfaction at the time of decision-making, it might not have been included in the paper on the subject of "shared decision making" that was the subject of this review since they are intended to measure the results of decision-making rather than assess decision-making processes.

With respect to the 9 steps of SDM subjected to assessment, Step 4 ("information on the benefits and risks of the options") and Step 5 ("investigation of the patient's understanding and expectations) (12 instruments; 80%) were the most frequently included in the extracted instruments, followed by Step 6 ("identification of both partners' preferences") and Step 7 ("negotiation") (10 instruments; 66.7%). Kaiser et al.<sup>30</sup> and Samson et al.<sup>31</sup>reported that, when decisions are made between a physician and patient, it is important for the physician to provide information pertaining to both risks and benefits of treatment so that the patient shares that understanding. As requirements for SDM, Elwyn et al.<sup>32</sup> and Stacey et al.<sup>33</sup> noted the importance of making decisions while taking into consideration patient preferences, as well as risks, benefits,

and uncertainty regarding treatment. The proportion of instruments that included items pertaining to Steps 1, 2, 8, and 9 were low. The reason for this may be that, while the steps are important elements when preparing for SDM and/or reflecting on the processes involved, some aspects of these elements are difficult to grasp. Thus, it is likely that these steps were not extracted as items of the instruments. On the other hand, the US Preventive Services Task Force<sup>34</sup> states that patients should understand their disease (seriousness of symptoms) and risks to be avoided, as well as the risks and benefits of treatment options and the uncertainty of alternatives, and contemplate what medical recipients value in decision making. In the present study, although the proportion of instruments that focused on presupposed elements or post-decisional factors of SDM (i.e., Steps 1, 2, 8, and 9) was low, those steps are considered important in light of the fact that going through a process of communication is the essential part of SDM.

Among the 16 instruments examined in this study, SDM-Q-9 included most steps; however, none of the instruments covered all 9 steps. One possible reason for this is that there are separate instruments for evaluating SDM processes and outcomes. The API, Decisional Registry Scale, and the Man-Son-Hang scale were originally developed to measure the outcomes of SDM, i.e., what changes are brought about as a result of practicing SDM. Thus, these instruments are not intended to evaluate the processes of SDM. Therefore, it is understandable that the extracted instruments did not cover all 9 steps. As our findings suggest, instruments for evaluating SDM differ in what they measure according to the purpose for which they were created, 35 and thus, it is necessary to select one that suits the objective of the evaluation. When selecting an instrument to assess SDM, we should first determine whether the subject of interest is the process or outcome of SDM; for the former, there is a need to clarify which one of the 9 steps is of particular focus. This would then allow for selection of the appropriate assessment instrument for the SDM process of interest.

The analysis of disease areas for which the extracted instruments were used revealed cancer and mental disorders to be most common. According to Whitney et al., <sup>36</sup> SDM is best suited for cases in which treatment results are highly uncertain (i.e., multiple options are available); cancer and mental disorders represent such areas. On the other hand, the role of SDM in areas with relatively high evidence reliability (i.e., there is one particular treatment that is expected to yield favorable outcomes) is smaller. In such areas, the communication style likely adopted by medical practitioners is informed consent. In the future, assessment instruments for SDM will likely be used primarily in areas in which there is considerable uncertainty about evidence, and where multiple options exist.

This study has several limitations. First, the present study was conducted using only literature databases that were available on the Internet. However, as we used 6 databases, the risk of missing important articles is likely to be small. Second, the articles assessed in this study included those pertaining to the development of assessment instruments; however, with regard to those, we did not examine what treatment scenes might be appropriate. Third, literature searches were conducted in March 2016. Since previous reviews targeted articles published up to 2011, our review is meaningful in that it provides updated information. Nonetheless, further updates using information from more recent literature are warranted.

#### Conclusion

We identified 16 assessment instruments used in 115 articles concerning SDM as the main theme. The most commonly used instrument was the OPTION scale, followed by SDM-Q-9. Step 4 ("informing on the benefits and risks of the options") was covered by most instruments, followed by Step 5 ("investigation of the patient's understanding and expectations"). Cancer and mental disorders represented areas in which these instruments were most frequently used.

Table 1.Process model of shared decision making

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Table 2.Assessment instruments and steps covered (of 9 steps)

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Table 3.Percentage of questions about process model of SDM (9 steps) included

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Table 4.Diseases for which the evaluation index was used

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Figure 1.Study flow diagram

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