A qualitative systematic review of internal and external influences on shared decision-making in all health care settings

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Review question/objective

The objective of this review is to identify and synthesize the best available evidence related to the meaningfulness of internal and external influences on shared-decision making for adult patients and health care providers in all health care settings.

The specific questions to be answered are:

- What are the internal and external influences on shared decision making from the perspective of adult patients in all health care settings?
- What are the internal and external influences on shared decision making from the perspective of health care providers caring for adult patients in all health care settings?

Background

Patient-centered care is emphasized in today's healthcare arena. This emphasis is seen in the works of the International Alliance of Patients' Organizations (IAOP) who describe patient-centered healthcare as care that is aimed at addressing the needs and preferences of patients.[1] The IAOP presents five principles which are foundational to the achievement of patient-centered healthcare: respect, choice, policy, access and support, as well as information.[1] These five principles are further described as:

- respect for the patient's needs, preferences, values, autonomy, and independence;
- the right of the patient to have a choice to participate as a partner in making healthcare decisions based on their individual abilities and preferences;
- meaningful and active involvement in healthcare policy-making through sharing in decision-making to ensure that patients are at the center of the policy design;
- support of a patient's access to safe, quality and appropriate services; and
- the development and offering of age appropriate, linguistically, educationally, and culturally designed information that will enable the individual patient to make decisions about their healthcare needs.

Within the description of these five principles the idea of shared decision-making is clearly evident.

The concept of shared decision-making began to appear in the literature in the 1990s.[2] It is defined as a "process jointly shared by patients and their health care provider. It aims at helping patients play an active role in decisions concerning their health, which is the ultimate goal of patient-centered care."[3(p.23)] The details of the shared decision-making process are complex and consist of a series of steps including:

- the recognition that a decision can or must be made;
- identifying the possible courses of action;
- listing the pros, cons, and other characteristics of each possibility;
- comparing the options and identifying one as probably better than the rest;
- accepting or rejecting options resulting in the final choice;
- authorization of the final choice; and
- implementation of that choice.[4]

Three overall representative decision-making models are noted in contemporary literature. These three models include: paternalistic, informed decision-making, and shared decision-making.[5] The paternalistic model is an autocratic style of decision-making where the healthcare provider carries out the care from the perspective of knowing what is best for the patient and therefore makes all decisions. The informed decision-making model takes place as the information needed to make decisions is conveyed to the patient and the patient makes the decisions without the healthcare

provider involvement.[5] Finally, the shared decision-making model is representative of a sharing and a negotiation towards treatment decisions.[5] Thus, these models represent a range with patient non-participation at one end of the continuum to informed decision making or a high level of patient power at the other end.[5] Several shared decision-making models focus on the process of shared decision-making previously noted. A discussion of several process models follows below.

Charles et al.[5] depicts a process model of shared decision-making that identifies key characteristics that must be in evidence. The patient shares in the responsibility with the healthcare provider in this model. The key characteristics included:

- the participation of at least two parties,
- both parties take steps to participate in the process of treatment decision-making,
- information sharing occurs as a prerequisite to share in decision-making,
- an ultimate decision is made, and
- both parties agree to the decision.

This model illustrates that there must be at least two individuals participating, however, family and friends may be involved in a variety of roles such as the collector of information, the interpreter of this information, coach, advisor, negotiator, and caretaker.[5,6] This model also depicts the need to take steps to participate in the shared decision-making process. To take steps means that there is an agreement between and among all involved that shared decision-making is necessary and preferred. Research about patient preferences, however, offers divergent views. The link between patient preferences for shared decision-making and the actuality of shared decision-making in practice is not strong.[5] Research concerning patients and patient preferences on shared decision-making points to variations depending on age, education, socio-economic status, culture, and diagnosis.[7-12]

Healthcare providers may also hold preferences for shared decision-making; however, research in this area is not as comprehensive as is patient focused research.[13] Elwyn et al.[14] explored the views of general practice providers on involving patients in decisions. Both positive and negative views were identified ranging from receptive, noting potential benefits, to concern for the unrealistic nature of participation and sharing in the decision-making process.[14] An example of this potential difficulty, from a healthcare provider perspective, is identifying the potential conflict that may develop when a patient's preference is different from clinical practice guidelines.[15] This is further exemplified in healthcare encounters when a situation may not yield itself to a clear answer but rather lies in a grey area. These situations are challenging for healthcare providers.[12]

The notion of information sharing as a prerequisite to shared decision-making offers insight into another process. The healthcare provider must provide the patient the information that they need to know and understand in order to even consider and participate in the shared decision-making process. This information may include the disease, potential treatments, consequences of those treatments, and any alternatives, which may include the decision to do nothing. Without knowing this information the patient will not be able to participate in the shared decision-making process. The complexity of this step is realized if one considers what the healthcare provider needs to know in order to first

assess what the patient knows and does not know, the readiness of the patient to participate in this educational process and learn the information, as well as, the individual learning styles of the patient taking into consideration the patient's ideas, values, beliefs, education, culture, literacy, and age. Depending on the results of this assessment the health care provider then must communicate the information to the patient. This is also a complex process that must take into consideration the relationship, comfort level, and trust between the healthcare provider and the patient.[16]

Finally, the treatment decision is reached between both the healthcare provider and the patient. Charles et al.[5] portrays shared decision-making as a process with the end product, the shared decision, as the outcome. This outcome may be a decision as to the agreement of a treatment decision, no agreement reached as to a treatment decision, and disagreement as to a treatment decision. Negotiation is a part of the process as the "test of a shared decision (as distinct from the decision-making process) is if both parties agree on the treatment option."[5(p.688)]

Towle and Godolphin[17] developed a process model that further exemplifies the role of the healthcare provider and the patient in the shared decision-making process as mutual partners with mutual responsibilities. The capacity to engage in this shared decision-making rests, therefore, on competencies including knowledge, skills, and abilities for both the healthcare provider and the patient. This mutual partnership and the corresponding competencies are presented for both the healthcare provider and the patient in this model. The competencies noted for the healthcare provider for shared decision making include:

1. Develop a partnership with the patient.
2. Establish or review the patient's preferences for information.
3. Establish or review the patient's preferred role in decision-making.
4. Ascertain and respond to the patient's ideas, concerns, and expectations.
5. Identify choices and evaluate the research evidence.
6. Present evidence, taking into account competencies 2 and 3, in a way that helps the patient to reflect on and assess the impact of alternative decisions with regard to his or her values and lifestyle.
7. Negotiate a decision in partnership with the patient and resolve conflict.
8. Agree on an action plan and complete arrangements for follow-up.[17]

Patient competencies include:

1. Define the preferred health care provider-patient relationship.
2. Find a healthcare provider and establish, develop, and adapt a partnership.
3. Articulate health problems, feelings, beliefs, and expectations in an objective and systematic manner.
4. Communicate in order to understand and share relevant information.

5. Access information.
6. Evaluate information.
7. Negotiate decisions, give feedback, resolve conflict, and agree on an action plan.[17]

This model illustrates the shared decision-making process with emphasis on the role of the healthcare provider and the patient very similar to the prior model.[5] This model, however, gives greater emphasis to the process of the co-participation of the healthcare provider and the patient. The co-participation depicts a mutual partnership with mutual responsibilities that can be seen as "reciprocal relationships of dialogue."[18(p. 1297)] For this to take place the relationship between and among the participants of the shared decision-making process is important along with other internal and external influences such as communication, trust, mutual respect, honesty, time, continuity, and commitment.[18-21] Cultural, social, and age group differences; evidence; and team and family are considered within this model.

Elwyn et al.[22] presents yet another model that depicts the shared decision-making process; however, this model offers a view where the healthcare provider holds greater responsibility in this process. In this particular model the process focuses on the healthcare provider and the essential skills needed to engage the patient in shard decisions. The competencies outlined in this model include:

1. Implicit or explicit involvement of patients in the decision-making process.
2. Explore ideas, fears, and expectations of the problem and possible treatments.
3. Portrayal of equipoise and options.
4. Identify preferred format and provide tailor-made information.
5. Checking process: Understanding of information and reactions.
6. Checking process: Acceptance of process and decision-making role preference, involving the patient to the extent he or she desires to be involved.
7. Make, discuss or defer decisions.
8. Arrange follow-up.[22]

The healthcare provider must demonstrate knowledge, competencies, and skills as a communicator. The skills for communication competency require the healthcare provider to be able to elicit the patient's thoughts and input regarding treatment management throughout the consultation. The healthcare provider must also demonstrate competencies in assessment skills beyond physical assessment that includes the ability to assess the patient's perceptions and readiness to participate.[23] In addition, the healthcare provider must be able to assess the patient's readiness to learn the information that the patient needs to know in order to fully engage in the shared decision-making process, assess what the patient already knows, what the patient does not know, and whether or not the information that the patient knows is accurate. Once this assessment is completed the healthcare provider then must draw on his/her knowledge, competencies, and skills necessary to teach the patient what the patient needs to know to be informed. This facilitates the notion of the tailor-made

information noted previously.[16,22,24] The healthcare provider also requires competencies in how to check and evaluate the entire process to ensure that the patient does understand and accept with comfort not only the plan being negotiated but the entire process of sharing in decision-making.[14,22] In addition to the above, there are further competencies such as competence in working with groups and teams, competencies in terms of cultural knowledge, competencies with regard to negotiation skills, as well as, competencies when faced with ethical challenges.[16]

Shared decision-making has been associated with autonomy,[25] empowerment,[26] and effectiveness and efficiency.[27] Both patients and health care providers have noted improvement in relationships[28] and improved interactions[29] when shared decision-making is in evidence. Along with this improved relationship and interaction enhanced compliance is noted.[20,30] Additional research points to patient satisfaction[31,32] and enhanced quality of life.[33] There is some evidence to suggest that shared decision-making does facilitate positive health outcomes.[34-36]

In today's healthcare environment there is greater emphasis on patient-centered care that exemplifies patient engagement, participation, partnership, and shared decision-making. Given the shift from the more autocratic delivery of care to the shared approach there is a need to more fully understand the what of shared decision-making as well as how shared decision-making takes place along with what internal and external influences may encourage, support, and facilitate the shared decision-making process. These influences are intervening variables that may be of significance for the successful development of practice-based strategies that may foster shared decision-making in practice. The purpose of this qualitative systematic review is to identify internal and external influences on shared decision-making in all health care settings.

A preliminary search of the Joanna Briggs Library of Systematic Reviews, MEDLINE, CINAHL, and PROSPERO did not identify any previously conducted qualitative systematic reviews on the meaningfulness of internal and external influences on shared decision-making.

Keywords

Shared decision making, qualitative, experiences

Inclusion criteria

Types of participants

This review will consider studies that include adult patients (18 year of age or older) of all races and ethnicities regardless of health status or condition and health care providers, including but not limited to nurses, advanced practice nurses, and physicians, caring for such patients who are involved in a shared decision-making process.

Phenomena of interest

This review will consider studies that investigate the internal and external influences on shared decision-making including but not limited to communication, trust, mutual respect, honesty, time, continuity, consistency, commitment, autonomy, empowerment, age, education, socio-economic status, culture, and diagnosis for adult patients and health care providers in all health care settings, where shared decision-making is defined as a joint process characterized by sharing and negotiating between the patient and health care provider that results in a mutually agreed upon decision.

Types of studies

This review will consider interpretive studies that draw on the internal and external influences on shared decision making on adult patients and health care providers including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

Search strategy

The search strategy aims to find both published and unpublished studies. A three-step search strategy will be utilized in this review. An initial limited search of MEDLINE and CINAHL will be undertaken followed by an analysis of the text words contained in the title and abstract, and of the index terms used to describe an article. A second search using all identified keywords and index terms will then be undertaken across all included databases. Thirdly, the reference list of all identified reports and articles will be searched for additional studies. Studies published in English language will be considered for inclusion in this review. Studies published from the beginning of the searched databases to the current date of the review will be considered for inclusion in this review.

The databases to be searched include:

PubMed, CINAHL, EMBASE, Healthsource: Nursing/Academic Edition, PsychInfo, Scopus

The search for unpublished studies will include:

Proquest Dissertations and Theses Database, MEDNAR, Virginia Henderson International Nursing Library, New York Academy of Medicine

Initial keywords to be used will be:

Shared decision-making, influence, qualitative

Assessment of methodological quality

Papers selected for retrieval will be assessed by two independent reviewers for methodological validity prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix I). Any disagreements that arise between the reviewers will be resolved through discussion, or with a third reviewer.

Data collection

Data will be extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix II). The data extracted will include specific details about the phenomena of interest, populations, study methods and outcomes of significance to the review question and specific objectives.

Data synthesis

Qualitative research findings will, where possible be pooled using JBI-QARI. This will involve the aggregation or synthesis of findings to generate a set of statements that represent that aggregation, through assembling the findings rated according to their quality, and categorizing these findings on the basis of similarity in meaning. These categories are then subjected to a meta-synthesis in order to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice. Where textual pooling is not possible the findings will be presented in narrative form.

Conflicts of interest

None to disclose.

Acknowledgements

None.

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Appendix I: Appraisal instruments

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: ☐ Include ☐ Exclude ☐ Seek further info. ☐

Comments (Including reason for exclusion)

_____

_____

_____

Appendix II: Data extraction instruments

JBI QARI Data Extraction Form for Interpretive & Critical Research

Reviewer _____ Date _____

Author _____ Year _____

Journal _____ Record Number _____

Study Description

Methodology

Method

Phenomena of interest

Setting

Geographical

Cultural

Participants

Data analysis

Authors Conclusions

Comments

Complete Yes ☐ No ☐

Findings	Illustration from Publication (page number)	Evidence		
		Unequivocal	Credible	Unsupported

Extraction of findings complete Yes ☐ No ☐