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

Marie Truglio-Londrigan PhD, RN^{1,2}
Jason T Slyer DNP, RN, FNP-BC^{1,2,3}
Joanne K Singleton PhD, RN, FNP-BC^{1,2}
Priscilla S Worral PhD, RN^{1,2,4}

- 1. Pace University, College of Health Professions, New York, NY.
- The Northeast Institute of Evidence Synthesis and Translation(NEST): A Collaborating Center of the Joanna Briggs Institute
- 3. Joanna Briggs Institute, Faculty of the Health Sciences, The University of Adelaide
- 4. Upstate University Hospital, Upstate Medical University Health System, Syracuse, NY

Corresponding author:

Marie Truglio-Londrigan mlondrigan@pace.edu

Executive summary

Background

Shared decision-making is a process that patients and healthcare providers actively engage in. The aim of this process is for patients to have a participatory role in the shared decisions pertaining to their care. There are many internal and external influences that may encourage, support, and facilitate the shared decision-making process. These influences are intervening variables that may foster shared decision-making in practice.

Objective

To synthesize the best available evidence on internal and external influences on shared decision-making for adult patients and healthcare providers.

Inclusion criteria

Types of participants

Adult patients and healthcare providers who are involved in a shared decision-making process.

Phenomena of interest

Internal and external influences on shared decision-making.

Types of studies

Qualitative studies, including designs such as phenomenology, grounded theory, ethnography, action research, and qualitative descriptive.

Search strategy

A three-step search strategy was used to identify published and unpublished English language qualitative research studies though November 2012.

Methodological quality

Two independent reviewers, using the Qualitative Assessment and Review Instrument from the Joanna Briggs Institute, assessed retrieved papers for methodological quality.

Data collection

Data were extracted using the Joanna Briggs Institute's Qualitative Assessment and Review Instrument data extraction tool.

Data synthesis

Data were synthesized using the Joanna Briggs Institute approach to meta-synthesis by meta-aggregation using the Qualitative Assessment and Review Instrument software package.

Results

Eight studies were included in this review. From these studies, 61 study findings with a credibility assessment of unequivocal or credible were subsequently aggregated into 11 categories on the basis of similarity of meaning. These categories yielded three synthesized findings of influences on shared decision-making: *Patient-centered care*, *Bridging the knowledge gap*, and *Dimensions of decision-making*.

Conclusions

Patient-centered care involves the development of a relationship based in trust and facilitated by communication between the patient and the healthcare provider. Bridging the knowledge gap takes place as the healthcare provider and the patient work in a partnership to gather information to identify the specific educational needs of each patient, while identifying and addressing barriers. Decision-making may take shape and form in varying dimensions from active participation and sharing to one where the healthcare provider assumes a more paternalistic approach or the patient assumes an autonomous role. Aspects of patient-centered care where a trusting, compassionate relationship is forged between patient and provider have the potential to both facilitate and support the achievement of a shared decision.

Keywords

Shared decision making, qualitative, experiences

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. 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. 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 decisionmaking 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 healthcare 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. depicts a process model of shared decision-making that identifies key characteristics that must be in evidence.⁵ The patient shares in the responsibility with the healthcare provider in this model. The key characteristics include:

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.⁷⁻¹³

Healthcare providers may also hold preferences for shared decision-making; however, research in this area is not as comprehensive as is patient-focused research.¹⁴ Elwyn et al. explored the views of general practice providers on involving patients in decisions.¹⁵ 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.¹⁵ 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.¹⁶ 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.¹¹

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 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 healthcare provider must then 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.¹⁷

Finally, the treatment decision is reached between both the healthcare provider and the patient. Charles et al. portrays shared decision-making as a process with the end product, the shared decision, as the outcome.⁵ This outcome may be a decision as to the agreement on 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 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.

Patient competencies include:

- 1. Define the preferred healthcare 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 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.

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."^{19(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.¹⁹⁻²² Cultural, social, and age group differences; evidence; and team and family are considered within this model.

Elwyn et al. 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.²³ In this particular model, the process focuses on the healthcare provider and the essential skills needed to engage the patient in shared 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.

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 include the ability to assess the patient's perceptions and readiness to participate.²⁴ In addition, the healthcare provider must be able to assess the patient's readiness to learn the information that the patient needs to know 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 healthcare providers then must draw on their knowledge, competencies, and skills necessary to teach patients what they need to know to be informed. This facilitates the notion of the tailor-made information noted previously. 17, 23, 25 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. $^{15,\ 23}$ 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. 17

Shared decision-making has been associated with autonomy, empowerment, effectiveness and efficiency. Both patients and healthcare providers have noted improvement in relationships and interactions when shared decision-making is in evidence. Along with this improved relationship and interaction, enhanced adherence and compliance is also noted. Additional research points to

patient satisfaction and enhanced quality of life.³¹⁻³³ There is some evidence to suggest that shared decision-making does facilitate positive health outcomes.^{12,34,35}

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.

Internal influences are those factors that exist within the patient and/or provider that may have an impact on the ability of shared decision-making to take place and be sustained. Examples of internal influences for the health care provider include, but are not limited to, their awareness and beliefs about shared decision-making, interpersonal skills and competence in sharing information with patients, self-efficacy, and lack of motivation. Examples of internal influences for the patient include, but are not limited to, their awareness of shared decision-making, literacy and educational attainment, trust for the provider, self-efficacy, and state of health.

External influences are those factors that are external to the patient and/or the provider that may have an influence on the ability of shared decision-making to take place and be sustained. Examples of these external influences include, but are not limited to, contextual resources such as time, cost restraints, and access to needed information in the form of education that may be shared with the patient.

A preliminary search of the Joanna Briggs Institute Database 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.

The objectives, inclusion criteria, and methods of analysis for this review were specified in advance and documented in a protocol.³⁶

Objectives

The objective of this review was 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 healthcare providers in all health care settings.

The specific questions to be answered were:

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

Inclusion criteria

Types of participants

This review considered studies that include adult patients (18 years of age or older) of all races and ethnicities regardless of health status or condition and healthcare 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 considered 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 healthcare 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 healthcare provider that results in a mutually agreed upon decision.

Types of studies

This review considered interpretive studies that draw on the internal and external influences on shared decision-making on adult patients and healthcare providers including, but not limited to, designs such as phenomenology, grounded theory, ethnography, action research, qualitative description, and feminist research.

Search strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was utilized in this review. An initial limited search of MEDLINE and CINAHL was 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 was then undertaken across all included databases. Thirdly, the reference lists of all identified reports and articles were searched for additional studies. Studies published in the English language were considered for inclusion in this review. Studies published from the beginning of the searched databases to the current date of the review were considered for inclusion in this review.

The databases searched include:

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

The search for unpublished studies included:

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

Initial keywords used were:

Shared decision-making, influence, qualitative

Full list of keywords:

Qualitative research, qualitative, decision making, shared decision making, shared decision*, shared medical decision, physician patient communication, patient provider communication, patient participation, influence*, factor*, view*

See Appendix I for the detailed search strategy used in each database searched.

Assessment of Methodological quality

Papers selected for retrieval were 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 II). Any disagreements that arose between the reviewers were resolved through discussion, or with a third reviewer.

Data collection

Data were extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix III). The data extracted included 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 were, where possible, pooled using JBI-QARI. This involved 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 were then subjected to a meta-synthesis by meta-aggregation to produce a single comprehensive set of synthesized findings that can be used as a basis for evidence-based practice.

Review results

Description of studies

A comprehensive search of the literature found 8923 papers, including duplicates. Five additional papers were identified from a review of the references lists of relevant studies. After review of the titles, keywords, and abstracts, 8825 papers were excluded. The full texts of 103 papers were retrieved for further review and assessed against the inclusion criteria. An additional 87 papers were excluded at this stage for not meeting the inclusion criteria of this review. Many of these explored decision-making, but not specifically a shared decision-making process. The 16 remaining papers underwent critical appraisal. Eight were excluded due to a lack of methodological rigor, leaving eight papers for inclusion in this review. See Figure 1 for a summary of the selection process. Details of the included studies such as study methodology, phenomena of interest, settings, participants, data analysis and conclusion can be found in Appendix IV. A list of those papers excluded after retrieval of the full text and the reason for exclusion can be found in Appendix V.

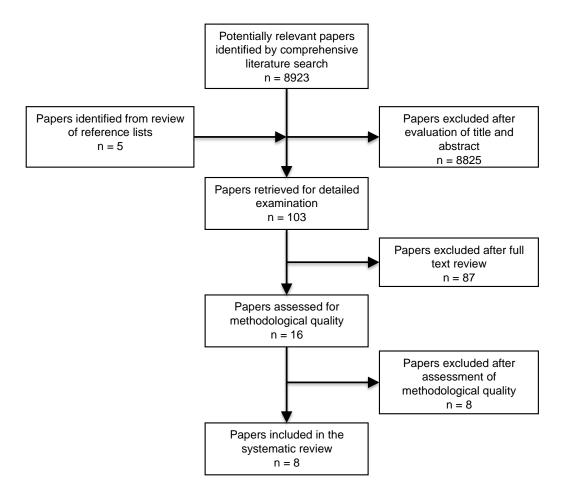


Figure 1: Selection process of articles to be included in the review.

Methodological quality

Two reviewers (JTS, MTL), using the critical appraisal instrument from JBI-QARI (Appendix II), independently assessed 16 articles for their methodological quality. A third reviewer was engaged to resolve any disagreements. The reviewers had pre-determined that if an article did not meet the criteria for questions 8 and 10 on the JBI-QARI appraisal instrument, it would be excluded from the review; however, as the majority of studies selected for inclusion were qualitative descriptive in nature, the reviewers agreed that as long as there was an adequate representation of the participants' voices and the conclusions drawn by the study authors flowed from the analysis of the presented data, a study was deemed to have sufficient quality for inclusion in this review.

Eight articles were excluded based on methodological quality (Appendix VI). These articles had an inadequate representation of participant voices. Two studies categorized their findings according to a predetermined model; the themes based on this model would not add a significant contribution to this systematic review. Eight studies were included in the systematic review. Details of the critical appraisals for the included studies can be found in Table 1.

Table 1: Methodological quality

Number of studies included and excluded

Number of studies included	Number of studies excluded					
8	8					

Final Assessment Table

Citation	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Edwards et al ³⁷	U	Y	Y	Y	Y	N	N	Y	Y	Y
Lown, Clark, Hanson ³⁸	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Mahone, et al. ³⁹	Υ	Y	Y	Y	Y	N	N	Y	Y	Y
Peek et al. ⁴⁰	U	Y	N	Y	Y	N	N	Y	Y	Y
Seale et al. ²¹	Y	Y	Y	Y	Y	N	N	Y	U	Y
Shepherd, Butoe, Tattersall ¹¹	C	Y	Y	Y	Y	N	N	Y	Y	Y
Truglio-Londrigan ¹⁷	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Upton et al. ³⁰	U	Y	Y	Y	Y	N	N	Y	N	Y
%	50.0	100	87.5	100	100	12.5	12.5	100	75	100

Results

Eight articles were determined to be of reasonable methodological quality and were included in this systematic review.

11,17,21,30,37-40 Five articles explored provider perspectives on facilitators and barriers to shared decision-making;
11,17,21,30,37 one article explored facilitators and barriers from the patient's perception;
and two articles included both patient and provider perspectives.
Possible 11,17,21,30,37 one study used a phenomenological approach;
the other seven studies were qualitative descriptive in

nature. 11,17,21,30,37-39 Details of the included studies can be found in Appendix IV. A short description of the eight studies follows.

Edwards et al. conducted a qualitative descriptive study to identify the views of professionals skilled in shared decision-making, exploring both opportunities and challenges for implementation.³⁷ Focus group exit interviews involving general practitioners (two focus groups with nine general practitioners in each group) occurred two months after the completion of an explanatory trial that evaluated a training intervention for shared decision-making and risk communications.

Lown, Clark, and Hanson conducted a qualitative descriptive study using focus groups composed of 85 patients and primary care physicians to explore both the patients' and physicians' perspectives about attitudes and behaviors during the patient-physician encounter where shared decision-making occurs.³⁸

Mahone et al. conducted a qualitative descriptive study using seven focus groups to study the attitudes and behaviors of patients and physicians that facilitate shared decision-making in a local mental health clinic.³⁹

Peek et al. conducted a qualitative research design using a phenomenological methodology to come to understand the barriers and facilitators to shared decision-making among African-Americans with diabetes. Twenty-four individual in-depth semi-structured interviews followed by five focus groups were conducted. Participants were followed by primary care physicians at an urban academic medical center.

Seale et al. conducted a qualitative descriptive study using semi-structured interviews.²¹ The perspectives of 21 general adult psychiatrists on consultations involving anti-psychotic medications were noted. These perspectives included facts and descriptions concerning the extent to which shared decision-making is reported in everyday working practice. Psychiatrists reported methods for creating therapeutic alliances that included negotiation of medication use and consideration of the impact of coercion were also described.

Shepherd, Butow, and Tattersall conducted a qualitative descriptive study. 11 Semi-structured telephone interviews with 22 cancer physicians revealed facts and a description of what influences cancer physicians to involve their patients in reaching treatment decisions.

Truglio-Londrigan conducted a qualitative descriptive study with semi-structured telephone interviews.¹⁷ Interviews were performed with 10 home-care nurses looking at their past experience of shared decision-making with patients in home-care from the nurse's perspective.

Upton et al. conducted a qualitative exploratory study using semi-structured interviews involving 20 primary care nurses' views on shared decision-making and explored how sharing decisions with patients can be facilitated.³⁰

A total of 61 findings with supporting illustrations were extracted from the eight included papers. Each finding was assigned a level of credibility: Unequivocal [U], Credible [C], or Unsupported [US], according to the criteria from the Joanna Briggs Institute (See Appendix VII for more details). The study findings are listed in Appendix VIII. Five findings were determined by the reviewers to be unsupported by the illustrations provided in the article. One finding was derived from a study question

that was unrelated to the objectives of this review. These unsupported or unrelated findings are reported in Appendix VIII but were excluded from the meta-synthesis.

Results of the meta-synthesis of qualitative research findings

For this meta-synthesis, voices from all studies, provider perspectives and patient perspectives, were synthesized collectively and simultaneously as the reviewers deemed shared decision-making to take place relationally, and as such the results are also presented collectively. The reviewers identified that both internal and external influences for shared decision-making were offered by both patients and providers.

Meta-synthesis of studies included in the review generated three synthesized findings. These synthesized findings were derived from 61 study findings with a credibility assessment of either Unequivocal or Credible that were subsequently aggregated into 11 categories on the basis of similarity of meaning. The categories that emerged from the study findings were:

- Patient reflection: patient reflection facilitates the patient being able to contemplate the alternatives and then potentially returning to the healthcare provider with decision pertaining to their care.
- Trust: trust, as a concept, facilitates the shared decision-making process as the patient sees the healthcare provider as being available, accessible, and approachable.
- Patient education: patient education is essential so that the patient has the information that they need to know to participate in shared decision-making.
- Provider reflection: provider reflection is the turning inward process that the provider engages in. This process encourages a questioning of the experience and coming to an understanding of alternative options for the patient.
- Patient/provider relationship: relationships unfold between those involved in the shared decision-making experience. The relationship is a connection that is developed and sustained over time exemplified by trust, respect, caring, and understanding.
- Barriers: barriers have the potential to block shared decision-making. Barriers may block actions of the provider and/or the patient. Barriers may be intra-personal, inter-personal, or extra-personal.
- Negotiation: negotiation is a process that takes place in the shared decision-making experience where those involved participate in a give and take dialogue. The dialogue involves sharing of information including the disclosure of risks, uncertainties, and challenges leading to the agreed upon choice.
- Provider skills: provider skills involves having the information that patients need to know to be
 active in the shared decision-making experience as well as being skillful in imparting the
 needed information to the patient.
- Paternalism: paternalism is when the provider assumes a protective and directive stance in an experience of decision-making. The stance is either assumed by the provider under their sole discretion or the patient grants the provider permission to be paternalistic.

- Patient autonomy: patient autonomy is the state of being able to be independently active, responsible, and accountable for shared decision-making.
- Patient assessment: assessment is the investigation process whereby information is gathered. The information assists the providers in knowing those involved in the shared decision-making experience. The provider applies the information gathered to determine what decision needs to be made, what information the patient needs to know to make the decision, how to deliver the information, what role the patient wishes to assume in the shared decision-making experience, and how to evaluate the outcomes.

Meta-synthesis 1: Patient-centered care

This meta-synthesis is comprised of 15 findings placed into four categories (Figure 2). Healthcare providers need to be aware that foundational to the shared decision-making experience is a patient/healthcare provider relationship that is based in trust and respect, and that the care offered is individualized for each patient based on shared decisions.

The first category, *Patient Reflection*, is comprised of two findings. *Patient factors: Fear and denial* provides insight on how patient reflection is important; however, many patients may be fearful and, as a result, do not want to hear what they need to know to make decisions. *Patient: understands and expresses feelings, preferences, and information about self* demonstrates how patients must be in touch with their ideas, emotions, feelings, and understanding in order to share of themselves and be receptive to shared decision-making.

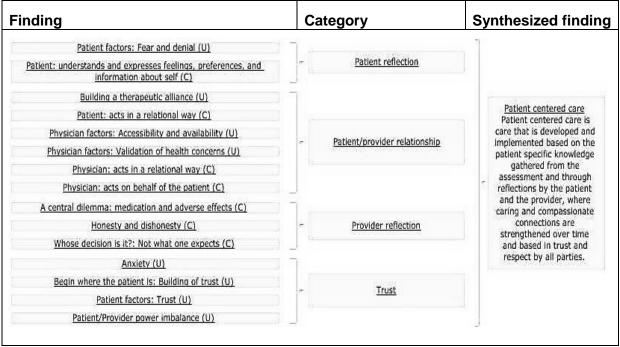


Figure 2: Patient-centered care

The second category, *Patient/Provider Relationship*, is comprised of six findings. *Building a therapeutic alliance* highlights the need for a co-operative relationship for shared decision-making where there is a partnership as evidenced by negotiated agreements. *Physician factors: Accessibility and availability* illustrates how physicians (healthcare providers), who take time to see their patients

and hear what they have to say, and most importantly listen, create a context for shared decision-making and the building of the co-operative partnering relationship. *Physician factors: Validation of health concerns* illustrates how physicians (healthcare providers) need to listen, hear, and understand patient concerns so that there is a validation leading to mutual understanding culminating in shared decision-making. *Patient: acts in a relational way* and *Physician: acts in a relational way* both highlight how the physician as the healthcare provider and the patient actively seek a personal connection with each other based on trust and respect, enabling and sustaining the shared decision-making experience. *Physician: acts on behalf of the patient* provides insight on how once a decision is negotiated, the physician (healthcare provider) will act on behalf of the patient to assist the patient in successfully implementing their shared decision.

The third category, *Provider Reflection*, is comprised of three findings. *A central dilemma: Medication and adverse effects* provides insight into the reflections of providers when it comes to some treatment modalities with potent side effects and how reflective practice is very important in terms of the type and amount of information to tell patients. In other words, how does the provider strike a balance given a particular medication that may offer the best treatment but the worst side effects? How the provider provides this information in the best way possible signals the complexity of the provider's reflections in the shared decision-making experience. *Honesty and dishonesty* is reflective of the previous finding in this category; however, there is added emphasis on the importance of reflection and the value of honesty when working with patients about risks and adverse effects and the importance of trust (noted in the upcoming category). The reflective component is noted in the need to be honest but reflecting on how to be honest while not focusing too much on the negatives. *Whose decision is it?*: *Not what one expects*, highlights how, in the shared decision-making experience, sometimes patients' decisions are not in line with the healthcare providers' and how there needs to be a soul searching process in these experiences that may require a re-negotiation and even seeking outside consultations.

The fourth category, *Trust*, is comprised of four findings. *Anxiety* highlights how some patients are unable to take in any information for shared decision-making because they may feel so overwhelmed with their diagnosis; however, there is another side of shared decision-making in that the active participation may in fact relieve a patient of the paralysis they feel with anxiety. *Patient/Provider power imbalance* provides insight into the sense of powerlessness that exists when there is a power imbalance between the healthcare provider and the patient. This imbalance facilitates a sense of not having a right to ask questions, being afraid to speak, and feelings of discomfort with authority. *Patient factors: Trust* highlights that when the healthcare provider takes time to talk, listen, and ask questions, the patient develops a sense of comfort, whereby, they feel more willing and able to ask questions and participate in shared decision-making. *Begin where the patient is: Building of trust* again highlights that trust is built over time within the context of a relationship where information is shared and processed.

The categories were then aggregated to give the synthesized finding: *Patient-Centered Care* (Figure 2). This care is developed and implemented based on the patient specific knowledge gathered from the assessment and through reflections by the patient and the provider, where caring and compassionate connections are strengthened over time and based in trust and respect by all parties.

Meta-synthesis 2: Bridging the knowledge gap

This meta-synthesis is comprised of 28 findings placed into four categories (Figure 3). Healthcare providers must be aware that there are multiple barriers to shared decision-making. Barriers may be externally imposed as they are environmentally derived and/or patient, family or healthcare provider derived. Barriers, once identified via assessments, have the potential to be addressed depending on the knowledge, competencies, and attitudes of the provider. The facilitation of shared decision-making may take shape as barriers are addressed and patients are provided the information that they need to know to engage in shared decision-making.

As illustrated in Figure 3, the first category, *Barriers*, is comprised of five findings. *Barriers of shared decision making (cost)* highlights costs as an external factor that creates a barrier for shared decision-making. *Barriers of shared decision-making (time constraints*) highlights time as an external barrier. The need for time to engage individuals in the shared decision-making process also demonstrating the connection to the previous finding as time may cost additional monies. *Barriers to shared decision-making (quality outcomes framework [pay for performance guidelines)]* is another externally created barrier as quality systems search for measureable quality outcome indicators without focusing on patient choices and preferences. *Consumer barriers* include low literacy and/or limited education, and thus a lack of information necessary to participate in shared decision-making. *Provider barriers* include limited understanding of shared decision-making or how to initiate and sustain shared decision-making.

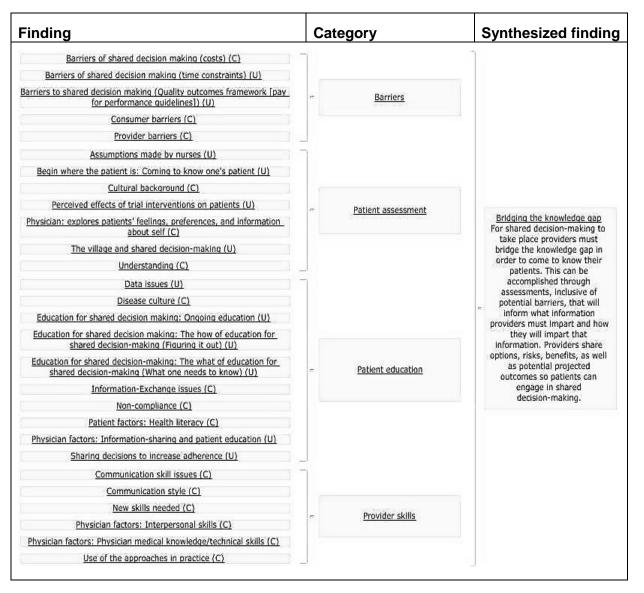


Figure 3: Bridging the knowledge gap

The second category involves *Patient Assessment*, which is comprised of seven findings. *Assumptions made by nurses* illustrates how patient assessments are critical for accurate, clear, and concise information. The nurse (healthcare provider) uses the patient assessment data, as it is patient-specific, to avoid a practice based on assumptions. *Begin where the patient is: Coming to know one's patient* is a direct outcome of the patient assessment and is a facilitator to avoid a practice based in assumptions. *Cultural background* is an important part of the patient assessment and an important aspect of coming to know one's patient, thus building a body of knowledge about one's patient. *Perceived effects of trial interventions on patients* explores how patients react to the use of shared decision-making by providers and how providers need to make an assessment of when patients prefer to share in the decision, take an autonomous role, or defer to the provider's judgment. *Physician: explores patients' feelings, preferences, and information about self* illustrates how the physician (healthcare provider) must continually gather assessment data about not only objective facts, but information concerning patients ideas, values, beliefs, and how patients perceive their self

and the role of self in the shared decision-making process. The village and shared decision-making brings an understanding that throughout the assessment process the healthcare provider must be aware that the patient lives in a life world where there may be others involved in their care, including community-based social supports and a network of care providers, that needs to be assessed and may be involved in the shared decision-making process. *Understanding* highlights for the healthcare provider the need to continually assess what the patient knows and what the patient does not know including misunderstandings.

The third category involves Patient Education, which is comprised of 10 findings. Data issues highlights the importance of having data and information to offer to patients and, that different forms of information may be more beneficial for different patients to facilitate the shared decision-making process. Disease culture considers how healthcare providers must be aware of what individual patients' understandings are in general and also what patients' understanding is related to a specific disease; different diseases may be more commonly understood. Patient factors: Health literacy illustrates the importance of healthcare providers being knowledgeable about and shaping patient information to the literacy of the patient to facilitate shared decision-making. Information-exchange issues considers whether or not information is exchanged and the different outcomes that unfold when information is not exchanged. Physician factors: Information-sharing and patient education highlights the importance of the physician (healthcare provider) in providing information to the patient so that there is a sharing of information for shared decision-making. Non-compliance illustrates the importance of sharing information to enhance patient participation in the plan of care. Education for shared decision-making: Ongoing education demonstrates the need for education where information is shared to be ongoing. Sharing decisions to increase adherence demonstrates that, with information provided in an educational format, patients have the information that they need to know to be involved in shared decision-making, leading to ongoing participation in management strategies. Education for shared decision-making: The what of education for shared decision-making (what one needs to know) demonstrates that healthcare providers must know what they must teach their patients; what the facts are that patients need to know to be involved in the shared decision-making process. Education for shared decision-making: The how of education for shared decision-making (figuring it out) concerns how the healthcare provider will teach the patient, drawing on the information gathered during the assessment.

The fourth category involves *Provider Skills*, which is comprised of six findings. *Communication skill issues* highlights the fact that for shared decision-making certain skills needed to be in evidence. *New skills needed* demonstrates that for shared decision-making additional skills may be necessary to facilitate such a process, for example: coaching, negotiation, and use of technology such as electronic decision aids. *Communication style* involves working with the patient, determining how best to communicate, and determining the patients' role in the shared decision-making process. *Physician factors: Interpersonal skills* demonstrates that interpersonal skills create a sense that the physician was receptive, thus facilitating being comfortable on the part of the patient, making it easier for the patient to talk to the physician and ask questions. *Physician factors: Physician medical knowledge/technical skills* highlights the fact that patients are keenly aware of their physicians' knowledge and this awareness gives patients the impetus to take a more active role in the own care and participate in shared decision-making. *Use of the approaches in practice* demonstrates that with a

shared decision-making approach there was a more balanced experience where patients achieved a greater responsibility for health.

The categories were then aggregated to give the synthesized finding: *Bridging the Knowledge Gap* (Figure 3). For shared decision-making to take place, providers bridge the knowledge gap in order to come to know their patients. This can be accomplished through assessments, inclusive of potential barriers, that will inform what information providers must impart and how they will impart that information. Providers share options, risks, benefits, as well as potential projected outcomes so that patients can engage in shared decision-making.

Meta-synthesis 3: Dimensions of decision-making

This meta-synthesis is comprised of 18 findings placed into three categories (Figure 4). Healthcare providers need to be aware that within the experience of shared decision-making, negotiation takes place between the healthcare provider and the patient.

As illustrated in Figure 4, the first category, Negotiation, is comprised of 10 findings. Commitment to patient centered practice demonstrates that where there is shared decision-making there is negotiation, as the healthcare provider generates a co-operative relationship by using strategies such as communicating in the language a patient understands, along with the provision of various alternative treatment options with discussion for the expressed purpose of shared decision-making. Existence of treatment options illustrates how the presence, absence, or non-clarity/uncertainty of treatment options directly effects whether the healthcare provider embraces shared decision-making. Treatment options marked by uncertainty, where the best option may not be known, creates the context for patient involvement in shared decision-making, as negotiation is frequently necessary to reach the best patient-centered decision. Impact of treatment on patient highlights how healthcare providers are more likely to facilitate shared decision-making when the treatment has the potential to impact the patient's lifestyle and self-image. Patient's involvement in negotiations to reach decisions that best fit their lifestyle and needs is facilitated with this shared decision-making. Stages of disease presents how shared decision-making may have the tendency to occur at different stages in a disease process. For example, shared decision-making may be facilitated in situations where treatment options are initially offered, treatments are changed, and/or goals of treatment altered. These dialogues set the stage for negotiation towards patient-centered decisions regarding care. Involvement of preferences illustrates how patients are all different in terms of preferences with regard to how involved they wish to be in the sharing of decisions pertaining to their care. How involved patients wish to be and the role they assume needs to be brought out in the open and at times negotiated with them depending on the existence of treatment options and the impact of treatment. Patient: discusses information and options and Physician: discusses information and options illustrates how, in periods of negotiation noted in shared decision-making, there is a back and forth process as the patient and the physician (healthcare provider) question, listen, and come to understand one another, leading to a consensus and a shared decision. In this back and forth process there is a need to obtain ongoing feedback that signals if there may need to be an adjustment in how information is sent so that the receiver of the information understands. Patient: shares control/negotiates a decision and Physician: shares control/negotiates a decision highlights how in these particular findings there is a conscious acknowledgement of areas of agreement and areas of disagreement with regard to the specific decision to be made. The finding also stresses how shared

decision-making is dynamic in that control and power may be shared at times, while at other times control and power may be shifted to the patient or the physician (healthcare provider). *Outcomes* highlighted the finding of enhanced independence when patients achieve goals that they had an active role in sharing of decisions made with negotiations. The shared decision-making leads to an enhanced ability to engage in self-management, greater effectiveness in treatments, and enhanced patient satisfaction.

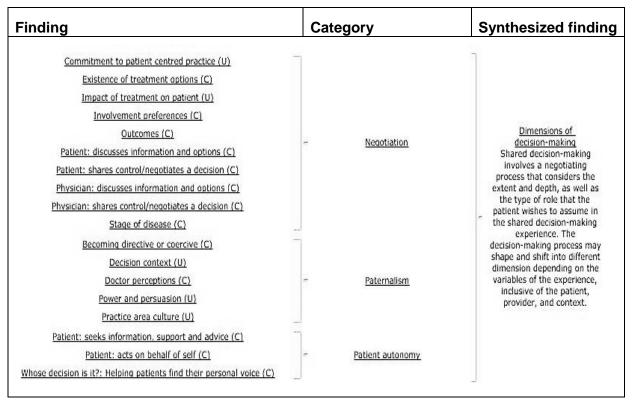


Figure 4: Dimension of decision-making

The second category, *Paternalism*, is comprised of five findings. *Doctor perceptions* presents the scenario where physicians (healthcare providers) perceived that patients wanted treatment, especially in situations where treatment means living or dying and that this superseded the sharing of decisions. *Practice area and culture* highlights the notion that the culture of the practice area may influence how shared decision-making is facilitated or not facilitated. For example, different specialties may have varying approaches to care and how shared decision-making is viewed as a viable option to pursue or not. *Decision context* demonstrates how healthcare providers, making decisions pertaining to care, self-determine how much to involve patients based upon the situation and/or the health condition. In conditions where decisions are concrete such as emergencies or those where there is clear evidence of the treatment options, providers may assume that patients want a certain outcome and therefore do not consult with patients to share in decisions. *Power and persuasion* highlights how the healthcare provider uses persuasion to facilitate the patient's agreement to particular treatment decisions; however, complete power sharing is not possible due to the fact that the nurse, because of clinical expertise, created an unequal partnership with the patient. *Becoming directive or coercive* highlights

the need for the healthcare provider to demonstrate the necessary judgment and assume directive approaches in areas during periods of negotiation marked by openness and transparency. This finding also illustrated how healthcare providers need to consciously negotiate with themselves in an intentional way, for there are times when the provider may fall into a coercive paternalistic practice, void of the possibility of shared decision-making, without the consent of the patient to do so. This stance at times damaged alliances necessary for shared decision-making.

The third category, *Patient Autonomy*, is comprised of three findings. *Patient: seeks information, support and advice* provides insight into how patients, to obtain different views, will look outside the physician (healthcare provider) for information that will help them in their decision-making. *Patient: acts on behalf of self* highlights how the implementation of any shared decision-making rests with the patient and how any changes in care must be made by the patient. *Whose decision is it?: Helping patients find their personal voice* highlights that decisions are ultimately the patient's, for these decisions directly affect the patient, and that healthcare providers must continually seek ways to facilitate patients to use their voices in care that pertains to them.

The categories were then aggregated to give the synthesized finding: Dimensions of decision-making (Figure 4). Shared decision-making involves a negotiating process that considers the extent and depth, as well as the type of role that the patient wishes to assume in the shared decision-making experience. The decision-making process may shape and shift into different dimensions depending on the variables of the experience, inclusive of the patient, provider, and context.

Discussion

The objective of this review was to present the best available evidence related to the meaningfulness of internal and external influences on shared decision-making for adult patients and healthcare providers in all health care settings. The comprehensive literature search identified 16 studies that were assessed for methodological quality. Eight of these studies met the inclusion criteria and were deemed of sufficient methodological quality for inclusion in this review.

Internal and external influences for shared decision-making, as identified by both patients and healthcare providers, were grouped into 11 categories. These categories yielded three synthesized findings of influences on shared decision-making: *Patient-centered care*, *Bridging the knowledge gap*, and *Dimensions of decision-making*.

Shared decision-making is a process representing either a dyad model of a healthcare provider and patient and/or a model composed of multiple individuals exemplifying an intra/interdisciplinary team including the individual patient/family, and community members. This systematic review focuses on the dyad model. The authors of this systematic review recognize the dyad model as one in which work is conducted in a partnership that is co-participatory and as such this discussion will seek to answer these questions looking at the internal and external influences of both the patient and the healthcare providers simultaneously.

Patient-centered care has been identified as care that is provided in a respectful manner that is responsive to the patient's preferences, needs, and values. In addition, patient-centered care has also been noted to be care whereby patients are given the information that they need to know to be actively engaged and share in decisions pertaining to their care. For patient-centered care to take

place, the health care system needs to be ready, willing and able to make necessary adjustments to meet individual patient needs.⁴³

The results of this systematic review highlight the complexity of shared decision-making, which is an action-oriented, ongoing process taking place in a relationship. 17,44 The relationship that is established is an exemplar of a partnership where the healthcare provider and the patient work with one another to achieve a common goal. In the context of this systematic review, the common goal is the sharing in the process that leads to a consensus on a particular decision which is mutually agreed upon.²¹ An outcome of this participatory relationship is that of trust. Trust is seen as an important influence as the healthcare provider and patient come to work with one another and know one another. 17,37,38,40 The concept of trust is identified as both a process and an outcome. 45 As a process it is dynamic, evolutionary, and developmental. Trust begins when a patient enters into a relationship with the healthcare provider. Over time, patients come to trust their healthcare provider, the outcome, as patients learn and witness how their provider is committed to them and their care. In addition, patients come to see, through their observations, the competence of their provider with regard to the provider knowledge and how that knowledge is shared with patients. 31,40 Similarly, healthcare providers, over time, come to trust in patients. Providers work with their patients and observe their patients' commitment to being open and honest. In turn, patients share with their healthcare providers personal ideas and beliefs with regard to their care and what they are willing to accept and not accept.

This systematic review also highlights the importance of communication for both building and sustaining the relationship and the development of trust. Communication is much more than the sender, received, and feedback models that are presented in the literature. This review illustrates how important it is for healthcare providers to listen, hear, and reveal that they understand what their patients are telling them. In addition, healthcare providers who are attentively listening will hear not only what is said but also what is not said; they use their communication skills to bring to the surface and make the unknown known. Many times this is done via skillful observations that lead to skillful reflective questioning. This type of skillful questioning fosters reflection in the healthcare provider, patient, family, or other team members. This type of questioning also signals to the individual patient that their healthcare provider is interested in them, wants to understand them, and respects them.

Bridging the knowledge gap involved the gathering of information so that healthcare providers come to know and understand their patients with regard to the patient's needs, wants, and desires, including desires pertaining to shared decision-making. 11,17,21,46 For instance, the gathering of information during an assessment is critical to come to know one's patient. This gathering of data is more than filling in the boxes on an assessment form. It is a process that a competent practitioner engages in and it is ongoing. As part of the patient assessment, the following information needs be gathered in a thoughtful and reflective manner:

- demographic information about the patient and the patient's family;
- the patient's cultural emphasis;
- diagnosis(es);
- what the patient knows and does not know about their diagnosis(es) and treatment(s);

- what information is understood;
- what information is misunderstood;
- · what information is missing;
- how best to impart that information given specific learning styles and preferences; and most importantly,
- what role does the patient wish to hold in the shared decision-making process.

Furthermore, the healthcare provider must be able to analyze the information gathered and identify any potential barriers that need to be addressed to maximize the shared decision-making experience. Healthcare providers not only need to be competent and skillful in their questioning, but they must continually engage in self-reflective questioning to ensure that they are not making decisions about whether or not the patient wishes to engage in shared decision-making based on assumptions. For example, the literature presents some evidence that older adults may be less likely to be involved in shared decision-making. Assuming that this may be true for all older adults facilitates a practice based on assumptions rather than a practice based on individual and specific patient preferences, which are based in evidence gathered through detailed assessments.

The outcomes of the assessment will reveal specific questions related to patient education:

- What decisions need to be made?
- What type of information does the patient needs to hold to bridge the knowledge gap and engage in the decision-making process?
- What is the best way to impart that information?
- What role does a particular patient wish to have in decision-making?

Bridging the knowledge gap²⁴ and how best to impart this information deserves consideration. In the health care decision-making context, patients may need to be informed and educated about what treatment options are available to them as well as what the impact is for these treatments.^{17,30,38-40} How the information is exchanged is also important, given the diversity of learning styles as well as individual patient preferences, education and literacy levels, needs, wants, and desires.^{17,39}

This systematic review also brings to light the notion that decision-making has many dimensions and, depending on the patient and the particular experience of the patient, there may be different dimensions of decision-making that need to be engaged. The healthcare provider's and the patient's abilities at negotiation are critical for these dimensions to unfold at various points in time depending upon the patients' identified needs, wants, and desires. First, this systematic review highlights that negotiation takes place internally within the provider. For example, healthcare providers have noted how there is a constant self-reflective dialogue that takes place and that this dialogue focuses on what information needs to be shared, how much information needs to be shared, and when the information needs to be shared. Much of this dialogue involves a reflection on what they are observing and hearing. Negotiation is also taking place between the heath care provider and the patient. This negotiation is noted to be a give and take marked by a sharing of information along with dialogue, whereby a common ground, which results in consensus, is reached. As 38,39,47 The shared decision is marked by acceptance and a dedication to work together in the implementation of the decision

pertaining to the patient's care. This working together is based on a trusting relationship where information is shared and discussed. This co-participation suggests an experience of shared decision-making where there is no imbalance of power; rather, the power is shared. There was evidence in this systematic review that there are times when a patient autonomously made a choice to not share in the decision-making process and gave permission to the healthcare provider to assume a more direct or paternalistic role. In these situations, the patient chooses to yield their first order decision to the healthcare provider. This decision, however, is jointly arrived at with specific rationale. Conversely, patients may take an autonomous role in decision-making. This may include seeking information from sources external to the patient-provider relationship to aid in decision-making. In these instances, providers should ensure that these decisions are informed by current best evidence. Moral or ethical dilemmas may arise, however, in instances where patients autonomously make decisions that are not in line with best practices.

Shared decision-making is a process that takes place in a relationship and unfolds within a particular context. Internal and external influences may facilitate the shared decision-making process that unfolds between the patient and the healthcare provider.

External influences include the time, cost, and external pressures, such as pressure from insurance companies who may dictate reimbursement rates if outcomes that they deem important are not reached, as opposed to outcomes that patients may deem important.^{21,30,37,39} Certain external influences may be important for both facilitating and sustaining shared decision-making. For instance, a supportive environment may offer programing for health care professionals that will enhance relationship, communication, assessment, education, and negotiation skills development. Additionally, external influences in the environment that will facilitate support for healthcare providers in the form of consultations when and if moral or ethical issues arise may be beneficial.

Internal influences may include: the healthcare providers' own awareness of what shared decision-making is, the process involved, the attitudes pertaining to shared decision-making, and the inherent sharing of power that is essential in this process. Internal influences involving the healthcare provider also include the need for interpersonal skills that are necessary to develop, sustain, and enhance the relationship between the patient and the healthcare provider. Communication skills are necessary to come to know one's patient, to build a database of information about the patient, and to gather information for evaluation purposes. The healthcare provider's questioning of the patient also signals to individual patients that their healthcare provider is interested in them, wants to understand them, and respects them.

Another internal influence is the healthcare provider's ability to identify, through the educational assessment, what information the patient needs to know and how to teach that information. In addition, to bridge the knowledge gap, the healthcare provider must have the ability to evaluate how the exchange of information is taking place and whether or not any issues are encountered. For example, providers can use teaching and learning strategies such as teach back to assess a patient's understanding of the information being exchanged to ensure the patient has the correct information to share in the decision making process. If barriers are encountered, how effective the healthcare provider is in addressing these barriers is also important. Other internal influences include how comfortable the healthcare provider is with regard to being involved in this type of detailed educational

encounter and how comfortable the provider is sharing the type of information that needs to be shared. This again highlights the external influences previously discussed.

Internal influences concerning the patient also deserve consideration. For example, how comfortable the patient is in shared decision-making and, in particular, the negotiation process when they may view the healthcare provider as having the knowledge and skills that they themselves do not have may pose a challenge.³⁸ Another internal influence is the experience of fear and denial that may occur as a patient learns to come to terms with a health condition. These feelings may create a barrier for patients from participating in shared decision-making.⁴⁰

Limitations

It became apparent during the review process that while many authors use the term shared decision-making, the meaning of this term used by authors was not consistent with the definition as defined in this review. Whereas many authors write of shared decision-making, what is being described is patient participation in decision-making, as opposed to a joint sharing of the decision-making process between the patient and the provider. Therefore, by staying true to the definition of shared decision-making as defined in this review, a limited number of papers exploring facilitators and barriers to shared decision-making, especially from the perspective of the patient were identified for inclusion in this review.

This review sought articles published in the English language. It is unknown if there are other studies focusing on facilitators and barriers of shared decision-making published in other languages.

Studies excluded following the critical appraisal process may have contained relevant findings; however, they did not meet the methodological requirements set for inclusion in this review.

Conclusion

This review included eight studies out of which three synthesized findings with respect to influences on shared decision-making were generated. These were patient-centered care, bridging the knowledge gap, and dimensions of decision-making. Patient-centered care involves the development of a relationship based in trust and facilitated by a communication process where the patient is encouraged to speak and the healthcare provider listens, hears, and understands. Furthermore, the healthcare provider, who is competent in communication, uses questioning to facilitate both selfreflection and the opportunity for the patient to engage in the reflective process. Bridging the knowledge gap takes place as the healthcare provider and the patient work together in partnership. Again, to build the shared decision-making experience, the healthcare provider uses communication skills to gather information in the assessment process to identify the specific educational needs of each patient while barriers are identified and addressed. Decision-making may take shape and form in varying dimensions from active participation and sharing in all decisions to one where the healthcare provider assumes a more directive and paternalistic approach, or the patient assumes an autonomous role. The decision pertaining to these dimensions is decided upon collectively between the healthcare provider and the patient. Hence, the patient grants permission for the healthcare provider to assume a more directive and active role for a moment. Conversely, a collective decision can be made to allow the patient to act autonomously. For shared decision-making to take place, all parties involved in the decision must have the necessary knowledge to make decisions. Aspects of patient-centered care where a trusting, compassionate relationship is forged between patient and provider will support the achievement of a shared decision.

Implications for practice

Drawing from the synthesized findings from this review, several recommendations for facilitating internal and external influences to initiate, improve, and/or sustain shared decision-making experiences emerged. The grading of each recommendation is based on JBI Levels of Evidence (Appendix IX).

- A patient-centered environment is facilitated when the patient/provider relationship is built on a foundation of trust and respect by both parties. Both patients and providers must continually reflect on past and current experiences, while honestly sharing knowledge, ideas, and feelings to reach a shared decision (JBI Level of evidence = 2).
- Both patients and the healthcare providers need to acknowledge their own attitudes and beliefs concerning power, power imbalance, and the sharing of power (JBI Level of evidence = 2).
- Patients and healthcare providers participate in an assessment, as a shared endeavor, whereby healthcare providers gather information to come to know their patients' individual needs, wants, and desires and patients feel comfortable sharing such information (JBI Level of evidence= 2).
- Healthcare providers need to identify potential barriers to shared decision-making during the assessment and integrate strategies to eliminate these barriers (JBI Level of evidence = 2).
- Healthcare providers must provide education to their patients so that patients have the information necessary to engage in shared decision-making (JBI Level evidence= 2).
- Health care organizations need to offer educational programs that will influence the
 healthcare providers' competencies and skills with regard to shared decision-making inclusive
 of program development on what shared decision-making is and the process of shared
 decision-making, relationship development, communication, the variety of assessment
 needed, reflective practice, and negotiation. These programs will serve to strengthen shared
 decision-making as one of the decision-making models evident in the practice environment
 (JBI Level of evidence = 2).
- Moral and ethical issues may arise when patients autonomously choose an intervention not in line with best practice or when conflicts arise when the health care environment challenges the healthcare provider from implementing a strategy that has been decided upon jointly by the provider and the patient. Health care organizations should provide supports for healthcare providers such as consultations when such issues arise (JBI Level of evidence = 2).
- Healthcare providers need to offer patient-centered education, support, and coaching to the
 patient who may wish to be an active participant in the shared decision-making experience
 but who may not have the competencies (JBI Level of evidence = 2).

Implications for research

This systematic review highlights that there is a need for continued studies in the area of shared decision-making. Further research should focus on:

- Examining strategies that will facilitate internal and external influences on shared decisionmaking, as well as determining the effectiveness of these strategies on health outcomes.
- Exploring shared decision-making across a variety of health care settings to come to know and understand how each of these varying cultural environments influences the facilitation of shared decision-making.
- Further exploration and description of the reflective process that takes place for the healthcare provider and the patient.
- Exploring and describing the negotiation process that unfolds between the healthcare provider and the patient.
- Exploring exactly what influences the attitudes of the healthcare provider and patient have on the shared decision-making experience.
- Exploring competencies that are held by the patient for shared decision-making to take place.
- Examination of the notion of the dimensions of shared decision-making in general; for instance, is it possible that the decision-making is really inclusive of the multiple models presented in this systematic review (paternalistic—with the permission of the patient; informed decision-making; and shared decision-making) and that depending on the particular experience and the particular moment in time, inclusive of the patient, the disease, the context, and the family, what model is exemplified may shift depending on the particular experience.

Conflict of Interest

None to disclose.

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- Truglio-Londrigan M, Slyer JT, Singleton JK, Worral P. A qualitative systematic review of internal and external influences on shared decision-making in al health care settings. JBI Library of Systematic Reviews and Implementation Reports. 2012;10(58):4633-46.
- 37. Edwards A, Elwyn G, Wood F, Atwell C, Prior L, Houston H. Shared decision making and risk communication in practice: A qualitative study of GPs' experiences. Br J Gen Pract. 2005;55:6-13.
- 38. Lown BA, Clark WD, Hanson JL. Mutual influence in shared decision making: A collaborative study of patients and physicians. Health Expect. 2009;12(2):160-74.
- 39. Mahone IH, Farrell S, Hinton I, Johnson R, Moody D, Rifkin K, et al. Shared decision making in mental health treatment: Qualitative findings from stakeholder focus groups. Arch Psychiatr Nurs. 2011;25(6):e27-36.
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- 45. Johns JL. A concept analysis of trust. J Adv Nurs. 1996 Jul;24(1):76-83.
- 46. Radwin LE. 'Knowing the patient': A review of research on an emerging concept. J Adv Nurs. 1996 Jun;23(6):1142-6.
- 47. Øien A, Steihaug S, Iversen S, Råheim M. Communication as negotiation processes in long-term physiotherapy: A qualitative study. Scand J Caring Sci. 2010;25:53-61.
- 48. Henderson S. Power imbalance between nurses and patients: A potential inhibitor of partnership in care. J Clin Nurs. 2003;12(4):501-8.
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Appendix I: Search strategy

PubMed: Searched November 8, 2012

- 1. "qualitative research" [MeSH Terms] OR "qualitative" [All Fields]
- 2. "decision making" [MeSH Terms] "decision making" [All Fields]
- 3. "shared decision making"
- 4. "shared decision*"
- 5. "shared medical decision"
- 6. "physician patient communication"
- 7. "patient provider communication"
- 8. "patient participation"[MeSH Terms] OR "patient participation"[All Fields]
- 9. 2 OR 3 OR 4 OR5 OR 6 OR 7 OR 8
- 10. influence*
- 11. factor*
- 12. view*
- 13. 10 OR 11 OR 12
- 14. (1 AND 9 AND 13) AND (English[lang] AND adult[MeSH])

CINAHL: Searched November 8, 2012

- 1. (MH "Qualitative Studies") OR "qualitative"
- 2. (MH "Decision Making") OR "decision making"
- 3. "shared decision making"
- 4. "shared medical decision"
- 5. shared decision*
- 6. "patient provider communication"
- 7. "physician patient communication"
- 8. "patient participation"
- 9. 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8
- 10. Influence*
- 11. factor*
- 12. view*
- 13. 10 OR 11 OR 12
- 14. (1 AND 9 AND 13) Limiters English Language; Age Groups: All Adults

PsychINFO: Searched November 8, 2012

- 1. DE "Qualitative Research" OR qualitative
- 2. DE "Decision Making" OR "decision making"
- 3. "shared decision making"
- 4. "shared decision*"
- 5. "shared medical decision"
- 6. "physician patient communication"
- 7. "patient "provider communication"
- 8. "patient participation"
- 9. 2 OR 3 OR 4 OR 5 OR 6 OR 7
- 10. influence*
- 11. factor*
- 12. view*
- 13. 9 OR 10 OR 11

14. (1 AND 8 AND 12) Limiters - English language, Age Groups: Adulthood 18 years & older

Embase: Searched November 8, 2012

- 1. 'qualitative research'/exp OR 'qualitative research'
- 2. qualitative
- 3. 'decision making'/exp OR 'decision making'
- 4. 'shared decision making'
- 5. 'shared decision'
- 6. 'shared medical decision'
- 7. 'physician patient communication'
- 8. 'patient provider communication'
- 9. 'patient participation'/exp OR 'patient participation'
- 10. influence*
- 11. factor*
- 12. view*
- 13. #1 OR #3
- 14. #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10
- 15. #11 OR #12 OR #13
- 16. #14 AND #15 AND #16 AND ([adult]/lim OR [aged]/lim) AND [english]/lim AND [embase]/lim

Scopus: Searched November 18, 2012

- 1. ((ALL("qualitative research" OR "qualitative") AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci)) AND
- 2. ((ALL("decision making") AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci)) OR
- 3. (ALL("shared decision making") AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci)) OR
- 4. (ALL("shared decision*") AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci)) OR
- 5. (ALL("shared medical decision") AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci)) OR
- 6. (ALL("physician patient communication") AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci)) OR (ALL("patient provider communication") AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci)) OR (ALL("patient participation") AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci))) AND
- 7. 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8
- ((ALL(influence*) AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci)) OR
- (ALL(factor*) AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci)) OR
- 10. (ALL(view*) AND SUBJAREA(mult OR medi OR nurs OR vete OR dent OR heal OR mult OR arts OR busi OR deci OR econ OR psyc OR soci)))) AND
- 11. 10 OR 11 OR 12
- 12. 1 AND 9 AND 13
- 13. 14 AND (adult) AND (LIMIT-TO(LANGUAGE, "English")) AND (LIMIT-TO(SUBJAREA, "MEDI") OR LIMIT-TO(SUBJAREA, "NURS") OR LIMIT-TO(SUBJAREA, "HEAL"))

Healthsource: Nursing/Academic Edition: Searched December 20, 2012

- 1. "qualitative research"
- 2. Qualitative
- 3. 1 OR 2
- 4. "decision making"
- 5. "shared decision making"
- 6. "shared decision*"
- 7. "shared medical decision"
- 8. "physician patient communication"
- 9. "patient provider communication"
- 10. "patient participation"
- 11. 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10
- 12. influence*
- 13. factor*
- 14. view*
- 15. 12 OR 13 OR 14
- 16. (2 AND 11 AND 15)

ProQuest Dissertations and Theses: Searched December 7, 2012

- 1. "shared decision making"
- 2. "qualitative research" or "qualitative inquiry"
- 3. 1 AND 2

Mednar: Searched December 7, 12012

1. "shared decision making" and "qualitative research"

Virginia Henderson: Searched December 7, 2012

- 1. "shared decision making" and "qualitative research"
- 2. "Shared decision making" and "qualitative inquiry"

NY Academy of Medicine: Searched December 7, 2012

1. "shared decision making" and "qualitative research"

Appendix II: Appraisal instruments

QARI appraisal instrument

JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research

Reviewer Date								
Author Year Record Number								
	Yes	No	Unclear	Not Applicable				
 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?								
Is there congruity between the research methodology and the interpretation of results	? 🗆							
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 fu	rther info.				
Comments (Including reason for exclusion)								

Appendix III: Data extraction instruments

QARI data extraction instrument

& Critical Research			
Reviewer		ite	
Author	Ye	ar	
Journal	Re	ecord Number	
Study Description			
Methodology			
Method			
Phenomena of interes	st		
Setting			
Geographical			
Cultural			
Participants			
Data analysis			
Authors Conclusions			
Comments			
Complete	Yes 🗆	No □	

Findings	Illustration from	Evidence		
	Publication (page number)	Unequivocal	Credible	Unsupported
Extraction of findings complete Yes \(\square\) No \(\square\)				

Appendix IV: Included studies

Edwards A, Elwyn G, Wood F, Atwell C, Prior L, Houston H. Shared decision making and risk communication in practice: A qualitative study of GPs' experiences. Br J Gen Pract 2005;55:6-13.³⁷

13."	
Methodology	Qualitative descriptive
Method	Focus group exit interviews occurring two months after the completion of a randomized controlled trail evaluating a training intervention for shared decision-making and risk communications; 2 groups of 9 general practitioners each
Phenomena of interest	To identify trained general practitioners' views on opportunities for and challenges to implementing shared decision-making and risk communication
Setting	Not specified
Geographical	Gwent Health Authority, Wales, United Kingdom
Cultural	Nationalized health care; Physicians in general practice for 1 - 10 years in Wales who had participated in a randomized controlled trial for shared decision-making training
Participants	18 of 20 general practitioners, in practice for 1-10 years, who participated in a randomized controlled trial lasting 6 months that included training in shared decision-making skills and the use of risk communications. Training included four workshops of three hours each.
Data analysis	Focus groups were audiotaped; data were transcribed and anonymized. Data were examined and categorized in terms of interview questions. Agreement among researchers was by discussion. Themes were confirmed with participants.
Author's conclusions	Physicians were positive about shared decision-making and using risk communication tools, but were selective about when they thought patient involvement was appropriate and feasible. With more training (experientially based, continuous rather than one-time interventions), more time, higher expectations from patients for involvement in decision-making, and financial or accreditation incentives, shared decision-making might be more broadly implemented.

Lown BA, Clark WD, Hanson JL. Mutual influence in shared decision making: a collaborative study of patients and physicians. Health Expect. 2009;12(2):160-74. ³⁸		
Methodology	Qualitative descriptive	
Method	Focus groups	
Phenomena of interest	Explore both patients' and physicians' perspectives about attitudes and behaviors during the patient-physician encounter where shared decision-making occurs.	
Setting	Hospital based and primary care settings	
Geographical	Cambridge, MA, USA; Boston MA, USA; and Bethesda, MD, USA	
Cultural	East coast, USA	
Participants	A total of 85 physicians (greater than 3 years post residency) and patients with chronic conditions who have experience with making health care decisions when there were treatment choices	
Data analysis	Constant and comparative method and grounded theory techniques used to develop themes from written descriptions by participants of physician behaviors and attitudes	
Author's conclusions	The study illustrated "mutual influence of patients and physicians on each other'	

Mahone IH, Farrell S, Hinton I, Johnson R, Moody D, Rifkin K, et al. Shared decision making in mental health treatment: qualitative findings from stakeholder focus groups. Arch Psychiatr Nurs. 2011;25(6):e27-36.³⁹

Methodology	Qualitative descriptive
Method	Focus group
Phenomena of interest	Attitudes and behaviors of patients and physicians that facilitate shared decision-making
Setting	Mental health clinic
Geographical	Central Virginia, USA
Cultural	Mental health clinic in Central Virginia, USA
Participants	Family members (n=4); psychiatrists and psychiatric nurse practitioners (n=4); nurses, case managers, and support staff (n=6); three consumer groups (n = 8, 7, 9); n= 44 total participants divided into 7 focus groups
Data analysis	Detailed transcripts of interviews entered into NVivo for content analysis to identify, code, and categorize primary patterns in the data. Independent analysis of the transcripts and coding compared for agreement. Themes brought to member of focus group to assess accuracy and validity.
Author's conclusions	Implementing SDM in public mental health will impact consumers and their families, providers, prescribers, and administrators. More research is needed in this area.

Peek ME, Wilson SC, Gorawara-Bhat R, Odoms-Young A, Quinn MT, Chin MH. Barriers and facilitators to shared decision-making among African-Americans with diabetes. J Gen Intern Med. 2009;24(10):1135-9.⁴⁰

1
Phenomenology
Individual semi-structured interviews followed by 5 focus groups to
validate themes extracted from individual interviews.
Understand the barriers and facilitators to shared decision-making
among African-Americans with diabetes
Urban academic medical center
Urban setting; no further description.
African-Americans
African-Americans with diabetes mellitus (21 years of age or older)
with an established relationship with a primary care provider at an
urban academic medical center (n=24, in depth interviews; n=27,
amongst five focus groups).
Interviews transcribed into Atlas.ti 4.21 software. Codebook
developed by an iterative process. 2 reviewers independently coded
each transcript.
Barriers and facilitators of shared decision-making exist among
African-Americans with diabetes mellitus that can be adequately
addressed by primary care providers in the outpatient setting.

Seale C, Chaplin R, Lelliott P, Quirk A. Sharing decisions in consultations involving antipsychotic medications: A qualitative study of psychiatrists' experiences. Soc Sci Med. 2006;62:2861-73.²¹

Methodology	Qualitative descriptive
Method	Semi-structured interviews
Phenomena of interest	Psychiatrists' perspectives on consultations involving anti-psychotic medications, assessing the extent to which shared decision-making is reported in everyday working practice and describing psychiatrists' reported methods for creating a therapeutic alliance that includes negotiation of medication use and consideration of the impact of coercion.
Setting	2 mental health care trusts
Geographical	England
Cultural	Caucasian psychiatrists in England
Participants	21 psychiatrists from 2 mental health care trusts in England who provided community psychiatric services to adults.
Data analysis	Thematic qualitative analysis. NVIVO qualitative data analysis software used to core and retrieve text.
Author's conclusions	Psychiatrists believe a more patient-centered practice is evident now and they show a strong preference for a cooperative therapeutic alliance with patients. Obstacles particular to psychiatric practice may stand in the way, including patient competence.

Shepherd HL, Butoe PN, Tattersall MH. Factors which motivate cancer doctors to involve their patients in reaching treatment decisions. Patient Educ Couns. 2011;84:229-35. ¹¹		
Methodology	Qualitative descriptive	
Method	Semi-structured telephone interviews	
Phenomena of interest	What influences cancer physicians to involve their patients in reaching treatment decisions?	
Setting	Not specified	
Geographical	All 5 major states of Australia represented	
Cultural	Australian cancer physicians	
Participants	Australian cancer physicians who treated breast, colorectal, gynecological, hematological, and prostate/urological cancers were enlisted. n=22	
Data analysis	Framework analysis approach. Data organized using NVIVO 7	
Author's conclusions	Cancer physicians express different support of patient involvement in decision-making dependent on the context, impact, and effect that involvement may have. Physicians describe meeting patient involvement preferences challenging.	

Truglio-Londrigan, M. Shared decision-making in home-care from the nurse's perspective: Sitting at the kitchen table - a qualitative descriptive study. J Clin Nurs. 2013:22(19-20):2883-95.¹⁷

Methodology	Qualitative descriptive, with elements of phenomenological overtones
Method	Open ended telephone interviews
Phenomena of interest	The experience of shared decision-making in home-care from the nurses perspective
Setting	Home-care in the United States
Geographical	Participants located throughout the United States
Cultural	Participants were all alumni of Pace University, College of Health Professions, New York, NY and able to communicate in English
Participants	Nurses recruited form the alumni of Pace University, College of Health Professions, New York, NY with past or present experience in home care. n=10
Data analysis	Colaizzi's method of data analysis was used, which seeks to describe the phenomenon of interest resulting in an accounting of the facts of the experience
Author's conclusions	The findings present shared decision-making as a complex, multi-dimensional, and fluid process. Four themes emerged with additional subthemes. A comprehensive understanding of the events of shared decision-making can assist home-care nurses in their practice.

Upton J, Fletcher M, Madoc-Sutton H, Sheikh A, Caress AL, Walker S. Shared decision making or paternalism in nursing consultations? A qualitative study of primary care asthma nurses' views on sharing decisions with patients regarding inhaler device selection. Health Expect. 2011;14:374-82.³⁰

Methodology	Qualitative exploratory
Method	Semi-structured interviews
Phenomena of interest	Investigate primary care asthma nurses' views on shared decision-making and explore how sharing decisions with patients can be facilitated.
Setting	United Kingdom general practice sites
Geographical	United Kingdom
Cultural	Female nurses
Participants	20 experienced female asthma nurses practice in general practice in the United Kingdom.
Data analysis	Framework approach with support of NVivo software.
Author's conclusions	A discrepancy between nurses' understanding of and the depiction of shared decision-making in policy and literature exists. In this study, nurses used shared decision-making as a tool to support their agenda rather than create a sense of equality between the patient and provider. The study indicates that attitude shifts and improved knowledge are needed for shared decision-making to occur.

Appendix V: List of excluded studies after full text review

Aasen ME, Kvangarsnes M, Heggen K. Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. Scand J Caring Sci. 2012;26(1):61–9.

Reason for exclusion: Not shared decision-making.

Adams R, Price K, Tucker G, Nguyen AM, Wilson D. The doctor and the patient-How is a clinical encounter perceived? Patient Educ Couns. 2012;86(1):127–33.

Reason for exclusion: Mixed methods study where qualitative data is used to create a questionnaire for quantitative analysis.

Avis M. Choice cuts: An exploratory study of patients' views about participation in decision-making in a day surgery unit. Int J Nurs Stud. 1994;31(3):289–98.

Reason for exclusion: Not shared decision-making.

Bastiaens H, Van Royen P, Pavlic DR, Raposo V, Baker R. Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries. Patient Educ Couns. 2007;68(1):33–42.

Reason for exclusion: Not shared decision-making.

Beaver K, Jones D, Susnerwala S, Craven O, Tomlinson M, Witham G, et al. Exploring the decision-making preferences of people with colorectal cancer. Health Expect. 2005;8(2):103–13.

Reason for exclusion: Not shared decision-making.

Beaver K, Craven O, Witham G, Tomlinson M, Susnerwala S, Jones D, et al. Patient participation in decision making: views of health professionals caring for people with colorectal cancer. J Clin Nurs. 2007;16(4):725–33.

Reason for exclusion: Not shared decision-making.

Begum S, Grunfeld EA, Ho-Asjoe M, Farhadi J. An exploration of patient decision-making for autologous breast reconstructive surgery following a mastectomy. Patient Educ Couns. 2011;84(1):105–10.

Reason for exclusion: Not shared decision-making.

Belcher VN, Fried TR, Agostini JV, Tinetti ME. Views of older adults on patient participation in medication-related decision making. J Gen Intern Med. 2006;21(4):298–303.

Reason for exclusion: Not shared decision-making.

Benin AL, Wisler-Scher DJ, Colson E, Shapiro ED, Holmboe ES. Qualitative analysis of mothers' decision-making about vaccines for infants: the importance of trust. Pediatr. 2006;117(5):1532–41.

Reason for exclusion: Not shared decision-making.

Bieber C, Müller KG, Blumenstiel K, Schneider A, Richter A, Wilke S, et al. Long-term effects of a shared decision-making intervention on physician-patient interaction and outcome in fibromyalgia: a qualitative and quantitative 1 year follow-up of a randomized controlled trial. Patient Educ Couns. 2006;63(3):357–66.

Reason for exclusion: Mixed methods study. The aims of the quantitative aspect were not congruent with the objectives of this systematic review.

Blix-Lindstrom S, Christensson K, Johansson E. Women's satisfaction with decision-making related to augmentation of labour. Midwifery. 2004;20:104–12.

Reason for exclusion: Not shared decision-making.

Boivin A, Légaré F, Gagnon MP. Competing norms: Canadian rural family physicians' perceptions of clinical practice guidelines and shared decision-making. J Health Serv Res Policy. 2008;13(2):79–84.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Cheung NF, Mander R, Cheng L, Chen VY, Yang X. Caesarean decision-making: negotiation between Chinese women and healthcare professionals. Evidence Based Midwifery. 2006;4(1):24–30.

Reason for exclusion: Not shared decision-making.

Clark HD, O'Connor AM, Graham ID, Wells GA. What factors are associated with a woman's decision to take hormone replacement therapy? Evaluated in the context of a decision aid. Health Expect. 2003;6(2):110–7.

Reason for exclusion: Not shared decision-making.

Davies L, Rhodes LA, Gorssman DC, Rosenberg MC, Stevens DP. Decision making in head and neck cancer care. Laryngoscope. 2010;120, 2434-2445.

Reason for exclusion: Not shared decision-making.

Davis RE, Dolan G, Thomas S, Atwell C, Mead D, Nehammer S, et al. Exploring doctor and patient views about risk communication and shared decision-making in the consultation. Health Expect. 2003;6(3):198–207.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Doherty C, Doherty W. Patients' preferences for involvement in clinical decision-making within secondary care and the factors that influence their preferences. J Nurs Manag. 2005;13(2):119–27.

Reason for exclusion: Not shared decision-making.

Edwards M, Davies M, Edwards A. What are the external influences on information exchange and shared decision-making in healthcare consultations: A meta-synthesis of the literature. Patient Educ Couns. 2009;75(1):37–52.

Reason for exclusion: Literature review.

Edwards A, Elwyn G, Smith C, Williams S, Thornton H. Consumers' views of quality in the consultation and their relevance to 'shared decision-making' approaches. Health Expect. 2001; 4:51-161.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Ekdahl AW, Andersson L, Friedrichsen M. "They do what they think is the best for me." Frail elderly patients' preferences for participation in their care during hospitalization. Patient Educ Couns. 2010;80(2):233–40.

Reason for exclusion: Not shared decision-making.

Eliott AJ, Olver I. Dying cancer patients talk about physician and patient roles in DNR decision making. Health Expect. 2011;14(2):147–58.

Reason for exclusion: Not shared decision-making.

Elwyn G, Gwyn R, Edwards A, Grol R. Is "shared decision-making" feasible in consultations for upper respiratory tract infections? Assessing the influence of antibiotic expectations using discourse analysis. Health Expect. 1999;2(2):105–117.

Reason for exclusion: Not population of interest involves parental decision-making.

Entwistle V, Watt I, Gilhooly K, Bugge C, Haites N, Walker A. Assessing patients' participation and quality of decision-making: Insights from a study of routine practice in diverse settings. Patient Educ Couns. 2004;55(1):105–13.

Reason for exclusion: Not shared decision-making.

Fraenkel L, McGraw S. Participation in medical decision making: the patients' perspective. Med Decis Making. 2007;27(5):533-8.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review

Fried TR, Bradley EH. What matters to seriously ill older persons making end-of-life treatment decisions?: A qualitative study. J Palliat Med. 2003;6(2):237–44.

Reason for exclusion: Not shared decision-making.

Gibson J. Use of quality research to analyze patient and clinician decision making in carotid endarterectomy. J Vasc Nurs. 2002;20(2):60–7.

Reason for exclusion: Not shared decision-making.

Goscha RJ. Finding common ground: Exploring the experiences of client involvement in medication decision making using a shared decision making model [PhD Thesis]. Lawrence, KS: University of Kansas; 2009. (UMI Number: 3386638).

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Greenfield J. A health partnership: A qualitative study of patients, nurses, and medical practitioners on collaborative decision-making. 1995; Doctor of Philosophy in Health Care Services (UMI number: 9616786).

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Groff JY, Mullen PD, Byrd T, Shelton AJ, Lees E, Goode J. Decision making, beliefs, and attitudes toward hysterectomy: A focus group study with medically underserved women in Texas. J Womens Health Gend Based Med. 2000;9:S39–S50.

Reason for exclusion: Not shared decision-making.

Haidet P, Kroll T, Sharf B. The complexity of patient participation: Lessons learned from patients' illness narratives. Patient Educ Couns. 2006;62(3):323–9.

Henderson S. Influences on patient participation and decision-making in care. Prof Nurse. 2002;17(9):521–5.

Reason for exclusion: Not shared decision-making.

Hudak PL, Clark JP, Hawker GA, Coyte PC, Mahomed NN, Kreder HJ, et al. "You're Perfect for the Procedure! Why Don't You Want It?" Elderly Arthritis Patients' Unwillingness to Consider Total Joint Arthroplasty Surgery: A Qualitative Study. Med Decis Making. 2002;22(3):272–8.

Reason for exclusion: Not shared decision-making.

Hughes CM, Goldie R. "I just take what I am given": adherence and resident involvement in decision making on medicines in nursing homes for older people: a qualitative survey. Drugs Aging. 2009;26(6):505–17.

Reason for exclusion: Not shared decision-making.

Husain LS, Collins K, Reed M, Wyld L. Choices in cancer treatment: a qualitative study of the older women's (>70 years) perspective. Psychooncology. 2008;17(4):410–6.

Reason for exclusion: Not shared decision-making.

Jones JB. Hormone replacement therapy: women's decision-making process. Soc Work Health Care. 1999;28(3):95–111.

Reason for exclusion: Not shared decision-making.

Kehler D, Christensen B, Lauritzen T, Christensen MB, Edwards A, Risør MB. Cardiovascular-risk patients' experienced benefits and unfulfilled expectations from preventive consultations: a qualitative study. Qual Prim Care. 2008;16(5):315–25.

Reason for exclusion: Not shared decision-making.

Kryworuchko J, Stacey D, Peterson WE, Heyland DK, Graham ID. A qualitative study of family involvement in decisions about life support in the intensive care unit. Am J Hosp Palliat Care. 2012;29(1):36–46.

Reason for exclusion: Not shared decision-making.

Laplante-Lévesque A, Hickson L, Worrall L. Factors influencing rehabilitation decisions of adults with acquired hearing impairment. Int J Audiol. 2010;49(7):497–507.

Reason for exclusion: Not shared decision-making.

Malta M, Todd CS, Stibich MA, Garcia T, Pacheco D, Bastos FI. Patient-provider communication and reproductive health among HIV-positive women in Rio de Janeiro, Brazil. Patient Educ Couns. 2010;81(3):476–82.

Reason for exclusion: Not shared decision-making.

Markovic M, Manderson L, Quinn M. Treatment decisions: a qualitative study with women with gynaecological cancer. Aust N Z J Obstet Gynaecol. 2006;46(1):46–8.

Matlock DD, Nowels TC, Masoudi AF, Sauer HW, Bekelman BD, Main SD, et al. Patient and Cardiologist Perceptions on Decision Making for Implantable Cardioverter-Defibrillators: A Qualitative Study. Pacing Clin Electrophysiol. 2011;34(12):1634–44.

Reason for exclusion: Not shared decision-making.

Matlock DD, Nowels CT, Bekelman DB. Patient perspectives on decision making in heart failure. J Card Fail. 2010;16(10):823–6.

Reason for exclusion: Not shared decision-making.

McGuire AL, McCullough LB, Weller SC, Whitney SN. Missed expectations? Physicians' views of patients' participation in medical decision-making. Med Care. 2005;43(5):466–70.

Reason for exclusion: Not shared decision-making.

Mishra IS, Gioia D, Chilaress S, Barnet B, Webster LR. Adherence to Medication Regimens among Low-Income Patients with Multiple Comorbid Chronic Conditions. Health & Social Work. 2011;36(4):249–58.

Reason for exclusion: Not shared decision-making.

Moffat M, Bell J, Porter M, Lawton S, Hundley V, Danielian P, et al. Decision making about mode of delivery among pregnant women who have previously had a caesarean section: a qualitative study. BJOG. 2007;114(1):86–93.

Reason for exclusion: Not shared decision-making.

Moreau A, Carol L, Dedianne MC, Dupraz C, Perdrix C, Lainé X, et al. What perceptions do patients have of decision making (DM)? Toward an integrative patient-centered care model. A qualitative study using focus-group interviews. Patient Educ Couns. 2012;87(2):206–11.

Reason for exclusion: Not shared decision-making.

Moser A, H, Widdershoven G. Competency in shaping one's life: autonomy of people with type 2 diabetes mellitus in a nurse-led, shared-care setting; a qualitative study. Int J Nurs Stud. 2006;43(4):417–27.

Reason for exclusion: Not shared decision-making.

Müller-Engelmann M, Keller H, Donner-Banzhoff N, Krones T. Shared decision making in medicine: The influence of situational treatment factors. Patient Educ Couns. 2011;82(2):240–6.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Naik AD, Schulman-Green D, McCorkle R, Bradley EH, Bogardus ST. Will older persons and their clinicians use a shared decision-making instrument? J Gen Intern Med. 2005;20(7):640–3.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Nazareth I, Jones L, Irving A, Aslett H, Ramsay A, Richardson A, et al. Perceived concepts of continuity of care in people with colorectal and breast cancer -- a qualitative case study analysis. Eur J Cancer Care. 2008;17(6):569–77.

O'Brien MA, Whelan TJ, Charles C, Ellis PM, Gafni A, Lovrics P, et al. Women's perceptions of their treatment decision-making about breast cancer treatment. Patient Educ Couns. 2008;73(3):431–6.

Reason for exclusion: Not shared decision-making.

O'Reilly F, O'Connell D, O'Carroll A, Whitford D, Long J. Sharing control: User involvement in practice based methadone maintenance. Ir J Psychol Med. 2011;28(3),129-33.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Parsons S, Harding G, Breen A, Foster N, Pincus T, Vogel S, Underwood M. Will shared decision making between patients with chronic musculoskeletal pain and physiotherapists, osteopaths and chiropractors improve patient care? Fam Pract. 2012;29,203-12.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Peek ME, Odoms-Young A, Quinn MT, Gorawara-Bhat R, Wilson SC, Chin MH. Race and shared decision-making: perspectives of African-Americans with diabetes. Soc Sci Med. 2010;71(1):1–9.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Peek M, Quinn MT, Gorawara-Bhat R, Odoms-Young A, Wilson SC, Chin MH. How is shared decision-making defined among African-Americans with diabetes? Patient Educ Couns. 2008;72:450-8.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Pieters HC, Heilemann MV, Maliski S, Dornig K, Mentes J. Instrumental relating and treatment decision making among older women with early-stage breast cancer. Oncol Nurs Forum. 2012;39(1):E10–9.

Reason for exclusion: Not shared decision-making.

Pieterse AH, Baas-Thijssen MCM, Marijnen CAM, Stiggelbout AM. Clinician and cancer patient views on patient participation in treatment decision-making: a quantitative and qualitative exploration. Br J Cancer. 2008;99(6):875–82.

Reason for exclusion: Qualitative results reported in quantitative manor.

Plowden KO. To screen or not to screen: factors influencing the decision to participate in prostate cancer screening among urban African-American men. Urol Nurs. 2006;26(6):477–82.

Reason for exclusion: Not shared decision-making.

Price EL, Bereknei S, Kuby A, Levinson W. New elements for informed decision making: A qualitative study of older adults. Patient Educ Couns. 2012;86(3),335-41.

Reason for exclusion: Not shared decision-making.

Saba GW, Wong ST, Schillinger D, Fernandez A, Somkin CP, Wilson CC, Grumbach K. Shared decision making and the experience of partnership in primary care. Ann Fam Med. 2006;4(1):54-62.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Sainio C, Eriksson E, Lauri S. Patient participation in decision making about care: The cancer patient's point of view. Cancer Nurs. 2001;24(3):172-9.

Reason for exclusion: No shared decision-making.

Sainio C, Lauri S. Cancer patients' decision-making regarding treatment and nursing care. J Adv Nurs. 2003;41(3):250–60.

Reason for exclusion: Not shared decision-making.

Sainio C, Lauri S, Eriksson E. Cancer patient's views and experiences of participation in care and decision making. Nurs Ethics. 2001;8(2):3–5.

Reason for exclusion: Not shared decision-making.

Sanders T, Skevington S. Do bowel cancer patients participate in treatment decision-making? Findings from a qualitative study. Eur J Cancer Care. 2003;12(2):166–75.

Reason for exclusion: Not shared decision-making.

Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: a narrative review. Patient Educ Couns. 2006;60:102–14.

Reason for exclusion: Narrative literature review. Included qualitative studies reviewed and none meet the inclusion criteria for this review.

Schaufel MA, Nordrehaug JE, Malterud K. "So you think I'll survive?": a qualitative study about doctor-patient dialogues preceding high-risk cardiac surgery or intervention. Heart. 2009;95(15):1245–9.

Reason for exclusion: Not shared decision-making.

Schulman-Green DJ, Naik AD, Bradley EH, McCorkle R, Bogardus ST. Goal setting as a shared decision making strategy among clinicians and their older patients. Patient Educ Couns. 2006;63:145-51.

Reason for exclusion: Not shared decision-making

Searle A, Gale L, Campbell R, Wetherell M, Dawe K, Drake N, et al. Reducing the burden of chronic wounds: prevention and management of the diabetic foot in the context of clinical guidelines. J Health Serv Res Policy. 2008;13:82–91.

Reason for exclusion: Not shared decision-making.

Sheppard VB, Adams IF, Lamdan R, Taylor KL. The role of patient-provider communication for black women making decisions about breast cancer treatment. Psychooncology. 2011;20:1309–16.

Reason for exclusion: Not shared decision-making.

Sinding C, Wiernikowski J. Treatment decision making and its discontents. Soc Work Health Care. 2009;48(6):614–34.

Reason for exclusion: Not shared decision-making.

Singh S, Butow P, Charles M, Tattersall MH. Shared decision making in oncology: Assessing oncologist behavior in consultations in which adjuvant therapy is considered after primary surgical treatment. Health Expect. 2010;13:244-57.

Reason for exclusion: Quantitative methodology.

Smith SK, Dixon A, Trevena L, Nutbeam D, McCaffery KJ. Exploring patient involvement in healthcare decision making across different education and functional health literacy groups. Soc Sci Med. 2009:69:1805-12.

Reason for exclusion: Explores effects of health literacy on decision-making.

Stenner KL, Courtenay M, Carey N. Consultations between nurse prescribers and patients with diabetes in primary care: a qualitative study of patient views. Int J Nurs Stud. 2011;48(1):37–46.

Reason for exclusion: Not shared decision-making.

Stevenson FA, Barry CA, Britten N, Barber N, Bradley CP. Doctor-patient communication about drugs: the evidence for shared decision making. Soc Sci Med. 2000;50(6):829–40.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Tarzian AJ, Neal MT, O'Neil JA. Attitudes, experiences, and beliefs affecting end-of-life decision-making among homeless individuals. J Palliat Med. 2005;8(1):36–48.

Reason for exclusion: Not shared decision-making.

Thistlethwaite J, Van der Vleuten C. Informed shared decision making: Views and competencies of pre-registration house officers in hospital and general practice. Educ Prim Care. 2004;15:83-92.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Thompson AGH. The meaning of patient involvement and participation in health care consultations: a taxonomy. Soc Sci Med. 2007;64(6):1297–310.

Reason for exclusion: Not shared decision-making.

Thornton H, Edwards A, Elwyn G. Evolving the multiple roles of "patients" in health-care research: reflections after involvement in a trial of shared decision-making. Health Expect. 2003;6(3):189–97.

Reason for exclusion: Not a study

Torke AM, Corbie-Smith GM, Branch WT. African American patients' perspectives on medical decision making. Arch Intern Med. 2004;164(5):525–30.

Reason for exclusion: Not shared decision-making.

Vesey S, Leslie P, Exley C. A pilot study exploring the factors that influence the decision to have PEG feeding in patients with progressive conditions. Dysphagia. 2008;23(3):310–6.

Reason for exclusion: Not shared decision-making.

Walter F, Emery J, Rogers M, Britten N. Women's views of optimal risk communication and decision making in general practice consultations about the menopause and hormone replacement therapy. Patient Educ Couns. 2004;53(2):121–8.

Reason for exclusion: Not shared decision-making.

Watanabe Y, Takahashi M, Kai I. Japanese cancer patient participation in and satisfaction with treatment-related decision-making: A qualitative study. BMC Public Health. 2008;8:77-86.

Weiss M, Montgomery A, Fahey T, Peters T. Decision analysis for newly diagnosed hypertensive patients: A qualitative investigation. Patient Educ Couns. 2004;53(2):197–203.

Reason for exclusion: Evaluation of a decision-making aid.

Wills CE, Holmes-Rovner M. Patient comprehension of information for shared decision making: State of the art and future directions. Patient Educ Couns. 2003;50(3),285-90.

Reason for exclusion: Not shared decision-making.

Winkler EC, Reiter-Theil S, Lange-Riess D, Schmahl-Menges N, Hiddemann W. Patient involvement in decisions to limit treatment: the crucial role of agreement between physician and patient. J Clin Oncol. 2009;27(13):2225–30.

Reason for exclusion: Not shared decision-making.

Woltmann EM, Whitley R. Shared decision making in public mental health care: perspectives from consumers living with severe mental illness. Psychiatr Rehabil J. 2010;34(1):29–36.

Reason for exclusion: Not shared decision-making.

Zoffmann V, Harder I, Kirkevold M. A person-centered communication and reflection model: Shared decision-making in chronic care. Qual Health Res. 2008;18(5):670-85.

Reason for exclusion: Aim of study is not congruent with the objectives of this systematic review.

Appendix VI: Excluded studies based on critical appraisal

Berger S, Braehler E, Ernst J. The health professional-patient-relationship in conventional versus complementary and alternative medicine. A qualitative study comparing the perceived use of medical shared decision-making between two different approaches of medicine. Patient Educ Couns. 2012;88:129-37.

Reason for exclusion: Inadequate representation of participants' voices.

Ekdahl AW, Hellstrom I, Andersson L, Friedrichsen M. Too complex and time-consuming to fit in! Physicians' experiences of elderly patients and their participation in medical decision making: a grounded theory study. BMJ Open. 2012;2:e001063. Doi: 10.1136/bmjopen-2012-001063

Reason for exclusion: Inadequate representation of participants' voices.

Elwyn G, Edwards A, Gwyn R, Grol R. Towards a feasible model for shared decision making: Focus group study with general practice registrars. BMJ. 1999;139:753-6.

Reason for exclusion: Inadequate representation of participants' voices.

Elwyn G, Edwards A, Kinnersley P, Grol R. Shared decision making and the concept of equipoise: The competences of involving patients in healthcare choices. B J Gen Pract. 2000;50:892-897.

Reason for exclusion: Inadequate representation of participants' voices; fit data into a predetermined model

Fillion E. How is medical decision-making shared? The case of haemophilia patients and doctors: The aftermath of the infected blood affair in France. Health Expect. 2003;6:228-41.

Reason for exclusion: Inadequate representation of participants' voices.

Maffei RM, Dunn K, Zhang J, Hsu CE, Holmes JH. Understanding behavioral intent to participate in shared decision-making in medically uncertain situations. Methods Inf Med. 2012;5(4):301-8.

Reason for exclusion: Inadequate representation of participants' voices.

Stevenson FA. General practitioners' views on shared decision making: A qualitative analysis. Patient Educ Couns. 2003;50:291-293.

Reason for exclusion: Inadequate representation of participants' voices

Towle A, Godolphin W, Grams G, Lamarre A, Putting informed and shared decision making into practice. Health Expect. 2006;9:321-332.

Reason for exclusion: Inadequate representation of participants' voices; fit data into a predetermined model

Appendix VII: Degrees of credibility for qualitative studies

The congruency between study findings and the supporting data from the included studies was graded to illustrate the degree to which the interpretation of the research is credible, according to the levels outlined in JBI-QARI. The information presented below includes a description of the categories that are used to support the final synthesized findings.

Unequivocal [U]: evidence beyond reasonable doubt, which may include findings that are matter of fact, directly reported/observed and not open to challenge.

Credible [C]: evidence that is, albeit an interpretation, plausible in light of the data and theoretical framework. The interpretation can be logically inferred from the data but, because the findings are essentially interpretive, they can be challenged.

Not Supported [NS]: when neither of the other two level descriptors applies and when, most notably, findings are not supported by the data.

Appendix VIII: List of study findings/conclusions

Shared decision making and risk communication in practice: A qualitative study of GPs' experiences (Edwards et al., 2005)³⁷

Finding 1	Views on the training process [U] – Not related to SR objective
Illustration	"I think we have to distinguish between training for the study and training for life. I wouldn't have considered that that was adequate training if you were genuinely trying to alter doctors' behaviour. I mean we were prepared to try and learn this stuff for the purpose of this study. And I think if you were training doctors to change their behaviour you would have to hammer the message home a little more." (p. 8; provider)
	"I didn't feel I acquired any new skills really. I just felt I had more information to give patients on these four subjects." (p. 8; provider)
	"Doing our arm of the study made perfect sense because you did the risks and looked at it in terms of risk management and then you did the shared decision making and the way it rolled would be the way that it would naturally be rolled out." (p. 8; provider)
Finding 2	Perceived effects of trial interventions on patients [U]
Illustration	"It improves your relationship with the patient if you share information, give them as much information as possible." (p. 9; provider)
	"Sometimes it meets with a really flat response because it's something that they have never really encountered before. Sometimes you will be surprised and they turn around and say "well yeah, of course I want to be involved". But sometimes people turn around and say "tell me what to do doc." (p. 9; provider)
Finding 3	Communication skill issues [C]
Illustration	"I think we overestimate our abilities to do that. And, er, I think trying to use the shared decision-making model, there is a point in the model which I find most alien to natural practice, is where you are actually meant to ask the patient how they wish to proceed. You might say "do you want to decide, do you want me to decide, or should we decide together?" And I find this impossible to get across to patients and through chance the first two that were on my tape, if you had asked me beforehand, before I got to that stage in the consultation, I would have predicted that the first patient would have said "you decide" and the second one would have wanted to decide from the way they took the information and what I knew about them already, and the way I looked at them and decided what sort of person they were. And I would have been completely the wrong way round." (p. 9; provider)

Finding 4	Data issues [U]
Illustration	"That's why it was so nice to get the file [of risk information]. To get the white file was really nice to then be able to explain the risks." (p. 10; provider)
	"I disagreed with some of the information that was in the leaflet as well. There was some of it that was incomplete, so that I found difficult." (p. 10; provider)
	"It would be nice to have that amount of information for a wider range of conditions, but who would be responsible for updating it and how could it be continuously updated to a high enough level to be meaningful?" (p. 10; provider)
Finding 5	Use of the approaches in practice (time, patients, conditions, provider intent to use) [C]
Illustration	"I think we have got to teach people how to take more responsibility for their own health. And I think this would be a step towards it." (p. 10; provider)
	"Seven-and-a-half minutes to do something like this is impossible." (p. 10; provider)
	"I think also your communication skills get better or I hope they do as you get more experienced as a GP. And I think with SDM [shared decision making] you get better at dressing it up and then gauging if they are in a position to make a decision do they want a decision made for them or not. So you get better at watching people's faces," (p. 11; provider)

Mutual influence in shared decision making: a collaborative study of patients and physicians $(Lown\ et\ al.,\ 2009)^{38}$

Finding 1	Patient: acts in a relational way [C]
Illustration	"[It helps] having an open and candid dialogue and relationship so that pretty much anything can be discussed If you have the trust, then you find that you aremore willing to put those things out on the table." (p. 165; patient)
Finding 2	Physician: acts in a relational way [C]
Illustration	"Express caring in that interaction – this is what the physicians can do. And the quality of that caring is what enhances the intrinsic motivation of the patient tot take the responsibility." (p. 165; provider)

Finding 3	Patient: understands and expresses feelings, preferences, and information about self. [C]
Illustration	"(The) patient was emotionally available. She was in touch with some emotions she was having when the physician in the story gave an indication that they were receptive. She let the flow take place. She shared herself." (p. 165; patient)
Finding 4	Physician: explores patients' feelings, preferences, and information about self [C]
Illustration	"What out being able to say, 'What is it that you're most afraid of?' nothing else would have happened in that conversation" (p. 165; provider)
Finding 5	Patient: discusses information and options [C]
Illustration	"[I]t's extremely important that there is a language that is understandable by the patientAnd that the physician takes time out to get feedback. 'Did you really understand what just was communicated?'Sometimes information can be given in too large a dose, even though it may be clear." (p. 167; patient)
Finding 6	Physician: discusses information and options [C]
Illustration	"[Y]ou don't understand something, you ask again. You know what, 'I don't understand the sensitivity and specificity stuff. Put it into different words.' You're going through and letting people know it, rather than just nodding your head." (p. 167; provider)
Finding 7	Patient: seeks information, support, and advice [C]
Illustration	"[M]y strategy really is to take a friend to listen with me because I don't always hear what I really should, what the person said. I may hear what I thought they said and that person can strike a balance for me and put things in some objective perspective." (p. 167-8; patient)
	"I mean, it's very useful to talk to non-doctors about a dilemma because they don't see it in an occupationally routinized way. I think it's going outside of medicine to bring things to the medical encounter – literature, religion." (p. 168; patient)

Finding 8	Physician: seeks information, support, and advice [NS]
Illustration	No quote provided to support this theme
Finding 9	Patient: shares control/negotiates a decision [C]
Illustration	"We sort of realized that there's a meta-process that has to occur first, which is the physician and the patient have to agree about how the decision is going to get made. Some patients will want the physician basically to lead them and say, 'This is what you should do.' And other patients basically would have the physician explains the alternatives to them. So the first step actually is to come together and create a decision about how the process will be implemented." (p. 168; patient)
Finding 10	Physician: shares control/negotiates a decision [C]
Illustration	"It's the shifting of control, too. I mean, in him giving her control, then she handed it over [to him]. And it's a dynamic that in any interaction goes back and forth." (p. 168; provider)
Finding 11	Patient: acts on behalf of self [C]
Illustration	"[U]ltimate control of patients' health decisions resides with the patient. These are strategies – be mindful of behavioral changes, they've got to be owned by the patient'" (p. 169; patient)
Finding 12	Physician: acts on behalf of the patient [C]
Illustration	"[Y]ou can lay out, 'Well these options exist, but your insurance will prevent us from doing something.' But if we go out of the box and go at it a different way, another solution is possible. A willingness to circumvent system issues." (p. 169; provider)

Shared decision making in mental health treatment: qualitative findings from stakeholder focus groups (Mahone et al., 2011)³⁹

Finding 1	Provider barriers [C]
Illustration	"For example, if I as a case manager am making my consumers award of this new model, this new way of doing things, it's going to take yearsSo I think that there's got to be more than just service providers. There has got to be agency awareness." (p. 31; provider)
	"The insurance company makes the decision I've had a number of decisions about meds be totally thrown overboard when they go into the hospital. So I think that's a practical barrier—that there are more forces here than you'd think that control what is prescribed." (p. 31; provider)
Finding 2	Consumer barriers [C]
Illustration	"I think the question of insight is different. I wasn't bringing up cognitive impairment. I was bringing up insight and I think that is something separate. So we have to be careful not to equate those two in terms of a concern because insight is not accepting that you even need to be in the office, meeting with the provider at that time, because you have nothing wrong with you, so why should you even be there?" (p. 32; provider)
Finding 3	Information-Exchange issues [C]
Illustration	"The doctor should inform you of your medicines because it's something that your body is going to go through and you have to be apprised of these things so you're not in shock or anything." (p. 33; patient)
Finding 4	New skills needed [C]
Illustration	"You do find doctors who are very nonlistening. They haven't been taught proper listening skills, or call it communication skills." (p. 34; patient)
Finding 5	Outcomes [C]
Illustration	"The goal is to try and help the consumer achieve their goals." (p. 34; provider)

"It gives them more enthusiasm to actually want to recover. If you force them they're not going to give it their all. The goal is to get them to the highest level of independence." (p. 34; provider)

Barriers and facilitators to shared decision-making among African-Americans with diabetes (Peek et al., 2009) 40

Patient/Provider power imbalance [U]
"I thought that since I had these top doctors, that I probably had no right to question them on anything because they were the top of the line" (p. 1137; patient)
"A lot of [African-Americans] are scared to speak up and ask questions and voice their opinions. Living in poverty, you're not used to getting certain treatment anyway" (p. 1137; patient)
Patient factors: Health Literacy [C]
"I let the doctor manage my diabetes Yeah, I leave it to him because he is the professional and he would know more about it than I would" (p. 1137; patient)
"I think now that I have become a little more knowledgeable about the disease, I don't hesitate to question, to ask. 'What's the benefit of this pill?' (p. 1137; patient)
Patient factors: trust [U]
"[My doctor] too time and I felt like I could trust her now I feel more comfortable talking to her about my health. She would listen and talk to me about decisions and medications." (p. 1137; patient)
Patient factors: Fear and denial [U]
"I think I was probably 'chicken' and didn't want to hear [about my disease] I think I could have talked to them if I had wanted to" (p. 1137; patient)
Patient factors: Self-efficacy: [NS]

Illustration	"Well, at first I really didn't understand about the diabetes, but I felt better when I got the meter That's when I really felt good, and I tell everybody now that 'If you don't have a meter to test yourself, you just don't know' The meter has really helped, and when my husband uses his, then I use mine." (p. 1137; patient)
Finding 6	Physician factors: Information-sharing and patient education [U]
Illustration	"Well, I feel that some [physicians] you can't trust because you don't get all of the information that you should have like your overall tests and the advice and all that stuff I don't think that they give you the right answers to your tests." (p. 1137; patient)
Finding 7	Physician factors: Validation of health concerns [U]
Illustration	"[Doctors] need to listen to what you're saying and understand what you are saying how are they supposed to know what's bothering you if they don't listen." (p. 1137; patient)
Finding 8	Physician factors: Accessibility and availability [U]
Illustration	"Just all around she is gooda good person, a good doctor When I am ill and I call her office for advice of something, she returns my call." (p.1137; patient)
Finding 9	Physician factors: Interpersonal skills [C]
Illustration	"Some [of the] things that made me comfortable with him is that he just had a personal touch He made you feel good and he really tried tohe had a warm personality, you know." "[My doctor] told me that he likes for me to ask him questions, because he said that when you're a patient and you're educated, it's much easier to treat youSo if I'm affected [with a problem], I'm supposed to let him knowHe's a very good doctor and he's very receptive he's a very nice person and I like the way he does things" (p. 1137; patient)
Finding 10	Patient factors: Family experiences: [NS]
Illustration	"At first I was thinking, 'Do I really have diabetes?' And I was thinking about the family members that had it I had a great grandmother who actually went blind and had amputations and it really hadn't dawned on me that it could go that direction. But, still, that probably made me think about how you are really playing with fire, So now I talk with Dr. X about it, and I'm on track with it." (p.

	1137; patient)
Finding 11	Physician factors: Physician medical knowledge/technical skills: [C]
Illustration	"They know more about the treatments and what's pertaining to the treatments, and if they suggest it to me and explain it to me, then I will make the other half of the decision regarding whether I should take it or not. And I like that about them bringing it to me." "They took a real deep interest in finding out what's wrong, so that's why I felt like I could talk to them about anything. Because they were real inquisitive and well-trained." (p. 1137; patient)

Sharing decisions in consultations involving anti-psychotic medications: a qualitative study of psychiatrists' experiences (Seale et al., 2006)²¹

Finding 1	Commitment to patient centred practice [U]
Illustration	"I've learned how to negotiate with individuals about their medications. Also, I think our practice has changedwell I think our practice has changes. We are a lot more open to discussion and debate, information and choice, which is how it should be really. [It is] partly because of the whole changing focus of mental health, user groups, community based etcetera." (p. 2865; provider)
Finding 2	A central dilemma: medication and adverse effects [C]
Illustration	"I think it's a mainstay of treatment- what I mean by that is that other forms of treatment are effective but are considerably less effective if the drug treatment isn't being given whereas the drug treatment doesn't depend on the others to have its effect in its area." (p. 2865; provider
Finding 3	Building a therapeutic alliance [U]
Illustration	"I genuinely see us as in it together, if you like, that it's a partnership and it's not going to work if I am somehow in a position of superiority and they're in a subordinate subject position. I think it just won't work." (p. 2866; provider)
Finding 4	Honesty and dishonesty [C]
Illustration	"I don't feel that I have all the answers, I feel that's very liberating (laughs). If I don't know something, I just tell the patient, 'I'm sorry I don't know that' or I feel

	happy to say, 'I'm not very good at that.' " (P. 2867; provider)
	"If you emphasis too much the side effects sometimes you feel that you are increasing the probability of the person saying 'no I don't want to take this medication.' " (p. 2867; provider)
Finding 5	Becoming directive or coercive [C]
	"I felt that because she didn't have a particular suggestion [and was particularly unwell] that that was the cue for me to be as it were more paternalistic really and say well this is that I think we should do from your past experience from my experience, let's give it a try." (p. 2868; provider)
Illustration	"I like to think that most of the time I'm collaborative but that I can recognize when I need to be more authoritative-authoritarian if you like I will be directive if somebody is too unwell to make a choice. In community or the outpatient setting it will be less so but there will still be occasions when I have to do that, so being able to recognise when. But I actually think I am collaborative and involve patients." (p. 2868; [provider)
Finding 6	Non-compliance [C]
Illustration	"Normally we spend a long time getting somebody stable on a particular medication and they call up for an urgent appointment and when they come it is very very clear that the carer or relative has said 'you're fine now, stop medication'We work extremely hard with some very complex people with polypharmacy which is difficulty to work with, finally get them well, and it all happens again. And again and again." (. 2868; provider)
	"The chief reason would include forgetfulness, so non intentional not taking it including due to being distracted by their ill health. Another one might be feeling that there isn't a health problem that requires medicine, and that both being explained to them, or is explained and not accepted by them. Another may be family culture or relatives, they say 'pull yourself together' or it's a sign of weakness if you take medicines. Another might be fear of side effects, or actual side effects, which may come on much earlier than the beneficial effects of course. Another may be the conviction medicines won't work. Another may be dislike or western capitalists and drug companies and a preference to go for homeopathic or other alternative remedies. Those are just a few that come to mind." (p. 2869; provider)

Factors which motivate cancer doctors to involve their patients in reaching treatment decisions (Shepherd, Butoe, & Tattersall, 2011)¹¹

Finding 1	Decision context [U]
Illustration	"It depends on the disease so that if it's a disease where I think there's a clearly the best therapy I'll probably even in some way try to steer them against sharing the decision because I would have made my mind up form the scientific evidence that is the best." (p. 231; provider)
	"I say look if you have appendicitis you are having your appendix out at 5 o'clock today. Whether you're ready or not. Whether you've got meetings or other things on, we don't really care. You're having it out and the surgeon rolls her eyes at you if you think there's anything to discuss or so [] Um, so there, is no shared decision making that thing. It's very black and white type of thing." (p. 231; provider)
Finding 2	Existence of treatment options [C]
Illustration	"So there are many decisions of the breast. Often, the fundamental one is O.K. we can do a, wide excision and radiotherapy [] or we can do a mastectomy. The results withe many are pretty much equal in terms of survival [] there is a, there's a choice between the deformity of the mastectomy, whilst avoiding 5 weeks of daily radiotherapy which knocks them about bit and it's totally disruptive to their life. [] And in almost every breast is a, a multichoice discussion and then very few is it cut and dried." (p. 231; provider) "we've been thrust into it that's why, we're used to it. [] certainly in prostate I mean ah, it's an area where we just don't know what the right answer is, so you have to involve the patient. You're fool if you don't." (p. 231; provider)
Finding 3	Impact of treatment on patient [U]
Illustration	"Sex. Yeah, ah so yes I'm being a bit provocative but I mean the impact of taking off a breast is significant to a woman and therefore, for me to disfigure, if, if I were a breast surgeon, to disfigure somebody in that way I'd have to have the support of the patient. They have to say; yes I want my breast off I don't want to feel that I've imposed. And for a lot of prostate cancers and loss of sexual function, the impotence and things like that, and for me to take that away from somebody I think that probably I have to have them ask me to do it rather tan me impose it on them [] that, crudely and maybe simplistically, [is] what I think it is." (p. 231; provider)

Finding 4	Disease culture [C]
Illustration	"when someone gets leukaemia well they've often never heard of it or hardly heard of it and got all sorts of strange preconceptions and it's such a foreign entity that they [] say, and doctor I don't know anything about leukaemia but you tell me what to do. Whereas with breast cancer women and with prostate they might say, yeah, um I know a lot about this, it's in the news." (p.231; provider)
Finding 5	Stage of disease [C]
Illustration	"The second scenario I guess would be in advanced disease where often people have had a number of treatments, and so the chances of further treatments working is getting increasingly small [] the chance of just feeling worse because of side-effects is narrowing. [] the chance of benefit might be 10%, and chances of getting some side-effects are 30-40%. And, its your call as to whether you just want us to treat symptoms as opposed to give you a treatment that may improve the disease but probably won't" (p. 231; provider)
Finding 6	Practice area culture [U]
Illustration	"you tend to discuss the things that you think are treatments you can offer, or treatments that you think you're good at, or you would be [] fell are appropriate." (p. 232; provider)
	"I guess I'm aware that you know I'm the surgeon and I'm aware that I am biased towards surgery as a treatment option. I think most people if they were honest would actually admit that they are probably biased towards the treatments that they use" (p. 232; provider)
Finding 7	Communication style [C]
Illustration	"I guess that's the skill of the consultation [] trying to work those people out [] whether you need to bring them back a couple times, whether you need to get other people involved or whether they're truly just passive and happy to leave you be. I mean at the bottom, the bottom line is that, again I'm confident with my advice, but I want to know how they're going to react if it doesn't go well. So if they're gonna stay passive and [] accept the problems that are there, and keep going, well that's fine, bit if problems occur and they become aggressive and, and blameful, well then um, I'm going to push them to be much more ah active. [Mmm, Mmm] Ah now, God only knows how you sort that out. [] I guess that's seat-of-your=pants stuff sometimes isn't it?" (p. 232;

	provider)
Finding 8	Doctor perceptions [C]
Illustration	"I'm assuming that they want to survive and live and that there's clear evidence with clinical trials, that this gives the best survival rate so I'm not too worried if they are so anxious they can't under, they can't make the, the appropriate decision. Although, I've made a judgment that [] this is going to give them the best survival, based on the evidence." p.232
Finding 9	Anxiety [U]
Illustration	"anxiety paralyses a lot of people but often if you engage in the decision process, sharing process that dissolves a lot of the anxiety." (p. 233; provider)
Finding 10	Gender [NS]
Illustration	"[] they always tell me exactly w hat I can do with my chemotherapy or not" (p. 233; provider)
Finding 11	Cultural background [C]
Illustration	"the culture of certain countries does vary enormously form Australia. What they expect of doctors, how they behave to doctors, how much respect they have for doctors [] will involve how much involvement they want in the decision-making." (p. 233; provider)
Finding 12	Understanding [C]
Illustration	"I would say more highly educated or more widely read people would prefer to be involved because they actually want to hear about - and often read a lot of stuff." (p. 233; provider)
	"I mean sometimes you're worried even though you think you are using plain English they're lost. I mean some people don't know where their stomach is, I mean they're really generally don't know where it is and then they're kind of embarrassed and it's kind of like how can they [make a decision]?" (p. 233; provider)

Finding 13	Involvement preferences [C]
Illustration	"You have a set of people who say whatever you say doctor [] another set who will um, ah very small subset who in cancer patients, who have their own plan. [] You have to sort of present to them the options, and then it's up to them, and then the ones in the middle who are very reasonable and you explain why you think a course of action is the best and get them to come on board with it" (p. 233; provider)
	"I think it's a [] bit of a mixture. It surprises you who says, I'll just try on what you think I should do, and the people that say no, no, I need, I need all the information to make a decision. [] I don't think I can say oh one group, I can't generalise that well with them I don't think" (p. 233; provider)

Shared decision-making in home-care from the nurse's perspective: sitting at the kitchen table - a qualitative descriptive study (Truglio-Londrigan, 2013)¹⁷

Finding 1	Begin where the patient is: Building of trust [U]
Illustration	"I think my role was to maintain open lines of communication and continue to prod this mother and give her as much information as she could tolerate and also known when to back off" (p. 5; provider)
Finding 2	Begin where the patient is: Coming to know one's patient [U]
Illustration	"I was concerned that I was dealing with a child and the family. The mother was totally overwhelmed, very slow learner was she a visual learner or an auditory learner? It turned out to be she was more visual." (p. 6; provider) "The child initially did not want to have anything to do with us so initially I
	was doing everything, and then one of the things that I got the other to do was finally to prick the child's finger and get a reading. And then the child began to show some interest." (p. 6; provider)
Finding 3	Education for shared decision making: The what of education for shared decision-making (What one needs to know) [U]
Illustration	"She needed an explanation of what was happening to her mother's kidney. What's happening to her wound? If the blood pressure was too low, what

	should I do? If the sugar goes too low, what should I do?" (p. 6; provider)
Finding 4	Education for shared decision making: The how of education for shared decision-making (Figuring it out) [U]
Illustration	"[it is important to ensure that the patient is able to] process and understand the information" (p. 7; provider)
	"It wasn't a complicated dressing. She had a full-length mirror in her bedroom and she could stand there and make sure she was putting it on right." (p. 7; provider)
Finding 5	Education for shared decision making: Ongoing education [U]
Illustration	"I remember asking the mother; what if your child has this kind of symptom and you can't get food, what would you carry in your pocketbook? She told me would give a diet coke. I knew I was in trouble" (p. 7; provider)
	"Before I went to a patient's home, I would look back at my notes form the visit before I would say to them, you know the last time we discussed this you said you would try such and such, did you?" (p. 7; provider)
Finding 6	The village and shared decision-making [U]
	"I would say that the family involvement was very effective in terms of being there for her mothershe even told me; I will speak to the doctor about this because I want to know" (p. 7; provider)
Illustration	"Members of the interdisciplinary team would come together to talk to the client about what was going on and what our proposed plan was and see what the client is willing to have or not have and, the client really has access to everybody on the team" (p. 7; provider)
Finding 7	Whose decision is it?: Not what one expects [C]
Illustration	"The biggest problem we has was that he wanted to inject the insulin by himself. He just could not inject himself" (p. 8; provider)
	"We need to validate whether we were making the right decision, whether the approach was correct So it took a bit of soul searching; when you are going

	through this, you need somebody else to validate." (p. 8; provider)
Finding 8	Whose decision is it?: Helping patients fine their personal voice [C]
Illustration	"I wouldn't push her And it got to the point where she would talk about [the dressing], and then it got to the point where she agreed to look at it But then she got to the point where she stood up in front of a mirror and took off the dressing, and she looked at it" (p. 9; provider)

Shared decision making or paternalism in nursing consultations? A qualitative study of primary care asthma nurses' views on sharing decisions with patients regarding inhaler device selection (Upton et al., 2011)³⁰

Finding 1	Providing information and offering limited choice [NS]
Illustration	"The hope is that you've given them the information, that they can make that informed choice, and I think that's what shared decision making is" (p. 377; provider)
Finding 2	Power and persuasion [U]
Illustration	"Sometimes it obviously has to be a compromise, in an idealistic world everybody would listen to what you're saying and do it, it doesn't work like that so you have to compromise to a certain degree and sometimes quite big compromises but mm, if you get to know someoneyou can jut slowly chip away and just hope that at some point they may be ready to make that change." (p. 378; provider) "Shared decision-making (is when) you would be the informer, to give the patient the choicesand for the patient to decide with you for themselves what
	their preference would be, and then to come to some agreement somewhere in the middle about what would suit you both. So trying to sort of trying to gently sway them maybe towards what you fell would be the best option, but also listening to their opinion." (p. 378; provider)
	"80-90% of the time it's basically more on my decision. It's going to be isn't it because I'm the one with the power and the inhalers to show them you know, unless they have some particular knowledge, it's skewed in my favor." (p. 378; provider)

Finding 3	Sharing decisions to increase adherence [U]
Illustration	"if you don't have shared decision-making, if you inflict an inhaler on a patient that they don't want, they're not going to use it, and if they're not going to use it then their controls not going to be good, so they're going to have symptoms. And when you look at exacerbation rates and those sorts of audit markers it's not good from our side either'." (p. 379; provider)
Finding 4	Assumptions made by nurses [U]
Illustration	"It's alright saying 'I want this 'touchy-feely' trendy partnership with the patient', but there are some patients, would I be wrong in saying maybe the older patients, I don't want to generalize, who actually want to be told what to doSo you're always making that decision based on the patients communication to you you don't always get it right, it's a lot of assumptions." (p. 379; provider)
Finding 5	Barriers of shared decision making (time constraints) [U]
Illustration	"If you haven't got time, it's easier to say 'you're going to have this one' and off they go, it takes longer if you come to a joint agreement because you've got to discuss all the options first and let the person have an input into the final decision." (p. 379; provider)
Finding 6	Barriers of shared decision making (costs) [C]
Illustration	"Our primary care trust (PCT) is telling us to take people off combined inhalers (and) that we are to take them off certain branded inhalers, We've had to overhaul absolutely everybody and put them back on to single inhalers, and to use metered dose inhalers." (p. 379; provider)
Finding 7	Barriers to shared decision making (Quality outcomes framework [pay for performance guidelines]) [U]
Illustration	"QOF [quality outcomes framework] guide is tick boxes and you sort of lose perception and you lose the focus on patient care I think, sometimes I know I'm doing it, I can feel myself not really taking much notice of the patient." (p. 379; provider)

Appendix IX: Joanna Briggs Institute levels of evidence for studies of meaningfulness

Level 1	Meta-synthesis of research with unequivocal synthesized findings.
Level 2	Meta-synthesis of research with credible synthesized findings.
Level 3a	Meta-synthesis of text/opinion with credible synthesized findings.
Level 3b	One or more single research studies of high quality.
Level 4	Expert opinion.