

Ottawa Decision Support Tutorial



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Introduction

Introduction to the Ottawa Decision Support Tutorial

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Target Audience

The Ottawa Decision Support Tutorial improves health professionals' understanding of decision support, shared decision making, and how to effectively engage individuals in decisions related to their health and social care. It

may also be relevant for others involved in counseling and supporting patients* making any difficult decisions. The tutorial has been completed by administrators/ managers, case managers, chaplains, chiropractors, community health workers, counsellors, dietitians, early childhood educators, health educators, health coaches, helpline operators, human resource advisors, journalists, kinesiologists, librarians, midwives, nurses (registered nurses, registered practice nurses), occupational therapists, pharmacists, physiotherapists, physicians, psychologists, researchers, research assistants, respiratory therapists, policy makers, social workers, and speech-language therapists.

Learning Objectives

Upon completing the Ottawa Decision Support Tutorial, participants should be able to:

- describe concepts of decision support and how it fits with shared decision making
- identify difficult decisions requiring decision support
- explain how to assess patients' decisional needs
- tailor decision support to patients' decisional needs
- explain how to use patient decision aids
- discuss how to evaluate decision support interventions

*patient was the term chosen to represent patients, clients, consumers, and individuals involved in making health decisions for themselves or for someone else (e.g., family member, friend, surrogate, caregivers).

How to Proceed Through the Tutorial

1. Complete the 9 sections (1 to 2 hours).
The sections are followed by self-assessment questions that provide you with feedback on your responses; these questions may be reviewed or re-answered as often as you want. If you do not complete this tutorial in one sitting, you can log back in at any time and resume the tutorial where you left off (only if you remember your username and password).
2. Write the final quiz to obtain a certificate.
When you have completed the Ottawa Decision Support Tutorial, there is a final quiz covering all of the sections. Participants achieving 75% or higher receive a certificate of completion. Click on the link to your "Certificate of Completion" on the Final Quiz page, and print a copy of the certificate for your records. Please note that those who do not get the 75% mark, can retake the module and the test by creating a new username and password.
3. Share your views of the tutorial.
At the end of the tutorial, you will be offered a survey to provide feedback. This survey is optional and anonymous. We aim to regularly update this tutorial and appreciate your suggestions on how best we can improve the tutorial. If you have any questions or comments please contact decisionaid@ohri.ca.

Other Helpful Hints

Download and print the [PDF version of this tutorial](#).

Navigate as you go. There are links in the left-hand menu to go to any section or self-test in the tutorial. The menu items on the left of the screen will tell you where you are in this tutorial. You can return to the previous section by clicking on the "Back" button or go forward by clicking on the "Next" button at the bottom of each page. The "Logout" button ends your session and returns you to the login page.

Privacy Statement

Any information collected is for the purpose of evaluating the Ottawa Decision Support Tutorial and will be kept confidential. If you are taking this tutorial for credit, your grade on the final quiz could be forwarded to your instructor. Otherwise, you will not be identified in any publications or presentations about the tutorial.

Development of the Tutorial

The Ottawa Decision Support Tutorial was originally developed in 1998 by Annette O'Connor RN, PhD and MJ Jacobsen RN, MEd in the School of Nursing and Department of Epidemiology at the University of Ottawa. It was based on the Ottawa Decision Support Framework and empirical evidence. For the update with new evidence in 2003, the tutorial was moved to the website at the Ottawa Hospital Research Institute to make it more broadly available and free of charge. In 2011, it was made available in French. In 2021, it was updated with the 20th anniversary systematic reviews of the Ottawa Decision Support Framework.¹⁻³

Effectiveness and Use of the Tutorial

The Ottawa Decision Support Tutorial improves knowledge of decision support. The tutorial has been evaluated in: (a) two randomized trials with nurses practicing in health call centres and in oncology/palliative care,^{4,5} (b) one pre-/post-test study of health professionals working at a cancer helpline,⁶ (c) a descriptive study with nursing students,⁷ and a 2019 evaluation with 6000 participants.⁸ When the tutorial was combined with a skills-building workshop, participants improved the quality of decision support that they provided.^{4-6,9}

It is routinely used by health professionals and students in Canada and other countries.

Financial Disclosure

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1. Decision Support and Shared Decision Making

Throughout their lives, patients* face many difficult health decisions. For example:

- Which birth control method should I use?
- Should I have surgery to correct my vision?
- Are my symptoms severe enough to warrant stronger medications with more serious side effects?
- Should I receive care at home or in a facility (e.g., dialysis, nursing care)?

Decision making is the process of choosing among alternatives, which may include continuing with one's current plan of care (status quo). For some elective diagnostic tests and treatments, an alternative may be active monitoring (watchful waiting). During deliberations, patients need to understand and consider:

- that there is an explicit decision to be made
- the available options for their situation
- the features of these options: known benefits, harms, other outcomes/features, scientifically uncertain outcomes
- the personal value or desirability of these features

Although patients prefer an option that has the desired features and avoids the undesired ones, there is often **no clear best choice**. There may be more than one reasonable option with features that patients value differently.

For example, over 3000 healthcare treatments have been classified as: 11% beneficial, 24% probably beneficial, **7% need to weigh known benefits versus risks**, 5% probably not beneficial, 3% likely to be ineffective or harmful, and **50% insufficient evidence of usefulness**.¹⁰ Therefore for the majority of these treatments there is no clear best choice. Even among the more beneficial options, patients may have more than one option whose features are valued differently.

Most patients want to be involved in making difficult health decisions. However, they may not be aware that they have options nor invited to participate in decisions by their health professionals.¹¹ Moreover, health professionals' usual approach to counseling patients about difficult decisions does not always lead, to informed choices that are based on what matters most to the patient.¹²

1.1 Decision support

According to the Ottawa Decision Support Framework,¹ decision support for difficult decisions is structured assistance in deliberating on the options and communicating with others. It is tailored to the patient's decisional needs and aims to achieve decisions that are informed and based on the features of options that patients' value most. Elements of decision support include:

- establishing rapport and facilitating interactive communication
- clarifying the decision point and inviting the patient to participate in making the decision
- assessing and addressing the patient's decisional needs using tailored decision support, including
 - facilitating receptivity to information and deliberation
 - providing information and outcome probabilities, and verifying understanding
 - clarifying personal values
 - discussing decisional roles
 - supporting deliberation and mobilizing resources
 - monitoring decisional needs and facilitating progress in decisional stages

1.2 Shared decision making

Decision support for difficult decisions where there is no clear best answer fits into the broader concept of **shared decision making**, a process of engaging patients to participate in any health care decision, including those with a recommended option or options. At its core, **shared decision making** is an interpersonal, interdependent process in which the health professional and the patient relate to and influence each other as they collaborate in making decisions about the patient's health care.¹³ Shared decision making is patient specific, and it relies on research-based evidence, the health professionals' clinical expertise, and the unique attributes of the patient and his or her family. When making the decision together, the expertise of each other is recognized: a) health professionals are experts in diagnosing the problem and identifying options, known benefits, harms, other outcomes/features, and scientifically uncertain outcomes; and b) patients are experts in understanding their personal circumstances and judging the value or personal importance they attach to the features of each option.

When 40 shared decision making models were analysed (including the Ottawa Decision Support Framework), the most common elements included:¹⁴

- Create choice awareness (e.g., make need for decision explicit)
- Deliberate
- Describe treatment options
- Learn about the patient and check understanding
- Tailor information on pros/cons (benefits, risks, costs)
- Clarify the patient's preferences (e.g., concerns, goals of care, values for features)
- Make or explicitly defer the decision

Other elements of shared decision making include: determine next steps (48%), mutual agreement (35%), determine roles in the decision making process (35%), advocate patient views (30%), reach foster partnership (30%), provide recommendation (25%), gather support and information (20%), provide neutral information (20%), patient questions (20%), offer time (20%), healthcare professional preferences (18%), prepare (15%), healthcare professional expertise (10%), and patient expertise (8%).¹⁴

1.3 Patient engagement in decision making

Engaging patients to participate in making decisions is a necessary component of patient-centred care, informed consent, health care improvement, and patient-oriented research. Informed consent generally implies that patients are informed of their options including benefits and harms. The health care improvement programs of high income countries identify shared decision making as an important strategy to meet their aims of improved: 1) patients' outcomes; 2) patients' experiences; 3) clinicians' experiences; and 4) optimisation of costs.^{15,16} The following are examples supporting patient participation in decision making:

- In Canada, the Ontario consent legislation requires that patients are consenting to treatment after being informed of their alternative options.¹⁷ British Columbia identifies shared decision making as a key strategy for health care improvement.¹⁶
- In the USA, Washington State passed the first informed-consent legislation in 2007 to indicate the need for shared decision making as evidence of informed consent to treatment.¹⁸ Their description of shared decision making includes patient engagement in decision making, use of patient decision aids, and the need to ensure patients understand available treatment alternatives. Washington State established the first program to certify patient decision aids in 2016.¹⁹ Other states in the USA are in varying stages of drafting similar legislation.^{18,20} In terms of health care improvement, the importance of shared decision making was identified in 2008.¹⁵
- The law on consent in the United Kingdom changed in 2015 to require that health professionals: a) make sure patients are aware of their alternative options and the harms involved; b) share information using clear terms; and c) document the consent process.²¹ In 2021, [NICE](#) released guidance on Shared Decision Making.

- In Australia, the 2017 revised National Safety and Quality Health Service Standards used for hospital accreditation requires shared decision making in Standard 2.²²

[Appendix A](#) provides a glossary of decision support terms used in the tutorial.

*patients is the term chosen to represent patients, clients, consumers, and individuals involved in making health decisions for themselves or for someone else (e.g., family member, friend, substitute decision maker).

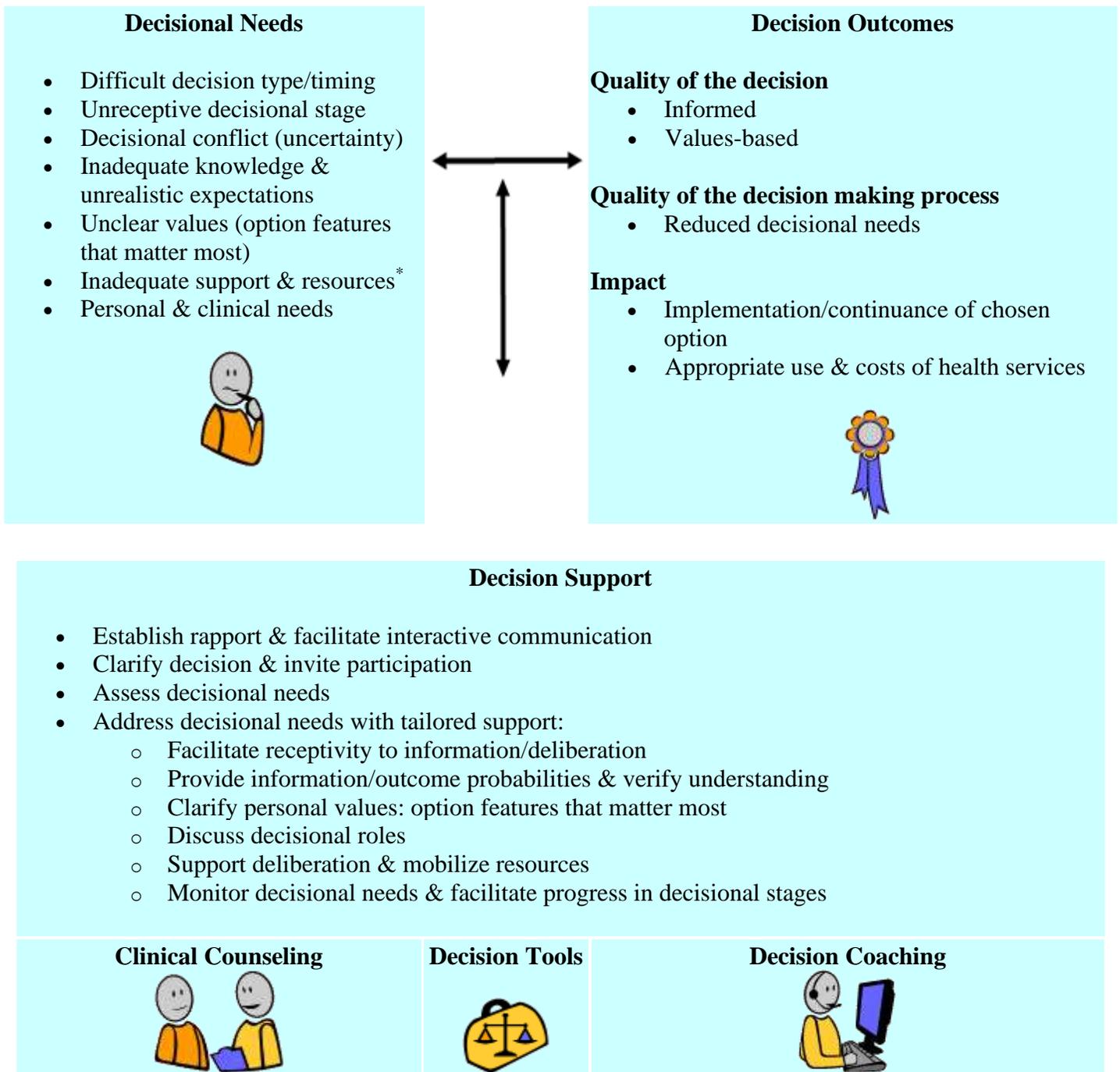
2. Conceptual Foundation: The Ottawa Decision Support Framework

This tutorial is guided by the Ottawa Decision Support Framework (ODSF)^{1,23} that uses concepts and theories from several disciplines. The ODSF conceptualizes the support needed by patients, families, and their health professionals for 'difficult' decisions with multiple options whose features are valued differently. It guides health professionals and researchers in assessing patients' **decisional needs**, providing **decision support** interventions (clinical counseling, supplementary decision tools, decision coaching), and evaluating **decisional outcomes** (Figure 1).

The ODSF asserts that decision support interventions that address patients' decisional needs improve decisional outcomes (quality of the decision and decision process), which may favourably impact implementation of the chosen option and the appropriate use and costs of health services.

A 2020 review of ODSF-based studies (>100 decisions, >50,000 patients, 18 countries, 5 continents)¹ confirmed the decisional needs listed below and showed that ODSF-based patient decision aids were superior to usual care in improving decision quality and reducing decisional needs. Further research is needed to study downstream impacts (e.g., continuance of chosen option, costs) and to evaluate decision coaching.²⁴

Figure 1: Ottawa Decision Support Framework



*Inadequate support and resources to make/implement the decision include information inadequacy/overload; inadequate perceptions of others' views/practices; social pressure; difficult decisional roles; inadequate experience, self-efficacy, motivation, skills; inadequate emotional support, advice, instrumental help (e.g., transportation), and inadequate financial assistance, health/social services.

2.1 ODSF elements

The ODSF elements are summarized below. **Definitions** are listed in the [Appendix A glossary](#). **Theoretical underpinnings** are described [here](#). The three ODSF elements are:

- a. **Decisional Needs.** Needs are deficits that can adversely affect the quality of a decision (informed, match most valued features) and require tailored decision support. They include:
 - **Difficult decision type/timing:** decision has multiple options, scientifically uncertain outcomes, or known outcomes/other features that patients value differently; decisions that are urgent, delayed, or unpredictable.
 - **Unreceptive decisional stage:** lacks openness to receive information/deliberate in their current stage of decision making (not thinking about it, actively considering, close to choosing, taking steps toward/already implemented).
 - **Decisional conflict:** personal uncertainty about the best course of action when choice among options involves risk, loss, regret, or challenge to one's personal values.
 - **Inadequate knowledge** of essential relevant facts to make a decision: health problem/condition, options, and their features (known benefits, harms, other outcomes/features; scientifically uncertain outcomes).
 - **Unrealistic expectations** or perceptions of one's chances of outcomes (benefits, harms, other).
 - **Unclear values** or personal importance of each option's features (known benefits, harms, other outcomes/features, scientifically uncertain outcomes).
 - **Inadequate support and resources** to make/implement decision: information inadequacy/overload; inadequate perceptions of others' views/practices; social pressure; difficult decisional roles with others involved in the decision (e.g. clinicians, families); inadequate experience, self-efficacy, motivation, skills; inadequate emotional support, advice, instrumental help; and inadequate financial assistance, health/social services.
 - **Personal/clinical needs** that affect decision quality and require tailored support according to: age, gender, education, marital status, ethnicity, socioeconomic status, occupation, locale, diagnosis & duration of condition, health status (physical, emotional, cognitive, social limitations), religion/spirituality.²⁵
- b. **Decisional Outcomes.**
 - **Quality of the decision.** The main aim of decision support is to help patients make a high quality decision. How do you judge quality for difficult decisions with more than one reasonable option whose features are valued differently? The quality of decisions can be determined by whether they are:^{26,27}
 - **Informed** with the best available evidence; evidence derived from research: i) Does the patient have essential knowledge for decision making (health problem/condition, options, and their features)? ii) Are the patient's expectations realistic (perceived chances of outcomes are aligned with evidence for similar patients)?
 - **Values-based:** Does the patient's chosen option match the positive/ negative features that matter most to them?
 - **Quality of the decision making process.** According to the ODSF, high quality decisions are achieved by addressing patient's decisional needs using a structured process of decision support (see elements in section c). When evaluating the decision making process, questions include: Were structured elements of decision support used?²⁸ Are decisional needs reduced (e.g. fewer patients feel uninformed, unclear about personal values, and unsupported in decision making; fewer unsure patients)?
 - **Impact.** Better decisions and decision making may have positive downstream effects on:
 - **Implementation/continuance of chosen option.** Does the patient implement and adhere to chosen option for as long as it is clinically appropriate?
 - **Appropriate use/costs of health services.** Is the use of health services aligned with patients' informed preferences (e.g., **reduced overuse** of options that informed patients

do not value; **improved underuse** of options that informed patients value)? Are costs of health services aligned with changes in overuse and underuse?

c. **Decision Support.** The health professional provides structured assistance in deliberating on the options and communicating with others in a manner that is tailored to the patient's decisional needs. The process involves:

- Establishing rapport and facilitating interactive communication
- Clarifying decision point and inviting participation
- Assessing the patient's decisional needs
- Addressing decisional needs with tailored support by:
 - facilitating receptivity to information/deliberation
 - providing information and outcome probabilities and verifying understanding
 - clarifying personal values (option features that matter most)
 - discussing decisional roles
 - supporting deliberation and mobilizing resources
 - monitoring decisional needs and facilitating progress in decisional stages

Depending on the context, decision support is provided using **clinical counseling** which may be supplemented with **decision tools**, and/or **decision coaching**.

Clinical counseling is provided by health professionals with the disciplinary competence, legal authority, and accountability to:

- identify/diagnose a problem/health condition;
- identify an explicit decision point;
- identify options;
- provide decision support including supplementary decision tools or referral to decision coaching;
- facilitate implementation of the final decision.



Examples of professionals include audiologists, nurse practitioners, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, medical social workers, speech language therapists.

Supplementary decision tools include patient decision aids (condition-specific) or personal decision guides (for any decision):

Patient decision aids are condition-specific, evidence-based tools to prepare a patient to participate in making a specific and deliberated choice with one's health professionals. At a minimum, they make explicit the decision, provide information on the disease/condition, options and their features (known benefits, harms, other outcomes/features, scientifically uncertain outcomes), and help patients clarify the personal value of these features by describing them and/or asking the patient to rate their importance. They are used after one's health professional's diagnosis/option identification and before or during final deliberations with this health professional. When introduced before final deliberations, patient decision aids can be used by the patient alone or with a decision coach. Ideally, the patient decision aids are linked into care processes. See A to Z inventory of Patient Decision Aids and their score in meeting international quality standards [here](#).



Personal decision guides are generic decision tools that do not have condition-specific information about options and are used to structure the process of deliberation for any difficult health or social decision. The [Ottawa Personal Decision Guide](#) (individual or for 2)²⁹ helps people to clarify their perceptions of the decision, explore their knowledge, values and support,

assess their decisional needs (SURE test), and plan to address decisional needs. It can be self-administered or administered by a health professional such as a decision coach.



Supplementary **decision coaching** is nondirective guidance by trained health professionals to develop patients' deliberation and implementation skills in preparation for their discussion with the health professional who identified options. Coaching can be provided in person (individual, group) or using communication technologies (telephone, Internet). Decision tools such as condition-specific patient decision aids or personal decision guides (individual or for 2 people)²⁹ may be used. Ideally, the health professional who identifies the options refers patients to decision coaches as part of the care pathway when usual approaches are not likely to, or do not resolve, decisional needs. However, some decision coaches are accessed directly by patients (e.g., call centers funded by health plans).

The remainder of this tutorial focuses on the complete range of decision support interventions for assessing and addressing patients' decisional needs.

3. Difficult Decision, Personal Needs and Unreceptive Decisional Stage

This section focuses on decision support interventions to clarify the decision and tailor decision support according to decisional needs such as difficult decision type or timing, personal and clinical needs, and unreceptive decisional stage.

3.1 Clarify the decision and invite participation

Close to half of patients consistently report that they didn't even know that a decision was being made. Therefore, after the health professional identifies/diagnoses a problem or health condition, it is important that the health professional helps the patient to understand that there is a difficult decision to be made and invites active participation in decision making. For a review on communication skills when providing decision support, see: [Communication skills when providing decision support](#).

3.2 Tailoring Decision Support according to Difficult Decision and Personal needs

The health professional tailors decision support according to the difficult decision, whose characteristics include more than one reasonable option (including the status quo), scientifically uncertain outcomes, known outcomes/features that patients value differently, and time frames for deliberation that may be urgent, delayed, or unpredictable. Examples of difficult decisions are:

- **screening and diagnostic testing**
(e.g., amniocentesis, genetic testing)
- **aggressive treatments when simpler options fail**
(e.g., for attention deficit disorder, acne, back pain, gastric reflux, arthritis, hot flashes, menorrhagia, benign prostate enlargement, stable angina)
- **developmental transitions**
(e.g., reproduction, birth control, parenting, caregiving, aging)
- **location of care**
(e.g., birth, illness, chronic conditions, dementia, end of life)
- **intensity of care**
(e.g., newborn with very low birth weight, end stage disease)

The health professional also tailors decision support according to patients' personal and clinical needs. Patients may have special needs arising from their: age, gender, education, marital status, ethnicity, socioeconomic status, occupation, locale, diagnosis & duration of condition, health status (physical, emotional, cognitive, social limitations), religion/spirituality.³ When there are limitations, the family or substitute decision maker may need to be involved. Family involvement may also be needed for some decisions affecting both individuals (e.g. reproduction, birth control, parenting, home dialysis, caregiving). The health professionals' approaches may vary according to their training, practice setting, experience, and style of communication.

3.3 Unreceptive Decisional Stage

The health professional tailors decision support according to the patients' current stage of decision making:

- not thinking about options
- actively considering options
- close to choosing an option
- taking steps toward/already implemented an option (including maintain the status quo).

Health professionals usually facilitate patients' progress through the earlier stages with information and support in deliberation. However, some patients may be unreceptive to information/deliberation³ because they:

- have prematurely decided (e.g., hasty decision making, premature closure)

- have powerful emotions affecting their ability to process information
- deny or lack acceptance of their condition or need for treatment
- are unmotivated because the decision is too far off in the future or unpredictable
- do not feel they are entitled to make decision for themselves (e.g. disadvantaged populations, lower and middle income countries)³⁰

The health professional assesses the patient's openness to information and deliberation. In cases where patients are unreceptive, their openness is facilitated with **stage-based support** addressing causes:

Unreceptive to information or deliberation due to	Intervention
Premature decision	<ul style="list-style-type: none"> • Prevent with timely access to relevant essential information. • If already decided, assess openness to discuss what led to this decision. • Check understanding of essential facts and address needs.
Powerful emotions affecting information processing	<ul style="list-style-type: none"> • Allow time to process diagnosis and need for treatment, as appropriate. • Facilitate access to essential information at the right time. • Facilitate emotional expression, show empathy, reframe previous illness/option experiences, highlight strengths, give comfort, offer hope.
Deny or lack acceptance of their condition or diagnosis	<ul style="list-style-type: none"> • Explain diagnostic tests, how their results compare to the normal range, disease progression, as appropriate.
Unmotivated because decision too far off or unpredictable	<ul style="list-style-type: none"> • Revisit the decision closer to when it needs to be made.
Culturally disempowered groups	<ul style="list-style-type: none"> • Develop trusting relationship; try to understand the cultural views of the individuals and engage in a relationship building process.

4. Decisional Conflict



Patients who face difficult decisions often feel uncertain about the best option for them (decisional conflict).³ This section describes how to assess and address decisional conflict.

Decisional conflict is a state of **personal uncertainty about which course of action to take** when choice among options involve risk, loss, regret, or challenge to one's personal values. The conflict or discomfort a person feels when facing a difficult decision is within one's head and not between two individuals. The main manifestation of decisional conflict is **verbalized uncertainty** (e.g., "I'm not sure what to do."). This was reported by 49% of patients who faced a difficult decision.³ Other manifestations of decisional conflict while making a decision include (% patients):

- questioning what is important to them (57%)
"I don't know about amniocentesis. I have to think carefully about what I would do if I found out the baby was abnormal. What are my beliefs?"
- worrying what could go wrong/concerned about undesired outcomes (48%)
"I keep thinking about the things that could go wrong if I have this surgery;" "I could have a complication;" "I may not recover."
- feeling distressed or upset while attempting decision making (25%)
- feeling physically stressed- tense muscles, racing heartbeat, or difficulty sleeping (25%)
Signs of increased muscle tension, onset of restlessness, increased heart rate; "I feel wound up...I can't sleep...my hands shake."
- constantly thinking about options (21%)
"This decision is all I have been thinking about lately. My family is getting impatient with me because I keep dwelling on this decision."
- wavering between options (19%)
"One day I think I will take the medication, the next day, I change my mind."
- wanting to delay the decision (18%)
"I keep putting it off...I don't want to have to face this choice right now."

A key question to ask when assessing decisional conflict is: **Do you feel sure about the best choice for you?**^{29,31} or in other lay words, how comfortable are you facing this decision?

Health professionals cannot change a patient's personal uncertainty that stems from the **inherent** nature of their difficult decision. However, they can reduce the following **modifiable** decisional needs that exacerbate personal uncertainty:

- inadequate knowledge
- unrealistic expectations
- unclear values
- inadequate support.

Effective interventions to reduce these modifiable decisional needs are described in the next sections of this tutorial. They also reduce patients' feelings of uncertainty and the proportion of patients who are undecided.¹²

5. Inadequate Knowledge/Information, and Unrealistic Expectations



Patients who face difficult decisions don't always know enough to make an informed decision.¹² This section describes how to assess and address the decisional needs of inadequate knowledge and information, information overload, and unrealistic expectations.

5.1 Inadequate Knowledge

The patient **does not know essential relevant facts** to make a decision. Essential facts vary by decision but may include the patient's health problem/condition, options and features of each option. Examples of features are the known benefits, harms (e.g. side effects), procedures involved (e.g. take daily pill), and scientifically uncertain outcomes (e.g. unknown long-term effects).

In a Canadian survey, only 43% of participants (n=1010), who received health care in the last 12 months, reported that the advantages and disadvantages of options were often or always presented.¹¹ In 52 international studies of over 13,000 patients facing difficult decisions, those who received usual care scored 57% on knowledge tests. Those who had essential facts in decision aids in preparation for or during clinical counseling scored 70% and also felt more informed.¹²

To screen for knowledge during counseling, health professionals can ask: **Do you know the benefits and risks of each option?**^{29,31}

If patients answer 'no', the health professional **provides information on essential relevant facts** to enable informed decision making. The format and pace of information is tailored to the decision and trajectory of care (e.g., decisions about birth control, prenatal and labour care, cancer treatments, dialysis, dementia care). Once information is provided, it is important to **verify the patient's understanding of essential facts**.

If patients answer 'yes', health professionals check patients' knowledge of essential facts, acknowledge what they know, and address knowledge deficits/misconceptions.

5.2 Information inadequacy / overload

In 82% of 45 decisional needs studies patient reported lacked of information quality, **lack of the appropriate amount of information, and/or lack of timely access to information**.³ It can be prevented with timely access to essential relevant facts. If patients present with overload, health professionals check patients' knowledge of essential facts, acknowledge what they know, and address knowledge gaps and misconceptions.

Some decisional needs studies reported that patients need **more information about other patients' experience** of options regarding birth control, breast cancer treatment, menopause, dialysis, location of post-acute care, and implantable cardiac devices.³ The effectiveness of providing vicarious experiences (e.g. patient stories/narratives) has not been established.³² However, if they are used, the health professional provides balanced positive/negative experiences of easily imagined physical, emotional, social effects, using verbal descriptions, images, videos, or trained peer patients. The chances of these experiences happening to them needs to be presented to avoid the mistaken impression that each experience is equally likely.

5.3 Unrealistic Expectations

Expectations are perceptions of one's chances (probabilities) of outcomes (e.g. benefits, harms, side effects). They are unrealistic if a patients' perceptions of their chances are not aligned with the current evidence for similar patients. For example patients may exaggerate or minimize their chances with statements such as: "That option never works", "My mother had successful natural childbirths and so will I". Other patients may be aware

of the outcomes (e.g., surgical benefits and complications) but unaware of the chances of these outcomes. For example, they may believe that complications occur in 50 out of 100 patients when they occur in 2 out of 100 patients. Unrealistic expectations are common. In 17 studies involving over 5,000 patients who faced difficult decisions, 73% had unrealistic expectations of their chances of outcomes after receiving usual care.¹² When probabilities were presented in patient decision aids during or in preparation for counseling, unrealistic expectations reduced to 43%.¹²

The health professional re-aligns unrealistic expectations by presenting the chances (probabilities) of outcomes for similar patients. Probabilities are described using event rates with common denominators and time periods. For example, when explaining the efficacy of 17-year old Sara's current birth control methods (condoms and sometimes withdrawal), one would say:

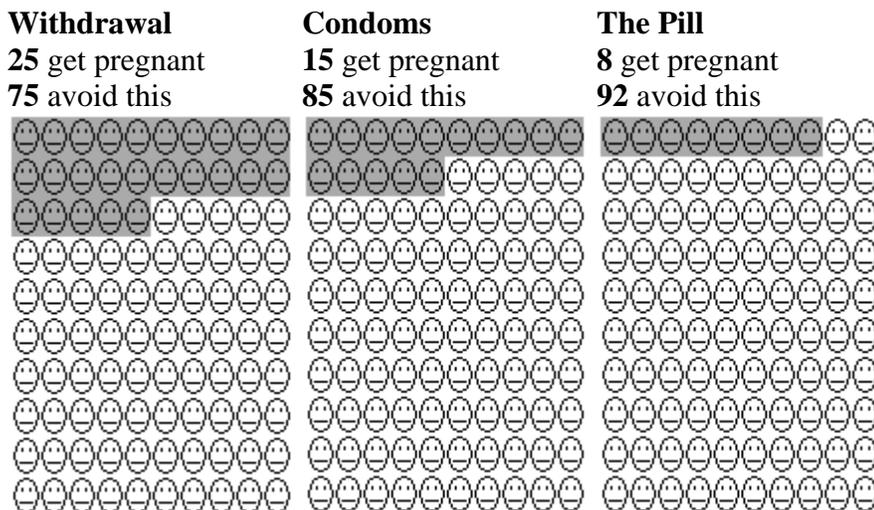
"If 100 women like you used withdrawal for 1 year, 25 would get pregnant. If 100 women used condoms for 1 year, 15 would get pregnant."

A figure may also be used:

How well does my birth control method work?

These blocks of 100 faces show our 'best estimate' of what happens to women who choose different birth control options for **1 year**. Each 'face' stands for one woman and there is no way of knowing in advance which woman stands for you.

The women who are shaded grey (☹️) get pregnant and the women with no shading (😊) do not get pregnant. You can see that the pill is best at preventing pregnancies, followed by condoms, and then withdrawal. Using condoms and the pill together further decreases the chances of getting pregnant. There are also other birth control options you can consider.



Sometimes patients have **difficulty believing that the numbers apply to them.**³ This happens if the numbers are unfamiliar or patients do not believe they represent the type of person who would experience the event in question (e.g., getting pregnant).³³ Providing easily imagined experiences of patients like them may be helpful, although the effectiveness of such an approach has not been established.³² For example:

Sara: "I don't think my chances of getting pregnant are that high, because it has worked so far."

Health professional: "Yes, you were in the group who did not get pregnant last year, but there is no way of knowing if you will be in this same group this year.

Do you know anyone like you who did get pregnant? ... What happened to them? ...

I can share the experience of young women like you who used your methods and got pregnant... If the risks were as low as you think they are, we would see far fewer unplanned pregnancies than we do."

6. Unclear Values for Option Features



Difficult decisions have features of options that patients value differently based on their own experiences and circumstances. Features include known benefits, harms, other outcomes/features, and scientifically uncertain outcomes. Once patients understand these **features**, they can make informed judgements about their **desirability or personal importance** (i.e., values or preferences). They can share their views with others (health professionals, family) and choose the option with the features that matter most to the patient (their preferred choice).

However, some patients feel unclear about which features matter most to them (21% of 1220 patients in 7 studies).³ Moreover, in a survey of 1010 Canadians, who reported receiving health care in the last year, only 39% were asked about their values and preferences.¹¹ Preference misdiagnosis occurs when patients' preferences are not incorporated into the decision.³⁴

Patient decision aids reduce feeling unclear about what matters most compared to usual care and improve the match between the patients' chosen option and their informed values for option features.¹² However further research is needed to understand the best ways to clarify and communicate what matters most. This section explains how to assess and address patients' unclear personal values.

After health professionals verify that patients know the features of options, a question to ask is: **Are you clear about which benefits and risks matter most to you?**^{29,31} Based on their response, the health professional facilitates patients' communication about the positive and negative features that they value most.

When an option's positive and negative features are both important, the health professional can ask patients:

- Which is more important: "**Does relieving your symptoms matter more to you than the complications?**"
- To rate their personal importance using numerical rating: "**How much does symptom relief matter to you on a scale from 0 to 5?** '0' means it does not matter at all. '5' means it matters a great deal. **How much does the risk of complications?**"
- To use a patient decision aids ([A to Z Inventory](#)) or the [Ottawa Personal Decision Guide](#) that help patients' to rate the personal importance of option features.

When option features are **difficult to value because they are difficult to imagine**,⁴⁷ the health professional may provide vicarious experiences (e.g., patient stories/narratives), although their effectiveness is not established.³² The physical, emotional, social effects of different features can be described using easily imagined verbal descriptions, images, videos, or trained peer patients. It is important to provide a balance of positive and negative experiences. For example, in the case of stroke, patients are helped to understand how this outcome can affect their physical function (e.g., ability to walk, work, carry out daily activities), emotional function (e.g., discouraged, sad); and social function (e.g., withdrawn, avoid social activities).

As patients clarify what matters most, they may identify an option that they are leaning toward. The health professional notes the fit between this option and their values. Sometimes patients ask health professionals what they would do/advise if they/their relatives had to decide. It is important to use balanced values-based responses. (if X matters most, I would/patients usually choose Option A; if Y matters most, I would/ patients usually choose Option B").

Case study: 85-year-old Demetri has had several falls in his senior's apartment despite a recent risk assessment with adjustments to his medicines and safety measures in his apartment. His worried daughter asks him to consider moving to the adjacent building with assisted living services. They visit the new building, with a kitchenette/bathroom, 24-hour access to support staff as well as cleaning and laundry services and optional meals in the dining room. Demetri meets with residents he knows about their experiences living there, but he remains undecided.

At a routine visit, his health professional notices his bruises from the last fall. Demetri describes how he is torn between staying where he feels more independent and moving to the assisted living facility where he will feel more secure if he falls. His health professional asks him to rate the importance of "being more independent" from 0 to 5, where 0 means it "does not matter at all" to him and 5 means it "matters a great deal" to him. Then he is asked to rate "feeling more secure when he falls" from 0 to 5.

Demetri says that feeling more independent is rated as **4** out of 5 and feeling more secure is rated as **5** out of 5. When Demetri is asked what this means to him he says: "I need to move to assisted living. The question is no longer if I should move but when". The health professional notes the match between what matters most and the chosen option.

Reason to stay in Senior's Apartment	How much does it matter to you?	Reason to move to Assisted Living	How much does it matter to you?
I will be more independent.	1 2 3 4 5	I will feel more secure.	1 2 3 4 5

7. Inadequate Support and Resources



Patients who face difficult decisions commonly lack the quality, appropriate amount, or timely access to support and resources needed to make and implement the decision.¹ **Information inadequacy / overload** was discussed earlier (section 5.2). This section explains how to assess and address other decisional needs:

- Unclear decisional roles
- Inadequate perceptions of others' views/practices
- Social pressure
- Inadequate experience, self-efficacy, motivation, skills
- Inadequate emotional support, advice, instrumental help (e.g., transportation), financial assistance, health / social services

7.1 Discuss Decisional Roles

Patients' decisional roles are less passive once they know that the best choice depends on how they value the different features of options.¹² Therefore, their preferred decisional role is discussed after providing information and clarifying values. Preferred roles³⁵ can be:

- **Shared:** with the health professional and/or important others (e.g., family, friends, legal substitute decision maker)
- **Patient-led:** prefers to make decision on their own after considering others' views
- **Delegated:** prefers the health professional or important others to make decision after considering patient's views

7.2 Difficult Decisional Roles

Sometimes identifying or implementing patients' preferred decisional roles can be difficult and interventions can be tailored to the type of difficulty:

Type of decisional role difficulty

Unclear decisional role

Mismatch between an informed person's **preferred** decisional role and **actual** role.

Difficulty deliberating with health professional(s) because patient/family:

- have not established a relationship with the health professional(s)
- do not perceive they have a positive relationship with the health professional(s) (e.g., hierarchical power relationships, lack of trust, mutual respect, empathy, compassion, honesty, clear communication)

Difficulty involving family in deliberation, (e.g., patient does not want to worry family, family lacks knowledge)

Intervention

Discuss roles after providing information and values clarification.

During subsequent deliberation, check that patients are satisfied with their actual role.

An essential first step in providing decision support is to establish rapport and facilitate interactive communication. See [guidance on communication skills](#).

Assess/address the patient's/family member's decisional needs using the [Ottawa Personal Decision Guide for Two](#)²⁹

Assess/address decisional needs using the generic [Ottawa Personal Decision Guide for Two](#)²⁹

If needed, use conflict resolution strategies discussed under decisional need 7.2.1 Social Pressure.

Provide family-centered intervention(s) such as:

Difficult shared family deliberation due to:

- different information needs, conflicting values
- communication barriers and pre-existing social/family dysfunction
- Assess family structure (promoting a relationship of trust)
- Facilitate the expression of the emotions of all family members
- Use circular questioning and reframing to de-escalate conflict
- Facilitate access to support/group education relevant to the decision

7.3 Other Decisional Needs classified under Inadequate Support and Resources

A question to ask when assessing inadequate support and resources is: **Do you have enough support and advice to make a choice?**^{29,31} If yes or no, the health professional can probe decisional needs.

7.3a Inadequate perceptions of others' views/practices and social pressure. Patients can be unaware of, misperceive, or lack clarity about what others decide or what important others think is the appropriate choice (e.g., spouse, family, friends, health professionals, society). They may also receive conflicting recommendations from others or feel pressure from important others to choose a specific option.

The health professional assesses these decisional needs by asking: **Who else is involved? Which option do they prefer? Is this person pressuring you? How can they support you?**²⁹

To address inadequate perceptions of others' views / practices, the health professional describes how others differ in their opinions and practices regarding available options, for example:

- the percentage of patients who choose each option
- the differences in health professionals' opinions or practice guidelines.

It is also helpful to present the reasons behind these differing opinions and practices.

If there is **social pressure** to choose a specific option, conflict resolution approaches may be useful but have not been tested. This includes exploring the nature of the pressure (including its source), the areas of agreement and disagreement, and the reasons behind different points of view. Patients are guided to: a) verify their perceptions or misconceptions of others' opinions; b) focus only on the opinions of those whose opinions matter most (i.e. ignore peer pressure to choose an option); and c) handle relevant sources of pressure (e.g., family members who have a legitimate stake in the decision). Strategies for dealing with people who are exerting pressure include:

- plan how to communicate information and personal values
- invite others to discuss their perceptions of options, benefits, harms, and values to find areas of agreement and disagreement. The [Ottawa Personal Decision Guide for Two](#) may be helpful.
- mobilize social support
- identify a mediator, if needed

- rehearse communication strategies through role-playing

7.3b Inadequate experience, self-efficacy (confidence in one's ability), **motivation** (readiness/interest), **skills** (abilities) to make/implement a decision.

The health professional provides structured guidance in deliberation and builds the patient's skills in these areas. Strategies for building self-confidence include encouraging and facilitating positive self-talk, acknowledging the patient's own strengths, and assisting the patient to draw upon positive past experiences. By providing structured guidance in deliberation, the health professional illustrates the steps of decision making and discusses how to communicate their preferences to others, possibly through role play.

7.3c Inadequate emotional support, advice, instrumental help (e.g., transportation), **financial assistance, health and social services** to make / implement a decision.

The health professional provides support or mobilizes access to resources such as patient advocates, family, friends, support groups, and services from voluntary/government sectors.

8. Monitor Decisional Needs and Progress in Decisional Stages

This section explains how to monitor patients' decisional needs and their progress in moving through the stages of decision making, and how to assess the quality of a difficult decision.

8.1 Monitor decisional needs. After providing decision support, the health professional screens for any remaining decisional needs. One question assesses feeling sure of the best choice and the next three questions ask about decisional needs contributing to feeling sure: feeling informed, feeling clear about personal values, and feeling supported to make a choice (see Table below).³¹ Some people find it easier to ask the first question at the end. If the patient answers no to one or more of these questions, the health professional probes and addresses the specific issue(s).

SURE Acronym	Items	Yes [1] No [0]
Sure of myself	Do you feel sure about the best choice for you?	
Understanding information	Do you know the benefits and risks of each option?	
Risk-benefit ratio	Are you clear about which benefits and risks matter most to you?	
Encouragement	Do you have enough support and advice to make a choice?	

The SURE Test © O'Connor and Légaré, 2008.

As noted in section 4. **Decisional Conflict**, the health professional cannot change a patient's personal uncertainty that stems from the inherent nature of their difficult decision. Therefore, patients may still feel uncertain because it is a difficult decision.

The SURE Test is based on the more detailed Decisional Conflict Scale and both are reliable and valid instruments.³⁶⁻³⁹

8.2 Monitor progress in decisional stage

When patients have reduced decisional needs, fewer are undecided. A key question²⁹ to assess decisional stage is:

How far along are you with making a choice?

- Not thought about it
- Thinking about it
- Close to choosing
- Made a choice

Decision support is most useful for patients who are thinking about the options and less so for informed patients who have already selected a chosen option.

8.3 Assess the quality of the decision The health professional determines whether the decision is:

Informed. During decision support to address **inadequate knowledge and unrealistic expectations**, the health professional verified patients' knowledge of essential facts and realistic perceptions of the chances of outcomes.

Values based. During decision support to address **unclear values**, the health professional assessed the features of options that patients value. The health professional determines whether the patient's preferred option matches the features that matter most.

9. Decision Tools and Decision Coaching

9.1 Decision Tools

Decision tools supplement clinical counseling and **include patient decision aids** (condition-specific) and **personal decision guides** (for any health or social decision).

Should you take Drug A when your current treatment is not controlling your disease X?

Disease X is ... It causes symptom y and complication z. Your current treatment is not controlling your disease X. Drug A may reduce symptom y and your risk of complication z. However, you may have side effect p or increase your risk of complication q.

What are your options?

- Take Drug A. You take a daily pill.
- Continue your current drug.

Which benefits and risks matter most?

If 100 people take Option A for 1 year

- 29 more people reduce symptom y
- 1 less person gets complication z
- 3 more people get side effect p
- 2 more people get complication q

How much it matters

0	1	2	3	4	5
0	1	2	3	4	5
0	1	2	3	4	5
0	1	2	3	4	5

Which option do you prefer?

Take Drug A Continue current drug I am not sure

What are your decision making needs?

- Do you feel sure about the best choice for you? Yes No
- Do you know the benefits and risks of each option? Yes No
- Are you clear about which benefits and risks matter most to you? Yes No
- Do you have enough support and advice to make a choice? Yes No

Based on the Ottawa Consult Decision Aid © 2013 Stacey, Légaré, O'Connor, OHRI & uOttawa, Canada.

9.1a Patient Decision Aids are evidence-based tools to **prepare a patient to participate** in making a specific and deliberated choice with one's health professional. According to IPDAS international standards, at a minimum, they **make explicit the decision, provide information** on the disease/condition, options and their features (known benefits, harms, other outcomes/features, scientifically uncertain outcomes), and **help patients clarify the personal value** of these features by describing them and/or asking the patient to rate their importance.^{12,40}

They are used after one's health professional's diagnosis/option identification and are designed to be used either before or during the consultation with this health professional. The brief decision aid on the left is intended to be used during the consultation.

Decision aids differ from general patient educational materials because they focus on a specific decision and do not promote compliance with a recommended option. The message in patient decision aids is that

there is no clear best answer for everyone. And they should provide balanced information.

Patient decision aids have been developed for a variety of difficult screening, diagnostic, treatment, and end-of-life decisions.¹² Web-based written materials can be printed or used online (including videos). A list of currently available patient decision aids and their quality based on meeting the International Patient Decision Aid Standards (IPDAS)^{40,41} is found in the "[A to Z Inventory of Decision Aids](#)".

Research from more than 100 randomized controlled trials¹² show that patient decision aids are better than usual care in improving the quality of the decision (knowledge scores, accurate expectations) and decision making (reduced decisional needs: fewer undecided and fewer feel uninformed, unclear about personal values). Using patient decision aids is not associated with harms or adverse events. More research is needed to determine their effects on implementation and continuance of the chosen option and the appropriate use and costs associated with health services.

Ottawa Personal Decision Guide
For People Making Health or Social Decisions

1. Clarify your decision.
What decision do you face?
What are your reasons for making this decision?
When do you need to make a choice?
How far along are you with making a choice?
 Not thought about it Close to choosing
 Thinking about it Made a choice

2. Explore your decision.

Knowledge
List the options and benefits and risks you know.

Values
Rate each benefit and risk using stars (*) to show how much each one matters to you.

Certainty
Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0* not at all 5* a great deal	Reasons to Avoid this Option Risks / Disadvantages / Cons	How much it matters to you: 0* not at all 5* a great deal
Option #1				
Option #2				
Option #3				

Which option do you prefer? Option #1 Option #2 Option #3 Unsure

Support
Who else is involved?
Which option do they prefer?
Is this person pressuring you? Yes No Yes No Yes No
How can they support you?
What role do you prefer in making the choice?
 Share the decision with...
 Decide myself after hearing views of...
 Someone else decides...

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3. Identify your decision making needs. Adapted from The SURE Test © 2024 © Connor & Lagers

Knowledge Do you know the benefits and risks of each option? Yes No

Values Are you clear about which benefits and risks matter most to you? Yes No

Support Do you have enough support and advice to make a choice? Yes No

Certainty Do you feel sure about the best choice for you? Yes No

If you answer 'no' to any question, you can work through steps two and four, focusing on your needs. People who answer 'no' to one or more of these questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes.

4. Plan the next steps based on your needs.

Decision making needs Things you could try

Knowledge
If you feel you do NOT have enough facts
 Find out more about the options and the chances of the benefits and risks.
 List your questions.
 List where to find the answers (e.g. library, health professionals, counsellors):

Values
If you are NOT sure which benefits and risks matter most to you
 Review the stars in step two to see what matters most to you.
 Find people who know what it is like to experience the benefits and risks.
 Talk to others who have made the decision.
 Read stories of what mattered most to others.
 Discuss with others what matters most to you.

Support
If you feel PRESSURE from others to make a specific choice
 Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends).
 Find help to support your choice (e.g. funds, transport, child care).
 Focus on the views of others who matter most.
 Share your guide with others.
 Ask others to fill in this guide. (See where you agree. If you disagree on facts, get more information. If you disagree on what matters most, consider the other person's views. Take turns to listen to what the other person says matters most to them.)
 Find a person to help you and others involved.

Certainty
If you feel UNSURE about the best choice for you
 Work through steps two and four, focusing on your needs.

Other factors making the decision DIFFICULT
List anything else you could try:

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9.1b Personal Decision Guides are used for any decision to help patients identify their decisional needs, plan the next steps, track their progress, and share their views about the decision. The [Ottawa Personal Decision Guide](#) is used for difficult health or social decisions. There is a version for one person and another for two people (e.g., patient/family member or parents). The guide helps them:

1. clarify the decision
2. explore their knowledge, values and support
3. assess their decisional needs (SURE test)
4. plan to address decisional needs

The guide is used when a health professional anticipates that the patient may have difficulty making a decision, or when the patient expresses difficulty making a decision. It can be self-administered or health professional-administered. Details on how to use it with a decision coach is described in the next section.

9.2 Decision Coaching

Decision coaching is supplementary nondirective guidance by trained health professionals to develop patients' deliberation and implementation skills in preparation for their final deliberations with the health professional who identified options.^{1,42,43} It can be provided in person (in an individual or group setting) or using communication technologies (e.g., telephone) with supplementary decision tools. Ideally, the health professional who identifies options refers patients to decision coaches as part of the care pathway when usual care approaches are not likely to or do not resolve decisional needs. For example, a nephrologist diagnoses renal failure, offers dialysis options, and refers the patient to a nurse who prepares the patient for a final discussion and decision-making with the nephrologist.

Some decision coaches are accessed directly by patients (e.g., call centers funded by health plans). Decision coaches use the full range of decision support interventions to address decisional needs. When they use the [Ottawa Personal Decision Guide](#) or the [Ottawa Personal Decision Guide for Two](#), the support process is as follows:

- a. **Clarify the decision:** The coach asks about the specific decision, when the decision has to be made (timing), the stage of the patient's decision making, and their leaning.
- b. **Explore the decision** by probing the patient's knowledge, values, and support needs. The patient lists, or the coach asks the patient to identify the options and their features to assess knowledge. Then, the patient is asked to use stars (0-5) to rate how much each feature matters to them (clarify values for option features). It is not necessary to complete this step in one sitting; the purpose is to determine gaps or questions as a basis for planning next steps.
- c. **Assess needs for support from others** by determining the patient's preferred role in decision making. More information about others involved (e.g., people, opinions, pressures, ways they can support) can be probed if there appears to be support problems. The focus should be on others who are most involved and important in the decision.
- d. **Screen for unresolved decisional needs** using the 4-item SURE test.³¹
- e. **Plan next steps:** The decision coach and/or the patient checks strategies to address the patient's unresolved decisional needs pertaining to knowledge, values for option features, and support. A list of strategies is provided. As the decisional needs resolve or change, the SURE test can be repeated and updated.

Another element of decision coaching is to screen for implementation needs. Implementation needs are often higher when the patient is responsible for implementing the chosen option (e.g., getting a prescription filled, taking medication regularly, renewing the prescription).

Randomized controlled trials evaluating decision coaching with or without a patient decision aid showed improved knowledge and no harms (e.g., no worsening of decision regret or anxiety). The effect on other outcomes is either improved or no difference.^{24,42} In a pre/post study with 45 children having type 1 diabetes and their parents, children and their parents had lower decisional needs (felt more sure, informed, values clarity, and supported) and >90% were satisfied with the decision coaching.^{44,45}

Case study: A 9-year-old girl, Jane, has type 1 diabetes and been receiving 2 to 3 insulin injections per day since she was diagnosed with diabetes five years ago. Her parents inquired about switching her to an insulin pump. At the diabetes clinic, the endocrinologist agrees that both are reasonable options for Jane and refers them to the decision coach.

The trained decision coach uses the Ottawa Personal Decision Guide for Two with information on insulin options added from a recent Clinical Practice Guideline.^{44,45} The coach, together with Jane and her parents, starts by clarifying the decision and the stage of decision making by first asking Jane and then asking her parents. This approach to decision coaching by focusing on the child first is to encourage Jane's involvement and discourage parents' biasing her responses.

The decision coach continues by asking Jane to rate the importance of "having more flexibility with daily activities and meals" from 0 to 5, where 0 means it "does not matter at all" and 5 means it "matters a great deal" to her. Then she is asked to rate "carrying the pump" from 0 to 5. This continues for all of the benefits and harms of the 2 options and Jane and her parents may add benefits and harms that are important to them that are not already listed. The decision coach also facilitated discussion between the parent and child.

Appendices

Appendix A: Glossary of Decision Support Terms

Decision making

The process of choosing between alternatives, which may include doing nothing.

Decisional needs

Deficit that can adversely affect the quality of a decision (informed, match most valued features) and require tailored decision support. Decisional needs include:

Difficult decision type / timing:

Challenging characteristics of the decision:

- a. **type** or class of decision (e.g., multiple options; scientifically uncertain outcomes; known outcomes and other features that patients value differently) and
- b. **time frame** for deliberation (e.g., urgent, delayed, or unpredictable).

Unreceptive decisional stage:

Lacks openness to receive information and/or to deliberate in their current stage of decision making about options (not thinking about, actively considering, close to choosing, taking steps toward/already implemented). Contributing factors may include denial, hasty decision making, premature closure, powerful emotions affecting information processing, lack of acceptance of condition or need for treatment, being unmotivated, e.g., because decision too far off in the future or unpredictable.

Decisional conflict:

A state of personal uncertainty about which course of action to take when choice among options involve risk, loss, regret, or challenge to one's personal values (specify the focus of conflict, such as personal health, family relationships, career, finances, or other life events).⁴⁸ The hallmark behavioral manifestation is verbalized uncertainty. Other manifestations while making a decision include: worrying what could go wrong/concerned about undesired outcomes, wanting to delay the decision, questioning what is important to them, feeling distressed or upset while attempting decision, wavering between options, feeling like they cannot get the decision off their minds, feeling physically stressed (e.g., tense muscles, a racing heartbeat, difficulty sleeping). Although personal uncertainty arises from the inherent nature of the difficult decision, modifiable decisional needs can exacerbate it: inadequate knowledge, unrealistic expectations, unclear values, and inadequate support.

Inadequate knowledge:

Unaware or lacks cognizance of essential relevant facts to make a decision: health problem/condition; options; features of options (known benefits, harms, and other outcomes and features; scientifically uncertain outcomes).

Unrealistic expectations:

- a. unaware of one's chances or probabilities of outcomes (e.g., benefits, harms, other) for each option; or
- b. perceptions of one's chances of outcomes are not aligned with the current evidence for similar patients.

Unclear values:

Lacks clarity regarding desirability or personal importance of the features of options: known benefits, harms, other outcomes and features; scientifically uncertain outcomes.

Inadequate support and resources:

Lacks the quality, appropriate amount, and/or timely access to support and resources needed to make and implement the decision.

- a. **Information inadequacy / overload:** Lacks the quality, appropriate amount, and/or timely access to essential relevant information for decision making: health problem/condition, available options and their features. Examples include known benefits, harms, other outcomes and features, outcome probabilities, scientifically uncertain outcomes, others' experiences with options, e.g., procedures, side effects, outcomes.
- b. **Inadequate perceptions:** others' views/practices: Unaware of, misperceives, or lacks clarity about what others decide or what important others think is the appropriate choice (e.g., spouse, family, friends, health professional(s), society). Receives conflicting recommendations from others.
- c. **Social pressure:** Perception of persuasion, influence, coercion from important others (e.g., spouse, family, friends, health professionals, or society) to choose a specific option.
- d. **Difficult decisional roles:** Problematic involvement in decision making, whose manifestations may include:
 - o unclear decisional role (shared with important other[s]; patient-led after considering important other[s] views; delegated after important other[s] considers patient's views).
 - o mismatch between an informed person's preferred decisional role and actual role.
 - o difficulty deliberating with health professional. Examples of contributing factors are: the patient/family has not yet established a relationship with health professional or does not perceive they have positive relationship with the health professional (e.g., trust, mutual respect, empathy, compassion, honesty, clear communication).
 - o difficult shared family deliberation. Examples of contributing factors may include different information needs, different values, communication barriers, pre-existing social/family dysfunction (see personal needs).
 - o difficulty involving family in deliberations, e.g., because patient does not want to worry family, family lacks knowledge.
- e. **Inadequate experience, self-efficacy** (confidence in one's ability), **motivation** (readiness/interest), **skills** (abilities) to decide/implement a decision.
- f. **Inadequate emotional support, advice, instrumental help** (tangible assistance e.g. transportation to appointment, child care during treatments), **financial assistance, health and social services** to make/implement a decision.

Personal / Clinical needs:

Special personal and clinical characteristics that affect the quality of the decision and require tailored decision support. For example, interventions may need to be tailored according to characteristics listed below.

- Patients' characteristics: age, developmental stage, gender, education, marital status, ethnicity, socioeconomic status, occupation, locale, diagnosis & duration of condition, health status (physical, emotional, cognitive, social limitations), religion/spirituality.
- Health Professionals' characteristics: age, gender, ethnicity, clinical education, specialty, clinical practice locale, experience, counseling style.

Decisional Outcomes

Quality of the decision:

The extent to which the chosen option is:

- a. **informed** (patient has essential knowledge and realistic outcome expectations) and
- b. **values-based** (choice matches features that matter most to the patient).

Quality of the decision making process:

Reductions in decisional needs including the proportion who:

- a. are undecided, and
- b. feel uninformed, unclear values, and unsupported.

Impact:

Downstream effects of the quality of the decision/decision making process on:

- **Implementation/continuance of chosen option:** Does the patient implement and adhere to chosen option for as long as it is clinically appropriate (e.g., fill and refill prescriptions, continue therapy)?
- **Appropriate use & costs of health services:**
 - a. alignment of use with informed preferences (e.g., reduced overuse of options that informed patients don't value; improved underuse of options that informed patients value) and
 - b. alignment of costs with changes in overuse and underuse.

Decision Support

Structured assistance in deliberating about the decision and communicating with others. It is tailored to the patients' decisional needs and aims to achieve decisions that are informed and based on features that patients value most. It involves:

1. establishing rapport and facilitating interactive communication;
2. clarifying decision and inviting participation;
3. assessing the patient's decisional needs; and
4. addressing decisional needs with tailored support:
 - a. facilitating receptivity to information/deliberation;
 - b. providing information and outcome probabilities and verifying understanding;
 - c. clarifying personal values (option features that matter most);
 - d. discussing decisional roles;
 - e. supporting deliberation and mobilizing resources; and
 - f. monitoring decisional needs and facilitating progress in decision making stages.

Decision support is delivered as part of **clinical counseling**, which may be supplemented with **decision tools** and/or **decision coaching**:

Clinical counseling:

Provided by health professionals who have the disciplinary competence, legal authority, and accountability to:

- a. identify/diagnose a problem/health condition;
- b. identify options;
- c. **provide decision support**, which may include referring patients to a decision tools (e.g., patient decision aid) and/or coaching to prepare for a final deliberation consult or using decision tools during the deliberation consult; and
- d. facilitate implementation of the final decision by making a referral, writing a prescription, ordering screening/diagnostic tests, performing surgery, providing care or therapy, etc.

Examples of professionals include audiologists, nurses, nurse practitioners, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, medical social workers, speech language therapists.

Decision tools:

They include patient decision aids (condition-specific) or personal decision guides (generic for any decision):

Patient decision aids (PtDAs):

Supplementary, condition-specific, evidence-based tools to prepare a patient to participate in making a specific and deliberated choice with one's health professionals. At a minimum, they make explicit the decision, provide information on the disease/condition, options and their features (known benefits, harms, other outcomes/features, scientifically uncertain outcomes), and help patients clarify the personal value of these features by describing them and/or asking the patient to rate their importance.^{12,40} They are used after one's health professional's diagnosis/option identification and before or during final deliberations with this health professional. When used before final deliberations, they can be used by the patient alone or with a decision coach. Ideally, they are linked into care processes. See A to Z inventory of Patient Decision Aids and their quality in meeting international standards [here](#).

Personal decision guides:

Generic tools that do not have condition-specific information about options and are used to structure the process of deliberation for any difficult health or related social decision. For example, the [Ottawa Personal Decision Guide](#) (individual or for 2)²⁹ helps people to clarify their perceptions of the decision, explore their knowledge, values and support, assess their decisional needs (SURE test), and plan to address decisional needs. It can be self-administered or administered by a health professional such as a decision coach.

Decision coaching:

Supplementary nondirective guidance by trained health professionals to develop patients' deliberation and implementation skills in preparation for their final deliberations with the health professional who identified options. Coaching can be provided in person (individual, group) or using communication technologies (telephone, Internet). Decision tools such as a condition-specific PtDA or generic personal decision guides (individual or for 2)²⁹ may be used. Ideally, the health professional who identifies options refers patients to decision coaches as part of the care pathway when basic approaches are not likely to or do not resolve decisional needs. However, some decision coaches are accessed directly by patients (e.g., call centers funded by health plans).

Patient-centered care

"Providing care that is respectful of and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions".⁴⁶

Shared decision making

The process whereby health professional(s) and the patient make decisions together. It recognizes the unique expertise:

- a. health professionals are experts in diagnosing the problem and identifying options, known benefits, harms, other outcomes/features, probabilities of outcomes, and scientifically uncertain outcomes; and
 - b. patients are experts in understanding their personal circumstances and judging the value or personal importance they attach to each option's known benefits, harms, other outcomes/features, and scientifically uncertain outcomes.
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References

1. Stacey D, Legare F, Boland L, et al. 20th Anniversary Ottawa Decision Support Framework Part 3: Overview of systematic reviews and updated framework. *Medical Decision Making*. 2020.
2. Hoefel L, Lewis KB, O'Connor AM, Stacey D. 20th Anniversary update of the Ottawa Decision Support Framework Part 2: Sub-analysis of a systematic review of patient decision aids. *Medical Decision Making*. 2020.
3. Hoefel L, O'Connor AM, Lewis KB, et al. 20th Anniversary update of the Ottawa Decision Support Framework Part I: A systematic review of the decisional needs of people making health or social decisions. *Medical Decision Making*. 2020.
4. Murray MA, Stacey D, Wilson KG, O'Connor AM. Skills training to support patients considering location of end-of-life care: A randomized control trial. *Journal of Palliative Care*. 2010;26(2):112-121.
5. Stacey D, O'Connor AM, Graham ID, Pomey MP. Randomized controlled trial of the effectiveness of an intervention to implement evidence-based patient decision support in a nursing call centre. *Journal of Telemedicine and Telecare*. 2006;12:410-415.
6. Stacey D, Chambers SK, Jacobsen MJ, Dunn J. Overcoming barriers to cancer helpline professionals providing decision support for callers" An implementation study. *Oncology Nursing Forum*. 2008;35(6):1-9.
7. Stacey D, Higuchi KAS, Menard P, Davies B, Graham ID, O'Connor AM. Integrating patient decision support in an undergraduate nursing curriculum: An implementation project. *International Journal of Nursing Education Scholarship*. 2009;6(1):1-18.
8. Boland L, Légaré F, Carley M, et al. Evaluation of a shared decision making educational program: The Ottawa Decision Support Tutorial. *Patient Education and Counseling*. 2019;102(2):324-331.
9. Adekpedjou R, Stacey D, Brière N, et al. Engaging Caregivers in Health-Related Housing Decisions for Older Adults With Cognitive Impairment: A Cluster Randomized Trial. *The Gerontologist*. 2020;60(5):947-957.
10. Evidence BC. What conclusions has Clinical Evidence drawn about what works, what doesn't based on randomised controlled trial evidence? . 2015; <http://clinicalevidence.bmj.com/x/set/static/cms/efficacy-categorisations.html>.
11. Haesebaert J, Adekpedjou R, Croteau J, Robitaille H, Légaré F. Shared decision-making experienced by Canadians facing health care decisions: a Web-based survey. *CMAJ open*. 2019;7(2):E210-E216.
12. Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews*. 2017(4).
13. Légaré F, Wittman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health Aff*. 2013;32.
14. Bomhof-Roordink H, Gärtner FR, Stiggelbout AM, Pieterse AH. Key components of shared decision making models: a systematic review. *BMJ open*. 2019;9(12):e031763.
15. Berwick DM, Nolan TW, Whittington J. The triple aim: Care, health, and cost. *Health Affairs*. 2008;27(3):759-769.
16. British Columbia Ministry of Health. Patient, family, caregiver and public engagement framework 2018. 2018; <https://www2.gov.bc.ca/assets/gov/health/about-bc-s-health-care-system/health-care-partners/patients-as-partners/patients-as-partners-framework.pdf>.
17. Ontario. Health Care Consent Act 1996. 2010. http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_96h02_e.htm#BK0.
18. Shafir A, Rosenthal J. Shared decision making: advancing patient-centered care through state and federal implementation. Washington, D.C.: National Academy for State Health Policy;2012.
19. Washington State Health Care Authority. Patient Decision Aid Certification Criteria. 2016; http://www.hca.wa.gov/hw/Documents/sdm_cert_criteria.pdf.
20. Elwyn G, Burnstin H, Barry MJ, et al. A proposal for the development of national certification standards for patient decision aids in the US. *Health Policy*. 2018;122:703-706.
21. Sokol DK. Update on the UK law on consent. *British Medical Journal*. 2015;350:1-2.

22. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards (2nd Ed). 2017; <https://www.safetyandquality.gov.au/sites/default/files/2019-04/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf>.
23. O'Connor AM, Tugwell P, Wells G, Elmslie T, Jolly E, Hollingworth G. A decision aid for women considering hormone therapy after menopause: Decision support framework and evaluation. *Patient Education & Counseling*. 1998;33(3):267-279.
24. Jull J, Kopke S, Boland L, et al. Decision coaching for people making healthcare decisions (protocol). *Cochrane Database of Systematic Reviews*. 2019(7):1-16.
25. O'Neill J, Tabish H, Welch V, et al. Applying an equity lens to interventions: using PROGRESS ensures consideration of socially stratifying factors to illuminate inequities in health. *J Clin Epidemiol*. 2014;67(1):56-64.
26. Sun Q. Predicting downstream effects of high decisional conflict: Meta-analysis of the Decisional Conflict Scale, University of Ottawa, Master of Science in Systems Science, School of Management; 2004.
27. Sepucha KR, Levin CA, Uzogara EE, Barry MJ, O'Connor AM, Mulley AG. Developing instruments to measure the quality of decisions: early results for a set of symptom-driven decisions. *Patient Education & Counseling*. 2008;73(3):504-510.
28. Stacey D, Taljaard M, Drake ER, O'Connor AM. Audit and feedback using the brief Decision Support Analysis Tool (DSAT-10) to evaluate nurse-standardized patient encounters. *Patient Education and Counseling*. 2008;73:519-525.
29. O'Connor A, Stacey D, Jacobsen M. Ottawa Personal Decision Guide. 2015. <https://decisionaid.ohri.ca/decguide.html>.
30. Hawley ST, Morris AM. Cultural challenges to engaging patients in shared decision making. *Patient Educ Couns*. 2017;100(1):18-24.
31. Legare F, Kearing S, Clay K, et al. Are you SURE? Assessing patient decisional conflict with a 4-item screening test. *Canadian Family Physician*. 2010;56(8):e308-e314.
32. Bekker HL, Winterbottom AE, Butow P, et al. Do personal stories make patient decision aids more effective? A critical review of theory and evidence. *BMC Medical Informatics and Decision Making*. 2013;13(2):S9.
33. Tversky A, Kahneman D. The framing of decisions and the psychology of choice. *Science*. 1981;211:453-458.
34. Mulley AG, Trimble C, Elwyn G. Stop the silent misdiagnosis: Patients' preferences matter. *British Medical Journal*. 2012;345:e6572.
35. Degner LF, Sloan JA, Venkatesh P. The control preferences scale. *Canadian Journal of Nursing Research*. 1997;29(3):21-43.
36. O'Connor AM. Validation of a Decisional Conflict Scale. *Medical Decision Making*. 1995;15(1):25-30.
37. Garvelink MM, Boland L, Klein K, et al. Decisional Conflict Scale Use over 20 Years: The Anniversary Review. *Medical Decision Making*. 2019;39(4):301-314.
38. Garvelink MM, Boland L, Klein K, et al. Decisional Conflict Scale Findings among Patients and Surrogates Making Health Decisions: Part II of an Anniversary Review. *Medical Decision Making*. 2019;39(4):315-326.
39. Ferron Parayre A, Labrecque M, Rousseau M, Turcotte S, Legare F. Validation of SURE, a four-item clinical checklist for detecting decisional conflict in patients. *Medical Decision Making*. 2013;34(1):54-62.
40. Joseph-Williams N, Newcombe R, Politi M, et al. Toward minimum standards for certifying patient decision aids: A modified Delphi consensus process. *Medical Decision Making*. 2013;34(6):699-710.
41. Elwyn G, O'Connor A, Stacey D, et al. Developing a quality criteria framework for patient decision aids: online international Delphi consensus process. *British Medical Journal*. 2006;333(7565):417-422.
42. Stacey D, Kryworuchko J, Bennett C, Murray MA, Mullan S, Legare F. Decision coaching to prepare patients for making health decisions: A systematic review of decision coaching in trials of patient decision aids. *Medical Decision Making*. 2012;32(3):E22-33.

43. O'Connor AM, Stacey D, Legare F. Coaching to support patients in making decisions. *British Medical Journal*. 2008;336:228-229.
44. Lawson ML, Shephard AL, Feenstra B, Boland L, Sourial N, Stacey D. Decision coaching using a patient decision aid for youth and parents considering insulin delivery methods for type 1 diabetes: a pre/post study. *BMC Pediatr*. 2020;20(1):1.
45. Feenstra B, Lawson ML, Harrison D, Boland L, Stacey D. Decision coaching using the Ottawa family decision guide with parents and their children: A field testing study. *BMC Medical Informatics and Decision Making*. 2015;15(5):1-10.
46. Care CoQoH. *Crossing the Quality Chasm: A new health system for the 21st century*. Washington, D.C.: Institute of Medicine;2001.
47. Fischhoff B, Slovic P, Lichtenstein S. Knowing what you want: measuring labile values. In: Wallsten TS, ed. *Cognitive Processes in Choice and Decision Behavior*. Hillsdale, NJ: Lawrence Erlbaum Associates; 1980:117–41.
48. Herdman TH, Kamitsuru S. *NANDA International Nursing Diagnoses: Definitions & Classification 2015-2017*. Oxford, UK: Wiley Blackwell; 2015.

