Ottawa Decision Support Tutorial

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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. It may also be relevant for others involved in counseling and supporting patients* making health decisions. The tutorial has been completed by administrators/ managers, case managers, chaplains, chiropractors, community health, counsellors, dietitians, early childhood, 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
- identify difficult decisions requiring decision support
- explain how to assess patients' decisional needs
- tailor decision support to patients' 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).

How to Proceed Through the Tutorial

1. Complete the 10 sections (1 to 2 hours).
   The first 9 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. Section 10 is a case study that shows an example of providing decision support incorporating a patient decision aid. 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.
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.
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. 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 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 2007, 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. The most recent update was May 2015.

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, (b) one pre-/post-test study of health professionals working at a cancer helpline,[1-3] and (c) a descriptive study with nursing students.[4] When it is combined with a skills-building workshop, these studies showed that participants had improved the quality of decision support they provided.

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

Financial Disclosure

Financial support for the development of the Ottawa Decision Support Tutorial was provided by a federal research grant from the Government of Canada. Updates are paid for in kind by the University of Ottawa Research Chair in Knowledge Translation to Patients.

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1. Decision Support and Shared Decision Making (SDM)

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

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

Decision making is the process of choosing among alternatives, which may include doing nothing. During deliberations, patients need to understand and consider:

- options available for their particular situation;
- chances of benefits, harms, and side effects (including the level of scientific uncertainty);
- their values or the personal importance that they place on benefits, harms, side effects, and scientific uncertainties.

Although patients usually prefer an option that is most likely to achieve desired benefits and avoid harms, there is often **no clear best choice**. There may be more than one medically reasonable option. Moreover, the best choice may depend on how patients value the known benefits and harms plus scientific uncertainties about the effects of different options. 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**.[5] Hence, for 86% of these treatments there is no clear best choice. Although most patients want to be involved in making difficult health decisions, they may not even be aware that they have options. Moreover, health professionals' usual approach to counseling patients about optional treatments does not always lead to informed decisions that are based on what matters most to the patient.[6]

Decision support 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 patient's values. The steps involve: clarifying the decision, assessing patient's decisional needs, providing information and probabilities of outcomes, clarifying personal values, enhancing support from others and resources, and monitoring/facilitating progress in decision making. Decision support helps patients to engage in decision making in roles that they prefer (e.g. keep, share, or delegate control in decision making).

Shared decision making is a process whereby health professional(s) and a patient make decisions together. It recognizes the expertise of each participant. Health professionals are experts in diagnosing the problem and identifying options, benefits, harms, side effects, probabilities of outcomes, and scientific uncertainties. Patients are experts in understanding their personal circumstances and judging the value or personal importance they attach to the benefits, harms, side effects, and scientific uncertainties of options.

The essential shared decision making elements include:[7]

- Define/explain the problem
- Present options
- Discuss pros/cons (benefits, risks, costs)
- Clarify the patient's values/preferences
- Discuss the patient's ability/self-efficacy
- Discuss health professional's knowledge/recommendations
- Check/clarify the patient's understanding
- Make or explicitly defer the decision
- Arrange follow-up

Other elements include: provide unbiased information, define the patient's desired role in the decision making process, present evidence including probabilities, and reach mutual agreement on the best option.[7]

Engaging patients to participate in making decisions is a necessary component of patient-centred care and informed consent. Informed consent generally implies that patients are informed of their options including benefits and harms. For example:

- In Ontario, Canada, the consent legislation requires that patients are consenting to treatment after being informed of their alternative options.[8]
- 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.[10] 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. Other states in the USA are in varying stages of drafting similar legislation.[10]
- 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.[9]

Appendix A provides a glossary of decision support terms used in the tutorial.

[*]patients 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).

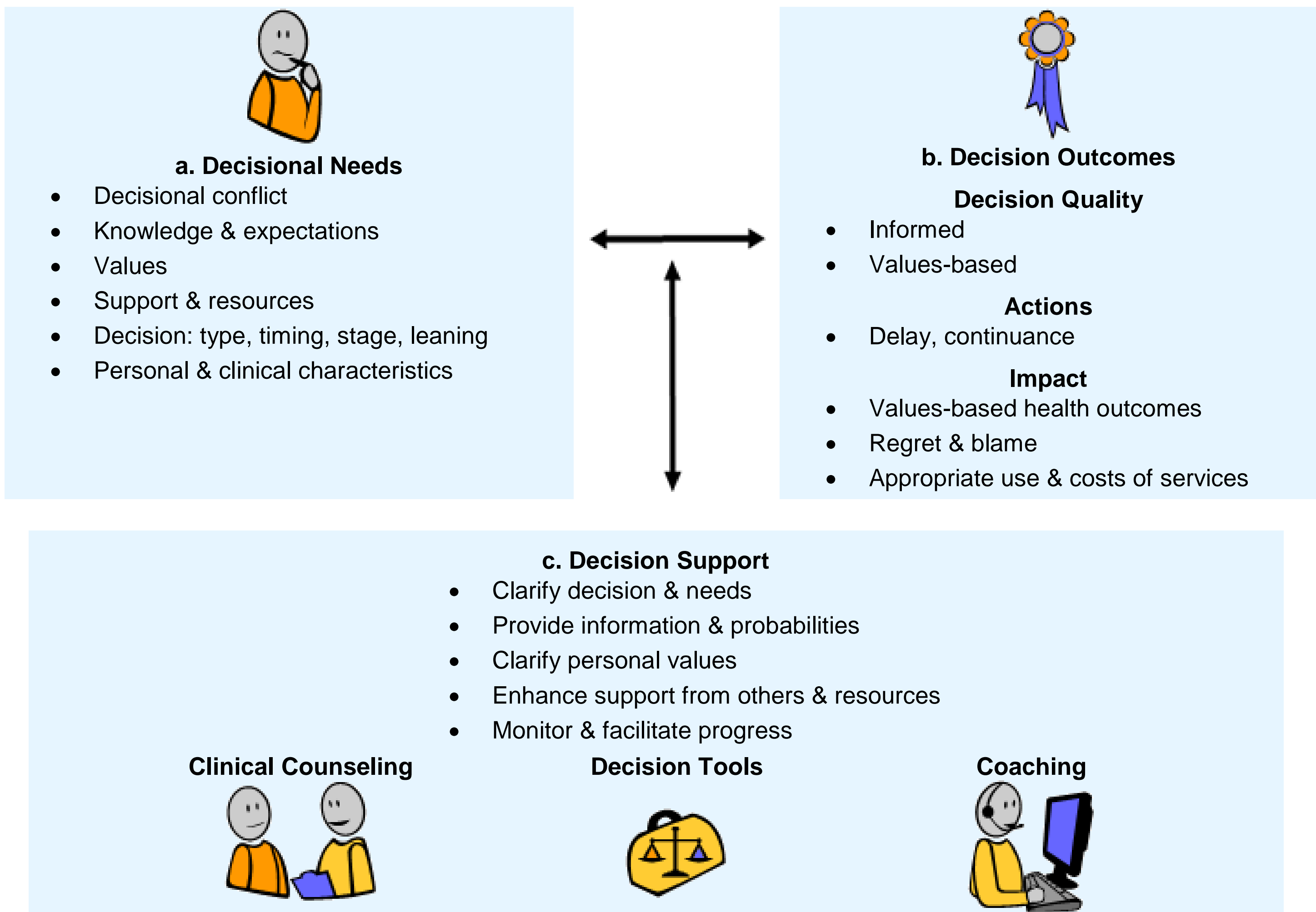
2. Conceptual Foundation: The Ottawa Decision Support Framework

The conceptual underpinning of this tutorial is the Ottawa Decision Support Framework (Figure 1). It has three key elements: a) decisional needs, b) decision outcomes, and c) decision support.

According to this framework, unresolved decisional needs adversely affect decision outcomes. Decision support can improve decision outcomes by addressing decisional needs using clinical counseling, decision tools and/or decision coaching.

The framework applies to all individuals involved in decision making including the patient, family members and health professionals.[4,11] It uses concepts and theories from psychology, social psychology, economics, and social support.[12-20]

Figure 1: Ottawa Decision Support Framework



The three framework elements are summarized below:

a. **Decisional Needs.** Needs are gaps between what is and what should be. Unresolved decisional needs can adversely affect the decision outcomes. Examples include:
   - Decisional conflict about the best course of action (personal uncertainty about the best course of action)
   - Inadequate knowledge of condition, options, benefits, risks, scientific uncertainties
   - Unrealistic expectations of the likelihood of benefits and risks
   - Unclear values or personal importance of benefits, risks, scientific uncertainties;
   - Inadequate support from others or resources (e.g., unclear/biased views of others, social pressure, mismatch in preferred/actual decision making roles, inadequate confidence and skills in decision making;

inadequate access to information, emotional support, instrumental help, financial assistance, health & social services);
  - o Complex decision characteristics such as:
    - type: multiple options, scientifically uncertain outcomes, known benefits and harms that patients' value differently; permanent effects;
    - timing: urgent or delayed
    - stage and leaning to a specific option: not wanting to engage in the decision making process, denial, premature or hasty decision making.
  - o Special needs arising from patients' personal or clinical characteristics including age, developmental stage, sex, socioeconomic status, ethnicity, education, diagnosis and its duration, and limitations in physical, emotional, cognitive or social abilities.

If decisional needs are unresolved, patients are less likely to make informed decisions.[6] They are also more likely to delay decisions, feel regret, express dissatisfaction, and blame others for poor outcomes.[21-23]

b. **Decision Outcomes.** The aim of decision support is to help patients make a "good" decision (also referred to as decision quality). Defining a good decision is challenging when the best choice depends on the patient's views regarding outcomes that matters most. Several studies conclude that good decisions are:[24,25]
  - o Informed with best available evidence (i.e., Does the patient understand the key facts about their condition, options, benefits, harms, scientific uncertainties? Are the patient's expectations of likely outcomes realistic?)
  - o Informed with the patient's values (i.e., Is there a match between the option that is chosen and the positive and negative features that matter most to an informed patient?)

Other outcomes include:
  - o Taking action (e.g., Did the patient delay or make a decision?, Did the patient continue with (adhere to) their chosen option?)
  - o Achieving values-based health outcomes (Did the patient achieve positive outcomes (e.g., symptom relief that matters most) or avoid negative outcomes (e.g., side effects that matter most))
  - o Minimizing emotions such as regret or blame
  - o Using health services appropriately and related costs (e.g., Is there are reduction in over-use of optional health services that informed patients don't value?, Is there an improvement in under-use of optional services that informed patients value?)

c. **Decision Support**. The health professional provides structured assistance in deliberating on the options and communicating with others that is tailored to the patient's decisional needs. The process involves:
  - o clarifying the decision
  - o assessing the patient's decisional needs (see section "a" above.);
  - o providing information and probabilities on outcomes to address knowledge deficits and unrealistic expectations;
  - o clarifying the patient's values by describing other patients' experiences or asking them to rate the personal importance of benefits, harms, or side effects;
  - o enhancing support from others and resources;
  - o monitoring and facilitating progress in decision making.

Depending on the context, decision support can be provided using clinical counseling, decision tools, and/or decision coaching.

Health professionals need to be aware that they tend to over-use factual information about options and under-use other strategies to support decision making. The remainder of this tutorial focuses on the complete range of decision support strategies that can be used to address patients' decisional needs.

3. Clarify the Decision

Decision support needs to focus on a specific decision. The health professional assesses the patient's understanding of the decision that needs to be made. It is important to be explicit about the decision because about half of patients report that they didn't even know that a decision was being made.[26]

Examples of decisions requiring decision support include:

- screening and diagnostic testing
  (e.g., prostate specific antigen screening, prenatal screening, genetic screening for fetal defects, genetic testing for risk of disease)
- aggressive treatments for health problems when simpler options fail
  (e.g., attention deficit hyperactivity disorder, acne, back pain, gastric reflux, arthritis, hot flashes, menorrhagia, prostate enlargement, stable angina)
- developmental transitions
  (e.g., reproduction, 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)

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4. Decisional Conflict and Characteristics of the Decision and Participants

This section focuses on assessing and addressing decisional needs related to decisional conflict, the characteristics of the decision, and the characteristics of participants (e.g., patients and health professionals). When health professionals consider how to address these needs, they usually cannot change the inherent nature of the decision nor the patients. However, they can tailor their decision support to the patient's needs.

4.1 Decisional Conflict. Decisional conflict is personal uncertainty about which course of action to take among competing options that may involve risk, loss, regret or challenge to personal life values.[27] A common indication of decisional conflict is patients saying they feel uncertain or uncomfortable with the decision (e.g., "I'm not sure what to do."). In three surveys, about 50% of patients expressed personal uncertainty, even after making a decision with their physician.[28-30] Other indications of decisional conflict include:[27,28]

- Concerns about undesired outcomes (e.g., "I keep thinking about the things that could go wrong if I have this surgery;" "I could have a complication;" "I may not recover".)
- Wavering between choices (e.g., "One day I think I will take the medication, the next day, I change my mind".)
- Delaying the decision (e.g., "I keep putting it off…I don't want to have to face this choice right now.")
- Questioning personal values or what is desirable or important to them (e.g., "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?")
- Being preoccupied with the decision (e.g., "This decision is all I have been thinking about lately. My family is getting impatient with me because I keep dwelling on this decision.")
- Showing signs and symptoms of distress or tension (e.g., signs of increased muscle tension, onset of restlessness, increased heart rate; "I feel wound up…I can't sleep…my hands shake.")

The frequency of these indications of decisional conflict can vary according to the characteristics of the decision and the patient involved. These are described below. There are also some modifiable factors that contribute to decisional conflict (feeling uninformed, unclear regarding personal values, and unsupported in decision making). These modifiable factors are described in sections 5 to 7.

4.2 Characteristics of Decisions include type, timing, stage and leaning.

4.2a Types of Decisions. The degree of decisional need may vary according to the:

- Class of decision: Higher rates of physical stress from decision making were reported by those who had made decisions about placing a relative in an institution (54%) or medical treatment (46%) as compared with those deciding about birth control (23%).[28] Decision delay was more common among those deciding about placing a relative in an institution (50%) compared with those making surgical decisions (20%). In primary care, greater rates of uncertainty have been reported among those who decided about vaccines and management of diabetes, pain, depression, and hypertension.[30]
- Number of options: having multiple options increases the cognitive burden of comparing differences across options.
- Scientific uncertainty: decisional needs may be greater when the benefits and harms of options need to be weighed and/or there is not even research.
- Seriousness of outcomes: decisional needs may be greater for life-threatening outcomes (e.g. death, heart attack).
- Irrevocable decisions: it is often more difficult to make a decision that can't be reversed such as surgical removal of an organ.

4.2b Urgent or Delayed Timing of Decision. The time frame or urgency with which a decision needs to be made influences decisional needs. For example, having to make difficult decisions on short timelines may increase stress, but very long timelines may increase decision delay.

4.2c Decision Stage and Leaning. Four stages of decision making are described below (see Table). The aim of decision support is to help patients progress in their stage of decision making. Sometimes the final decision does not involve a

change in what they are doing. For example, patients may choose to decline discretionary options such as prostate specific antigen testing, amniocentesis for pregnant woman, or palliative surgery.

Decisional conflict is greater as patients start to consider the options and then tends to diminish after the decision is made.[15]

In the very early and very late stages of decision making, it is important to assess if patients are open to new information and being engaged in decision making. Otherwise, decision support may be irritating or not helpful. For example, patients are less open to discussing a decision when in shock or denial in the early stages of a diagnosis and after they have decided, even if closure is premature (hasty decision making). To prevent premature closure, health professionals can provide timely access to balanced information and decision support.

The table below describes common decision making stages, magnitude of decisional conflict, assessment of decisional needs, and supporting strategies.

Stage of decision making	**Patients' decisional conflict is usually:**	**Assess & address needs**
Not thinking about options	Higher	Assess if open to getting new information (the patient may still be in shock or denial). If the patient is open to decision making, provide information. If not open to decision making, discuss issues that are immediately relevant to the patient.
Actively thinking about options	Higher	Decision support is usually most helpful now.
Close to making a choice	Lower	Assess openness to discussing what led them to the choice they are close to making. Verify his/her understanding of options.
Taking steps or already implemented the chosen option (including maintaining the status quo)	Lower and will often increase if given decision support [31]	If the patient has already decided, assess openness to discussing what led the patient to the steps/choice he/she has taken. Verify his/her understanding of options. Sometimes, patients will start implementing an option even though they are not fully committed to it (e.g. not aware of other options; putting a family member's name on a waiting list for a nursing home that specializes in dementia, even though the decision about placement has not been finalized by the family). Other patients may be implementing choices that they tend to reconsider over time (e.g. in cases of chronic conditions such as depression, attention deficit disorder).

4.3 Personal and Clinical Characteristics of Participants

The health professional tailors decision support to patient's diagnosis, stage of disease, and duration of condition. Decision support should also be tailored to the patient's sex, age, developmental stage, education, occupation, socioeconomic status, and ethnicity. In two studies, which controlled for other potential factors, women reported higher decisional conflict than men.[28] A clinical study of patients considering warfarin therapy found that older patients had higher decisional conflict.[32] In contrast, the Canadian survey found that younger patients had higher decisional conflict and also had a more independent role in decision making.[28]

Health professionals also need to adapt their approaches to the patient's physical, emotional and cognitive abilities.[33,34]It is important to involve the family or a personal advocate when the patient's abilities are limited. Studies have found that providing decision support to patients with poor health literacy results in larger improvements in knowledge.

The characteristics of health professionals will also influence decision support provided based on their training, practice setting, experience, and style of communication.

5. Knowledge and Expectations

This section focuses on assessing and addressing inadequate knowledge and unrealistic expectations.

5.1 Inadequate Knowledge.

The health professional assesses the patient's understanding of the options and their benefits and harms. Questions that can be used to assess knowledge include: "What do you see as your options?", "What are the benefits and harms?" Benefits can also be described as: advantages, pros, or reasons to choose an option. Harms can also be described as: risks, disadvantages, cons, side effects, or reasons to decline an option.

The patient's knowledge is inadequate if there is a lack of agreement between his/her responses and what is known about the options. Also, the patient may state his/her needs (e.g. "I don't know what I can do to relieve these symptoms…I need to find out about the side effects").

The health professional addresses inadequate knowledge by providing information or facilitating access to information about their health situation, the options available, known benefits, harms, side effects, and scientific uncertainties. Information on outcomes should be presented in sufficient detail to enable understanding. The information may be provided by the health professional (e.g., clinical counseling or coaching) and using decision tools (e.g., written materials and/or videos). The format and pace of information should be tailored to the patient's information needs.

It is important to re-assess the patient's understanding after the information has been provided (e.g., ask the patient to summarize the options, benefits and harms). The focus should be on information that is "essential" for decision making.

5.2 Unrealistic Expectations of Benefits and Harms.

The health professional also assesses the patient's understanding of the probability or likelihood of outcomes. Questions when assessing expectations include: "How likely does that happen?", "What are the chances of that happening in your situation?" or "How frequently/often does that happen?"

Expectations are unrealistic if the outcomes are inappropriately exaggerated or minimized. For example, "That treatment gives everyone cancer", "My mother had a beautiful natural childbirth when I was born and I will do the same" or "That treatment never works".

Unrealistic expectations can be addressed by the health professional (e.g., clinical counseling or coaching) and using decision tools (e.g., written materials and/or videos) that include:

Probabilities. Health professionals can provide probabilities of the outcomes for each option, as observed in other patients with characteristics similar to the patient facing the decision.[35] When providing probabilities, it is best to use the same denominator across all the options. For example, "Out of 100 patients like you with x condition, 10 feel less pain with option A and 15 feel less pain with option B".

Stories. Health professionals can use stories or narratives to describe the outcomes so that patients can more easily imagine them and identify with them.[19] In cases where the patient overestimates the chances of an outcome occurring, the health professional can acknowledge the possibility, but then describe a personal story in which the outcome did not happen. In cases where the patient underestimates the chances of an outcome occurring, the health professional can acknowledge the possibility, but then describe a personal story for which the outcomes did happen.

Please refer to the examples below.

Case Example of Re-aligning Expectations
Sara is 17 years old and visits a Primary Care Clinic looking for birth control options. She and her partner are willing to use a condom, although sometimes they use the withdrawal method (coitus interruptus). Sara doesn't think that she has a great risk of getting pregnant, because she has been lucky so far.

Using probabilities.

<u>Health professional:</u> "Many believe that their chances of becoming pregnant are very low, so you are not alone in thinking this way. But the chances may be higher than you think with the methods you are using. For example, if 100 women like you used withdrawal methods for 1 year, 25 would get pregnant; if condoms are used for 1 year, 15 would get pregnant; and if birth control pills were used for 1 year, 8 would get pregnant."

These blocks of 100 faces show our 'best estimate' of what happens to women who choose different options for **1 year**.[36] 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.

Using Stories.

A health professional can provide stories if Sara still believes her risks for getting pregnant using current methods are lower than these probabilities.

<u>Sara:</u> "I know lots of my friends use my approach and never got pregnant."

<u>Health professional:</u> "Do you know of friends and acquaintances that did become pregnant? What happened to them? I can share my experience with hundreds of young women we see at our clinic who use your methods of birth control and get pregnant. If the risks of getting pregnant were as low as you think they are, we would see far fewer unplanned pregnancies than we do."

6. Personal Values

This section is focused on assessing and addressing unclear personal values.

Values refer to the personal importance or desirability of the features of each option. The health professional needs to recognize that the patient's personal values reflect their own experiences, circumstances, and abilities. What matters most to one patient may differ from another.

The following are examples of comments that reveal patients' values: "I can tolerate those side effects if it relieves my headaches"; "For me, the cure is worse than the disease. "I don't believe in taking pills". Other 'feeling type words' a patient may use when discussing values include: "good/bad", "important", "matters most", "worried", "concerned about", "tolerate", "desire", "comfortable", "unacceptable", "bothersome", "outweigh", "trade-offs", "worth it", "number one thing", "priority", "put up with", "happy with", "personal cost too great".

The patient may indicate that he/she is unclear about his/her values using comments like: "I haven't given much thought about the pros and cons"; "I feel miserable and need some relief but I worry a lot about the risks"; "It's hard to say whether the advantages outweigh the disadvantages".

Unclear values can be addressed by the health professional (e.g., clinical counseling or coaching) and using decision tools (e.g., written materials and/or videos) using strategies or exercises to clarify values including:

a. **Describe what it's like to experience the outcomes.** Patients cannot judge the value of outcomes based only on an abstract or vague understanding.[14] Therefore, outcomes need to be described in familiar terms. For example, rather than merely providing a label for an outcome (e.g., stroke), patients are helped to understand how this outcome will affects 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). Providing descriptions of real experiences help patients judge whether or not they personally attach importance to each outcome. Experiences can be described in scenarios or video interviews with patients about their experiences. The international DIPEx organization, begun at Oxford, is a research-based initiative focused on sharing patient experiences (www.dipexinternational.org).
b. **Ask the patient to consider which positive and negative features of each option matters most.** A health professional can ask the question directly ("What matters most to you…symptom relief or side effects?"). Alternatively, they can ask the patient to rate the level of importance using: numerical rating scales (0 = not at all important to 10 = very important) or graphic exercises (adding 0 to 5 stars as shown in case example below). Rating systems may help patients identify which options have the features that matter most to them.[37]
c. **Share values with others.** Health professionals and family members are not very good at judging the values of others. What patients talk about most is not necessarily what they value most. The patient should be encouraged to express the features of options that matter most to them either verbally or using ratings described above.

Case study: 51-year-old Maria is considering hormone therapy because more conservative approaches have not relieved the severe hot flashes that disturb her sleep, and ability to function at work and at home. Her health professional has explained the annual risks and benefits for a woman taking estrogen and progestin but Maria remains unsure. Her health professional asks her to rate the importance of relieving her symptoms using "0 to 5 stars" (0 stars is not important and 5 stars very important).

As shown below, Maria says relief from symptoms is worth 5 stars (*****).
Then the health professional asks her to rate the importance of avoiding the risk of blood clots. Maria says she would rate this as 2 stars (**).
When her health professional asks Maria what that means to her, she realizes that the relief of her symptoms is more important to her than the worry about blood clots. She decides to give hormone therapy a try.

Benefits	How much does it matter to you?	Risks	How much does it matter to you?
Relief from severe hot flashes and sleep problems that affect function at work and home.	* * * * *	Blood clots If 1000 women in their 50's took HRT for 1 year, 999 are OK but 1 may develop a blood clot in the lung, leg, or brain.	* *

7. Support and Resources

This section focuses on assessing and addressing inadequate support from others and resources.

a) Unclear or biased views from others.

The health professional asks the patient about the opinions of others who are affecting the decision. The patient may express these as: "I'm not sure what my (health professional/family) thinks of these options.", "What do other patients do in this situation?" or "I don't want to disappoint the surgeon."

To address unclear or biased views from others, the health professional can describe examples of others' choices in a balanced manner, so that the patient is aware that patients choose different options and there is no "one size fits all". The health professional may also provide statistics on variation in choice, for example the percentage of patients who choose the different options that are available, the differences in health professionals' opinions, or the differences in practice guidelines. It is also helpful to present the rationale behind the differing opinions. Often, differences in choices reflect scientific uncertainty, differences in patient's circumstances, tolerance for risk or uncertainty, or the patient's personal values.

b) Social pressure.

The health professional assesses if the patient is feeling pressure from family, health professionals, or society to choose a specific option. For example, "My family has made it very clear they think I should breast feed." or "I feel society disapproves of people choosing any other option but this one."

To address social pressure, the health professional can explore the nature of the pressure (including its source), the areas of agreement and disagreement, and the reasons behind different points of view. The patient is 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:

- planning how to communicate information and personal values;
- inviting others to discuss their perceptions of options, benefits, harms, and values to find areas of agreement and disagreement;
- mobilizing social support; and
- identifying a mediator, if needed.
- rehearsing strategies through role-playing.

c) Mismatch in preferred/actual role in decision making.

Patients can be classified into three profiles of preference for decisional control: those who want to keep, share, or delegate control for decision making.[38,39] The health professional assesses the patient's preferred role in decision making and the actual role provided to determine if there is a mismatch. For example the patient may say, "My surgeon is hopeless in discussing options other than surgery…it's his way or the highway," "I have no one to talk to about this decision," "My mother can't take care of herself and my sisters have told me they want nothing to do with figuring out where she should live. It's on my shoulders, but I would rather share the decision with my sisters."

It is important to note that the patient's preferred role in decision making can change and providing decision support often increases the patient's desire for active participation in decision making.[6] Therefore, patients need adequate information about the issues and time to consider which decision making role they prefer to take.

Ideally, the type of support the health professional provides depends on the patient's preferred decision making role. Patients who want to be more independent in the process of thinking about the options (e.g., "keepers") may ask their health professional for input on the scientific information. Health professionals might start by providing guidance to patients who want to shared decisions (e.g., "sharers") who would then be more prepared to be actively involved in the decision. Health professionals might use a more advisory role with patients who want to delegate decision making to

someone else (e.g., "delegators") by verifying their understanding, discussing their personal values, and reflecting back on what seems to be the best option.

d) Inadequate skills and self-confidence in decision making.

Decisional conflict is greater in those who feel unskilled in decision making.[28] When assessing the patient's ability to make health decisions, he/she may express his/her needs as follows: "I've never had to make a decision like this before; I'm not sure I can do this."

The health professional can build skills and confidence in decision making by encouraging and facilitating positive self-talk, acknowledging the patient's own strengths, and assisting the patient to draw upon positive past experiences. The health professional provides structured guidance in the steps of decision making and discussing how to communicate what their preferences to others, possibly through role play.[40-47]

e) Inadequate resources.

Resources are available, accessible assets that are required to make and implement the decision. Types include: information, advice, personal advocates, emotional support, instrumental help, financial assistance, health & social services. Sources include: social networks, professional networks, support groups, voluntary agencies, and the formal health care, education, and social sectors.

The health professional assesses if there are other resources necessary for making or implementing the decision. Examples of inadequate resources expressed by the patient includes: "There are no groups in our town that provide information or support for families affected by schizophrenia", "If I choose option 1, I need to have the treatment in another city which increases costs on the family."

The health professional explores with the patient ways to access the resources needed to make the decision.

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8. Monitor and Facilitate Progress

This section focuses on monitoring progress in decision making and providing additional decision support to facilitate progress.

a) Re-assess stage of decision making

Once the patient's needs have been addressed, it is important to monitor their progress in resolving needs and moving through the stages of decision making to make a good decision. As discussed in Section 4, the four stages of decision making are: a) not thinking about options; b) actively thinking about options; c) close to making a choice; and d) taking steps to or already implemented the chosen option. Additional decision support should be tailored to their stage of decision making.

Stage of decision making	**Patients' decisional conflict is usually:**	**Assess & address needs**
Not thinking about options	Higher	Assess if open to getting new information (the patient may still be in shock or denial). If the patient is open to decision making, provide information. If not open to decision making, discuss issues that are immediately relevant to the patient.
Actively thinking about options	Higher	Decision support is usually most helpful now.
Close to making a choice	Lower	Assess openness to discussing what led them to the choice they are close to making. Verify his/her understanding of options.
Taking steps or already implemented the chosen option (including maintaining the status quo)	Lower and will often increase if given decision support [31]	If the patient has already decided, assess openness to discussing what led the patient to the steps/choice he/she has taken. Verify his/her understanding of options. Sometimes, patients will start implementing an option even though they are not fully committed to it (e.g. not aware of other options; putting a family member's name on a waiting list for a nursing home that specializes in dementia, even though the decision about placement has not been finalized by the family). Other patients may be implementing choices that they tend to reconsider over time (e.g. in cases of chronic conditions such as depression, attention deficit disorder).

b) Screen for unresolved decisional needs

The SURE test can be used to screen for unresolved decisional needs. One question assesses feeling sure of the best choice and the other questions focus on decisional needs contributing to feeling sure; specifically, feeling informed, feeling clear about personal values, and feeling supported to make a choice (see Table below).[48] If the patient responds "No" to one or more of the four questions, they have unresolved decisional needs.

Decisional needs can be assessed in greater detail using the 16 item Decisional Conflict Scale.[49] The SURE Test and the original Decisional Conflict Scale are both reliable and valid instruments.[49,50]

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.

c) Assess the quality of the decision

A good decision is informed with the best available evidence and based on the patient's values. Two questions in the SURE Test elicit patients' perceptions of feeling informed and clear about values. However, probing is still required to find out specifically what the patient knows and values. A health professional can assess the quality of the decision formally by using a knowledge test of the key facts and asking patients to rate their values. It can also be assessed informally by verifying if patients:

- understand key information relevant to their options (e.g., benefits, harms, scientific uncertainties);
- have realistic expectations of the chances of benefits and harms; and
- have a preferred option that matches the benefits that matter most to them.

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9. Methods of Delivering Decision Support

9.1 Clinical Counseling

Clinical counseling is non-directive for decisions with multiple options, uncertain outcomes, or benefits and harms that patients value differently. It is provided by health professionals who have the expertise, accountability and scope of practice to: a) identify/diagnose a health problem; b) identify options, benefits, harms, side effects, probabilities, and scientific uncertainties; and c) facilitate implementation of the final decision by making the referral, writing a prescription, ordering screening and diagnostic tests, performing surgery, providing therapy etc. Health professionals include audiologists, nurses, nurse practitioners, occupational therapists, pharmacists, physicians, physiotherapists, psychologists, social workers, speech language therapists.

In the case of medical conditions, physicians and nurse practitioners provide counseling by clarifying the medical decision, providing information on options, benefits, and risks, clarifying the patient's values and by screening for difficulties in decision making or implementation.[51] For those experiencing difficulties, patients can be referred to decision tools and decision coaching.

9.2 Decision Tools

Decision tools include decision guides and patient decision aids that are designed to prepare patients for decision making.

a) The **Ottawa Personal Decision Guide** is a generic tool for any decision. There is a version for 1 person and another version when there are 2 people involved in making the decision (e.g., parent/child, husband/wife). It helps patients and their health professionals: clarify the decision, explore the patient's knowledge, values and support; assess the patient's unresolved decisional needs; and make plans to address these needs. The guide may be useful when a health professional anticipates that the patient may have difficulty making a decision, or when the patient expresses difficulty making a decision. The guide can be self-administered or health professional-administered. For more details on how to use the health professional-administered version, see section 9.3 Decision Coaching.

b) **Patient Decision Aids** focus on specific decisions for patients with specific diagnoses or conditions. They prepare patients to engage in decision making with their health professionals and do not replace discussion in the consultation.[6]According to the International Patient Decision Aids Standards (IPDAS) Collaboration[24,52] patient decision aids:

- Make explicit the decision
- Provide information on the disease/condition, options, benefits, harms, scientific uncertainties
- Present probabilities of outcomes tailored to the patient's health risk factors (optional)
- Clarify values by describing outcomes and/or asking the patient to rate the importance of benefits and harms
- Provide patient stories (optional)
- Provide guidance in the steps of decision making and communicating with others (optional)
- Summarize findings to share with the health professionals (optional)

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.

Patient decision aids have been developed for a variety of screening, diagnostic, medical, treatment, and end-of-life decisions.[6] They are usually printed materials or video that can be used before, during or after discussion in the consultation. Web-based materials can be printed or used online. A list of currently available patient decision aids is found in the "A to Z Inventory of Decision Aids" on the Patient Decision Aids website.

Research from more than 100 randomized controlled trials show that patient decision aids are better than usual care.[6]More specifically, they:

- Increase patient participation in decision making without increasing anxiety
- Improve decision quality by:
  - increasing knowledge of options, benefits, harms
  - creating more realistic expectations of the chances (probabilities) of benefits and harms occurring
  - ensuring a better match between personal values and choice
- lower decisional conflict
- help the undecided patient make a decision

Patient decision aids may also have a role in addressing under-use and over-use of some options.[6] For example, patient decision aids reduced the number of patients who choose surgery when they learn of other less-invasive options. Decision aids also increased colon cancer screening that was under-used and lowered prostate cancer screening that was over-used.

9.3 Decision Coaching

Decision coaching is decision support provided by a trained facilitator who is non-directive. The decision support aims to develop the patient's skills in thinking about the options, preparing for discussing the decision in a consultation with his/her health professional, and implementing the chosen option.[53,54] Decision coaching is provided face to face or using the telephone by a member of the healthcare team within the practice or through a call centre. Decision coaching is used alone or combined with decision tools.

Decision coaching strategies include:[54]

- clarifying decision and monitoring needs
- facilitating access to evidence-based information
- verifying understanding
- clarifying personal values
- enhancing skills in deliberation, communication, and accessing support from others and resources
- monitoring and facilitating progress in decision making and achieving decision quality

Decision coaching can be used with the Ottawa Personal Decision Guide to provide decision support. Each seeks to:

a. **Clarify the decision:** The first step focuses on clarifying 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, benefits and harms to assess knowledge of options and outcomes. Then, the patient is asked to use stars (0-5) to rate how much each benefit and risk matters to them (clarify values). It is not necessary to complete this step in one sitting; the purpose is to determine gaps 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 that is designed to inform clinical practice.[48] If the patient responds "No" to one or more items, there are unresolved decisional needs and he/she is in decisional conflict. Decisional conflict predicts downstream delay or discontinuance of chosen option, regret, and the tendency to blame their health professional for bad outcomes.[21-23]
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, and support. A list of strategies is provided. As the decisional needs resolve or change, questions can be repeated and updated.

10. Case Study: Decision Support Using a Patient Decision Aid

Mrs. G visits her primary care physician Dr. R. She is a 67 year old woman living with her 68 year old husband. They are both retired with a 40 year old married son.

Mrs. G is in good health with the exception of osteoarthritis of the right knee, which has bothered her for the past 15 years. Her pain was controlled somewhat with acetaminophen (Tylenol), but being an active walker, she switched to over-the-counter anti–inflammatory medication, which provided better pain relief. Following a small gastrointestinal bleed, she was prescribed celecoxib (Celebrex), which controlled her pain very well without adverse effects. When the evidence on cardiovascular risk of COX-2 inhibitors (the class of medications that belongs to celecoxib) was published, she decided to switch back to acetaminophen. However, her knee pain is not as well controlled, which affects her ability to go for walks with her grandchildren.

Today, she visited her primary care physician Dr. R to discuss the benefits and risks of trying celecoxib again. Dr. R informed her that the decision depended on her views. If she thought her current symptoms were sufficiently intolerable to warrant the extra risk of serious side effects (e.g., heart attack), then taking celecoxib could be a reasonable option. If she thought the risk was too great, then she should stick with her current regime. Mrs. G was still not sure what to do. Dr. R referred her to a nurse to provide decision coaching.

Initial Contact with the Decision Coach

[The nurse and Mrs. G exchange greetings. The nurse asks her to explain the decision.]
Mrs. G: I want to learn more about the risk of heart attack from taking celecoxib. I took it before and it worked much better than acetaminophen, but I got scared by the risk of heart attack. I would like to know my chances if I were to start celecoxib again…maybe it would be worth it to have less pain so I can be more active again and walk with my grandchildren. But, I am not going to take a big risk. My husband had a heart attack and I want to avoid that.
Nurse (clarifies the decision and assesses decisional needs): So you are not sure whether to stay with acetaminophen or switch to celecoxib…you want more information about the risks to judge whether the pain relief is more important to you than the risks. Is that what you are saying?
Mrs. G: Yes, that's right.
Nurse (assesses decisional needs): Is there anything else making this difficult to decide?
Mrs. G: I can't think of anything…
Nurse (assesses support): Who else is involved in making this decision?
Mrs. G: Well, Dr. R. My husband is interested in knowing more…naturally he is concerned about risks…although he thinks the choice is up to me and Dr. R…and so do I…
Nurse (provides decision tool with information on options, chance of outcomes, values clarification exercise, and assessment of decisional needs): Here is a patient decision aid you can work through. It is made for women in your age group. It has information about benefits and risks (including the chances), helps you consider what is most important to you and what else you need to prepare you for decision making.
Mrs. G: I will give it a try…
Nurse: Is there anything else you would like to discuss right now?
Mrs. G: No, I don't think so. Would it be possible to stop by when I see Dr. R at the next appointment?
Nurse: Yes, I can see you before your appointment. Please bring your completed decision aid with you.

Follow-up Contact with the Decision Coach

Note, not all patients will remember to bring their decision aid with them. Below are two examples of follow up coaching when: a) Mrs. G remembered to bring her decision aid; and b) when Mrs. G forgot to bring her decision aid.

Situation A. Decision Coaching with a Decision Aid

[Mrs. G's completed decision aid is available here and a one page summary is available here.]

Nurse (clarifies the decision): How far along are you with this decision?
Mrs. G: I am pretty sure I want the celecoxib.
Nurse (re-assess decisional needs): Would it be helpful if we review your responses to the decision aid together? They are summarized on this form that you can show Dr R.
Mrs. G:: Yes, that would be good.
[The nurse and Mrs. G look at the form together.]
Nurse (re-assess decisional needs): As you mentioned, you feel celecoxib is the best choice for you?
Mrs. G: Yes.
Nurse (verify understanding of key information): Looking at your answers to the questions here, you know the differences between the options…that celecoxib has a greater chance of pain relief, but acetaminophen has the smallest risks such as heart attack or bleeding. Six more patients out of 1000 patients who take celecoxib have a heart attack each year compared to those that only took acetaminophen. You mentioned that your big concern was the chance of heart attack, what did you think of the numbers you saw?
Mrs. G: Well, I was surprised the risk was so low. I thought the risk would be much greater. So although there is an increased chance it could happen to me, the increase is small and I am willing to accept that extra risk to avoid the pain.
Nurse: What other questions did you have?
Mrs. G: I can't think of any. The information was clear.
Nurse (verify personal values): You say here that you are clear about which benefits and risks matter most to you? Pain relief was "5 out of 5", and the risks were "2 out of 5". Is that correct?
Mrs. G: Yes, pain relief is more important…
Nurse (verify support): You seem to have good support and you seem comfortable with the decision.
Nurse (plan next steps): What do you see as the next steps?
Mrs. G: I plan to discuss this with Dr R.
Nurse: Sounds good…is there anything else you need from me?
Mrs. G: No, I think I am set.

Situation B. Decision Coaching without a Completed Patient Decision Aid

[Mrs. G. and the nurse exchange greetings.]
Nurse (clarifies the decision): How far along are you with this decision?
Mrs. G: I am pretty sure I know what I want…the celecoxib.
Nurse (re-assess decisional needs): Would it be helpful if we go over the things you considered before deciding?
Mrs. G: Yes, that would be fine.
Nurse (verify understanding of key information): So would you say you know the options that are available to you?
Mrs. G: Yes, the information was about the options Dr. R mentioned, continue with acetaminophen or switch to the celecoxib…it also had traditional anti-inflammatories, but Dr. R. did not advise this because I had bleeding from it before.
Nurse: Do you feel you know both the benefits and risks of acetaminophen and celecoxib?
Mrs. G: Yes.
Nurse: What do you see as the main differences between acetaminophen and celecoxib?
Mrs. G: Well, not as many patients get pain relief from acetaminophen. It's true in my case, but celecoxib has a greater chance of heart attack and the chance of bleeding is also higher.
Nurse: Your big concern before was the chance of heart attack, what did you think of that?
Mrs. G: Well, I was surprised the risk was actually so low. I thought it was much bigger, but it was only 7 out of 1000 with acetaminophen and 13 out of 1000 with celecoxib. So although there is an increased chance it could happen to me, the increase is small and I am willing to accept that extra risk to avoid the pain.
Nurse: Do you feel informed on your options?
Mrs. G: Yes, the information was helpful…
Nurse (clarify personal values): And you are clear about which benefits and risks matter most to you?
Mrs. G: To me, the most important thing is pain relief. It is more important than the added risks – the small risk of heart attack.
Nurse: …and the small chance you could bleed again?
Mrs. G: Yes.
Nurse (verify support): So would you say you have enough support and advice to make a choice?
Mrs. G: Yes, my husband is happy with my decision. I would like to run this by Dr R of course.
Nurse: Would you say you are choosing without any pressure from others?
Mrs. G: Everyone has told me it is up to me. I don't feel anyone is trying to get me to choose one way or another.
Nurse (re-assess decisional needs): It sounds like you are feeling sure about the best choice for you?
Mrs. G: Yes, as long as Dr R agrees.
Nurse: You seem comfortable with your decision. Is there anything else I can do for you?
Mrs. G: No, I appreciate your help, thanks very much.

Appendices

Appendix A: Glossary of Decision Support Terms

Decision coaching
Decision support provided by a trained health professional who is non-directive. The decision support aims to develop the patient's skills in deliberating on the options, preparing for discussing the decision in a consultation with his/her health professional, and implementing the chosen option.[53,54] Decision coaching is provided face to face or using the telephone by a member of the healthcare team in the practice or at a call centre. Decision coaching is used alone or in combination with decision tools.

Decisional conflict
Uncertainty about which course of action to take when choice among competing actions involves risk, loss, regret or challenge to personal life values (specify the focus of conflict, such as personal health, family relationships, career, finances, or other life events).[27]

Decision knowledge
Understanding of the health problem or situation, options and outcomes (e.g., benefits, harms).

Decision leaning
The inclination to choose one option over the others.

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

Decisional needs
Gap between what is and what should be in terms of optimal decision making. Unresolved decisional needs that can adversely affect decision outcomes include: decisional conflict, inadequate knowledge, unrealistic expectations, unclear values, inadequate support from others or resources, difficult or complex decision, urgent/delayed timing, unreceptive decision making stage, participants' characteristics such as cognitive limitations, poverty, limited education, and physical, emotional or social dysfunction.

Decision pressure
Perception of persuasion, influence, coercion from other(s) to select one option.

Decision quality
The extent to which the chosen option best matches the value that an informed patient places on potential benefits, harms, and scientific uncertainties.

Decision support
Structured assistance in thinking 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 patients' values. The steps involve: clarifying the decision, assessing the patient's decisional needs, providing information and probabilities of outcomes, clarifying personal values, enhancing support from others and resources, and monitoring/facilitating progress in decision making. Decision support helps patients to engage in decision making in roles that they prefer (e.g. keep, share, or delegate control in decision making).

Decision timing
The time frame or urgency with which a decision needs to be made.

Decision type
The class or characteristic of the choice that needs to be made (e.g. developmental transition or clinical options (screen, test, treat, palliate)), number of options, degree of risk/uncertainty, seriousness of outcomes, margin for error (i.e. whether it is irrevocable).

Expectations
A patient's perceptions of the likelihood or probability of outcomes for each option.

Health professional characteristics that influence the decision and decision making
Age, gender, ethnicity, clinical education, specialty, practice locale, experience, style of communication.

Motivation
Readiness and interest in decision making.

Others' opinions
Perceptions of what others decide or what others think is the appropriate choice. This may include the patient's spouse, family peers, and health professional(s).

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".[55]

Patient characteristics that influence the decision and decision making

Age, gender, education, marital status, ethnicity, occupation, locale, diagnosis & duration of condition, health status (physical, emotional, cognitive, social), socio-economic status, and social capital.

Patient decision aid

Evidence-based interventions designed to prepare patients to participate in making specific and deliberate choices among healthcare options. They supplement (not replace) discussion within the consultation.[6] Patient decision aids: a) make explicit the specific decision; b) provide evidence-based information on the health condition, the options, associated benefits and harms, probabilities, and scientific uncertainties; c) help clarify the value of the benefits, harms, and scientific uncertainties; and d) guide in the steps of decision making and communicating their informed values with others involved in the decision (e.g., health professional, family, friends).

Personal experience

Past exposure to the situation, options, outcomes and/or the decision making process.

Quality of the decision making process

The extent to which the patient is helped to recognize that a decision needs to be made; know about the available options and associated procedures, benefits, harms, probabilities, and scientific uncertainties; understand that values affect the decision; be clear about which features of the options matter most to them (e.g. benefits, harms, and scientific uncertainties); discuss values with their health professional(s); and become involved in decision making in the ways they prefer.

Resources

Available, accessible assets that are required to make and implement the decision. Types include: information, advice, emotional support, instrumental help, financial assistance, health & social services. Sources include: social networks, professional networks, support groups, voluntary agencies, and the formal healthcare, education, and social sectors.

Roles

The way a participant wants to be involved in making the decision. Decisions are often made on their own 'keeper', shared with someone else 'shared', or deferred to someone else 'delegated'.

Self-confidence

Belief in one's abilities to make a decision (includes participating in shared decision making) and to implement the chosen option.

Shared decision making

The process whereby health professional(s) and the patient make decisions together. It recognizes the expertise of each participant. Health professionals are experts in diagnosing the problem and identifying options, benefits, harms, side effects, probabilities of outcomes, and scientific uncertainties. Patients are experts in understanding their personal circumstances and judging the value or personal importance they attach to the benefits, harms, side effects, and scientific uncertainties of options.

Skills

Abilities in making and implementing a decision.

Stages

The stages of decision making are: not thinking about options; actively thinking about options; close to making a choice; and taking steps or already implemented the chosen option. Deciding not to change or to do nothing may a viable option.

Values

Desirability of, or personal importance attached to, outcomes of options.

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