

**2012 UPDATED CHAPTER F:
COACHING / GUIDANCE IN DELIBERATION AND COMMUNICATION**

**SECTION 1:
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SECTION 2: CHAPTER SUMMARY

This chapter presents an update on coaching and guidance in deliberation and communication that is provided within or alongside patient decision aids. However, decision coaches may perform similar supportive functions while providing patients with other educational materials to support discussion of options and their attributes. Similarly, materials other than patient decision aids may incorporate guidance.

What is this dimension?

Coaching and guidance are structured approaches designed to help patients think about their options in preparation for discussing and agreeing upon the best option with their practitioner(s). An assumption underlying both concepts is that the process of decision making requires cognitive activities to understand options and their attributes, as well as two-way communication to verify understanding, clarify patients' informed preferences, and discuss preferences with the practitioner(s) and significant others involved in the decision. *Coaching* is provided by a trained individual, either in-person or remotely (telephone or Internet) who is supportive but non-directive in the decision. Using an iterative verbal exchange, elements of coaching include assessing decisional needs, providing information, verifying understanding, clarifying preferences, building skills, screening for implementation needs, and facilitating progress in decision making. Coaching may be given before and/or after using a patient decision aid, as part of the delivery of one, or in the absence of a decision aid. *Guidance* is provided within a patient decision aid or as a resource alongside the decision aid. It is evidenced by: a) a list of steps in the decision making process or worksheet that can be completed and shared with the practitioner(s) and/or significant others involved in the decision; b) a list of questions or prompts asking patients to identify their questions to ask the practitioner(s) or decision coach; and/or c) an automated summary of the patients' priorities and decisional needs that can be given to the patient and shared with their practitioner(s), decision coach, and/or significant others involved in the decision.

What is the theoretical rationale for including this dimension?

Patients are better able to participate in making decisions about their healthcare if they are supported in the process of thinking about a decision and discussing it with others.

What is the evidence to support including or excluding this dimension?

In 98 randomized controlled trials of patient decision aids to the end of 2010, 11 studies (11.2%) included coaching and 63 studies (64.3%) provided guidance. Compared to usual care, coaching provided by healthcare professionals improved knowledge, and decision aid plus coaching improved knowledge and participation in decision making while decreasing mean costs. However, the improvement in knowledge was similar when coaching alone was compared to a patient decision aid alone. The impact of other comparisons on outcomes was more variable, with some trials showing positive effects and other trials reporting no differences. None of the outcomes were worse when patients were exposed to decision coaching. No trials evaluated the effect of guidance provided within patient decision aids. More detailed decision aids are likely to include one or more elements of guidance and compared to simpler decision aids, these detailed decision aids produced higher knowledge, more realistic expectations, and a greater match between patients' values and choice.

**SECTION 3:
DEFINITION (CONCEPTUAL/OPERATIONAL) OF THIS QUALITY DIMENSION**

a) Updated Definition

Coaching and guidance are structured approaches designed to help patients think about their options in preparation for discussing and agreeing upon the best option with their practitioner. An assumption underlying both of these concepts is that the process of decision making requires cognitive activities to understand options and their attributes, as well as two-way communication to verify understanding, clarify patients' informed preferences, and discuss preferences with the practitioner(s) and significant others involved in the decision.

Coaching is provided by a trained individual, either in person or remotely (telephone or Internet), who is supportive but non-directive in the decision. Using an iterative verbal exchange, elements of coaching include:

- a) assessing the patients' decision making needs;
- b) providing information on their options, benefits, and harms (e.g. verbally or with patient education resources such as patient decision aids);
- c) verifying their understanding; d) clarifying their values associated with the attributes of the options, and their attitude toward risks;
- e) building their skills in deliberating, communicating, and accessing support;
- f) screening for implementation needs; and
- g) facilitating progress in decision making. Although the patient may express their leaning toward a specific option to the decision coach, agreeing upon an option occurs during consultation with the practitioner.

Trained health professionals, students, or laypeople provide coaching before and/or after using a patient decision aid, as part of the delivery of one, or in the absence of decision aids. Synonyms include decision support, counseling, mentoring, empowering, instructing, and facilitating decision making processes.

Guidance is provided within a patient decision aid or as a resource alongside the decision aid, and is evidenced by:

- a) a list of steps or systematic approach for making a decision;
- b) a worksheet that can help patients to clarify their values associated with the options' attributes and that can be shared with their practitioner;
- c) a list of questions and/or an invitation for users to identify questions to ask the practitioner (or decision coach); and/or
- d) an automated summary of the patients' priorities and decisional needs (e.g. knowledge, values, preference, results of decision analysis) that can be given to the patient and shared with the practitioner(s), decision coach, and/or significant others involved in the decision.

b) Changes from Original Definition

In the original IPDAS background document, six definitions were only provided in the glossary at the end of the document. These definitions were primarily based on Greenfield, Kaplan, and colleagues' concept of health coaching (Greenfield et al., 1985; Greenfield et al., 1988) and communication processes (Bennett, 1976; Bensing, 1992; Cegala, 1996; Roter, 1993) (see Appendix I).

The updated definition is provided for the two main concepts – coaching and guidance – and includes the same fundamental descriptions as the original sets of definitions. The original three sub-concepts of 'coaching in communication', 'coaching in deliberation' and 'coaching methods' are now subsumed under the larger concept of coaching. The original three sub-concepts of 'guidance in communication', 'guidance in deliberation' and 'guidance methods' are now subsumed under the larger concept of guidance. The rationale for this change was to have explicit definitions for the two main concepts within this chapter and thereby simplify how we communicate about these concepts.

For the updated definition of "coaching", balanced instruction was removed and replaced by non-directive support. In this update, more details on the elements of coaching were added to be consistent with more recent literature on decision coaching (Légaré et al., 2010c; O'Connor et al., 2008; Stacey et al., 2008c; Stacey et al., 2012; Woolf et al., 2005).

For the updated definition of "guidance," the main change was adding the automated summary of the patients' decisional information that is used in some clinical settings and that is available as a print-out for some online decision aids (Patient Decision Aids Research Group, 2010; Stacey et al., 2008b).

c) Emerging Issues with Definitions

Automated decision guidance using telephone menus or e-tools is evolving. Although it may be called automated decision coaching (O'Connor et al., 2008), human interaction is not involved and therefore it fits with the definition of guidance.

SECTION 4:

THEORETICAL RATIONALE FOR INCLUDING THIS QUALITY DIMENSIONS

a) Updated Theoretical Rationale

There are several rationales informing the use of coaching and guidance within or alongside patient decision aids; several of which are from current or emerging decision-making theories or conceptual models (Durand et al., 2008).

Achieving a Higher Quality Decision

The objective of patient-oriented decision support is to help patients make higher quality decisions that are informed with the best available evidence and that reflect the patients' values for the options' attributes (Sepucha et al., 2004; Ratliff et al., 1999). The main hypothesis underlying the

use of guidance and coaching within or alongside patient decision aids is that patients are better able to participate in making decisions about their healthcare and achieving a higher quality decision, if they are supported in the process of thinking about a decision and discussing it with others.

To help patients make higher quality decisions, coaching and guidance may seek to do one or more of the following:

- Improve patients' deliberation skills, by:
 - increasing critical reflection, anticipating and avoiding common pitfalls (e.g. anchoring, misconceptions, etc.) that can undermine effective decision making;
 - taking someone through the steps of decision making;
 - helping patients become more informed by providing information, tailoring information, brainstorming and answering questions, stimulating patients to ask questions, and/or verifying understanding;
 - clarifying patients' values by facilitating reflection, completing values clarification exercises, and/or sharing others' experiences; and/or
 - building self-efficacy in decision making.
- Enhance patients' skills in communicating with their practitioner(s), by:
 - helping patients prepare questions and identify concerns;
 - teaching skills for raising difficult subjects;
 - facilitating patients' communicative capacity in the process of decision making; and/or
 - providing a worksheet or list of questions to share with the practitioner.
- Improve follow-through on the chosen option, by helping patients to anticipate and overcome barriers to implementing the desired option.
- Reduce patients' emotional distress (including decisional conflict; see Appendix) and/or improve their ability to use coping and problem-solving skills.

Avoiding Decision Pitfalls

Patients and practitioners do not naturally follow the axioms of normative decision theory (Fishburn, 1988; Howard & Matheson, 1989; Russo, 1990), but when inconsistencies are highlighted, many willingly change their choices to be more aligned with these principles (see appendices). Thus, explicit guidance or decision coaching in the steps of deliberation can overcome some of common decision-making pitfalls.

Improving Quality of Patient-Provider Communication

Two-way communication is essential for shared decision making but does not guarantee that shared decision making has occurred (Charles et al., 1997; Makoul & Clayman, 2006). Two-way communication using high quality content (e.g. the provision and comprehension of evidence-based information, and the acknowledgment of individual values and preferences), coupled with strong patient-provider relationships have been linked to greater satisfaction and positive health outcomes. Alternatively, poor communication has been linked to dissatisfaction, conflict, and worse outcomes.

Many studies have documented the poor quality of communication between patients and providers (Hack et al., 2005; Kiesler & Auerbach, 2006). Examples of poor communication include: a) one-way communication in which the physician dominates the discussion; b) focus limited to medical facts, not thoughts/feelings or values associated with the options' attributes; and c) documentation using a traditional problem-oriented note that does not incorporate elements of two-way communication or shared decision making (Donnelley, 1992). Therefore, patients and practitioners may benefit from coaching and/or guidance to foster more two-way, higher quality communication.

Enhancing Learning

As with all adults, patients learn in different ways (Knowles et al., 1998; Knowles, 1990; Mezirow, 1990). Some patients prefer to learn from others, some prefer written, video, or interactive materials, and some prefer more than one approach to learning. Many researchers argue that learning and skill acquisition happen most effectively when patients are engaged in the process, often with support of a mentor or coach, rather than simply receiving factual information (Bandura, 1977; Knowles et al., 1998). Patients are more apt to learn when messages and information are tailored to their situation, their needs, and their concerns (Knowles, 1990; Knowles et al., 1998; Krueter & Ricardo, 2003).

Minimizing Emotional Distress

A new diagnosis can cause significant emotional distress and can disrupt coping and problem-solving skills. Psychosocial services can help address excessive emotional distress. However, emotions are often important in personal decision making, before, during and after the decision (Blom & Montgomery, 1997). First, emotions may propel the patient to deliberate and to act in support of or in opposition to an option. Second, emotions may give the patient positive or negative feedback. For example, during the decision process the patient may start to feel anxiety or fear about what is going to happen and may start anticipating decision regret.

Decisional conflict is another type of emotional arousal that commonly occurs in patients making health decisions. It is defined as uncertainty about which course of action to take when choosing among actions that involve risk, loss, regret or challenge to personal life values (O'Connor, 1995). Some emotional arousal appears to be necessary to stimulate patients' desire and capability to participate effectively in decision making (Bekker et al., 2003). The individualized approach used in coaching may improve the likelihood that patients' emotions are considered throughout the decision making process, particularly when clarifying importance of attributes of options and acknowledging their concerns.

Decision Making Conceptual Models that Inform Decision Coaching

The Interprofessional Shared Decision Making Model (IP-SDM), the Framework for Decision Coach Mediated Shared Decision Making, and the FAST model of critical reflection (see Appendix) have been used to inform the role of a decision coach alongside patient decision aids (Belkora, 2009; Légaré et al., 2010b; Légaré et al., 2010c; Stacey et al., 2008c; Stacey et al., 2010).

The IP-SDM Model

This model assumes that two or more healthcare professionals collaborate to achieve SDM with the patient either concurrently or sequentially; one of these professionals may undertake the decision coaching role. According to this model, the decision coach is a health professional trained to support the patient's involvement in the shared decision making process. This process involves making explicit that a decision needs to be made, exchanging information (including the use of patient decision aids), clarifying values/preferences, determining feasibility of options, reaching a choice, and implementing the chosen option. The interprofessional team members, including the decision coach, may have varying levels of involvement at different steps of the decision making process, but overall they share a common understanding of this process (from deliberation to implementation of the chosen option). The IP-SDM model has been validated in primary care and home care clinical environments (Légaré et al., 2011; Légaré et al., 2010c) and shown to be relevant in research studies evaluating patients' decision making needs in the intensive care unit and renal dialysis decision making (Kryworuchko et al., 2011; de Rosenroll, 2011).

The Framework for Decision Coach Mediated Shared Decision Making

This framework expands the traditional patient-practitioner dyad to include the role of decision coaching and integrates the Ottawa Decision Support Framework interventions as the key elements in the coaching role (Stacey et al., 2008c; O'Connor et al., 1998). The Framework for Decision Coach Mediated SDM assumes that higher quality decisions are achieved when patients and practitioners participate in decision making and a decision coach facilitates patient engagement in this process. Decision coaching involves a) assessing patients' decisional conflict and related modifiable deficits in knowledge, values clarity and support; b) tailoring decision support to meet patients' needs by facilitating access to patient decision aids and/or providing evidence-based information, verifying understanding, clarifying values, building skills in deliberation, communication and accessing support; c) monitoring and facilitating patients' progress in decision making; and d) screening for factors influencing decision implementation, including patients' motivation and self-efficacy, and other potential barriers impeding implementation. The updated Ottawa Decision Support Framework includes decision coaching as one of the ways of delivering decision support with a similar description (O'Connor, 2006). The Ottawa Personal Decision Guide is a tool that can be used to facilitate the provision of decision coaching with patients. Compared to controls, health professionals who were trained in decision coaching were more likely to assess patients' decisional needs, discuss values associated with their options, and assess for support needed from others involved in the decision (Stacey et al., 2006b; Stacey et al., 2008a; Murray et al., 2010).

The FAST Model

The FAST model of critical reflection (Formulate issues, Analyze issues, Synthesize insights, Translate insights into action) informed the decision coaching role as part of the patient decision aid implementation at the Breast Care Center at the University of California in San Francisco (Belkora, 2009; Belkora et al., 2008; Belkora et al., 2009; Belkora et al., 2010b). The coaching role in this program was designed to help patients—after they have reviewed a patient decision aid (or education materials in the absence of a decision aid)—to formulate issues that they will

subsequently analyze with their practitioners. Decision coaches in this program include post-baccalaureate, premedical students (see Appendix I).

Decision Making Conceptual Models that Inform Guidance

To the best of our knowledge, the Ottawa Decision Support Framework is the only conceptual model that explicitly includes the element of guidance (Stacey et al., 2010).

The Ottawa Decision Support Framework

This framework asserts that participants' (e.g. individual, couple, family, practitioner) decisional needs will affect the achievement of a higher quality decision, which, in turn, affects actions or behaviours (e.g. delay), health outcomes, emotions (e.g. regret, blame), and appropriate use of health services (O'Connor et al., 1998; O'Connor, 2006). Furthermore, decision support interventions are designed to address modifiable decisional needs. Guidance is one example of a decision support intervention (e.g. guiding clients to consider which benefits and harms are most important to them). It is also described as a way to structure the process of decision making by making explicit a set of steps and encouraging patients to communicate their informed preferences with others involved in the decision (e.g. practitioner, family, friends). The Ottawa Decision Support Framework has been commonly used a) for developing patient decision aids in Canada, Australia, the United Kingdom, and the United States (Durand et al., 2008; Stacey et al., 2011) as well as b) for training healthcare professionals in shared decision making (Légaré et al., 2012a).

b) Changes from the Original Theoretical Rationale

Since the original coaching/guidance chapter was written, there has been a theory analysis of existing shared decision making conceptual models (Stacey et al., 2010), and several newer models have appeared in the literature that make explicit the role of coaching (Belkora, 2009; Légaré et al., 2010b; Légaré et al., 2010c; Stacey et al., 2008c; Stacey et al., 2010). Also, the Ottawa Decision Support Framework was added to this updated chapter as a conceptual model that includes guidance as an element in patient decision aids (O'Connor et al., 1998; O'Connor, 2006).

c) Emerging Issues/Research Areas in Theory/Rationale

Unfortunately, barriers interfere with the delivery of decision coaching within routine clinical practice (Légaré et al., 2008; Stacey et al., 2006a; Stacey et al., 2008a; Wirmann & Askham, 2006). Examples of barriers include: a) lack of awareness, knowledge and skills in decision coaching among health professionals; b) inadequate decision coach training; c) lack of time in clinical practice interfering with developing and using decision coaching skills; and d) inadequate environmental supports to facilitate the decision coach role. Therefore, the theoretical models underpinning decision coaching/guidance interventions need to be incorporated into broader conceptual frameworks about implementation.

SECTION 5: EVIDENCE BASE UNDERLYING THIS QUALITY DIMENSION

a) Updated Evidence Base

The following evidence summary for coaching/guidance is based on findings from the Cochrane Collaboration Review of patient decision aids, which included trials to the end of 2009 (N=86) (Stacey et al., 2011), as well as an updated search of patient decision aid trials published to the end of 2010 (N = 12).

For decision coaching, we also used a sub-analysis of trials that evaluated decision coaching within trials of patient decision aids (Stacey et al., 2012). This sub-analysis a) included trials that allowed the impact of decision coaching provided by a healthcare professional to be compared to another intervention and/or usual care, and b) excluded studies in which patients were exposed to coaching in both arms of the trial (Bekker et al., 2004; Green et al., 2004; Lalonde et al., 2006; Miller et al., 2005). One other trial was excluded because only 12 of 136 women (8.8%) in the intervention group considering fibroid treatment were actually exposed to decision coaching (Solberg et al., 2010).

Evidence about Decision Coaching

Of 98 trials of patient decision aids, 11 (11.2%) included decision coaching provided by nurses, genetic counselors, pharmacist, physicians (who were not the practitioner for the patient), psychologists, or health educators. **Table 1** summarizes the findings from studies that evaluated decision coaching. When decision coaching provided by a healthcare professional was compared to usual care, there was an improvement in knowledge. However, the improvement in knowledge was similar when coaching alone was compared to a patient decision aid alone. Decision aid plus decision coaching compared to usual care improved knowledge and participation in decision making while decreasing mean costs. The impact of other comparisons on outcomes was more variable, with some trials showing positive effects and other trials reporting no differences. Overall, none of the outcomes were worse when patients were exposed to decision coaching. Interestingly, in the one study in which decision coaching was optional (Solberg et al., 2010), few women initiated contact with the coach, and, overall, only 9% allocated to the intervention group were exposed to the coaching intervention (includes patient-initiated or coach-initiated contact).

Table 1: Summary of Findings for Decision Coaching (“n” = number of studies)

	Positive Results*	Mixed Results	No Difference
Decision Coaching versus Usual Care (n = 1)	<ul style="list-style-type: none"> ▪ improved knowledge (Green, 2001) 		
Coaching plus a Decision Aid versus Usual Care (n = 5)	<ul style="list-style-type: none"> ▪ improved knowledge (Hamann, 2006; Lerman, 1997; van Peperstraten, 2010) ▪ decreased mean costs (Kennedy, 2002; van Peperstraten, 2010) ▪ fewer physical limitations to lifestyle activities (Kennedy, 2002) <ul style="list-style-type: none"> ▪ decreased hysterectomies for more conservative options (Kennedy, 2002) ▪ increased psycho-education rather than medication for schizophrenia (Hamann, 2006) ▪ increased single embryo transfers compared to double embryo transfer (van Peperstraten, 2010) 	<ul style="list-style-type: none"> ▪ had an enhanced perceived/preferred involvement in decision making* (Hamann, 2006; van Peperstraten, 2010) or showed no difference in participation (Vodermaier, 2009) <ul style="list-style-type: none"> ▪ were either more satisfied with the decision making process* (Kennedy, 2002) or showed no difference in satisfaction (Vodermaier, 2009) ▪ had an improved feeling informed subscale* (van Peperstraten, 2010) but showed no difference in total decisional conflict (Vodermaier, 2009) 	<ul style="list-style-type: none"> ▪ values-choice agreement (Lerman, 1997) ▪ satisfaction-uncertainty and control levels (van Peperstraten, 2010) ▪ anxiety or depression (van Peperstraten, 2010) ▪ uptake of genetic testing (Lerman, 1997; Vodermaier, 2009)
Coaching versus Decision Aids (n = 4)	<ul style="list-style-type: none"> ▪ increased values-choice agreement (Rothert 1997) ▪ similar improvements in knowledge (Deschamps, 2004; Green, 2001; Hunter, 2005; Rothert, 1997) ▪ increased satisfaction with the decision making process (Hunter, 2005) 	<ul style="list-style-type: none"> ▪ decreased decisional conflict* (Rothert et al., 1997) or showed no difference (Deschamps, 2004; Hunter, 2005) 	<ul style="list-style-type: none"> ▪ participation (Deschamps., 2004) ▪ preparation for decision making (Deschamps 2004) ▪ use of hormones for menopause (Deschamps, 2004; Rothert, 1997) or uptake of prenatal screening (Hunter, 2005) ▪ adherence to hormones for menopause (Deschamps, 2004; Rothert, 1997) ▪ anxiety or pregnancy outcomes (Hunter, 2005)
Coaching plus a Decision Aid versus Decision Aid Alone (n = 4)	<ul style="list-style-type: none"> ▪ increased participation in decision making (Davison, 1997) ▪ decreased in mean costs (Kennedy 2002) ▪ had similar improvements in knowledge (Lerman, 1997) 		<ul style="list-style-type: none"> ▪ values-choice agreement (Lerman, 1997) ▪ satisfaction with the decision making process (Kennedy, 2002) ▪ uptake of hysterectomy (Kennedy, 2002), genetic testing (Lerman, 1997), or prostate cancer screening (Myers, 2005); ▪ health outcomes (Kennedy, 2002), anxiety or depression (Davison, 1997)

*= $p < 0.05$

Evidence about Guidance

Of 98 RCTs, 63 RCTs (64.3%) used patient decision aids that contained some sort of guidance in deliberation and/or communication. The amount of guidance varied considerably. **Table 2** summarizes the types of guidance provided (not mutually exclusive).

Table 2: Types and Frequency of Guidance Provided Within Patient Decision Aids

Type of Guidance	Frequency	References
Step-by-step process for making the decision	27	
Worksheet with questions relevant to the decision making process	31	
Administered by the physician in the consultation or by a research assistant (e.g. decision boards, decision cards, or computer program)	9	Johnson et al., 2006; Langston et al., 2010; Mann et al., 2010; Mullan et al., 2009; Thomson et al., 2007; Vodermaier et al., 2009; Whelan et al., 2003; Whelan et al., 2004; Weymiller et al., 2007
Encouraged patients to communicate with their practitioners by asking questions and sharing their preferences	7	Bekker et al., 2004; Dolan & Frisina, 2002; Gattellari & Ward, 2003; Langston et al., 2010; Rothert et al., 1997; Street et al., 1995; Vuorma et al., 2004
Interactive computer programs: inherently guided the patient through the decision aid and decision making process	6	Bekker et al., 2004; Evans et al., 2010; Kuppermann et al., 2009; Protheroe et al., 2007; Sheridan et al., 2006; Volk et al., 2008
One or more questions that asked patients to clarify their preferences	4 +	Gattellari & Ward, 2003; Kennedy et al., 2002; Leung et al., 2004; Vuorma et al., 2004; + many worksheets and step-by-step included these questions
Summaries that could be shared with the practitioner(s) during the consultation (e.g., completed worksheets/workbook, computer printout indicating treatment preferences, letter with results of decision analysis)	42	

Trials of patient decision aids do not compare varying intensities of guidance, and, therefore, the relative effectiveness of these approaches is not clear (Stacey et al., 2011). However, more detailed decision aids are more likely to include one or more of these elements of guidance in deliberation or communication. The Cochrane Collaboration Review of patient decision aids (2011) found that, compared to simpler patient decision aids, these more detailed decision aids produced higher gains in knowledge, more realistic expectations, and a greater match between patients' values and their chosen option.

Other Evaluative Studies

One large randomized controlled trial involved 174,120 individuals with selected medical conditions who were exposed to health coaches that provided instruction over the telephone on shared decision making, self-care, and behavioural change (Wennberg et al., 2010). Compared to the usual care group, the enhanced group a) had lower cut points for including individuals, based on their predicted future costs and health conditions, and b) received a higher dose of coaching (5 versus 3 outreach calls). Findings revealed that patients in the enhanced group were more likely to be sent a decision aid (41% versus 11%) for preference-sensitive conditions that put them at risk for a surgical intervention (e.g. lumbar surgery, knee/hip replacement, cardiac revascularization, prostatectomy, hysterectomy). Although there were reductions in medical costs and hospitalizations for those in the enhanced group, a sub-analysis of patients with preference-sensitive conditions (n=18,351) showed no differences between groups.

Two systematic reviews were conducted to evaluate interventions to enhance the quality of the patient-physician communication (Griffin et al., 2004; Harrington et al., 2004). One review of interventions to alter patient-physician communication included interventions such as engaging the patient in discussion of the problem, encouraging questions and participation in decision making about management, and discussion of emotions and feelings (Griffin et al., 2004). These interventions produced positive psychological outcomes in 26 of 35 trials (e.g. reduced anxiety and depression, enhanced quality of life and well-being) and positive physical outcomes in 11 of 25 trials (e.g. reduced pain and improved functional status). Another systematic review of interventions directed at enhancing patients' participation in the consultation included interventions focused on question-asking, raising concerns, and requesting clarification or checking understanding (Harrington et al., 2004). Of 16 studies, 10 reported significant increases in patient participation and 5 had non-significant increases. Furthermore, patients who had greater participation also experienced more sense of control and preferred to be more active in the consultation.

However, two other systematic reviews found that interventions focusing only on patients (such as in many patient decision aids) or only on practitioners with whom the decision is to be made may have limited impact in achieving shared decision making (Légaré et al., 2010a; Légaré et al., 2012). In fact, when the focus was only on increasing the participation of patients without interventions targeting practitioners, patients were more likely to independently make decisions rather than sharing the decision with their practitioner (Stacey et al., 2011). Therefore, interventions that stimulate patient engagement such as patient decision aids and practitioner engagement, such as education, are more likely to increase uptake of shared decision making. These findings reinforce the need for training individuals who will provide decision coaching.

b) Changes from the Original Evidence Base

This update adds findings from randomized controlled trials of patient decision aids from 2005 to the end of 2010. As well, the findings were added from a sub-analysis of the effect of coaching on the chosen option, the process of decision making, and outcomes. Finally, this update includes findings from recent systematic reviews focused on interventions to enhance communication between patients and healthcare professionals and/or interventions to enhance shared decision making in the consultation.

c) **Emerging Issues/Research Areas in Evidence Base**

1. On Coaching

More evaluative investigation is required to understand a) the added effect of decision coaching beyond the patient decision aid, b) which population(s) could most benefit from decision coaching, c) who is best to deliver this intervention—a health professional or lay coaches; and d) the effect of a coaching intervention that is tailored to the unique factors influencing patients' baseline decisional needs and/or their decision making process.

Furthermore, when decision coaching is provided by healthcare professionals within a clinical setting, can its delivery be spread out among different members of the interprofessional team, or does one member of the team need to take responsibility for this role?

Another area requiring further evaluation is the use of decision coaching in patients with chronic conditions in which the decision situation is revisited over time and/or there is a series of different decisions to be made (Montori et al., 2006).

2. On Guidance

There are no known randomized trials that we could find that have measured the effect of guidance in patient decision aids and/or of summary tools used to inform the decision making process within the patient-practitioner consultation. Therefore, research is required to determine the contribution of guidance within patient decision aids or used alongside decision aids. Research is underway to better understand the constructs of automated guidance within technology-based decision support systems.

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**APPENDIX I:
CONCEPTS IN COACHING AND GUIDANCE**

❖ **Health Coaching**

Greenfield, Kaplan, and colleagues pioneered the concept of health coaching (Greenfield et al., 1985; Greenfield et al., 1988). In their model, the coach's goals are to encourage patients during their clinic visit with their practitioner to: (1) ask questions, (2) recognize relevant medical decisions, and (3) negotiate these decisions with their provider. In addition, techniques were taught to have patients overcome potential barriers in discussions with their provider such as embarrassment, fear of appearing foolish, forgetting to bring up an issue, and intimidation by the provider. In several controlled trials of patients with different conditions (such as diabetes, hypertension, and cancer), they found that patients who underwent an intervention to better understand their medical condition and were coached to better talk with their provider were more active in the conversation with their provider, more assertive during these conversations, and elicited twice the number of factual statements from their provider. Patients in the intervention group also expressed a significantly stronger desire to participate in the medical decision making process.

❖ **Decisional Conflict Theory:**

Although the majority of behavioral decision theory highlights how often patients stray from the normative ideals, Decisional Conflict Theory took a slightly different approach by trying to define those conditions under which decision makers seem to follow a more vigilant process. Janis and Mann (Janis & Mann, 1977) studied emergency decision making, and found that decision makers tended to be more vigilant when they (a) realized a threat if they stay with the status quo, (b) realized a threat if they changed to the first alternative, (c) hoped that they could find some better options, and (d) believed that they have sufficient time to search and deliberate. This means that there needs to be some anxiety or conflict in order to motivate patients to deliberate, but not too much, or else it will interfere with cognitive processing. Janis and Mann also developed some interventions designed to promote vigilance and improve the quality of decisions. Some patient decision aids incorporate these techniques (e.g. balance sheet exercise).

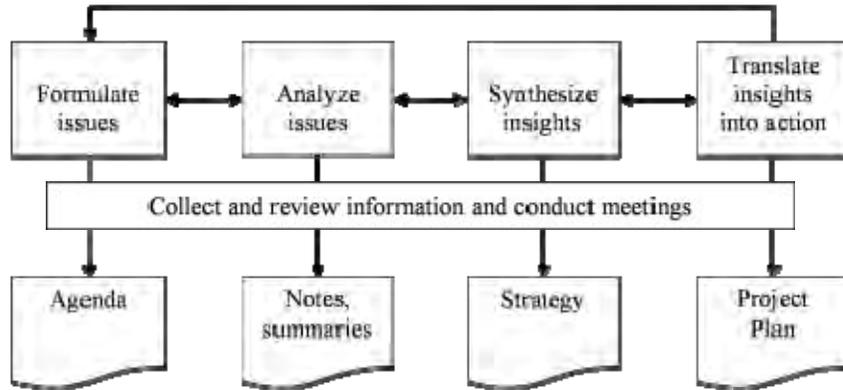
❖ **Communication Processes**

In general, communication between patients and their physicians consists of the process by which a transmitter and a receiver of messages interact in a defined social context (Bennett, 1976). The information exchange consists of communication that includes the transmission, acquisition and transformation of information (Cegala, 1996). The communication between a patient and his/her physician consists of instrumental elements (giving directives, seeking clarification, asking questions, providing information, advising, etc.) and of emotional elements (social behaviour, agreement/disagreement, paraphrase, checking understanding, attention, empathy, reassurance, etc.) (Bensing, 1992; Roter, 1993). Certain authors refer to relational communication, which is a type of communication that includes the establishment of a rapport and a demonstration of emotional support (Cegala, 1996). However, the concept of communication, taken in isolation, does not presuppose that a decision making process is occurring or is going to occur. This is in line with the results of a systematic review of the literature on personalized risk communication in the context of screening tests (Edwards, 2004). Although personalized risk communication was shown to be positively associated with the

uptake of screening tests, there was no evidence that this increase was related to informed decision making by consumers.

❖ **FAST Process for Critical Reflection**

Belkora recently elaborated the CPRS model, anchoring it in more general and portable theories and processes. The FAST process (www.fastprocess.org; (Belkora, 2009) consists of iterative steps for Formulating issues (including questions and concerns), Analyzing them, Synthesizing insights, and Translating the insights to actions or reformulations of the initial issues.



The FAST process takes place in the context of gathering information, conducting meetings, and obtaining (if necessary) other forms of support. For example, in medicine, related psychosocial support services may include navigation (e.g. assistance accessing medical services) and emotional support. Each step in the FAST process has associated outputs. The Formulation step should generate an agenda of issues to be discussed. In medicine this may include the patient’s list of questions and concerns. The Analysis step should generate notes or summaries – in medicine these may include physician notes or letters as well as patient or accompanier notes and audio-recordings. The Synthesis step should produce a strategy document, which in medicine might be a multi-disciplinary treatment plan. And the Translate step should produce a project plan, which in medicine might include a treatment plan, a nursing care plan, or a survivorship plan.

The FAST process and its structured sub-processes have served as the foundation for a decision and communication aiding demonstration project at the University of California, San Francisco (UCSF) Breast Care Center (Belkora et al., 2008; Belkora et al., 2009; Belkora et al., 2010b). Funded in part by the Foundation for Informed Medical Decision Making, the Decision Services unit deploys recent college graduates act as coaches or facilitators of critical reflection. They deliver decision aids to patients, and administer question-listing, audio-recording, and note-taking interventions. Systematic reviews previously showed that decision aids are associated with increased patient knowledge (Stacey et al., 2011), question-listing is associated with increased question-asking (Kinnersley et al., 2008; Kinnersley et al., 2007), and consultation recordings and summaries are associated with increased information recall (Pitkethly et al., 2008). Decision Services is the first sustained implementation that combines these interventions.

**APPENDIX II:
ORIGINAL CHAPTER F**

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Original Rationale/Theory

The objective of a patient decision aid is to help patients make a good decision — one that is well-informed, reflects the patients.’ values, and is implemented. To support this goal, guidance and coaching methods may seek to do one or more of the following:

- Improve understanding by providing information, tailoring information, brainstorming and answering questions, and checking understanding;
- Clarify values by facilitating reflection, taking someone through values clarification exercises, and sharing others’ experiences;
- Improve deliberation by anticipating and avoiding common pitfalls (e.g. anchoring, mis-imagining, etc.) that can undermine effective decision-making, and taking someone through the steps of decision making;
- Improve patient - practitioner communication by helping patients prepare questions and concerns, by teaching skills for raising difficult subjects, and by providing a worksheet or list to share with doctor;
- Improve follow-through by helping patients anticipate and overcome barriers to implementing desired options;
- Reduce emotional distress and anxiety; and
- Improve ability to use skills for coping and problem solving.

Avoiding Decision Traps

Patients and practitioners do not naturally follow the axioms of normative decision theory; however, when inconsistencies are highlighted, many willingly change their choices to be more aligned with the principles. Thus, explicit guidance in the steps of deliberation is often beneficial to help overcome some of common decision-making traps.

Quality of Patient-Provider Communication

Open communication is essential for shared decision making. However, many studies have documented that, the quality of communication between patients and providers is poor. Good communication and strong patient-provider relationships have been linked to greater satisfaction and positive health outcomes. Poor communication, conversely, has been linked to dissatisfaction,

conflict, and worse outcomes. Patients and practitioners may benefit from guidance in more open communication.

Ways of Learning

Patients learn in different ways. Many patients prefer and find it more effective to learn from others as opposed to a book, video or pamphlet. Many researchers argue that learning and skill acquisition does not happen when individuals simply receive factual information but happens most effectively by actually engaging in the process, often with support of a mentor or coach.

Emotional Distress

A new diagnosis can cause significant distress and anxiety, and can disrupt coping and problem solving skills. Coaching or counselling that can help patients reduce this emotional distress. Furthermore, anxiety may increase patients' desire and capability to participate effectively in decision making.

There is no single theory or method that has been used consistently or evaluated extensively to address all of these goals. Theories of decision making often do not address emotional or communication needs. Likewise, theories of communication, coping, and self-efficacy do not address issues of decision making under risk and uncertainty. Most guidance/coaching with patient decision aids has a limited focus – for example in, either enhancing understanding of information or clarifying values. There are very few data on the relative impact of the different methods on the quality of decisions, and thus limited evidence to support or refute any of the different theories for using guidance or coaching methods in patient decision aids.

Original Evidence

RCTs Involving Patients Facing Actual Choices

Of the 29 individual patient decision aids evaluated in the 34 RCTs included in the Cochrane Review, 19 were available for review of their content (O'Connor et al., 2003). Of these, 17 (89%) patient decision aids contained some sort of guidance/coaching in deliberation and/or communication. The amount of guidance varied considerably:

- 4 patient decision aids with a worksheet only were evaluated in 9 trials (Barry et al., 1997; Bernstein et al., 1998; Holmes-Rovner et al., 1999; Kennedy et al., 2002; Murray et al., 2001a; 2001b; Morgan et al., 2000; O'Connor et al., 1998; O'Connor et al., 1999; Rothert et al., 1997)
- 5 patient decision aids with a list of the steps of decision making and a worksheet were evaluated in 5 trials (Dodin et al., 2001; Goel et al., 2001; Man-son-Hing et al., 1999; McBride 2002; Rostom et al., 2002)
- 2 patient decision aids with a worksheet plus coaching were evaluated in 3 trials (Kennedy et al., 2002; Rothert et al., 1997; Holmes-Rovner et al., 1999)
- 6 patient decision aids with coaching only were evaluated in 7 trials (Davison et al., 1999; Davison et al., 1997; Dolan et al., 2002; Green et al., 2001; Holmes-Rovner et al., 1999; Lerman et al., 1997; Rothert et al., 1997).

The Cochrane Review found that more complex patient decision aids produced higher gains in knowledge, more realistic expectations, and a greater match between patients' values and choice. One trial found that patients in the study arm involving a patient decision aid plus coaching by a nurse had fewer hysterectomies and incurred lower costs than either of the other two study arms (patient decision aid only and control) (Kennedy et al. 2002). For the most part, the trials of patient decision aids do not compare varying intensities of coaching/guidance, and therefore the relative effectiveness of these methods is not clear.

Other Evaluative Studies

Many studies have documented poor quality of communication during medical consultations (Braddock et al., 1999; Marvel, Epstein et al. 1999). Examples of poor communication include: a) physicians tend to dominate the discussion and patients tend to withdraw; b) the focus is on medical facts, not thoughts or feelings; and c) the traditional medical interview that gets documented with the SOAP note does not leave room for shared decision making (Donnelley, 1992; Lipkin et al., 1995; Singer, 1992). A systematic review of RCTs found that the quality of patient-physician communication influences health outcomes such as emotional status, symptom resolution, functional and physiologic status, and pain (Stewart, 1995). Some of the characteristics of quality communication included engaging patient in discussion of problem, encouraging questions and participation in decision-making about management, and discussion of emotions and feelings. Interventions designed to increase these behaviours have been shown to positively affect outcomes (Greenfield et al., 1985; 1988). Without good communication, patients tend to become dissatisfied and disenroll from health plans (Davies et al., 1986), to change physicians (Kasteler et al., 1976; Kaplan et al., 1996), to initiate complaints against physicians (Roter, 1977), and to be non-compliant with medical recommendations (Korsch et al., 1968; Francis et al., 1969).

However, interventions that focus only on patients (such as many patient decision aids) or only on physicians (Keller & Carroll, 1994; Joos et al., 1996; Fallowfield et al., 1998) may have limited impact. Studies that engage both patients and physicians may have the biggest impact (Brown et al., 1999; Sepucha et al., 2000).

A review of psychosocial interventions in cancer care found that different psychosocial interventions (including education, behavior training, coping techniques and group support) may positively affect psychosocial outcomes, and increase participation in decision making (Fawzy et al., 1995).

Other Relevant Literature

The adult learning literature, as well as theories in organizational behavior and management science, suggests that learning is a social process, not merely the receipt of knowledge. Patients are more apt to learn when messages and information are targeted or tailored to their situation, their needs, and their concerns (Knowles, 1990; Knowles et al., 1998; Krueter & Ricardo, 2003). In addition, patients may be more apt to learn when helped by others, and when actually engaged in actions. (Argyris & Schon, 1978; Argyris et al., 1985; Bandura, 1982; Knowles et al., 1998; Lave & Wenger, 1991; Lewin, 1952).

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ORIGINAL APPENDIX I: DETAILED CONCEPTS

Theories – Specific Types

a) *Normative Decision Theory* (i.e. expected utility theory or subjective expected utility theory) posits a set of axioms to which decision makers should subscribe, in order to ensure that their actions are most likely to generate the results they desire (Fishburn, 1988; Howard & Matheson 1989).

b) *Psychological Decision Theory* attempts to explain the cognitive pitfalls that can lead to decisions that violate one or more of the axioms of rationality. One pitfall involves the heuristics commonly used by patients when they make judgements about events (Kahneman & Tversky, 2000; Redelmeier et al., 1993; Russo & Schoemaker, 1989; Tversky & Kahneman, 1981). Another pitfall involves the preference reversal phenomenon, which is a fairly pervasive inconsistency in patients' choices under uncertainty. The preference reversal phenomenon is explained by Prospect Theory (perhaps the most commonly-cited psychological decision theory), which argues that these

inconsistencies depend on whether the options in a choice situation are framed in terms of the prospect of relative gains or relative losses.

c) *Decisional Conflict Theory*: Although the majority of behavioral decision theory highlights how often patients stray from the normative ideals, Decisional Conflict Theory took a slightly different approach by trying to define those conditions under which decision makers seem to follow a more vigilant process. Janis and Mann (Janis & Mann, 1977) studied emergency decision making, and found that decision makers tended to be more vigilant when they (a) realized a threat if they stay with the status quo, (b) realized a threat if they changed to the first alternative, (c) hoped that they could find some better options, and (d) believed that they have sufficient time to search and deliberate. This means that there needs to be some anxiety or conflict in order to motivate patients to deliberate, but not too much, or else it will interfere with cognitive processing. Anis and Mann also developed some interventions designed to promote vigilance and improve the quality of decisions. Some patient decision aids incorporate these techniques (e.g. balance sheet exercise).

Methods – Specific Types

a) *Health Coaching*: Greenfield, Kaplan, and colleagues (1985; 1988) pioneered the concept of health coaching. In their model, the coach's goals are to encourage patients during their clinic visit with their practitioner to: (1) ask questions, (2) recognize relevant medical decisions, and (3) negotiate these decisions with their provider. In addition, techniques were taught to have patients overcome potential barriers in discussions with their provider such as embarrassment, fear of appearing foolish, forgetting to bring up an issue, and intimidation by the provider. In several controlled trials of patients with different conditions (such as diabetes, hypertension, and cancer), they found that patients who underwent an intervention to better understand their medical condition and were coached to better talk with their provider were more active in the conversation with their provider, more assertive during these conversations, and elicited twice the number of factual statements from their provider. Patients in the intervention group also expressed a significantly stronger desire to participate in the medical decision making process.

b) *Consultation Planning and Recording*: Sepucha, Belkora and colleagues developed and evaluated a series of interventions designed to facilitate deliberation and improve communication in medical consultations concerning decisions about treatment of breast cancer. The interventions (called Consultation Planning (CP) and Consultation Recording (CR)) are based in three disciplines: decision analysis, action research, and action science. They use a trained facilitator to elicit and structure a patient's questions and concerns (in CP), to share them with the practitioner, and then to use them as an agenda to guide the consultation, which is also facilitated and recorded (in CR). A notable aspect of these decision support methods is that the focus is not on information provision; instead, the goals are to uncover, order, and prioritize the understanding of patients and practitioners, to promote more open communication, and to facilitate a consensus that addresses the patient's values and needs. Two small controlled trials suggest that these methods significantly increase the quality of communication, the quality of decisions, and both patient and practitioner satisfaction with the process. (Sepucha et al. 2000; 2002) A large, multi-site randomized trial will evaluate CP/CR with or without shared decision making videos (developed by the Foundation for Informed Medical Decision Making), to explore the relative impact of information-focused and communication-focused support for patients with breast cancer.

c) *The “E4” Model* rejects paternalistic and consumer-driven roles for physicians, and embraces the interpretive and deliberative visions of how patients and physicians should interact (Keller & Carroll, 1994). Further, this model encourages physicians to engage the patient, empathize with the patient, educate the patient, and enlist the patient. Keller and Carroll prescribe a specific class of interpretive and deliberative responses and run workshops to teach empathic communications to physicians (Platte & Keller, 1994). Physicians find these workshops useful; however, there is no evidence that their intervention improves the quality of communication in consultations with patients, or improves the quality of the patient-physician relationship.