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Actively Engaging with Patients in Decision-Making

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OBJECTIVES

- Appreciate the history and evolution of medical decision-making models in health care
- Understand the psychological processes genetic counseling patients utilize for decision-making
- Describe decision-making challenges that are particular to the genetic counseling encounter
- Recognize barriers to informed decision-making that create decisional conflict or discord
- Define and apply the shared decision making (SDM) model to the genetic counseling encounter
- Apply specific techniques and approaches to effectively facilitate SDM

A Brief History of the Medical Encounter: From Paternalism to Shared Decision-Making

In the history of modern medicine, there has been a measurable shift from the beneficence model, in which the health care provider is deferred to as the expert, to the autonomy model, which recognizes the value and importance of increased patient involvement in decision-making (Will 2011). The genetic counseling profession has prioritized patients' autonomy and psychosocial needs from its outset (Weil 2003). The shift in the profession's history has been from a primarily information-giving (educative) role to one that actively incorporates psychotherapeutic methods to help facilitate adaptation to the genetic condition, risk and the process of informed decision-making (Shugar 2017).

Genetic counseling patients are often called upon to make complex choices under less than ideal circumstances. These challenging circumstances may include time constraints, presenting health concerns in themselves, their pregnancy or their child, uncertainty of outcomes, emotional and psychological strain, and complex medical information to decode. Research has shown that patients frequently make

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decisions in binary, not probabilistic terms (i.e. the perception that an outcome either will or will not happen) (Lippman-Hand and Fraser 1979). Moreover, patients rarely rely solely on quantitative data regarding risk and occurrence (Pierce 1993). A purely probabilistic approach fails to convey the nuance of the value – "what life would be like" – given a decision. Instead, patients consider the complex, social and emotional consequences – the meaning of the decision over time (Beeson and Golbus 1985; Kessler 1989). Genetic decisions are especially challenging because both probabilities and values, and their complex interplay, are difficult to conceptualize.

The expertise that genetic counselors bring to their patients is built on their observations of the processes and outcomes of diverse individuals making difficult and complex decisions. This expertise empowers the genetic counselor to share information and interact in a way that allows the patient to imagine alternative scenarios, and thus "enhance self-determination, promote autonomy, and therefore advance beneficence" (Suter 1998, p. 163). Hence, genetic counselors play a key role in facilitating decision-making. They must be able to skillfully accomplish several tasks, including assessing the patient's readiness to make a decision, identifying potential barriers to decision-making, and empowering patients to make a choice that is informed and aligned with their own values, beliefs, and preferences.

Medical decision-making models exist on a spectrum from physician-centric to patient-centric. At one end, the beneficence ("clinician as agent") model presumes that health care providers know what is best for the patient and relies on their judgment alone to decide what choice should be made (Charles et al. 1997; Will 2011). At the other end, the "informed" model purports that information empowers the patient to become an autonomous decision-maker. At its extreme, the informed model restricts the health care provider's role to providing the factual or scientific information patients need for making a decision. The informed model promotes non-directiveness as the "central ethos" of medical decision-making and excludes the health care provider from influencing decision-making beyond providing information. Non-directiveness in genetic counseling is aptly argued by Weil to be an "historic relic" and offers at most a narrow and limiting approach to helping patients. Rather, he suggests we "bring the psychosocial component into every aspect of work" (Weil 2003, p. 207). While both the beneficence and informed models of decision-making share the value of the patient's best interest first and foremost, neither involves a shared approach to decision-making.

The SDM model represents an ideal compromise between these two polar approaches. SDM can be broadly defined as "a process in which clinicians and patients work together to clarify treatment, management or self-management support goals, sharing information about options and preferred outcomes with the aim of reaching mutual agreement on the best course of action" (Coulter and Collins 2011, p. 2). In the context of genetic counseling SDM has been defined as "a collaborative approach in which clinicians educate, support, and guide patients as they make informed, value-congruent decisions" (Birch et al. 2019, p. 40).

Psychological Aspects of Decision-Making

Numerous psychological theories of decision-making have been developed to understand and predict human decision-making. Rational (evidenced-based) theories can be broadly categorized as normative vs. descriptive.

Simply put, normative theory addresses how people "should" or "ought to" make decisions if they were to use purely rational, calculated thought to achieve an optimal course of action.

Normative decision theory uses rational consideration (such as mathematical calculation and objective data) to maximize the utility of a course of action. Practically, this theory is most readily applied in developing methodological approaches for problem solving in "context-poor" circumstances, such as policy-decision-making. In contrast, descriptive theory takes into account how people actually make decisions. Nuanced influences (e.g. the situational context, the environment, the characteristics of the decision) are considered as factors impacting decision- making. The descriptive approach may be more useful in understanding decision-making in "context-rich" circumstances, where the rationality is informed not just by numbers and data, but by "human cognitive architecture and driven by intuition and emotions such as the aim to minimize regret" (Djulbegovic and Elqayam 2017, p. 915).

The practice of decision-making exemplifies a spectrum from the straightforward to the complex, associated in large part with the degree of uncertainty involved in the assurance and interpretation of the outcome (Croskerry 2002). The nature of this broad process is illustrated by a continuum of patient choices based on a rational, data-driven approach versus an approach that is instinctive and irrational (Broadstock and Michie 2000).

How do people make decisions? Simply described, people who make truly informed decisions summon both their minds (thinking) and their hearts (feeling). The "thinking" part of decision-making is coined in psychology as the analytic process**.** An analytic process suggests our choices are made by a rational process that assesses the pros and cons of various options to maximize a desired outcome. This highly rational process takes facts and probability into account but does not consider the *contextual* aspects of the decision to be made, such as patient-specific circumstances, values and emotions (Ubel and Lowenstein 1997).

The "feeling" part of decision-making is coined in psychology as the automatic process**.** An automatic process suggests decisions are made instinctively, relying on gut feelings grounded in heuristics to reach a desired outcome (Griffin et al. 2001). Relying on feelings and conclusions based on personal experiences and observations does not necessarily objectively weigh the true risks and benefits of one's options.

For the purposes of this chapter, we will present two relevant and applicable concepts that are often in play when patients make complex decisions: heuristics, and fuzzy trace theory. It is important for the genetic counselor to recognize these psychological and cognitive phenomena in their patients and in themselves, in order to limit bias and identify barriers to decision-making.

Patients' Use of Heuristics to Make Decisions

What Are Heuristics?

Research has demonstrated that patients instinctively use "rules of thumb" to simplify risk estimates and take cognitive "short cuts" known as heuristics, when processing information for decision-making (Tversky and Kahneman 1974). Heuristics involve biases derived from personal experiences, which may unintentionally affect choice (McDonald 1996).

Research investigating the use of heuristics specifically in interpreting and applying genetic information reveals that their use is quite prevalent, both among the lay population and among genetic counselors (Dewhurst et al. 2007). Cognitive research demonstrates that individuals employ heuristics when there is more information available than is possible to absorb and assimilate. Decision-making can therefore be hindered by the stress and confusion of information overload. As such, heuristics help to reduce chronic information overload in order to consider multiple options. Similarly, the language used to frame options relevant to a decision may prompt a short cut and subsequently influence decision-making.

For example, the wording used to describe an option may evoke an image or emotion that overrides the outcome likelihood and thereby influences decision-making. This appears to be especially true in situations that involve uncertainty, inconsistency and incomplete information (Tversky and Kahneman 1981).

There are dozens of decision-making and behavioral heuristics, including:

- ***Framing*** heuristics imply that patients are more sensitive to loss than to gain. The patient would risk more to avoid loss (death) than to achieve equal gain (survival). *Example: Patients will often choose a medication with severe side effects if it will save their life, but many people do not engage in cancer screening protocols that could increase the chance of living longer.*
- ***Availability*** heuristics refer to biases whereby the patient overestimates the likelihood of the most dramatic outcome (likelihood of developing a rare disease) and underestimates a more typical outcome (likelihood of developing a common disease). Outcomes that are easily retrievable from memory or that can be vividly imagined are more likely to be chosen than those for which only a vague image exists. *Example: A patient wants prenatal testing for Prader-Willi syndrome because a neighbor has an affected child, but she declines a flu vaccine for her three-year-old child in day care.*
- ***Representativeness*** heuristics rely on stereotypes, in particular, *Like follows like*. This rule of thumb may contribute to individuals making a decision using subjective judgments. *Example: A patient believes that he will develop Huntington disease because he resembles his affected father and because neither of them completed high school.*
- ***Ambiguity effect*** heuristics consist of the avoidance of options for which there is incomplete information. *Example: A patient decides not to have prenatal screening because it cannot give her a definite answer.*
- ***Confirmation bias*** is the tendency to seek or interpret information that supports a preconceived idea. *Example: A patient reports that she has two friends who each had a baby when they were past 40 years of age and, since those babies are fine, her baby will be fine, too.*
- ***Omission bias*** is the tendency to judge harmful action (commission) as worse than equally harmful inaction (omission). *Example: A patient will not have testing for colon cancer despite a strong family history because he believes he will lose his ability to purchase life insurance.*
- ***Outcome bias*** is the tendency to judge a decision by its eventual result instead of the quality of the decision at the time it was made. *Example: A patient regrets having testing for the breast cancer gene despite a strong family history because the test result detects a variant of unknown significance.*
- ***Optimistic bias*** is the tendency for the average person to believe she or he is at less than average risk. *Example: A patient believes that because she is healthy and her family history is negative for birth defects, she is not at increased reproductive risk despite being 43 years old at delivery.*

Why Are Heuristics Important to Understand?

While the use of heuristics is a natural psychological process that helps patients and clinicians make complex decisions, it can also lead to decisional bias. In a study by Brown et al. (2017) looking at how BrCa 1 and 2 gene carriers decide on risk-reducing mastectomy, it was found that patients rely on the "use emotion as a heuristic" (p. 9) in decision-making. The authors aptly suggested that "the inescapable emotionality of a patient's decision does not mean that it cannot be respected as valid. The corollary is that patients need to be supported to make, or review, these decisions in ways that meet normative expectations while being consistent with the reality of the psychological processes involved in decision-making" (p. 11). Notably,

both the patient and the genetic counselor may be using heuristics. It is therefore essential that genetic counselors are aware of the potential influence of heuristics on their patients' and on their own decision-making process and actively explore the thinking behind this process. The genetic counselor's role is not to resist or replace heuristic reasoning, but rather to "ensure that patients have considered the range of options and consequences and how they would be affected by these" (Brown et al. 2017, p. 10).

Patients Recall Information Differently: Fuzzy Trace Theory

In addition to the influence of heuristics, the manner in which patients remember and process information provided by genetic counselors can influence decision-making. Reyna and Brainerd (1998) describe fuzzy-trace theory, a dual process theory for recall that is impacted by a number of factors including developmental life stages (e.g. childhood vs adulthood). At its essence, fuzzy-trace theory refers to distinct processes of recall: gist and verbatim. In gist traces, individuals understand and recall an overarching, intuitive or unconscious representation of a past event (e.g. presented information), or the bottom line. In verbatim traces, individuals access a more precise, logical understanding.

Reyna's (2008) research indicates that adults are more likely to rely on the gist of information (its bottom-line meaning) rather than on the verbatim details when judging risk or making a decision. Thus, precise information about risk is not useful if patients cannot ascribe meaning or context to this risk. She proposes that health care providers use an integrated, comprehensive intervention that includes information formatting, providing information retrieval prompts and reducing confusion in information processing to promote decisions that lead to better health outcomes. One such innovative intervention, a Web-based "intelligent tutor" called BRCA Gist, was created to support the provision of information and subsequent decision-making around genetic testing for breast cancer. This intervention is grounded in fuzzy trace theory and is intended to increase gist knowledge and comprehension by presenting information that is most meaningful for decision-making along with visual aids that convey "the bottom-line gist meaning of core concepts" (Wolfe et al. 2015, p. 48).

Biesecker et al. (2017) suggest that fuzzy trace theory is relevant to decision-making in the genetic counseling context as individuals who can incorporate the gist of the information might make decisions with greater confidence and less decisional regret. Furthermore, a recent study by Gornick et al. (2019) illustrates how gist memory can impact understanding of medical terminology, even those terms thought to represent plain language. In their study, gist understanding was thought to underlie the ascription of additional meaning to the term "actionable" by lay participants. These findings have clear implications for decision-making, both the potential for miscommunication based on medical jargon and a patient's processing approach. Gornick et al. (2019) recommended that health care providers explain "what they mean" in order to reduce the potential for negative impact on decision-making.

Why is Fuzzy Trace Theory Important?

A major component of a genetic counselor's role in the clinical setting is communicating risk to their patients. Patients rely on genetic counselors to put their risk into context and help them give it meaning to ensure they have an accurate representation. Understanding the mental processes that impact risk perception (and in turn, decision-making), reinforces the need for genetic counselors to present genetic information in multiple formats and attribute meaning to risk.

Informed Decision-Making

Heuristics and fuzzy trace theory refer to the ways in which individuals process information. It is also known that being informed with relevant knowledge increases decisional satisfaction and emotional well-being and lowers decisional conflict (Baker et al. 2018). Genetic counselors typically determine the key informational components deemed important for informed decision- making even when demonstrating flexibility in meeting the patient's information preferences. Informational decision aids (discussed below) may complement the direct provision of information in an effort to support decision-making that is informed, deliberated and consistent with a patient's personal values and preferences.

Decisions in Genetic Counseling – What Makes Them Unique?

Discussion and even frank debate surrounding genetic exceptionalism in health care has abounded since the early 1990s, especially as related to genetic testing and/or genetic information (Witt and Witt 2016). While the relevance or lack thereof of such debate could be viewed as somewhat tangential to this chapter, there is merit in considering if and how decision- making surrounding genetic issues aligns with or differs from decision-making in other areas of health care. Importantly, such exploration allows genetic counselors to integrate research on decision-making undertaken in other areas of health care (Smets et al. 2007).

Several facets of genomic medicine are sufficiently unique as to be routinely integrated into genetic/genomic counseling regarding decision-making, while others may be intrinsic to other areas of health care. One of the most salient and distinguishing features of genetic testing is the potential impact of genetic test results on family members and occasionally, on communities. Apropos of this feature, Ross (2001) notes "What makes modern genetics exceptional, then, is that it forces us to realize that we are not isolated individuals, but members of communities" (p. 142). In other areas of health care, family members may be invited to participate in the discussion and decision-making about diagnoses and treatment approaches, and they may well be impacted by emotional and other sequelae, but the focus remains on the primary patient. Genetic counselors routinely engage patients in considering issues relevant to family members when discussing genetic testing including with whom and how results might be shared, anticipating potential responses and impact on family dynamics, and downstream implications (e.g. risks) for family members (Emery 2001). While such situations may arise in other areas of health care (e.g. cardiac work up for arrhythmia syndromes, ocular work up for retinitis pigmentosa), anecdotally, they are rarely explored by non-genetics health care providers.

Genetic counselors facilitate complex and nuanced decision-making related to prenatal diagnostic screening/testing and predictive pre-symptomatic testing. Non-genetic health care providers including obstetricians, midwives, and family physicians similarly address such issues both within and outside of genetic testing contexts (e.g. abnormal prenatal screening, predictive nature of cholesterol testing); however, there is likely less focus on pre-test discussion of potential testing outcomes and how these might factor into individual decision-making. Other issues that genetic counselors often raise regarding genetic testing include the duration of DNA storage, and the potential for reclassification of test results and reanalysis. These latter issues are unlikely to present in other areas of health care as routinely as they arise in genetics and may impact decision-making. Genetic counselors not only prompt their patients to consider the implications of their decisions for family members, they also sensitively and expertly support the decision-making process (Smets et al. 2007).

The combination of uncertainty, the probabilistic nature of risk assessments and genetic test results, and the option of learning about secondary findings contribute to the complexity of decision-making about genetic testing (Witt and Witt 2016). Test results that pertain to screening (e.g. carrier, newborn screening) and those arising as secondary findings may be particularly challenging for individuals to process and incorporate into decision-making, especially when pertaining to conditions outside of their frame of reference (LeRoy 2004). As well, the timing of genetic testing in the diagnostic odyssey may influence decision-making, especially regarding genetic testing options (e.g. parents of babies in the neonatal intensive care unit may be less likely to opt for secondary findings during diagnostic testing than would parents of older children) (Smith et al. 2018). Again, other areas of health care include similar issues (e.g. lesions unrelated to the primary indication for diagnostic imaging, cardiac risk assessments based on lipid profiles); however, "genomic technologies introduce uncertainties of unique scales and types" (Han et al. 2017, p. 918) as well as layers of optionality. When recommending a radiologic examination, for example, health care providers typically do not advise in advance about the possibility of incidental findings and then ask whether the patient still wishes to pursue the investigation.

Many additional factors that are not unique to the genetics setting are highly relevant to decision-making and explored during genetic counseling. These include, but are not limited to, cultural attributes, financial challenges, social support networks, geographic location (e.g. urban vs rural), and health literacy and numeracy.

Behavioral Economics and Decision-Making

Drawing from existing fields of study on decision-making, behavioral economics provides insights that can inform genetic counseling practice. Behavioral economics studies the "forces and principles of decision-making behaviors" primarily as they impact the economic landscape (Moore et al. 2018, p. 242). Blumenthal-Barby et al. (2015) note that information provision is not necessarily correlated with its rational utilization. They caution that neglecting lessons gleaned from behavioral economics could lead to "the last mile problem" in which huge financial investment in technology development does not lead to improved human behavior and decision-making. Their paper focuses on the relationship between information provision and utilization outcome with attention to cognitive biases including "information-seeking bias, affect bias and impact bias" and how these biases might create obstacles in the effective implementation of genomic testing. Such biases are clearly relevant to the field of genetic counseling. Moreover, the authors propose strategies to address these biases.

Information-Seeking Bias

Simply, information-seeking bias refers to the tendency to seek information even when such information is not meaningful. Blumenthal-Barby et al. (2015) suggest providing patients with information that has clinical utility – not necessarily an easy proposition given the rapidly changing landscape of genomic information.

Affect Bias

Affect bias refers to the overlay of emotion (e.g. fear) on risk perception and subsequent behaviors. Blumenthal-Barby et al. (2015) recommend contextualizing and framing risk information, which resonates well with genetic counseling practice. For instance, genetic counselors often explain risks

in different ways (e.g. presenting both the chance for the problem to occur and the chance for it to not occur) particularly when they perceive that patient anxiety may interfere with information processing. As well, genetic counselors may use primary empathy to address patient emotions and their potential impact on risk perception.

Impact Bias

Impact bias refers to the tendency for individuals to anticipate a more intense emotional response of lengthy duration. This bias then tends to lead to inaccurate predictions of the impact of health conditions or testing outcomes. As an exemplar, Blumenthal-Barby et al. (2015) note the potential motivation to modify lifestyle behaviors following genomic testing that indicates an increased risk for cardiac disease, but patients overestimate the impact of the positive motivation. Thus far, research does not support positive sustained behavioral change following genomic testing. The authors suggest potential motivational approaches to encourage sustained behavioral change.

In a research study, Moore et al. (2018) considered behavioral concepts of relativity, deliberation, and choice architecture to guide relationship building in nursing practice to support complex decision-making in genetics. Relativity refers to understanding the benefits and limitations of relevant options and the related concept of anchoring which refers to the influence of first impressions. Stepping beyond heuristics, deliberation requires thoughtful effort to identify new options within the relevant context. Deliberation addresses the complexity of genomic decision-making and the variability from person to person vis-à-vis background and other factors. Choice architecture refers to the "art of shaping decisions by designing choices within a framework that will encourage a certain choice" (p. 244) while still supporting autonomous decision-making. Intrinsic to the decision-making landscape are decisions made by clinicians in test selection, the actual information provided to patients, and the approach taken in providing information. Such clinical decisions, whether deliberative or intuitive, can influence the patient's decision-making process. Genetic counselors along with other clinicians are reflective. Moore et al. (2018) described the "information asymmetry" between nurses with content expertise and patients with personal context expertise and suggested that behavioral economic approaches can open dialogs which in turn can balance the asymmetry and support genomic decision-making for patients. These concepts have direct relevance to genetic counseling practice.

Binning and Decision-Making

One approach to examining unique factors that may impact decision-making in genetic counseling involves binning general types of decisions. Potential issues unique to genetic counseling can be explored as related to each of these bins, as follows. At a micro level (first bin), one might regard decision-making as beginning at the outset of an interaction during contracting. During this interaction, genetic counselors inquire about patient concerns, perceptions, experiences, etc. Contracting (establishing a mutually agreed upon agenda between the patient/family and the genetic counselor) is often not considered from the perspective of decision-making. However, arguably, by generating trust during contracting and catalyzing a positive feedback loop, patients may consciously and subconsciously decide to share additional key information that impacts the rest of the session (including more significant subsequent decision-making issues).

A second bin involves genetic counselors facilitating decision-making about diagnostic or screening testing for presenting clinical issues and/or clinical care issues (e.g. adhering to surveillance for individuals testing positive for cancer predisposing pathogenic variants). As noted above, layers of complexity may

accompany decision-making regarding whole exome/genome sequencing for diagnostic purposes, where a diagnosis could drive management strategies, but fear about secondary variants could overwhelm patients/family members. Approaches such as choice architecture or motivational interviewing may be integrated into a SDM model in order to frame health-based outcomes (Ash 2017).

A third bin, and perhaps the area that most reflects the need for advanced genetic counseling skills to support decision-making, involves autonomous decision-making. These decisions may involve predictive pre-symptomatic testing, prenatal diagnostic testing, pregnancy management decisions following prenatal test results, options regarding learning about secondary findings along with primary diagnostic variants, among others.

Barriers to Decision-Making, Decisional Conflict, and Discord

The perceived difficulty of any medical decision is subjective and depends on several factors, including the preparedness of the individual making the decision and the complexity of the decision being considered. Challenging decisions tend to involve those with uncertainty regarding diagnosis, risks, and test information. Layering on anticipated or experienced emotional responses adds to the complexity. Difficult decisions may represent choosing a course of action that conflicts with innate values and beliefs (e.g. in the prenatal setting), ends a life plan (e.g. in the NICU), or offers an element of certainty to a situation previously skirted (e.g. predictive testing for Huntington disease). Patients are faced with making decisions based on shifting data that are intellectually challenging, even for those with genetics literacy, along with approximated information of staggering emotional significance. Some decisions are irrevocable and irreversible; others may be reversible. Genetic counselors should be equipped to reconsider information provided and must be comfortable with a changing landscape and lack of certainty in order to best support their patients.

Clinician-Generated Barriers

Genetic counselors themselves can contribute toward impaired patient decision-making. Psychological barriers such as burnout, countertransference reactions, and ethical conflict may interfere with the clinician's engagement, negatively affecting their positive regard or empathy toward the patient. There are also psychological processes that can interfere with patient decision-making. For instance, the way in which the clinician presents the information may influence the final decision in a biased manner (Pierce and Hicks 2001). Although, framing effects can occur consciously and appropriately, where the clinician intentionally presents information in a manner that is likely to influence a decision in a specific way (cf. Blumenthal-Barby et al. 2015), when done unconsciously, framing may be detrimental. Genetic counselors may incorporate value-laden words or labels (stigma) into discussions which can lead to unrealistic fear or reassurance about a choice. They may unintentionally devote more time to discussing a much less likely outcome, inadvertently giving it more significance than it warrants. Even the genetic counselor's general affect (cheerful, anxious, distant) and non-verbal cues can influence a patient's interpretation of the information provided. Genetic counselors must be mindful of the potential of these framing effects, in order to better recognize them and minimize clinician-mediated bias.

Informational Barriers

Information is powerful. In fact, the communication of genetic information has been described by peers as a central therapeutic goal in genetic counseling practice (Austin et al. 2014). Information alone can be

used as a psychosocial tool (use of authority) to alleviate the distress of emotions like guilt, shame or fear (Kessler et al. 1984). Patients may lack crucial genetic or medical information or may have misinformation as barriers to making an informed, value-congruent decision. Genetic counselors have a responsibility to identify and address these barriers with their patients.

Emotional/Psychological Barriers

A patient in an emotionally heightened state (whether it be associated with anger, sadness, guilt, shame or fear), will have difficulty providing and attending to information required to make any decision. Such situations call for immediacy – addressing and exploring the observed distress with the patient, acknowledging and normalizing the feelings. Only when this distress is alleviated, can the genetic counselor transition back to the decision-making process. Patients with apparent mental health diagnoses may require additional support from a mental health professional to make a major decision. In such cases, it may be appropriate to defer the decision until further support can be obtained.

Cultural Barriers

Patients from non-dominant cultures are more likely to receive disparate health care (Smedley et al. 2003). This inequity is likely due to a combination of personal, socioeconomic, and health system factors. In a study looking at cultural challenges, Hawley and Morris (2017) identified several factors contributing to cultural minorities' decreased engagement in SDM. These factors include knowledge gaps about treatment (in part due to language barriers), systemic discrimination leading to lowered trust in health care providers, a culturally embedded belief in a paternalistic relationship with the health care provider, and spiritual/religious beliefs that may supersede their belief in the medical model. These factors, if not acknowledged and addressed, will contribute toward a reluctance to engage in SDM. Efforts should be made to tailor counseling methods to ensure an accurate understanding of risk and benefits. This may include using interpreters, providing resources in the patient's mother tongue language or involving extended family members in the decision-making process.

The genetic counselor can also become an unintentional cultural barrier to SDM. For instance, a discussion of consanguinity may be interpreted as negative judgment of the patient's culture. Asking a patient who has a paternalistic view of medicine to make an autonomous choice may result in intimidation, frustration, or loss of trust. Taking the time to discuss how decision-making can be approached, modifying the decision-making process according to cultural needs, and providing information in a culturally sensitive way with patients will optimize engagement in the SDM process and safeguard cultural comfort.

Applying Shared Decision-Making in the Genetic Counseling Encounter

The approach of SDM has gained traction throughout health care in Western countries and aligns well with patient centered care. In SDM, health care providers engage patients in a dialog to share information relevant to the decision at hand, consider the options, and support patients in the process of making an informed and jointly agreed upon decision (Elwyn et al. 2012). "At its core, SDM is a process in which decisions are made in a collaborative way, where trustworthy information is provided in accessible formats about a set of options, typically in situations where the concerns, personal circumstances, and contexts of patients and their families play a major role in decisions" (Elwyn et al. 2017). The model ultimately supports patient autonomy through a deliberative process; however, the health care provider

has the opportunity to contribute her/his perspective, especially when pertinent to supporting positive health outcomes. As such, the shared decision-making model (SDM) aligns with the revised definition of genetic counseling (Resta et al. 2006). Moreover, given the often multiple, complex and value-laden options presented to patients in the genetics arena, the SDM provides a particularly relevant framework for genetic counselors (Birch et al. 2019; Smets et al. 2007)

Several studies have evaluated the SDM from the perspective of patients and non-genetics health care providers. In the genetic counseling context, Birch et al. (2019) evaluated the extent to which a sample of genetic counselors involve their high-risk pregnant patients in SDM. Notably, the genetic counselor participants had not received specific training in SDM. Their study found that genetic counselor participants scored highest on measures of equipoise (balance of forces or interests), and listing options and explaining pros and cons. The researchers hypothesize that these behaviors are likely reflective of educational background and expertise in communicating complex information and providing options. Participant scores for the remaining elements of SDM range from minimal (e.g. assessing preferred approach to receiving information, and involvement in decision-making) to intermediate (demonstrated infrequently) (e.g. exploring patient expectations, concerns, and understanding). Birch et al. (2019) concluded that while genetic counselors regularly practice a number of SDM behaviors, their practice could be enhanced by integrating formal education on this approach into graduate school curricula.

Full disclosure of information, including limitations, risks, and benefits, and available options, remains key in the SDM. Information is exchanged regarding preferences for management and the possible consequences to and effects on the patient's well-being. Such information is integrated with the expression of values, preferences, beliefs, customs, and traditions. Patients are also likely to become better informed and understand influential factors and confounding circumstances when they are invited to describe their reasoning process (White and Curtis 2006).

While there are variations in the application of the SDM model, they share four common characteristics. Both the clinician and patient are actively involved in: (i) the treatment decision-making process, (ii) sharing of information, (iii) expressing preference for treatment options, and (iv) arriving at a mutually agreeable treatment decision (Charles et al. 1999). Birch et al. 2019 asserted that genetic counseling "provides a natural context for SDM because there are often multiple options for patients to choose from, each with complex pros and cons, but with no clear choice that is clinically the 'best' for all patients in all situations. Further, genetic-related decisions are frequently very much value-based and preference-driven" (p. 41). While there are many iterations and interpretations of the SDM model, we present two in this chapter that are highly applicable to the genetic counseling process.

Three Talk Model The "Three Talk Model," proposed by Elwyn et al. (2017) rests upon the deliberative process and involves three stages (modified following a rigorous consultative process): (i) introducing choice, (ii) presenting options, and (iii) supporting decision-making. The elements of the revised model are briefly described below and illustrated in Figure 3.1. The Three Talk Model is not a prescriptive approach; genetic counselors should continue to solicit and attend to the patient's values, beliefs, and other factors. Patients may require time to consider the options and to discuss with trusted family members and others on their path to making a decision and therefore, more than one meeting may be indicated. As well, decision support aids can be valuable resources for supporting the decision-making process.

- Team talk: In the first step, "*team talk,*" the genetic counselor establishes and provides support through the process of discussing the available choices. The patient is encouraged to articulate her/his goals to

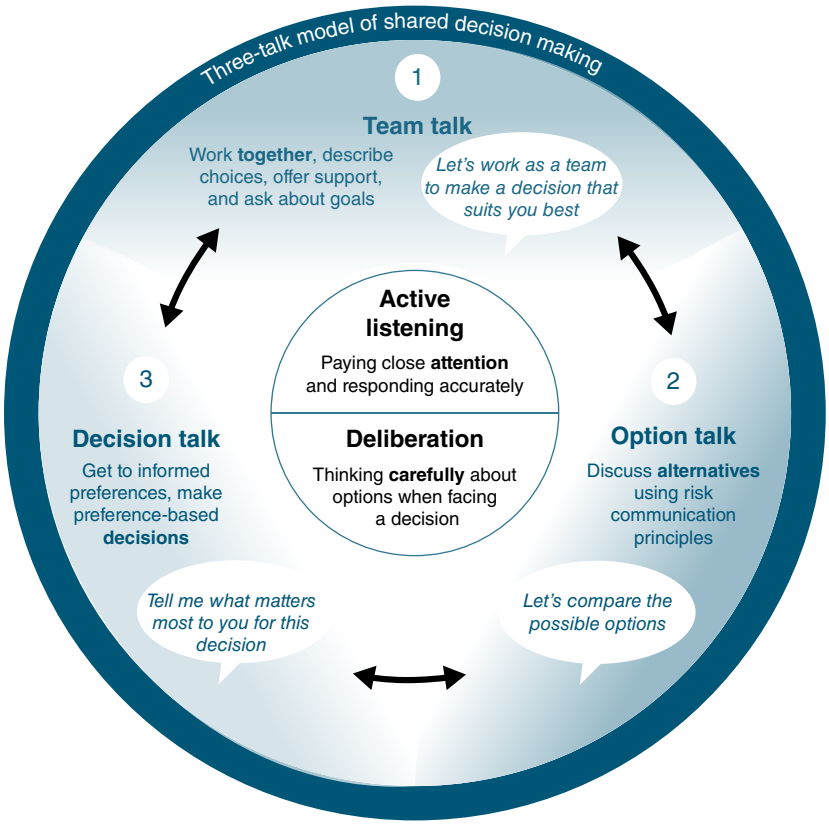

Figure 3.1 Three talk model of shared decision making. *Source:* Reprinted with permission from John Wiley & Sons.

begin to guide decision-making. Elements from the previous model iteration that can provide additional structure for this step include: indicating that individuals perceive options and outcomes differently and that existing uncertainty contributes to the challenges in decision-making; recognizing that decision-making is a complex process that relies upon many factors beyond the factual information; and checking in with the patient to assess emotional response and encouraging the dialog.

- Option Talk: Step two, *"option talk,"* involves comparing testing/management options including potential benefits and limitations and incorporating risk communication strategies. As per the previous iteration of Elwyn et al.'s (2017) decision-making model, the genetic counselor should gauge knowledge and understanding of options. Decision aids may be helpful in this process. The genetic counselor explores the patient's preferences, reviews and "checks in" for comprehension and emotional responses. Validation of the complexity and emotional investment can be helpful in supporting the patient through this process.
- Decision Talk: In step three, "*decision talk,*" with ongoing support and input from the genetic counselor, the patient chooses an option based on her/his personal preference. In the dialog, the patient may be asked about her/his preferences and perceptions of the options and to anticipate outcomes. This may

provide clarity for the patient and provide insight for the genetic counselor. If the patient is not ready to make a decision, the genetic counselor may offer additional time and opportunity to revisit. Certainly, in some situations, not making a decision remains an option. As noted by Elwyn et al. (2017), this model represents "a simplification of a complex, iterative, dynamic and often recursive process" (p. 217). Nevertheless, it is still a valuable framework within which to approach SDM in the clinic.

Integrative Model

The "Integrative Model" proposed by Makoul and Clayman (2006) clearly describes elements and qualities of SDM and can be readily applied to the genetic counseling process. In this model, the clinician brings to the table a spirit of mutual respect, flexibility/individualized approach, finding a middle ground, partnership, two-way information exchange, and reciprocal deliberation/negotiation. The specific elements presented in the integrative model offer a practical and straightforward framework for early-career and experienced genetic counselors alike to engage effectively with patients in SDM (Table 3.1).

These elements can be viewed by the genetic counselor as the "micro-skills" employed in effective SDM. These micro-skills are not necessarily performed in a linear order. Rather the genetic counselor should employ and repeat them dynamically and responsively, according to each encounter's and patient's needs.

Limitations of Shared Decision-Making Models

As with any theoretical construct, SDM models have their limitations. Feudtner et al. (2018) argue that the current SDM model oversimplifies the decision-making process, insomuch as it implies that situations involve a single problem with several potential solutions. They refer to this as a "one-to-many" SDM model (p. S134) and suggest that a many-to-many SDM model (that accounts for several problems requiring different possible solutions) is a more balanced depiction of decision-making experienced by patients and their families. They also point out that decision-making represents a continuum with relevant decisions being made both in advance of and downstream from the presenting problem.

Table 3.1 Integrative model of shared decision making.

Elements of SDM[a]
Define/explain problem
Define roles (desire for involvement)
Present unbiased options and evidence
Discuss pros/cons (benefits/risks/costs)
Actively explore patient values/preferences
Discuss patient ability/self-efficacy
Clinician knowledge/recommendations
Check/clarify understanding
Make or explicitly defer decision as a mutual agreement
Arrange follow-up

[a] Adapted from Makoul and Clayman (2006).

Another limitation in many SDM models is the absence of reference to specific psychosocial skills to address patients who present with psychosocial complexity. A recent analysis of SDM models by Pavlo et al. (2019) addresses this deficiency in SDM models in the context of working with patients with serious mental illness. They argue that SDM neglects "what may be the most important, and transformative aspect of SDM – the relationship [between the patient and health care provider] itself" (p. 333). They propose a Relational Model of SDM, and suggest that elements of empathy, support, trust and respect are as fundamental and central as the sharing of information to the success of SDM encounters.

In the context of genetic counseling, psychosocial complexity has been defined as "the patient-specific social, emotional and psychological barriers that interfere with the usual process of genetic counseling" (Shugar 2017, p. 217). Patients and families receiving genetic counseling are often faced with treatment options while under extreme emotional or psychological strain. It is essential that genetic counselors utilize the necessary psychosocial tools (such as primary empathy, immediacy, and challenging observed discrepancies, and normalizing) to achieve optimal genetic counseling goals and outcomes. One of the major tasks of genetic counseling is to promote adaptation to risk, the genetic condition and the process of informed decision-making (Shugar 2017). Thus, genetic counselors must remember the importance of assessing and responding to a patient's level of psychosocial adaptation accordingly throughout the process of SDM.

Both the Three Talk and integrative SDM models allow genetic counselors to visualize and apply SDM in a complementary way. The discrete micro-skills in the integrative model can be applied to and repeated in the different stages of the Three Talk model. Mentally merging these models ensures the genetic counselor is considering both the "big picture" and the specific tasks of the SDM process. Selected genetic counseling approaches and techniques relevant to these SDM models are presented in Table 3.2.

Tailoring SDM to Culture Family Structure and Special Populations

Shared decision-making relies upon effective dialog between the health care provider and the patient. The world view and expectations of specific cultures, family structures, and special populations can impact not only the dialog but also the decision-making process in genetic counseling. Genetic counselors should be aware of the potential for these influences, to avoid a breakdown of the counseling relationship.

Genetic counselors strive to approach patients and their families with cultural sensitivity in all aspects of their interactions. Cultural awareness and sensitivity as relevant to genetic counseling are addressed in a more fulsome manner in Chapters 11 and 12 of this text. Beyond consideration of race, ethnicity, and apparent cultural attributes, culture can be defined as "a pattern of learned beliefs, values, and behavior that are shared within a group; it includes language, styles of communication, practices, customs, and views on relationships" (Betancourt 2004, p. 953). Culture influences how individuals interpret life events (Perkins 2008), and includes attributes such as socioeconomic status, educational background, language, geographic locale, etc. (Derrington et al. 2018). This broad definition of culture reminds us of the potential of great diversity in the patient populations that genetic counselors encounter.

In SDM, genetic counselors must consider cultural attributes of the patient and integrate these into the dialog, encouraging the patient/family to express their perspective in an authentic voice (Derrington et al. 2018). Genetic counselors should have a heightened self-awareness throughout both cis-cultural and cross-cultural genetic counseling interactions, especially as their own reactions might impact the decision-making process. Derrington et al. (2018) suggest the following: "avoid self-referentialism; beware of homogenization; practice cultural humility; cultivate self-awareness; respect patient preferences for SDM; acknowledge the moral relevance of culture" (p. 191).

Table 3.2 Genetic counseling approaches to support shared decision making.

Three Talk Model	Integrative model microskills (elements)	Examples of genetic counseling approaches relevant to decision-making
Team Talk	Define/explain problem Define roles (desire for involvement) Actively explore patient values/preferences Discuss patient ability/ self-efficacy Check/clarify understanding	Explore the patient's engagement in the genetic counseling process during the contracting phase Explicitly invite the patient to be a partner in the process – to question, voice their opinions and emotions and share Explore the patient's culture, educational level and understanding of problem to identify barriers and tailor genetic counseling to the patient Pay attention to verbal and non-verbal cues and use them to guide psychosocial responses Be curious about the patient's narrative and ask questions Look for themes in a patient's narrative and identify and share connections Embrace strong emotions. Be curious about where they are coming from. Use primary empathy often Use advanced empathy sparingly, and when appropriate Replace value-laden terms with neutral ones when presenting risks, benefits and options and check for understanding Present risks and benefits in different ways and from different perspectives Ask direct questions. Allow for each member in the family to share her/his specific thoughts preferences and concerns. For deferred decisions, gently (and non-judgmentally) challenge the patient to explicitly share her/his reason why.
Option Talk	Present unbiased options and evidence Discuss pros/cons (benefits/ risks/costs) Actively explore patient values/preferences Check/clarify understanding	
Decision Talk	Actively explore patient values/preferences Discuss patient ability/ self-efficacy Clinician knowledge/ recommendations Make or explicitly defer decision as a mutual agreement Arrange follow-up	

Cultural attributes may also impact the patient's willingness to engage in SDM at all as s/he might prefer a directed recommendation from the genetic counselor and decline outright to engage in SDM. Cultural assumptions, including East–West cultural stereotypes, should be avoided both with respect to preferences for autonomous decision-making and for involvement of family members in the process (Alden et al. 2018). Authentic exchange of cultural perspectives from the lens of both the patient and the genetic counselor is intrinsic to supporting the decision-making process.

Consideration of diverse patient populations should include the lesbian, gay, bisexual and transgender (LGBT) community. While significant advances in legal rights have been achieved in many countries and jurisdictions, LGBT individuals, especially those representing visible minorities, continue to encounter disparities in the health care setting, often due to a lack of understanding of LGBT health issues among health care providers and implicit and explicit attitudes (Chin et al. 2016; Nathan et al. 2019). Facilitation of decision-making in the genetic counseling setting may have added complexities associated with medical treatment, such as that recently reported involving a trans-feminine youth with a BrCa1 pathogenic variant (Wolf-Gould et al. 2018). Peek et al. (2016), and subsequently Chin et al. (2016), provide a SDM

approach to address the intersection of LGBT status and race that provides insights relevant to the genetic counseling setting. These insights include: "the influence of each individual's perception of himself or herself, given his or her intersecting identity axes of sexual orientation, gender identity, race, and ethnicity; the clinician's perception of the patient, given these identities and vice versa; and the influence of social networks and society. Understanding these complex inter- and intra-personal dynamics is critical for engaging in effective, empathetic communication and SDM" (Chin et al. 2016, p. 592).

In family centered care, competing interests and preferences of different family members may challenge the genetic counselor in implementing a SDM approach. This can be especially challenging in the pediatric setting where parents or surrogate care givers may have different preferences and reach different decisions. As well, they may vary in their comfort with having their child participate in the decision-making. In the geographic jurisdiction of the authors (Ontario, Canada), there is no age of majority at which time a child has decision-making authority regarding his/her own health care and treatment. Rather, genetic counselors and other health care providers assess the capacity of the child/adolescent to participate in the decision-making process and to be able to provide informed consent where needed. Competing preferences may also present in family members of geriatric patients and/or individuals who do not have the capacity to provide informed consent and actively participate in decision-making. When individuals in adolescence or adulthood lack decision-making capacity, Wasserman and Navin (2018) propose that health care providers solicit patient preferences. They note that preference capacity differs from decision-making capacity and that individuals may be able to indicate a preference for one option over another even in the face of impaired decision-making capacity. Their assertions can apply to those situations involving a surrogate decision-maker and have direct relevance for genetic counselors in facilitating decision-making for vulnerable individuals.

In each of these situations involving vulnerable patients (i.e. pediatric, geriatric, intellectually disabled), additional issues may influence decision-making beyond the best interest of the patient. For example, parents may make decisions driven by concern about health risks for their other children; similarly, family members of geriatric patients or individuals with intellectual disability unable to make their own decisions, may be concerned about their own health risks or reproductive risks. Some family members may express these concerns openly, while others might suppress their concerns, sensing an obligation to make the best decision for the patient at hand. Feudtner et al. (2018) argue that "the specific decisions we make are fundamentally shaped by how we make sense of being in a relationship as a surrogate decision-maker" noting the personal sense of duty experienced by parents/surrogates along with the responsibility of being good decision makers and adhering to "operational rules of conduct" (p. 134). They also assert that health care providers tend to focus on the educative components and not enough on attending to the psychological factors unique to surrogate decision makers. In facilitating decision-making in these situations, genetic counselors should try to explore and validate competing interests with key family members.

Approaches and Tools for Facilitating Decision-Making

With increasing utilization of genetic testing in mainstream medicine and a limited genetic counseling workforce to support pre-test informed consent, it is abundantly evident that novel tools are needed to deliver some or all of the educative components related to genetics and genomic testing; such tools can also serve as a genetic counseling adjunct to guide complex decision-making (Adam et al. 2018). Decision

aids have long existed to support complex decision-making in various settings including the prenatal context. For example, the Ottawa Decision Support Framework was developed by Annette O'Connor to involve all stakeholders, patients, family members, and health care providers in the decision-making process and to address decisional conflict. This decision aid and others incorporate concepts from psychology, decision analysis (https://decisionaid.ohri.ca/odsf.html), social support, and economics. In 2003, Glyn Elwyn and Dawn Stacey led an international collaborative including researchers, health care providers, and other stakeholders to develop a framework "to enhance the quality and effectiveness of patient decision aids...with a set of criteria for improving their content, development, implementation, and evaluation": the International Patient Decision Aids Standards (IPDAS) (http://ipdas.ohri.ca/using.html 2013).

Decision aids are increasingly innovative and interactive in their design, which is particularly relevant to the technological capacity of many if not most current users. Numerous decision aids have been developed including those focused on effective information delivery, to those supporting values-based - (Birch et al. 2019; Bombard et al. 2018; Green et al. 2005). As well, relatively new approaches, such as chatbots, support patients in accessing genetic concepts, risk assessments, and testing with inherent genetic counselor workload efficiencies. Decision aid evaluations indicate that both patients and health care providers acknowledge the utility of these modalities to support decision-making (Adam et al. 2018; Green et al. 2005; Pacyna et al. 2019; Reumkens et al. 2019; Shickh et al. 2018; Stacey et al. 2017; Willis et al. 2018).

Summary

A primary role for the genetic counseling profession is helping patients make complex, sometimes life-altering decisions. Awareness of the psychological aspects (fuzzy trace, heuristics, and decisional bias) as well as barriers to decision-making enables the genetic counselor to better facilitate informed decision-making. The model (SDM) offers an effective and powerful approach for engaging with patients as partners in decision-making. As the demand for genetic counseling services increases in the future, the profession will be called upon to offer innovative approaches and tools (such as decision-aids, chatbots) to complement SDM and the genetic counseling process.

Learning Activities

Introduction

The following case scenarios and accompanying activities provide the student with an opportunity to:

1) Practice the micro-skills required for effective SDM
2) Consider the psychological processes underlying decision-making for genetic counseling patients (heuristics and fuzzy trace effects)
3) Identify and address potential barriers to decision-making (psychological/emotional, informational, cultural)
4) Identify and address potential genetic counselor biases and psychological processes that may interfere with effective decision-making.