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PROFESSIONAL ISSUES

Balancing Genetics (Science) and Counseling (Art) in Prenatal Chromosomal Microarray Testing

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Abstract Genetic counselors frequently are called upon to assist patients in understanding the implications of prenatal testing information for their pregnancies and their family's lives. The introduction of highly sensitive testing such as chromosomal microarray has generated additional kinds of uncertainty into the prenatal period. Counselors may feel uncomfortable or inadequately prepared to engage in discussions with prospective parents who are faced with making critical, and timely, decisions about a pregnancy based on uncertain information. As highly sensitive prenatal testing becomes routine in prenatal care, counselors may be in search of approaches to prenatal counseling, as well as specific skills to approach, engage with, and help families find resolution in such challenging circumstances. To assist genetic counselors, we describe practice skills and provide language for approaching conversations with prospective parents. When clinicians regularly provide care to patients and families making life-altering decisions under conditions of significant uncertainty, discomfort is common and compassion fatigue is likely. We make recommendations directly to the genetic counselor working in reproductive and perinatal settings to enhance training and self-care and to decrease discomfort in balancing the scientific- and art- demands of genetic counseling.

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Introduction

With the improved ability to more finely identify variation throughout the genome, uncertainty surrounding prenatal test results and their implications has increased. The uncertainty associated with many genetic variants identified through prenatal genomic testing frustrates prospective parents and clinicians. Conveying the science of such findings is difficult for the clinician, and sometimes the art of counseling the family in those circumstances is even more daunting. Prospective parents enter the genomic service space with tremendous variation in health literacy, numeracy, genomic knowledge, information seeking tendencies, cognitive or mental health challenges, tolerance for uncertainty, and expectations of pregnancy and parenting. Ultimately, patients must make life-changing decisions, frequently based on genomic test results with uncertain implications. Such an endeavor requires help from clinicians who feel comfortable with both the science of genomic medicine and the art of counseling within the context of uncertainty.

In this paper, we briefly review the evolution of prenatal genetic counseling in the face of uncertainty as well as principles of patient-centered practice as they are applied to genetic counseling. We discuss the ways genomic discovery has increased the kinds of uncertainty counselors must address with prospective parents and the ways individuals adapt to uncertainties. Then, we draw on findings from the general counseling and the genetic counseling literatures as well as our work with a large, federally funded study of prenatal chromosomal microarray analysis (CMA) to suggest recommendations for practice throughout the prenatal testing trajectory.

We end with discussion of how genetic counselors can attend to their own needs to enable them to be most effective with their patients.

Evolution of Counseling in the Context of Genetics and Genomics

Genetic counselors across practice settings are frequently called upon to assist patients with genetic information at each step from the introduction of testing, to review of results, to assisting patients with adapting and responding to results (Bernhardt 2014). The earliest genetic counselors focused on conveying facts and probabilities to promote "rational" decision making (Pauker and Pauker 1977; Reed 1974). Yet, these counselors had very little genetic information to interpret for and with patients (Stern 2009). Thus, their professional focus was on counseling clients, primarily in prenatal and pediatric settings, about inheritance patterns, chromosomal disorders, and a limited choice of emotionally- and morally-challenging options.

With the development of masters-level genetic counseling, the field moved to emphasize psychosocial counseling and autonomous, values-based decision-making (Marks 1993; Veach et al. 2007). The Reciprocal – Engagement Model of genetic counseling emerged as a result of identifying the tenets, goals, strategies, and behaviors involved in genetic counseling (Veach et al. 2007). With this model, the relationship between the patient and genetic counselor supports the goals of conveying genetic information, understanding patients' emotions and values, and supporting patient autonomy (Resta et al. 2006; Veach et al. 2007). Scientific advances facilitating testing for Mendelian disorders and, more recently, for conditions caused by changes throughout the genome, have led to genetic counseling sessions that are predominated by education about technological aspects of testing that may yield complex, nuanced, and uncertain results (Meiser et al. 2008).

Genetic counselors must convey this scientific uncertainty while simultaneously providing support, exploring patients' psychosocial contexts for tolerating and interpreting such information, helping the patient to clarify and articulate values, and assisting the patient to make decisions (Austin et al. 2014). We argue that, in the face of a professional space defined by increasing uncertainty, genetic counseling must return to its roots in providing a balance between the science of genomics and the art of counseling.

Balancing Genetic (Science) and Counseling (Art)

Genetic counseling is grounded in the principal that 'genetic information is the key' to informed decisions (Veach et al. 2007). When clear information about the implications of genomic findings is unavailable, this foundation of genetic counseling becomes more challenging. Due to beliefs about the infallibility of biomedical knowledge, prospective parents may have unrealistic expectations about the certainty with which CMA results can be interpreted and effectively acted upon. This jeopardizes pre-existing expectations that prenatal testing is meant to provide assurances about the health of a fetus (Hunt et al. 2005). To build strong alliances with families, and to practice in accordance with the mission of the profession (Resta et al. 2006), genetic counselors must work with families to identify what is known and what is unknown, and to move counseling beyond discussion of scientific limitations to help families create pathways through uncertainty. These pathways are forged by articulating the limits of prenatal genomic testing, identifying crossroads where prospective parents have choice, presenting the array of options available at those moments, helping families consider their tolerance for risk, and supporting families through decision making and adaptation.

Research on counseling and therapeutic relationships consistently shows that the counselor's theoretical approach to counseling is less important than the presence of a strong working alliance or therapeutic relationship (Wampold 2010). Such a working relationship is characterized by common factors such as empathy, warmth, positive regard and congruency /authenticity (Djurdjinovic 2009; Gelso and Carter 1994; Rogers 1957), and other facilitating aspects of the working alliance, such as collaborative work towards goals/tasks, willingness to address ruptures in the alliance, and shared problem-solving (Eunpu 1997; Lambert and Barley 2002; McDaniel 2005). Effective counseling is focused on building rapport within a nonjudgmental and nurturing environment (Bachelor 1995; Kessler 2001). This is often called the "holding environment" (Winnicott 1960), a physical and emotional space of safety where patients can be open and vulnerable with the counselor. The holding environment is characterized by use of active listening, additive empathy (identifying underlying emotion on a deeper level than the patient has overtly expressed), promotion of open self-disclosure, trust, and collaborative work to convey to the patient that they are not alone. Many psychotherapy researchers draw on Saleebey's (2006) strengths perspective to help counselors of all types recognize that, to make painful decisions in the face of uncertainty, patients do not need to be "empowered" so much as to be helped to identify and draw upon existing strengths to adapt priorities and cope with expectations (Peterson et al. 2002). Grounding scientific information within such a nurturing relationship is foundational for the recommendations that follow.

Counseling through Uncertainty

Genetic variation identified on prenatal CMA testing can be uncertain in terms of molecular consequence, pathogenicity,

clinical relevance and penetrance (Westerfield et al. 2014). For example, for some novel but likely deleterious genomic variations, no information is available about the expected phenotype. Especially pertinent to copy number variants, there is a tremendous amount of phenotypic variability associated with known deletion/duplication syndromes. Interpretation of the significance of copy number variants found on prenatal samples is further complicated because most of the available phenotypic information is derived from children who were tested because of the presence of symptoms, skewing the data towards the severe end of the spectrum (Martin et al. 2015). Most CNVs are associated with a range of probabilities of various potential complications, and it is generally not possible to assess fetal clinical involvement, especially with regards to neurocognitive development.

When counseling prospective parents about uncertain information, it becomes important to consider sources of scientific uncertainty, and to differentiate between reducible (for example, uncertainty associated with misunderstanding or not seeking out the scientific data) and non-reducible (for example, uncertainty associated with the absence of scientific data or uncertainty related to probability) uncertainties. Han et al. (2011) have identified three sources of uncertainty. The first derives from probability, referring to an indeterminacy of a phenotypic outcome. The second derives from ambiguity relating to lack of credibility, reliability, or adequacy of information or evidence. The third source derives from complexity, represented by the multiplicity of factors contributing to uncertainty. Han (2013) also suggests that non-scientific aspects of uncertainty, such as a patient's personal goals or outlooks on life will influence how uncertainty is perceived and managed by the patient. The locus of uncertainty, that is, whether it exists in the mind of the patient or the clinician or both should also be addressed.

Yet, uncertainty exists in all facets of daily life. When we are faced with novel experiences or concepts, our brains automatically attempt to interpret them within the context of our established worldviews. When this is not possible, we create new mental representations that define the properties and parameters of uncertainty to make it understandable and manageable (Kahneman et al. 1982). These representations are influenced by our disposition, the context within which we perceive uncertainty to impact our lives, our ability to tolerate risk (Weber et al. 2002), and our expectations of ourselves, important others, and our social and physical worlds. Additionally, people may feel constitutionally bound to continue seeking information in the face of uncertainty (maximizers) or may be satisfied with the level of information presented to them (satisficers) (Parker et al. 2007). These perceptions often shape the ways individuals seek out resources, make decisions, and cope with the aftermath of a decision or event.

In medicine, patients and providers seek to minimize uncertainty. Given the nascent state of genomic testing and the broad dimensions of uncertainty currently associated with much genomic information, our efforts to mitigate uncertainty in the prenatal and perinatal periods will be challenged for the foreseeable future. Clients may be angered by the limitations of prenatal genomic testing and direct their frustration towards counselors, threatening the therapeutic relationship (Djurdjinovic 2009). When uncertainty threatens prospective parents' treasured, and often unquestioned, values or goals, counselors can gently interrogate the origin and nuances of those values to nurture flexibility. But frequently, uncertain prenatal testing results may leave counselors without confidence, believing they are unable to help families who saw promise in seeking out genomic information. To assist genetic counselors in these highly charged, uncertain encounters with prospective parents, we draw on recommendations from several studies and integrate those recommendations with general genetic counseling and therapeutic relationship development strategies. We describe practice skills and provide language for approaching these challenging conversations with prospective parents.

Recommendations for Genetic Counseling Practice

The recommendations that follow are drawn from our research with patients, families, and clinicians confronted with positive, and frequently uncertain, findings from CMA. Our studies used quantitative and qualitative methods to explore genetic counselors' and prospective parents' needs and experiences with prenatal CMA testing; the findings are presented elsewhere (Bernhardt et al. 2014, 2012; Rubel et al. 2015; Walser et al. 2015, 2016; Werner-Lin et al. 2015). Although the recommendations emerge from our research involving prenatal CMA testing, they may be applicable in genetic counseling situations involving uncertain results beyond the setting of prenatal CMA.

We Recommend That, to Consolidate Discussion of Uncertainty and Frame Prenatal Decision Making as a Family Concern, Genetic Counselors Encourage Partners to Attend Appointments Together

Before the first appointment has even happened, the structure of the counseling relationship and who is legitimately involved with prenatal decision-making is established by who attends the appointments. Although universal partner participation may be unrealistic given the structure of work and family obligations, particularly for minimally resourced clients, encouraging partners to attend the initial and subsequent appointments sends the message that they are intimately involved and that their support and input are welcome and

necessary (see Table 1). This encouragement frames prenatal testing as a family concern that has implications for the future of the family unit. Such a framing will minimize the need for pregnant women to act as conduits of complex, nuanced, and emotionally charged information (Werner-Lin et al. 2015). This is particularly important when information is uncertain. With both partners present, each hears that the information itself is uncertain, rather than opening the woman up to charges of not having gathered or recalled enough information if the partner wants a "complete" report upon her return from the appointment. When partners attend genetic counseling sessions together, they can engage in discussion with the genetic counselor directly about how much genetic information they desire, share their own knowledge base about the nature of uncertain information, and make "real time" decisions about testing and acting on results. Both partners hear the genetic counselor's assessment of what information is clear and what is uncertain or unable to be known. To facilitate participation of partners (after HIPAA clearances) providers may request email or phone information and reach out directly to elicit questions or concerns and invite them to attend sessions (Walser et al. 2016).

We Recommend Counselors Approach Assessment as an Ongoing Process

Genetic counselors will best serve prospective parents using a model of thorough and ongoing assessment that starts with the first contact regarding prenatal genetic testing. Through such assessment, counselors can help prospective parents to identify and articulate what information is uncertain, evaluate what aspects of uncertainty are important to the prospective parent(s), and assess how they and family members are coping with that uncertainty.

Table 1 Pre-counseling phone contact

Counseling Goals	Suggested genetic counselor language
Set the stage for counseling as an opportunity for partners to learn about the limits of certainty associated with some prenatal findings.	"*I know it is difficult to arrange schedules for multiple people, but I strongly encourage you to bring* (*use name if at all possible*) *to our appointment. Issues of prenatal testing are complex and it is helpful to have more than one set of ears learn about possible outcomes. Additionally, I will be able to answer his/her questions if s/he attends rather than forcing you to be the go-between.*"
Assess barriers and help problem-solve to allow the partner to attend.	"*Is there something I can do that will make it easier for you to bring him/her along*?"

Pre-Test Counseling

Thorough assessment allows counselors to follow and respond to the fluidity of patients' informational, emotional, and social needs throughout the pregnancy. The use of pre-test counseling as a time for building rapport and assessing patient fears, strengths, and expectations cannot be overstated (Etchegary et al. 2008; Veach et al. 2007). This permits the counseling relationship to develop prior to disclosure of test results. With prenatal CMA testing, prospective parents often want all available information (Walser et al. 2015), and they may simultaneously feel pressure to consent to highly sensitive testing even when they have strong feelings against its use or have little idea what action they may take as a result of specific findings (Hillman et al. 2013).

An early area for assessment is the patient's risk tolerance, or how much uncertainty a person can manage emotionally. Although assessment tools such as the DOSPERT are available to measure risk tolerance (Blais and Weber 2006), genetic counselors can broadly assess risk tolerance by asking prospective parents about what type (cognitive, psychiatric, physiological), intensity (mild to severe) and levels (chance of clinical presentation) of uncertainty make them uncomfortable with regard to the pregnancy and what risks they are willing to accept as they relate to the potential outcomes of the genomic findings. Probing gently about such outcomes may help prospective parents clarify their intent for seeking prenatal testing (see Table 2).

Helping families begin to identify possible decision-points, expectations, and decisional styles is part of an ongoing assessment that starts in the pre-testing session. Despite counseling around the possibility of finding a positive result, prospective parents often undergo testing without consideration of the downstream consequences (Bernhardt et al. 2012). Thus, the return of a pathogenic or uncertain finding is a devastating surprise. Families need help during pre-testing counseling to consider their expectations and the potential for positive results. The use of *priming* (asking questions or giving hypothetical scenarios before there is an actual problematic result) may allow for deliberative decision-making if such results are received (Lobel et al. 2005; McCoyd 2013; White 2005). Genetic counseling sessions often also ignore attitudes about abortion and about parenting a child with a disability (Farrelly et al. 2012). The majority of patients will not need to make decisions related to a positive or an uncertain test result. However, for that small percent who do have a problem detected, to have an established relationship will add comfort and it is worth the time spent with all patients (McCoyd 2015). If not considering these possibilities until the results are conveyed, families may struggle with decision making throughout the pregnancy and beyond (Bernhardt et al. 2012). A discussion of these issues before prenatal testing results are available may better prepare couples faced with

Table 2 Initial assessment during pre-test counseling

Counseling Goals	Suggested genetic counselor language
Identify (gaps in) what the patient understands about the risk of an uncertain finding.	"*Let us talk about what would happen if you got a result indicating that your baby has a variant that we do not yet understand well enough to interpret for you.*"
Identify patient/family beliefs about their ability to parent a child with various types of conditions.	"*People often hope prenatal testing will tell them that their baby is healthy, yet we can never guarantee that. What would be the types of problems a baby could have that would be the most difficult for you to handle*?"
Prepare patient/family to consider decision-making before needing to do it under conditions of the stress of positive results.	"*What thoughts have you had about what you might do if we find results indicating your baby might have a learning disability or developmental delay that meant s/he could not attend typical classroom settings*? *What about a physical impairment, such as cleft lip or a missing limb*?"
Assess the family's sense of comfort with making a decision when uncertainty means we can only indicate possibilities of a problem.	"*If we found results that indicated the possibility that the baby could have a serious problem, but we were not sure how likely it might be to happen, how comfortable would you be making a decision about how to proceed with the pregnancy*?"

making a decision in the midst of a crisis (Bernhardt et al. 2012; McCoyd 2013).

Returning Uncertain Results

Counselors may provide information about CMA to couples who view testing as an "offer too good to pass up" but who are then blind-sided by uncertain and unquantifiable risks revealed in their results (Bernhardt et al. 2012). This outcome challenges the perspective that knowledge is power.

In a situation where biomedical information is unclear, patients may seek other sources of knowledge to find certainty. Identifying the ways patients gather information in the face of uncertainty is an important piece of the on-going assessment (see Table 3). Clinicians will best serve prospective parents by advising them on how to search for and sort through the array of available online information (Bernhardt et al. 2012; Walser et al. 2016), including medical literature, links to support groups (online and in-person), and reputable websites (Rubel et al. 2015). Helping patients to recognize whether they tend to continue to search for information even after it is clear they have exhausted the limits of knowledge (maximizers) or whether they can be satisfied with the information provided by the genetic counselor (satisficers) (Schwartz et al. 2002) will help them place such information- searching into perspective.

Beyond empirically validated resources, patients will seek to personalize information to their specific situation. Some will seek out spiritual and religious advisors. Others will focus 'internally' to the ways they experience their pregnancy physically, or to 'gut instinct,' for direction and clarity (McCoyd 2015; Rubel et al. 2015). Many will approach members of their social networks to learn from other women's experiences with high-risk pregnancies, or about the experiences of other families raising a child with a variant similar to that of their fetus. The stories to which people have been exposed greatly influence these expectations, their sense of risk, and what they are able to tolerate in their own pregnancy and parenting experience (Winterbottom et al. 2008). This means that genetic counselors need to explore the stories families bring to counseling as well as to help them see these stories as a way they process uncertainty into a sense of increased certainty. To create a climate of acceptance and open communication in the clinic, counselors can recognize the ways knowledge derived outside the biomedical setting is legitimate and meaningful for patients. These other sources of knowledge seek to answer the unanswerable questions that uncertain CMA findings generate (Rubel et al. 2015). Through acknowledging these other sources of information and respecting them, counselors help patients understand and sort through information of varying quality and type.

We Recommend Genetic Counselors Deliver Important Informational Content, and View Such Content as Necessary but Insufficient for Informed Decision Making

Informational Content

Genetic counselors are tasked with providing as much information as possible about the potential child's expected health and development. Counselors may feel uncomfortable or inadequately prepared to engage in discussions with prospective parents who are faced with making decisions about pregnancy termination based on uncertain information (Bernhardt et al. 2014). Communicating about uncertainty may result in

Table 3 Return of uncertain results

Counseling Goals	Suggested genetic counselor language
Use simple language that does not indicate panic or worry, although patients may respond that way.	"*Your initial testing left us with some questions about the health of your baby. We'd like to talk with you about what we have learned and talk about your options moving forward.*"
Map expectations to reduce anxiety and help patients engage in discussion.	"*These uncertain results not only affect your thoughts about your baby, but may affect your whole family. What ways do you see these results affecting your family? What are your concerns?*"
Identify information-seeking tendencies of patients and family members. Do they tend towards being maximizers or satisficers?	"*How do you approach gathering information about a new experience? Are you the type of person who goes right to the internet and searches for every last source? Do you go to friends, clergy, and/or family members first?*"
Help the family understand you are entering a contested space. Demonstrate your ability in supporting them no matter what their beliefs or considerations and let them lead the way.	"*Families often have strong opinions about pregnancy termination, but most have not been faced with the kind of information and uncertainty that I am sharing with you. What sorts of thoughts do you have about pregnancy termination when there are questions about the baby's health?*"
Inquire about previous experience with difficult decisions to remind patients and families of their capacity to evaluate and navigate dilemmas.	"*Can you tell me about a difficult decision you had to make in the past?*" "*Can you think of a time when you had to make a hard decision based on unclear or uncertain information? How did you approach that decision?*"

information overload and confusion because of the complexity of the information itself (Han 2013). Information should therefore be tailored according to how much information is desired by the patient and the pace of delivery (Epstein and Gramling 2013). This information combined with the patient's assessment of the potential child's quality of life and concern about the challenges the family will face if the pregnancy is carried to term, become important metrics for prospective parents' decision-making about whether to continue or terminate an affected pregnancy (McCoyd 2008; Walser et al. 2016).

Counselors must understand *how* to explain terminology associated with genetic variants (e.g. penetrance vs. variable expressivity) in a way that is accessible (Roter et al. 2009). Counselors must identify and clarify misconceptions, encourage patient dialogue with counselors about relevant concepts, and avoid fueling uncertainty by creating additional barriers to understanding (see Table 4). Messages are more credible when delivered by a trusted provider, therefore developing a strong relationship is crucial to supporting an environment for informed and shared decision-making (Politi and Street 2011). Counselors often get bogged down in explaining the details of genomic processes with specificity that is not necessary to a patient's decision making (Redlinger-Grosse 2014). Asking patients to explain to the genetic counselor what they perceive as known or uncertain can help both counselor and patient to understand the critical aspects of the situation without getting lost in the science, and can prompt the counselor to correct misunderstandings.

Decisional Support

Issues reproductive genetic counselors find critical to decision making may be less important to prospective parents (Farrell et al. 2015). Counselors should seek direction from patients by asking them what they identify as most important (Walser et al. 2015). In social work, there is an adage to "start where the client is." This allows the genetic counselor to assess primary concerns rather than trying to mind-read or moving into a pre-planned approach that is not tailored to the specific patient. Identifying and exploring patient concerns builds trust and a strong working alliance (Taylor-Brown and Johnson 1998). Such conversations

Table 4 Shared understanding of informational content

Counseling Goals	Suggested genetic counselor language
Use a "teach back" method to assess adequacy of information and understanding. Frame with 'always' to demonstrate this is a routine part of the counseling process and that she has not been singled out.	"*I always ask patients to use their own words to describe to me what we have talked about today so that I can make sure I have given you all the information you need to move forward from here.*"
Assess the patient's ability to manage anxiety associated with the scientific communication.	"*When I talk about the test result do you feel like you are hearing and understanding my explanation or does it start to all feel like words in a word salad?*"

can reveal social, moral, or ethical pressures towards adopting a specific course of behavior, and permit counselors to examine these pressures to help prospective parents decide how to incorporate that knowledge into their decision making.

We recommend that before sessions, counselors gather all available clinical and scientific information relevant to the findings that might be central to pregnancy-related decision making, deliver this information clearly and succinctly, assess understanding, and then move beyond informational content to emotional reactions and decisional support. This may include discussion of how families have made difficult decisions in the past and what happens when family members disagree with each other about highly emotional or contested topics (see Table 5). When family members disagree with each other, we recommend separating members, even briefly, to enable candid discussion, evaluate for risk of coercion or violence, and balance the discussion with the counselor as mediator, if necessary.

We Recommend That Counselors Address Emotional Content Openly and Directly

Prospective parents often exhibit emotional cues during genetic counseling and counselors vary in their willingness to acknowledge and enhance prospective parents' affective responses (Duric et al. 2003). Duric et al. (2003) found that when genetic counselors acknowledged and empathetically responded to an initial emotional cue, patients were more likely to disclose other emotions and less likely to show depressive symptomatology after the session than those whose affective content was overlooked. Yet, even the most experienced counselors may struggle to tolerate the emotional lability present in the consultation room following return of uncertain CMA results.

Return of pathogenic or uncertain CMA results often surprises prospective parents who, even though adequately counseled about the likelihood of their discovery, do not entertain the possibility of personally receiving such a result. Families may express anger, fear, sadness, or anxiety. Some will cry and others will yell at the clinician. Some may become preternaturally quiet and disengaged. Clinicians must remember that their comments may trigger strong emotions and that working through them with prospective parents will yield stronger provider/patient partnerships and greater trust. To begin, we suggest counselors name the emotions expressed by prospective parents in order to begin discussion about aspects of results that triggered these emotions and to validate

Table 5 Decision support

Counseling Goals	Suggested genetic counselor language
Validate confusion and the possibility of being stalled. Restate your investment and participation.	"*Because we cannot give you definitive information, you may not see a clear pathway through this. I'd like to think this through with you and keep talking about the challenges you imagine from each course of action.*"
Use this variation on solution-focused questioning to help families anticipate that a decision can be made. Such questioning may prompt the intuitive process that often accompanies decision-making under conditions of uncertainty.	"*If you awoke in the morning and the decision that considered all the uncertainty here was already made, what do you think you would be feeling*? (*pause for identification of feeling*) *What do you think that decision might be*?"
Assess the extent to which the couple experiences (or anticipates) tension in the relationship due to the uncertain results.	"*Do you have a sense that you and your partner are likely to approach your decisions about the pregnancy similarly in light of the uncertainty of the information*?"
Evaluate the couple/family's decision making style and assess for coercion.	"*What happens when you and your partner disagree about big decisions*? *For instance, if you felt like you wanted to continue the pregnancy and your partner did not want to continue the pregnancy, how do you think the two of you would negotiate that*?"
Separate family members who disagree with each other, even briefly, to enable candid discussion, evaluate for risk of coercion or violence, and balance the terms of the discussion with the counselor as mediator.	"*Ma'am, please come with me for a moment so we can check in with the nurse. Sir, you can wait right here, we'll be back in a moment….I wanted to talk with you alone for a moment to ask whether you have any concerns about your safety if you disagree with your partner about how to proceed with this uncertain information.*"
Identify whom the patient/family seeks out for advice. If they say they cannot consult these typical sources of advice due to fears of negative judgment or stigma, they may need a referral.	"*Are there people in your spiritual community or among your friends with whom you would wish to discuss making this decision*? *Why or why not might you actually consult with them about this*?"

patients' reactions (see Table 6). Going beyond just naming an expressed emotion to tentatively identifying underlying feelings about the pregnancy and the results helps to take patients to deeper levels of insight, self-awareness, and the ability to process emotions towards sound decisions rather than impulsive reactions.

Preparing Families for Ebbs and Flows of Distress

Counselors can minimize emotional uncertainty for prospective parents by educating them about common periods of increased distress and relief throughout the process of prenatal testing. For example, waiting for parents' testing results to confirm whether a fetus' CNV was *de novo* or inherited was identified as the most stressful period for some families (Werner-Lin et al. 2015). During this period, couples' relationship to the pregnancy and to the anticipated experience of parenting may shift dramatically, transforming the 'hoped for' experience into something tentative and uncertain. This is an optimal time to evaluate the prospective parents' confidence in their ability to cope and to increase the intensity of psychosocial support of families. Preparing families in advance for this distress normalizes and validates intense feelings of worry or loss.

During the initial crisis of receiving a positive finding, patients may approach trusted loved ones for emotional support, so an examination of the support system's existence and ability to help buffer stress is essential (Cohen and Wills 1985). The chronic nature of genomic uncertainty, however, may place a strain on social relationships within which shock, denial, and/or grief are initially processed. This may tax physical, emotional, financial, and social resources in many ways and over long periods of time.

Some patients may be overwhelmed by the need for a decision on whether to continue the pregnancy and, in the face of uncertainty, experience "analysis paralysis" due to being overwhelmed by the number and gravity of choices to be made (Schwartz 2004). Genetic counselors need to be prepared with referrals to other providers who can meet with prospective parents to assist with decision-making, adaptation to decisions, and support over the long term, including connecting families with resources for evaluating the child over time. Providers who are uncomfortable providing reproductive counseling about uncertain CNV results should refer patients to clinicians with more experience and comfort (Walser et al. 2016).

We Recommend Preparing Families for Hard Choices and Distinguishing between Urgent Decisions and Important Decisions

As families come to understand the array of possible phenotypes their baby may express, they may begin to question long-untested moral and ethical beliefs (Rubel et al. 2015). It is important to validate that the patient must make a decision

Table 6 Managing intense emotions in the consultation room

Counseling Goals	Suggested genetic counselor language
Continue to build trust and rapport by responding to the patient's identified concerns.	"*We covered a lot of information about the findings and the uncertainty about what they mean for your baby, for you, and for your family. How are you feeling about everything we have discussed so far?*"
Identify what part of the discussion the patient/family is reacting to. This also serves to assess how much of the discussion they are absorbing: it is possible that patients/families stopped 'hearing' information.	"*We have talked about a number of ways these results have raised questions about your baby and there's lots of frustration about the level of uncertainty in these results. What is most frustrating for you right now?*"
Help the family to name the feeling. Give family permission to stay with their feelings.	"*I want you to feel comfortable discussing any emotion with me. What are you feeling right now?*"
Validate the patient/family's response to uncertain results. Identify the patient/family concern to demonstrate a desire for empathic connection. Check to be sure you are right and give the patient permission to correct you.	"*The kinds of choices you have now are confusing and you are not sure how to proceed. Is that right? Please let me know if I am not following you because I want to help.*"
Identify how you are going to proceed with the family so they feel in partnership with you. Assure them you will attend to their concerns even as you share options.	"*While we go through all of your options, please let me know if it seems I am not following your concerns.*"
For patients who do not share emotions easily, inquire about thoughts or attitudes first, rather than feelings to help them tolerate discussion of uncertainty.	"*You seem very, very quiet. I know that this information is hard to process. Can you share what thoughts you are having as I have shared the findings with you?*"

without having all of the information they would wish. Acknowledge what is unknown. Then, acknowledge what IS known about the capacities they feel they have for making the decision, for parenting a child who may have or develop medical conditions of varying severity, and for coping with the aftermath of a decision, whatever it is.

Urgent decisions include those about whether to consider pregnancy termination. Yet, these decisions often trigger strong emotions and are fraught with social, moral, ethical, and religious dilemmas. Counselors may find it difficult to ask prospective parents their thoughts and feelings about abortion (Farrelly et al. 2012). The use of clear, direct language will facilitate conversation focused on patient needs (see Table 7).

Once genetic counselors have supported values clarification with prospective parents, they can help families identify how their risk tolerance influences their current decisions, when such decisions can/should be reassessed, and a timeline appropriate to the presenting situation. For example, decisions about pregnancy termination are time-constrained due to legal restrictions on abortion based on gestational age. This is an urgent decision. Consideration of post-natal support services and early intervention are *important* decisions, but they are not yet *urgent*; pathogenic or uncertain CNVs are often associated with conditions of unpredictable onset and severity so making treatment decisions prior to a baby's birth may be premature.

The complexity associated with uncertain or pathogenic variants may precipitate a period of crisis within families. To cope effectively, families may move rapidly towards decisional endpoints ahead of their utility and necessity (Werner-Lin et al. 2015). This type of foreclosure is not an informed decision; it is an impulsive move before all the available information is collected. Helping prospective parents to see the difference is a key aspect of helping them distinguish between important and urgent decisions (see Table 7). Counselors can validate the need for these decisions, as well as the reasons to allow time for reflection (when possible) and not impulsive decision making. We recommend a gentle shift in conversation that acknowledges family concerns and then moves families back towards urgent and timely considerations (e.g.: additional confirmation testing of parents/siblings; consideration of abortion; possibilities for therapeutic intervention in the perinatal period) (see Table 8).

The Aftermath of Decision-Making

Coping with uncertainty and grief associated with a positive prenatal finding is not a discrete or time-limited event, and some patients will manage uncertainty with greater ease than others. Unlike earlier conceptions of grief that involved stages/phases such as Kubler-Ross' stages, (Kubler-Ross 1969), we now understand that grief and loss are iterative and involve meaning making (Neimeyer 2001), a sense of being entitled to one's grief (Doka 2002), and are more defined by postmodern conceptions of grief theory than by recipes on how to do grief well (McCoyd and Walter 2016). This requires the counselor to continually explore patients'/family's ways of making sense of what is happening to them, not only in terms of the specific information being conveyed, but in terms of what meaning that information has for them individually and as a family.

Table 7 Distinguishing between urgent versus important decisions

Counseling Goals	Suggested genetic counselor language
Normalize and validate worry. Identify the most pressing concerns to support conversation tailored to meet the patients' most pressing needs.	"*When genetic information is not clear, it is often hard to talk about what to do next. Do you have a sense of which decisions feel pressing to you and which feel like they can be postponed*?"
Identify choices to free families from decisional paralysis and to increase mastery towards decision making.	"*You have a number of ways you can proceed from here and I would be happy to talk with you about all of your options so that you can make decisions that work for your family and your baby.*"
Elicit thoughts about pregnancy termination. Patients and families with strong pro-life convictions often do not have emotional space in their social and cultural worlds to consider termination. Be clear that you are not questioning their values, but trying to ensure they feel safe to discuss all options.	"*Tell me your thoughts about terminating a pregnancy.*" "*Often, families make decisions without even realizing it. You said you would not consider termination and I'd like to ask you about that before we proceed.*"
Help families to consider which decisions are important and which urgent.	"*There are many decisions swirling in your head at this point. It can be helpful for us to sort out which ones are urgent, that is, you lose the chance to make choices if you wait too long* (*such as pregnancy termination*) versus *which ones are important, such as whether your relatives should consider future genetic testing.*"

Table 8 Addressing the aftermath of decisions made

Counseling Goals	Suggested genetic counselor language
Identify areas for anticipatory guidance to help families articulate their concerns and anticipate challenges.	"*Tell me what you envision for yourself and your family moving forward.*" "*When a child is born who carries an uncertain genetic variant, we find that many parents become overly concerned about every little thing their child does or does not do. How might the result affect the way you monitor your child*?"
Attend to pacing by validating the family's interest in resources and framing desires about when such resources might be sought out.	"*We can certainly talk about early intervention supports and medical specialists. We can connect you with some of those supports now or, if you wish, we could wait until after the baby is born and we see how he or she is doing.*"

Should a family decide to continue a pregnancy, helping to actively prepare them to fully stand behind their decision is important. They must be helped to consider whether they will interpret every odd behavior on the part of their child as an indicator of the uncertain genetic variant showing its phenotype. Meaning making may include accepting the child as a full family member. Helping to prepare families to have ongoing contact over time with perinatologists, pediatricians, genetic counselors, and genetically informed mental health practitioners is a vital aspect of preparing the family for the future (Bernhardt et al. 2012).

Genetic Counselors' Experiences

Genetic counselors will vary in their own tolerance for uncertainty in their lives and in their work. When clinicians regularly provide care to patients and families making life-altering decisions under conditions of significant uncertainty, discomfort is common and compassion fatigue may result (Bernhardt et al. 2009, 2010). Clinicians must be aware of the resources at their disposal for managing distress (their own and their patients') as well as how to identify their need for greater supports. Here, we make recommendations directly to the genetic counselor to enhance training and self-care in ways that decrease discomfort in balancing the scientific- and art- demands of prenatal genetic counseling. We continue to draw on our research with genetic counselors offering CMA to prospective parents. Yet, the recommendations below may be useful across genetic counseling settings.

We Recommend Continuing Education and Peer-Supervision Focused on Communication Skills and Training Workshops to Enhance Counselor Confidence and to Permit Reflective Practice

Genetic counselors have expressed a high degree of interest in continuing education about prenatal CMA and counseling about uncertain results (Bernhardt et al. 2014). To help prospective parents make a decision under conditions of uncertainty, clinicians must themselves become comfortable with uncertainty (Bernhardt et al. 2014). It can be uncomfortable to sit with families as they struggle to understand phenotypic variability, the limitations of genomic knowledge to date, and the lack of concrete outcomes data. Attending educational workshops and trainings can add to a sense of competence and understanding about where the limits of certainty exist. When one is aware of the limits of knowledge and learns to embrace uncertainty as a part of the human condition, the level of frustration as a result of such uncertainty is lowered. Reframing uncertainty as a normal and customary part of life that challenges everyone to live with a certain degree of unpredictability can help to reduce unrealistic expectations of having certainty and predictability in all things. In the same way counselors work to help individuals avoid expectations of perfection, genetic counselors must help themselves and their patients to recognize that predictability is not a possible or even preferred outcome in all things; hence, nature tends towards unpredictability and variance rather than total predictability and sameness.

Peer Supervision

Examining counseling sessions afterwards with peers or supervisors will help counselors understand where their own feelings got in the way of listening fully and empathically to patient concerns. Even more, such discussion will allow the genetic counselor to gain support from peers who understand and who can provide perspective when one is beginning to experience compassion fatigue (Kennedy 2000). By building relationships with colleagues that allow for case processing and support of one another, genetic counselors take the first steps in assuring that they can stay fresh enough to continue to provide support to patients under conditions of uncertainty and emotional intensity. The uncertainty, and shared frustrations over the limits of information, will be understood by other genetic counselors as a part of the genetic counseling environment. Such connections can be made within one's area of practice or beyond, and such empathy among colleagues allows the support and professional growth necessary to continue this hard work (Hiller and Rosenfield 2000).

We Recommend That Counselors Engage in a Variety of Self-Care Modalities to Help Them Attend More Completely to Patient Anxiety That May Result from Uncertainty

Compassion fatigue is the experience of emotional, and subsequent physical, exhaustion resulting from helping others through emotionally challenging and intense experiences (Benoit et al. 2007). Genetic counseling sessions across settings are often brimming with intense emotion: fear, worry, anger, sadness, and frustration about the limits of information. Witnessing such intensity, and working with it in a concentrated time frame, takes a toll on providers. Such fatigue must be recognized and honored to prevent burnout, to enable responsible and competent practice, and to maintain a good balance between work and home life (Benoit et al. 2007; Bernhardt et al. 2009).

To avoid compassion fatigue, genetic counselors must continue to experience compassion satisfaction (see the Professional Quality of Life Scale, www.proqol.org) and engage in self-care. Ideas for self-care are available from multiple sources (Mathieu 2007) and are deeply personal. Engaging in contemplative practices such as mindfulness will allow the counselor to monitor her own feelings, biases, and assumptions to permit self-acceptance while also enhancing patient care. This awareness will help her engage in active listening, identify indications of patient's understanding and receptivity, and assist patients in making personal meaning of the information and choices offered (Bernhardt et al. 2014).

Conclusion

The uncertainties inherent in our new genomic technologies mean that the information genetic counselors need to share with prospective parents and other patients is fraught with challenges about decision-making in the face of that uncertainty. Risk tolerance, decision-making skills, ability to manage emotion, and values all interact within the genetic counseling relationship in ways that require the counselor to manage not only the science of the genetics, but the art of the counseling. Here, we have provided guidance and verbiage for genetic counselors to enable them to interact with prospective parents to assess how they are interpreting information the genetic counselor is providing, not only through the scientific lens, but through the emotional and psychosocial impact of that information (and its uncertainty). Use of these recommendations, which are empirically grounded (Bernhardt et al. 2012, 2014; Rubel et al. 2015; Walser et al. 2015, 2016; Werner-Lin et al. 2015), can assist the genetic counselor in managing these challenging interactions. Additionally, we urge genetic counselors to attend to their own need for support and information to enable them to thrive in their profession under high levels of uncertainty.

Compliance with Ethical Standards

Conflict of Interest Allison Werner-Lin, Judith L. M. McCoyd and Barbara A. Bernhardt declare that they have no conflict of interest.

References

Austin, J., Semaka, A., & Hadjipavlou, G. (2014). Conceptualizing genetic counseling as psychotherapy in the era of genomic medicine. *Journal of Genetic Counseling, 23*(6), 903–909. doi:10.1007/s10897-014-9728-1.

Bachelor, A. (1995). Clients' perception of the therapeutic alliance: A qualitative analysis. *Journal of Counseling Psychology, 42*, 323–327. doi:10.1037/0022-0167.42.3.323.

Benoit, L. G., Veach, P. M., & LeRoy, B. S. (2007). When you care enough to do your very best: Genetic counselor experiences of compassion fatigue. *Journal of Genetic Counseling, 16*(3), 299–312. doi:10.1007/s10897-006-9072-1.

Bernhardt, B. (2014). Genetic counselors and the future of clinical genomics. *Genome Medicine, 6*(7), 48–51.

Bernhardt, B. A., Rushton, C. H., Carrese, J., Pyeritz, R. E., Kolodner, K., & Geller, G. (2009). Distress and burnout among genetic service providers. *Genetics in Medicine, 11*(7), 527–535. doi:10.1097/GIM.0b013e3181a6a1c2.

Bernhardt, B. A., Silver, R., Rushton, C. H., Micco, E., & Geller, G. (2010). What keeps you up at night? Genetics professionals' distressing experiences in patient care. *Genetics in Medicine, 12*(5), 289–297. doi:10.1097/GIM.0b013e3181db82d9.

Bernhardt, B. A., Soucier, D., Hanson, K., Savage, M. S., Jackson, L., & Wapner, R. J. (2012). Women's experiences receiving abnormal prenatal chromosomal microarray testing results. *Genetics in Medicine, 15*(2), 139–145. doi:10.1038/gim.2012.113.

Bernhardt, B. A., Kellom, K., Barbarese, A., Faucett, W. A., & Wapner, R. J. (2014). An exploration of genetic counselors' needs and experiences with prenatal chromosomal microarray testing. *Journal of Genetic Counseling, 23*(6), 938–947. doi:10.1007/s10897-014-9702-y.

Blais, A. R., & Weber, E. U. (2006). A Domain-Specific Risk-Taking (DOSPERT) scale for adult populations. *Judgment and Decision Making, 1*, 33–47. doi:10.1002/bdm.414.

Cohen, S., & Wills, T. A. (1985). Stress, social support and the buffering hypothesis. *Psychological Bulletin, 98*(2), 310–357.

Djurdjinovic, L. (2009). Psychosocial counseling. In W. Uhlmann, J. Schuette, & B. Yashar (Eds.), *A guide to genetic counseling* (2nd ed.). Wiley.

Doka, K. J. (Ed.) (2002). *Disenfranchised grief: New directions, challenges and strategies for practice*. Champaign: Research Press.

Duric, V., Butow, P., Sharpe, L., Lobb, E., Mesier, B., Barratt, A., et al. (2003). Reducing psychological distress in a genetic counseling consultation for breast cancer. *Journal of Genetic Counseling, 12*, 243–264. doi:10.1023/A:1023284219871.

Epstein, R. M., & Gramling, R. E. (2013). What is shared in shared decision making? Complex decisions when the evidence is unclear. *Medical Care Research and Review, 70*(1 suppl), 94S–112S. doi:10.1177/1077558712459216.

Etchegary, H., Potter, B., Howley, H., Cappelli, M., Coyle, D., Graham, I., et al. (2008). The influence of experiential knowledge on prenatal screening and testing decisions. *Genetic Testing, 12*(1), 115–124. doi:10.1089/gte.2007.0057.

Eunpu, D. L. (1997). Systemically-based psychotherapeutic techniques in genetic counseling. *Journal of Genetic Counseling, 6*(1), 1–20. doi:10.1023/A:1025630917735.

Farrell, R. M., Nutter, B., & Agatisa, P. K. (2015). Patient-centered prenatal counseling: Aligning obstetric healthcare professionals with needs of pregnant women. *Women & Health, 55*(3), 280–296. doi:10.1080/03630242.2014.996724.

Farrelly, E., Cho, M. K., Erby, L., Roter, D., Stenzel, A., & Ormond, K. (2012). Genetic counseling for prenatal testing: where is the discussion about disability? *Journal of Genetic Counseling, 21*(6), 814–824. doi:10.1007/s10897-012-9534-6.

Gelso, C., & Carter, J. (1994). Components of the psychotherapy relationship: Their interaction and unfolding during treatment. *Journal of Counseling Psychology, 41*(3), 296–306. doi:10.1037/0022-0167.41.3.296.

Han, P. K. (2013). Conceptual, methodological, and ethical problems in communicating uncertainty in clinical evidence. *Medical Care Research and Review, 70*(1 suppl), 14S–36S. doi:10.1177/1077558712459361.

Han, P. K., Klein, W. M., & Arora, N. K. (2011). Varieties of uncertainty in health care a conceptual taxonomy. *Medical Decision Making, 31*(6), 828–838. doi:10.1177/0272989X11393976.

Hiller, E., & Rosenfield, J. M. (2000). The experience of leader-led peer supervision: Genetic counselors' perspectives. *Journal of Genetic Counseling, 9*(5), 399–410. doi:10.1023/A:1009402231506.

Hillman, S. C., Skelton, J., Quinlan-Jones, E., Wilson, A., & Kilby, M. D. (2013). "If it helps…" the use of microarray technology in prenatal testing: Patient and partners reflections. *American Journal of Medical Genetics Part A, 161*(7), 1619–1627. doi:10.1002/ajmg.a.35981.

Hunt, L. M., de Voogd, K. B., & Castañeda, H. (2005). The routine and the traumatic in prenatal genetic diagnosis: Does clinical information inform patient decision-making? *Patient Education and Counseling, 56*(3), 302–312. doi:10.1016/j.pec.2004.03.004.

Kahneman, D., Slovic, P., & Tversky, A. (1982). *Judgment under uncertainty: Heuristics and biases*. New York: Cambridge University Press.

Kennedy, A. L. (2000). A leader-led supervision group as a model for practicing genetic counselors. *Journal of Genetic Counseling, 9*(5), 391–397. doi:10.1023/A:1009450114667.

Kessler, S. (2001). Psychological aspects of genetic counseling. XIV. Nondirectiveness and counseling skills. *Genetic Testing, 5*(3), 187–191.

Kubler-Ross, E. (1969). *On death and dying*. New York: Macmillan.

Lambert, M. J., & Barley, D. E. (2002). Research summary on the therapeutic relationship and psychotherapy outcome. In J. C. Norcross (Ed.), *Psychotherapy relationships that work* (pp. 17–32). New York: Oxford University Press.

Lobel, M., Dias, L., & Meyer, B. A. (2005). Distress associated with prenatal screening for fetal abnormality. *Journal of Behavioral Medicine, 28*, 65–76. doi:10.1007/s10865-005-2564-x.

Marks, J. H. (1993). The training of genetic counselors: Origins of a psychosocial model. In D. M. Bartels, B. S. LeRoy, & A. L. Caplan (Eds.), *Prescribing our future: Ethical challenges in genetic counseling* (pp. 15–24). New York: Aldine de Gruyter.

Martin, C. L., Kirkpatrick, B. E., & Ledbetter, D. H. (2015). Copy number variants, aneuploidies, and human disease. *Clinics in Perinatology, 42*(2), 227–242. doi:10.1016/j.clp.2015.03.001.

Mathieu, F. (2007). Transforming compassion fatigue into compassion satisfaction: Top 12 self-care tips for helpers. Retrieved from http://www.compassionfatigue.org/pages/Top12SelfCareTips.pdf.

McCoyd, J. L. M. (2008). "I'm not a saint": burden assessment as an unrecognized factor in prenatal decision making. *Qualitative Health Research, 18*(11), 1489–1500. doi:10.1177/1049732308325642.

McCoyd, J. L. M. (2013). Preparation for prenatal decision-making: a baseline of knowledge and reflection in women participating in prenatal screening. *Journal of Psychosomatic Obstetrics and Gynecology, 34*(1), 3–8. doi:10.3109/0167482X.2012.757590.

McCoyd, J. L. M. (2015). Critical aspects of decision-making and grieving after diagnosis of fetal anomaly. In M. S. Verp & J. P. Galst (Eds.), *Prenatal and preimplantation diagnosis: The burden of choice* (pp. 269–285). New York: Springer.

McCoyd, J. L. M., & Walter, C. A. (2016). *Grief and loss across the lifespan: A biopsychosocial approach* (2nd ed.). New York: Springer Publishing.

McDaniel, S. H. (2005). The psychotherapy of genetics. *Family Process, 44*(1), 25–44. doi:10.1111/j.1545-5300.2005.00040.x.

Meiser, B., Irle, J., Lobb, E., & Barlow-Stewart, K. (2008). Assessment of the content and process of genetic counseling: A critical review of empirical studies. *Journal of Genetic Counseling, 17*(5), 434–451. doi:10.1007/s10897-008-9173-0.

Neimeyer, R. A. (2001). *Meaning reconstruction & the meaning of loss*. Washington, D.C.: American Psychological Association.

Parker, A. M., Bruine de Bruin, W., & Fischhoff, B. (2007). Maximizers versus satisficers: Decision-making styles, competence, and outcomes. *Judgment and Decision Making, 2*(6), 342–350.

Pauker, S. P., & Pauker, S. G. (1977). Prenatal diagnosis: A directive approach to genetic counseling using decision analysis. *The Yale Journal of Biology and Medicine, 50*(3), 275.

Peterson, N. A., Hamme, C. L., & Speer, P. W. (2002). Cognitive empowerment of African Americans and Caucasians: differences in understandings of power, political functioning, and shaping ideology. *Journal of Black Studies, 3*, 336–351.

Politi, M. C., & Street, R. L. (2011). The importance of communication in collaborative decision making: Facilitating shared mind and the management of uncertainty. *Journal of Evaluation in Clinical Practice, 17*(4), 579–584. doi:10.1111/j.1365-2753.2010.01549.x.

Redlinger-Grosse, K. (2014). It is time: a commentary on "an exploration of genetic counselors' needs and experiences with prenatal chromosomal microarray testing". *Journal of Genetic Counseling, 23*(6), 933–934. doi:10.1007/s10897-014-9726-3.

Reed, S. (1974). A short history of genetic counseling. *Social Biology, 21*(4), 332–339.

Resta, R., Biesecker, B. B., Bennett, R. L., Blum, S., Estabrooks Hahn, S., Strecker, M. N., et al. (2006). A new definition of genetic counseling: National Society of Genetic Counselors' task force report. *Journal of Genetic Counseling, 15*(2), 77–83. doi:10.1007/s10897-005-9014-3.

Rogers, C. R. (1957). The necessary and sufficient conditions of therapeutic personality change. *Journal of Consulting Psychology, 21*, 95–103. doi:10.1037/h0045357.

Roter, D. L., Erby, L., Larson, S., & Ellington, L. (2009). Oral literacy demand of prenatal genetic counseling dialogue: Predictors of learning. *Patient Education and Counseling, 75*(3), 392–397. doi:10.1016/j.pec.2009.01.005.

Rubel, M., Werner-Lin, A., Barg, F., Kellom, K. & Bernhardt, B. (2015). *Expert knowledge influences decision-making for couples receiving positive prenatal chromosomal microarray testing results*. Chicago, IL: Podium presentation. Annual meeting, American Public Health Association.

Saleebey, D. (Ed.) (2006). *The strengths perspective in social work practice* (4th ed.). Boston: Pearson Education.

Schwartz, B. (2004). *The paradox of choice: Why less is more*. New York: Harper Perennial.

Schwartz, B., Ward, A., Monterosso, J., Lyubomirsky, S., White, K., & Lehman, D. R. (2002). Maximizing versus satisficing: Happiness is a matter of choice. *Journal of Personality and Social Psychology, 83*, 1178–1197.

Stern, A. M. (2009). A quiet revolution: The birth of the genetic counselor at Sarah Lawrence College, 1969. *Journal of Genetic Counseling, 18*(1), 1–11. doi:10.1007/s10897-008-9186-8.

Taylor-Brown, S., & Johnson, A. M. (1998). *Social work's role in genetic services*. Washington, DC: National Association of Social Workers.

Veach, P. M., Bartels, D. M., & LeRoy, B. S. (2007). Coming full circle: A reciprocal-engagement model of genetic counseling practice. *Journal of Genetic Counseling, 16*, 713–728. doi:10.1007/s10897-007-9113-4.

Walser, S. A., Kellom, K. S., Palmer, S. C., & Bernhardt, B. A. (2015). Comparing genetic counselor's and patient's perceptions of needs in prenatal chromosomal microarray testing. *Prenatal Diagnosis, 35*(9), 870–878. doi:10.1002/pd.4624.

Walser, S. A., Werner-Lin, A., Russell, A., Wapner, R. J., & Bernhardt, B. A. (2016). "Something extra on Chromosome 5": parents' understanding of positive prenatal Chromosomal Microarray Analysis (CMA) results. *Journal of Genetic Counseling*, 1–11. doi:10.1007/s10897-016-9943-z.

Wampold, B. E. (2010). Research evidence for common factors models: A historically situated perspective. In B. L. Duncan, S. D. Miller, B. E. Wampold, & M. A. Hubble (Eds.), *The heart & soul of change* (2nd ed.). Washington, DC: APA Press.

Weber, E. U., Blais, A.-R., & Betz, N. (2002). A domain-specific risk-attitude scale: Measuring risk perceptions and risk behaviors. *Journal of Behavioral Decision Making, 15*, 263–290.

Werner-Lin, A., Barg, F. K., Kellom, K. S., Stumm, K. J., Pilchman, L., Tomlinson, A. N., et al. (2015). Couple's narratives of communion and isolation following abnormal prenatal microarray testing results. *Qualitative Health Research, 22*(12), 1–13. doi:10.1177/1049732315603367.

Westerfield, L., Darilek, S., & van den Veyver, I. B. (2014). Counseling challenges with variants of uncertain significance and incidental findings in prenatal genetic screening and diagnosis. *Journal of Clinical Medicine, 3*(3), 1018–1032. doi:10.3390/jcm3031018.

White, R. J. (2005). A priming/temperament model of System 1 and System 2 decision-making processes. *Dissertation Abstracts International: Section B: The Sciences and Engineering, 66*(6-B), 3439.

Winnicott, D. W. (1960). The theory of the parent-infant relationship. *International Journal of Psychoanalysis, 41*(6), 585–595 Accessed at http://icpla.edu/wp-content/uploads/2012/10/Winnicott-D.-The-Theory-of-the-Parent-Infant-Relationship-IJPA-Vol.-41-pps.-585-595.pdf.

Winterbottom, A., Bekker, H. L., Conner, M., & Mooney, A. (2008). Does narrative information bias individual's decision making? A systematic review. *Social Science & Medicine, 67*(12), 2079–2088. doi:10.1016/j.socscimed.2008.09.037.