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PROFESSIONAL ISSUES

An ethical framework for genetic counseling in the genomic era

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Abstract

The field of genetic counseling has grown and diversified since the profession emerged in the early 1970s. In the same period, genomic testing has become more complex, profitable, and widespread. With these developments, the scope of ethical considerations relevant to genetic counseling has expanded. In light of this, we find it helpful to revisit how ethical and relational variables are used to inform genetic counseling practice. Our specific focus is on whether, and to what extent, it is ethically acceptable for genetic counselors to make normative recommendations to patients. This article builds on prior literature that has critiqued nondirectiveness, a concept that has influenced and constrained the modern profession of genetic counseling since its origin. In it, we review scholarly efforts to move beyond nondirectiveness, which we believe privilege patient autonomy at the expense of other important values. We then argue that genetic counselors should favor a more explicit commitment to the principles of beneficence and non-maleficence, as well as a broader understanding of autonomy and the relational variables that impact genetic counseling. Finally, to translate our arguments into practice, we present a framework of six considerations that genetic counselors should take into account when deciding whether it is ethically acceptable, or even desirable, to make recommendations to patients in certain areas of their work.

KEYWORDS

counseling techniques, cultural competence, ethics, genetic counseling, genetics services, genome sequencing, practice models, professional development

1 | INTRODUCTION

Since the inception of their profession, genetic counselors have helped patients and families adapt to varied circumstances and make decisions influenced by powerful emotions. In doing so, they have had to reconcile ethical principles with the diverse values of their patients. While this challenge is not unique in medicine, it has preoccupied genetic counselors disproportionately because such a large share of genetic counseling work involves nuanced discussions about reproductive choices and the impact of difference and disability on people's lives.

Historically, the profession of genetic counseling has relied on 'nondirectiveness' to guide practice. Nondirectiveness has been defined in various ways: as a counseling method designed to be value-neutral (Caplan, 1993); as the prevention of coercion or persuasion in genetic counseling(Hamby & Biesecker, 2000); as a commitment not to impose one's own values on patients (Fine, 1993); and as a counseling strategy that supports autonomous decision-making (Bartels, LeRoy, McCarthy, & Caplan, 1997). The original ethical justification for practicing nondirectively was to respect individual patient autonomy, construed largely as non-interference in patient decision-making (Stern, 2009). This ethos grew out of a genuine respect for persons, particularly concerning reproductive choice and disability rights. The profession's emphasis on nondirectiveness has also been understood as an effort to distance genetic counseling from the morally fraught history of eugenics (Resta, 1997).

As the field of genetics and genomics has diversified over the past decade, the concept of nondirectiveness has come under increasing pressure (Arribas-Ayllon & Sarangi, 2014; Rehmann-Sutter, 2009). This is because the complexity and number of ethical considerations relevant to genetic counseling has increased (Clarke, 2017) and because nondirectiveness has been counterproductive in efforts to establish therapeutic relationships with patients (Biesecker, 2002).

One consequence of the profession's historical emphasis on nondirectiveness has been some confusion about genetic counselors' purview to make normative claims or recommendations as part of their practice (Pennacchini & Pensieri, 2011; Redlinger-Grosse, Veach, & MacFarlane, 2013). This confusion persists despite evidence that genetic counselors are making increasingly proactive, evidence-based recommendations in some clinical settings (Kruger et al., 2019). Today's genetic counselors are also involved in developing guidelines and position statements (Druker et al., 2017; Levin & Varga, 2016; Sturm et al., 2018). In light of this work, it seems disingenuous to claim that genetic counseling is premised on a wholesale deference to patient choice.

In this article, we argue that in today's wide-ranging terrain of genetic counseling, the profession should adopt a more expansive view of the ethical principles and considerations that impact their work. While we recognize that new models of genetic counseling practice are emerging, most of them continue to emphasize some version of patient autonomy as the core principle guiding the profession. To complement prior work that has attempted to move away from nondirectiveness, we argue that genetic counselors should embrace a more *explicit* commitment to the principles of beneficence and non-maleficence, in addition to a broader understanding of both individual autonomy and the relational variables that influence the counseling process. To translate our arguments into practice, we present a framework of six considerations that can help genetic counselors determine whether and why it might be acceptable, or even desirable, to provide recommendations to patients as part of their practice.

2 | AUTONOMY IN GENETIC COUNSELING

Genetic counseling is a relatively young profession. Since the 1990s, several of its leaders have called for the abandonment of nondirectiveness as a guiding concept (Biesecker & Peters, 2001). Arguments against nondirectiveness include that it limits a counselor's engagement with the recipients of counseling (Biesecker, 2002); precludes counselors from discussing evidence-based medical recommendations (Clarke, 2017); is not practically attainable (Brock, 1991), and reflects the profession's Western cultural bias (Weil, 2003).

While we concur with prior critiques of nondirectiveness, we recognize there are compelling reasons for genetic counselors to promote *respect for persons* using other approaches, including balanced, client-centered communication. This respect is especially crucial when counselors present information about the lived experiences of people with genetic conditions. We also recognize the need to defer to patient autonomy in the many preference-sensitive areas that genetic counseling touches upon. In bioethics, recognition of an individual's right to define one's own conception of what is good (for oneself) is a response to a long history of medical paternalism (Fine, 1993). In genetic counseling specifically, valuing patient autonomy expresses respect for the emotionally complex and nuanced nature of decisions about reproduction, pregnancy management, living with a genetic condition, and raising children with special needs. Since the widespread introduction of noninvasive prenatal testing, evidence suggests that women's autonomy is being eroded by the routinization of prenatal risk assessment, a trend that makes it more important than ever for counselors to actively help prospective parents engage in reflective, decision-making about childbearing that is consistent with their own values (Lewis, Hill, & Chitty, 2017). By suggesting that genetic counselors have growing purview to make recommendations in some areas of their practice, we in no way seek to undermine genetic counselors' long-standing commitment to providing balanced, nonjudgmental information about genetic conditions and reproductive planning.

That individual autonomy and the related concept of respect for persons still have *value* in genetic counseling does not prevent us from questioning the outsized role these principles have played relative to other considerations that might motivate genetic counselors to make recommendations about certain topics. While the tension between making professional recommendations and respecting patient autonomy is perhaps most appreciable in the context of prenatal genetic counseling, empirical data show that many women prefer clear recommendations about which prenatal genome sequencing results to receive (Sullivan et al., 2019) and that the burden of responsibility they feel about prenatal decision-making can be alleviated by positive affirmation from a counselor (Salema, Townsend, & Austin, 2019). That some prospective parents desire guidance about their prenatal testing does not imply that a genetic counselor should override a patient's right to make autonomous choices about his/her/their pregnancy. Rather, it challenges the assumption that all prospective parents want total decisional independence concerning pregnancy risk assessment (Shiloh, 1996).

3 | RELATIONAL THEORY IN GENETIC COUNSELING

Scholarship over the past decade has produced some alternatives to nondirectiveness, primarily by turning to relational theories (Forbes Shepherd, Browne, & Warwick, 2017; Ryan, Virani, & Austin, 2015). Convincingly, leaders in the field have argued that genetic counseling is best conceptualized as a form of time-limited, highly circumscribed psychotherapy (Austin, Semaka, & Hadjipavlou, 2014). According to this model, the goal of counseling is to develop a therapeutic relationship with patients to meet their emotional and

informational needs. The concept of 'relational autonomy' is used to describe the core principle relevant to psychotherapeutic genetic counseling (Ryan et al., 2015).

Relational autonomy, defined as 'the conviction that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants' (Mackenzie & Stoljar, 2000) captures the interplay between individual and familial interests that is a core part of the genetic counseling process. It recognizes that clinicians may provide meaningful guidance to a patient by virtue of developing a relational bond with him/her/them and encourages attention to the emotional needs of patients and their family members at the same time (Walter & Ross, 2014).

Relational factors also play a central role in the reciprocal-engagement model (REM), which describes both the teaching and education functions of genetic counseling while recognizing that patients' emotions, experiences, and characteristics lead them to make different decisions in light of similar facts (Veach, Bartels, & LeRoy, 2007). A strength of the REM is that it highlights the value of providing accurate information while keeping the counseling relationship at the center of what genetic counselors do.

While they describe useful ideas, relational theories are relatively silent about whether and why genetic counselors might be justified in making professional recommendations in specific aspects of practice. This is because on their own, relational theories do not provide a framework for specifying and balancing conflicts between autonomy and other ethical values. The National Society of Genetic Counselors' (NSGC) Code of Ethics, which provides a comprehensive list of principles and responsibilities that genetic counselors uphold in many areas of diverse work, does not provide this either. Section II of the NSGC Code of Ethics, which concerns genetic counselors' relationships with clients, stipulates that genetic counselors should 'enable their clients to make informed decisions, free of coercion, by providing or illuminating the necessary facts, and clarifying the alternatives and anticipated consequences' while respecting 'their clients' beliefs, inclinations, circumstances, feelings, family relationships, sexual orientation, religion, gender identity, and cultural traditions' ('National Society of Genetic Counselors: NSGC Code of Ethics', n.d.). While we do not disagree with the NSGC's guidance, we believe that further specification of these values in differing contexts might be useful to the profession.

We agree with others (Clarke, 2017) that it is necessary to revisit the balance of ethical values that guide genetic counseling practice, because contemporary genetic counselors work in some settings that differ drastically from the ones the profession originated in. In the past, most genetic counselors were concerned with diagnosing rare, life-altering conditions. Today, many counselors are asked to assess health risks and facilitate decision-making in a variety of medical subspecialties, including some where genome-guided medical management can impact disease morbidity and mortality. Genetic testing and family history assessment are now being used to identify patients who need heightened cancer screening or patients who have adverse reactions to certain drugs. Even when genetics touches upon emotional and ethical issues that people have different moral views about, the relevant testing has become more complicated to interpret and is being generated from more sources than ever before. This complexity increases the risk that genetic information will be misinterpreted or used inappropriately with harmful effects (Farmer et al., 2019). Against the backdrop of these developments, genetic counselors' expertise is more important than ever.

Our core claim is that owing to the expanded scope and complexity of genetic counseling work, the profession should favor a more explicitly normative framework that gives genetic counselors broader license to make recommendations while operating within a well-defined scope of practice.

4 | AN ADAPTED ETHICAL FRAMEWORK

The framework we present in this article does not refute the idea that respect for individual autonomy will always be an important value in medicine. Our main premise is that the profession of genetic counseling has emphasized individual autonomy at the expense of defining more explicit roles for beneficence and non-maleficence in genetic counseling practice, even though these values have been invoked in debates about genetic counseling for decades (Caplan, 1993). Beneficence, a welfarist principle, implies that genetic counselors should use professional judgment and evidence to assess whether genetic testing might *benefit* a patient irrespective of her views about it. Non-maleficence, a principle of harm minimization, implies that genetic counselors use expertise and evidence to prevent genetic testing and information from being used *harmfully*, where possible.

Building on prior work, our framework also recognizes the importance of relational theory to genetic counseling. It does this by considering the depth of a genetic counseling relationship and a counselor's role in the health care system as variables that should influence practice. We also posit that genetic counselors are ethically bound to consider the family as a unit of significance. This compels counselors to reconcile patients' autonomy interests with more nuanced concerns about benefits and harms to families. Where we do give deference to individual autonomy in our framework, we insist on a broad conception of autonomy that asks more of a genetic counselor than non-interference in patient decision-making (Hodgson & Spriggs, 2005). Our fuller notion of autonomy asks genetic counselors to use their unique skillset to help patients incorporate genetic information into truly informed, confident, and voluntary decision-making.

In what follows, we propose six considerations that can help a genetic counselor determine whether and why it might be ethically acceptable to provide recommendations to a patient or family: (a) Goal of counseling; (b) Clinical relevance of genetic information; (c) Informational burden of test options or results; (d) Relational considerations; (e) Role-based considerations; and (f) Familial considerations. The first three considerations pertain to the nature of the content being discussed in a counseling session; the last three

pertain to relational aspects of genetic counseling that affect a counselor's purview to influence patient decision-making. These six domains do not constitute a code of ethics or a prescriptive set of universal rules. Rather, they offer general guidance about areas of genetic counseling practice where a more proactive approach involving recommendations may serve a patient or family's best interests.

4.1 | Goal of counseling

Genetic counseling is a versatile profession. Goals of the genetic counseling process may include providing information about test options, assessing psychological well-being, helping patients and families communicate about genetic risk, facilitating adaptation to grief and loss, interpreting results, assisting with decision-making and referrals, or some combination of these things (National Society of Genetic Counselors' Definition Task Force et al., 2006). Genomic testing and family history assessment can be used to answer qualitatively different questions, some of which are technical and mundane, others of which raise forceful emotions and divergent points of view. No clinician should ever make assumptions about what another person values, and as such, eliciting patients' goals is a fundamental aspect of the genetic counseling skillset.

Across the contexts where genetic testing and family history assessment are used, some goals are met with more moral consensus than others. Women have wide-ranging views about the desirability of diagnosing an intellectual disability syndrome prenatally, and the issue of abortion is perennially divisive (Sapp et al., 2010; van Schendel et al., 2017). However, most people value analytically valid test results and proven, low-risk interventions that can minimize disease-associated morbidity and mortality (Lim et al., 2017).

It follows from this that genetic counselors have more purview to provide recommendations to patients when the goal of genetic counseling is to impart technical information, such as information about the strengths and limitations of available tests. The same applies when genetic testing or family history assessment has the potential to facilitate an outcome that is widely understood to be good, such as the minimization of a patient's physical or emotional pain. In areas of practice that touch on strongly held or differing conceptions of what is good, a counselor may have less purview to make recommendations.

The degree of moral consensus or controversy about a counseling goal is not the sole source of information that counselors should use to determine the acceptability of counseling directively. Taken to an extreme, such logic might lead counselors to dismiss strongly endorsed values held by a minority of patients. Nonetheless, public attitudes and medical expert consensus can provide useful information about the range of values and interests that matter in relation to a given counseling goal. This is not to say that information about public attitudes can substitute for a patient's articulation of his/her/their *own* values in specific cases; it is merely one consideration among many that should be taken into account.

4.2 | Clinical utility of genetic information

Genomic testing can provide information about diseases with differing prevention and treatment options. Ongoing research is generating evidence about which genetic findings are considered 'actionable' according to criteria that take into account the severity and likelihood of a clinical outcome and the effectiveness of available interventions associated with findings in different genes (Webber et al., 2018). The concept of 'actionable genetic information' can be interpreted broadly, to include results that impact patients' financial, family planning, and lifestyle decisions or it can be interpreted narrowly, as a subset of results that point to effective medical interventions. Interview data show that patients' perceptions of actionability are highly context-dependent and that patients endorse a broader conception of actionability than medical professionals do (Jamal et al., 2017).

A key part of the person-centered genetic counseling process is to help patients explore what might change for him/her/them in light of a test result. When the consequences of a genetic test result are contingent upon personal and contextual variables, we recognize that patient choice plays a critical role in determining how to act upon genetic information. However, when genetic information quite clearly has the potential to improve a patient's health through accessible, effective medical intervention, we agree with others that clinicians are bound by duties of beneficence to encourage patients to pursue an evidence-based course of action, taking care to remain within a well-defined scope of practice (McGuire et al., 2013). In the face of information that could potentially improve survival or quality of life by triggering a referral to a physician for follow-up assessment, there is less of a compelling reason to treat genetic information differently than other medical information that may be undesirable to learn yet clinically useful.

4.3 | Informational burden of test options or results

Genetic risk assessment varies in terms of its complexity and corresponding informational burden. The genomic tests that are commonly used today interrogate dozens or even hundreds of genes and have different sensitivities and specificities for each condition tested, depending on the methodology being used. Empiric risk data and polygenic risk scores also involve a number of opaque limitations and caveats (De La Vega & Bustamante, 2018; Martin et al., 2019). Many of the conditions tested for are rare, with poorly understood natural histories, making it challenging for the average person to comprehensively understand the range and limits of the information a test might provide (Schrijver et al., 2012). Genomic testing is also interpreted using a series of inferences and analytical steps that rely on information in the scientific literature and in public and private

databases. Tests have varied technical specifications and may detect variants with unclear clinical significance.

The complexity and uncertainty associated with genetic information can be difficult to discuss in a concise and impartial manner that is accessible to patients (Han et al., 2017; Skinner, Raspberry, & King, 2016). This is particularly true when a test detects a variant of uncertain clinical significance (VUS) (Culver et al., 2013). There is evidence that healthcare providers, including physicians, may over-interpret the clinical significance of VUSes, using them to guide medical management when this is at best wasteful and at worst harmful (Plon et al., 2011). Because of their unique expertise and duty to minimize harms to patients, genetic counselors play an important role in pointing out which tests or approaches to risk estimation do not have strong associated evidence. This is not to imply that genetic counselors should make *all* the decisions about the use of genetic risk information in a patient's medical management; of course, a physician's assessment of the role between a genotype and phenotype remains key. Rather, as a member of a team who is trained in genetics and genomics, a genetic counselor should recommend an evidence-based course of action to patients and colleagues who might otherwise allow patient care to be influenced by a test result or risk estimate that has a tenuous association with disease.

4.4 | Relational considerations

Thus far, we have focused on the roles genetic counselors play as medical providers who educate patients about diagnostic or risk information. This obscures the reality that some of the most meaningful aspects of genetic counseling have less to do with testing than the provision of psychological support and empathy. Genetic counseling relationships take many forms and can be short-term or long-term, in-person, or long-distance. In general, the closer and more substantive a relationship between a genetic counselor and patient is, the more purview a counselor has to tailor recommendations for him/her/them based on an understanding of his/her/their needs.

At least two aspects of a counseling relationship are ethically salient. The first is the degree to which empathy has been established between counselor and patient. Patients consistently report higher satisfaction with genetic counseling when it resembles a therapeutic relationship characterized by genuine empathy and low verbal dominance (Dijkstra, Albada, Klöckner Cronauer, Ausems, & van Dulmen, 2013; Roter, Ellington, Erby, Larson, & Dudley, 2006). Evidence also suggests that genetic counseling is more effective at promoting positive health behavior change and minimizing decisional regret when genetic counselors establish genuine empathy with a patient or family (Duric et al., 2003). This is not surprising; the very information genetic counselors need to know about their patients comes through listening and dialogue.

Fundamentally, the goal of psychotherapeutic genetic counseling is to establish 'a helping relationship in which one person has the knowledge and skills relevant to helping another person address a problem through conversation' (Austin et al., 2014). This model does not preclude counselors from tailoring information based on patients' needs or from using crisis intervention skills, grief counseling techniques, and behavior change interventions to benefit patients. In fact, veteran genetic counselors have long argued that a psychotherapeutic model of genetic counseling is more effective at achieving desired outcomes through purposeful intervention than purely didactic counseling methods (Barbara B. Biesecker & Peters, 2001).

A second relevant feature of a counseling relationship is the degree of shared cultural understanding between patient and counselor. While genetic counselors practice in increasingly diverse societies and have a rapidly growing international presence, the profession remains overwhelmingly white, female, and young (Abacan et al., 2019). Evidence demonstrates that systemic, cultural, and linguistic barriers pose challenges to effective communication and counseling about genetic risk (Gutierrez et al., 2017; Muller et al., 2018; Rapp, 1993; Schaa, Roter, Biesecker, Cooper, & Erby, 2015). In many societies, the unit of decisional significance is the household or community (Rotimi et al., 2007), challenging an individual autonomy-focused model of genetic counseling. Even within the same society, there may be socioeconomic and cultural differences affecting the rapport between a patient and counselor, many of which are exacerbated in a medical environment that fosters power asymmetries between patients and providers (Halbert et al., 2012; Mittman, Bowie, & Maman, 2007). Sociocultural or linguistic differences may erode a patient's ability to make informed decisions; power differentials may undermine truly voluntary decision-making. As such, both are ethical concerns for a genetic counselor. Owing to the challenges of building meaningful short-term relationships with patients and overcoming sociocultural biases, genetic counselors should continue to conduct research that explores best practices for maximizing the value of short-term interactions with patients (Buchanan, Rahm, & Williams, 2016; Cloutier et al., 2017; Schmidlen, Schwartz, DiLoreto, Kirchner, & Sturm, 2019) and promote self-awareness about how sociocultural biases impact counseling processes and outcomes (Schaa et al., 2015).

The closer and more therapeutic a relationship a genetic counselor has with a patient, the more likely it is that the counselor truly understands his/her/their preferences, decision-making style, and appetite for information. Similarly, the more culturally synchronized a counselor and patient are, the more likely they are to operate based on a shared ethical frame of reference. It is in the context of these deeper and more therapeutic relationships that counselors may use what they know about a patient to more confidently tailor normative recommendations for him/her/them.

4.5 | Role-based considerations

The institutional vantage point (i.e., clinical, research, industry) of a genetic counselor also affects his/her/their ethical responsibilities. While all genetic counselors have a professional responsibility to

provide compassionate and accurate counseling to their patients, counselors who work in direct patient care settings have the strongest and most explicit duties to maximize the benefits and minimize the harms of genetic counseling and testing. Motivated by beneficence and non-maleficence, genetic counselors practicing in clinical roles should recommend the genetic and genomic tests with highest sensitivity and specificity, fewest limitations, and which are priced most reasonably given a patient or family's needs. To do so is not the same as forcing patients to be tested; rather, it is an exercise of professional judgment to distinguish high-quality, relevant tests from those that are unreliable, irrelevant to a patient's needs, or poor value for money.

Genetic counselors who work in research settings may also assume duties of care to patients. This is especially true when they see research participants and families with rare diseases who do not have access to care outside of a study. Yet many research studies have limited resources to clinically confirm research results, return them to patients, and provide responsible follow-up. When counseling a research participant, a genetic counselor has a primary responsibility to convey the purpose of the research study and the limits of what information and services the study can provide. If the research participant's medical needs would be better served elsewhere, a research-based genetic counselor should make this clear and recommend other avenues for a patient to receive necessary care.

Since the 1990s, a growing number of genetic counselors have taken jobs in industry, where many of them provide direct patient care via telemedicine ('National Society of Genetic Counselors: NSGC Professional Status Survey', n.d.). These new kinds of counseling relationships have raised questions about conflicts of interest (Stoll, Mackison, Allyse, & Michie, 2017). In addition, a new class of so-called 'consumer-initiated' testing has become available, granting access to genetic testing with indirect or minimal involvement of a healthcare provider (Ramos & Weissman, 2018). These developments place new responsibilities on genetic counselors to serve as intermediaries between the commercial interests of for-profit laboratories and patients seeking testing.

Genetic counselors working in commercial settings must recognize that conflicts of interest exist and have the potential to undermine trust in the profession. In addition to being transparent about conflicts of interest, where possible, genetic counselors should base their practice on guidelines, evidence, and the goals of maximizing benefits and minimizing harms. By incorporating the values of transparency, beneficence, and non-maleficence into their practice, industry genetic counselors have a crucial role to play in bolstering the legitimacy and integrity of their field as new genomic products and markets emerge. They should work to mitigate the role of commercial interests in making genetic testing available to patients, and at times, this may require them to be directive. To practice 'nondirectively' from an industry vantage point would risk diverting patients to other sources of recommendations about genomics, such as commercial advertising or mainstream media. These sources of information have been found to be incomplete (at best) and misleading (at worst), making it highly irresponsible for genetic counselors to wholly defer to them.

4.6 | Familial considerations

The sixth ethically salient consideration we highlight is that much genetic and genomic information is shared by family members. Broadly speaking, there are two rationales for involving a patient's relatives in the genomic testing process. The first is to benefit a patient's *relatives* by identifying whether they are at increased risk of developing a preventable or treatable disease (Hampel, 2016; Sturm et al., 2018). The second is to benefit a *patient*, either by identifying the most informative family member to test, exploring how a variant segregates with disease in a family, or determining whether a variant occurred 'de novo' in a patient (Richards et al., 2015). Contacting a patient's relatives is not a peripheral matter in genetic counseling; it is an essential step in maximizing the accuracy, precision, and utility of genetic testing.

Concerning the first reason for involving relatives (i.e., to benefit them), the bioethics literature is divided about the extent of genetic counselors' responsibilities. The issue arises most frequently in discussions about whether genetic counselors ever have 'duties to warn' at-risk relatives about an inherited disease risk when doing so goes against a patient's expressed preference. Some argue that a genetic counselor's primary duty is to his/her/their patient. Under this view, a counselor must never breech the sanctity of patient confidentiality (Rothstein, 2018). Others have pointed out that in practice, it is rare for patients to insist strongly on non-disclosure of genetic test results to relatives (Dheensa, Fenwick, & Lucassen, 2016). Instead of viewing confidentiality to the individual patient as the default priority, they suggest that genetic information should be conceptualized as familial. Under this so-called 'joint account' model, the disclosure of medically useful genetic information to relatives is the default practice unless there are strong reasons to privilege individual patient confidentiality (Parker & Lucassen, 2004). Our view is that these frameworks represent extremes, and that there are good reasons to help patients disclose medically useful information to relatives in many, if not all cases.

Concerning the second reason for involving relatives (i.e., to benefit the patient), it is now clear that familial testing is a crucial method of understanding the penetrance and pathogenicity of a genetic variant. As guidelines show, familial testing can provide critical information needed to classify a genetic variant according to best practices (Richards et al., 2015). While it is never the place of a genetic counselor to force a patient to disclose information against his/her/their will, we feel that duties of care and group beneficence should motivate genetic counselors to recommend familial testing when it is medically indicated or will add clarity to a genetics evaluation. In many instances, failure to collect familial samples for testing means that a patient is left with an inconclusive or uninformative result that cannot be used to inform care.

We agree with others that an individual-focused analysis of direct benefits and harms excludes important ethical considerations that should factor into genetic counseling (Wilfond, Fernandez, & Green, 2015). Although the details of specific cases will vary, in general we see a need for genetic counselors to consider the risks and benefits that might accrue to a patient in a wider family context. For example, a child diagnosed with an inherited cancer syndrome is unlikely to do well if his mother develops an advanced, undetected cancer because she was unaware of her own elevated cancer risk.

We understand that some think relatives have a 'right not to know' genetic information about themselves. While there are clearly circumstances where patients should be allowed to opt out of learning information that could be wasteful or harmful, we find it ethically untenable to accept an absolutist interpretation of the 'right not to know' the *primary* goal of genetic counseling practice, because it is based on largely hypothetical worries about the psychological harms of genetic information which have not been borne out by evidence (Berkman, 2017; Prince & Berkman, 2018).

There may be reasons for patients and families to opt out of learning or disclosing genetic information, in cases where an at-risk relative is severely ill or nearing end of life, has other more emergent emotional issues to grapple with, or is highly vulnerable to discrimination or stigma based on the results of genetic testing. Along similar lines, we realize that there is controversy about where disclosure of predictive genetic information to a child might foreclose opportunities for that child to make self-determined health decisions later in life (Garrett et al., 2019). That said, we do not accept that withholding clinically relevant health information from a patient's relatives should be a *default* orientation of genetic counseling, because it does not give due ethical weight to the benefits of targeted health interventions that genetic information can lead to, such as cancer and cardiovascular screening or avoidance of life-threatening anesthesia. Genetic counselors have training and skills that can help families manage the disclosure of genetic risk information, even when it is practically and emotionally challenging to do so.

5 | CONCLUSION

In this article, we have argued that genetic counselors have more reason than ever to consider the benefits and harms of genetic testing (to both patients and families) when providing counseling, and that considerations related to beneficence and non-maleficence give counselors license to provide recommendations to patients in at least some circumstances. As the field of genetic counseling diversifies, we have also suggested that genetic counselors should reflect on the nature of their relationships with patients and families, their roles in the healthcare system, and the ethical implications of these variables. While individual patient autonomy always matters in health care, we believe autonomous decision-making is best served by providers who make carefully chosen, relevant recommendations to patients based on clinical expertise and informed by the expressed preferences, emotions, and values of patients and, where relevant, their family members. Critically, our assertion that genetic counselors should feel *licensed* to make evidence-based recommendations does not *preclude* counselors from deferring to patient preferences in situations where countervailing personal, familial, emotional, or cultural values matter more.

Some argue that ethical frameworks are little more than checklists of values that lack coherence or normative force because they are divorced from the comprehensive, overarching theories they originated from (Clouser & Gert, 1990). Responses to this rest on at least three assertions: (a) that there may be reasonable disagreement about the right outcome of a real-life ethical dilemma; (b) that the interpretation and specification of principles are desirable and necessary steps in applied ethics; and (c) that practicability is an important criterion for judging the adequacy of an applied ethical framework (Beauchamp, 1995; Beauchamp & Childress, 2013).

These three assertions map well onto preoccupations about ethics that have been raised in the field of genetic counseling. Genetic counselors have always been concerned with respecting pluralism, recognizing that two patients with the same genetic risk may arrive at different, equally justifiable responses to the same information. They also strive to incorporate particular facts of a case, including aspects of context and specific patient preferences, into their counseling. As clinicians, genetic counselors are predominantly concerned with norms that can be put into practice, as we have tried to do in this article.

The goal of bioethics is not to provide a single, unifying theory of right or wrong behavior. Rather, it is to provide a stable yet flexible method of identifying values that may be in conflict or traded off when decisions are made in real life. In this tradition, our framework is meant to be a point of departure for additional interpretation, specification, and balancing. To say that an updated ethical framework for genetic counseling practice might be *useful* is not to claim that there is a universal system of ethics that applies to all problems that genetic counselors are faced with, nor that ethics is a sufficient lens to base all of genetic counseling practice upon. We merely assert that genetic counselors should embrace a wider range of established ethical principles that can be adapted to add clarity to their challenging work.

AUTHOR CONTRIBUTIONS

Leila Jamal, ScM, PhD, CGC, conceived the initial idea for this manuscript, drafted the first draft, and incorporated revisions to the final draft. Will Schupmann, BA, provided substantive input on the conceptual arguments in this manuscript and contributed several rounds of critical revisions to the final draft. Benjamin E. Berkman, JD, MPH, provided initial feedback on the conceptual idea underlying this manuscript and contributed several rounds of critical revision to the final draft. All authors agree to be accountable for all aspects of this work and have approved this draft for review publication by the Journal of Genetic Counseling.

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COMPLIANCE WITH ETHICAL STANDARDS

Conflict of interest

Leila Jamal, Will Schupmann, and Benjamin Berkman declare that they have no conflict of interest.

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