

Henry Ford Health

Henry Ford Health Scholarly Commons

Pathology Articles

Pathology and Laboratory Medicine

4-23-2022

Investigating factors that influence genetic counselors' decisions to refer patients to mental health providers

Taylor J. Hayes

Henry Ford Health, thayes9@hfhs.org

Mitchell Cunningham

Angela Trepanier

Follow this and additional works at: https://scholarlycommons.henryford.com/pathology_articles

Recommended Citation

Hayes T, Cunningham M, and Trepanier A. Investigating factors that influence genetic counselors' decisions to refer patients to mental health providers. *J Genet Couns* 2022.

This Article is brought to you for free and open access by the Pathology and Laboratory Medicine at Henry Ford Health Scholarly Commons. It has been accepted for inclusion in Pathology Articles by an authorized administrator of Henry Ford Health Scholarly Commons.

ORIGINAL ARTICLE

Investigating factors that influence genetic counselors' decisions to refer patients to mental health providers

Taylor Hayes^{1,2}  | Mitchell Cunningham^{1,3} | Angela Trepanier¹

¹Center for Molecular Medicine and Genetics, Wayne State University School of Medicine, Detroit, Michigan, USA

²Henry Ford Health System, Detroit, Michigan, USA

³Mercy Clinic - Genetics, Mercy Hospital St. Louis, St. Louis, Missouri, USA

Correspondence

Taylor Hayes, Henry Ford Health System, 3031 W. Grand Blvd., Suite 700 Detroit, Michigan, 48202 USA.

Email: thayes9@hfhs.org

Abstract

Genetic counselors (GC) serve patients who are often in distress at the time of their consultation. GC competency includes providing short-term, client-centered counseling, while using community resources, such as mental health providers (MHPs), for psychosocial support. The purpose of this study was to assess the mental health referral practices of GCs; specifically, the rate of referrals, factors influencing a GC's decision to refer, and barriers to referrals. GCs working in direct patient care for at least one year were recruited to take a novel 27 question survey created based on the results of a previous qualitative study. A link to the web-based survey was distributed through the National Society of Genetic Counselors Student Research Program and American Board of Genetic Counselors by email. A total of 144 individuals opened the survey for an estimated response rate of 3%. A majority of respondents (54.3%) reported they assess a patient's need for a mental health referral at least half of the time. The mean number of referrals made in the past 12 months was 5.13. After post-hoc analyses, there were no differences in referral rates between specialties. Common referral indications included patient history of mental illness, distress about having a genetic condition, and limited social support. Common barriers to referral were financial or insurance related, patient receptiveness, and the patient not perceiving a benefit. GCs felt that providing psychosocial support is within their scope of practice, but that MHPs are better equipped to manage long-term needs and those related to a mental health condition. This study provides insight into how GCs decide when they can manage patient distress, circumstances that prompt a referral to MHPs, and barriers. Recognizing common referral indications and barriers may lead to better strategies for connecting patients with such services.

KEYWORDS

genetic counseling, Genetic counselors, mental health, psychosocial assessment

1 | INTRODUCTION

In 2018, almost 1 in 5 adults in the United States experienced a form of mental illness, but less than half sought treatment through a mental health provider (Substance Abuse & Mental Health Services Administration, 2019). Mental health providers, including psychologists, psychiatrists, clinical social workers, and licensed professional

counselors, are specifically trained in diagnosing mental illness, providing long-term therapy, and for some, prescribing medications. Their work is "...focused on helping individuals move toward individuation, independence, and rational thinking" (Sommers-Flanagan & Sommers-Flanagan, 2012).

Given the prevalence of mental illness, genetic counselors likely encounter patients who may benefit from mental health services

fairly frequently. Furthermore, individuals presenting for genetic counseling services often face a variety of distressing situations, such as the risk or diagnosis of a serious health condition in themselves or a relative(s), which alone may prompt a need for psychological support. For instance, Vos et al. (2013) found that a little more than a quarter of Dutch breast and ovarian cancer patients who received genetic counseling and testing for *BRCA1/2* requested psychological help at the time of the initial counseling session. A large proportion who requested help did not have psychopathology but were having difficulty coping with cancer, distress about surgical decision making, or challenges with familial communication, (Vos et al., 2013). A study evaluating emotional distress in an oncology setting identified factors associated with a need for mental health intervention including high levels of distress, poor social support, and direct request for support by the patient (Söllner et al., 2001).

In a pediatric genetics setting, the diagnosis of a rare disease can cause parents to experience decreased hope, a sense of being overwhelmed, as well as generalized anxiety, fear, anger, frustration, and uncertainty (Krabbenborg et al., 2016; Pelentsov et al., 2016). In their study of parents of children with rare diseases, Pelentsov et al. (2016) found that 46% of parents felt socially isolated, 53% felt anxious and fearful, and 46% felt angry and frustrated. In a prenatal genetic counseling setting, patients who received a diagnosis of a fetal abnormality experienced increased psychological burden consisting of inner conflict and fear (Kowalcek, 2007). Such situations thus potentially prompt a need for further intervention either managed by the genetic counselor or by referral to a mental health professional.

Genetic counselors are trained to, "...identify, assess, and empathically respond... (p. 4)" to patient concerns and, "...use a range of genetic counseling skills and models to facilitate informed decision-making and adaptation to genetic risks or conditions... (p. 4)" (Accreditation Council for Genetic Counseling Practice Based Competencies, 2019). This includes being able to identify patients who require mental health intervention (Veach et al., 2007; Vos et al., 2013). Differences between genetic counselors and mental health professionals have been described, such as time spent with the patient and the primary indication for the counseling (Cunningham et al., 2018; Kuramoto-Crawford et al., 2015; Peters, 1994). It remains unclear, however, when managing a psychosocial concern is no longer in the genetic counselor's scope of practice and a referral is needed. There are currently no guidelines for when genetic counselors should make referrals to mental health providers. Further, how often genetic counselors decide to make such referrals and factors that influence referrals are largely unknown.

In 2018, Cunningham et al. conducted a qualitative study to explore mental health referrals in genetic counseling. The study consisted of 28 semi-structured interviews of genetic counselors who had referred at least one patient to mental health services within the previous year. Interview questions focused on common reasons for these referrals, barriers to making the referrals, and the perceived scope of practice of a genetic counselor in providing psychosocial services. Transcripts were analyzed and responses were sorted into

What is known about this topic

Genetic counselors are trained to assess the psychosocial needs of their clients and determine when referral for additional psychological support is warranted (ACGC Practice-Based Competencies, 2019). However, little is known regarding how often genetic counselors conduct such assessments and make referrals.

What this study adds to the topic

This study quantifies how often genetic counselors assess their clients' needs for additional psychological support, how often they make mental health referrals, common indications for referral and barriers to referral.

common themes. The study identified three primary reasons that genetic counselors make referrals: patient difficulty adapting to the genetic diagnosis or risk, patient difficulty deciding about how to manage genetic disease or risk, and indications not related to the genetic counseling visit such as previous diagnosis of mental illness. The study also explored factors that may hinder referrals. These included barriers relating to the patient, barriers relating to the genetic counselor's work environment, and barriers relating to mental health services (Cunningham et al., 2018). While thematic saturation was met, the qualitative nature of the research did not allow for quantification of how often referrals were made, the most common indications, and barriers to making referrals.

The purpose of this study was to quantitatively assess the mental health referral practices of genetic counselors. Specifically, we aimed to assess how often genetic counselors refer patients to mental health providers, factors that influence the decision to refer (reasons for referral), and barriers to making referrals.

2 | METHODS

2.1 | Participants

Eligible participants were genetic counselors who have worked in a direct patient care position for at least 12 months at the time of the survey. Participants were identified through either membership with the National Society of Genetic Counselors (NSGC) or being a diplomat of the American Board of Genetic Counseling (ABGC).

2.2 | Instrumentation

A novel survey was developed based on the results of a previous qualitative study (Cunningham et al., 2018). The research team developed a draft survey in the Qualtrics web-based platform in consultation with the Wayne State University Research Design

and Analysis Unit who provided input on overall survey design (e.g., question clarity, format) and statistical analysis considerations. Once reviewed and modified, the survey was piloted by eight practicing genetic counselors who provided feedback on the quality and clarity of the questions, as well as technical aspects of the survey.

The final survey consisted of 27 questions. The survey included demographic questions including years of experience, current area(s) of practice (specialty), and service delivery model(s) used. Participants were then asked if they have ever assessed a patient for a mental health referral and/or referred a patient to mental health providers. Those who had made a referral were asked how many referrals they made in the past 12 months, for which indications, and which indications were most common. All participants were asked about challenges they have, if any, in making referrals to mental health providers. Response items to multiple choice questions about referral practices were derived from the qualitative study of Cunningham et al. (2018). The survey concluded with open-ended questions asking how the participant ultimately makes the decision to refer to a mental health provider versus manage a psychosocial concern.

2.3 | Procedures

The survey was distributed through both the NSGC Student Research Survey Program and the ABGC Research Program. A link to the survey was distributed through NSGC on January 23, 2020 to an estimated 4,600 recipients via email. A reminder was sent on February 6, 2020 to the same recipients. The link to the survey was also distributed through ABGC on January 15, 2020 to 4,559 recipients via email. Participants were offered the chance to be in a drawing to receive one of five \$25 gift cards for taking part in this study. Responses were collected from January 23 through March 31, 2020. This study was determined to be exempt by the Wayne State University Human Investigations Committee Institutional Review Board.

2.4 | Data analysis

Descriptive statistics were generated for each demographic variable. Comparisons were made between demographic variables and factors influencing referrals, indications, frequency of referrals, and barriers. Descriptive statistics including mean, median, standard error, and range were calculated for the number of referrals to mental health providers. Frequency of participants responding “yes” to having experienced each indication for referral and barrier to referral were reported. In order to determine the most common indications for referral, we totaled how often each indication was ranked across each participants’ top three list. We used the same approach for identifying the most common barriers. A crosstab analysis was performed comparing indications for referral across cancer, pediatric,

and prenatal genetic counseling settings. All “other” responses (e.g., other indications, other barriers) and responses to open-ended questions were reviewed by two members of the research team (TH and AT) and coded for themes using both inductive and deductive (based on themes identified by Cunningham et al., 2018) approaches.

To assess differences in referral rates by specialty, we first had to assess the normality of the referral rate distribution. Standardized estimates of skewness and kurtosis were calculated for referral rates by dividing the values of the skew and kurtosis statistics by the standard errors of skewness and kurtosis, respectively. The alpha level 0.001 ($z_{crit} = 3.29$) was used to evaluate the significance of these standardized skewness and kurtosis values because the sample sizes are large ($n > 200$). Furthermore, given the large sample sizes, the distributions of each variable were inspected (Tabachnick & Fidell, 2013). The referral rate was significantly positively skewed and leptokurtic as informed by the shape of its distributions, as well as the magnitude and significance of their skew and kurtosis statistics values. Due to the overwhelming evidence for non-normality, a Kruskal-Wallis H test was chosen over a one-way ANOVA to compare the rate of referrals among cancer, prenatal, and pediatric subgroups. A post-hoc pairwise comparison of specialties was performed and further adjusted by the Bonferroni correction for multiple tests. Statistical significance was considered at $p < .05$. All analyses were performed using SPSS version 26 (IBM Corp).

3 | RESULTS

3.1 | Demographics

There were 144 responses to the survey out of an estimated 4,559 to 4,600 genetic counselors who received the survey link, resulting in an estimated response rate between 3.13% and 3.16%. Of these responses, 10 participants reported that they had either been practicing for less than a year or were not providing genetic counseling directly to patients. This resulted in a total of 134 eligible participants whose characteristics are summarized in Table 1 (usable response rate of 2.9%). Participants’ years of experience as a genetic counselor ranged from 1 year to 39 years, with a median of 5 years. The years of experience working in their current area of practice ranged from 1 year to 26 years with a median of 4 years. Genetic counselors from all six NSGC regions were represented in this study, with the highest amount ($n = 44$) from region 4 (comprised of Arkansas, Iowa, Illinois, Indiana, Kansas, Michigan, Minnesota, Missouri, North Dakota, Nebraska, Ohio, Oklahoma, South Dakota, Wisconsin, and Ontario). The large majority ($n = 120$) reported providing genetic counseling services in-person rather than over the phone or through telegenetics. When asked to select one area of practice in which the participant works for the purpose of this study, the largest frequency was found in cancer ($n = 52$), followed by prenatal ($n = 31$) and pediatrics ($n = 16$). Participants responding “other” reported practicing in ophthalmology, assisted reproductive technology, and carrier screening settings.

TABLE 1 Participant demographics

Characteristic	n/N (%)
Experience total	
1–5 years	70/131 (53.4%)
6–10 years	39/131 (29.8%)
11–15 years	10/131 (7.6%)
>15 years	12/131 (9.2%)
Experience in current setting	
1–5 years	85/130 (65.4%)
6–10 years	28/130 (21.5%)
11–15 years	7/130 (5.4%)
>15 years	10/130 (7.7%)
NSGC region	
Region 1 (Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, Vermont, Canadian Maritime Provinces)	9/130 (6.9%)
Region 2 (District of Columbia, Delaware, Maryland, New Jersey, New York, Pennsylvania, Virginia, West Virginia, Quebec, Puerto Rico, Virgin Islands)	27/130 (20.8%)
Region 3 (Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee)	22/130 (16.9%)
Region 4 (Arkansas, Iowa, Illinois, Indiana, Kansas, Michigan, Minnesota, Missouri, North Dakota, Nebraska, Ohio, Oklahoma, South Dakota, Wisconsin, Ontario)	44/130 (33.9%)
Region 5 (Arizona, Colorado, Montana, New Mexico, Texas, Utah, Wyoming, Alberta, Manitoba, Saskatchewan)	15/130 (11.5%)
Region 6 (Alaska, California, Hawaii, Nevada, Oregon, Washington, British Columbia)	13/130 (10.0%)
Predominant service delivery model	
In-person counseling	120/131 (91.6%)
Telephone counseling	5/131 (3.8%)
Telegenetics	5/131 (3.8%)
Group genetic counseling	0/131 (0%)
Other (equal split)	1/131 (0.8%)
Reported specialty	
Cancer	52/129 (40.3%)
Prenatal	31/129 (24.0%)
Pediatrics	16/129 (12.4%)
General Genetics	9/129 (7.0%)
Cardiology	5/129 (3.9%)
Genomic Medicine	2/129 (1.6%)
Neurogenetics	4/129 (3.1%)

TABLE 1 (Continued)

Characteristic	n/N (%)
Metabolic disease	3/129 (2.3%)
Preconception	2/129 (1.6%)
Other	5/129 (3.9%)

3.2 | General referral patterns to mental health providers

Out of the 129 participants who responded, 70 (54.3%) reported that they assess whether a patient could benefit from a referral to a mental health provider at least half of the time. A reported 120/130 (92.3%) participants had discussed with a patient the possibility of being referred to a mental health provider. Out of 119 participants who answered the question, 99 (83.2%) had referred or facilitated a referral of a patient to a mental health provider. From that group, 83/95 (87.3%) had done this in the past 12 months.

A total of 92 participants were asked how many referrals they had made to a mental health provider in the past 12 months. The responses ranged from 0 to 100 with a mean of 5.13 and a median of 3. Figure 1 depicts a histogram of the responses. The two participants reporting the highest and second-highest number of referrals in the past 12 months noted that access to exceptional mental health services within their institution and operating a clinic specific to a condition associated with mental health concerns, respectively, contributed to their referral rate.

The number of referrals was compared among participants working in cancer, prenatal, and pediatric settings. A Kruskal-Wallis H test showed that there was a statistically significant difference in number of referrals made between the three areas of practice, $\chi^2(2) = 6.093, p = .048$, with a mean rank in referral numbers of 32.25 for cancer, 45.55 for pediatrics, and 44.18 for prenatal. Using pairwise comparisons of area of practice, there was found to be a trend toward statistical significance between cancer and prenatal ($p = .030$). However, after a Bonferroni correction was applied, this comparison was no longer significant ($p = .091$).

3.3 | Indications for referrals to mental health providers

Participants were asked to respond “yes” or “no” to the question “in the past 12 months, have you ever referred/suggested a patient be referred to a mental health provider for the following reasons?” and were provided a list of 10 unique indications. The frequency of “yes” responses for each indication are shown in Table 2. The most frequent indication was “patient has a personal history of mental illness and indicates they are having symptoms”

FIGURE 1 Histogram of genetic counselor's referrals to mental health providers in the past 12 months from 92 total responses. GC, genetic counselor; MHP, mental health provider

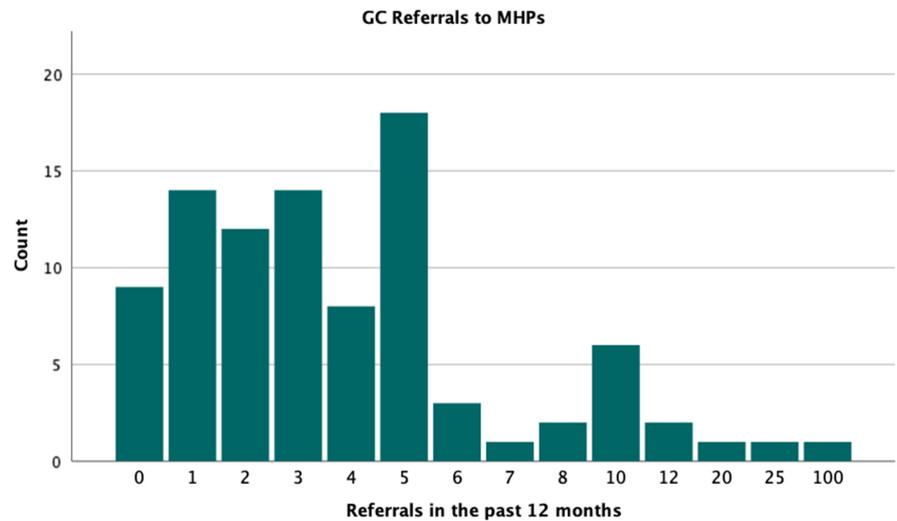


TABLE 2 Reported indications for referrals for all participants and by select areas of practice

Indication	Total n/N, (%)	Cancer n/N, (%)	Pediatrics n/N, (%)	Prenatal n/N, (%)
Patient has a personal history of mental illness and indicates they are having symptoms	62/92 (67.4%)	23/38 (60.5%)	8/10 (80.0%)	21/26 (80.8%)
Anxiety or difficulty coping related to having a genetic condition	47/92 (51.1%)	23/38 (60.5%)	8/10 (80.0%)	6/26 (23.1%)
The patient has limited social support or is not seeking social support	62/93 (66.7%)	25/39 (64.1%)	8/10 (80.0%)	18/26 (69.2%)
Difficulty coping or distress related to the termination of pregnancy for a genetic indication	28/92 (30.4%)	2/38 (5.3%)	0/10 (0.0%)	24/27 (88.9%)
Psychological reaction to genetic testing result	41/91 (45.1%)	14/28 (50.0%)	4/10 (40.0%)	15/27 (55.6%)
Patient prompted or requested a referral	47/92 (51.1%)	17/37 (45.9%)	5/10 (50.0%)	17/27 (63.0%)
Anxiety or difficulty coping related to being at risk of a genetic condition	36/92 (39.1%)	22/28 (78.6%)	2/10 (20.0%)	7/26 (26.9%)
Difficulty making a decision about genetic testing or management	17/92 (18.5%)	6/38 (15.8%)	0/10 (0.0%)	10/27 (37.0%)
Concerns about patient safety	12/91 (13.2%)	5/38 (13.2%)	1/10 (10.0%)	4/26 (15.4%)
Referral to a mental health provider is a required component of the genetic counseling or genetic testing service	2/90 (2.2%)	1/38 (2.6%)	0/10 (0.0%)	1/25 (4.0%)

(62/92, 67.4%). When asked for additional indications for making referrals, responses included having a diagnosis of cancer, pregnancy challenges (such as IVF, infertility, and miscarriage), strained family relationships, and specific diagnoses that are associated with psychiatric conditions (e.g., 22q11.2 deletion syndrome).

Additionally, participants were asked to rank their first, second, and third most frequent reasons for referring patients to a mental health provider in the past 12 months. The three most common reasons for referring patients to mental health providers were “patient has a personal history of mental illness and indicates s/he is having symptoms,” “anxiety or difficulty coping related to having a genetic

condition,” and “the patient has limited social support/is not seeking social support.”

Reasons for referrals experienced by genetic counselors were compared across participants working in cancer, prenatal, and pediatric settings. The crosstab frequency analysis is provided in [Table 2](#). The indication that was reported most frequently across the entire study sample (“patient has a personal history of mental illness and indicates s/he is having symptoms”) was reported frequently by participants working in all three specialties. This indication, along with “anxiety or difficulty coping related to having a genetic condition” and “the patient has limited social support/is not seeking social support” was tied for the most frequent responses for pediatric

Barrier	n/N (%)
Financial or insurance barriers to patient accessing services	59/108 (54.6%)
The patient was not receptive	56/107 (52.3%)
The patient does not see a benefit in referral	52/107 (48.6%)
You have difficulty finding mental health providers with sufficient understanding of genetic conditions/sequelae	42/106 (39.6%)
General lack of availability of mental health providers	45/107 (54.6%)
You do not have the medical authority to make referrals	25/107 (23.4%)
Patient perceived stigma associated with mental health services	41/107 (38.3%)
Other challenges regarding the referral process	14/63 (22.2%)
The patient has concerns about the specific mental health provider	9/107 (8.4%)
The patient is fearful of accepting a referral	2/107 (1.9%)

TABLE 3 Reported barriers to making referrals

counselors. The most frequent indication encountered by cancer counselors was “anxiety or difficulty coping related to being at risk of a genetic condition” (22/28, 78.6%). However, this was a much less frequent indication for pediatric and prenatal genetic counselors. The most frequent indication reported by prenatal counselors was “difficulty coping or distress related to the termination of a pregnancy for a genetic indication” (24/27, 88.9%). This indication was not reported by pediatric genetic counselors and rarely for cancer genetic counselors.

One participant, when asked for additional thoughts about indications, elaborated on the need for referrals when experiencing pregnancy challenges.

In the prenatal session, we see many pregnant women who struggle with anxiety, depression and bipolar disorder. Some have mental health services, but I typically ask how they are doing and whether they are managed by a mental health provider. Pregnancy can be a very stressful time and many women express experiencing some psychological concerns. Just taking the time to listen to them and refer them for further counseling with a mental health provider can provide them some support.

Another participant highlighted the uniqueness of each case and the importance of assessing their social support and extent of intervention needed.

I think these are very case by case; I think it depends on the patient and on the network/resources they have already accessed. As genetic counselors, we are trained to provide on the spot psychosocial support, especially when it is related to genetic indications/reason for referral. Long-term healing and coping are areas where I feel we are not only less trained, but we are not as good a resource for most patients as a true mental health provider is. Our schedules are not usually adapted to routinely

checking in with the same patients. While some institutions have found ways to work with this, or adapt to it, I think it is in the best interest of patients to have providers whose sole role is to help care for their mental health and when I suggest a referral, it is not necessarily because I don't want to/can't support my patient, it is because I want them to have better access to someone who can regularly tend to these needs.

3.4 | Barriers to referrals to mental health providers

Similar to indications for referral, participants were asked to respond “yes” or “no” to the question “in the past 12 months, have you encountered any of the following challenges when referring/suggesting a patient be referred to a mental health provider?” and were provided a list of 10 unique challenges and barriers. The frequency of “yes” for each indication is shown in Table 3. The most frequent challenge encountered was “financial or insurance barriers to patients accessing services,” reported by 59/108 (54.6%) participants. Other challenges identified by respondents included geographic challenges, lack of priority for the patient, and that the genetic counselor was unsure where the patient should be referred.

When participants were asked to rank their first, second, and third most frequent barriers encountered in the past 12 months, the three most frequent responses were “financial barriers to patients accessing services,” “the patient was not receptive,” and “the patient does not see a benefit in referral.”

Additional comments elaborated on how geographic restraints complicate the referral process, especially when the genetic counselor is in a different location than the patient.

It's difficult with telehealth because you are not aware of who is available in the patient's specific health system. People I know in Utah wouldn't help someone in Hawaii.

Participants also mentioned the complexity of making a referral in a pediatric setting when the parents of a patient need a referral.

I would say that more often I am making an informal recommendation for mental health services versus a formal referral. Part of that is due to the fact that often the parent(s) would be the people I would refer and in pediatrics their son/daughter is my actual patient. It is often challenging to make formal referrals for a parent when they are not my patient. Sometimes I can write recommendations for family members in my patient's note, but I have found that follow-through is generally poor when I am making recommendations for parents at the child's appointment.

3.5 | Perceived role of genetic counselors in mental health referrals

Genetic counselors were asked whether they “strongly agree,” “somewhat agree,” “neither agree nor disagree,” “somewhat disagree,” or “strongly disagree” to seven statements pertaining to their role as a genetic counselor. The results of this question are shown in Table 4. The statements to which the highest proportion of participants strongly or somewhat agreed were “patients who need support for a mental health condition are better managed by a mental health provider than by me” (104/106, 98.1%) and “mental health providers are better suited to provide long-term psychosocial support for patients than I am” (104/107, 97.2%). The statements to which the most participants strongly or somewhat disagreed was “I typically make referrals to mental health providers for patient psychosocial

issues unrelated to genetic indications” (25/106, 23.6%) and “I am trained to identify mental health concerns in patients and refer as needed” (17/107, 15.8%).

Additionally, an open-ended question was posed to participants asking, “how do you ultimately make the decision to refer/suggest a patient be referred to a mental health provider versus to manage a psychosocial concern?” Many genetic counselors indicated the deciding factor was whether the psychosocial concern requires long- or short-term attention.

If the concern seems to need long term follow-up, I refer to psychological services. I view my role more as ‘crisis counseling’ and a psychologist’s role as long term care.

Other responses included whether the root of the psychosocial concern itself is more severe or not specifically related to genetics.

If the concern is not an acute reaction to new information that seems within normal limits, but rather something persistent, out of the ordinary in terms of severity, or the patient has an existing mental health concern, I would refer.

Participants also reported basing the decision on a “gut feeling” or lack of comfortability.

When I feel like I am not adequately supporting the patient or feel uncomfortable with ordering the testing based on the information the patient expresses or their lack of understanding the ramifications of testing.

TABLE 4 Perceived role of a genetic counselor

	Strongly or somewhat agree n/N (%)	Neither agree nor disagree n/N (%)	Strongly or somewhat disagree n/N (%)
I am trained to identify mental health concerns in patients and refer as needed.	81/107 (75.7%)	9/107 (8.4%)	17/107 (15.8%)
I provide support to patients during a crisis related to a genetic risk or diagnosis.	102/107 (95.3%)	2/107 (1.9%)	3/107 (2.8%)
I am equipped to manage psychosocial issues related to indications for genetic counseling.	97/106 (91.5%)	4/106 (3.8%)	5/106 (4.7%)
One of my roles as a genetic counselor is to remove the perceived stigma of using mental health services.	82/107 (76.6%)	18/107 (16.8%)	7/107 (6.5%)
Mental health providers are better suited to provide long-term psychosocial support for patients than I am.	104/107 (97.2%)	2/107 (1.9%)	1/107 (0.9%)
Patients who need support for a mental health condition are better managed by a mental health provider than by me.	104/106 (98.1%)	1/106 (0.9%)	1/106 (0.9%)
I typically make referrals to mental health provider for patient psychosocial issues unrelated to genetic indications.	56/106 (52.8%)	25/106 (23.6%)	25/106 (23.6%)

Some participants noted that it is not their decision whether to make a referral, but another member of the healthcare team.

I work with a team that is led by neurologists and includes psychiatry. Generally, I leave it up to neuro to refer to psychiatry, but I will occasionally discuss it with patients if they bring it up or are expressing concerns that I think they would benefit from seeing our psychiatrist.

4 | DISCUSSION

Building on a previous qualitative study (Cunningham et al., 2018), we employed a cross-sectional, quantitative study design to further identify and quantify factors that influence genetic counselors' referrals to mental health providers. To our knowledge, this study is the first to quantify how often referrals are made, the most common referral indications, and the most commonly-encountered barriers to referral. While a slight majority of respondents reported that they assess mental health referral needs of their patients at least half of the time, on average they only made about five referrals per year. Referral rates did not vary significantly across cancer, prenatal, and pediatric specialties. The most common reason for referral was that the patient had a personal history of mental illness. The most commonly encountered barrier to making mental health referrals were patient financial circumstances. Overall, we were able to begin to elucidate the role of genetic counselors in making mental health referrals and the factors that influence such referrals.

4.1 | Factors influencing referrals

Among those who made mental health referrals, the average number per year was relatively small (5.13). Genetic counselors see an average of 10.4 new patients and 4.5 return patients a week (NSGC PSS, Service Delivery and Access, 2020) equating to roughly 500 new patients a year, with variation across specialties. As such, the results of this study suggest that only about 1% of patients are referred for mental health services, despite the fact that up to 20% of people may experience mental illness in their lifetime (Substance Abuse & Mental Health Services Administration, 2019). A possible reason for the limited number of referrals is that patients present to genetic counseling with inherent strengths. One of the tenets of the Reciprocal Engagement Model of Genetic Counseling is that patients are resilient (Veach et al., 2007). Genetic counselors report using resilience-enhancing strategies such as recognizing patient strengths, helping them adapt and feel in control, and facilitating empowerment most of the time (Hartmann et al., 2015). Patients' inherent resilience in addition to the use of such strategies may promote adequate adaptation in a majority of cases thus not warranting referral.

A different reason for the seemingly low rate of mental health referrals could be related to the finding that genetic counselors are not always the team member responsible for making referrals or referrals are already integrated into other aspects of the patient's medical care. Such is the case often times for patients with a cancer diagnosis or those seeking pre-symptomatic screening for Huntington's disease (Huntington's Disease Society of America, 2016; Matthews et al., 2002). The degree to which these factors affect the rate of referrals to mental health in genetic counseling remains unclear. The two participants who reported the largest number of referrals had built in mechanisms for referring. This speaks to potential value of setting up referral networks, when possible, to more easily facilitate referrals when needed.

In terms of indications for referral, the most common was that the patient had a history of mental illness. This suggests that genetic counselors making referrals recognize that a history of mental illness can impact adaptation to genetic risk and prompt the need for additional, longer term support. Interestingly, despite the fact that decision making is a common component of genetic counseling sessions, only about one-fifth of respondents overall reported "difficulty making a decision" as an indication for a mental health referral. The somewhat low frequency of this referral indication overall could be due to the fact that facilitating informed, value-based decision making is a genetic counselor competency (Accreditation Council for Genetic Counseling, 2019).

The fact that prenatal genetic counselors were much more likely to note "difficulty making a decision" as a referral indication than pediatric or cancer genetic counselors may speak to the complexity of prenatal decision making. Identifying an increased risk or diagnosis of a genetic condition in the fetus signals the (potential) end of the dream of a normal pregnancy, a denial of a hoped-for future, and a dual burden of choice and loss. Prenatal decision-making may be fraught with uncertainty (Werner-Lin et al., 2019) and require expectant parents to make decisions unfamiliar to them, often under time constraints. Decision science defines these three factors as key elements of challenging decisions (Biesecker, 2019).

Most expectant parents have the resilience needed to manage the stress and anxiety that can be associated with evaluating pregnancies for a genetic risk (Biesecker, 2019). However, several studies have shown that termination of pregnancy is an emotional event, especially when the decision is based on a fetal anomaly or genetic indication (Asplin et al., 2014; Daugirdaitė et al., 2015; LaFarge et al., 2013). The distress, when combined with other pre-existing factors, can be so great that it leads to adverse parental outcome (Bosco, 2000). As such, it is not surprising that a relatively higher number of prenatal genetic counselors made mental health referrals for patients with distress related to termination of pregnancy. Given the challenging nature and emotional impact of some of the decisions made in prenatal genetic counseling it is important to ensure that genetic counselors have the skills needed to determine when patients may benefit from a mental health referral and the resources to make such referrals.

This study also broadened the list of indications for which genetic counselors make mental health referrals. Several participants reported making referrals for patients with cancer in general given the emotional distress associated with having cancer (Stafford et al., 2015; Vos et al., 2013). Participants also noted making referrals for genetic conditions associated with an increased risk of mental health disorders. Examples of such conditions include 22q11.2 deletion syndrome, Prader-Willi syndrome, and Rubinstein-Taybi syndrome (Bassett et al., 2011; Vaerhoeven et al., 2009; Vogels et al., 2004). A third novel referral indication was for those experiencing reproductive challenges such as multiple miscarriages, infertility, and undergoing in vitro fertilization (IVF). Struggling with fertility and/or having unsuccessful IVF cycles can increase a person's emotional distress (Boivin et al., 2011; Verhaak et al., 2007). For individuals and couples who have experienced multiple pregnancy losses and are presenting for genetic counseling, the National Society of Genetic Counselors recommends making referrals to support groups and family therapists as appropriate (Laurino et al., 2005).

Common indications for mental health referrals varied across participants working in cancer, pediatric, and prenatal settings. A higher proportion of cancer genetic counselors referred patients for anxiety related to the risk of a genetic condition when compared to pediatric and prenatal counselors. This is in line with several studies that have indicated the high emotional distress that can be felt by patients who are being tested for a hereditary cancer syndrome (Pasacreta, 2003; Vos et al., 2013).

While there was a small sample of pediatric genetic counselors for this study, none indicated that they had referred a patient to help make decisions about testing or management. This could indicate a higher motivation among parents to follow through with management for their children than they would for their own health, as exemplified by the high uptake of children enrolling in clinical trials compared to adults (Rothmier et al., 2003). Alternatively, this result could be the result of more physician involvement in pediatric settings leading to more directive counseling related to referrals (Chappuy et al., 2006; Zupancic et al., 1997).

The variation in indications for referrals across the specialties highlights the unique and overlapping patient circumstances and emotional states encountered in each type of counseling. Such a variation indicates that developing universal guidelines for making referrals in any practice setting may not be appropriate. Rather it is important to pay specific attention to the most common indications/stressors in each area major of practice and tailor referral practices accordingly.

4.2 | Barriers to referrals

The most common barriers to making mental health referrals were financial/insurance barriers, the patient being unreceptive, and the patient not seeing a benefit in the referral, similar to those identified by Cunningham et al. (2018). Inadequate health insurance coverage can limit access to mental health services for older patients with

cancer (Weinberger et al., 2011). The lack of patient receptivity as a barrier to mental health services is not unique to genetic counseling as it is a common barrier in the mental health community (Clement et al., 2015). Furthermore, it is well established that there is a treatment gap, defined as the difference in the proportion of people who have a condition and those who receive needed care, when it comes to mental health (Kazdin, 2019). In the United States, it is estimated that only 15%–30% of those needing mental health services receive them; the rate is even lower globally. Common barriers include cost/inadequate insurance coverage, limited number of providers, stigma, and cultural sensitivities (Kazdin, 2019). These barriers speak to the important role of healthcare providers, including genetic counselors, in advocating for adequate coverage of mental health services and reducing the stigma related to receiving such services in order to increase needed access.

Additional barriers that were identified included the difficulty of connecting a patient to mental health services in their community when genetic counseling is provided from a distance, such as through telegenetics or telephone counseling. Providing genetic counseling through telehealth-telephone and audiovisual formats is becoming increasingly common; prior to the COVID-19 pandemic 36% and 28% of genetic counselors reported using these formats, respectively (National Society of Genetic Counselors, 2020b) but the rate has increased substantially. Coordination of care with local healthcare providers has previously been noted as challenge of using these service delivery models, since the genetic counselor may not be familiar with available services in the patient's community (Zierhut et al., 2018). Another challenge brought to light was making a referral for the parent of a patient in a pediatric setting. Parents of children requiring extensive medical care, especially those with a chronic illness or born with a birth defect, are more likely to experience psychological distress than average (Leonard et al., 1993; Lindström et al., 2010; Skreden et al., 2010). Since the parent is not the patient, identifying how to make appropriate referrals can be challenging.

4.3 | Role of a genetic counselor in mental health referrals

Similar to previous studies, respondents felt that their role as a genetic counselor is to provide short-term support versus long-term support to their patients (Cunningham et al., 2018; Vos et al., 2013). This has been previously described as a "filter" model, in which it is a genetic counselor's role to identify those who could benefit from long-term psychological support. While this concept of identification and referral is in line with both the NSGC scope of practice (National Society of Genetic Counselors, 2020a) and genetic counseling practice-based competencies (Accreditation Council for Genetic Counseling, 2019), not all respondents agreed that they are trained to do this. Little if any research is available regarding how genetic counseling students are trained to assess the need for mental health referrals. As such, it is not possible

to determine if current training methods are sufficient or if more robust methods are needed. However, limited training in how to screen patients for risk of mental health conditions has been identified as a barrier to referrals in primary care (Avalos et al., 2019). As such, further investigation of genetic counseling student training may be beneficial.

4.4 | Study Limitations

The sample size of this study may have limited our ability to make comparisons across the specialties. There is also a potential for selection bias among the participants who chose to take part as those genetic counselors may typically refer more patients or make more assessments for mental health concerns. While our survey instrument was developed from a previous qualitative study (Cunningham et al., 2018) and piloted, it has not been validated. In order to enhance accurate recall, most questions in the survey were asked in regard to the past 12 months of practice, which could exclude informative experiences that happened before that timeframe. Finally, genetic counselors working in several areas of practice were asked to answer with respect to just one area of practice for the purpose of the study. As such, this study did not capture their whole scope of referral experiences.

4.5 | Practice Implications

Overall, the low response rate of this study limits the generalizability of the results. Nonetheless, we identified that a subset of genetic counselors feels like they were not adequately trained to identify and refer patients who could benefit from mental health services. As such, additional training in graduate programs and through continuing education could be of benefit. This study also broadened the list of indications for which mental health referrals are made in genetic counseling. This information may help practitioners identify additional factors that could prompt an assessment for a mental health referral.

4.6 | Research Recommendations

This study asked participants to report their experiences making referrals. Future studies could take a more direct approach using a prospective design or retrospective chart review to quantify the rate of referral and indications. Targeted recruitment of genetic counselors in under-represented specialties is needed to capture experiences in areas such as neurogenetics and cardiovascular genetic counseling whose patients face unique stressors. It would also be valuable to learn about the proportion of patients referred to mental health providers who follow through with the referral. Such a study could help to evaluate the efficacy and outcome of the referrals being made.

5 | CONCLUSIONS

This study evaluated genetic counselors' practices of referring patients to mental health providers and the factors that influence their decisions to refer.

We found that a slight majority of respondents are assessing whether their patients could benefit from mental health referrals at least half of the time; however, referrals are being made infrequently. Common reasons for referrals to mental health providers included having a personal history of mental illness, the emotional distress of having a genetic condition, and lack of social support. Common barriers encountered were financial or insurance barriers, the patient not being receptive, and the patient not seeing a benefit in the referral. Genetic counselors agreed that mental health providers are better suited to provide psychosocial support for concerns that are long-term or solely related to a mental health condition. The findings from this study provide insight on the genetic counselor's role in identifying and assessing for mental health concerns and is a first step in developing an evidence base for best practices in making appropriate referrals to mental health providers.

AUTHOR CONTRIBUTIONS

Authors Taylor Hayes, Angela Trepanier, and Mitchell Cunningham confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All of the authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

ACKNOWLEDGEMENTS

This study was conducted in fulfillment of a Masters' degree requirement at Wayne State University. All funding for this study was provided by the Wayne State University Genetic Counseling Program. We would like to thank the Wayne State Research Design and Analysis Unit for their help in survey design and data analysis. The authors would also like to thank all genetic counselors who participated in the study and provided their insight. Jehannine Austin served as Action Editor for this manuscript.

COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

Taylor Hayes, Angela Trepanier, and Mitchell Cunningham declare that they have no conflicts of interest.

HUMAN STUDIES AND INFORMED CONSENT

This study was reviewed and granted an exemption by the Wayne State University Institutional Review Board. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained for individuals via information

sheet; participants had to read the information sheet and select that they agreed to the terms of the study before they could voluntarily complete the online survey.

ANIMAL STUDIES

No non-human animal studies were carried out by the authors for this article.

DATA SHARING AND DATA ACCESSIBILITY

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ORCID

Taylor Hayes  <https://orcid.org/0000-0001-7367-4127>

REFERENCES

- Accreditation Council for Genetic Counseling. (2019). *Practice-Based Competencies for Genetic Counselors (Domain II)*. Retrieved August 3, 2021 from <https://www.gceducation.org/practice-based-competencies>
- Asplin, N., Wessel, H., Marions, L., & Georgsson Öhman, S. (2014). Pregnancy termination due to fetal anomaly: Women's reactions, satisfaction and experiences of care. *Midwifery*, 30(6), 620–627. <https://doi.org/10.1016/j.midw.2013.10.013>
- Avalos, L. A., Flanagan, T., & Li, D.-K. (2019). Preventing perinatal depression to improve maternal and child health- a healthcare imperative. *JAMA Pediatrics*, 173(4), 313–314. <https://doi.org/10.1001/jamapediatrics.2018.5491>
- Bassett, A. S., McDonald-McGinn, D. M., Devriendt, K., Digilio, M. C., Goldenberg, P., Habel, A., Marino, B., Oskarsdottir, S., Philip, N., Sullivan, K., Swillen, A., & Vorstman, J. (2011). Practical guidelines for managing patients with 22q11.2 deletion syndrome. *The Journal of Pediatrics*, 159(2), 332–9.e1. <https://doi.org/10.1016/j.jpeds.2011.02.039>
- Biesecker, B. B. (2019). The psychological well-being of pregnant women undergoing prenatal testing and screening: A narrative review. Special Report. Looking for Psychosocial Impacts of Genomic Information. *Hastings Center Reports*, 49(3), s53–s60. <https://doi.org/10.1002/hast.1017>
- Boivin, J., Griffiths, E., & Venetis, C. A. (2011). Emotional distress in infertile women and failure of assisted reproductive technologies: Meta-analysis of prospective psychosocial studies. *BMJ (Clinical Research Ed.)*, 342, d223. <https://doi.org/10.1136/bmj.d223>
- Bosco, A. F. (2000). Caring for the caregiver: The benefit of a peer supervision group. *Journal of Genetic Counseling*, 9(5), 425–430. <https://doi.org/10.1023/A:1009458316485>
- Chappuy, H., Doz, F., Blanche, S., Gentet, J.-C., Pons, G., & Tréluyer, J.-M. (2006). Parental consent in paediatric clinical research. *Archives of Disease in Childhood*, 91(2), 112–116. <https://doi.org/10.1136/adc.2005.076141>
- Clement, S., Schauman, O., Graham, T., Maggioni, F., Evans-Lacko, S., Bezborodovs, N., Morgan, C., Rusch, N., Brown, J. S. L., & Thornicroft, G. (2015). What is the impact of mental health related stigma on help-seeking? A systematic review of quantitative and qualitative studies. *Psychological Medicine*, 45(1), 11–27. <https://doi.org/10.1017/S0033291714000129>
- Cunningham, M., Morreale, M., & Trepanier, A. (2018). Referrals to mental health services: Exploring the referral process in genetic counseling. *Journal of Genetic Counseling*, 27(1), 289–300. <https://doi.org/10.1007/s10897-017-0147-y>
- Daugirdaitė, V., van den Akker, O., & Purewal, S. (2015). Posttraumatic stress and posttraumatic stress disorder after termination of pregnancy and reproductive loss: A systematic review. *Journal of Pregnancy*, 2015, 646345. <https://doi.org/10.1155/2015/646345>
- Hartmann, J. E., Veach, P. M., MacFarlane, I. M., & LeRoy, B. S. (2015). Genetic counselor perceptions of genetic counseling session goals: A validation study of the Reciprocal-Engagement Model. *Journal of Genetic Counseling*, 24, 225–237. <https://doi.org/10.1007/s10897-013-9647-6>
- Huntington's Disease Society of America (2016). *Genetic testing protocol for Huntington's disease*. Retrieved August 3, 2021 from: <https://hdsa.org/news/huntingtons-disease-society-of-america-releases-updated-genetic-testing-protocol-for-huntingtons-disease/>
- Kazdin, A. E. (2019). Annual research review: Expanding mental health services through novel models of intervention delivery. *Journal of Child Psychology and Psychiatry*, 60(4), 455–472. <https://doi.org/10.1111/jcpp.12937>
- Kowalcek, I. (2007). Stress and anxiety associated with prenatal diagnosis. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 21(2), 221–228. <https://doi.org/10.1016/j.bpobgyn.2006.11.009>
- Krabbenborg, L., Vissers, L. E. L. M., Schieving, J., Kleefstra, T., Kamsteeg, E. J., Veltman, J. A., & Van der Burg, S. (2016). Understanding the psychosocial effects of WES test results on parents of children with rare diseases. *Journal of Genetic Counseling*, 25(6), 1207–1214. <https://doi.org/10.1007/s10897-016-9958-5>
- Kuramoto-Crawford, S. J., Han, B., Jacobus-Kantor, L., & Mojtabei, R. (2015). Differences inpatients' perceived helpfulness of depression treatment provided by general medical providers and specialty mental health providers. *General Hospital Psychiatry*, 37(4), 340–346. <https://doi.org/10.1016/j.genhosppsych.2015.04.006>
- Lafarge, C., Mitchell, K., & Fox, P. (2013). Perinatal grief following a termination of pregnancy for foetal abnormality: The impact of coping strategies. *Prenatal Diagnosis*, 33(12), 1173–1182. <https://doi.org/10.1002/pd.4218>
- Laurino, M. Y., Bennett, R. L., Saraiya, D. S., Baumeister, L., Doyle, D. L., Leppig, K., Pettersen, B., Resta, R., Shields, L., Uhrich, S., Varga, E. A., & Raskind, W. H. (2005). Genetic evaluation and counseling of couples with recurrent miscarriage: Recommendations of the National Society of Genetic Counselors. *Journal of Genetic Counseling*, 14(3), 165–181. <https://doi.org/10.1007/s10897-005-3241-5>
- Leonard, B. J., Brust, J. D., & Nelson, R. P. (1993). Parental distress: Caring for medically fragile children at home. *Journal of Pediatric Nursing*, 8(1), 22–30.
- Lindström, C., Åman, J., & Norberg, A. L. (2010). Increased prevalence of burnout symptoms in parents of chronically ill children. *Acta Paediatrica*, 99(3), 427–432. <https://doi.org/10.1111/j.1651-2227.2009.01586.x>
- Matthews, A. K., Brandenburg, D. L., Cummings, S., & Olopade, O. I. (2002). Incorporating a psychological counselor in a cancer risk assessment program: Necessity, acceptability, and potential roles. *Journal of Genetic Counseling*, 11(1), 51–64. <https://doi.org/10.1023/A:1013820515603>
- National Society of Genetic Counselors (2020a). *Genetic counselor scope of practice*. Retrieved August 3, 2021 from <https://www.nsgc.org/Policy-Research-and-Publications/State-Licensure-for-Genetic-Counselors/Model-Legislative-Provisions/scope>
- National Society of Genetic Counselors (2020b). *Professional Status Survey, Service Delivery and Access*. Retrieved August 3, 2021 from <https://www.nsgc.org/Policy-Research-and-Publications/Professional-Status-Survey> (member-only access)
- Pasacreta, J. V. (2003). Psychosocial issues associated with genetic testing for breast and ovarian cancer risk: An integrative review. *Cancer Investigation*, 21(4), 588–623. <https://doi.org/10.1081/cnv-120022380>
- Pelentsov, L. J., Fielder, A. L., Laws, T. A., & Esterman, A. J. (2016). The supportive care needs of parents with a child with a rare disease:

- Results of an online survey. *BMC Family Practice*, 17(1), 88. <https://doi.org/10.1186/s12875-016-0488-x>
- Peters, J. A. (1994). Suicide prevention in the genetic counseling context. *Journal of Genetic Counseling*, 3(3), 199–213. <https://doi.org/10.1007/BF01412227>
- Rothmier, J. D., Lasley, M. V., & Shapiro, G. G. (2003). Factors influencing parental consent in pediatric clinical research. *Pediatrics*, 111(5), 1037–1041. <https://doi.org/10.1542/peds.111.5.1037>
- Skreden, M., Skari, H., Malt, U. F., Haugen, G., Pripp, A. H., Faugli, A., & Emblem, R. (2010). Long-term parental psychological distress among parents of children with a malformation—A prospective longitudinal study. *American Journal of Medical Genetics Part A*, 152A(9), 2193–2202. <https://doi.org/10.1002/ajmg.a.33605>
- Söllner, W., DeVries, A., Steixner, E., Lukas, P., Sprinzl, G., Rumpold, G., & Maislinger, S. (2001). How successful are oncologists in identifying patient distress, perceived social support, and need for psychosocial counseling? *British Journal of Cancer*, 84(2), 179–185.
- Sommers-Flanagan, J., & Sommers-Flanagan, R. (2012). *Counseling and psychotherapy theories in context and practice: Skills, strategies, and techniques*, 2nd ed. John Wiley & Sons Inc.
- Stafford, L., Judd, F., Gibson, P., Komiti, A., Mann, G. B., & Quinn, M. (2015). Anxiety and depression symptoms in the 2 years following diagnosis of breast or gynaecologic cancer: Prevalence, course and determinants of outcome. *Supportive Care in Cancer*, 23(8), 2215–2224. <https://doi.org/10.1007/s00520-014-2571-y>
- Substance Abuse and Mental Health Services Administration (2019). *Key Substance Use and Mental Health Indicators in the United States: Results from the 2018 National Survey on Drug Use and Health*. Retrieved August 3, 2021 from: <https://store.samhsa.gov/product/key-substance-use-and-mental-health-indicators-in-the-united-states-results-from-the-2018-national-survey-on-drug-use-and-health/PEP19-5068>
- Tabachnick, B. G., & Fidell, L. S. (2013). *Using Multivariate Statistics*, 6th ed. Pearson.
- 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(6), 713–728. <https://doi.org/10.1007/s10897-007-9113-4>
- Verhaak, C. M., Smeenk, J. M. J., Evers, A. W. M., Kremer, J., Kraaijmaat, F. W., & Braat, D. (2007). Women's emotional adjustment to IVF: A systematic review of 25 years of research. *Human Reproduction Update*, 13(1), 27–36. <https://doi.org/10.1093/humupd/dml040>
- Verhoeven, W. M. A., Tuinier, S., Kuijpers, H. J. H., Egger, J. I. M., & Brunner, H. G. (2009). Psychiatric profile in Rubinstein-Taybi syndrome. *Psychopathology; Basel*, 43(1), 63–68. <https://doi.org/10.1159/000260045>
- Vogels, A., Hert, M. D., Descheemaeker, M. J., Govers, V., Devriendt, K., Legius, E., Prinzie, P., & Fryns, J. P. (2004). Psychotic disorders in Prader-Willi syndrome. *American Journal of Medical Genetics Part A*, 127A(3), 238–243. <https://doi.org/10.1002/ajmg.a.30004>
- Vos, J., van Asperen, C. J., Oosterwijk, J. C., Menko, F. H., Collee, M. J., Garcia, E. G., & Tibben, A. (2013). The counselees' self-reported request for psychological help in genetic counseling for hereditary breast/ovarian cancer: Not only psychopathology matters. *Psycho-Oncology*, 22(4), 902–910. <https://doi.org/10.1002/pon.3081>
- Weinberger, M. I., Bruce, M. L., Roth, A. J., Breitbart, W., & Nelson, C. J. (2011). Depression and barriers to mental health care in older cancer patients. *International Journal of Geriatric Psychiatry*, 26(1), 21–26. <https://doi.org/10.1002/gps.2497>
- Werner-Lin, A., McCoyd, J. L. M., & Bernhardt, B. (2019). Actions and uncertainty: How prenatally diagnosed variants of uncertain significance become actionable. Special Report: Looking for the Psychosocial Impacts of Genomic Information. *Hastings Center Report*, 49(3), s61-s71. <https://doi.org/10.1002/hast.1018>
- Zierhut, H. A., MacFarlane, I. M., Ahmed, Z., & Davies, J. (2018). Genetic counselors' experiences and interest in telegenetics and remote counseling. *Journal of Genetic Counseling; New York*, 27(2), 329–338. <https://doi.org/10.1007/s10897-017-0200-x>
- Zupancic, J. A. F., Gillie, P., Streiner, D. L., Watts, J. L., & Schmidt, B. (1997). Determinants of parental authorization for involvement of newborn infants in clinical trials. *Pediatrics*, 99(1), e6. <https://doi.org/10.1542/peds.99.1.e6>

SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

How to cite this article: Hayes, T., Cunningham, M., & Trepanier, A. (2022). Investigating factors that influence genetic counselors' decisions to refer patients to mental health providers. *Journal of Genetic Counseling*, 00, 1–12. <https://doi.org/10.1002/jgc4.1582>