

Exploring genetic counselors' perspectives in assessing mental health and suicide risk in the pediatric setting

by

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Introduction: In the United States, suicide rates have steadily increased over time in those aged 10-to-24. Risk factors for youth suicide include mental health conditions, chronic illnesses, and certain life-limiting conditions. Pediatric genetic counselors (GCs) work with patients aged 0-to-18 and may serve at-risk patients. No studies have examined whether pediatric GCs routinely assess mental health concerns or suicide risk during a genetic counseling session. It is also unknown whether personal or institutional barriers exist in this setting, limiting a GC's ability to assess at-risk youth. The study aimed to determine pediatric GC practices and perspectives regarding routinely assessing mental health and suicide risk and to identify perceived barriers and training GCs have received.

Methods: I created an anonymous online survey through Qualtrics XM that comprised multiple-choice questions, including some fill-in-the-blank answer choices. The survey was advertised on social media and sent via an email invitation to GCs through the National Society of Genetic Counseling (NSGC) listserv.

Results: There were 34 board-certified pediatric GCs that responded. Not every respondent answered each question. Half of the respondents do not assess suicide risk, and half sometimes assess mental health. Half believe GCs should assess suicide, primarily when indicated. Most respondents indicated that GCs should assess mental health at every session. The top reason

respondents do not assess mental health or suicide risk is a lack of understanding of best practices for assessing mental health or suicide risk in the pediatric setting.

Conclusions: The results suggest that GCs do not routinely assess mental health and suicide risk during pediatric genetic counseling sessions. GCs also need education on best practices for mental health and suicide risk assessment for this setting. Most respondents indicated that GCs should assess mental health at every session, while only half reported that GC should assess suicide. More research on this topic is needed, and limitations of the study exist, including small sample size. The study has public health significance because GCs may be able to identify youth at risk. With the increasing rates of youth suicide, GCs need to consider taking more preventative action.

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Preface

With my sincere gratitude, I would like to thank my thesis chair, Dr. Robin Grubs, for inspiring this work and providing me with her knowledge, expertise, time, and overall support and for helping me navigate this process; I could not have done this without her.

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Thank you to my partner and to my classmates for your unwavering encouragement and support during this process and our entire journey together through graduate school.

One of my favorite quotes that inspire me is from Gandhi, which reads, “In a gentle way, you can shake the world.” Becoming a genetic counselor and public health professional is one positive way I believe I can gently shake the world. I am incredibly grateful for my education at the University of Pittsburgh and the remarkable people I met during this journey. Another reason I love this quote is because it reminds me of my mother, who worked in healthcare for over twenty years before passing away. She was such a kind and gentle soul that impacted many people while she was with us, and she remains the most significant influencer in my life. I want to dedicate this work to her.

1.0 Introduction

In the United States, suicide is a significant public health concern and suicide rates have steadily increased over time. The National Institute of Mental Health defines suicide as “death caused by self-directed injurious behavior with intent to die as a result of the behavior” (2022). In the National Vital Statistics Report, data obtained from death certificates from 2000 to 2018 from all 50 states in the United States showed that over time, there had been a rising rate of suicide in those aged 10 to 24 (Curtin, 2022). In the United States, between 2007 and 2018, the suicide rate among those aged 10 to 24 increased by 57.4%. Due to increasing suicide rates, in 2021, The American Academy of Pediatrics (AAP) deemed suicide a national emergency. Other pediatric organizations also supported this declaration including the Children’s Hospital Association and the American Academy of Child and Adolescent Psychiatry (American Academy of Pediatrics [AAP], 2021).

A well-known risk factor for suicide attempts in adolescents is depression (Greydanus et al., 2010). In a review assessing the link between increased suicide risk and chronic illness, Greydanus et al. noted that adolescents with chronic illnesses are at an increased risk of experiencing depression, which consequently may cause suicidal ideation. The authors concluded that this population should be regularly screened for depression by their primary and specialty care providers (Greydanus et al., 2010). In the pediatric genetics setting, genetic conditions often constitute a chronic illness, and some may be life-limiting. Barker et al. conducted a systematic review and meta-analysis revealing high levels of anxiety and depression in youth and young adults living with conditions considered to be life-limiting (2019). Findings included

recommending routine screening for mental health problems including appropriate risk mitigation plans and the use of validated suicidal risk assessment screening tools (Barker et al., 2019).

Validated screening tools for suicide risk assessment are successful at identifying children and adolescents in the pediatric setting. According to a literature review that examined the effectiveness of pediatric suicide screening, providers who screen patients in the pediatric setting for suicide, including in the outpatient setting, were appropriately able to identify those at-risk and provide proper intervention (Milliman et al., 2021). Additionally, of the 119 patients assessed for suicidal ideation, 38 percent who screened positive did not have any previously known mental health concerns (Doupnik et al., 2017).

There is limited literature regarding whether screening for mental health concerns or suicidal risk assessment is performed in the pediatric genetic counseling setting. It is also unknown whether personal or institutional barriers exist in this setting that may limit a genetic counselor's ability to assess those at risk. By identifying genetic counselors' screening practices and possible barriers, genetic counselors and institutions can appropriately address gaps in care and begin to make the necessary adjustments to their clinical practices and institutional policies. To address the gap in the current literature, I created and distributed a Qualtrics survey to genetic counselors using the National Society of Genetic Counselors (NSGC) listserv. The following are the specific aims of the study:

1.1 Specific aims

Specific Aim 1: Determine whether pediatric genetic counselors routinely conduct mental health and suicide risk assessments.

Specific Aim 2: Assess pediatric genetic counselors' perspectives regarding whether they believe mental health and suicide risk assessments should be performed and their perceived barriers in performing these assessments.

2.0 Manuscript

2.1 Background

Overall, the rates of youth suicide in the United States have been on the rise, and among youth aged 5 to 19, suicide was one of the top ten causes of death in 2020 (Centers for Disease Control and Prevention [CDC], 2023). In 2021, the CDC released a vital statistics report comparing suicide rates from 2020 and 2021 by age. The report showed a statistically significant increase in the 15- to 24-year-old age group, increasing from 14.2 to 15.3 percent (Curtin et al., 2022). Furthermore, data collected from the CDC on suicide deaths in children and adolescents aged 5 to 18 years in the United States from 1999 to 2017 analyzed by Mishara and Stijelji (2020) found a significant annual percentage change of 14.69% in suicide rates in children aged 5 to 11 starting in 2012 to 2017.

Studies examining suicide in young children under ten are limited; however, researchers have identified some precipitating circumstances among children aged 5 to 11. For instance, Ruch et al. conducted a qualitative study reviewing case narratives from the National Violent Death Reporting systems from 37 states in the United States and identified four significant themes (2021). These themes included mental health conditions, suicide-related issues, trauma, and family, peer, or school-related issues (Ruch et al., 2021). Among mental health conditions in this age group, attention deficit hyperactive disorder was the most common that showed a significant risk for suicide.

Researchers have also conducted studies exploring risk factors for suicidal behavior in adolescents. The World Health Organization defines this age group as anyone aged 10 to 19

between childhood and adulthood (World Health Organization, 2022). Multiple risk factors identified for suicide in the adolescent age group include mental health conditions, previous suicide attempts, family factors, personality characteristics, availability of means, specific life events, and imitation (Bilsen, 2018). A common mental health condition identified as a major precipitating factor for suicide in adolescents is depression (Thapar et al., 2012). Other precipitating mental health conditions include anxiety, disruptive behavior, eating, substance abuse, adjustment, and other psychiatric disorders (Greydanus et al., 2010). Additionally, some data have suggested that adolescents experiencing chronic illness have higher rates of depression and anxiety, therefore, identifying chronic illness as a risk factor for suicide (Greydanus et al., 2010). The CDC defines a *chronic illness* as a condition that lasts one year or more, where ongoing medical attention is needed, and activities of daily living are limited, or both (CDC, 2021).

In addition to chronic illnesses, research has found that depression and anxiety may be higher in youths with life-limiting conditions. A life-limiting condition, defined by Fraser & Parslow (2017), is a condition with no cure in which an individual will ultimately die because of the disease or secondary health issues associated with the disease. For those aged 6 to 24 years old with life-limiting conditions, Barker et al. performed a systematic review and meta-analysis of 37 articles. They discovered that the prevalence of depression and anxiety was higher than in the general population, and the prevalence varied depending on the condition (Barker et al., 2019). Multiple genetic conditions begin in childhood and are considered chronic and life-limiting, such as cystic fibrosis, Duchenne muscular dystrophy, juvenile Huntington's disease, and certain lysosomal storage diseases or metabolic conditions. In addition, specific mental health issues may be a primary symptom of multiple genetic conditions.

2.1.1 Practices regarding assessing mental health and suicide risk in the pediatric outpatient setting

2.1.1.1 Assessment recommendations

Based on the increasing rates of youth suicide and growing awareness of risk factors, including depression, the United States Preventative Services Task Force has recommended that healthcare providers assess mental health in the pediatric setting (Mangione et al., 2022). Additionally, the American Academy of Pediatrics (AAP) recommends that pediatric healthcare providers conduct universal suicide screening in clinical practice for all youth aged 12 and above at least once a year to identify at-risk youth (AAP, 2022). The AAP has also recognized pediatricians' vital role in addressing pediatric mental health. It has a policy statement explicitly addressing mental health competencies for pediatricians, including those who work in pediatric subspecialty practices caring for children with chronic conditions (Green et al., 2019).

With the increasing amount of literature and professional organizations recognizing the need for assessing suicide in the pediatric setting, some pediatric healthcare systems are starting to trial universal depression screening to identify suicide risk. Crandal et al. performed a retrospective study exploring the implementation of a universal depression screening of patients aged 12 to 17 at the Rady Children's Hospital in San Diego. Healthcare providers provided screenings in both the in-patient and outpatient settings, including specialty care (2022). Patients screened in the outpatient specialty care setting comprised 40.4% of participants (n=95,613) (Crandal et al., 2022). Results revealed that 13.4% (n=38,668) of outpatient specialty care patients screened positive for depression and suicide risk (Crandal et al., 2022).

2.1.1.2 Medical providers and patients

Moreover, research has indicated that youth patients and their guardians believe assessing suicide risk is appropriate in the outpatient pediatric setting. One study found that 75% (n=32) of medically ill patients aged 8 to 21 felt it was acceptable to perform suicide risk screening in the clinic setting, and 84.4% of guardians indicated that providers should ask children about suicide risk at their appointment (Tipton et al., 2020). Bradley-Ewing et al. found similar results after conducting a multisite study which showed that 90% of guardians of adolescent patients aged 10 to 21 believed the regular doctors office is the most suitable place to screen for suicide, and 54% believed the best place to screen is at a specialty clinic (Bradley-Ewing et al., 2020). However, a survey of 671 primary care providers (PCP) practicing in Pennsylvania (n=7,577) determined that less than half of providers screen for general psychosocial well-being at most well visits. The study showed that 24.7% of Pennsylvania providers screen when concerns are suspected, 25.4% screen for suicide at most well visits, and 55.9% screen only when suicide risk is suspected (Diamond et al., 2011). Diamond et al. speculated that providers who completed the survey were likely interested in mental health. Due to selection bias and the study findings of low universal screening rates for mental health and suicide among providers in Pennsylvania, Diamond et al. suggest that the rate of PCPs in the general population screening for mental health problems is probably lower than rates among PCPs in Pennsylvania (Diamond et al., 2011).

2.1.1.3 Genetic counselors

Currently, there is no identified literature on practices among genetic counselors (GCs) in the pediatric setting regarding whether they perform mental health or suicide risk assessments. There is also limited research on GCs perceptions about whether GCs should perform these risk assessments in the pediatric setting or what barriers exist. Twenty-two core practice-based

competencies fall within four specific domains to ensure GCs can successfully practice. Domain II includes competencies related to a GCs interpersonal, psychosocial, and counseling skills. Within this domain, it is a GCs responsibility to "assess clients psychosocial needs and evaluate the need for intervention and referral" (Accreditation Council for Genetic Counseling, 2019, p. 5).

Existing literature explores factors GCs consider when referring to mental health services and their perceived roles and perceptions about their scope of practice regarding mental health. Hayes et al. found that 54.3% (n=129) of GCs assess whether a mental health referral is needed half of the time during a session (2022). In exploring GCs perceived roles in mental health, Hayes et al. (2022) found that 75.5% of counselors (n=107) somewhat or strongly agreed with the statement "I am trained to identify mental health concerns in patients and refer as needed" (p.1119). 95.3% of GCs also somewhat or strongly agreed that they could provide support when a patient is in crisis due to a genetic risk or diagnosis (Hayes et al., 2022). Additionally, top barriers to GCs providing referrals to mental health services included barriers to accessing services due to insurance or financial limitations, lack of mental health care provider availability, and the lack of patient receptiveness to referral (Hayes et al., 2022). In the pediatric setting, the top referral indications included patients who had experienced mental health illness before and were experiencing symptoms, patients who were experiencing anxiety or having trouble coping with a genetic condition, or if the patient did not or were not looking for social support (Hayes et al., 2022). However, the study was limited in drawing inferences from the pediatric setting due to the limited sample size of participants working in the pediatric setting (16 out of the 129 survey participants).

Additionally, a qualitative study by Cunningham et al. found that common indications for GCs to refer to mental health services (specifically GCs in the adult cancer setting) included

anxiety related to a diagnosis and having limited social support (Cunningham et al., 2017). The researchers also concluded that the GCs could use their risk assessment skills to identify patients needing a mental health referral (Cunningham et al., 2017).

2.1.2 Study objectives

Overall, research indicates known risk factors for suicide in the pediatric setting, which include specific mental health conditions, chronic illnesses, and certain life-limiting conditions. Genetic counselors working across pediatric sub-specialties may serve patients who face these risk factors. It is unknown whether GCs assess pediatric mental health concerns or suicide risk. It is also unknown whether personal or institutional barriers exist in this setting that may limit a GC's ability to assess those at risk. The study aimed to address current gaps in the literature by determining whether pediatric genetic counselors routinely conduct a mental health and suicide risk assessment and to assess pediatric genetic counselors' perspectives of perceived barriers in performing a mental health and suicide risk assessment. By identifying genetic counselors' practices related to screening and possible barriers, genetic counselors and institutions can appropriately address gaps in care and begin to make the necessary adjustments to their clinical practices and institutional policies.

2.2 Methods

2.2.1 Study design

The data for the study were collected using an online survey that I created and distributed through Qualtrics XM. Before distribution, I piloted the initial survey with members of the thesis committee and the 2023 University of Pittsburgh Genetic Counseling class. After piloting the survey, I made modifications, including re-wording and combining specific questions and adding alternative response options such as open text options and "prefer not to answer." The final survey included 53 questions designed to elicit genetic counselors' perspectives and practices regarding assessing mental health and suicide risk in the pediatric setting and to identify perceived barriers and training genetic counselors have received in this area (Appendix C). I defined *mental health* as a child's mental, emotional, and behavioral well-being. The survey also included demographic questions addressing age, geographic location of employment, years of experience working as a genetic counselor, and gender identity. Most survey questions were multiple choice and included some open-ended, fill-in-the-blank, select-all answer choices and skip-and-display logic. Depending on the participants' responses, not all questions were displayed. Before survey distribution, the Institutional Review Board (IRB) determined that the study was not research involving human subjects as defined by the United States Department of Health and Human Safety and Food and Drug Administration regulations (Appendix A.2).

2.2.2 Participants

I distributed the survey to genetic counselors working or who have previously worked in a pediatric setting in the United States or Canada by sending an e-mail invitation (Appendix B) to complete the survey to the National Society of Genetic Counseling (NSGC) listserv on November 30, 2022, with a reminder sent on December 14, 2022, and January 11, 2023. I defined the pediatric setting as working with patients aged 0 to 18. I also promoted the survey via official social media platforms on the Facebook page and Twitter account of the University of Pittsburgh Genetic Counseling Program on November 28, 2022, December 12, 2022, and January 9, 2023 (Appendix B). The survey was open for a total of eight weeks.

2.2.3 Data analysis

I downloaded data from the Qualtrics XM survey into Excel for descriptive and statistical analysis and to assist in creating a codebook for exploratory analysis of open-ended question responses. The chi-square test for independence was used along with an alpha value of 0.05 and calculated in Excel to determine if the age of a GC or years of experience working as a GC in the pediatric setting is associated with a GC assessing mental health or suicide risk during a session (Tables 6 to 8 in Appendix D).

In addition, I performed an exploratory qualitative analysis by reviewing open-ended responses and creating a codebook (Appendix E) that was generated and defined based on participant responses. I then grouped coded responses to identify common categories from responses. Some participant responses were edited slightly for clarity.

2.3 Results

2.3.1 Respondent characteristics

A total of 37 board-certified genetic counselors responded to the survey. One respondent only completed the first question (“Are you a genetic counselor who is board-certified or board-eligible?”), while two indicated they do not or have not worked in a pediatric setting; therefore, they could not move forward in the survey, leaving 34 respondents. Respondent demographics are in Table 1. Of the 34 respondents, 30 indicated they currently work in a pediatric setting, while four indicated they do not work but had previously worked in a pediatric setting. In addition, 28 of the 34 surveys had 100% completion, six surveys were incomplete, and each survey question had a response rate of less than 100%. The respondents were board-certified genetic counselors (n=28), with 17 respondents aged 20 to 29 and 5 respondents aged 30 to 34. Other age groups had two or fewer respondents. Regarding gender identity, 26 respondents were female, with one male and one questioning. The geographic location of respondents included nine in region four, seven in region five, six in region two, five in region three, and one in region one.

The pediatric specialty areas included 30 respondents from general medical genetics, 12 from inpatient, 11 from metabolism, and nine from neurogenetics. Other specialty areas with five respondents or fewer included pediatric oncology, lysosomal storage disorder, ophthalmology, and cardiovascular (Table 1, Figure 6 in Appendix D). Respondents could select all areas of specialization that applied to them, including an option for free text response. Written in specialties included hematology and endocrine disorders. The time in practice working as a GC and working in the pediatric setting for most of the respondents was 1 to 4 years.

Table 1. Respondent demographics

| Demographic Variable | Value | n | Frequency |
|--|----------------------------|----------|------------------|
| Age (years) (n=28) | 20 - 24 | 1 | 4% |
| | 25 - 29 | 16 | 57% |
| | 30 - 34 | 5 | 18% |
| | 35 - 39 | 2 | 7% |
| | 40 - 44 | 2 | 7% |
| | 45 - 49 | 0 | 0% |
| | 50 - 54 | 2 | 7% |
| | 55 + | 0 | 0% |
| Gender Identity (n=28) | Man | 1 | 4% |
| | Woman | 26 | 93% |
| | Questioning | 1 | 4% |
| Experience working as a GC (years) (n=28) | <1 | 4 | 14% |
| | 1 - 4 | 17 | 61% |
| | 5 - 9 | 3 | 11% |
| | 10 - 14 | 0 | 0% |
| | 15 - 19 | 1 | 4% |
| | 20 - 24 | 1 | 4% |
| | 25 - 29 | 2 | 7% |
| | 30 + | 0 | 0% |
| Experience working as a GC in a pediatric setting (years) (n=34) | <1 | 6 | 18% |
| | 1 - 4 | 20 | 59% |
| | 5 - 9 | 4 | 12% |
| | 10 - 14 | 1 | 3% |
| | 15 - 19 | 1 | 3% |
| | 20 - 24 | 0 | 0% |
| | 25 - 29 | 2 | 6% |
| | 30 + | 0 | 0% |
| **Pediatric Specialty (n=77) | Oncology | 2 | 3% |
| | Metabolism | 11 | 14% |
| | Lysosomal storage disorder | 6 | 6% |
| | General medical genetics | 30 | 39% |
| | Inpatient | 12 | 16% |
| | Neurogenetics | 9 | 12% |
| | Ophthalmology | 1 | 1% |
| | Cardiovascular | 5 | 6% |
| Other | 2 | 3% | |

Table 1. Respondent demographics (continued)

| | | | |
|-----------------------------|----------|---|-----|
| *Geographic location (n=28) | Region 1 | 1 | 4% |
| | Region 2 | 6 | 21% |
| | Region 3 | 5 | 18% |
| | Region 4 | 9 | 32% |
| | Region 5 | 7 | 25% |
| | Region 6 | 0 | 0% |

** indicates question with select all answer choices. *Geographic location, region 1: CT, MA, ME, NH, RI, VT, CN Maritime providences. Region 2: DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI, Quebec. Region 3: AL, FL, GA, KY, LA, MS, NC, SC, TN. Region 4: AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI, Ontario. Region 5: AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Sask. Region 6: AK, CA, HI, ID, NV, OR, WA British Columbia.

2.3.2 Genetic counseling practices

2.3.2.1 Performing mental health and suicide risk assessments

I asked survey participants questions to assess their current practices of performing a mental health or suicide risk assessment during their genetic counseling sessions. As shown in Figure 1, of the 34 respondents, nine indicated they assess mental health during a genetic counseling session, six indicated they do not, and 19 indicated they sometimes assess mental health. Not every respondent answered when asked whether they assess suicide risk; of the 30 respondents, no respondents indicated they assess suicide risk; however, 14 indicated sometimes, and 16 indicated they do not.

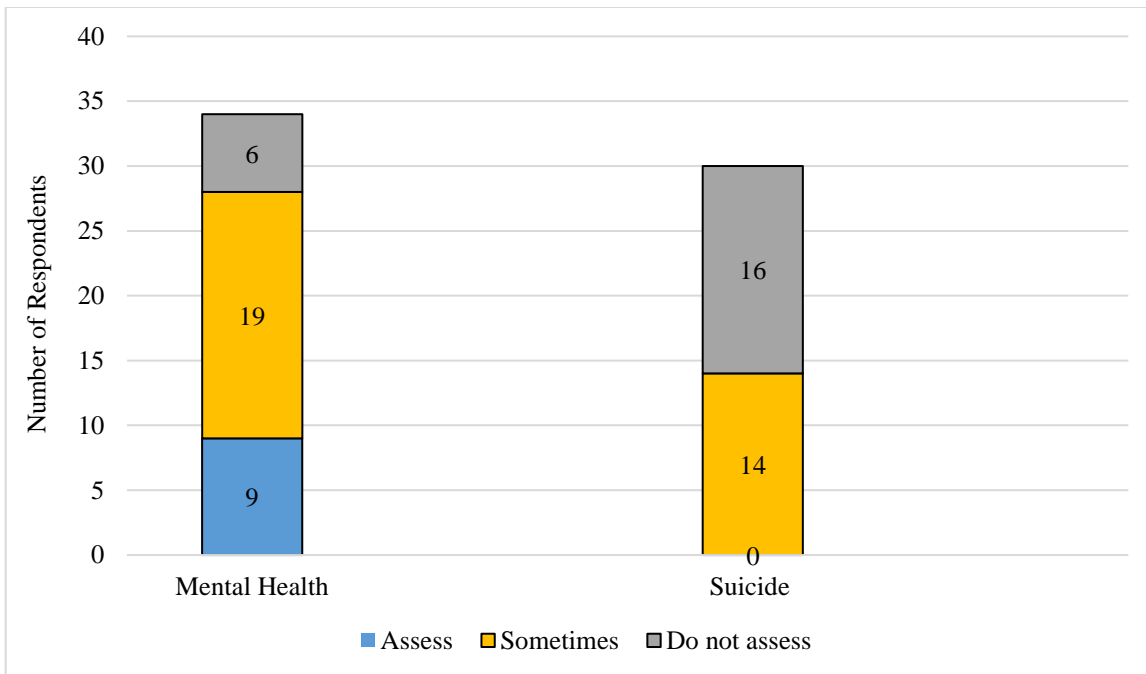


Figure 1. Number of respondents who assess mental health (n=34) and suicide risk (n=30)

No statistically significant association was found between the age of the GC (under or over age 30) and whether GCs assess the patient's mental health or suicide risk (Table 11 in Appendix D). In addition, I found no statistically significant association between the years a GC has practiced in the pediatric setting (less than four years or over four years) and whether GCs assess the patient's mental health or suicide risk (Table 11 in Appendix D).

Concerning how often participants assess their school-age or older patient's mental health (n=24), ten indicated "at every genetic counseling session when the patient is of an appropriate age or developmental ability," 12 indicated "as needed—I only ask if there seems to be a reason (e.g., physical or verbal cues by patient and, or, their guardian)," and 2 indicated "other." In the "other" answer choice, one participant wrote, "often in hEDS [Hypermobile Ehlers Danlos syndrome] clinic or if there are concerning cues or documentation in [the] chart. Another participant wrote, "As needed, but this is not just informed by the family and patient, but also the

care team, age of [the] patient, and severity of results.” When asked about how often participants are assessing suicide risk (n=14), all the respondents indicated “as needed.”

2.3.2.2 Age of patients receiving mental health and suicide risk assessments

I asked respondents through a select-all question to choose the ages of their patients whose mental health they are assessing. The age group that respondents selected the most included patients between the ages of 13- to-18 (24 selections), followed closely by patients between 11-to-12 years old and over 18 (23 selections). Patients aged 8-to-10 were selected by respondents 18 times; respondents selected the 5- to 7-year-old age group 14 times and the 3 to 4-year-old age group eight times (figure 2). For suicide risk assessment (n=54), the age group that respondents selected the most were patients between 16 to 18 years old (14 selections), followed by 13-to-15 years old (13 selections), those over 18 years old (12 selections) and then those between 11-to-12 years old (9 selections). Patients aged ten or younger were selected three times or less (figure 2).

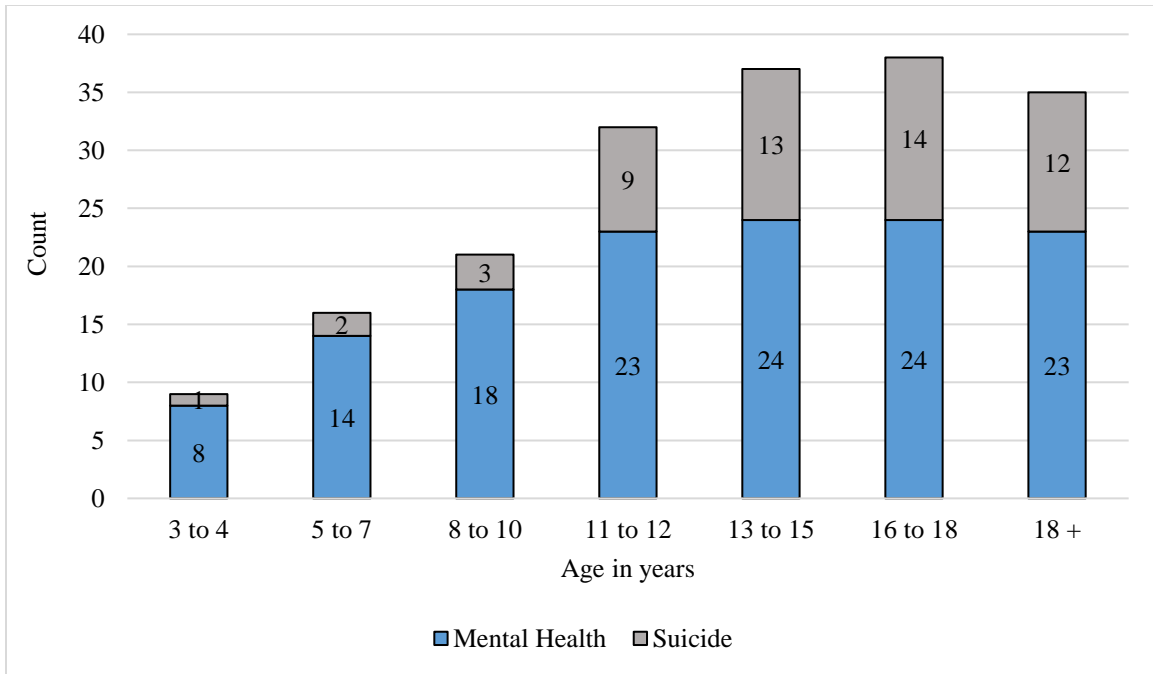


Figure 2. Count of patient age group assessed for mental health or suicide risk (select all that apply)

2.3.2.3 How risk assessment is performed

For respondents who perform a mental health risk assessment, I asked respondents to select how they perform their mental health risk assessments in a select all that apply question. The highest answer selected by respondents (21 selections) was "I ask general questions to my patient's parent(s)/guardians." Followed by "I ask general questions to my patients directly," selected by respondents 16 times. The answer option of using a risk assessment tool was not selected, and four respondents selected "other." If "other" was selected, there was a request to specify by writing in a free-text response, and no respondents wrote in a response. When asked about a suicide risk assessment, using a suicide risk assessment tool was selected once. The screening tool specifically selected was the Ask Suicide-Screening Questions (ASQ). Moreover, there were 12 selections for "I ask general questions to my patient directly," seven selections for "I ask general questions to my

patient's parent(s)/guardian(s)," and one selection for "other," but no write-in response was provided (figure 3).

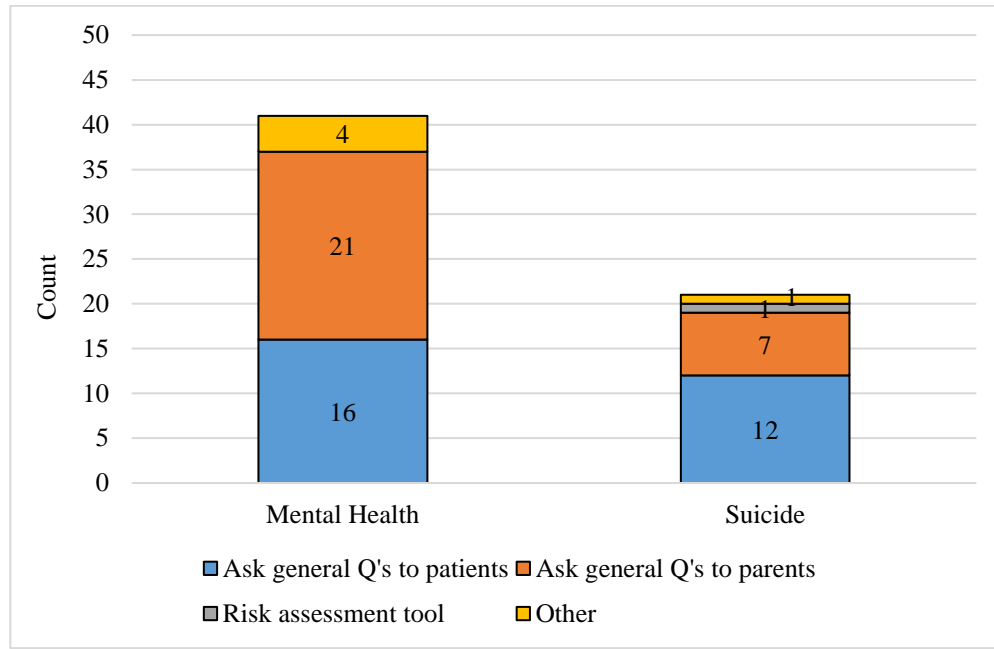


Figure 3. Count of how many respondents assess patient mental health and suicide risk (select all that apply)

2.3.2.4 Reasons why risk assessment is not performed

Only a few respondents responded to the question about why they do not conduct an assessment. For both mental health and suicide risk assessment, the most selected reason is "I don't know what the best practice is for assessing patients' mental health [or suicide risk] in the pediatric setting." Other chosen responses for mental health included "I know the patient's mental health is being assessed by a different provider," "I don't feel comfortable discussing mental health with patients," "there is not enough time during genetic counseling appointments," and "patients' lack of access to mental health services in the community" (Table 2). Other responses for suicide risk assessment included "I don't feel comfortable discussing suicide risk with patients," "not enough time during a genetic counseling appointment," "I know the patient's risk of suicide is being

assessed by a different provider," "patients' lack of timely access to mental health services in the community," "lack of support staff to follow up with patients," and "patient's lack of access to mental health services in the community." Written in free text responses for suicide risk included "feels out of scope," and "if there aren't any indications of potential suicide risk in [the] chart, I do not address unless I notice concerning signs in patients."

Table 2. Respondent responses as to why they do not assess their patient’s mental health or suicide risk

| Question | Value | Mental Health | Suicide |
|---|--|---------------|-----------|
| If you do not assess your patient’s (mental health/suicide), why not? (Select all that apply) | Lack of support staff to follow up with patients | 0 | 3 |
| | Patient's lack of access to services in the community | 1 | 3 |
| | Patient's lack of timely access to services in the community | 0 | 4 |
| | There is not enough time during a GC appointment | 1 | 6 |
| | I don't feel comfortable discussing with patients | 2 | 7 |
| | I know patient's _____ is assessed by a different provider | 3 | 6 |
| | I don't know what the best practice is | 4 | 9 |
| | Other | 0 | 2 |
| Total (n) | | 11 | 40 |

2.3.3 GC perceptions

2.3.3.1 Patients and their parent(s)/guardian(s)

Half of the respondents indicated they believe patients or their guardians want their child to be asked about their mental health during an appointment if they are of appropriate age or developmental ability (n=30). In contrast, half of the respondents were unsure. In addition, most respondents (23) indicated not being sure whether they believe patients or their guardians want GCs to ask their children about suicide during an appointment (n=30). In contrast, four respondents believe patients or guardians want GCs to ask their child about suicide, and three indicated they

do not believe patients or their guardians want GCs to ask their children about suicide during an appointment (Table 3).

Table 3. Respondent response as to whether they believe patients or their guardians want their child to be asked about mental health or suicide (n=30)

| Question | Value | Mental Health | Suicide |
|---|---|---------------|-----------|
| Do you believe patients, or their guardians want their child to be asked about their (mental health/suicide) during an appointment? | Yes, if patient is of an appropriate age or developmental ability | 15 | 4 |
| | No | 0 | 3 |
| | I'm not sure | 15 | 23 |
| | Total (n) | 30 | 30 |

2.3.3.2 Performing risk assessments

Regarding respondents' perceptions about whether GCs should be assessing mental health during sessions, 27 indicated yes, one indicated no, and two preferred not to answer (n=30). When asked whether GCs should be assessing suicide risk during sessions, 14 indicated yes, 11 indicated no, and three preferred not to answer (n=28, Figure 4).

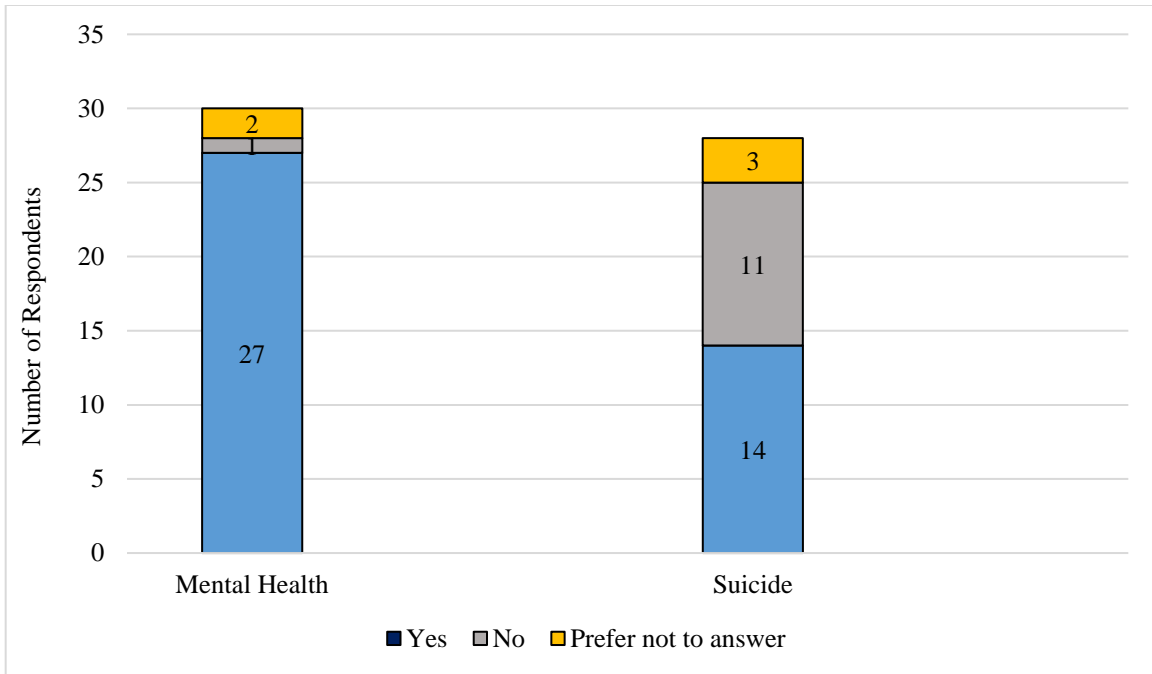


Figure 4. Number of respondents who believe mental health (n=30) or suicide risk (n=28) should be assessed

As shown in Figure 5, most respondents, 21, indicated that GCs should assess their patient's mental health at every session when the patient is of appropriate age or developmental ability; five reported that GCs should assess only when indicated (i.e., if there seems to be a reason from physical or verbal cues by a patient and, or their guardian), and two preferred not to answer (n=30). In contrast, 21 of the respondents reported that GCs should assess their patient's suicide risk only when indicated (i.e., if there seems to be a reason from physical or verbal cues by the patient and, or their guardian) and six respondents indicated that GCs should assess suicide risk at every session (n=28). None of the respondents indicated that GCs should not assess mental health or suicide risk.

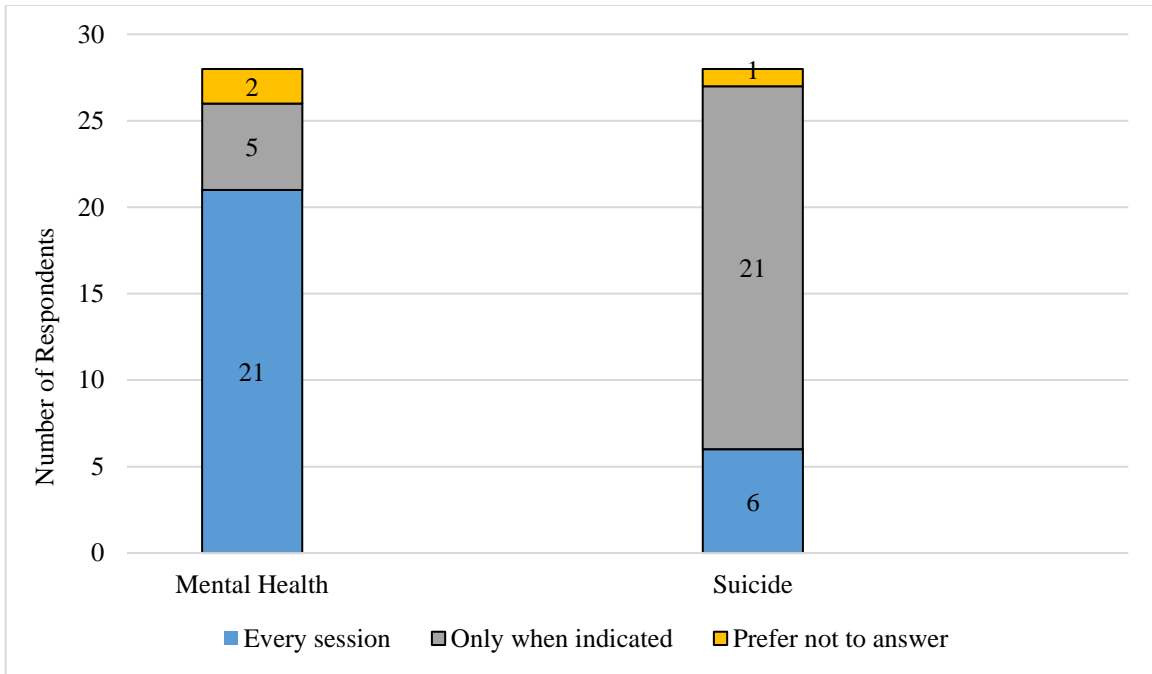


Figure 5. How frequently respondents believe mental health (n=30) or suicide risk (n=28) assessment should be performed

When I asked about how GCs should assess their patient's mental health and suicide risk, 18 respondents indicated GCs should assess mental health by asking general questions, seven indicated by using a standardized mental health risk assessment tool, one preferred not to answer, and two indicated "other" (n=28). Written responses included "asking general questions and following up with standardized tools as needed, but we likely need more training to use tools" and "asking general and specific questions. A tool might seem unfeeling?"

For suicide risk assessment (n=28), half of the respondents indicated using a standardized suicide risk assessment tool, and nine by asking general questions. Two preferred not to answer, and three indicated "other." Written in responses included, "I'll admit I'm starting to doubt my previous answer as I take this survey. Maybe we should assess suicide risk in some way?", "honestly not sure, would love to learn more," and "outside of scope."

2.3.4 Barriers

Approximately two-thirds of respondents (18) reported experiencing barriers that prevented them from assessing their patient's mental health during GC sessions. Nine indicated they had not experienced barriers, and one preferred not to answer. For suicide risk assessment, 16 indicated they had encountered barriers, nine indicated they had not, and three preferred not to answer.

The top barriers preventing a mental health assessment that respondents selected included not enough time during a session (11 selections), lack of training on how to assess a patient's mental health (11 selections), and the patient's parent(s) or guardian(s) (e.g., a parent verbalizing they do not want the GC to ask their child about this) (10 selections). Other barriers were selected by respondents eight times or less. The barriers are displayed in Table 4.

The top barrier preventing a suicide risk assessment that respondents selected included a lack of training on how to assess for suicide risk (16 selections), the patient's parent(s) or guardian(s) (e.g., a parent verbalizing they do not want the GC to ask their child about this) (9 selections), and not enough time during genetic counseling sessions (9 selections). Other barriers were also selected by respondents eight times or less (Table 4). Regarding a lack of training as a barrier (n=28), half of the respondents indicated receiving training during their genetic counseling graduate program on assessing patient mental health during sessions. In contrast, 18 respondents reported not receiving training during their genetic counseling graduate program on assessing patient suicide risk (Figure 8, Appendix D).

Table 4. Selected barriers preventing mental health or suicide risk assessments (select all that apply)

| Value | Mental Health | Suicide Risk |
|---|----------------------|---------------------|
| Lack of training on how to assess patients' risk | 11 | 16 |
| Not enough time during GC sessions | 11 | 9 |
| Patients' parents/guardians (e.g., a parent verbalizing that they do not want their child to be asked about this) | 10 | 9 |
| Lack of timely services in community (e.g., long wait lists for patients to be seen in timely manner) | 8 | 6 |
| Lack of institutional resources (e.g., social workers, psychologists, etc.) | 8 | 3 |
| Lack of services in community | 5 | 2 |
| Not within my scope of practice | 4 | 7 |
| Other | 3 | 2 |
| Total (n) | 60 | 54 |

2.3.5 Institutional capacity

Fourteen respondents (n=28) indicated their employer or institution has the appropriate resources to implement a universal mental health and suicide risk assessment tool in their clinic, seven reported that their employer or institution does not, and 3 preferred not to answer. Four respondents reported that a universal mental health and suicide risk assessment tool is already being implemented in their clinic by their employer or institution.

For respondents who reported that their employer or institution does not have the appropriate resources in place for a universal mental health screening (n=28), four respondents believe this is due to a lack of sufficient training; three believe it is due to a lack of institutional support (i.e., lack of leadership support, insufficient workflow to support screening, lack of appropriate staffing) and one selected “other” and wrote, “we might have something, I just am not aware of it.”

For respondents who indicated that their employer or institution does not have the appropriate resources in place for a universal suicide risk assessment (n=11), six selected that it is due to a lack of sufficient training, four selected it is due to lack of institutional support (i.e., lack of leadership support, insufficient workflow to support screening, lack of appropriate staffing) and one selected it is due to lack of teamwork (i.e., lack of good communication, the collaboration between staff).

2.3.6 Open-ended responses

In an open-text question format, participants identified what they saw as the benefits of assessing mental health (n= 23) and suicide risk (n=13) during genetic counseling sessions. I coded responses and grouped codes addressing common areas into categories. Categories were determined based on the frequency of responses (Table 16 and Table 17, Appendix E). Some participant responses contained codes that related to several categories. Three main categories emerged from coding and included: identifying mental health concerns, providing interventions, and the ability to provide comprehensive care. Coding also revealed additional categories specific to mental health or suicide risk (Table 17, Appendix E).

Multiple responses described how respondents felt that assessing mental health or suicide risk could identify mental health concerns promptly. For instance, one participant shared, "In general genetics, we are often asking lots of questions and sometimes uncover issues that haven't been formally addressed before by other specialists/PCPs. In this way, we are identifying where children may need help". Several other statements made by respondents described how assessment could "identify unmet needs and make appropriate referrals" and could lead to "uncovering

something that needs to be addressed quickly" or "uncovering a plan to self-harm that needs intervention," and "identifying if a patient is in crisis."

Several respondents also shared similar feelings about being able to provide interventions such as referrals and resources to patients as a benefit of assessing risk. One participant shared how "appropriate referral to mental health services can be placed." Additionally, another respondent stated, "If there are mental health concerns, the benefit is providing resources, referrals, tools, etc."

Another benefit of assessment described by participants is the ability of GCs to provide comprehensive care to patients. One participant remarked, "It is part of our holistic assessment; there should not be such a strong distinction between physical and mental health." Another respondent shared, "We are a holistic profession – why take care of their physical needs and not their mental health needs? We know that having a genetic condition creates additional obstacles, barriers, and stressors for children that can negatively impact their mental health".

The last survey question asked if there was anything else participants felt we should know about the topic. Since only six participants responded and most answers were shorter than others, I did not code these responses. However, participants shared helpful information. Some participants shared that although they felt assessment would be valuable, more training on best practices and using standardized risk assessment tools are needed. Lastly, another participant shared a story about their patient who died by suicide and how it profoundly impacted them, highlighting the importance of suicide risk assessment in genetics.

2.4 Discussion

2.4.1 Participants

Most respondents identified as women, were in their twenties, and had one to four years of overall experience working as a GC, including in the pediatric setting. This demographic profile is similar to respondents who completed the 2022 National Society of Genetic Counselors (NSGC) Professional Status Survey (PSS). The PSS reported that 93% of the 2,859 respondents identified as women, while 28% have one to four years of experience working as GC and are in their twenties (NSGC, 2022). In the study, 61% of the 28 respondents had one to four years of experience working as a GC and were in their 20s. Of the pediatric specialties, many respondents work or have worked in general medical genetics. The primary geographic regions respondents represented included regions four and five. In contrast, representation from regions two and three was limited, and there was little to no representation from regions one or six.

2.4.2 GC practices

There was a difference between respondents' practice of assessing mental health risk versus suicide risk. None of the respondents indicated they assess suicide risk at every session, and over half reported they do not assess suicide risk. In contrast, approximately a quarter of respondents assess their patient's mental health at every session, and six of the 34 respondents selected they do not. Of those who sometimes assess suicide risk or mental health, it is on an as-needed basis. Although this study focused on whether GCs are performing mental health and suicide risk assessments, Hayes et al. explored factors influencing GCs' referral of patients to mental health

services and discovered similar results. They found that half of the GC respondents (54%) assessed whether a patient needed a mental health services referral half of the time during a session (Hayes et al., 2022).

The 13-to-18 or older age groups had the most selections from respondents when asked to identify the ages of patients they assess for mental health or suicide risk. This finding suggests that respondents evaluate patients of similar ages for mental health and suicide risk. More patients over the age of eleven up to eighteen or older are being assessed compared to children under eleven. For children aged four to ten, the prevalence of suicidal ideation is typically less than one percent (Nock et al., 2013); however, studies among this age group are limited. Although small, risk still exists, and from the findings, respondents have performed mental health and suicide risk assessments on children as young as three to four. Therefore, it is crucial to recognize that if clinics pursue universal suicide screening in the future, screening children younger than ten may be necessary. The prevalence of suicidal behaviors varies among age groups, and there is a substantial increase in suicidal ideation after age 12 (Nock et al., 2013).

Regarding mental health concerns, according to the 2021 Youth Risk Behavior Survey (YRBS) data, 29% of high schoolers experienced poor mental health within the last 30 days of completing the survey, and 42% of had persistent feelings of sadness or hopelessness every day for at least two weeks. There was limited data available for middle schoolers. On the YRBS, poor mental health included depression, anxiety, or stress (CDC National Center for HIV, Viral Hepatitis, STD, and TB Prevention Division of Adolescent and School Health, 2023). Thus, despite finding that respondents are not routinely performing risk assessments, it is worth noting that when respondents are conducting an assessment, it is done more frequently on age groups at higher risk of poor mental health and suicidal ideation than less high-risk age groups.

Furthermore, of respondents who do assess their patient's mental health and suicide risk, most do not use a risk assessment tool and instead ask general questions either to the patient directly or to their guardian(s). This finding is consistent with results from Cunningham et al., who reported that most GCs do not use a psychosocial assessment tool when deciding whether to initiate a mental health referral and suggested that GCs rely on their psychosocial assessment skills instead of an assessment tool when initiating a mental health referral (Cunningham et al., 2017).

The results from this study suggest that pediatric GCs are not routinely conducting mental health and suicide risk assessments, as both assessments are mostly done sometimes and on an as-needed basis. In the pediatric genetic setting, certain conditions are considered chronic and some life-limiting. As previously discussed, high levels of anxiety and depression are associated with youth living with life-limiting conditions (Barker et al., 2019). Depression in adolescents is a known risk factor for suicide attempts, and there has been an increased link between suicide risk and those living with chronic illness (Greydanus et al., 2010). Universal depression screening to identify suicide risk in both the in-patient and outpatient settings has identified patients with depression and suicide risk (Crandal et al., 2022). Genetic clinics in the pediatric setting that have not implemented routine screening practices may miss the opportunity to identify children at risk for suicide.

2.4.3 GC perceptions

2.4.3.1 Patients and their parent(s)/guardian(s)

The data suggest that GCs do not know whether patients and their guardians want a suicide risk assessment conducted during an appointment, as most respondents were unsure when queried about this issue. Respondents reported less uncertainty in asking about mental health; half of the

respondents indicated that patients or their guardians want mental health assessed during an appointment, and half were unsure. Research completed on patient and guardian perceptions regarding assessing suicide risk in the pediatric outpatient setting indicates that youth patients and guardians believe suicide assessment is appropriate in the outpatient setting. Tipton et al. found that in medically ill patients (patients aged 8 to 21 diagnosed with primary immune deficiency, cancer, or neurofibromatosis type 1), 75% felt it acceptable to screen for suicide risk in the clinical setting (2020). In a multi-site study involving 269 adolescents aged 10-to-21 and 246 of their parents, Bradley-Ewing et al. found that 74% of guardians reported feeling comfortable with their child receiving suicide risk screening (2020). When researchers asked the patient's guardians about what setting they believe is the best place for suicide screening, 54% indicated a specialty clinic (Bradley-Ewing et al., 2020). While there is no research on patients' or their guardian's thoughts on performing risk assessments in the genetics setting, from the literature, overall, patients and guardians believe it is appropriate for healthcare providers to ask about suicide (Bradley-Ewing et al., 2020). Therefore, more education is needed to inform GCs of current patient and guardian perceptions in asking about suicide during an appointment. More education can help clarify possible misconceptions GCs may have, help GCs feel more comfortable assessing their patient's risks, and reduce stigma around this issue.

2.4.3.2 Performing risk assessments

Interestingly, GCs' practices do not align with GCs' beliefs about performing risk assessments. There is a difference in respondents' current assessment practices compared to their beliefs. The results indicate that most respondents sometimes assess mental health when indicated; however, most believe GCs should assess mental health at every session. Furthermore, no respondent reported assessing suicide risk, and almost half assessed as needed. However, half of

the respondents believe GCs should assess suicide risk, and over half selected that GCs should assess suicide risk when indicated. A few respondents (six of the 28) believe GCs should assess suicide risk at every session. Respondents had the opportunity to write about why they believe GCs should assess mental health, and respondents provided no answers, whereas respondents provided multiple responses regarding the benefits. Most notably, respondents reported the benefits of identifying concerns to be the ability to offer interventions and to provide comprehensive care to patients.

2.4.4 GC barriers

Although research has indicated that most guardians feel comfortable with their child receiving suicide risk screening (Bradley-Ewing et al., 2020), from the study results, one of the top barriers selected by respondents preventing a mental health and suicide risk assessment was the patient's parents(s) or guardian(s). Other top barriers included a lack of training in mental health and suicide risk assessment and a lack of time during sessions.

Regarding lack of training, many respondents received no training on suicide risk assessment during their graduate genetic counseling education. In contrast, half reported receiving training on mental health assessment. Interestingly, this finding differs from current research on GCs' perceived roles in mental health, as 95% of GCs somewhat or strongly agreed that they could provide support when a patient is in crisis due to a genetic risk or diagnosis (Hayes et al., 2022) and 75.5% of counselors somewhat or strongly agreed with the statement "I am trained to identify mental health concerns in patients and refer as needed" (p.1119). Further research is needed to explore the discrepancy about why GCs are not including formal mental health or suicide

assessments in their sessions if, based on the previous study, most feel somewhat or strongly that they can identify these concerns and refer as needed.

To overcome some barriers preventing GCs from performing mental health and suicide risk assessments, such as a lack of time and perceived parent or guardian wishes, the clinic could incorporate universal mental health and suicide screening into the clinical workflow. For example, clinics could incorporate a validated screening tool for depression, such as the Patient Health Questionnaire-9 (PHQ-9), into the patient rooming process or while taking vital signs. Some healthcare organizations have trialed incorporating depression screening into the rooming process and found success. Iturralde et al. (2017) performed a quality improvement project to determine the feasibility of screening adolescents with chronic illness for depression in pediatric subspecialty clinics. They found it to be effective, feasible, and not to impede the clinical workflow.

The Parkland Health and Hospital system also conducts universal suicide screening using a validated tool for every pediatric patient-provider encounter, including the outpatient pediatric setting. Staff verbally administer the tool as part of the check-in process or triage (in-patient), which takes less than one minute (Roaten et al., 2021). While research has shown validated tools to be successful, healthcare systems must have appropriate follow-up processes before implementation. Roaten et al. (2021) performed a retrospective study on the Parkland Health and Hospital system using a universal suicide screening. Roaten et al. concluded that universal suicide screening identified suicide risk in 3% of pediatric patient encounters and that "the key to efficiently and effectively managing identified suicide risk is in the creation of robust clinical pathways involving safety planning, lethal means counseling, and referral to outpatient care" (Roaten et al., 2021, p.427).

2.4.5 Institutional capacity

Some institutions already implement the use of universal mental health and suicide risk assessment tools. For clinics that do not have a universal mental health or suicide risk assessment, the results suggest it is primarily due to a lack of sufficient training and institutional support (i.e., lack of leadership support, insufficient workflow to support screening and lack of appropriate staffing). Diamond et al. (2011) also found a lack of training to be a reason why primary care providers in Pennsylvania were not performing suicide risk assessments for their adolescent patients, in addition to lack of time and lack of insurance compensation.

To overcome a lack of training preventing GCs from performing mental health and suicide risk assessments, genetic counseling graduate programs and healthcare organizations can provide additional training. For example, in addition to teaching students how to assess mental health, graduate programs can incorporate training on performing suicide risk assessments into their curriculum, educate their students on the importance of this issue in the pediatric setting, and ensure students feel competent in their ability to assess their patient's mental health and suicide risk. Healthcare organizations can also provide compensated training and continuing education credits for mental health and suicide risk assessment training.

2.4.6 Study limitations

A significant limitation of the study is the sample size. Given the small sample size of 34, it is not possible to know if there is no true statistical association between the age of the GC (under or over age 30) or years a GC has practiced in the pediatric setting (less than or over four years) and whether they assess patient mental health or suicide risk. Also, because of the small sample

size and low participation rate, it cannot be determined if the sample is representative of the entire target population (board-certified GCs working or who have previously worked in the pediatric setting), impacting the validity of the results. For example, in 2022, from the NSGC professional status survey (PSS), out of all the genetic counseling practice areas, 616 out of 2,737 GCs (23%) indicated working in pediatrics (NSGC, 2022). Although the demographic profile of respondents from our survey is similar to the PSS (women, in their 20s, with one to four years of overall experience working as a GC), our sample size is small, making it difficult to determine if the sample represents the target population.

Additional limitations include selection and information bias, which may skew the results. Specifically, non-response bias is a limitation because GCs interested in mental health or suicide may have chosen to participate in the study due to a particular interest in the topic. Informational biases, including recall and reporting bias, also exist because data are from self-reported responses. For instance, although the survey was anonymous, some respondents may have found specific questions more sensitive and chose not to answer honestly or skip the question altogether. Thus, it is possible biases impacted the results so that respondents may have indicated that they are screening for suicide risk more than they are. Additionally, some respondents may no longer work in the pediatric setting and may not accurately recall practices.

2.4.7 Directions for future research

To our knowledge, this study is the first to investigate current GC practices, beliefs, and possible barriers to performing mental health and suicide risk assessments in the pediatric setting, and more studies exploring this topic are needed for GCs to gain a deeper understanding of this topic. In the future, conducting a similar survey and including questions to determine GC's

educational preferences on how they would like to learn more about conducting assessments would be helpful. Using different recruitment methods to obtain a larger sample size would also be beneficial to combat lower statistical power and bias.

Additionally, it would be valuable to understand the perspectives of healthcare leadership and physicians working with pediatric patients in genetics to reveal possible implementation challenges and provider beliefs. Also, if, based on the results, respondents believe their clinic can support universal screening practices, it would be helpful to understand why institutions are not implementing them. It may also be beneficial to trial a validated screening tool in the pediatric genetics setting or survey existing institutions already implementing universal screening in their clinic to determine clinical utility further and ascertain their experience using a universal screening tool.

2.5 Conclusions

The study aimed to determine whether GCs in the pediatric setting routinely perform mental health and suicide risk assessments and to identify GC perceptions and barriers in conducting these assessments. The study revealed that respondents do not routinely assess mental health or suicide risk during pediatric GC sessions. However, most respondents believe GCs should assess mental health at every session, while half believe GCs should assess suicide risk and only when indicated.

As to why respondents do not assess their patient's mental health or suicide risk, the top reason reported was a lack of understanding about what the best practices are in the pediatric setting. Over half of the respondents experienced barriers preventing them from performing both

assessments. The top barrier selected for preventing a mental health assessment was a lack of time and training. The top barrier selected for preventing a suicide assessment was a lack of training. Regarding institutional capacity, half of the respondents believed their institution has the appropriate resources to implement a universal mental health and suicide risk assessment in their clinic.

GCs in the pediatric setting encounter children who have known risk factors for suicide, which can include depression and chronic and life-limiting conditions. With the prevalence of youth suicide increasing and the known clinical utility of universal suicide screening in the pediatric setting, it is necessary to understand the current practices and beliefs of GCs in performing risk assessments. The data suggest that GCs need more education on best practices for mental health and suicide risk assessment and more training on performing a suicide risk assessment. Half of the respondents believe their institutions can implement universal screening, however, is not done. A gap in care exists for identifying children at risk for mental health or suicide concerns. With proper training and institutional changes, GCs can start to close this gap and play a role in advocating for change within their healthcare system.

3.0 Research significance to public health and genetic counseling

3.1 Significance to public health

Assessment, policy development, and assurance comprise the core functions of public health. Each core function includes essential public health services (American Public Health Association [APHA], 2022). The study and the results address different aspects of each core function of public health. Within the core function of assessment, an essential public health service is to "investigate, diagnose and address health hazards and root causes" (APHA, 2022). As previously mentioned, poor mental health in children is an ongoing public health concern (CDC, 2022), and youth suicide is a significant public health challenge. The study investigated the assessment of mental health and suicide risk by identifying the practices and beliefs of genetic counselors (GCs) to learn how they address this public health issue within the pediatric genetics clinical setting. Determining current practices and beliefs about this issue helps identify potential practice improvements or gaps in existing care for this population so providers can appropriately address this issue.

Under policy development, an essential public health service is to "create, champion, and implement policies, plans, and laws that impact health" (APHA, 2022). Through existing studies, researchers have found that providers are not identifying children with mental health concerns, such as depression and suicidal ideation, in the clinical setting. Existing research also shows the clinical utility of providing universal mental health and suicide screening in the pediatric setting. The data from the study provides evidence that GCs are unlikely assessing mental health and suicide risk in the genetics setting. The results can help provide evidence for GCs to advocate and

champion policy changes within the genetics setting to incorporate universal mental health and suicide screening to impact youth health, in addition to supporting practice changes to address barriers preventing assessments from being performed.

Under the core public health function of assurance, an essential public health service is to "improve and innovate through evaluation, research, and quality improvement" (APHA, 2022). To our knowledge, no studies exist specifically looking at mental health and suicide risk assessment in the pediatric genetics setting, and this study brings awareness to this issue existing in the pediatric genetics setting and provides a starting point for future research on this topic.

3.2 Significance to genetic counseling

As previously mentioned, research has indicated that healthcare providers have been able to identify youth mental health concerns and suicide risk by assessing pediatric patients' mental health and suicide risk in the outpatient setting. The current study helps bring awareness to the need for mental health and suicide risk screening in the pediatric genetics setting, with the hopes that it will lead to GCs advocating for the implementation of universal mental health and suicide risk assessment in this setting.

The accrediting body for the genetic counseling profession, the Accreditation Council for Genetic Counseling (ACGC), has defined 22 practice-based competencies that GCs should demonstrate after completing their graduate training. The ACGC organized the competencies within four domains, and Domain II includes competencies related to a GC's interpersonal, psychosocial, and counseling skills. According to the ACGC (2019), it is a GC's responsibility to "assess clients' psychosocial needs and evaluate the need for intervention and referral" (p.5).

Therefore, this definition suggests that competent practice by a GC should include the ability to assess their pediatric patient's mental health and suicide risk when the patient is of an appropriate age and developmental ability. From the study findings, respondents are not routinely assessing mental health or suicide risk during pediatric GC sessions. This research highlights the need for GCs and those working with pediatric patients in genetics to re-examine their current clinical practices in assessing patients' mental health and suicide risk.

The data collected also showed that most respondents believe GCs should assess their patient's mental health at every session and suicide risk as needed; however, most are unsure what the proper practices are, do not feel trained, or feel they do not have enough time. By knowing these barriers, genetic counseling graduate programs, GCs, and healthcare organizations can start developing interventions to overcome these barriers.

For instance, to address the lack of training, the ACGC could consider requiring GC graduate programs to incorporate instruction on mental health and suicide risk assessment into their curriculum. Additionally, for post-graduate education, the National Society of Genetic Counseling (NSGC), the professional organization for genetic counselors, could develop continuing education sessions on this topic. To address the uncertainty GCs feel about what the proper practices are for mental health and suicide risk assessment in the pediatric setting, GC professional organizations such as NSGC could consider creating a task force to examine risk assessment guidelines and practice recommendations from other leading professional organizations such as the AAP to help and develop practice guidelines and issue a position statement on this topic.

4.0 Public health essay: analysis of mental health concerns in children with genetic conditions and special health care needs

4.1 Background

Suicide is a significant public health challenge, and in children aged 10 to 14, it was the second leading cause of death in 2020; in adolescents aged 15 to 19, it was the third leading cause (Centers for Disease Control and Prevention [CDC], 2021). Between 2007 and 2018, the suicide rate increased by 57.4% in the United States youth and young adults aged 10 to 24 (Curtin, 2020). With growing rates, in 2021, suicide was proclaimed a national emergency by the American Academy of Pediatrics (AAP) (American Academy of Pediatrics [AAP], 2021). For suicide prevention and early intervention, the AAP recommends that pediatric healthcare providers perform universal suicide screening in clinical practice for all youth aged 12 and above at least once a year (AAP, 2022).

The literature shows that risk factors and the prevalence of suicidal behaviors vary among age groups. Among children aged 5 to 11, the most common mental health condition identified as a significant risk factor for suicide is attention deficit hyperactive disorder (Ruch et al., 2021). A common mental health condition identified as a major precipitating factor for suicide in adolescents is depression. Other precipitating mental health conditions in adolescents include anxiety, disruptive behavior, eating disorders, substance abuse, adjustment, or other psychiatric disorders (Thapar et al., 2012). Researchers have suggested that for youth with chronic illness or life-limiting conditions, depression, and anxiety can also be higher (Pinquart & Shen, 2010; Barker et al., 2019).

Healthcare providers must recognize and treat depression to prevent suicide and promote well-being. In addition to the AAP's recommendation for universal suicide screening, the United States Preventative Task Force (USPSTF) recommends that youth who are between 12 to 18 years be screened for major depressive disorder (MDD), as it is "strongly associated with recurrent depression in adulthood; other mental disorders; and increased risk for suicidal ideation, suicide attempts, and suicide completion" (Mangione et al., 2022, p.E2). In the clinical setting, the most common screening tool healthcare providers use for MDD is the Patient Health Questionnaire (PHQ-9), which includes a question about suicide risk. Most depression screening tools have one question about suicide risk (Mangione et al., 2022).

Although universal suicide screening is recommended by the AAP and USPSTF, in clinical practice, Milliman et al. (2021) found that 62% of pediatric inpatients aged 10 to 21 indicated providers have never asked them about suicide in any setting. In a retrospective study exploring suicide in individuals aged 10 to 25, Rhodes et al. (2013) found that 80% had contact within the last year before their death with the healthcare system. The most common visit was in the outpatient setting, and not all visits were for mental health indications.

Universal suicide screening in the outpatient setting can help identify at-risk youth. As defined by Horowitz et al., suicide risk screening "can detect someone who is at imminent risk for suicidal behavior and those with suicidal thoughts who are not at imminent risk but are experiencing emotional distress that may lead to substantial morbidity if left undetected and untreated" (Horowitz et al., 2018, p.7). In a study by Roaten et al. (2021), over 90,000 patients aged 10 to 17 underwent universal screening for suicide. Providers identified a suicide risk with a positive screen in 2.9% of all pediatric healthcare encounters in inpatient and outpatient settings. Of the 2.9% positive screen rate, 2.3% was from patients presenting with nonpsychiatric problems.

Based on their findings, Roaten et al. (2021) concluded that "importantly, in the total sample, 2.3% of the nonpsychiatric encounters had a positive suicide risk screen, suggesting that a significant number of pediatric medical patients may have a risk that goes undetected without standardized screening" (p.427).

Research has suggested that pediatric suicide screening in the outpatient setting is effective. In a literature review, Milliman et al. (2021) concluded that providers who conduct a suicide assessment in the pediatric setting, including in the outpatient setting, could appropriately identify those at risk and provide proper intervention. In a retrospective study exploring the implementation of a universal depression screening of patients aged 12 to 17 in the inpatient and outpatient settings, Crandal et al. (2022) found that patients screened in the outpatient specialty care setting made up 40.4% of participants (n=95,613). Of the patients screened in this setting (n=38,668), 13.4% screened positive for depression and suicide risk.

With the increasing rates of youth suicide in the United States, it is crucial to identify at-risk youth so healthcare providers can take preventative action. Using validated screening tools to perform universal suicide screening in the pediatric setting has successfully identified at-risk children and adolescents. In addition to primary care settings, more pediatric specialty outpatient clinics should consider implementing universal suicide screening. The study aims to analyze data from the 2021 National Survey of Children's Health (NSCH) to help inform future universal screening considerations in the pediatric outpatient setting, specifically in the genetics setting.

4.1.1 Research questions

The following research questions guided this inquiry:

1. How do the rates of children experiencing mental health concerns requiring treatment differ between males and females?
2. Is having a genetic condition associated with a child having depression or anxiety?
3. How do the rates of children with special health care needs (CSHCN) receiving treatment/counseling for a mental/behavioral condition differ from children without special care needs receiving treatment/counseling?

4.2 Methods

The data analyzed are from the results of the 2021 NSCH administered from June 25, 2021, to January 14, 2022. Since 2016, the survey, administered annually by the United States Census Bureau, has been funded by the Health Resources and Services Administration's Maternal and Child Health Bureau (The Child & Adolescent Health Measurement Initiative [CAHMI], 2022). The overall goal of the survey is to gather information about children's health in the United States. The survey elicits information about various health topics, including a child's health status, healthcare access, and emotional and mental well-being (CAHMI, 2022). The dataset is publicly available for use.

The population of the data set included non-institutionalized children living in the United States and the District of Columbia between the ages of 0 to 17. For recruitment, the U.S. Census Bureau mailed a paper invitation to complete an online survey to 300,000 addresses in the United States and the District of Columbia. Some households also received a paper screening questionnaire included in the mailed invitation. If the respondent had one or more children aged 0 to 17 living in the household, they completed an initial screener questionnaire online. If the

respondents did not access the survey online, the U.S. Census Bureau mailed a paper screening questionnaire. The initial screener questionnaire included questions about the ages and sexes of all the children living in the household and more specific questions about the four youngest children that included demographic questions (race/ethnicity, housing status, language in household) and if they had any special health care needs. The data on the initial screener questionnaire consisted of 106,000 households and contained information on 119,241 children aged 0 to 17 years old (CAHMI, 2022).

After respondents completed the initial screener, one child from each household was randomly selected, and the household received an additional topical questionnaire to elicit information about that child. The topical questionnaire included three-age specific questionnaire versions depending on the child's age (0 to 5 years, 6 to 11 years, or 12 to 17 years), which the child's parent or caregiver completed (CAHMI, 2022). In 2021, 59% of households had age-eligible children living or staying in the household. The overall weighted response rate of the detailed topical questionnaires was 32% and included data on 50,892 children (CAHMI, 2022). Respondents completed 97% of the topical questionnaires, and 3% provided partial responses for the questionnaires. The data file had complete and partial responses from the topical questionnaire. Not all topical questionnaire questions had the same response rate; therefore, the total unweighted responses for each question differed. NSCH categorized a topical questionnaire as complete when respondents had valid answers for at least 40 of the 50 test questions and partial when respondents had valid answers for at least 25 of the 50 test questions (CAHMI, 2022). I analyzed the topical questionnaire data file to answer the research questions.

For this study, I performed all the statistical analysis of the topical questionnaire data using STATA (Stata/SE 17.0) software and a web calculator. The descriptive analysis describes the

child's demographic information, including race, age, and sex. Data include frequency tables, and I determined statistical significance by calculating a chi-square test of independence, along with an alpha value of 0.05, in a web calculator. I calculated proportions and odds ratios using a web calculator.

4.3 Results

4.3.1 Sample demographics

The data for the study included the topical questionnaire for 50,892 children, and of this sample, 11,172 (22%) were children and youth with special health care needs (CYSHCN). The demographic information is shown in Table 5. The sample included children ages 0 to 17, with 41% of children between the ages of 0 and 5, 27% between the ages of 6 and 11, and 32% between the ages of 12 and 17. In addition, 76% of children were “White alone,” with other races representing less than 10%. There were slightly more males (52%) than females (48%).

Table 5. Demographic data of the 2021 NSCH topical questionnaire

| Demographic | Value | Frequency | Percent |
|--|--|-----------|---------|
| Age of child (years) | 0 – 5 | 20,719 | 41% |
| | 6 - 11 | 14,007 | 27% |
| | 12 - 17 | 16,166 | 32% |
| Sex of child | Male | 26,468 | 52% |
| | Female | 24,424 | 48% |
| Race of child | White alone | 38,926 | 76% |
| | Black or African American alone | 3,572 | 7% |
| | American Indian or Alaska Native | 505 | 1% |
| | Asian alone | 3,014 | 6% |
| | Native Hawaiian and other pacific islander alone | 394 | 1% |
| | Two or more races | 4,481 | 9% |
| Child and youth with special health care need (CYSHCN) | Special health care needs | 11,172 | 22% |
| | No special health care needs | 39,720 | 78% |

4.3.2 Research questions

4.3.2.1 Mental health concerns requiring treatment

The NSCH topical questionnaire specifically asked guardians, “Does this child have any kind of emotional, developmental, or behavioral problem for which they need treatment or counseling?” (CAHMI, 2022, p.3). The number of males in the study (n=26,454) experiencing mental health concerns requiring treatment was 3,512 (13%), and the number of females (n=24,406) experiencing mental health concerns requiring treatment was 2,671 (11%). A chi-square test of independence found a statistically significant association between a child’s sex and whether they have a mental health concern for which they need treatment (p-value of <.00001), however, the overall difference between the number of males and the number of females is small (11% versus 13%).

4.3.2.2 Children with a genetic condition experiencing depression or anxiety

To determine whether a child had a genetic condition, the NSCH asked caregivers whether the child has ever been diagnosed with various types of conditions. For example, question A18 on the topical questionnaire reads, “Has a doctor or other healthcare provider EVER told you that this child has Cystic Fibrosis?” and question A17 reads, “Has a doctor or other healthcare provider EVER told you that this child has Blood Disorders (such as Sickle Cell Disease, Thalassemia, or Hemophilia)?” (CAHMI, 2022, p.4). A final question in this section asks if the child has ever been diagnosed with any other genetic condition.

To determine whether a child had depression or anxiety, the NSCH asked caregivers, “Has a doctor or other health care provider EVER told you that this child has depression?” and “Has a doctor or other health care provider EVER told you that this child has anxiety problems?” (CAHMI, 2022, p.3). The 2021 NSCH topical questionnaire data on the frequency of children with cystic fibrosis, blood disorders, or other genetic conditions who have experienced depression or anxiety are in Tables 16 to 21 in Appendix F.

Table 6. P-values and odds ratios for depression risk in children with cystic fibrosis, blood disorders or other genetic condition

| Risk of depression in children with: | Odds Ratio | p-value |
|--------------------------------------|------------|----------|
| Cystic fibrosis* | 3.43 | .00715 |
| Blood disorder* | 3.43 | < .00001 |
| Other genetic condition* | 3.04 | < .00001 |

*In each test, children with the condition are compared to children without the condition. Thus the “without” category includes children with all other genetic conditions.

Table 7. P-values and odds ratios for anxiety risk in children with cystic fibrosis, blood disorders or other genetic condition

| Risk of anxiety in children with: | Odds Ratio | p-value |
|-----------------------------------|------------|----------|
| Cystic fibrosis* | 3.28 | .001369 |
| Blood disorder* | 1.99 | .00004 |
| Other genetic condition* | 3.97 | < .00001 |

*In each test, children with the condition are compared to children without the condition. Thus the “without” category includes children with all other genetic conditions.

4.3.2.2.1 Cystic fibrosis

The proportion of children with cystic fibrosis (CF) (n=32) who experienced depression was 16%, while the proportion of children without CF (n=50,627) who experienced depression was 5%. The proportion of children with CF who experienced anxiety was 20%, while the proportion of children without CF (n=50,594) who experienced anxiety was 11%. (Figure 9, Appendix F). Additionally, a chi-square test of independence found an association between a child with CF and experiencing depression or anxiety. The results indicated that the odds of a child experiencing depression or anxiety are three times higher in children with CF when compared to children without CF. When comparisons were made between children with CF and children without CF experiencing depression or anxiety to determine statistical significance, the total count for children without CF also included children with other genetic conditions. However, the total number of such children is small enough that the set of all children without CF is a meaningful comparison group (i.e., it is almost entirely composed of children with no genetic conditions) (Tables 6 and 7, Figure 9 in Appendix F).

4.3.2.2.2 Blood disorders

The proportion of children with a blood disorder (n=225) who experienced depression was 16%, while that of children without a blood disorder (n=50,388) who experienced depression was 5%. The proportion of children with a blood disorder who experienced anxiety was 19%, while the proportion of children without a blood disorder (n=50,356) who experienced anxiety was 11% (Figure 10, Appendix F). A chi-square test of independence also found an association between a child with a blood disorder and experiencing depression (Table 6) or anxiety (Table 7). The results indicated that the odds of a child experiencing depression are three times higher in children with a blood disorder than in children without a blood disorder. Furthermore, the odds of a child experiencing anxiety are 1.9 times higher in a child with a blood disorder than in a child without a blood disorder. When comparisons were made between the two groups to determine statistical significance, the total count for children without blood disorders also included children with other genetic conditions.

4.3.2.2.3 Other genetic condition

The proportion of children with other genetic conditions who experienced depression was 13%, while the proportion of children without other genetic conditions who experienced depression was 5%. The proportion of children with other genetic conditions who experienced anxiety was 30%, while the proportion of children without other genetic conditions who experienced anxiety was 10% (Figure 11, Appendix F). In addition, a chi-square test of independence found an association between a child with other genetic conditions and experiencing depression (Table 6) or anxiety (Table 7). The results indicated that the odds of having depression in a child with a different genetic condition, other than a blood disorder of CF, is 3.04 times higher than a child with no other genetic condition and 3.97 times higher for anxiety than children without

other genetic conditions. When comparisons were made between the two groups to determine statistical significance, the total count for children without other genetic conditions also included children with CF and blood disorders.

4.3.2.3 Children and youth with special health care needs

The Health Resources and Services Administration's Maternal and Child Health Bureau define children and youth with special health care needs (CYSHCN) for the NSCH using the definition by McPherson et al. (1998) "children with a special health care need are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (p. 138). Genetic conditions, including Down syndrome and cystic fibrosis, are considered conditions among CYSHCNs. Ghandour et al. (2022) analyzed data from the 2016-2019 NSCH and found that genetic conditions were number 12 of the top 27 common health conditions among CYSCHNs.

The number of CYSHCN in the current study (n=11,165) experiencing mental health concerns (defined as some emotional, development, or behavioral problem) requiring treatment or counseling was 5,831 (52%), while the number of non-CYSHCN (n=39,695) experiencing mental health concerns requiring treatment or counseling was 352 (0.9%) (Table 22, Appendix F). A chi-square test of independence also found a statistically significant association between CYSHCN experiencing mental health concerns and requiring treatment or counseling (Table 8).

Table 8. P-values for CYSHCN and need to see a mental health provider or receive treatment for mental health or behavioral concern

| Variables | p-value |
|--|----------|
| CYSHCN and needs to see mental health provider | <0.00001 |
| CYSHCN and receiving treatment for a mental health or behavioral condition | <0.00001 |

The NSCH topical questionnaire elicited data about whether a child saw a mental health professional by asking caregivers, “During the past 12 months, has this child received treatment or counseling from a mental health professional?” (CAHMI, 2022, p.7). For this question, of CYSHCN (n=11,117), 36% saw a mental health professional, and 7% needed to. For non-CYSHCN (n=39,519), 3% saw a mental health professional, and 1% needed to (Table 23, Appendix F). A chi-square test of independence also found an association between CYSHCN and the need to see a mental health professional (Table 8).

4.4 Discussion and conclusion

Of the sample size, most male and female children had no mental health concerns requiring treatment. Of children who did, there was a statistically significant association between child sex and mental health concerns requiring treatment; however, the frequency of males was slightly higher than females. Interestingly, while the NSCH data indicate slightly more males with mental health concerns requiring treatment, the 2021 High School Youth Risk Behavior Survey (YRBS) found that high school females are likelier to report poor mental health than males in the United States (CDC, 2021). In the states with data on the YRBS for middle schoolers, females were also more likely to report poor mental health than males (CDC, 2021). Campbell et al. (2021) also

found that among 15-year-olds across 73 different countries (including the United States), girls' mental health is worse than 15-year-old boys. As known from the literature, in 2020, among youth aged five to nine, suicide was the tenth leading cause of death, the second leading cause of death among youth aged 10 to 14, and the third leading cause of death among youth aged 15 to 19 (CDC, 2020). In all three age groups, the suicide rates were higher among males than females (CDC, 2020). However, more research is needed to understand the mental health concerns and suicidal ideation among different demographic groups and to understand these issues in children under ten for tailored interventions.

To our knowledge, no published studies exist that explore the prevalence of mental health concerns and suicide risk in the pediatric genetic setting. However, as previously mentioned, certain genetic conditions with onset in childhood are considered chronic or life-limiting, and research suggests that youth with chronic illness and life-limiting conditions have a higher prevalence of depression and anxiety (Pinquart & Shen, 2010; Barker et al., 2019). Barker et al. (2019) conducted a systematic review and meta-analysis of 37 studies to determine the prevalence of anxiety and depression in individuals living with life-limiting conditions between the ages of 5 to 25. They concluded that anxiety is six times higher for those living with life-limiting conditions than the general population and that depression is also higher among this group than the general population (Barker et al., 2019).

Pinquart & Shen (2010) performed a meta-analysis of 340 studies and concluded that youth living with chronic conditions have higher levels of depressive symptoms and that certain chronic conditions place children at higher risk for experiencing depressive symptoms. As mentioned earlier, some genetic conditions in the pediatric setting can be chronic or life-limiting. Our findings from the NSCH provide further evidence that youth living with chronic or life-

limiting conditions may experience higher rates of anxiety or depression, as there was a statistically significant association between youth with CF, blood disorders, or other genetic conditions and reported depression or anxiety. In addition, based on the odds ratios calculated from the NSCH data, our findings indicate that the likelihood of children with CF, blood disorders, or other genetic conditions experiencing depression or anxiety is higher than children without these conditions. Generally, children with certain genetic conditions tend to have more contact with the healthcare system; therefore, it may be possible that due to more frequent exposure, if they do have depression or anxiety, it is more likely to be identified or diagnosed compared to children without certain genetic conditions.

Previous research shows a well-established association between certain mental disorders and youth suicide, including major depression. From a longitudinal study on childhood depression and the risk of suicide, Rao et al. (1993) suggested that children and adolescents with early-onset major depressive disorder (MDD) had higher rates of suicide compared to children and youth who did not. Additionally, a prospective case control study by Weissman et al. (1999) found higher rates of suicide and suicide attempts in adults who developed MDD in adolescence. Pelkonen & Marttunen (2003) also reviewed psychological autopsies of youth suicides to determine the epidemiology, risk factors, and prevention. They found that of children who have died by suicide, 50 to 70% experienced some mood disorder, with the most common being major depression. Based on the knowledge that depression is a major precipitating factor for youth suicide and the 2021 NSCH data showing an association between children with CF, a blood disorder, or other genetic conditions experiencing depression or anxiety, the study findings highlight the need for healthcare providers and clinical leadership in the pediatric genetic settings to consider the implementation of universal mental health and suicide risk screening.

In 2021, 7% of CYSHCN needed to see a mental health professional, and this healthcare need was unmet. Unfortunately, unmet healthcare needs in this population are common, and between 2019 to 2020, it was almost four times more likely that CYSHCN did not have their healthcare needs met compared to non-CYSHCN (Health Resources and Services Administration [HRSA] Maternal & Child Health, 2022). From the 2019 to 2020 NCHS data, mental healthcare was the most significant unmet healthcare need when comparing data from CYSHCN to non-CYSHCN. From 2019 to 2020, unmet mental health care for CYSHCN was 4% compared to 0.4% for non-CYSHCN (HRSA Maternal & Child Health, 2022). Based on the data analysis for this project, of the 2021 NSCH, 7% of CYSHCN had unmet mental health care needs versus 1% for non-CYSHCN.

It is essential to recognize that many pediatric genetic conditions qualify a child or youth as having a special health care need based on the validated five-item screener used by the Maternal and Child Health Bureau (MCHB). With this consideration, the data reveal that CYSHCN are experiencing mental healthcare needs that are going unmet, and healthcare providers may be missing opportunities to identify, support and provide appropriate interventions for children and youth in need of those services in the pediatric genetics setting. To help identify concerns, healthcare providers and clinical leadership in pediatric genetic settings should consider implementing universal mental health and suicide risk screening if not already doing so.

Various healthcare organizations already recognize the need for the early identification and treatment of mental health concerns. One of the leading pediatric organizations for children's health, the American Academy of Pediatrics (AAP), recommends that healthcare providers conduct universal suicide screening in clinical practice for all youth aged 12 and above at least once a year to identify at-risk youth (AAP, 2022). In 2009, the AAP released a policy statement

announcing mental health competencies for pediatricians in the primary care setting (Green et al., 2019). In 2019, the AAP revised this policy statement to reflect updated research in pediatric mental health and in recognition of how essential mental health competencies are not only for primary care providers but for providers working in pediatric subspecialty clinics caring for children with chronic conditions (Green et al., 2019). Because of the association between MDD and suicide, the USPSTF also recommends that youth between 12 to 18 years be screened for MDD (Mangione et al., 2022).

There are multiple screening tools to identify individuals at risk for depression and suicide that are easy to use and validated for use in the pediatric setting. The most common screening tool healthcare providers use to screen for childhood depression in the clinical setting is the Patient Health Questionnaire (PHQ-9), which includes a question about suicide risk and the Beck Depression Inventory (BDI), both self-reporting questionnaires (Patra & Kumar, 2022). Multiple validated tools also screen for suicide risk in the pediatric setting. The most common include the Ask Suicide Screening (ASQ), a self-reported questionnaire (Patra & Kumar, 2022).

There were several limitations to the study. Limitations include that the NSCH was a cross-sectional survey design, which does not allow for determining cause and effect. In addition, the data are self-reported based on guardian recall and not clinical diagnosis, which can contribute to information bias. Furthermore, the children were primarily white, limiting the generalizability of the study.

To conclude, the study aimed to analyze data from the 2021 NSCH to help inform future universal screening considerations in the pediatric outpatient genetics setting. The analysis revealed that slightly more males than females experience mental health concerns requiring treatment and that an association exists between a child with a CF, a blood disorder, or other

genetic conditions and experiencing depression or anxiety. Additionally, more CYSHCNs needed to see a mental health professional than non-CYSHCN; this need goes unmet for some.

The literature shows well-established evidence that depression in adolescents is a known risk factor for suicide and that there is a higher prevalence of depression and anxiety in youth living with chronic or life-limiting conditions. Multiple genetic conditions are considered chronic, life-limiting, or qualify a youth as having a special health care need; therefore, providers in the pediatric setting see patients at risk. Fortunately, providers can choose from multiple, easy-to-use, validated screening tools in the pediatric setting to help identify youth at risk for depression and suicide to provide early intervention. Considering the existing literature and the information yielded from the NSCH, it supports the recommendation that providers in the outpatient pediatric genetics setting should consider implementing universal mental health and suicide risk screening into their clinical practice.

Appendix A institutional review board approval



NOT HUMAN RESEARCH DETERMINATION

| | |
|---------------------|---|
| Date: | November 4, 2022 |
| Review Type: | Initial Study |
| IRB: | STUDY22100003 |
| PI: | Glenna Noska |
| Title: | Exploring genetic counselors' perspectives in assessing mental health and suicide risk in the pediatric setting. |
| Funding: | None |
| Documents Reviewed: | <ul style="list-style-type: none">• Thesis_Survey_IRB(1).docx, Category: Data Collection;• E-mail Script, Category: Recruitment Materials;• HRP-721-WORKSHEET, Category: IRB Protocol;• Social Media Invitation Script, Category: Recruitment Materials; |

The Institutional Review Board determined that the proposed activity is not research involving human subjects as defined by DHHS and FDA regulations.

Appendix A Figure 1. Institutional review board approval

Appendix B recruitment materials

Email invitation script

Exploring genetic counselors' perspectives in assessing mental health and suicide risk in the pediatric setting.

Mental health disorders among children and adolescents in the United States are on the rise, and **rates of suicide have increased substantially**. Currently, there is **limited literature** about whether genetic counselors assess mental health or perform suicide risk assessments in the **pediatric genetic counseling** setting. It is also unknown whether personal or institutional barriers exist in this setting that may limit a genetic counselor's ability to assess those at risk for suicide. **As experts in the field of pediatric genetic counseling, your insight into this topic is highly valued and needed.** For these reasons, I invite you to complete an online survey aiming to address these gaps in the literature to help inform our future practice.

This survey will serve as the basis for my master's thesis project that I am conducting as part of my training. The survey will include questions about whether genetic counselors assess mental health and suicide risk, their training on this topic, and the perceptions and perceived barriers genetic counselors have about evaluating mental health and suicide risk in the pediatric population.

Participation is voluntary; the survey will take about 10 to 15 minutes. There are no foreseeable risks associated with this project or direct benefits to you, and you may stop participating at any time by closing the web browser to the survey. If you choose not to participate, this will not affect your relationship with the University of Pittsburgh Genetic Counseling Program. The survey will

be **anonymous**, and responses will be kept on a secure cloud storage site. If you would like to participate, please click the arrow in the bottom right corner to proceed.

Thank you for your time and your willingness to help make this project possible. Should you have any questions or concerns, please contact me at gl8@pitt.edu.

Sincerely,

Glenna Noska

Second-year genetic counseling student

University of Pittsburgh Genetic Counseling Program

Social media invitation script

Facebook:

Genetic counselors--Are you or have you ever practiced in the pediatric setting? If so, your input is needed! Please consider taking this research survey for Glenna Noska, a Pitt Genetic Counseling student.

https://pitt.col.qualtrics.com/jfe/form/SV_8CdF07IIIcpaH3g

#GeneChat

Facebook profile used:



Twitter:

Genetic counselors--Are you or have you ever practiced in the pediatric setting? If so, your input is needed! Please consider taking this research survey for Glenna Noska, a Pitt Genetic Counseling student.

https://pitt.co1.qualtrics.com/jfe/form/SV_8CdF07IIIcpaH3g

#GeneChat

Twitter profile used:



Appendix C survey

Thesis Survey

Survey Flow

Standard: Screening (4 Questions)

Standard: Routinely assessing mental health (7 Questions)

Standard : Routinely assessing suicide (7 Questions)

Standard : GC perspectives (14 Questions)

Standard: Barriers (9 Questions)

Standard: Training received (7 Questions)

Standard: Demographic Questions (5 Questions)

Start of Block: Screening

Q2 Are you a genetic counselor who is board certified or board-eligible?

- Yes, I am a board-certified genetic counselor (1)
- Yes, I am a board-eligible genetic counselor (2)
- No (3)

Skip To: End of Survey If Are you a genetic counselor who is board certified or board-eligible? = No

Q3 Do you currently work in a pediatric setting? A pediatric setting is defined by working with patients aged 0 to 18 years.

- Yes, I am currently working in a pediatric setting (1)
- No, but I have worked in a pediatric setting before (2)
- No (3)

Skip To: End of Survey If Do you currently work in a pediatric setting? A pediatric setting is defined by working with pati... = No

Q4 How many years of experience do you have working as a genetic counselor in a pediatric setting? A pediatric setting is defined by working with patients aged 0 to 18 years.

- < 1 year (1)

- o 1 to 4 years (2)
- o 5 to 9 years (3)
- o 10 to 14 years (4)
- o 15 to 19 years (5)
- o 20 to 24 years (6)
- o 25 to 29 years (7)
- o 30 to 34 years (8)
- o 35 to 39 years (9)
- o 40+ years (10)

Q5 What is your area of specialization? (**Select all that apply**)

1. Pediatric oncology (1)
2. Pediatric metabolism (2)
3. Pediatric lysosomal storage disorder (3)
4. General pediatric medical genetics (4)
5. Pediatric inpatient (5)
6. Pediatric neurogenetics (6)
7. Pediatric ophthalmology (7)
8. Pediatric cardiovascular genetics (8)
9. Other (please specify) (9) _____

End of Block: Screening

Start of Block: Routinely assessing mental health

Q6 The next section of questions is to determine whether pediatric genetic counselors are **routinely assessing** their patients' mental health during genetic counseling sessions. For the purpose of the survey, we are using the Centers for Disease Control and Prevention definition of

mental health: "child mental health includes a child's mental, emotional, and behavioral well-being."

Q7 Do you assess your patient's mental health during a genetic counseling session?
Mental health is defined as a child's mental, emotional, and behavioral well-being.

- Yes (1)
- No (2)
- Sometimes (3)

Skip To: Q12 If Do you assess your patient's mental health during a genetic counseling session? Mental health is... = No

Q8 How often are you assessing your patient's (school-age or older) mental health?

- At every genetic counseling session when the patient is of an appropriate age or developmental ability (1)
- As needed--I only ask if there seems to be a reason (e.g., physical or verbal cues by patient and/or their guardian) (2)
- Other (please specify) (3) _____

Q9 How old are the patients you are assessing (**Select all that apply**)

- 10. 3 to 4 years old (7)
- 11. 5 to 7 years old (1)
- 12. 8 to 10 years old (2)
- 13. 11 to 12 years old (3)
- 14. 13 to 15 years old (4)
- 15. 16 to 18 years old (5)
- 16. Over 18 years old (6)

- Q10 How do you perform your mental health risk assessments? (**Select all that apply**)
17. I ask general questions to my patients directly (e.g., How are you feeling? Could you tell me about any times over the past few months that you've been bothered by stress or sadness?) (1)
18. I ask general questions to my patients' parent(s)/guardian(s) (e.g., Has there been a change in your child's mood within the past few weeks?) (2)
19. I use a risk assessment tools (3)
20. Other (please specify) (4) _____

Display This Question:

If How do you perform your mental health risk assessments? (Select all that apply) = I use a risk assessment tools

- Q11 What risk assessment tool do you use to assess your patient's mental health?
- Patient Health Questionnaire (PHQ-9) (1)
 - Columbia-Suicide Severity Rating Scale (C-SSRS) (2)
 - Self-Injurious Thoughts and Behaviors Interview (SITBI) (3)
 - I do not use a risk assessment tool (4)
 - Other (please specify) (5) _____

Display This Question:

If Do you assess your patient's mental health during a genetic counseling session? Mental health is... = No

- Q12 If you do not assess your patient's mental health, why not? (**Select all that apply**)
21. Lack of support staff to follow up with patients (e.g., social workers or mental health professionals) (1)

- 22. Patients' lack of access to mental health services in the community (2)
- 23. Patients' lack of timely access to mental health services in the community (e.g., a long wait time to access mental health services) (3)
- 24. There is not enough time during genetic counseling appointments (4)
- 25. I don't feel comfortable discussing mental health with patients (5)
- 26. I know the patient's mental health is being assessed by a different provider (6)
- 27. I don't know what the best practice is for assessing patients' mental health in the pediatric setting. (8)
- 28. Other (please specify) (7) _____

End of Block: Routinely assessing mental health

Start of Block: Routinely assessing suicide

Q13 The next section of questions is to determine whether pediatric genetic counselors are **routinely assessing suicide risk** during sessions. The National Institute of Mental Health defines suicide as death caused by self-directed injurious behavior with intent to die because of the behavior.

- Q14, Do you assess suicide risk in your patients during a genetic counseling session?
- Yes (1)
 - No (2)
 - Sometimes (3)

Skip To: Q19 If Do you assess suicide risk in your patients during a genetic counseling session? = No

- Q15 How often are you assessing your patient's (school-aged or older) suicide risk?
- At every genetic counseling session when the patient is of an appropriate age or developmental ability (1)

o As needed--I only ask if there seems to be a reason (e.g., physical or verbal cues by patient and/or their guardian) (2)

o Other (please specify) (3) _____

Q16 How old are the patients you are assessing? (**Select all that apply**)

29. 3 to 4 years old (7)

30. 5 to 7 years old (1)

31. 8 to 10 years old (2)

32. 11 to 12 years old (3)

33. 13 to 15 years old (4)

34. 16 to 18 years old (5)

35. Over 18 years old (6)

Q17 How do you perform your suicide risk assessment? (**Select all that apply**)

36. I ask general questions to my patients directly (e.g., Are you having thoughts about harming yourself or others?) (1)

37. I ask general questions or my patients' parent(s)/guardian(s) (e.g., Has your child tried or spoken about harming themselves or others recently?) (2)

38. I use a suicide risk assessment tool (3)

39. Other (please specify) (4) _____

Display This Question:

If How do you perform your suicide risk assessment? (Select all that apply) = I use a suicide risk assessment tool

Q18 What suicide risk assessment tool do you use?

o Ask Suicide-Screening Questions (ASQ) (1)

o Beck Scale for Suicide Ideation (SSI) (2)

- o Suicidal Ideation Questionnaire (SIQ) (3)
- o Patient Health Questionnaire (PHQ-9) (4)
- o Columbia- Suicide Severity Rating Scale (C-SSRS) (5)
- o Self-Injurious Thoughts and Behaviors Interview (SITBI) (6)
- o I do not use a suicide risk assessment tool (7)
- o Other (please specify) (8) _____

Display This Question:

If do you assess suicide risk in your patients during a genetic counseling session? = No

Q19 If you do not assess your patients' suicide risk, why not (**Select all that apply**)

- 40. Lack of support staff to follow up with patients (e.g., social workers or mental health professionals) (1)
- 41. Patients' lack of access to mental health services in the community (2)
- 42. Patients' lack of timely access to mental health services in the community (e.g., long wait lists for patients to be seen in a timely manner by a mental health professional) (3)
- 43. Not enough time during a genetic counseling appointment (4)
- 44. I don't feel comfortable discussing suicide risk with patients (5)
- 45. I know patient's risk of suicide is being assessed by a different provider (6)
- 46. I don't know what the best practice is for asking about suicide risk in the pediatric setting. (8)
- 47. Other (please specify) (7) _____

End of Block: Routinely assessing suicide

Start of Block: GC perspectives

Q38 The next section of questions is to **determine genetic counselors' perspectives** about assessing for mental health and suicide risk during a pediatric genetic counseling session.

Q39, Do you believe patients or their guardians want their child to be asked about their mental health during an appointment?

- Yes, if patient is of an appropriate age or developmental ability (1)
- No (2)
- I'm not sure (3)
- Prefer not to answer (4)

Q40, do you believe patients or their guardians want their child to be asked about suicide during an appointment?

- Yes, when patient is of an appropriate age or developmental ability (1)
- No (2)
- I'm not sure (3)
- Prefer not to answer (4)

Q41 Do, you believe mental health should be assessed during genetic counseling sessions?

- Yes (1)
- No (2)
- Prefer not to answer (3)

Display This Question:

If do you believe mental health should be assessed during genetic counseling sessions? =

Yes

Q42 What would you see as the benefits of assessing mental health during genetic counseling sessions?

Display This Question:

If Do you believe mental health should be assessed during genetic counseling sessions? =

No

Q43 Why do you believe mental health should not be assessed during genetic counseling sessions?

Q44, Do you believe suicide risk should be assessed during genetic counseling sessions?

- Yes (1)
- No (2)
- Prefer not to answer (3)

Display This Question:

If do you believe suicide risk should be assessed during genetic counseling sessions? = Yes

Q45 What would you see as the benefits of assessing suicide risk during genetic counseling sessions?

Display This Question:

If do you believe suicide risk should be assessed during genetic counseling sessions? = No

Q46 Why do you believe suicide risk should not be assessed during genetic counseling sessions?

Q47 How do you believe genetic counselors should assess their patients' mental health?

- Asking general questions (1)
- Using a standardized mental health risk assessment too (2)
- Prefer not to answer (3)
- Other (please specify) (4) _____

Q48 How do you believe genetic counselors should assess their patients' suicide risk?

- Asking general questions (1)

- o Using a standardized suicide risk assessment too (2)
- o Prefer not to answer (3)
- o Other (please specif) (4) _____

Q49 How often do you believe genetic counselors should be assessing their patients' mental health during genetic counseling sessions?

- o Never (1)
- o Every session when patient is of an appropriate age or developmental ability (2)
- o Only when indicated (i.e., if there seems to be a reason from physical or verbal cues by patient and/or their guardian (3)
- o Prefer not to answer (4)

Q50 How often do you believe genetic counselors should be assessing their patients' suicide risk during genetic counseling sessions?

- o Never (1)
- o Every session when the patient is of an appropriate age and developmental ability (2)
- o Only when indicated (i.e., if there seems to be a reason from physical or verbal cues by patient and/or their guardian (3)
- o Prefer not to answer (4)

Q51 Is there anything else you would like us to know about this topic?

End of Block: GC perspectives

Start of Block: Barriers

Q29 The next section of questions is to determine the **perceived barriers genetic counselors face** in assessing their patients' mental health and suicide risk in the pediatric setting.

Q30, have you encountered any barriers preventing you from asking your patients about their mental health during your genetic counseling sessions?

- Yes (1)
- No (2)
- Prefer not to answer (3)

Skip To: Q31 If Have you encountered any barriers preventing you from asking your patients about their mental hea... = Yes

Display This Question:

If Have you encountered any barriers preventing you from asking your patients about their mental hea... = Yes

Q31 What are those barriers? (**Select all that apply**)

- 48. Lack of institutional resources (e.g., social workers, psychologists, etc.) (1)
- 49. Lack of mental health services in the community (2)
- 50. Lack of timely mental health services in the community (e.g., long wait lists for patients to be seen in a timely manner by a mental health professional) (3)
- 51. Lack of training on how to assess patients' mental health (8)
- 52. Not enough time during genetic counseling session (4)
- 53. It is not within my scope of practice (5)
- 54. Patients' parent(s)/guardian(s) (e.g., a parent verbalizing they do not want their child to be asked about this) (6)
- 55. Other (please specify) (7) _____

Q32, Have you encountered any barriers preventing you from assessing your patients' risk for suicide during you genetic counseling session?

- Ye (1)

- o No (2)
- o Prefer not to answer (3)

Display This Question:

If Have you encountered any barriers preventing you from assessing your patients' risk for suicide d... = Yes

Q33 What are those barriers? **(Select all that apply)**

- 56. Lack of institutional resources (e.g., social workers, psychologists, etc.) (1)
- 57. Lack of mental health services in the community (2)
- 58. Lack of timely mental health services in the community (e.g., long wait lists for patients to be seen in a timely manner by a mental health professional) (3)
- 59. Lack of training on how to assess patients' risk for suicide (8)
- 60. Not enough time during genetic counseling sessions (4)
- 61. It is not within my scope of practice (5)
- 62. Patients' parent(s)/guardian(s) (e.g., a parent verbalizing they do not want their child to be asked about this) (6)
- 63. Other (please specify) (7) _____

Q34, Do you believe your employer/institution has the appropriate resources in place to allow a universal mental health risk assessment tool to be implemented in your clinic? For example, an assessment tool may include the Patient Health Questionnaire (PHQ-0), Columbia-Suicide Severity Rating Scale (C-SSRS), Self-Injurious Thoughts and Behaviors Interview (SITBI), etc.

- o Yes (1)
- o No (2)
- o Prefer not to answer (4)
- o Not applicable because this is already implemented in our clinic (3)

Display This Question:
If Do you believe your employer/institution has the appropriate resources in place to allow a univer... = No

Q35 Why do you believe your employer/institution does not have the appropriate resources in place? **(Select all that apply)**

64. Lack of teamwork (i.e., lack of good communication, collaboration between staff) (1)

65. Lack of institutional support (i.e., lack of leadership support, insufficient workflow to support screening, lack of appropriate staffing) (2)

66. Lack of sufficient training (3)

67. Other (please specify) (4) _____

Q36, Do you believe your employer/institution has the appropriate resources in place to allow a universal suicide risk assessment tool to be implemented in your clinic? For example, an assessment tool may include Ask Suicide-Screening Questions (ASQ), Beck Scale for Suicide Ideation (SSI), Suicidal Ideation Questionnaire (SIQ), etc.

Yes (1)

No (2)

Prefer not to answer (3)

Not applicable because this is already implemented in our clinic (4)

Display This Question:

If do you believe your employer/institution has the appropriate resources in place to allow a univer... = No

Q37 Why do you believe your employer/institution does not have the appropriate resources in place? **(Select all that apply)**

68. Lack of teamwork (i.e., lack of good communication, collaboration between staff) (1)

69. Lack of institutional support (i.e., lack of leadership support, insufficient workflow to support screening, lack of appropriate staffing) (2)

70. Lack of sufficient training (3)

71. Lack of funding (5)

72. Other (please specify) (4) _____

End of Block: Barriers

Start of Block: Training received

Q20 The next section of questions is to determine what **training genetic counselors have received** in assessing mental health and suicide risk.

Q21, Do you have additional training in mental health counseling? (e.g., certificate in mental health first aid, a degree in mental health counseling)

- Yes (1)
- No (2)
- Prefer not to answer (3)

Skip To: Q22 If Do you have additional training in mental health counseling? (e.g., certificate in mental health... = Yes

Display This Question:

If Do you have additional training in mental health counseling? (e.g., certificate in mental health... = Yes

Q22 Please enter the training you have in mental health counseling.

Q23 Did you receive training during your genetic counseling graduate program on how to routinely assess your patients' mental health during sessions?

- Yes (1)
- No (4)
- Do not recall (2)
- Prefer not to answer (3)

Q24 Did you receive training during your genetic counseling graduate program on how to routinely assess your patients' risk for suicide during sessions?

- Yes (1)
- No (4)
- Do not recall (2)
- Prefer not to answer (3)

Q25 Did you receive training through your previous or current employer on how to assess your patients' mental health? (e.g., support for CEU opportunities)

- Yes (1)
- No (2)
- Prefer not to answer (3)

Q26 Did you receive training through your previous or current employer on how to assess your patients' risk for suicide? (e.g., support for CEU opportunities)

- Yes (1)
- No (2)
- Prefer not to answer (3)

End of Block: Training received.

Start of Block: Demographic Questions

Q52 The next set of questions are related to demographics.

Q53 What is your current age?

- 20 to 24 years old (1)
- 25 to 29 years old (2)
- 30 to 34 years old (3)
- 35 to 39 years old (4)
- 40 to 44 years old (5)
- 45 to 49 years old (6)
- 50 to 54 years old (7)

- o 55 to 59 years old (8)
- o 60 to 64 years old (9)
- o 65+ years old (10)

Q54 What is the geographic location of where you work as a genetic counselor?

- o Region 1 (CT, MA, ME, NH, RI, VT, CN Maritime Provinces) (1)
- o Region 2 (DC, DE, MD, NJ, NY, PA, VA, WV, PR, VI, Quebec) (2)
- o Region 3 (AL, FL, GA, KY, LA, MS, NC, SC, TN) (3)
- o Region 4 (AR, IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, OK, SD, WI, Ontario) (4)
- o Region 5 (AZ, CO, MT, NM, TX, UT, WY, Alberta, Manitoba, Sask.) (5)
- o Region 6 (AK, CA, HI, ID, NV, OR, WA, British Columbia) (6)

Q55 How many years of experience do you have working as a genetic counselor?

- o <1 year (1)
- o 1 to 4 years (2)
- o 5 to 9 years (3)
- o 10 to 14 years (4)
- o 15 to 19 years (5)
- o 20 to 24 years (6)
- o 25 to 29 years (7)
- o 30 to 34 years (8)
- o 35 to 39 years (9)
- o 40+ years (10)

Q56 Which of the following best describes your gender identity?

- o Agender (1)

- Genderqueer (2)
- Hijra (3)
- Man (4)
- Non-binary (5)
- Pangender (6)
- Questioning (7)
- Transgender (8)
- Two Spirit (9)
- Woman (10)
- Prefer to self-describe (11) _____
- Prefer not to answer (12)

End of Block: Demographic Questions

Appendix D results

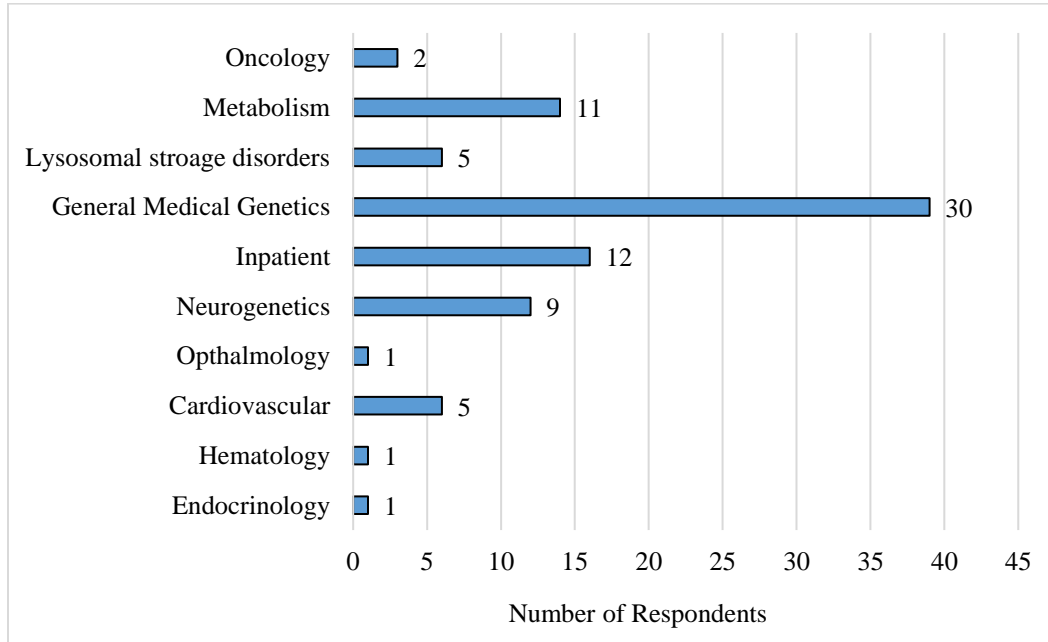


Figure 6. Pediatric specialty area reported by respondents

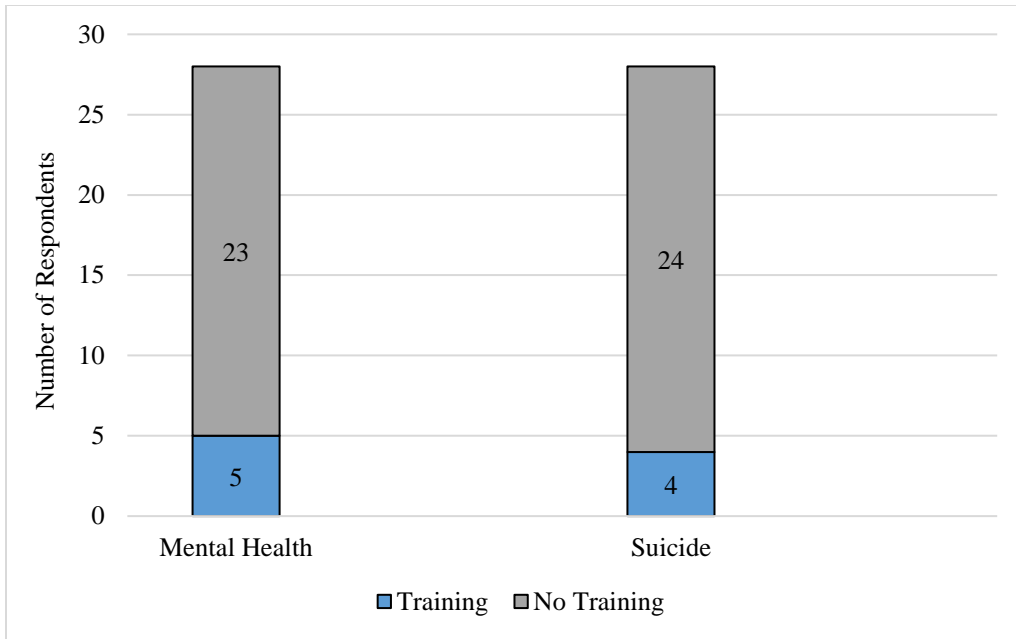


Figure 7. Number of genetic counselors who have received training on how to assess their patient’s mental health or suicide risk through their employer compared to genetic counselors who have not received training

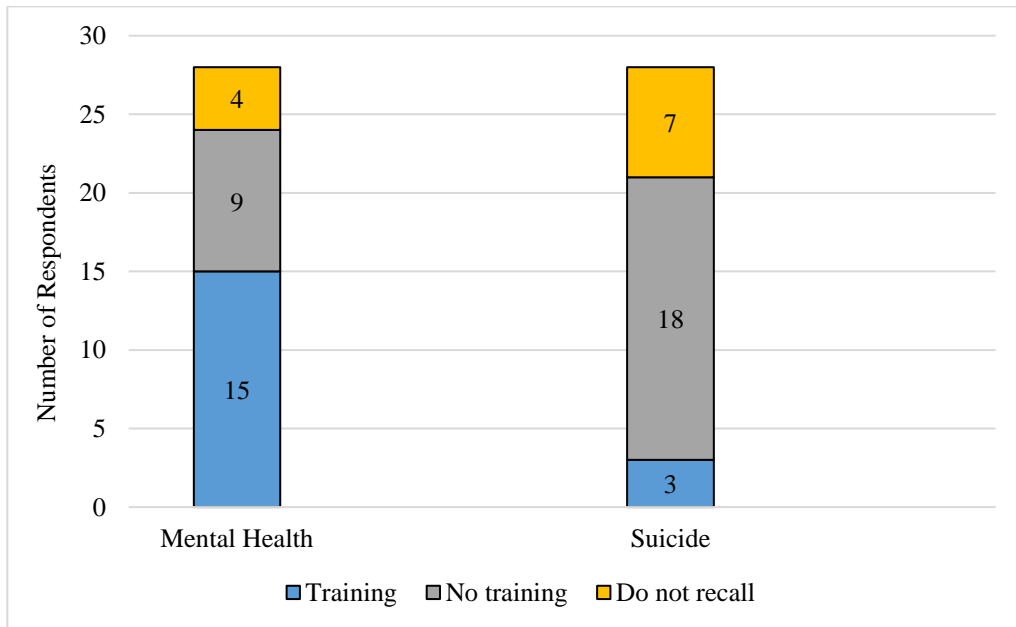


Figure 8. Number of genetic counselors who have received training on how to assess their patient’s mental health or suicide risk in genetic counseling graduate school compared to the percentage of genetic counselors who have not received training

Table 9. Chi-square values to determine whether an association exists between GC age or years of experience and whether mental health or suicide risk is assessed

| Variables | p-value |
|--|---------|
| GC Age and MH risk assessment | .567515 |
| GC age and suicide risk assessment | .996551 |
| Experience and MH risk assessment | .446501 |
| Experience and suicide risk assessment | .817521 |

Table 10. Age of GC (under or over age 30) and whether mental health (MH) is assessed, not assessed, or sometimes assessed

| Age of GC | MH assessed | MH not assessed | Sometimes | Total |
|--------------|-------------|-----------------|-----------|-------|
| Under age 30 | 5 | 4 | 8 | 17 |
| Over age 30 | 3 | 1 | 7 | 11 |
| Column total | 8 | 5 | 15 | 28 |

Table 11. Age of GC (under or over age 30) and whether suicide risk is assessed or sometimes assessed

| Age | Suicide risk not assessed | Suicide risk sometimes assessed | Total |
|--------------|---------------------------|---------------------------------|-------|
| Under age 30 | 9 | 8 | 17 |
| Over age 30 | 6 | 5 | 11 |
| Column total | 15 | 13 | 28 |

Table 12. Experience of GC and whether MH is assessed, not assessed, or sometimes assessed

| Years of experience | MH assessed | MH not assessed | Sometimes assessed | Total |
|---------------------|-------------|-----------------|--------------------|-------|
| Less than 4 years | 8 | 5 | 13 | 26 |
| Over 4 years | 1 | 1 | 6 | 8 |
| Column total | 9 | 6 | 19 | 34 |

Table 13. Experience of GC and whether suicide is not assessed or sometimes assessed

| Years of experience | Not assessed | Sometimes | Total |
|---------------------|--------------|-----------|-------|
| Less than 4 years | 12 | 11 | 23 |
| Over 4 years | 4 | 3 | 7 |
| Column total | 16 | 14 | 30 |

Appendix E results open-ended survey responses

Table 14. Color-coded codebook for open-ended survey responses

| CODE | DEFINITION OF CODE |
|-------------------|--|
| Bene-time | Participant comments about identifying issues that need to be address in a timely manner |
| Bene-identify | Participant comments about uncovering issues need to be addressed/intervention |
| Bene-unidentified | Participant comments if suicide is not asked, it may not be realized |
| Bene-unaware | Participant comments parents may not be aware of child’s suicidal risk |
| Bene-saving | Participant comments about assessing for suicide can be life saving |
| Bene-referral | Participant comments about providing appropriate referral to services |
| Bene-resource | Participant comments about being able to provide resources to patient |
| Bene-help | Participant comments about benefit of assessing to be helpful |
| Bene-access | Participant comments about access to care |
| Bene-ability | Participant comments about increased ability to provide psychosocial care |
| Bene-cope | Participants comments about helping patient cope by assessing mental health |
| Bene-follow | Participant comments about benefit of assessing allows for appropriate follow up |
| Bene-intervention | Participant comments about benefit of assessing provides intervention |
| Bene-holistic | Participant comments about comprehensive approach to care |
| Bene-important | Participant comments about mental health being just as important as physical and developmental health. |
| Bene-relevant | Participant comments about mental health being relevant to a patient’s genetic diagnosis |
| Bene-result | Participant comments about how assessing mental health can help GC consider about how the patient may react to testing result. |
| Bene-mindset | Participant comments about understanding a patient’s mindset as they undergo genetic testing by assessing mental health. |
| Bene-child | Participant comments about knowing the support needs of patients by assessing mental health |
| Bene-nonharmful | Participant comments that assessing for suicide is not harmful |
| Bene-family | Participant comments about knowing the support needs of families by assessing mental health |
| Bene-awareness | Participant comments about normalizing talking about mental health concerns by assessing mental health |
| Bene-cope | Participants comments about helping patient cope by assessing mental health |
| Bene-rapport | Participant comments about better connection with patients by assessing mental health |
| Bene-test | Participant comments about being able to better address the implications or impact of genetic testing results by assessing mental health |
| Bene-appropriate | Participant comments about assessing suicide can determine whether testing is appropriate at the given time. |

KEY:

Yellow—Coded responses grouped into main topic area: identifying mental health concerns.

Green—Coded responses grouped into main topic area: providing interventions.

Blue—Coded responses group into main topic area: ability to provide comprehensive care.

Gray—Topic area identified specific to benefits of mental health assessment.

Red—Topic area identified specific to benefits of suicide risk assessment.

No highlight—Miscellaneous single responses unable to be grouped into specific topic area.

Table 15. Topic areas and examples of responses regarding benefits of assessing mental and suicide risk

| Topic Area | Frequency of response | Illustrative examples |
|---|------------------------------|--|
| Benefits of assessing mental health and suicide risk | | |
| Identifying mental health concerns | 12 | “Uncovering a plan to self-harm that needs intervention.” |
| Providing interventions | 18 | “...providing intervention, developing a safety plan, referral to a mental health provider” |
| Ability to provide comprehensive care | 6 | “Comprehensive approach to health.” |
| Benefits of assessing mental health | | |
| Relevant to patient’s genetic diagnosis/condition | 5 | “...may be relevant to the patient's diagnosis, if there is a genetic diagnosis.” |
| Inform reaction to testing results | 3 | “Assessing possible reactions/response to genetic testing results...” |
| Insight into patient’s mindset | 2 | “It gives you an idea of a patient’s mindset as they’re going into genetic testing...” |
| Understand patient’s needs | 2 | “Know the support needs of our patients...” |
| Misc. | 5 | “Normalizing talking about mental health concerns...” “Better connection with patients...” |
| Benefits of assessing suicide | | |
| Not harmful | 2 | “Talking about suicide does not create additional risk, so I don’t see downsides even if the benefit is infrequent.” |
| Misc. | 1 | “Allows you to determine whether or not testing may be appropriate at this time.” |

Note: Some responses were complex and had multiple codes, therefore some responses were classified more than once.

Appendix F MPH essay results

Table 16. 2021 NSCH topical questionnaire data on frequency of children with cystic fibrosis and depression

| Genetic condition | Depression | No depression | Total |
|--------------------|------------|---------------|--------|
| Cystic Fibrosis | 5 | 27 | 32 |
| No Cystic Fibrosis | 2,596 | 48,031 | 50,627 |
| Total | 2,601 | 48,058 | 50,659 |

Table 17. 2021 NSCH topical questionnaire data on frequency of children with cystic fibrosis and anxiety

| Genetic condition | Anxiety | No anxiety | Total |
|--------------------|---------|------------|--------|
| Cystic Fibrosis | 9 | 23 | 32 |
| No Cystic Fibrosis | 5,390 | 45,204 | 50,594 |
| Total | 5,399 | 45,227 | 50,626 |

Table 18. 2021 NSCH topical questionnaire data on frequency of children with blood disorder and depression

| Genetic condition | Depression | No depression | Total |
|-------------------|------------|---------------|--------|
| Blood disorder | 35 | 190 | 225 |
| No blood disorder | 2,567 | 47,821 | 50,388 |
| Total | 2,602 | 48,011 | 50,613 |

Table 19. 2021 NSCH topical questionnaire data on frequency of children with blood disorder and anxiety

| Genetic condition | Anxiety | No anxiety | Total |
|-------------------|---------|------------|--------|
| Blood disorder | 43 | 182 | 225 |
| No blood disorder | 5,354 | 45,002 | 50,356 |
| Total | 5,397 | 45,184 | 50,581 |

Table 20. 2021 NSCH topical questionnaire data on frequency of children with other genetic condition and depression

| Genetic condition | Depression | No depression | Total |
|---------------------------|------------|---------------|--------|
| “other” genetic condition | 290 | 1,910 | 2,200 |
| No genetic condition | 2,300 | 46,044 | 48,344 |
| Total | 2,590 | 47,954 | 50,544 |

Table 21. 2021 NSCH topical questionnaire data on frequency of children with other genetic condition and anxiety

| Genetic condition | Anxiety | No anxiety | Total |
|---------------------------|---------|------------|--------|
| “other” genetic condition | 660 | 1,537 | 2,197 |
| No genetic condition | 4,713 | 43,599 | 48,312 |
| Total | 5,373 | 45,136 | 50,509 |

Table 22. 2021 NSCH topical questionnaire data on frequency of CSHCN and non-CSHCN with emotional, development, or behavioral problem requiring treatment or counseling

| Variable | Required treatment or counseling | No treatment or counseling required | Total | Percent requiring treatment or counseling |
|------------|----------------------------------|-------------------------------------|--------|---|
| CYSHCN | 5,831 | 5,334 | 11,165 | 52% |
| Non-CYSHCN | 352 | 39,343 | 39,695 | 0.8% |
| Total | 6,183 | 44,677 | 50,860 | 12% |

Table 23. 2021 NSCH topical questionnaire data on frequency of whether CYSHCN received treatment or counseling by a mental health professional in the past 12 months

| Variable | Saw mental health professional | Did not see mental health professional, but needed to | Did not see mental health professional, and did not need to | Total | Percent that saw mental health professional |
|------------|--------------------------------|---|---|--------|---|
| CYSHCN | 3,960 | 748 | 6,409 | 11,117 | 36% |
| Non-CYSHCN | 1,358 | 423 | 37,738 | 39,519 | 3% |
| Total | 5,318 | 1,171 | 44,147 | 50,636 | 11% |

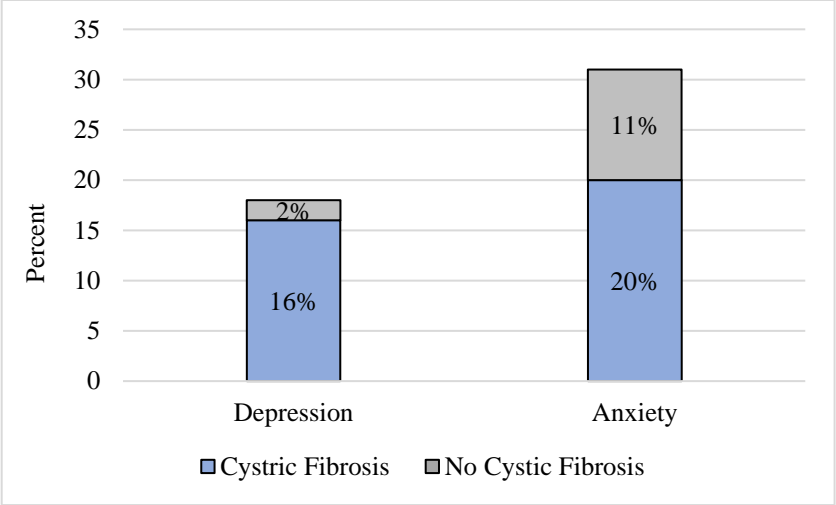


Figure 9. Percent of children with CF experiencing depression or anxiety compared to children without CF experiencing depression or anxiety

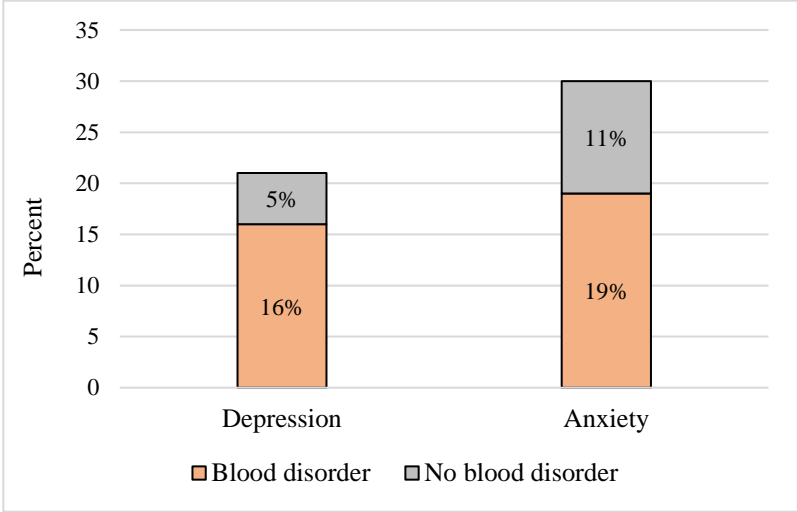


Figure 10. Percent of children with a blood disorder experiencing depression or anxiety compared to children without a blood disorder experiencing depression or anxiety

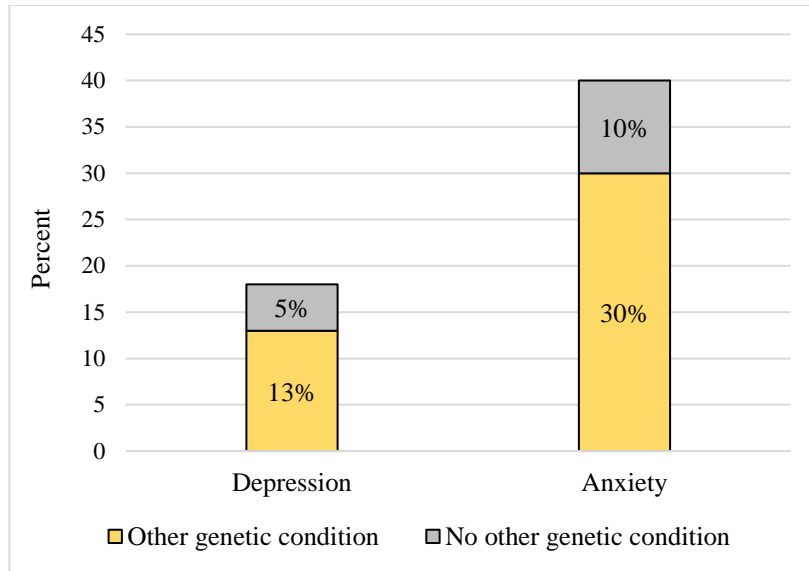


Figure 11. Percent of children with other genetic condition experiencing depression or anxiety compared to children without other genetic condition experiencing depression or anxiety

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