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Perceptions and Roles of Genetic Counselors in Perinatal Palliative Care: Where Are We Now?

Amanda Chamberlain

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Perceptions and Roles of Genetic Counselors in Perinatal Palliative Care:

Where Are We Now?

by

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Perceptions and Roles of Genetic Counselors in Perinatal Palliative Care:

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A

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by

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Perceptions and Roles of Genetic Counselors in Perinatal Palliative Care:

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After the identification of a life-limiting fetal diagnosis, a perinatal palliative care (PPC) team can provide specialized medical care and emotional support for the family throughout the pregnancy and after delivery. Although the growth of the field of PPC over the last ten years is well-documented, there is only one study to date that explores the experiences of genetic counselors with regards to PPC. This study seeks to further the understanding of genetic counselors' current perceptions of, experiences with, and roles in the delivery of PPC.

An edited version of the Perinatal Palliative Care Perceptions and Barriers Scale was used to collect data via anonymous online survey of practicing genetic counselors. A total of 75 responses were used. Genetic counselors were more likely to be familiar with PPC if PPC was available at their institution ($p=0.003$) and if they had high levels of personal comfort with PPC ($p<0.0001$). Multiple linear regression analysis revealed that familiarity with PPC, confidence in caring for families with a life-limiting fetal diagnosis, personal comfort with PPC, and barriers genetic counselors experienced in their clinical practice were all statistically significant predictors for variance in genetic counselors' comfort in referring to PPC. Conventional content analysis revealed that genetic counselors in our study generally believed that they are valuable members of the multidisciplinary team that participate in PPC.

The results of this study illustrate factors that impact referral comfort have evolved over the last ten years. The findings also exemplify the multidisciplinary nature of PPC and that PPC services are provided via a team of healthcare providers and other specialists. They also establish further support that genetic counselors are important part of the PPC team.

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Introduction

Congenital malformations continue to be the leading cause of infant mortality in the United States. In 2019, congenital malformations accounted for 20% of infant deaths (Xu, 2020). Modern prenatal screening methods can identify fetal anomalies more frequently and earlier in pregnancies, and some of the diagnoses identified are lethal or severely life-limiting. Diagnostic accuracy determines the ability of clinicians to provide a more detailed prognosis for fetuses with a life-limiting condition (Parravicini and Lorenz, 2014). In fact, ultrasound imaging combined with genetic testing and MRI can identify approximately 90% of life-limiting disorders (Breeze and Lees, 2013). Most families are not prepared for receiving test results that indicate fetal health concerns. When this happens, it can lead to intense emotional responses including grief, anger, isolation, and hopelessness (Detraux, 1998). Not only are parents facing extremely difficult decisions regarding next steps, they must also grieve the loss of the pregnancy and life of the child they were expecting.

When faced with abnormal test results or fetal anomalies that indicate a life-limiting fetal diagnosis, families often have two options: either terminate the pregnancy or continue the pregnancy until birth. For those who choose to continue their pregnancy, their care team is faced with a unique set of challenges. Decisions must be made that are in the best interest of the mother as well as the fetus (Bijma, 2008). Studies suggest that between 40-85% of parents who are given a diagnosis of a life-limiting fetal condition choose to continue the pregnancy when offered perinatal palliative care (PPC), (Flaig, 2019). The goal of PPC is to provide individualized care to the expectant mother and her family to address their emotional, spiritual, and physical needs. This care extends throughout the prenatal period, birth planning, delivery, and bereavement (Cole, 2017). Providers can also work with the families to implement ways in which they would like to

honor the life and death of their child including memory-making and the creation of keepsakes (Cortezzo, 2020).

The specialized, multidisciplinary nature of a PPC team is well-equipped to handle the complex medical issues of the expectant mother, fetus, and newborns as well as provide psychosocial and spiritual support to the families (Wool, 2013). Ongoing communication between the perinatal palliative care team and the family allows for continued emotional support and the formation of the most effective birth plan that address both medical and emotional needs of the family (Cole, 2017). The American College of Obstetrics and Gynecology (ACOG) published a Committee Opinion in which they suggest a framework for PPC programs which included “a formal prenatal consultation; development of a birth plan; access to other neonatal and pediatric specialties, as needed; and support and care during the prenatal, birth, and postnatal periods, including bereavement counseling” (ACOG, 2019).

While the landscape of PPC in the United States continues to evolve, little is known about the role of genetic counselors in the PPC team. Genetic counselors are often involved in the identification or disclosure of a life-limiting fetal diagnosis and therefore are in a unique position to interact with both the patient and a PPC team. In a 2011 study by Wool & Northam, a multicenter survey of perinatal palliative care services, genetic counselors were reported to be one of the main sources from which parents learned of a PPC program. This same survey further established the interdisciplinary nature of PPC by describing the various services provided by PPC programs and the settings in which they are provided (Wool et al., 2016). However, there is little information known about how genetic counselors perceive, interact with, and participate in the delivery of PPC.

To date, there is only one study to our knowledge that investigated the relationship between genetic counselors and the field of PPC. This study, published by Wool and Dudek in 2013,

characterized the views of PPC held by genetic counselors with the goal of improving the understanding of genetic counselors' views and practices with regards to PPC. The results of this study showed that genetic counselors had an overall positive perception of PPC. However, it also showed that while most genetic counselors had positive views of PPC, not all were very familiar with PPC as a field and they were not always comfortable or willing to consider a referral to PPC (Wool and Dudek, 2013).

The growth of PPC as a field over the last decade and the improvements in prenatal identification of life-limiting fetal diagnoses has driven an increased need and availability of PPC services. Given the changing landscape of both of these fields, the way in which genetic counselors interact with PPC is also likely to have evolved. We attempt to address this gap in our current knowledge and expand the understanding of the roles genetic counselors play in the delivery of PPC. We also aim to describe how the genetic counselors' perceptions of PPC and their practices have changed since last investigated.

Methods

A cross-sectional, mixed-method survey was developed to obtain data from a sample of prenatal and pediatric genetic counselors who have interactions with or an understanding of PPC teams. A modified version of the Perinatal Palliative Care Perceptions and Barriers Scale (PPCPBS) was used to collect data. Permission to use and edit this survey tool was obtained from Dr. Charlotte Wool in May 2021.

Sample and Procedures

The survey was administered using the web-based tool Qualtrics XM (Qualtrics, Provo, UT). Participants were recruited through the National Society of Genetic Counselors (NSGC) Student Research Survey Program. This program distributes surveys to genetic counselors who are

members of NSGC across North America via email containing a link to the survey. Emails with the survey links were sent out in September and October 2021 and January 2022, and a reminder email was sent two weeks after the first email in each instance. Participants were also recruited through the American Board of Genetic Counseling (ABGC) Student Research Protocol. This program distributes student survey requests once per month. The emails included a brief description of the study and directed the participants to complete the online survey with an incentive drawing of three \$20 Amazon gift certificates. At least one Likert scale had to be completed in its entirety for the response to be included in the analysis.

Instrumentation

An edited version of the Perinatal Palliative Care Perceptions and Barriers Scale (PPCPBS) was used to gather data from genetic counselors between September 2021 and January 2022. The original PPCPBS contains two subscales, six demographic items, two open-ended questions, as well as Likert scales to measure familiarity with PPC, and personal and referral comfort. The PCCPBS has shown validity and reliability (Wool and Northam, 2011). The tool has demonstrated its utility in its pilot study by Wool and Northam (2011) as well as Wool and Dudek (2013).

The subscales measuring perceptions and barriers remained unchanged from the original PPCPBS survey. The first subscale, labeled “Perceptions”, aims to assess the participants’ perceptions of PPC. It includes 24 items and uses a 6-point Likert scale (1 = agree strongly, 6 = disagree strongly). The scores can range from 24 to 144. Higher scores indicate more positive perceptions. The second subscale, called “Barriers”, aims to determine barriers to PPC experienced by genetic counselors. This subscale includes 22 items and uses a 6-point Likert scale (1 = always, 2 = very frequently, 3 = occasionally, 4 = rarely, 5 = very rarely, and 6 = never). Scores can range from 24 to 144. Higher scores indicate more barriers experienced by genetic counselors in their practice. Participants were also asked to report their area of practice, years of

practice in both prenatal and pediatric roles, and the number of cases they had encountered with a life limiting fetal diagnosis in the past 5 years.

In addition, four sliding scale questions were added to measure participants' prior familiarity with PPC, personal comfort with PPC, confidence in caring for patients with a life-limiting fetal diagnosis, and comfort referring patients to PPC. Additional demographic questions were added to gather information about genetic counselors' specialty and state of practice. Questions about availability of PPC services in the genetic counselors' area of practice and providers of PPC were also included.

The two open-ended questions in the original PPCPBS were replaced with questions designed to elicit the genetic counselors' views of their role within PPC. These were targeted at determining the participants' current roles within PPC teams, the delivery of PPC at their clinic/facility, and how genetic counselors can best be utilized in the delivery of PPC. The final section of the survey asked participants to report information about laws regarding pregnancy termination in their state and any impact these have on their referral practices.

Data Analysis

The data were analyzed using descriptive statistics. Data analysis was performed using STATA v14.1 (College Station, TX) software. Multiple linear regression analysis was completed to establish which independent variables were the best predictors of referral comfort. The relationships between referral comfort and the following variables were analyzed: perceptions, barriers, years of experience, personal comfort, confidence, and prior familiarity with PPC. Mann-Whitney U analysis was performed to explore relationships between independent variables. Fisher's exact tests were performed to identify associations between the availability of PPC and the work setting and familiarity of genetic counselors. Statistical significance was set at $p < 0.05$ for all statistical analysis.

Conventional content analysis was used to analyze responses to the open-ended questions. For each question, the authors AC, CD, RL, and KN independently coded the responses and identified themes. Themes were then compared between coders and evaluated for concordance. Illustrative quotes were then identified to demonstrate these themes.

Results

Demographics

A total of 99 genetic counselors responded to the survey. After applying the inclusion criteria, 75 responses were included in the analysis. Almost all respondents identified as White (n=54/60, 90%) and female (n=55, 91.7%). Most respondents were prenatal genetic counselors (n=42/63, 66.7%) or pediatric genetic counselors (n=15/63, 23.8%). The remaining genetic counselors split their time between specialties, either between all specialties (n=3/63, 4.76%), prenatal and pediatric (n=2/63, 3.2%) or adult and prenatal (n=1/63, 1.6%), (Table 1). The majority of the respondents practiced in an academic teaching hospital (n=35/60, 58.3%) and in an urban setting (n=38/59, 64.4%). Fifteen genetic counselors (n=15/59, 25.4%) had less than two years in clinical practice, 24 (n=24/59, 40.7%) had between 2 years and 6 years in clinical practice, and 20 (n=20/59, 33.9%) had over 6 years of experience (median= 3 years), (Table 1).

The participants were asked to report how many cases they had in which a life-limiting fetal diagnosis was made. There was a wide range of cases seen by genetic counselors (n=55, median=20, IQR=4-200). Most genetic counselors had less than 15 cases of a life-limiting fetal diagnosis in the last 5 years (n=25/55, 45.5%) while some had over 30 cases (n=15/55, 27.3%), (Table 1).

Table 1: Demographics and clinical experience of participating genetic counselors

Characteristic	Number of Responses	Percent
Race/Ethnicity (n=60)		
Asian	2	3.3
Hispanic	1	1.7
Native American/Pacific Islander	1	1.7
White	54	90.0
More than one of the above	1	1.7
Prefer not to answer	1	1.7
Gender Identity (n=60)		
Male	1	1.7
Female	55	91.7
Transgender	1	1.7
Non-binary	1	1.7
Prefer not to answer	1	1.7
Specialty (n=63)		
Prenatal	42	66.7
Pediatrics	15	23.8
Equal time in both prenatal and pediatrics	2	3.2
General (all specialties)	3	4.8
Equal time in both prenatal and adult	1	1.6
Clinical Setting (n=60)		
Academic teaching hospital	35	58.3
Community hospital	10	16.7
Private practice	5	8.3
Clinic/Public health facility	4	6.7
Other	6	10.0
Facility Location (n=59)		
Urban	38	64.4
Suburban	18	30.5
Rural	3	5.1
Years in Clinical Practice (n=59)		
<2 years	15	25.4
2 to <6 years	24	40.7
6 or more years	20	33.9
Number of LLFD Cases in Last 5 Years (n=55)		
<15 cases	25	45.5
16 to 30 cases	10	18.2
>30 cases	15	27.3

Availability and Provision of PPC

The participants were asked to select whether PPC was available in their area or at their clinic/facility. The majority responded that PPC is available at their clinic/facility (n=43/62,

69.4%). Only three responded that PPC is not available in their area or their clinic/facility (n=3/62, 4.8%), (Table 2).

Table 2: Availability of PPC in respondents' area of practice

Availability of PPC	n	%
Not available in my clinic or my area	3	4.8
Available in my area but not at my clinic/facility	16	25.8
Available at my clinic/facility	43	69.4

Participants then selected all of the providers that were involved in the provision of PPC at their facility. The providers most often involved in the provision of PPC were neonatologists (n=39/59, 66.1%), social workers (n=29/59, 49.2%), and palliative care specialists (n=26/59, 44.1%). Forty-one genetic counselors selected 3 or more different providers that were involved in the delivery of PPC (n=40/59, 67.8%). Sixteen respondents less frequently reported that genetic counselors were involved in PPC (n=16/59, 27.1%). Participants were then asked to select the primary provider of PPC at their facility. These results showed that palliative care specialists (n=23/57, 40.4%) and neonatologists (n=18/57, 31.6%) were the most common primary providers of PPC. Four respondents selected genetic counselors as the primary provider of PPC at their facility (n=4/57, 7.0%), (Table 3).

Table 3: Providers involved in delivery of PPC services

	Provider involved in PPC (n=59)		Primary Provider of PPC (n=57)	
	n	%	n	%
Advanced practice nurse	21	35.6	5	8.8
Neonatologist	39	66.1	18	31.6
Palliative care specialist	26	44.1	23	40.4
Genetic counselor	16	27.1	4	7.0
Social worker	29	49.2	2	3.5
Chaplain/religious counselor	22	37.3	0	0.0
Child life specialist	11	18.6	0	0.0
Mental health specialist	6	10.2	0	0.0
Fetal care navigator	0	0.0	1	1.8
Other	10	16.9	4	7.0

When exploring the association between availability of PPC and the hospital setting in which genetic counselors worked, PPC was more likely to be available at an academic teaching hospital than at other workplace settings (n=29/41, 70.7%, p=0.006). All genetic counselors that worked at an academic teaching hospital had PPC available at their clinic (n=29/35, 82.9%) or in their area (n=6/35, 17.1%). The three genetic counselors who responded that PPC was not available at their clinic or in their area all worked at a community-based hospital (n=3/3, 100%).

Perceptions and Barriers

Genetic counselors reported overall positive perceptions of PPC. The total scores for the Perceptions subscale were added up for each participant. The median score for the Perceptions subscale was 112 (n=75, IQR=107-120). The total scores for the Barriers subscale were also added up for each participant. The median score for the Barriers subscale was 99 (n=69, IQR=86-108), indicating that most genetic counselors experience a more positive environment for PPC in their area/facility.

Comfort and Familiarity

Genetic counselors were asked to report their familiarity with PPC prior to taking this survey on a scale of 1 to 100. Scores of over 90 were considered highly familiar with PPC. The median reported familiarity score was 92 (n=62, IQR=60-100). Respondents rated their confidence level in caring for families with a life-limiting fetal diagnosis. The median confidence score was 88.5 (n=60, IQR=30-100). Respondents also reported their personal comfort with PPC and their comfort with referring patients to PPC. The median personal comfort score was 90 (n=62, IQR=32-100) and the median referral comfort score was 98 (n=62, IQR=32-100), (Table 4).

Table 4: Reported scores of characteristics relating to genetic counselors' experiences with PPC

Characteristic	Number of Responses (n)	Median	Inner Quartile Range
Familiarity with PPC	62	92	60 – 100
Confidence when caring for families with a LLFD	60	88.5	30 – 100
Personal comfort with PPC	62	90	32 – 100
Comfort with referring patients to PPC	62	98	32 – 100

Multiple linear regression was used to test if perceptions, barriers, familiarity, confidence, and personal comfort significantly predicted referral comfort. For the purposes of the regression analysis, familiarity scores were grouped in two groups: highly familiar (familiarity score over 90) and not highly familiar (familiarity score of 90 and below). The medians for these groups were 82 (n=31) and 100 (n=31), respectively. Each of the variables were added into a linear regression model to identify predictors with statistical significance (Table 5). Each variable that had a statistical significance in one of the six models was added to a one regression model. In this model, it was found that perceptions were not a significant predictor of referral comfort (p=0.701) and was therefore left out of the final regression model.

Table 5: Regression results for referral comfort of participants (standard deviations of the mean)

	A	B	C	D	E	F
Constant	23.79	5.58	13.82	24.03	22.87	54.2
Perceptions	0.56** (0.26)	0.19 (0.27)	0.20 (0.27)	0.23 (.18)	0.25 (0.17)	0.09 (0.15)
Barriers		0.62** (0.18)	0.52* (0.17)	-0.27 (0.16)	-0.15** (0.17)	-0.49** (0.14)
Years in clinical practice			0.16 (0.43)	0.09 (0.30)	-0.18 (0.30)	-0.24 (0.24)
Personal comfort				0.78* (0.10)	0.69* (0.10)	0.25 (0.12)
Familiarity group					11.07** (4.38)	10.10** (3.62)
Confidence in caring for families with an LLFD						0.59* (0.12)
R Squared	0.07	0.22	0.22	0.63	0.63	0.75
Adjusted R Squared	0.05	0.20	0.18	0.60	0.59	0.72

Standard errors are reported in parentheses.

* and ** indicates significance at $p < 0.00$ and $p < 0.05$, respectively.

The following variables were found to be significant predictors of referral comfort: confidence in caring for families with LLFDs, personal comfort with PPC, barriers experienced in the genetic counselors' practice, and familiarity group (Table 6). Each of these variables were statistically significant in the final regression model.

Table 6: Final regression model for referral comfort for genetic counselors as standard deviations of the mean.

Variable	Coefficient	P value
Constant	63.25	0.000
Barriers	-0.48 (0.13)	0.001
Personal Comfort	0.27 (0.11)	0.022
Familiarity group	9.83 (3.27)	0.004
Confidence in caring for families with an LLFD	0.57 (0.11)	0.000
R Squared		0.74
Adjusted R Squared		0.72

Standard errors are reported in parentheses.

Mann-Whitney U tests were then conducted to further examine the relationship between familiarity and other independent variables. Results showed that confidence in caring for families with a LLFD was significantly different for highly familiar genetic counselors and those who were not highly familiar with PPC ($U=183.5$, $p=0.001$). Results also showed that personal comfort in referring families to PPC was significantly different between the familiarity groups ($U=138$, $p<0.0001$).

When examining the association between availability of PPC and genetic counselors' familiarity, a Fisher's exact test revealed that genetic counselors that had PPC available at their facility were more likely to be highly familiar with PPC ($n=27/42$, 64.3%) compared to those with PPC only available in their area ($n=4/16$, 25%, $p=0.003$). Of the 31 respondents that were highly familiar with PPC, 87.1% of them had PPC available at their facility ($n=27/31$), while only 50% of respondents that were not highly familiar with PPC had PPC services available at their facility ($n=15/30$).

Termination

Participants were asked if termination of pregnancy was allowed in their state of practice. Almost all genetic counselors practiced in a state where termination of pregnancy was allowed by law (n=58/62, 93.5%). The laws regarding termination ranged from limiting termination at 6 weeks gestation to up to 24 weeks gestation. When asked if the laws regarding termination affected their referral practices to PPC, 35 respondents replied no (n=35/61, 57.4%), while 26 respondents replied yes (n=26/61, 42.6%). Of the 4 participants who selected that termination is not allowed in their state, 3 of these respondents replied that these laws affected their referral practices (n=3/4, 75%).

Qualitative

Domain: Termination of Pregnancy

Content analysis was then used to identify themes common among genetic counselors regarding the impact of termination laws on their referral practices. Most genetic counselors who responded to this question mentioned that the laws restricted access to termination services. Many genetic counselors also mentioned the barriers that families may face in these situations. The resources that are necessary to access termination procedures appeared in several responses as a major limiting factor in a family or patient's ability to pursue this option. One respondent wrote, "I think that TOP laws in neighboring, abortion-hostile states ... foster a culture of abortion stigma so that when patients present for a second opinion, even though abortion is legal and accessible in Maryland and DC, their attitudes are quite cemented that this would never be a feasible option for them." Some responded that the restrictive laws affected patient decision making. In particular, several of these responses indicated that when life-limiting fetal diagnoses were identified near the gestational age at which termination is legal, it resulted in rushed decision making. The majority of the responses stated that restrictive termination laws increase the demand for PPC.

The barriers experienced by families with LLFDs due to termination restrictions impacts the number of families utilizing PPC services (Table 7).

Table 7: Themes identified in each domain of free response questions

Domain	n	Themes	Illustrative Quote
Provision of PPC at your facility	46	Multi-disciplinary team	As we consult families as a multidisciplinary team, we typically factor in all the aspects of the fetus (anomalies, genetics testing results, etc) to help determine a prognosis and then offer PPC to families when indicated as part of our multi-D meeting with the family
		Mainly provided by non-GC providers	Patients are offered PPC as an option when appropriate, and further discussions occur with MFM, NICU, social work, etc as they move through their pregnancy.
		No team dedicated to PPC	Unfortunately, there is no dedicated PPC team at our hospital, so the extent of PPC a patient receives is dependent on the providers they encounter during the pregnancy. If a genetic counselor is involved with the patient, we will work with the family to create a birth plan and to connect them with the neonatology team to draw up a plan for care
GC role in provision of PPC	46	Introduction to PPC	Ideally genetic counselors would initiate the process when the diagnosis is made. Including introducing the concept to the patient, explaining it, and making the initial referral.
		Referrals to PPC	Patients can have a prenatal consult with our PPC team. My role is to refer patients that are diagnosed prenatally and have continued communication throughout the pregnancy
		Coordinates PPC	I am the team lead for PPC. Patients see me first and I

			coordinate all care and oversee deliveries.
Utilization of genetic counselors	42	Psychosocial support/counseling	GCs are already very involved in discussion of diagnosis and prognosis, whether or not genetic testing is actually involved. We meet these patients during a very vulnerable time, when they are first learning about a possible or confirmed diagnosis. We SHOULD be providing compassionate care during this time, and then can be a trusted person talking about really hard choices.
		Introduction to PPC	I think genetic counselors (GCs) should understand what PPC is and be able to offer that to patients who continue their pregnancies when a life-limiting diagnosis is made, even if not available at their current hospital or hospital system. GCs should know who to contact to refer their patient to PPC services. GCs should also be able to discuss what PPC is with patients to help them decide if that is something they would like to pursue.
		Referrals to PPC	Genetic counselors can be utilized to inform patients about the option of palliative care and get them connected with the palliative care team.
		Member of multi-disciplinary team	Collaboratively as a member of the team in consultation with the various providers.
		PPC best provided by non-GC providers	While I think prenatal GCs are a great person to initiate the conversation about what a couple wants the care for their pregnancy and possible subsequent baby to look like, once a couple has elected to pursue continuation with PPC I feel other specialties

			(neonatologists and nurses) can better prepare the couple for what to expect and to provide updates throughout the process.
Pregnancy termination laws' effect on referral practices to PPC	20	Restricted termination access	I have had patients who received a diagnosis after the legal termination limit for my state who did not have resources to travel to a state with later limits, despite wanting to end the pregnancy. We discussed the option of PPC to reduce suffering.
		Increased demand for PPC	If termination were an option in my state in later pregnancy, there may be fewer families that take us up on PPC because they would choose to terminate. As it stands, the travel, financial, and time constraints of having to travel outside the state for a late-term termination are definite barriers to termination and therefore increase the uptake of PPC.
		Affects patient decision making	Families must make a decision between continuing and terminating a pregnancy when they may not have enough time to meet and discuss palliative options to know if that is the best option for them. With a time limit on such an important and impactful decision, some families may regret their decision either way (termination or palliative care) or feel rushed to make a choice.

Domain: Provision of PPC services

Most genetic counselors stated that PPC is provided by a multidisciplinary team of providers. Genetic counselors would often be mentioned as a member of this multidisciplinary team and perform a variety of roles. Most respondents indicated that the primary providers of PPC were

non-GC providers. Some of the professions mentioned in the responses were neonatologists, nurses, Maternal Fetal Medicine (MFM) physicians, and PPC specialists (Table 7). However, many genetic counselors also stated that there is no designated team for PPC at their institution. In these cases, some responses indicated that the care given to patients with a LLFD is dependent upon the providers they encounter throughout their pregnancy.

Domain: Genetic counselors' role in the provision of PPC

The most common response regarding the roles of genetic counselors in the provision of PPC services was by providing referrals to PPC. Many genetic counselors also expressed that their role was to introduce the option of PPC and have a discussion with patients about their options.

Some genetic counselors were very involved in the PPC process at their institution, including coordinating the program and care of the families who elected PPC. However, one genetic counselor stated that they did not feel comfortable in this role. For instance, “My institution does not have a designated PPC team. The genetic counselor is in charge of much more of these responsibilities (i.e. discussing options, birth plan, wishes for delivery, etc.) than I am used to, since I worked as a peds GC at an organization who had a wonderful PPC team ... Much more of the responsibility is placed on the GC than should be in my opinion.”

Domain: Utilization of genetic counselors in PPC services

Almost all of the genetic counselors that responded to this question included that they believe that genetic counselors should be involved in the introduction and discussion of PPC as an option. Similarly, the majority of respondents also believed that genetic counselors are in a position to refer patients to PPC when it is appropriate. Given the emotional nature of the providing PPC, many genetic counselors also recognized the ability of genetic counselors to provide psychosocial support and counseling during the diagnosis of LLFDs and the delivery of PPC services.

Responses to the previous question emphasized the multidisciplinary nature of PPC. Many respondents agreed that genetic counselors should not be the primary provider of PPC given the medical training required to discuss many aspects of PPC. Meanwhile, many responses to this question also stated that genetic counselors are well-equipped to be a member of the multidisciplinary team that provides PPC.

Discussion

This study aimed to establish the current perceptions, barriers, and experiences of a sample of genetic counselors with regards to PPC, and to compare these results with the results from the pilot study conducted by Wool and Dudek in 2013. Our study population was overall smaller and less experienced than their study population. In our cohort, approximately 66% (n=39/59) had less than 6 years of experience, while the Wool and Dudek cohort had 46.2% (n=98/212) genetic counselors with 0 to 5 years in clinical practice. The majority of both study populations worked at academic teaching hospitals and in urban environments. In their study, they reported an average of 108 (SD=9.27) on the subscale measuring perceptions of PPC, whereas our study found a median of 112. This shows that over the last decade, the perceptions of PPC have remained positive among genetic counselors.

Genetic counselors' prior familiarity was reported to be a mean of 8.38/10 (SD=2.32) while the median score of prior familiarity in this study was 92/100 (IQR=60-100), (Wool and Dudek, 2013). This shows that the familiarity scores reported in this study were overall higher than those reported in the 2013 study published by Dr. Charloote Wool and Martha Dudek. A possible explanation for this is the growth of the field of PPC in the last decade. PPC services are being provided in a greater number of hospitals and clinics across the country and many more PPC teams are in place. This would allow for more genetic counselors to become aware of PPC

programs since they are more likely to come in contact with PPC providers or have the ability to place referrals to their providers.

In the prior study by Wool and Dudek, the independent variables perceptions, barriers, years in clinical practice, personal comfort, and prior familiarity with PPC were all statistically significant predictors for referral comfort. It was reported that these five variables explained 51.7% of the variance in genetic counselors' referral comfort. This differs from our results in terms of both the variables that were statistically significant and how much variance was explained. In our study, the statistically significant predictors of referral comfort were barriers experience by genetic counselors, confidence in caring for families with a life-limiting fetal diagnosis, personal comfort with PPC, and familiarity with PPC. This shows that genetic counselors' referral comfort has been consistent but some of the factors that influence their referral comfort may have changed. For example, genetic counselors' perceptions were no longer a statistically significant predictor of referral comfort based on the data from this study. This indicates that overall positive perceptions of PPC do not currently affect referral comfort, while higher confidence in caring for families with life-limiting fetal diagnosis does. This shows a possible shift in the underlying motivations to refer to PPC.

Given that familiarity with PPC is a significant factor in determining referral comfort, it is important to identify the ways in which a genetic counselors' experiences affect familiarity. Based on data from this study, it appears that familiarity increases with the years of experience of a genetic counselor and with the availability of PPC at their institution or area. Since respondents were largely in favor of genetic counselors playing a role in the delivery of PPC, there is an opportunity to make novice genetic counselors more comfortable referring patients by increasing their familiarity with PPC. Potential avenues to address this could be education during graduate

training programs, continuing education programs for practicing counselors, or by more experienced genetic counselors serving as resources for genetic counselors less familiar with PPC.

These results further support that genetic counselors are qualified to participate in the delivery of PPC. Genetic counselors are often in a unique position to connect with families facing a life-limiting fetal diagnosis, as they help the patient understand results during the diagnosis of a life-limiting fetal conditions, and are able to build a relationship with the patient while remaining unbiased and non-directive (Williams et al., 2016). Importantly, Williams et al. showed that genetic counselors spent a significant amount of time addressing the patients' psychosocial needs and provided a depth of support that was not given by other health care providers (2016). In a multidisciplinary service such as PPC, it is important that both the medical and psychosocial needs of the patient are met, especially considering the heightened emotions and increased medical needs of families with a life-limiting fetal diagnosis.

With this in mind, the results of our study can be further put into context to illustrate the potential ways in which genetic counselors' skills can be best utilized in the delivery of PPC. According to our results, genetic counselors are best utilized in discussing the option of PPC, referring patients to PPC, and providing anticipatory guidance regarding next steps. As outlined in the Practice-Based Competencies for Genetic Counselors published by the Accreditation Council for Genetic Counseling, genetic counselors are trained in psychosocial and counseling skills as a part of their graduate training in addition to their genetics and genomics education (ACGC, 2019). One competency is that a genetic counselor should be able to "integrate knowledge of psychosocial aspects of conditions with a genetic component to promote *client* well-being" (ACGC, 2019). Therefore, it is within genetic counselors' scope to provide anticipatory guidance about life limiting conditions, including PPC. It is acknowledged that addressing the

psychosocial needs of patients during this difficult time is necessary and vital in the delivery of PPC and therefore an opportunity to utilize genetic counselors both prior to and after delivery.

While most genetic counselors responded that PPC was available at their institution or in their area, it is important to note that some said it was not available in their area or there is not a dedicated team to PPC. The growth of the field of PPC over the last ten years has been significant. In 2016, 35% PPC programs in the United States were less than five years old (Wool, 2016). Yet, there remains a need to continue to grow PPC in underserved areas so that all families with a life-limiting condition may benefit. In addition, PPC was more likely to be available at academic institutions and in urban areas, indicating an imbalance in the accessibility of PPC services, especially between urban and rural areas. Considering ACOG recommends that all families with a life-limiting fetal diagnosis be offered PPC, our results show that this is not yet a goal that has been achieved (ACOG, 2019). The statements from our participants further supports the need for dedicated PPC providers and teams.

The results of our study show reinforced that PPC is multidisciplinary, with most team reported to have three or more providers. Genetic counselors in this study acknowledged that PPC is best provided by non-genetic counseling healthcare providers, such as a palliative care specialist or neonatologist. While it is within genetic counselors' scope to provide support, anticipatory guidance and referrals, the details of the PPC plan are ideally developed by physician counterparts. This can be important when implementing or evaluating PPC teams because PPC teams should include providers that are trained to provide the appropriate care to the patient and family.

The timing of this study corresponded with major political strife regarding policies related to termination of pregnancy. Since terminating a pregnancy may affect when and how PPC could be offered or provided, we asked participants how laws in their state affected their referral

practices. Participants suggested that there seems to be a domino effect of outcomes due to state laws that have limitations on when termination of pregnancy procedures can be performed, impacting neighboring state resources. One downstream effect of these restrictions is an increase in the referrals to PPC. With less patients able to access termination procedures, it would stand to reason that they are continuing their pregnancy. Therefore, the amount of patients who are utilizing the services of a PPC may increase. This suggests that in a time where resources for pregnant people are shifting and healthcare providers in some states are limited in what they can legally provide to their patients, healthcare systems would benefit from the establishment or expansion of PPC services to meet the expected shift in demand.

While it is logical that restrictive abortion policies would lead to fewer termination procedures and more referrals to PPC, this study also showed an unexpected perspective as well: termination policies also decreased uptake of or referrals to PPC in some situations. This was due to the fact that families did not have adequate time to consider their options. The potential for these restrictions to rush or hinder patient decision-making is an important issue to acknowledge. Since life-limiting fetal diagnoses are often made at the anatomy scan which occurs around 20 weeks of pregnancy, this is past or very close to the gestational age limit for termination in many cases. Many free responses provided by our participants explained that this has the potential to pressure families to terminate without giving full consideration to all of their options because they only had a limited amount of time in which to make their decision. Several responses also mentioned the potential regret these families may experience as a result of this rushed decision making.

Study Limitations

The power of the study was limited by the low response rate and may have been a result of the length of some survey elements. There are approximately 696 genetic counselors who

indicated on the 2020 NSGC Professional Status Survey that they provide prenatal and/or pediatric genetic counseling. Thus, 75 responses is an estimated 10.8% response rate. Further, the participants who continued and completed the survey may have already had higher levels of familiarity with PPC and/or more positive perceptions of PPC prior to taking this survey. Therefore, there may be inherent bias in our sample population. All responses were self-reported and could be limited by the participants' interpretations of the questions and the way in which they were asked. Thus, these results may not be generalizable to all genetic counselors and all institutions.

Future Research

Future research should investigate the ways in which genetic counselors are educated about PPC both during their graduate training and on an on-going basis as practicing genetic counselors. Given that it appears most genetic counselors gain familiarity with PPC as their career progresses, it may be important to identify where and when genetic counselors receive information about PPC. This could help identify potential knowledge gaps and opportunities to provide genetic counselors with information earlier in their careers. Genetic counselors who are a part of PPC care teams could develop continuing education programs to bridge the gap and promote familiarity with PPC.

Another area for potential research is exploring the effect of changing abortion laws on the uptake of PPC services, including effects on patient decision making. Limitations on termination may constrain the amount of time that patients are able to use to make pregnancy decisions and thus cause ethical concerns. It may also increase the number of patients who carry a pregnancy with life limiting conditions to term due to restricted access. The shifting landscape has made it even more vital to learn more about the ways that abortion laws impact patient decision making in order to help providers navigate those complex situations with more ease and compassion. This

may also impact the number of families that decide to pursue PPC and in turn, impact the demand for PPC services as suggested by our respondents.

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