ORIGINAL RESEARCH



Perceived Changes to Obstetric Care and the Integration of Personal and Professional Life as a Pregnant Prenatal Genetic Counselor

Jennifer L. Rietzler 1,2 · Laura E. Birkeland 1 · Elizabeth M. Petty 1

Received: 22 January 2017 / Accepted: 2 January 2018 / Published online: 8 February 2018 © National Society of Genetic Counselors, Inc. 2018

Abstract

The impact of practicing as a prenatal genetic counselor while pregnant is unclear given the limited amount of published literature on this issue. To address this gap in knowledge, a total of 215 current and past prenatal genetic counselors provided insights regarding this personal yet professional juncture through completion of an online survey that allowed for both close-ended and open-ended responses. While participants agreed that experiencing pregnancy affected their perspectives and counseling in several ways, this paper focuses on one particular finding—that of the changes in their own obstetric care perceived by genetic counselors while working within the prenatal setting and being pregnant themselves. As a result of these changes, considerations about when to disclose a pregnancy to colleagues along with how to integrate personal and professional needs as a pregnant prenatal genetic counselor surfaced. Additional findings, practice implications, and research recommendations are discussed.

Keywords Self-disclosure · Patient-peer · Compassion fatigue · Favor · Well-being

Introduction

While biological, clinical, and psychosocial aspects of reproduction and pregnancy are often discussed in the prenatal genetic counseling setting for the sake of clients, how these life transitions may impact the practices and beliefs of prenatal genetic counselors themselves are not always recognized. Surprisingly, there remains a paucity of literature about how pregnancy may impact a genetic counselor's professional role despite the fact that the majority of genetic counselors are women (96%) of reproductive age (71%) who may go on to have children of their own (N= 1935; the NSGC Professional Status Survey 2014).

A previous study by Menezes et al. (2010) highlighted the "lived experience" of the prenatal genetic counselor by conducting 15 interviews with counselors working in a prenatal setting in the areas of Canada and Australia. Although commentaries of the counselors included expected terms such as "crisis," "grief," and "urgency," unanticipated was the

discussion of the impact their visible pregnancies had while working with patients undergoing adverse pregnancy outcomes. The participants of this study also reported difficulty in maintaining a realistic viewpoint while going through their own pregnancy, felt to be due to the frequency with which they witnessed fetal abnormalities occurring within their patient populations. Sentiments pertaining to this concept of increased anxiety for a pregnant prenatal genetic counselor due to one's own experience in the area have similarly been echoed through additional investigations since this study (Balcom et al. 2013; Clark 2010). While these previous studies unearthed valuable insights pertaining to a pregnant prenatal genetic counselor's experience, they have yet to address how a counselor's perception of their own obstetric care may differ during a pregnancy from others (e.g., clients, family, friends).

Purpose of the Present Study

To date, there have only been a select number of published investigations that have specifically examined how the challenges encountered by prenatal genetic counselors professionally may heighten once a pregnancy is introduced into the patient-counselor relationship or the counselor-colleague relationship (Clark 2010, 2012; Hatten 2002; Menezes 2010; Menezes et al. 2010). As part of a larger study designed to

Department of Obstetrics and Gynecology, University of Washington, Seattle, WA, USA



[☐] Jennifer L. Rietzler rietzlerjenny@gmail.com

Department of Pediatrics, School of Medicine and Public Health, University of Wisconsin-Madison, Madison, WI, USA

further assess perspectives of a prenatal genetic counselor (unpublished), we hypothesized that the state of pregnancy and thereafter, childrearing, impacts the prenatal genetic counselor in not only a biological but also psychological way. This paper focuses on findings related to (1) the perceived changes in obstetric care pregnant genetic counselors reportedly encounter while working within the prenatal setting and (2) how the pregnant prenatal genetic counselor integrates her newfound personal needs with her professional needs. We anticipate the results that follow will provide a framework for discussion of this topic in both genetic counseling training programs and in professional development.

Methods

Participants

Participants in the larger study consisted of either current or past prenatal genetic counselors who experienced a pregnancy prior to or during their clinical prenatal genetic counseling experience. Participants were also eligible for the study if they experienced parenthood through other means, such as adoption, fostering, stepchildren, or via surrogacy, and also had provided prenatal genetic counseling prior to or during the study. For this particular paper, we focused on analyzing data from participants whose pregnancy coincided with their time as a prenatal genetic counselor. Utilizing skip logic within our survey design, the data presented in this paper reflects the thoughts of participants who reportedly fit this criterion.

Online Survey

A cross-sectional online survey including 62 questions was created via the University of Wisconsin-Madison's Qualtrics Hosting Service. This survey was based on existing findings in the literature surrounding self-disclosure requests of pregnant prenatal genetic counselors and the reported increased anxiety regarding a counselor's own pregnancy (Balcom et al. 2013; Clark 2010, 2012; Hatten 2002; Hodgson et al. 2010; Keilman 2002; Menezes 2010, 2012; Menezes et al. 2010; McCarthy Veach et al. 2002; Vokits Cohen 2002). The research team's professional experience in the field of genetic counseling aided in overall survey design as well as the addition of novel questions. The survey was piloted online by five genetic counselors in order to identify and resolve any technical difficulties prior to distribution.

After reading a consent form highlighting the eligible participation criteria, participants were asked to respond to demographic questions along with both close- and open-ended questions regarding their pregnancy history and/or parenthood status in relation to their time spent as a prenatal genetic counselor. The survey also asked participants about specific

experiences during their own pregnancy (if applicable) and gathered information regarding their thoughts and feelings of overall counseling experiences while being both a parent and a practicing counselor. Many of these questions were set up via a series of Likert scales, particularly for ease of responding and out of respect for the participant's time. As skip logic was utilized for this survey, each question was not answered by every participant.

Procedure

Upon receipt of approval from the University of Wisconsin-Madison's Health Sciences Institutional Review Board in January of 2016, an invitation to participate in the online survey was sent to individuals enrolled in the National Society of Genetic Counselors' (NSGC) listsery ($\sim N = 2900$) along with the American Board of Genetic Counselors' (ABGC) listserv ($\sim N = 3705$). The language within the invitation included a description of the study as an exploration of pregnancy (and thereafter, parenthood) and its effects on prenatal genetic counselors and the prenatal genetic counseling session. According to the NSGC's most recent Professional Status Survey of Genetic Counselors, approximately 35% of the profession was reported to provide prenatal genetic counseling services in 2014. Given this statistic, roughly 1400 NSGC members would potentially be eligible to complete the survey. However, this reported percentage of practicing prenatal genetic counselors does not take into account the genetic counselors a part of the ABGC but not NSGC, nor the counselors that provided prenatal genetic counseling in the past. More importantly, there is no statistic that specifies a genetic counselor's pregnancy or parenthood history. As such, it is not possible to reliably ascertain a response rate for our larger study. Overall, a total of 215 participants completed more than 95% of the survey. Those participants who did not complete at least 95% of the survey were excluded from the analysis.

All data were collected anonymously and stored electronically via the web-based survey software. The survey was open and available for participation over the course of 2 weeks. A follow-up e-mail was sent through the ABGC and NSGC listserv after 1 week as a reminder for those who did not fully complete the survey or for those who had yet to participate. Participants had the option of being entered into a random drawing of three \$25 Amazon.com gift cards as compensation for completing the survey. These gift cards were considered menial in amount by the research team and were not believed to have influenced participation in any way.

Data Analysis

Descriptive statistics (means, medians, and frequencies) were calculated as appropriate for close-ended responses to the online survey. Statistical analyses (chi-square or Fisher's exact



test of independence) were performed using the SAS® software version 9.4 (Cary, North Carolina) to obtain and evaluate significance values ($p \le 0.05$) of the variables relating to the hypothesis in question. Variables were predetermined to identify domains (major topic areas) pertaining to the research aims that were pertinent to the broader study. More specific categories were identified within domains where applicable. Open-ended responses were not coded or statistically analyzed. Instead, a sample of these responses is presented by theme in this paper to provide context to close-ended questions (Table 3). As this was a quantitative study, a formal analysis of the open-ended responses was not completed.

Results

Participant Demographics

Table 1 contains a summary of demographic characteristics for survey participants of the larger study. Of the 215 total participants, all but eight identified themselves as female (96%, n = 207/215). Participants ranged in age from 25 years to greater than 45 years with the majority being between the ages of 35 to 40 years (32%, n = 69/215). Most participants self-identified as Caucasian (95%, n = 205/215), and the majority were in a marriage or domestic partnership (94%, n =202/215). These numbers are comparable to those reported in the NSGC's 2014 Professional Status Survey in which the demographic representation of genetic counselors was found to be 96% female and 92% Caucasian, with 71% of counselors under 40 years of age. The participants' genetic counseling experience ranged from less than 5 years to greater than 20 years, with roughly 28% of the counselors having between 5 and 10 years of experience (n = 60/215). Over half (59%) of respondents were providing prenatal genetic counseling at the time of survey completion (n = 127/215), with 61% of these counselors exclusively providing prenatal genetic counseling services (n = 78/127). Participants who were not exclusively providing prenatal genetic counseling had involvement in other clinics including adult and/or pediatric general genetics (48%, n = 65/134), cancer (31%, n = 42/134) 134), public health (4%, n = 6/134), or another type of specialty not listed (49%, n = 66/134).

For participants that were not providing prenatal genetic counseling at the time of survey completion, 50% had performed prenatal counseling less than 5 years ago (n = 44/88). In addition, the majority of participants reported that their prenatal genetic counseling practice was associated or affiliated with an academic or university medical center (72%, n = 154/214), with 63% of respondents involved in teaching (i.e., instructor for genetic counseling training program or supervisor of students/fellows) (n = 135/214).



 Table 1
 Demographic characteristics of survey participants

Variable	n (%)
Age (years)	
25–29	11/216 (5%)
30–34	41/216 (19%)
35–40	69/216 (32%)
41–45	30/216 (14%)
> 45	64/216 (30%)
Gender	
Female	207/215 (95%)
Male	8/215 (4%)
Race	
Asian or Asian Indian	8/216 (4%)
Black, African American	2/216 (1%)
White, Caucasian	205/216 (95%)
Other	4/216 (2%)
Ethnicity	(= /0)
Hispanic, Latino	6/215 (3%)
Non-Hispanic, non-Latino	209/215 (97%)
Ashkenazi Jewish ancestry	(> 1 /2)
Yes	28/215 (13%)
No/not that I am aware of	187/215 (87%)
Marital status	107/213 (07 70)
Divorced	9/215 (4%)
Domestic partnership	2/215 (1%)
Married	200/215 (93%)
Single	2/215 (1%)
Years of genetic counseling experience	2/213 (170)
< 5	22/215 (10%)
5–10	60/215 (28%)
11–15	52/215 (24%)
16–20	30/215 (14%)
> 20	51/215 (24%)
Currently providing prenatal counseling	31/213 (24%)
Yes	127/215 (50%)
No	127/215 (59%) 87/215 (40%)
	87/213 (40%)
Exclusively providing prenatal counseling Yes	79/127 (616/)
No	78/127 (61%)
	49/127 (39%)
Years since providing prenatal counseling	44/00 (500)
≤ 5	44/88 (50%)
>5	44/88 (50%)
Other specialties	(5/124 (40%)
Adult/pediatric general genetics	65/134 (48%)
Cancer	42/134 (31%)
Public health	6/134 (4%)
Other ^a	66/134 (49%)
Percent of current position in prenatal counse	
≤ 50%	33/49 (67%)
> 50%	16/49 (33%)
Percent of past position in prenatal counseling	9

Table 1 (continued)

Variable	n (%)
≤ 50%	22/86 (25%)
> 50%	63/86 (73%)
Work setting for prenatal counseling	, ,
Diagnostic—commercial	28/214 (13%)
Physician's private practice	52/214 (24%)
Private hospital/medical facility	83/214 (39%)
Public hospital/medical facility	147/214 (69%)
Other ^b	11/214 (5%)
Current or past prenatal practice associated university medical center	d with an academic or
Yes	154/214 (72%)
No	60/214 (28%)
Currently involved in teaching	
Yes	135/214 (63%)
No	79/214 (37%)

^a Majority of responses included cardiac, metabolic, lab, research, neurogenetics, and infertility/pre-implantation genetic diagnosis

Pregnancy History

The pregnancy history of participants (or their partners) is presented in Table 2. The numbers listed in this table are not representative of participants who did not wish to report their (or their partner's) pregnancy history. In brief, regardless of current counseling practice at the time of survey completion, 86% of participants reported being pregnant during their time as a prenatal genetic counselor (n = 186/215), and roughly 19% of participants reported experiencing pregnancy beforehand (n = 40/215). Sixteen out of 213 respondents were

pregnant during the time of survey completion (8%). Notably, 9% percent of participants reported a history of a pregnancy resulting in a miscarriage, stillbirth, or termination due to a known medical or genetic condition (n = 20/199). Eighty-four out of 212 respondents disclosed a personal history of a high-risk pregnancy or one for their partner (40%). The majority of respondents (or their partners) had undergone prenatal genetic screening and/or prenatal diagnostic testing (not including the newborn screen) at some point during a pregnancy (82%, n = 172/210), with approximately 44% of participants noting a personal or family history of a genetic condition/s (including Mendelian related, multifactorial, mitochondrial, and chromosomal) (n = 121/211). However, only 32% of participants had ever undergone prenatal genetic counseling for a pregnancy (n = 67/211).

Perceived Changes in Care for the Pregnant Prenatal Genetic Counselor

Who else can have a friend do a quick ultrasound over the lunch hour?

(Participant quote)

The majority of participants reportedly observed changes in obstetric care either because of being a genetic counselor or because of working in the same facility as their prenatal care provider (63%, n = 131/209). For example, 70% of participants reported that they received favors from colleagues and/ or peers during their pregnancies, such as checking of fetal heart tones or extra ultrasounds (n = 146/210). This response was significantly influenced by age. Participants > 35 years of age tended to report "yes" when asked whether they received favors from colleagues and/or peers during their pregnancies (p = 0.02). Other factors that contributed significantly to participants responding "yes" to receiving favors from their

Table 2 Pregnancy history of survey participants

Variable	(# of pregnancies) ^a			
	1	2	3	> 3
G—gravida	39	83	46	40
P—para	62	94	36	9
Term	73	82	28	3
Preterm	29	9	3	0
SAB—spontaneous abortion	43	12	7	5
TAB—therapeutic abortion	17	4	0	0
Stillbirth	3	0	0	0
Multiples	12	0	0	0
Attempted or achieved with assisted reproductive technology	12	6	1	3
Resulted in a miscarriage, stillbirth, or termination due to a known genetic condition	16	0	3	1

^a Number of participants who had experienced 1, 2, 3, or > 3 pregnancies applicable to the associated variable. Participants could respond to more than one option or did not need to report ($\sim n = 201$)

^b Majority of responses included not-for-profit clinical setting, government agency, non-commercial laboratory, consulting, and health maintenance organization (HMO)

colleagues and/or peers were whether or not the participant exclusively practiced prenatal genetic counseling (p = 0.03), had a family history of a genetic condition (p = 0.04), experienced a pregnancy history that included preterm labor (p = 0.01), or delivered multiples (p = 0.05). A factor that neared significance for receiving favors in the workplace (or the location in which the participant received obstetric care) was for a participant who experienced either a stillbirth or termination due to a known medical or genetic condition (p = 0.06). Responses to favors from colleagues and/or peers also depended on the type of setting the participant worked in at the time of their pregnancy and whether or not they were exclusively providing counseling in a prenatal setting (p =0.002). Those participants providing prenatal care in a private practice were more likely to respond "no" to receiving favors from colleagues (p = 0.005). As both a patient and peer, the majority of respondents noted that they did not need to contact their obstetric care provider or midwife more often than normal for increased anxiety during their pregnancy (66%, n = 138/208) (Fig. 1). A sample of open-ended participant responses that further illuminate these findings is presented in Table 3.

Forty percent of participants responded "yes" to having more options than their clients in choosing which provider would perform an invasive test (e.g., amniocentesis) (n = 88/209) whereas 30% of participants responded "no" (n = 61/209) (Fig. 2). Age of a counselor (> 35 years) also influenced whether or not participants were more likely to choose which provider would perform invasive testing (p = 0.05). However, the type of setting for providing prenatal care did not influence the response to choosing a provider for invasive testing (p = 0.07). Overall, participants reported having easier appointment scheduling for their prenatal care in comparison

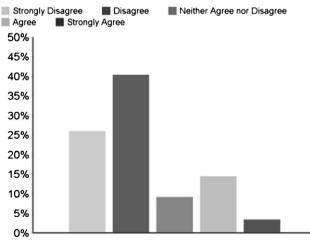


Fig. 1 Percentage of participant responses to "From your experience as a prenatal genetic counselor, do you believe you contacted your OB/GYN or midwife more often than normal for increased anxiety?" based on a Likert scale (n = 208*). ""Do not wish to report," "Not Applicable," and "Undecided" responses are not shown



to their clients ("yes" = 46%, n = 97/209) ("no" = 42%, n = 87/209), especially if they had a family history of a genetic condition (p = 0.02). If genetic testing was pursued during a pregnancy, the majority of participants reported not receiving test results any faster than their clients ("no" = 55%, n = 115/209) ("yes" = 32%, n = 67/209). Interestingly, this was not the case for participants who underwent genetic counseling for a pregnancy, as they were more likely to respond "yes" to receiving test results faster than their clients (p = 0.01). Regardless of the perceived turnaround time for results, 71% of participants "agree/strongly agree" that prenatal genetic counselors have better access to prenatal screening/testing versus the general population (n = 150/210) (Fig. 3). These quantitative findings are further supported through a sample of open-ended participant responses in Table 3.

Integrating Personal and Professional Needs

When questioned whether or not participants had been asked to be a mock patient or subject for training of another colleague on the job during a past or current pregnancy (e.g., to train a resident how to scan a fetus), more participants reported that they were "never/rarely" asked (70%, n = 141/203). Fifteen percent of participants "occasionally" were asked to be a mock patient (n = 31/203), and 7% felt they were "frequently/always" asked (n = 14/203). Table 3 includes examples of open-ended participant responses that are relevant to these findings.

Although the majority of participants reported that they "never/rarely" had apprehension about going into work as a pregnant prenatal counselor (60%, n = 121/203), 26% "occasionally" experienced apprehension (n = 52/203), and 9% "frequently/always" did (n = 18/203). This apprehension was more significant depending on the age of the counselor, as participants who were ≤ 35 years of age experienced apprehension more frequently (p = 0.02). Independent of age, apprehension was also more significant if the participant had a family history of a genetic condition (p = 0.03). In addition, more frequent apprehension experiences neared significance depending on whether the participant had a history of a child who either underwent genetic testing (not including the newborn screen) or had a genetics evaluation (p = 0.06).

Participants in the study were asked, "How do you think your profession as a genetic counselor influenced your disclosing of your/your partner's pregnancy to acquaintances, friends, family, and colleagues?" Responses varied depending on which individual a participant was disclosing to (Fig. 4). More often, participants decided to reveal their pregnancy earlier (before 12 weeks gestation) to colleagues (23%, n = 47/207) than to family (16%, n = 34/207), friends (8%, n = 17/208), and acquaintances (2%, n = 5/208) (Fig. 3). There were a number of significant factors impacting the timing of pregnancy disclosure for participants. These included the participant's

Table 3 Sample of participant responses to open-ended questions

Finding

Sample quotations

Receiving favors

- "I was working as a prenatal genetic counselor in my first pregnancy and I was able to get as many ultrasounds as I wanted at work. Now, as a laboratory genetic counselor in my next pregnancy, I greatly miss that benefit"—P1
- "I did receive more thorough/closer monitoring than I otherwise would have, as my first [pregnancy] had 'borderline' ventriculomegaly that might not have been reported had I not been friendly with the sonographer and the perinatologist"—P2
- "I think I asked my boss (who was also my maternal fetal medicine doctor during my pregnancy) about different things probably far more often than the average pregnant patient. It was easy access to answers as soon as I thought of a question—I just had to walk down the hall....Anytime I thought my baby wasn't moving as much, or had any other concern, I'd just ask one of my sonographers to take a quick look"—P3
- "I do know that one of my colleagues was able to get an 'extra' ultrasound at the last minute because she had bleeding and our [maternal fetal medicine doctor] said 'let's look.' I thankfully never had a need to ask for a 'favor' ultrasound, and never asked just to 'double check'"—P4
- "My co-worker did a quick gender scan while my in-laws were in town for their sake but we couldn't tell the gender anyway. Otherwise, I tried to be a totally normal patient!"—P5
- "I felt dizzy on a hot day once when I was 35 weeks [pregnant] and had one of our nurses check my blood pressure"—P6
- "I completed my prenatal care at a different hospital than where I was employed; however my obstetrician was aware I was a prenatal genetic counselor and let me make my own decisions regarding any and all screening/testing that involved genetics. [My doctor] would call me personally with my results (even when all were normal...not his usual method) since I would want additional information the nurses may not be able to tell me"—P1
- "The favor was having the lab leave the gender off of the cytogenetics report as I didn't want to know and didn't want my colleagues to see the report. After my daughter was born the lab gave me a copy of the karyotype"—P7
- "If I had wanted invasive testing, I would have been able to select who performs the procedure (and whether it is performed at a certain facility) and would also have been able to select what lab(s) to send samples to"—P8
- "I had an extra unofficial ultrasound at 16–17 weeks in each of my pregnancies because of my anxiety. My physician did give permission to our unit to do these scans. It helped me feel significantly less anxious"—P9
- "I experienced a post-amnio complication, and believe I was able to get in faster for [follow-up] than clients; could have been my awareness of what was needed, but may also have been my flexibility in being in proximity to the center"—P10
- "My OB called me at night at home with my abnormal quad screen results and offered to have me scanned in [labor and delivery] that evening. I declined that option, but one of the [maternal fetal medicine physicians] did a detailed ultrasound first thing the next day. I doubt that would have occurred if I did not work at the hospital and know everyone involved in my care"—P11
- "I did get a 4D ultrasound during a job interview (ha!) when I was 7 months pregnant (the radiologist wanted to practice with a machine on loan)"—P12
- "I was asked if I could be scanned to help calibrate a new ultrasound machine. I work very closely with our sonographers so I was very happy to help and did not feel any pressure when they asked"—P13
- "I was asked to be interviewed by a local news agency and videotaped getting an ultrasound when I was pregnant and our clinic was initiating our integrated screening program"—P14
- "I was pregnant just at a time when the first trimester screen was starting to be offered to women of average risk. I was literally the FIRST woman of average risk at my clinic to have it done. It actually worked out nicely, as there were some process issues we needed to work out"—P15

Disclosure of pregnancy

Mock patient

- "My supervisor (another prenatal genetic counselor) was the only person who knew of our pregnancy around 6 weeks. This was in case there was a miscarriage and I needed to leave work during the day"—P12
- "I had to tell people [about my pregnancy] where I worked earlier than I normally would as I was scheduled for a NT (nuchal translucency) measurement. Ideally, I would have liked to disclose later in pregnancy"—P16
- "I hadn't disclosed my pregnancy to anyone outside the family when I miscarried at 8 weeks, and everyone found out anyways 'cause I was off work for a week and I had to provide a doctors note. While it was confidential, people still put it together. It was really pointless in the end trying to keep it a secret"—P17
- "I needed to de-brief with my genetic counselor colleagues and felt that disclosing my pregnancy early to them helped with that"—P18
- "Most people don't tell their co-workers about their pregnancies before their family—but [prenatal genetic counselors] work together every day and we all know pregnancy is a hope not a promise. This way the medical assistants can draw a beta hCG, and we can have early weekly viability ultrasounds at work"—P19
- "Because of the workplace, once friends/colleagues knew, there was no point in not letting everyone know"—P20
- "I waited until 16 weeks to tell my colleagues and would have waited longer if I could"-P21



Table 3	(continued)

Finding	Sample quotations
Other implications	"Since I received my prenatal care elsewhere, I was able to tell my colleagues at the normal time"—P22 "[Prenatal genetic counselors] might have better access to screening/testing, but there is NO anonymity"—P23 "My doctor handed me my [test] result while I was in the break room eating lunch. He didn't realize he might need to call me in his office and let me process the news"—P24

Sample quotations are retrieved from participants (denoted as "P#"), wherein each "#" specifies a different participant (unless a participant is quoted more than once)

pregnancy history (p = <0.0001), especially if they experienced a high-risk pregnancy (p = <0.0001) or if the participant experienced a pregnancy that resulted in a miscarriage, still-birth, or termination due to a known medical or genetic condition in the fetus (p = 0.04). Some of these factors are highlighted via open-ended participant responses in Table 3.

Discussion

A total of 215 participants completed an anonymous, online survey initially designed to assess whether experiencing pregnancy and/or parenthood impacts the prenatal genetic counselor in not only a biological but also psychological way. For this paper, findings pertinent to the perceived changes in obstetric care reportedly experienced while working in the prenatal setting as a pregnant prenatal genetic counselor are discussed including the integration of newfound personal

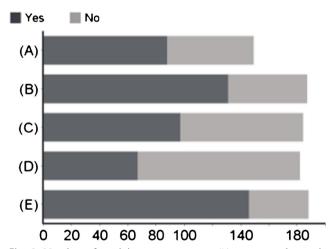


Fig. 2 Number of participant responses to "As a prenatal genetic counselor (GC), during your/your partner's pregnancy did you experience...?" (A) More options than your clients in choosing which provider would perform an invasive test (e.g., amniocentesis). (B) Changes in care either because of being a GC or because of working in the same facility of the care provider. (C) Easier appointment scheduling than your clients. (D) Receipt of test results faster than other clients. (E) Favors from co-workers (e.g., checking of fetal heart tones, extra ultrasounds) $(n = 209^*)$. *"Do not wish to report," "Not Applicable," and "Undecided" responses are not shown

needs with professional needs once pregnant. In the following sections, we address the practice implications of these findings along with our research recommendations and study limitations.

Perceived Changes in Care for the Pregnant Prenatal Genetic Counselor

Our study demonstrated that changes in obstetric care exist for the pregnant prenatal counselor either because of being a genetic counselor or because of working in the same facility as their prenatal care provider. For better or worse, many participants noted that they were able to have more ultrasounds than typically performed for the average prenatal patient—sometimes without charge (Table 3). Besides receiving extra ultrasounds, some participants reported receiving other favors from colleagues and/or peers, such as measuring of blood pressure when feeling faint or ill during their pregnancy or receiving results in a manner outside of the normal work flow (Table 3). This finding suggests that pregnant prenatal genetic counselors have the potential to tailor their obstetric care needs while working where they counsel, further supported

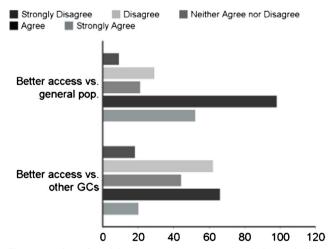


Fig. 3 Number of participant responses to, "In general, do you believe that prenatal genetic counselors (GCs) have better access to prenatal screening/testing vs. the general population? And vs. other types of GCs?" (n = 210*) based on a Likert scale. *"Do not wish to report," "Do not recall," and "Not Applicable" responses are not shown



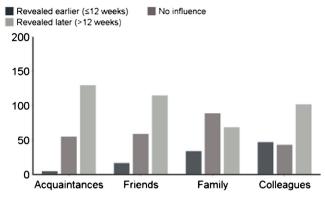


Fig. 4 Number of participant responses to, "How do you think your profession as a genetic counselor influenced your disclosing of your/your partner's pregnancy to acquaintances $(n = 208^*)$, friends $(n = 208^*)$, family $(n = 207^*)$, and colleagues $(n = 207^*)$?" "Do not wish to report," "Not Applicable," and "Undecided" responses are not shown

by the ease of access to those providers that surround them (Table 3). While we find it appropriate that colleagues and/or peers are sensitive to the prenatal counselor's desires about her obstetric care and that these individuals also acknowledge the counselor's background and experience in the area, there is lack of empirical evidence to suggest whether these strategies are effective in balancing the emotional well-being of the counselor given the circumstances.

Interestingly, in contrast to Menezes et al.'s (2010) findings, the majority of participants in our study did not report an increased amount of anxiety for their pregnancy while practicing as a prenatal genetic counselor. Although we expected the trend to be similar, possible explanations for this difference might be based on the reported ease of access to prenatal care providers at their workplace and/or the ease of access to prenatal screening/testing options compared to their clients (Table 3). Presumably, this could also be due to some counselors having more options than their clients in choosing the providers involved in their care. In this light, it seems reasonable to speculate that when the counselor has more of a direct role in decision-making for who provides her care, how they provide it, and when/where it happens, it could lessen a pregnant prenatal counselor's anxiety. Counselors who were > 35 years of age along with counselors who exclusively provided prenatal counseling at the time of the survey had more of an opportunity to be involved in the decisionmaking process. This could be due to having more experience/ seniority in their work place and/or having deeper or more trusting relationships with their colleagues and/or peers. Albeit, counselors may also have more confidence in confronting colleagues and/or peers about their obstetric care requests based on their age, potentially given their maternal age-related risks for fetal aneuploidy. Separate to age, counselors with an atypical pregnancy history or family history of a genetic condition also felt that they had more weight in deciding who would provide their care. One could argue that this

finding might also be a result of the relationships established in the workplace and counselors feeling comfortable enough to disclose this information to colleagues and providers so that their care can be managed more effectively for their needs.

Integrating Personal and Professional Needs

Findings from our study suggest that participants were typically not asked to be a mock patient or subject for training of another colleague on the job during a past or current pregnancy. Noteworthy, however, are the comments participants provided regarding this topic if they did happen to be a mock patient (Table 3). One of the participants actually confessed to being a mock patient while pregnant during an interview for a position. Of important note, most of the counselors acknowledged that they did not feel forced or incentivized to carry out these requests. This may have been due to the nature of the institution in which the counselors worked given that 72% of participants reported practicing at an academic or university medical center. Moreover, contributing to the education of others is a staple of the genetic counseling profession (National Society of Genetic Counselors: Code of Ethics) and 63% of the participants reported their role involved teaching or supervision of students in some way at time of survey completion. Participants also brought attention to their experiences being used as a mock patient when implementing or initiating new systems-level processes or techniques within the prenatal department where they worked (Table 3). It is unknown whether or not being a mock patient within their workplace contributes positively or negatively to the pregnant prenatal genetic counselor's overall perception of care—particularly given that accounts of shifting the focus of a counselor's personal pregnancy into a useful training tool for colleagues has yet to be addressed within the literature.

While participants reported a range of complex feelings in deciding when to disclose their pregnancies to colleagues, family, friends, and acquaintances, an important finding from this study emerged from the reactions of counselors when disclosing to their colleagues. Though it was anticipated that participants were more likely to reveal their pregnancy later (after 12 weeks gestation) to friends and acquaintances, unanticipated was the higher frequency of pregnancy disclosure earlier (before 12 weeks) to colleagues more often than to family. In commenting on their experiences, participants in the study expressed that they felt obligated to reveal their pregnancies earlier than desired to their colleagues because of the nature of where they worked, with a majority of participants wanting to disclose their pregnancies to colleagues later on in gestation (Table 3). This may be due to circumstance (such as an early ultrasound and/or OB appointment), rather than specific choice—a sentiment noted by a participant in the study (Table 3). Based on these findings, it appears that



pregnancy in the workplace for a counselor can assert her presence while shattering her privacy at the same time (Zucker 2015).

Anxieties and hesitancies about when to disclose a pregnancy to colleagues might also be due to the perceived changes in obstetric care prenatal genetic counselors reportedly encounter based on this study. Some participants went as far to say that they traveled outside of the city in which they worked to seek obstetric care in order to avoid their workplace and to preserve their anonymity (Table 3). Counselors might also initially avoid pregnancy disclosure based on the concern that colleagues will suspect an increased subjectivity in their interactions with patients—particularly given the previous literature that suggests prenatal counselors have a better understanding or a more intimate connection with their patients once experiencing pregnancy themselves (Balcom et al. 2013; Menezes et al. 2010; Hatten 2002; McCarthy Veach et al. 2002).

Aside from having hesitations with timing of pregnancy disclosure to colleagues, many participants within our study noted a willingness to disclose their pregnancy to colleagues earlier because of a need for support if something unexpected were to happen with their pregnancy. Given these findings, one potential option a pregnant prenatal counselor might consider is to disclose their pregnancy upfront to colleagues alongside any wishes for either maintaining privacy or the need for open communication.

Implications for Training/Practice

The results of the current study illustrate that for the trained prenatal genetic counselor, there are potential changes in obstetric care one may face when experiencing pregnancy, the consequences of which are unknown. Awareness of these findings may help place heightened emotions experienced by the pregnant prenatal genetic counselor into an understandable context, if applicable. Logical venues for education about this topic could include genetic counseling training programs. Preemptive exposure in genetic counseling training programs regarding potential changes in obstetric care or how a prenatal genetic counselor may approach pregnancy differently than her clients might also allow for students to better recognize or anticipate these experiences if they are to become pregnant in the future or experience parenthood through other means.

Another potential route for addressing this topic is through continuing education for genetic counselors. Although the majority of counselors in our survey felt supported and admitted to benefitting from their interactions with colleagues and/or peers while pregnant, a subset of counselors also reported frustrations in lacking anonymity when receiving obstetric care within the institution in which they worked. Should a prenatal genetic counselor suspect that receiving care from colleagues and/or peers might compromise their emotional

well-being during pregnancy and/or the environment in which they work, counselors could consider seeking additional avenues for receiving their prenatal care. We recognize that this is not always an option given that counselors can be limited by several factors to only seek care at their place of employment (e.g., health insurance). Albeit not necessary, some counselors may even consider switching specialties if they are uncomfortable with the idea of practicing in an area where they will receive obstetric care or feel unable to address their concerns with their colleagues upfront. Previous literature has already pointed out that some prenatal counselors will end up leaving their roles inevitably, simply due to the "burnout" that can proceed after experiencing the anxiety-provoking responsibilities of their profession combined with their own pregnancy experiences (Vokits Cohen 2002). Confronting the challenges of working in a prenatal setting while pregnant proactively with colleagues and caregivers could aid in one's transition and also alleviate some of the reported negative implications associated with this major life event for prenatal genetic counselors.

Future Research

As this paper only discusses findings pertinent to the pregnant prenatal counselor, additional research possibilities could include examining the implications of pregnancy and/or parenthood in other specialty areas of genetic counseling, such as an adult or pediatric general genetics setting. We anticipate that these challenges will be relevant to a range of other healthcare professionals as well (e.g., sonographers or maternal fetal medicine physicians), potentially normalizing the impact of pregnancy in the workplace and allowing for a more open discussion. Furthermore, it may be helpful to investigate how certain medical concerns, such as infertility, affect a prenatal genetic counselor—as a counselor in the position of wanting to become pregnant may find it challenging to work with a pregnant patient. Additionally, an exploration of a partner's pregnancy for a male prenatal genetic counselor would assess whether or not some of his issues are similar to those of his female colleagues. Finally, research aimed at identifying any tools that will help prenatal genetic counselors anticipate their own likely reactions to pregnancy as it progresses in the workplace as well as the reactions of others (particularly other medical professionals) will be especially helpful given the findings of our study.

Study Limitations

Several limitations of the present study suggest caution in drawing definitive conclusions. Primarily, participants of our survey may differ in important ways from non-respondents. For example, there is a possibility that participants of the survey had an invested interest in this topic (i.e., genetic



counselors experiencing less anxiety or compassion fatigue were more likely to participate, or conversely, to avoid participating in this study). This may limit the generalizability of the findings. Additionally, this paper focused exclusively on the pregnant prenatal genetic counselor's experience and as such, findings may not be applicable to other genetic counseling specialties. It must also be known that we conducted a number of univariate tests without controlling for familywise error. Although this is permissible in an exploratory study, it increases the likelihood that some of the significant findings may be due to chance.

Conclusions

This is one of the first studies to generate specific insights concerning a pregnant prenatal genetic counselor's obstetric care and how she might approach her pregnancy differently because of her experience within the prenatal setting. Findings of this study demonstrate that the way in which the prenatal genetic counselor responds to a pregnancy witnessed by colleagues and/or peers can depend on a number of factors, including pregnancy history, family history, age of the counselor, and the type of institution where the counselor provides prenatal counseling. This study has emphasized the need for education on this topic in training programs and through professional development in order to address the implications of being pregnant as a genetic counselor while working in the prenatal setting, including actionable ideas to help foster a workplace that supports the genetic counselor's right to privacy during their pregnancy if so desired.

Acknowledgements This study was completed in fulfillment of the requirements for the first author's Master of Science degree in Medical Genetics from the University of Wisconsin-Madison's Genetic Counselor Training Program. The investigators thank the 215 participants who completed the survey for their time spent taking the survey and their insights regarding this topic. They would also like to gratefully acknowledge those individuals who participated in the pilot survey including Kara Reynolds, Craig Adamski, Ashley Kuhl, Michelle Kempf-Weibel, and Natalie Berger. A special thank you to Margo Grady, Jason Flanagan, and Kimberly Anderson for their time and feedback as readers of the manuscript. Additionally, thank you to Qianqian Zhao and Mary Lindstrom for providing statistical data analysis and for their guidance and instruction with interpreting the data.

Compliance with Ethical Standards

Conflict of Interest Jennifer L. Rietzler, Laura E. Birkeland, and Elizabeth M. Petty declare that they have no conflict of interest.

Human Studies and Informed Consent All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all individual participants in the study.

Animal Studies No animal studies were carried out by the authors for this study.

References

- Balcom, J. R., McCarthy Veach, P., Bemmels, H., Redlinger-Grosse, K., & LeRoy, B. S. (2013). When the topic is you: genetic counselor responses to prenatal patients' requests for self-disclosure. *Journal* of Genetic Counseling, 22, 358–373.
- Clark, K. (2010). Life as a pregnant genetic counselor. *Journal of Genetic Counseling*, 19(3), 235–237.
- Clark, K. (2012). Life as a pregnant genetic counselor: take two. *Journal of Genetic Counseling*, 21, 27–30.
- Hatten, B. (2002). Pregnancy and genetic counseling: the other side of the fence. *Journal of Genetic Counseling*, 11(44), 299–300.
- Hodgson, J. M., Gillam, L. H., Sahhar, M. A., & Metcalfe, S. A. (2010). "Testing times, challenging choices": an Australian study of prenatal genetic counseling. *Journal of Genetic Counseling*, 19, 22–37.
- Keilman, K. (2002). Genetic counselor or patient-who am I today? Journal of Genetic Counseling, 11(4), 289–292.
- McCarthy Veach, P., Bartels, D. M., & LeRoy, B. S. (2002). Defining moments: important lessons for genetic counselors. *Journal of Genetic Counseling*, 11(4), 334–337.
- Menezes, M.A. (2010). Life on the front line: exploring person and professional impacts on healthcare professionals working with fetal anomaly. PhD thesis, Medicine, Dentistry & Health Sciences, Department of Pediatrics, The University of Melbourne.
- Menezes, M. A. (2012). Commentary on "life as a pregnant genetic counselor: take two". *Journal of Genetic Counseling, 21*, 31–34
- Menezes, M. A., Hodgson, J. M., Sahhar, M. A., Aitken, M., & Metcalfe, S. A. (2010). "It's challenging on a personal level"—exploring the 'lived experience' of Australian and Canadian prenatal genetic counselors. *Journal of Genetic Counseling*, 19, 640–652.
- National Society of Genetic Counselors: NSGC Code of Ethics [Internet].

 nsgc.org [cited 2017 June 18]. Available from: http://nsgc.org/p/cm/ld/fid=12
- Vokits Cohen, S. A. (2002). Lifetime continuing education: learning from my son. *Journal of Genetic Counseling*, 11(4), 281–284.
- Zucker, J. (2015). The pregnant therapist. The New York Times.

