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ORIGINAL RESEARCH

Assessment of Current Genetic Counselor Practices in Post-Visit Written Communications to Patients

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Abstract Providing patients with post-visit written communication (PVWC) is a long-standing component of genetic counseling. However the depiction of this practice in today's clinical landscape is limited. To better describe this practice, we surveyed practicing clinical genetic counselors to ask if they send post-visit communications to patients and if so, what are the types, the average length, and the average time spent writing. They were also asked the perceived purpose of providing PVWC, if/how the practice has changed over time, and factors influencing the practice. Eighty three percent (233/280) of participants reported sending patients PVWC. Of those, 93% sent at least one communication written in patient-friendly language. The type of communication varied by specialty. Prenatal genetic counselors were less likely to send patient-specific letters and hybrid letters (defined as letters with content intended for both a physician and a patient) than those in cancer genetics ($p = 0.010$, $p = 0.001$, respectively) or pediatric genetics ($p = 0.001$, $p = 0.004$, respectively). Prenatal genetic counselors spent less time on average writing post-visit communications (19.0 min) relative to those in cancer and pediatric genetics (30.6 min, $p = 0.027$ and 37.7 min, $p = 0.001$, respectively). The most commonly cited purpose for sending PVWC was to provide patients a formal account of what happened during the appointment. These data suggest PWVC are still regularly sent to patients but the practice is variable and is influenced by numerous factors including specialty, years of experience, and time constraints.

Keywords Genetic counseling practice · Letter writing · Written communication · Patient communication

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Introduction

Providing genetic counseling patients with a detailed, personalized post-visit summary letter has been considered an important part of the genetic counseling process for decades (Baker et al. 2002; Uhlmann et al. 2009). The book, A Guide to Genetic Counseling, arguably one of the definitive textbooks used in student training, refers to the patient letter as a "vital tool of the genetic counseling process" (Uhlmann et al. 2009, p. 318). A few studies have also identified patient letter writing as an element of genetic counseling clinical practice. Forrest et al. (2010) found that 79% of genetics professionals would send a post-visit summary letter to patients presenting for any of four hypothetical referral indications. In the cancer genetics clinical setting, Wham et al. (2010) found that 36.5% of genetic counselors write a patient letter following initial patient consultations.

Baker et al. (2002) introduced guidelines for writing patient summary letters in an effort to standardize content and provide a template for students to model during their education. The guidelines provide detailed information about what elements to include in a patient letter while acknowledging that content may vary by specialty and clinic. They also provide suggestions for formatting and emphasize writing in clear, concise, value-free and people-first language. Although published in 2002, these guidelines remain the only reference point for patient summary letters in genetic counseling.

Multiple studies have investigated the impact of summary letters on patients with overall positive results (Cassini et al. 2011; Hallowell and Murton 1998; Kausmeyer et al. 2006; Lobb et al. 2004). Hallowell and Murton (1998) found that 92% of women who had cancer genetic counseling thought that summary letters were valuable. Specifically, respondents said the letters aided in information recall, improved their understanding of the information discussed, served as a means of communicating with other clinicians, provided an explanation of potential risks for relatives, and aided in discussions with family members. Similarly, 97.9% of patients surveyed by Kausmeyer et al. (2006) indicated post-visit summary letters were useful for many of the same reasons. Summary letters have also been shown to decrease levels of post-visit anxiety and depression (Lobb et al. 2004), highlighting the potential psychosocial value of these communications. Finally, a study by Cassini et al. (2011) found that 94% of patients planned on referring to the summary letter in the future, showing the perceived value of these communications.

Since the Baker et al. (2002) guidelines were published, there have been significant changes in the practice of genetic counseling and in healthcare overall. For instance, in genetic counseling there has been an increase in the volume of patients seen (NSGC Professional Status Survey 2016). In healthcare systems, there is now wide spread implementation of electronic medical records (EMR), with a 336% increase in EMR use in physician practices between 2006 (11%) and 2013 (48%) (Hsiao and Hing 2014). Despite the potential benefits of sending post-visit summary information to patients, time constraints related to increasing patient volumes and formatting restraints related to standardized EMR templates may impact the genetic counselor's ability to write detailed patient letters.

To date, there have been no studies investigating if patient letters are routinely written across a variety of specialties, nor are there studies that evaluate the types of post-visit written communication (PVWC) that are sent to patients. Additionally, although Baker et al. (2002) published guidelines for patient letters, they were developed based on primarily the pediatric and adult (non-cancer) settings. Therefore, it is unclear whether the guidelines are routinely being used and if they are relevant across settings.

The purpose of this investigation was to characterize the practice of providing PVWC to genetic counseling patients. Specifically, we distributed a novel, online survey to clinical genetic counselors, to determine what proportion of genetic counselors provide patients with PVWC; characterize the types of communications sent; and evaluate the length and time spent writing. In addition, through open-ended questions, we assessed genetic counselors' perceptions of the primary purpose of these communications; if and how the practice of providing PVWC has changed over time; and what factors affect current counselor practice.

Methods

Participants

Eligible participants were full members of the National Society of Genetic Counselors (NSGC) currently involved in direct patient care. An initial recruitment email was sent to full members via the NSGC Student Research Survey Program ($N = 3200$). A link to the survey was imbedded in the email. The link took potential participants to the first page of the survey which included the study information sheet. Only those who consented to take part were able to access the remainder of the survey. Two weeks following the initial recruitment email, a reminder email was sent. The survey was made available from February 9, 2015 until March 9, 2015.

Instrumentation

The instrument developed for this mixed-methods study was a novel survey distributed through the Qualtrics web-based survey program. The first two questions of the survey included the study information sheet followed by a study eligibility question. Those who consented to participate were asked whether they currently provide genetic counseling services to patients. Those who indicated "no" were directed to the end of the survey and excluded from the study. The next part of the survey included four demographic questions that inquired about genetic counseling specialty, years in practice, regional location of practice, and type of practice setting (i.e. hospital system, private clinic, or educational institution). The next question then asked whether participants provide PVWC to patients. Those who answered 'no' were asked to explain why they do not and then were directed to the end of the survey.

The remainder of the survey included questions about current PVWC practices. Participants were first asked to select a single specialty for which they see the majority of patients. They were then asked to choose the type(s) of PVWC typically sent after an initial visit (Table 1), how long they spent writing each type (in minutes), and the average length (in pages). Recognizing that participants may send more than one type of PVWC to a single patient, they were also asked to estimate the total time spent writing all communications and the total number of pages they typically send. Participants were then asked whether they used an EMR to generate any portion of the PVWC.

The last part of the survey included several open-ended questions regarding opinions on potential factors that influence the type of PVWC sent, the primary purpose of providing PVWC and how respondents perceive their practice has changed over time. A final question asked for any additional information or comments regarding PVWC practice.

Table 1 Post-visit written communication types

Type	Description
Patient-specific	Post-visit written summary information addressed to and intended for patient (in patient-friendly language)
Physician-directed	Copy of post-visit written summary information addressed to and intended for MD
Consultation/clinic note	Copy of consultation/clinic note
Hybrid	Hybrid version of post-visit written summary information and clinic note (including information intended for MD and information intended for patient in patient-friendly language)
GC/clinic-specific information sheet	General information sheets/pamphlets written by GC/clinic
General information sheet	General information sheets/pamphlets developed by outside source
Other	Text box provided to add any other forms of communication sent to patients

A draft version of the survey was emailed to 25 clinical genetic counselors for feedback regarding readability and clarity. Four genetic counselors piloted the survey and recommended changes were incorporated. The survey was also reviewed by the Research Design and Analysis Unit at Wayne State University for content and organization, and to estimate the target sample size needed to achieve statistical power. Using G*Power Statistical Power Analysis for Windows, version 3.1.9.2, (*d* = .3; *alpha* = .05; *power* = .8), we estimated that a sample size of 180 would be required to detect a medium effect size for one-way ANOVA analyses and 191 for chi-square analyses.

Data Analysis

Statistical analyses were performed using IBM's Statistical Product and Service Solutions Statistics, Version 22 software. Descriptive statistics were generated on all demographic data including frequencies and as appropriate, means, medians and standard deviations. For any open-ended numeric responses, in cases where a participant provided a range such as with time or page length (i.e. 30–45 min), the mid-range was calculated to provide a single data point (i.e. 37.5 min). Chi square tests of independence were used to assess differences between specialty and the type of communication sent to patients with a Bonferroni correction to account for multiple comparisons. One-way ANOVA analyses were done to assess differences in continuously measured variables, such as average time spent writing PVWC and average length of communication types. Bonferroni post-hoc analysis was done to assess differences in time and length between specialties. A linear regression analysis was done to assess differences in average time spent writing summary communications when controlling for years of experience.

The open-ended responses were assessed using conventional content analysis (Hsieh and Shannon 2005). One researcher (ERV) analyzed the entire data set for common themes and coded them accordingly. A second researcher (EPC) then separately coded the entire data set using the same themes. Any discrepancies in coding and additional themes identified by the second researcher were discussed until consensus was reached.

The study was designated as exempt by the Wayne State University Institutional Review Board.

Results

Demographics

We received 289 responses; 9 individuals consented to participate, but did not record a response to any further questions. These participants were declared 'system missing'. The overall survey response rate was therefore 8.8% (280/3200). Forty-seven individuals (16.8%) reported demographic information, but answered 'no' when asked whether they send PVWC to patients; 83.2% (233/280) completed the remainder of the study. The demographic profile of the participants is recorded in Table 2 and was similar to that reported in the 2014 NSGC Professional Status Survey for practice setting, specialty, and years of experience (NSGC 2014). Using Chi-square tests of independence, we did not find any significant demographic differences between those participants who only answered the demographic questions and those who completed the entire survey.

Types of Communications

Table 3 shows how frequently each type of communication was sent and the mean page length per type of PWVC. Across specialties, general information sheets were sent most often (55%) and consultation notes were sent least often (31%). The average length ranged between 2.1 (*SD* = 0.98; *range* = 0–5) for patient-specific letters to up to 3.1 (*SD* = 1.5; *range* = 0–10) for hybrid letters, with no significant differences between types.

We performed pair-wise comparisons between specialty and PVWC type using a chi-square test of independence for the three most common specialties represented in our data set (prenatal, cancer and pediatrics). Based on Bonferroni correction, results were considered to be significant at $p < 0.017$ ($p = 0.05/3$). Prenatal genetic counselors sent significantly fewer patient-specific letters than those in cancer genetics

Table 2 Demographic information of participants

Specialty ($N = 280$)	*n (%)	Practice Setting (N = 280)	n (%)	Years Practice ($N = 216$)	^n (%)
Prenatal	61 (21.8)	University Medical Center	112 (40.0)	≤2 year	60 (27.8)
Cancer	103 (36.8)	Private Hospital/Clinic	69 (24.6)	>2–5 years	61 (28.2)
Pediatrics	27 (9.6)	Public Hospital/Clinic	76 (27.1)	5+ years	95 (44.0)
Cardiology	7 (2.5)	Diagnostic Laboratory	4 (1.4)		
Neurogenetics	8 (2.9)	Health Maintenance Organization	6 (2.1)		
Adult (Non-Cancer)	50 (17.9)	Government Organization	7 (2.5)		
Metabolic	5 (1.8)	Other	6 (2.1)		
ART/IVF	13 (4.6)				
Other	6 (2.1)				

*Participants could choose more than one specialty for which they see patients for initial demographic data

^Mean = 8.7 years; median = 5.0 years; range = 0.5–35.0 years

[$\chi^2(1,N = 135) = 6.70$, $p = 0.010$] or pediatric genetics [$\chi^2(1,N = 76) = 11.70$, $p < 0.001$]. This was also true for consultation notes [prenatal vs. cancer: $\chi^2(1,N = 136) = 3.90$, $p = 0.048$; prenatal vs. pediatric: $\chi^2(1,N = 134) = 11.96$, $p = 0.001$] and for hybrid letters [prenatal vs. cancer: $\chi^2(1,N = 75) = 10.69$, $p < 0.001$; prenatal vs. pediatric: $\chi^2(1,N = 74) = 8.44$, $p = 0.004$]. There were no significant differences between specialties for physician-directed letters or information sheets.

The mean number of communication types sent per patient was 2.42 ($N = 167$) across specialties. There were no significant differences detected across specialties using a one-way ANOVA analysis. At least one patient friendly communication type (patient-specific letter, hybrid letter, and/or general information sheet) was sent 93% of the time (Table 3). Seventy one percent of participants reported sending at least a patient-specific letter and/or hybrid letter- both communications written specifically for patients at or around the time of the visit. Participants working in a prenatal setting were significantly less likely to send any communication written specifically for patients (32%) when compared to those working in cancer (79%) or pediatric settings (83%) [$\chi^2(1,N = 124) = 23.86$, $p < 0.001$ and $\chi^2(1,N = 63) = 16.10$, $p < 0.001$, respectively].

Time Spent Writing Communications

The average total time spent writing PVWC across specialties was 30.3 min ($N = 177$; $SD = 23.4$). Results of a one-way ANOVA identified a significant difference, $F(6170) = 3.59$, $p = 0.002$, across specialty groups with between-group Bonferroni post-hoc tests revealing less time spent writing in prenatal cases ($M = 19.0$ min; $N = 32$; $SD = 15.2$) compared to pediatric ($M = 37.7$ min; $N = 35$; $SD = 27.0$, $p = 0.02$) and cancer ($M = 30.6$ min; $N = 96$; $SD = 21.2$, $p = 0.24$).

Table 3 PVWC sent to a typical new patient

Communication Type	All* Number sent	Cancer Number sent	Prenatal Number sent	Pediatrics Number sent	All* Mean Length per type
Patient-specific	83/185 (45%)	44/95 (46%)	9/40 (23%)^	22/36 (61%)	2.1 ($n = 81$) [*SD:* 0.98 (0–5)]
Physician-specific	58/184 (32%)	27/96 (28%)	15/39 (39%)	11/36 (31%)	2.3 ($n = 50$) [*SD*: 1.2 (0–7)]
Consultation note	57/186 (31%)	28/97 (29%)	5/39 (13%)^	17/36 (47%)	2.3 ($n = 47$) [*SD:* 1.3 (0–5)]
Hybrid	67/182 (37%)	42/95 (44%)	5/39 (13%)^	15/35 (43%)	3.1 ($n = 60$) [*SD:* 1.5 (0–10)]
Clinic-specific information sheet	71/183 (39%)	42/99 (42%)	15/39 (39%)	9/31 (29%)	2.6 ($n = 49$) [*SD:* 3.1 (0–20)]
General information sheet	101/183 (55%)	53/97 (55%)	19/38 (50%)	19/35 (54%)	2.5 ($n = 41$) [*SD:* 2.2 (0–10)]
Any communication intended for patients (patient-specific; hybrid; any information sheet)	154/166 (93%)	86/90 (96%)	28/34 (82%)	27/29 (93%)	
Any communication *written specifically* for patients (patient-specific; hybrid)	118/166 (71%)	71/90 (79%)	11/34 (32%)^	24/29 (83%)	
Any information sheet (clinic-specific and/or generic)	122/167 (73%)	69/91 (76%)	21/34 (62%)	20/29 (69%)	

*Includes cancer, prenatal, pediatrics, cardiology, neurology, adult (non-cancer) and metabolic disease

^Frequency of communication sent was significantly less in prenatal verses both pediatrics and cancer ($p < 0.017$)

Figure 1 shows the correlation of years of clinical genetic counseling experience and mean time spent writing PVWC. A linear regression analysis identified a statistically significant negative correlation ($B = -0.670$, $p = 0.002$), indicating that time spent writing PVWC decreases with increasing experience. However, when controlling for years of experience, pediatric counselors still spend significantly more time writing compared to prenatal counselors ($p = 0.002$); the difference between cancer and prenatal counselors was not statistically significant ($p = 0.055$).

One hundred seventeen participants out of 176 (66.5%) reported using an EMR system to generate any part of the PVWC. EMR use across specialties was not significantly different. There was no difference in the average time spent writing communications between counselors that use an EMR and those that do not; 30 min (SD = 22.5; *median* = 25 min) versus 31.1 min (SD = 25.4; *median* = 30 min), respectively. Participants who use an EMR were significantly more likely to send a copy of the consultation note to a patient [$\chi^2(1,N = 185) = 11.56$, $p = 0.001$]. Otherwise, there were no other significant differences for other types of communication.

Open-Ended Responses

Forty-five of the 47 participants that do not typically send PVWC indicated why they do not. The most commonly cited reason was because a consultation note is sent to the referring physician instead ($n = 20$). As one respondent noted:

> "*A typed summary of the visit, including reason for referral, family history discussion, summary of consultation and what [the patient] chose to do with testing is sent to the referring physician. A patient has access to this information if ever needed/desired.*"

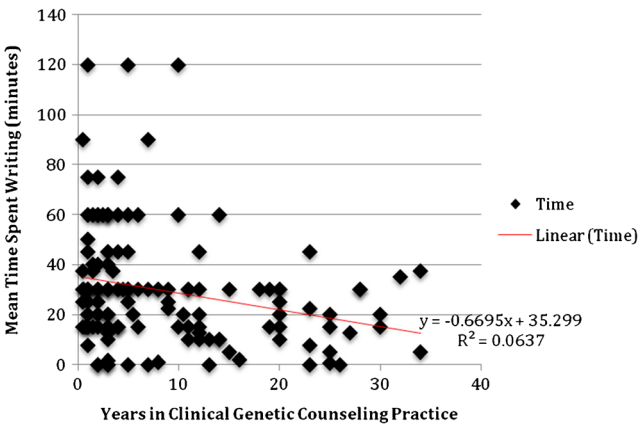

Fig. 1 Correlation plot of years of clinical genetic counseling practice and mean time spent writing post-visit summary communication

The second most common response was a lack of time ($n = 13$). Others stated they send only test results or other information ($n = 7$), that the practice is not part of the outlined job description or endorsed by the institution ($n = 4$), and a perceived lack of patient interest in receiving the information ($n = 4$).

Of the participants who reported sending PVWC, 183 provided additional information about the primary purpose of the communications. We identified six main themes as shown in Fig. 2. The majority of participants indicated PVWC provided the patient with a summary of what was discussed during the genetic counseling visit. Counselors noted numerous patient-specific benefits of providing summary information, illustrated in the following quote:

> "*To reiterate complex information, provide [patients] with a hard copy of information to [reference] in the future when they have questions or can't remember details, provide [patients] with limited understanding another source of information, provide overwhelmed [patients] with a resource they can use in their own time.*"

Additionally, many participants ($n = 97$) noted more than one reason for providing PVWC as stated in this quote:

> "*My post-visit written summaries serve several purposes: 1) as the consultation/clinic note to be placed in the patient's chart for our own records (i.e., as our primary documentation of the visit), 2) as information/correspondence to the referring provider and other providers involved in the patient's care, 3) as information for the patient to recap our discussion at their visit.*"

Participants were also asked what they consider to be the largest influence on their current practices of providing PVWC. Based on 172 responses, we identified seven themes as shown in Fig. 3. The desire to achieve patient education

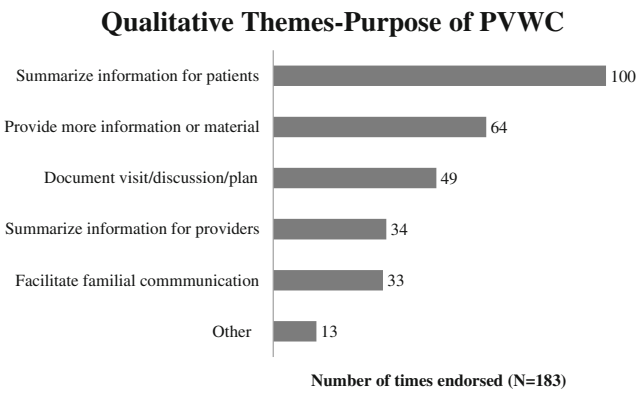

Fig. 2 Qualitative themes: purpose of PVWC

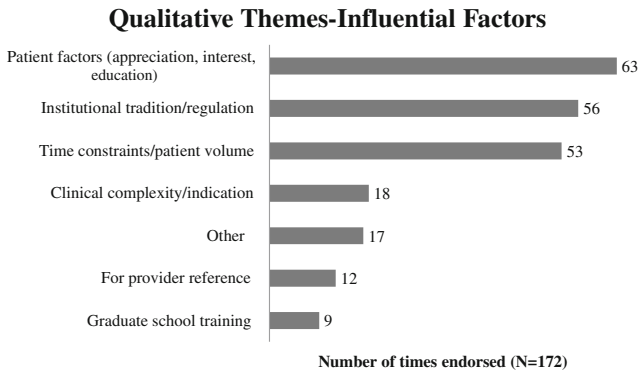

Fig. 3 Qualitative themes: influential factors

accounted for the largest influence on current practice. One participant summarized this as follows:

> "*I think these letters are important for our patients to help them understand difficult information.*"

Time constraints were also commonly cited as highly influential.

> "*Time. We are pushed to see more and more patients in less time, and I simply do not have time. Our GC group has a joint folder where we save letters that are generalizable or have useful sections; this saves some time, but not a lot. We also have a lot of responsibility for documenting the encounter for the MD, so it ends up being "double duty" if we also write a letter.*"

Additionally, institutional tradition/regulation was cited as a common influence by many participants. Some illustrative comments include: "*It's the way they have always done it at this clinic*", "*genetics group consensus for our practice at our institution*" and "*meeting compliance requirements for documentation in EMR*".

Participants were also asked if and how they believe the practice of PVWC has changed over time. Of the 97 participants responding, many (n = 47) reported sending fewer patient-specific letters in general. Others (n = 22) stated that if they do send a patient-specific letter, they commonly provide letters that contain less detail and are shorter than in previous years. As one respondent cited:

> "*MUCH, MUCH shorter! More targeted. Less of an "opportunity to educate" and more about documenting what has been done.*"

Additionally, several (n = 20) stated that they now utilized more templated formats as a result of EMR implementation.

Finally, 57 participants provided additional commentary about their specific communication practices. Many (n = 16) reiterated that PVWC's are a valuable resource for patients and families. A few (n = 10) noted that they do not provide summary information until results are returned or a diagnosis is made. Several (n = 7) also acknowledged that the practice of writing PVWC might be in a time of transition citing time-constraints, implementation of EMR-associated templates, and the ability of patients to find other resources for information regarding genetic conditions.

Discussion

Our study results suggest that a large majority of genetic counselors still regularly send some form of communication to new patients following the genetic counseling visit. The majority send PVWC types that include but are not limited to the traditional patient letter described by Baker et al. (2002). This appears to be true despite noted time constraints due to increasing patient volumes. Not only do genetic counselors seem to value sending PVWC, they favor sending communications such as patient-specific letters and information sheets that are presumably in a patient-friendly format. This is not surprising as participants cited patient education as the both the primary purpose for and largest influence on providing PVWC.

Overall, these results are not unexpected as the patient letter has long been identified as an important part of patient care in the field of genetic counseling (Baker et al. 2002; Uhlmann et al. 2009). Uhlmann et al. (2009) in A Guide to Genetic Counseling, recognize the letter as a communication tool that utilizes patient-friendly language, summarizes important points made during the clinic visit, documents patient-specific medical and family histories, and may also serve as a mechanism to prompt discussions with family members. Despite the potential to be a time-consuming activity, the value of writing these letters is emphasized early on in the training of a genetic counseling student. This approach is also consistent with the various studies that suggest the perceived benefits of receiving summary information by genetic counseling patients (Cassini et al. 2011; Hallowell and Murton 1998; Kausmeyer et al. 2006; Lobb et al. 2004).

We observed some differences in the type of patient communication sent by each specialty. Participants send patient-friendly communications more often in pediatrics and cancer genetics settings whereas they tend to favor sending physician-specific communications in the prenatal setting. A possible reason for this could be the time constraints inherent in prenatal practice. Genetic counselors might prioritize communication with referring physicians in order to expedite testing/management/follow-up. Additionally, many prenatal counseling indications (i.e., advanced maternal age, abnormal serum screening results) are specific to the current pregnancy and may not have lasting implications on postnatal

management or future risks if the pregnancy outcome is normal. Therefore, providing the patient with a letter to share with family members or to use as a future reference may not be necessary.

This is in contrast to pediatric genetics where children with a genetic diagnosis may require long term medical management necessitating lasting communication with parents. A PVWC is one way to promote this type of communication. In cancer genetics, as well as pediatrics, there may be more of a need for familial communication of test results. For example, in 2009 the Evaluation of Genomic Applications in Practice and Prevention (EGAPP) Working Group found sufficient evidence to recommend genetic testing in individuals with colorectal cancer specifically to reduce morbidity and mortality in their relatives (EGAPP Working Group 2009). With these types of recommendations in place, counselors may be additionally motivated to provide patient-specific written information to facilitate familial communication of risk and testing options.

The results of this study suggest that there are differences in the average time spent developing PVWC amongst genetic counseling specialties. We found that prenatal genetic counselors spent less time writing communications than their pediatric and cancer genetics colleagues. Despite this, there were no significant differences in the length of communications across specialties. In addition, using an EMR did not appear to impact the time spent writing overall. There may be other factors such as institutional requirements and formatting (e.g., template use), that influence writing time. Additional research is needed to further assess such influences.

When looking only at patient-specific communications, the length of communication averaged two pages. This is consistent with the two-page limit recommended by the patient letter writing guidelines published by Baker et al. (2002). Additionally, it is in line with a previous study that showed patients prefer a summary letter between two and three pages in length (Hallowell and Murton 1998). More recently, Roggenbuck et al. (2014) found that patients who were sent concise letters (about 1.5 pages in length) rated those letters higher in content/usefulness than patients who received longer letters (4–5 pages in length). These studies together with our results suggest two-page patient letters, on average, are typical and potentially optimal. This information could be useful in training students and in helping clinics establish reasonable standards for patient communications.

The majority of participants in this study (66.5%) stated they use an EMR system to generate at least a part of their PWVC. EMR users were significantly more likely to send consultation notes than non-users. This may be because documentation in the EMR is often required for legal or billing purposes. However, even with implementation of an EMR, the majority of counselors are still sending patient-friendly communications.

When looking at the individuals who did not send PVWC, a few cited perceived lack of patient interest. This is in contrast to Kausmeyer et al. (2006) and Cassini et al. (2011) who both found that the majority patients valued post-visit written information (97.9% and 99%, respectively). Additionally, the participants sending PVWC endorsed patient factors such as patient appreciation and interest as an influential factor most often. As patient demographic information was not obtained in our study, it is, however, difficult to make the generalization that all patient groups would value summary letters in the same way. The differences between the responses of these few individuals and other studies could be related to factors such as patient demographics (e.g., literacy level, spoken language) or referral indication. It would be worthwhile to address this potential discrepancy amongst genetic counseling professionals by evaluating the impact of summary letters on a variety of patient populations and clinic settings.

Study Limitations

There were several limitations to this study. We required participants to be currently practicing in clinical care. This reduced our sample size by excluding counselors who may have written PWVC in the past. Additionally, it is possible that only those genetic counselors who were particularly interested in letter writing or that write letters responded to our survey. Therefore, this sample is likely not representative of all genetic counseling professionals and may have led to an overestimated percentage of counselors sending PWVC. In the question assessing which PWVC the participant sent, we had several instances in which responses were absent. Although it is possible they meant to answer "no" to sending those communications, we did not include them in the analysis. This lowered the response rate to that particular question. As a result of all of the above, based on our power analysis estimates, our study was slightly underpowered, which may have prevented us from identifying some associations.

There were some limitations related to the survey design that may have affected the overall findings. Although we defined each type of PVWC in the survey instrument, it appears that some participants may not have fully understood the provided definitions/instructions. For example, it appeared that some individuals may have reported all the various types they have sent to any patient in the past instead of what they send to a "typical new patient". Additionally, a few participants reported answering questions as though they had already seen the patient for results disclosure, since they typically did not send PVWC until after test results were provided. Finally, we were unable to accurately calculate the time spent writing per communication type.

We did not evaluate how genetic counselors specifically use EMR systems, such as whether they are required to use a template or whether they have free-texting capabilities

allowing for patient-specific content. Strict EMR requirements may influence if or how a genetic counselor generates PWVC. Ultimately, more research is needed on how genetic counselors utilize EMRs and the impact on PVWC.

Future Research

Supplemental investigation into the practices of individual counseling specialties may be worthwhile to further elucidate the differences in PVWC practices. This could be accomplished by surveying members of individual special interest groups (SIGs) of the NSGC. A formal content analysis of communications provided to patients (currently ongoing) will ideally highlight what is actually written in patient communications and whether there are differences by specialty. This may help to assess whether the Baker et al. (2002) guidelines are still useful and relevant in the context of current clinical practice. It may also be worthwhile to investigate genetic counseling program training in written communication, as this has relevance to professional practice. Finally, more studies are needed that focus on the needs and perspectives of the patient with respect to written communication.

Conclusion

We sought to characterize genetic counselors' current practice of providing PVWC to patients as an initial step to encourage more research. Although a majority of our respondents are currently writing and sending PWVC, there appears to be tremendous variability associated with this practice. We have identified several factors influencing the practice including specialty, years of experience, EMR use and other institutional regulations, time constraints and patient factors. Based on previous literature and our current study, it appears that there is still some value in providing PWVC, thereby suggesting that the practice should continue in some capacity. Further research is ultimately needed to determine the PVWC best practices that will maximize genetic counselor efficiency while still providing patients with optimal care.

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Compliance with Ethical Standards

Conflict of Interest E. VandenBoom, A.M. Trepanier and E.P. Carmany declare that they have no conflict of interest.

Human Studies and Informed Consent All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

Animal Studies This article does not contain any studies with animals performed by any of the authors.

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