An exploration of genetic counseling information needs and information-seeking behaviors

Amy E. Donahue1,2 | April L. Hall3 | Elizabeth M. Petty1

1 School of Medicine & Public Health, University of Wisconsin-Madison, Madison, WI, USA
2 Medical College of Wisconsin, Milwaukee, WI, USA
3 Waisman Center, University of Wisconsin-Madison, Madison, WI, USA

Abstract
Genetic counseling is a rapidly growing field with increasingly diverse practice settings. The growth of genomics and precision medicine across all medical specialties has been accompanied by corresponding growth in the amount of information available to genetic counselors. However, few published studies on genetic counseling information needs and seeking behaviors exist, and none look at information use across the profession. Meanwhile, a substantial body of research exists on this topic for other healthcare professionals, providing an evidence base supporting profession-tailored information-related services and resources. The purpose of this cross-sectional study was to explore genetic counseling information needs and seeking behaviors and to compare these needs and seeking behaviors across genetic counseling students and genetic counselors broadly, as well as to explore differences across various professional subgroups of genetic counselors. Genetic counselors and genetic counseling students were recruited via the National Society of Genetic Counselors and accredited genetic counseling programs to complete an online survey assessing information needs and seeking behaviors. Respondents were asked how often they used 70 different resources; whether 16 specific situations required additional information and how long it would take to get it and about specific barriers to obtaining that information. The results included a range of observations, including that GeneReviews and PubMed are frequently used resources across all respondents, that genetic counselors working 0–5 years are significantly more likely to need additional information when counseling patients from different cultural backgrounds than those working 6+ years, and that not having enough time is a common barrier to getting information across various situations. These results provide initial evidence to guide additional study on the efficient use and provision of information within the genetic counseling field.

Keywords
genetic counseling, genetic counselors, information needs, information-seeking behavior, quantitative research, workforce

1 INTRODUCTION
Genetic counseling is a rapidly evolving field, with genetic counselors working in increasingly diverse settings. The substantial growth of genomic and precision medicine across medical specialties is also contributing to the profession's complexity. In order to provide up-to-date clinical guidance, education, and other services, genetic counselors must constantly seek out current and accurate
information. However, formal understanding of how genetic counselors find information is little to non-existent. Although it may seem clear, for example, that genetic counselors get information from journal articles and databases, this is an assumption. Studying when information is needed, what resources are used, and whether barriers to getting information exist is necessary to begin to establish an evidence base for information use in genetic counseling.

Definitions of information, information needs, and information-seeking behavior can be drawn from the field of information science to provide context for such study. Information itself is defined as anything that ‘(a) has meaning, (b) is communicated, (c) has an effect, and (d) is used for decision making’ (Fidel, 2012, pg. 6). Information needs are defined as an individual’s conscious or unconscious recognition of a knowledge ‘gap’ that has the potential to be filled (Belkin, 1978; Dervin, 1998; Taylor, 1968). Research on information needs using this definition seeks to identify what the gaps are as well as the situations where gaps exist. Information-seeking behavior, meanwhile, is ‘a catchall phrase that encompasses a variety of behaviors seemingly motivated by the recognition of ‘missing’ information’ (Case & Given, 2016, p. 93). Information-seeking behavior research looks at specific resources used and the reasons why information is or is not obtained.

Many studies exist on the information needs and seeking behaviors of various groups of professionals and patients in healthcare settings. There are over 2,000 articles that include the concepts of information needs, seeking, or behavior in the title with citations in PubMed (2019). A more systematic search would likely yield many more. While an in-depth review of these studies was outside the scope of this research project, a selection of historic, oft-cited articles was identified by the authors, with the assistance of a medical librarian. These articles provided insight into ways genetic counselors may be similar to, and differ from, other healthcare providers. For example, in their study on physicians and medical students, Osheroff et al. (1991) directly observed, recorded, and analyzed ‘expressions of a need for information’ and found that an average of five clinical questions came up for each patient—74% concerned patient care, and 26% of these ‘required a synthesis of patient information and medical knowledge’ (p. 577) to answer. Gorman (1995), in his seminal review of physicians’ information needs, found that many patient care questions are never actually pursued by physicians, and that there is a reliance on colleagues and other human interactions when information is sought out. Years later, in a 2014 review, Del Fiol, Workman, and Gorman still found ‘that the per-patient frequency of questions raised by clinicians ranges from 0.4 and 0.8 and that roughly two-thirds of these questions are left unanswered’. Additional recent studies have found that primary care physicians need information on diagnoses and treatment and different specialties such as general medicine and ophthalmology have different, specific needs (González-González et al., 2007; Shafi & Wani, 2011). Studies in nursing have uncovered findings like those in physicians. For example, Cogdill (2003) found through surveys and interviews that nurse practitioners frequently needed information related to drug therapy and diagnosis; for diagnostic questions, they were most likely to turn to colleagues for answers.

The many articles on information needs and seeking behaviors include studies of specific patient populations, including those with genetic conditions. It has been argued that genomics provides the ‘perfect information-seeking research problem’ because of the combination of large amounts of information and information sources; small numbers of genetics providers; societal and ethical dilemmas; and health literacy issues (Johnson, Case, Andrews, & Allard, 2005). Examples of genetic disorder-related research include studies of people who had genetic testing for hereditary cancer; patients and families with inherited bone marrow failure syndromes; and people who had genomic testing for diabetes risk. These three recent studies in the Journal of Genetic Counseling found that the resources used, or that could be used by patients seeking information, included genetic counselors (Hamilton et al., 2015; Meiser, Storey, Quinn, Rahman, & Andrews, 2016; Mills, Powell, Barry, & Haga, 2015).

Despite the amount of research done on other healthcare professionals’ and patient populations’ information needs and seeking behaviors, we identified only two published studies on the information needs of genetic counselors after an exhaustive literature search conducted with the assistance of a medical librarian. A study of cancer genetic counselors’ information needs when receiving a variant of uncertain significance (VUS) result found most respondents felt the VUS laboratory reports ‘lacked information’ such as references to published literature and prediction models and provided evidence for changing laboratories’ VUS reports (Scherr, Lindor, Malo, Couch, & Vadaparampil, 2015). The same study also suggested that future research should ‘examine cancer GCs’ awareness of these databases [MAPP-MMR, Align GVDG, PolyPhen, and ClinVar], barriers to use, and identify strategies or education for GCs to integrate these resources into clinical practice’ (Scherr et al., 2015). The other study, presented at a national library conference, looked at genetic counselors’ use of library resources in a single urban academic medical center. The authors found the center’s genetic counselors were interested in ‘automated alert services’ and needed access to unique resources beyond MEDLINE (Olmstadt & Anderson 2005).

Building off this existing research, the aim of this study was to collect a cross-sectional data set on genetic counseling information needs and information-seeking behavior through an online survey of genetic counselors and genetic counseling students. We hypothesized there would be differences in information needs, information-seeking behaviors, and barriers to information within genetic counseling subgroups, such as students versus practicing genetic counselors. We also suspected that there may be some commonalities between genetic counselors and other healthcare professionals in terms of information-seeking behavior; specifically, that colleagues are an important source of information in genetic counseling, as they have been found to be for physicians and nurses. Our goal is to provide an initial evidence base to promote further study and, as in studies of other healthcare professionals, to provide preliminary evidence that could support information resource purchasing decisions (Woolf & Benson, 1989) and the development of new (or improvement of current) information services (Urquhart & Crane, 1994).
2 | METHODS

The University of Wisconsin-Madison Health Sciences Minimal Risk Institutional Review Board granted an exemption to this study (protocol 2017-1409).

2.1 | Survey instrument

The 138-item online survey (Qualtrics, 2005) for genetic counselors and genetic counseling students contained a combination of closed and open questions that were informed by the research of other healthcare professionals described above. The survey questions analyzed in this study fell into four main categories: respondent demographics, genetic counseling background and experience, situational information needs and seeking behavior with set response choices, and specific resources used. (A fifth question category yielded a free-text qualitative data set that is not analyzed in this paper.) Demographic questions captured respondent age, gender identity, and race/ethnicity. An initial question differentiated between genetic counseling students and genetic counselors, either currently or previously practicing. Display logic was used for follow-up genetic counseling experience questions depending on which of these two groups the respondent chose. Students were asked about program graduation year and experience prior to entering a program while genetic counselors were asked when they graduated, number of years working as a genetic counselor, patient interaction, work setting, and specialty areas. Demographics and genetic counseling background and experience questions were adapted from the 2016 National Society of Genetic Counselors (NSGC) Professional Status Survey (PSS) (NSGC, 2017a, 2017b, 2017c). The PSS is administered by the NSGC and is designed to capture an inside view of the profession. It is sent to all NSGC members, members of the Canadian Association of Genetic Counselors, and diplomats of the American Board of Genetic Counseling (ABGC). The survey was piloted with genetic counseling students and genetic counselors, and feedback was incorporated into the final draft.

All respondents were shown the same ‘resources used’ and ‘situation’ questions (Table S1). These two categorical concepts were used in previous studies on information needs and information-seeking behavior in other healthcare groups (Cogdill, 2003; Woolf & Benson, 1989). However, the questions within these categories were novel and designed by the authors to be relevant to genetic counseling. We identified the 70 different resources by reviewing the resources recommended and used by students, faculty, and supervisors in the University of Wisconsin genetic counseling program, discussing with a medical librarian at the University of Wisconsin, and reviewing other genetic counseling library resource lists such as Ohio State University’s (Schulte, 2018). The resources were categorized as follows: books, journals, genetic resources/tools, other biomedical resources/tools, other online resources, colleagues, and ‘other’ (including medical records). Respondents were asked how often they used each resource: daily, frequently (>1×/month), occasionally (1×/month to 1×/year), rarely (<1×/year), or never. Alternatively, respondents could indicate that the resource was not available, that it was not relevant/not familiar, or ‘prefer not to respond’. There was an opportunity to provide free-text responses to share other resources not listed.

We also identified 16 specific situations to attempt to address different settings from clinical patient care (such as different types of test results and patient populations), laboratory settings (designing new genetic tests), and education of various groups. For each situation, regardless of whether they had experienced it, respondents were asked whether they would need information, how much time would be spent getting it, and about potential barriers to getting information. Respondents had the opportunity to enter free-text descriptions of additional situations, if desired.

2.2 | Participants and recruitment

An electronic link took participants directly to the online survey. Respondents were asked to read and agree to the consent form on the first page before continuing with the survey. The survey was anonymous and did not collect identifying information, including names, emails, or IP addresses.

Individuals who were (a) currently practicing genetic counselors, (b) previously practicing genetic counselors, or (c) students in a genetic counseling program accredited by the Accreditation Council for Genetic Counseling were eligible to take the survey. The link to the electronic survey was distributed through the NSGC ‘Student Research Survey Program’, the ABGC research request listserv, and through current directors of accredited genetic counseling training programs for distribution to students. Participants were eligible to enter a drawing for Amazon gift certificates. Survey recruitment emails (original invitation email to all three groups, plus one follow-up reminder email to the NSGC listserv and the program directors) were sent out, and responses were collected between January 8 and January 26, 2018.

2.3 | Data analysis

Respondents who clicked the submit button were marked by Qualtrics as ‘finished’ and included for analysis. Free-text responses were extracted and reviewed but were not otherwise qualitatively analyzed. Descriptive statistics were computed. Survey respondents’ demographic breakdown was compared to demographics published in the NSGC 2016 PSS. Responses from genetic counselors were compared to those of genetic counseling students. Within the genetic counselor group, comparisons were made based on patient interaction (yes/no), work setting (academic medical center/others), presence of other genetic counselors (solo vs. having coworkers), specialty (single specialty vs. multiple specialties, as well as cancer, prenatal, and pediatric individually vs. counselors who work in each those specialties in
addition to others), and years working as a genetic counselor (0–5, 6+). Fisher's exact tests were performed to assess for non-random relationships between comparison groups for both resource use and whether information was needed for a given situation. Separate analyses were performed for each resource and each situation. These analyses were performed using SAS™ statistical software, version 9.4 (SAS Institute Inc.). A p-value of less than .05 was considered significant.

3 | RESULTS

3.1 | Demographic summary

A total of 255 respondents indicated they were either a genetic counselor (n = 184) or genetic counseling student (n = 71), were marked as ‘finished’ by Qualtrics, and were included in the final data set. Response rates, using recent estimates of 4,000 genetic counselors (NSGC, 2017a) and 400 genetic counseling students (GC admissions match, 2018), were estimated to be 4.6% and 18%, respectively.

In the genetic counselor group, most (67%) were between the ages of 25–34 years, 96% were female, 83% were White (non-Hispanic), and 94% worked full-time. No genetic counselors from NSGC Region 1 completed the survey, although the distribution across the other regions was similar to the PSS results. Of the specialties reported, 57% reported cancer, 38% reported pediatric, and 29% reported general genetics. Over half the genetic counselor respondents (63%) reported working for 0–5 years, with the remainder spread across 6–15, 16–25, and 25+ years worked. These were combined into a ‘6+ years worked’ comparison group. The demographics across genetic counselors were within ±7% (95% confidence interval; Creative Research Systems, 2012) of the data set. Response rates, using recent estimates of 4,000 genetic counselors (NSGC, 2017a) and 400 genetic counseling students (GC admissions match, 2018), were estimated to be 4.6% and 18%, respectively.

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The genetic counseling students were mostly (95%) between the ages of 20–29 years, with 94% female and 76% White (non-Hispanic). No genetic counseling students from Region 5 completed the survey (the most highly represented was Region 4, at 42%). Just over half (52%) reported graduation in 2018 (the year the survey was conducted).

3.2 | Resources

At least one respondent indicated daily or frequent (more than once a month) use for each of the 70 resources. At least one respondent indicated they never used a resource for 50 of the 70 resources. For 59 of the resources (including UpToDate, librarians, general medical journals, and POSSUM [subscription dysmorphology database]), at least one respondent noted it was ‘not available’. Fifty-seven resources, including genetic counselor coworkers, other colleague(s), risk assessment tools (e.g., BRCApro), and Concert Genetics, had at least one respondent who indicated that it was ‘not relevant/not familiar’. Table S2 provides the usage response breakdown across the whole sample for each of the 70 resources (descending by daily use frequency). The ten top-ranked daily/frequently used resources and the ten top-ranked never used resources were identified across the data’s subgroups, and these lists were combined to identify the ‘top’ and ‘bottom’ ranked resources for the whole sample. The percentages of combined daily/frequent use for these selected resources across the whole sample as well as the subgroups are shown in Figure 1. Several resources were unique to a particular subgroup’s top ten. Laboratory geneticists were only in the top for genetic counselors with no patient interaction. Risk assessment tools were only in the top for genetic counselors who reported working in cancer. Genetic counselors who reported working in pediatrics made up the only group to have disorder-specific/patient organizations in the top ten.

Of the 32 resources identified through the process described above, 19 showed statistically significant differences in daily/frequently used between at least one subgroup comparison analyzed (Figure 1). A significant difference between genetic counseling students and genetic counselors was seen with the use of library websites, which was 66% versus. 29% respectively. A significantly higher percentage of genetic counseling students also used other genetic counseling students daily/frequently (96% vs. 10%). Concert Genetics, an online resource (free registration needed) for finding companies offering specific genetic tests launched in 2010, was significantly more likely to be used daily/frequently by genetic counselors working 0–5 years (33%) than those working 6+ (18%). There were also several significant differences in resources used daily/frequently when comparing the patient interaction and no patient interaction groups, including disorder-specific/patient organizations (48% vs. 26%). There were also commonalities: Internet search engines, GeneReviews, patient medical records, PubMed, genetic counselor coworkers, and Genetics Home Reference were used daily/frequently across most of the genetic counselor subgroups analyzed. However, significant differences were also found in this group of resources, in that significantly fewer solo genetic counselors used genetic counselor coworkers frequently and significantly fewer genetic counseling students used patient medical records frequently.

Resources frequently rated as ‘never used’ across the whole sample included h-GCAT (39% of total sample reported never used), several book titles including Oxford Desk Reference: Clinical Genetics & Genomics and Ethical Dilemmas in Genetics & Genetic Counseling (for each, 44% never used), and the London Medical Databases (45% never used). Twenty resources had significant differences when analyzing the ‘never used’ response across subgroups. More than a third of genetic counseling students (37%) indicated they never use POSSUM, while only 12% of genetic counselors said the same (p < .0001),
suggesting that practicing genetic counselors use POSSUM at least occasionally. There was also a significantly higher proportion of genetic counseling students compared to genetic counselors who never use UCSC Genome Browser (14% vs. 1%, \( p < .0001 \)), UpToDate (16% vs. 3%, \( p = .0005 \)), and Smith's Recognizable Patterns of Human Malformation (12% vs. 1%, \( p = .0007 \)).

Respondents shared a variety of additional resources used as ‘other’ free-text. Other colleagues were the most frequently reported, with 25 respondents entering one or more types. Nurses (including nurse practitioners) were mentioned 14 times. Other colleagues mentioned multiple times included dieticians, ‘MFM’ (presumably maternal–fetal medicine physicians), sonographers, laboratory technicians, and social workers. Other resources mentioned multiple times included the books Sanders’s Structural Fetal Abnormalities and Schneiders’s Counseling about Cancer, and the genetic databases Alamut, DECIPHER, and ExAC/gNOMAD. A complete listing of the ‘other’ free-text resource responses can be found in Table S3.

### 3.3 Situations

#### 3.3.1 Information needs

For each of the 16 possible situations included on the survey, over 50% of respondents across the entire sample indicated that ‘yes’ or ‘maybe’ information would be needed (Figure 2). The situations ‘helping with the development of new genetic tests’ and ‘presentations for healthcare professionals’, neither of which involve direct patient care, had the highest percentages of respondents indicating ‘yes’, information would be needed (96% for both). Additionally, 100% of respondents indicated either yes or maybe when seeing ‘patients with conditions not counseled on within six months’, as well as for ‘helping with the development of new genetic tests’. The percentage of those who indicated no information would be needed ranged from 0% to 29% across all situations, with the largest proportion indicating no information would be needed for negative/normal genetic test results.
The time needed to find information across all respondents varied by the specific situation (Figure S2). The situations 'development of new genetic tests' and 'presentations for healthcare professionals' had the highest percentages of >10 hr responses with 72% and 30% of all respondents indicating that option, respectively. Notably, these were also the situations with the highest percentages of respondents indicating information would be needed (and neither situation involves direct patient care). Meanwhile, although 'counseling patients on conditions often counseled on' and receiving a 'negative/normal result' had the highest percentages of respondents indicating no information would be needed (12% and 29%), for those who would or might need information, 81% and 65%, respectively, indicated that <1 hr’ would be enough for retrieving it.

### 3.3.2 | Barriers to information

The barriers faced by respondents in getting information also varied by the specific situation (Figure 3). Across all the situations,
8%–49% of respondents chose multiple barriers, while 23%–72% of respondents had ‘no problems’, depending on the situation. Not having enough time was a common barrier across all situations. Another common barrier was not being sure of the appropriate source of information. Across the whole sample, 72% indicated no barriers for negative/normal results, 64% indicated not having enough time to
find resources when counseling patients with conditions not coun-
seled on within 6 months, and 60% indicated not sure of the ap-
propriate resource when counseling patients from different cultural
backgrounds.

Box and whisker plots were used to compare barriers across all
situations for genetic counselors versus. genetic counseling stu-
dents and genetic counselors who interact with patients versus.
those who do not (Figure 4); statistical analysis was not performed.
Genetic counseling students appeared less likely to choose ‘no prob-
lems’, more likely to face any of the given barriers, and more likely
to choose multiple barriers than genetic counselors. Genetic coun-
seling students were also more likely to choose the barrier ‘not sure
of the appropriate resource’. Meanwhile, genetic counselors were
similar in the percentages of respondents having no problems or
multiple barriers regardless of patient interaction. Genetic counsel-
ors who do not interact with patients appeared more likely to face
issues with availability, knowing how to access, and knowing how to
use resources.

Respondents were asked to share comments about times they
were unable to get the information wanted; 31 respondents did so.
Twenty-two of the comments related to access to information. As
one respondent wrote, ‘It is extraordinarily frustrating to not have
access to any literature that is not open source. I always wonder
if there is new information I am missing that would benefit my pa-
tients’. Genetic counseling students and new genetic counselors
also expressed fears about losing access: ‘I work for a private clinic
and when my access to my Grad school university expires, I will no
longer have access to MANY journals and articles’. There were also
a few comments that spoke to not finding the right resource. One
student wrote ‘I was unaware of where to find information for a
presentation, but when I asked my director she pointed me to the
Sutherland book which had exactly what I needed, so it’s more just
learning which resources to turn to for what’. A genetic counselor
shared that ‘One area that I feel there may be a lack of access (or I
may not know where to access this information in a meaningful way)
is in pharmacogenetics’.

4 | DISCUSSION
This project was a broad, exploratory study, meant to uncover pat-
terns, generate additional hypotheses, and identify areas of further

![Figure 4](image-url)
exploration around the concepts of genetic counseling information needs and information-seeking behavior. It also provides some initial insights into differences within specific genetic counseling subgroups. Although these results are a first look at genetic counseling information needs and seeking behaviors and there are several limitations, they may point to some possible practice implications as well as new research questions.

4.1 | Practice implications

4.1.1 | Information needs

The situation-based questions explored genetic counseling information needs in direct as well as indirect (such as in a laboratory setting) patient care, and in support of education. It is telling that across all the situations more than half of respondents indicated ‘yes’ or ‘maybe’ information is needed. Although it would be impossible to capture every possible genetic counseling situation, these results support the idea that genetic counseling is an information-intensive field, where additional resources are often necessary for decision making. These results are also in concordance with the more targeted study of cancer genetics counselors’ information needs in the context of VUS reports, which found additional information was often desired (Scherr et al., 2015).

These findings also fit with the results of the studies that found additional information is often needed by various types of healthcare providers and that differences in the type of information needs that came up can vary even within a given profession (González-González et al., 2007; Gorman, 1995; Osheroff et al., 1991; Shafi & Wani, 2011). When justification is needed for information resources and services, these studies contribute to the evidence base. Similarly, our results may help justify providing organizational support for genetic counseling, which could take the form of better access to resources, training in how to use those resources, and quality-improvement projects around integration of information resources into workflows, such as the automated alert systems for genetic counselors identified by Olmstadt & Anderson (2005).

4.1.2 | Information-seeking behavior

The results from this research demonstrate differences within the genetic counseling field in terms of information-seeking behavior/resource use. Although our sample was a small percentage of the profession, and we did not analyze every possible comparison, these differences suggest generally that there may be opportunities for optimizing information seeking. For example, organizations may be able to save money by reviewing resource purchases that are not heavily used, or having libraries purchase single copies for multiple individuals’ occasional use. There may similarly be value in prioritizing accessibility of ‘top resources’ in certain settings, such as creating a shortcut within the electronic medical record to risk assessment tools in cancer clinics or purchasing the e-book version of a fetal anomalies text for a group of prenatal counselors. However, it is important to note that there may be additional reasons why genetic counselors are not using a certain resource, such as accessibility or not knowing about its existence, and it is important to consider those reasons before making resource allocation decisions. There may be opportunities in this area for targeted education services, for instance from a librarian. Understanding that there are differences in resource needs may be especially helpful to settings hiring new genetic counselors, and for new and existing genetic counseling training programs, as our results frequently found significant differences in resource use for genetic counseling students and for genetic counselors working 0–5 years.

The results of this research also provide some support for our suspicion that genetic counselors and genetic counseling students frequently use colleagues (including both other genetic counselors and other healthcare providers) as information sources, a behavior also reported in the physician and nurse literature. It may therefore be helpful to look at research on other healthcare professions’ use of colleagues to identify potential weaknesses and opportunities in genetic counseling. For instance, nursing research has shown that evaluation of the college may have more weight than the evaluation of the provided information (Marshall, West, & Aitken, 2013). Genetic counselors and genetic counseling students may similarly need to be aware of inclinations to trust a colleague without verifying/updating the provided information. On the other hand, there may be an opportunity in recognizing the importance of interdisciplinary communication skills and having opportunities to ask questions of colleagues within genetic counseling. Genetic counselors who do not have the same breadth of colleagues on site to consult (such as those in solo or rural settings) may benefit from having organizational support to maintain extended professional networks, specifically for accessing valuable information.

The barriers, or lack thereof, to getting information are also a component of information-seeking behavior, and this study suggests differences in the barriers seen in different genetic counseling situations. For some situations, including negative/normal results and presentations to the general public, most respondents indicated no problems. However, each situation had at least 18% of respondents indicating at least one barrier. Prioritizing the alleviation of more common barriers, such as lack of time, may have large impacts across many genetic counseling situations, although addressing this particular barrier may be challenging. Another approach may be tackling easier to remedy barriers first, such as enabling access to frequently used resources. The value of focusing on barriers with more feasible remedies is supported by the data from this study, which suggests that many types of situations may be positively impacted no matter what barrier is being addressed.

While these results cannot be used to predict specific interventions’ ability to successfully reduce or eliminate these barriers, identifying issues may still be useful for exploring what has been done in other contexts and to brainstorm creative solutions. For instance, research has shown that the implementation of
infobuttons, or 'context-sensitive knowledge links' (Cook, Teixeira, Heale, Cimino, & Del Fioro, 2017, p. 460–461), within electronic medical records may save physicians' time and may do the same for genetic counselors. The lack of time may also be an opportunity for libraries seeking to support their organization's genetic counseling users through services such as literature searches, setting up journal article alerts, and providing clinical medical librarian services such as attending case conferences (Kliegman, Ruggeri, & Smith, 2017). For issues around resource access, working with libraries to support institutional access and to connect with existing interlibrary loan structures, such as the National Library of Medicine's DOCLINE service, may be helpful (National Library of Medicine, 2003).

4.2 | Study limitations

A major limitation of this research was the low response rate, which impacts how generalizable the results are. This may have been partially due to the timing of the survey around the winter holidays. Recruitment issues may have also been at play. While all genetic counseling program directors received the request to forward the survey to students, there was no confirmation from individual programs that this was done. The complete lack of Region 5 genetic counseling students and Region 1 genetic counselors in the dataset was particularly noticeable. However, the respondents' distribution across other genetic counseling demographics as noted in the results can be used to support the use of this sample as a limited representation of the genetic counseling profession in the United States.

The length of the survey may have contributed to the lower response rate. While many respondents completed the survey in under 20 min, there were many free-text questions that may have lengthened the time for some. There were 312 surveys not 'finished' and therefore not included in this analysis, suggesting that many individuals partially completed the survey before stopping. There is also a limitation in the analyses of the data because no corrections were made to account for the multiple statistical tests, increasing the potential for substantial type I error. However, the analyses were done from the perspective that each resource and each situation was independent for each pair of comparisons, and the authors chose to reduce type II error in favor of identifying significant results to potentially explore further with additional, targeted research (Streiner & Norman, 2011).

It is also worth noting that while the survey was piloted with a small test group to help identify language that was confusing or frequently misunderstood, respondents may have interpreted questions in ways not intended, affecting their responses. However, there was a conscious decision to leave questions open to some interpretation, to allow for the development of new, potentially more focused hypotheses from this broad exploratory research. Finally, it was impossible to include every resource used or possible situation where information is needed in genetic counseling and those chosen for inclusion on this survey may reflect the authors’ own biases and experiences.

4.3 | Research recommendations

The results of this study led to some specific observations around the information needs and seeking behaviors of genetic counselors and genetic counseling students, and there is potential for many more. Additional, deep analyses focused on a specific genetic counseling subgroup such as students or cancer counselors, for example, may uncover additional lessons to be learned. The amount of time students spend getting information and whether there are differences between subgroups of students, or exploring the specific barriers to access that cancer counselors face and whether they are more likely to hit certain barriers for certain situations could be further explored, possibly with the dataset generated by this project (Donahue, Hall, Petty, 2018). Another project specifically using this data would be to thoroughly analyze the qualitative data from a set of responses to vignettes where respondents were asked to describe, using free text, the types of information they would need in certain scenarios, why it is needed, and how they would get it. This analysis may offer more specific information about the types of information genetic counselors feel is needed, and why, and provide more insight into how systems, services, and resources could meet those needs.

Beyond further analysis of this project's or a similarly collected cross-sectional dataset, additional research is needed to explore genetic counseling information needs and information-seeking behaviors in depth. (This research should also address the limitations described above.) For example, while our survey asks about hypothetical situations and scenarios based on our expertise, additional observational studies are needed to capture the information needs and seeking behaviors that actually occur in genetic counseling settings, and to see how our profession compares to physicians’ average of 5 clinical questions per patient (Osheroff et al., 1991). We also intended that the results from this initial study be used to generate hypotheses around interventions and outcomes. We envision research that, for instance, explores whether education on specific resources can help remove barriers around finding and using them or whether having a genetic counseling liaison librarian for literature searches and setting up automated alerts saves time. Ultimately, we hope that a better understanding of genetic counseling information needs and information-seeking behaviors will lead to improvements in our practice, and eventually to better patient care.

AUTHOR CONTRIBUTIONS

A.D. selected the project topic and performed the initial literature searches. A.D., E.P., and A.H. contributed to the design and implementation of the survey. A.D. was responsible for working with the biostatistician and the analysis of the results with guidance from A.H. and E.P. A.D. drafted the manuscript and addressed revisions;
A.D., E.P., and A.H. discussed the results and commented on the manuscript.

ACKNOWLEDGEMENTS
This research was conducted to fulfill a requirement for the Master of Genetic Counselor Studies graduate program at the University of Wisconsin School of Medicine and Public Health (UW-SMPH). The authors would like to thank Kathel Dunn and Christopher Hooper-Lane for their library science expertise and contributions to this project; Victoria Rajamanickam for her assistance with the statistical analyses; Catherine Reiser and Jessica Tarnowski for their guidance and help testing the surveys; the UW-Madison SMPH Department of Pediatrics for financial and biostatistical support; and the genetic counselors and genetic counseling students who participated in this research.

COMPLIANCE WITH ETHICAL STANDARDS
Conflict of interest
AED, ALH, and EZP 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 (5). Informed consent was obtained from all participants included in the study.

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

DATA AVAILABILITY STATEMENT
Data collected for this study are available through the publicly available repository MINDS@UW. The data file is available at http://digital.library.wisc.edu/1793/78637.

REFERENCES


SUPPORTING INFORMATION
Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Donahue AE, Hall AL, Petty EM. An exploration of genetic counseling information needs and information-seeking behaviors. J Genet Couns. 2020;00:1–12. https://doi.org/10.1002/jgc.1210