

Does Supply Equal Demand? The Workforce of Direct Patient Care Genetic Counselors in Wisconsin

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ABSTRACT

Background: Recent studies documented a shortage of direct patient care (DPC) genetic counselors in the United States. We aimed to survey genetic counselor members of the Wisconsin Genetic Counselors Association (WIGCA) to determine if the supply and demand was met within the state and where access to services can improve.

Methods: An email invitation was sent to all genetic counselor members of the WIGCA with a link to a confidential online survey. Survey questions addressed the workforce composition, elements that impact services, and professional satisfaction of practicing genetic counselors.

Results: The Wisconsin workforce currently has half of the projected need for full-time DPC genetic counselors. One-third of genetic counselors reported changing from direct to non-direct patient care positions. In-person services are concentrated within Milwaukee and Madison. Appointment wait times are decreased when patients meet with a genetic counselor only, and half of the genetic counselors reported moderate to high stress levels.

Discussion/Conclusion: A shortage of DPC genetic counselors in Wisconsin is confirmed due to the total full-time effort in direct patient care. Data provided here can be used to identify targets for increasing the number of DPC genetic counselors, maximizing time spent on patient care, and improving access.

BACKGROUND

As scientific knowledge regarding genetic conditions advances, the role of a genetic counselor has become increasingly important for understanding patient diagnoses and treatments. With new discoveries of disease-causing variants comes an increased demand for clinicians who know how to interpret genetic information.¹

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The growth of medical genetics in the new precision medicine era demonstrates the need for genetic counselors in patient care across specialties.² Genetic counseling has evolved out of primarily obstetrics, pediatrics, and oncology into specialties such as neurology, cardiology, endocrinology, and more. These roles allow for collaboration with physicians and advanced practice providers to guide genetic testing options and result interpretation, along with follow-up with proper treatment and management of genetic disease.² However, despite this recent collaboration, the most impactful barrier to patient care was the inaccessibility to a genetic professional.³ An imbalance in the workforce supply and demand may compromise patient care by contributing to increased appointment wait times and decreased access to services.

The National Society of Genetic Counselors (NSGC) defines direct patient care (DPC) as follows “a role that primarily involves counseling patients,” including case preparation, service delivery, and follow-up.⁴ Non-direct patient care, according to the group, is “a role that does not involve counseling patients.” Examples of non-clinical work include laboratory involvement, teaching, marketing, and administrative roles.⁴

The 2019 NSGC Professional Status Survey (PSS) documented that the most common work environments for genetic counselors are university medical centers, public hospitals, and diagnostic hospitals.⁵ Cohen and Tucker described a migration within the current workforce, wherein DPC genetic counselors are moving to non-DPC settings,¹ with the majority of non-DPC genetic counselors working in commercial laboratories.^{5,6} This migra-

tion is significant enough that, despite an increasing number of new genetic counselors entering the workforce, the proportion of genetic counselors in DPC settings decreased by nearly 40%, whereas genetic counselors in non-DPC settings increased by 130% within 2 years.¹ The authors suggest the reasons for this shift are related to salary and benefits, lack of feeling valued, and stressful work environment.¹

The burden to meet a growing clinical demand is placed on the genetic counselors who remain within the DPC workforce.⁷ Workforce supply and demand models from Dobson and DaVanzo provided an assumption that there should be 1 full-time equivalent (FTE) DPC genetic counselor for every 75,000 individuals in the population. The Census Bureau of Wisconsin reported a population of 5.8 million in 2018, which suggests a need for 77 FTE DPC genetic counselors in the state.⁶ A workforce study administered by the 2019 NSGC PSS to evaluate the genetic counseling workforce across the United States suggested that Milwaukee had relatively fewer genetic counselors (1.0%, n = 25/1,334) than 27 other US Metropolitan Statistical Areas.⁴ The Wisconsin genetic counselor workforce has not been further described in the medical literature. Our study aims to provide a thorough and detailed landscape characterizing the DPC genetic counselor workforce in the state, their experience, and access to services.

METHODS

Participants and Instrumentation

Participants were recruited from the genetic counselor membership of the Wisconsin Genetic Counselor Association (WIGCA) via email with a link to a confidential, online survey. The Institutional Review Board at the Medical College of Wisconsin determined the survey met criteria as a minimal risk project and approved the study with an informed consent process utilizing an informational letter (approval #PRO00033533). The survey design used Qualtrics (qualtrics.com, 2019) and was open for 2 weeks, with a reminder email sent after the first week. A workgroup of the WIGCA communications committee determined survey design and purpose by reviewing previous literature.^{1,4,5,8,9} The survey was modeled after similar studies designed to characterize the genetic counselor workforce in other states and consisted of 38 multiple choice and open-ended questions (Appendix A). Broad thematic areas were covered, including credentials, years of experience, institutional setting, job roles, and specialty area. A secondary study by Cohen and Tucker and the NSGC PSS influenced questions related to service elements, such as delivery model, location of services, patient volumes, appointment wait times, job responsibilities, utility of a genetic counselor assistant, job openings, and professional satisfaction.^{1,4,5,8,9} Open-ended questions allowed for participants to provide personalized responses. Responses were not required for every question, and some questions allowed for more than

Table 1. Demographics of Wisconsin Genetic Counseling Workforce

	Total FTE in Wisconsin	Total Direct Patient Care FTE	Total Non-Direct Patient Care
FTE (n=73)	67.85 (100%)	37.18 (55%)	30.67 (45%)
Certification	% (N=73)	Experience	% (N=73)
CGC	78% (n=57)	<1 year	8% (n=6)
LCGC	12% (n=9)	1-4 years	22% (n=16)
CGC and LCGC	6% (n=4)	5-9 years	25% (n=18)
Board eligible	4% (n=3)	10-14 years	18% (n=13)
No board certification	0% (n=0)	15-19 years	15% (n=11)
		20-25 years	5% (n=4)
		25+	7% (n=5)
Work Environment			% (N=73)
Hospital (state/local/private)			37% (n=27)
University/academic medical center			29% (n=21)
Laboratory (medical or diagnostic)			23% (n=17)
Other			11% (n=8)

Abbreviations: FTE, full-time equivalent; CGC, certified genetic counselor, LCGC, licensed certified genetic counselor.

Table 2. All Genetic Counseling Full-Time Equivalents (FTE) by Specialty

Specialty	Total FTE	% of Total FTE
Cancer	14.5	21%
Prenatal/reproductive	9.96	15%
Pediatrics	6.74	10%
Other clinical specialty	2.46	4%
Cardiology	1.53	2%
General adult	1.01	1.5%
Neurogenetics	0.73	1%
Newborn screen/metabolic disease	0.45	0.7%
Non-DPC specialty breakdown		
Lab	8.54	13%
Other non-DPC	16.4	24%
Education	3.29	5%
Administration	2.27	3%
Public health	0	0%
	New	Established
Average patient volumes per month		
DPC patient volume	47	8
Patient volumes per specialty		
Pediatrics (n=1)	21	16
Cancer (n=14)	33	8
Prenatal (n=5)	42	4
Multiple (n=38)	56	8

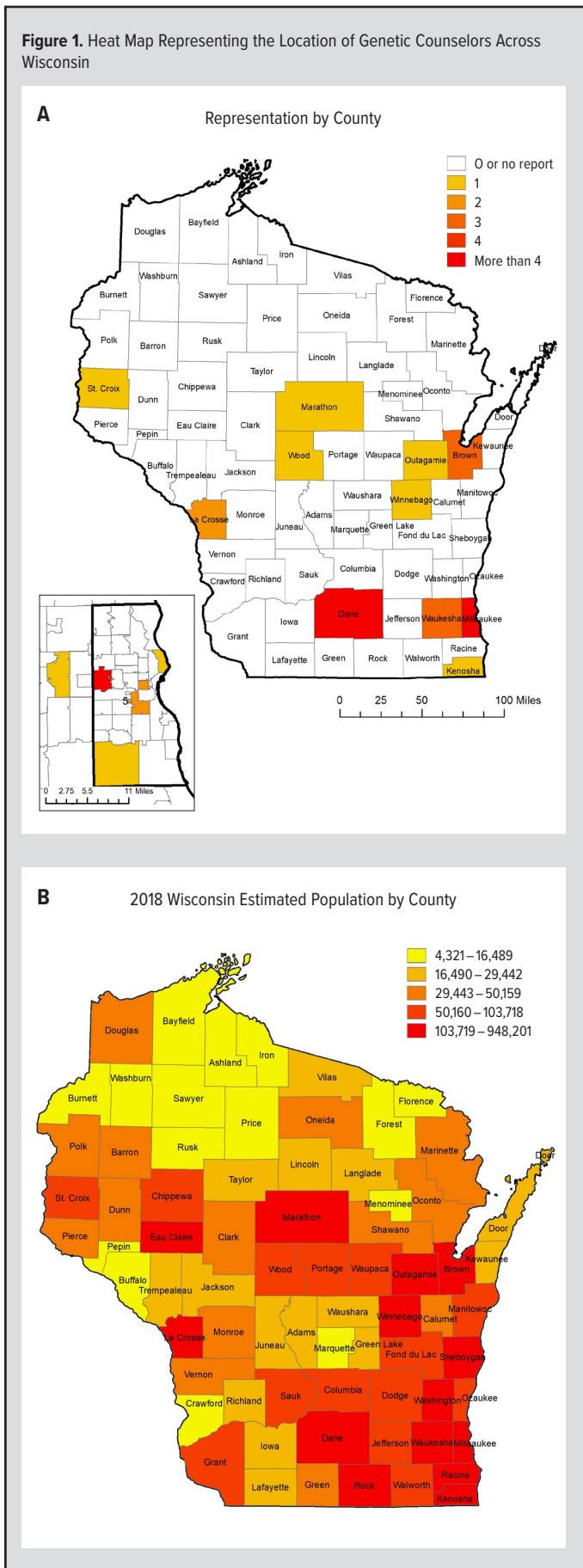
Abbreviation: DPC, direct primary care.

one option to be chosen; this is demonstrated by the different sample sizes encountered during analysis. The survey was piloted by members from the WIGCA workgroup, and revisions were made from the group's collective feedback. Time to complete the survey was estimated at 15 minutes.

Data Analysis

Analysis of all close-ended question responses (total numbers, percentages, and means) was performed using the Qualtrics Survey Software. In several close-ended questions, respondents

Figure 1. Heat Map Representing the Location of Genetic Counselors Across Wisconsin



were able to select “other” and fill in their personal response. Open-ended survey questions were not analyzed as they did not fit the scope of this manuscript. Maps were created using ArcGIS ArcMap, (version 10.5.1, ESRI @2017). The ZIP Code Tabulation Area (ZCTA) borders, Wisconsin counties’ borders, and state border shapefiles were obtained from the US Census TIGER/Line files. The Milwaukee County border shapefile was downloaded from the Milwaukee County Land Information Office Open Data files.

RESULTS

Composition of the Wisconsin Workforce

The 107 genetic counselor members in the WIGCA are thought to represent all genetic counselors living or working in Wisconsin. A total of 73 individuals completed the survey, with a total response rate of 68% (n=73/107). Demographic results are detailed in Table 1.

Participants were asked to divide their total FTE between their time as DPC and non-DPC. The FTE was determined on a scale of 0.0 to 1.0 with 1.0 FTE=40 hours a week, and 0.1 FTE =4 hours a week. Table 1 shows the total FTE of 67.85, comprised of both DPC (37.18 FTE, 55%) and non-DPC (30.67 FTE, 45%). These values reflect the FTE noted from respondents who split their FTE between DPC and non-DPC.

The majority of respondents are certified genetic counselors by the American Board of Genetic Counseling (96%, n=70/73). The remaining 4% (n=3/73) of respondents are board eligible. Wisconsin genetic counselors have experience ranging from less than 1 year to over 25 years. The experience range with the highest response rate is 5 to 9 years (25%, n=18/73). Respondents reported working mostly in one of three settings: a hospital (state, local, or private) (37%, n=27/73), an academic medical center (29%, n=21/73), or a laboratory (23%, n=17/73). Other environments included office of a physician, private practices, pharmaceutical companies, and professional organizations (11%, n=8/73). Additionally, 23% (n=17/73) of Wisconsin genetic counselors report always working remotely, while 56% (n=41/73) report never working remotely.

Factors That Impact Services

Service Model and Distribution

The survey results show that the majority of genetic counselors provide their services through in-person sessions (67%, n=48/72) versus an alternative service model, such as telephone consultation (7%, n=5/72), virtual (1%, n=1/72), and group session (0%, 0/72). For these particular data, 25% (n=18/72) of respondents indicated that they did not provide DPC.

Participants that provide DPC were asked to categorize their FTE by practice specialty and the ZIP code where their largest patient population receives genetic counseling services. In addition, each respondent’s FTE was divided by their time spent in

each specialty. These data, represented in Table 2, demonstrate the highest FTE in cancer (14.5 FTE), followed by prenatal/reproductive (9.96 FTE), and pediatric (6.74 FTE) specialties. Data also shows that genetic counselors are involved in a variety of specialties and roles; a total of 62% (n=45/72) of respondents divide their time across two or more specialties. Access to genetic counselors in specialties for pediatrics, cancer, and prenatal are located on maps in Appendix B.

Respondents provided the ZIP code for which they service most of their patients; 23 of the 709 Wisconsin ZIP codes were identified. They also reported servicing the bulk of their patients in Milwaukee (37%, n=19/52) and Madison (31%, n=16/52). Figure 1A shows the location of services across the state; 11 out of 72 (15%) counties have access to one or more genetic counselors, while the remaining 61 (85%) have none. Figure 1B shows the estimated populations across Wisconsin counties. Using this map, the Dobson and Davanzo model can be used to calculate the needed clinical demand of DPC genetic counselors within each county.

Patient Volumes

Patient volumes were totaled for genetic counselors practicing within the 3 main genetic counseling specialties (pediatrics, prenatal, and cancer), revealing an average of 55 patients a month per genetic counselor (Table 2). Most respondents provided services across multiple specialties and were grouped together as “multiple;” they tended to see the largest number of patients. This became a limitation as many respondents reported working in multiple specialties.

Time Spent on Case Management

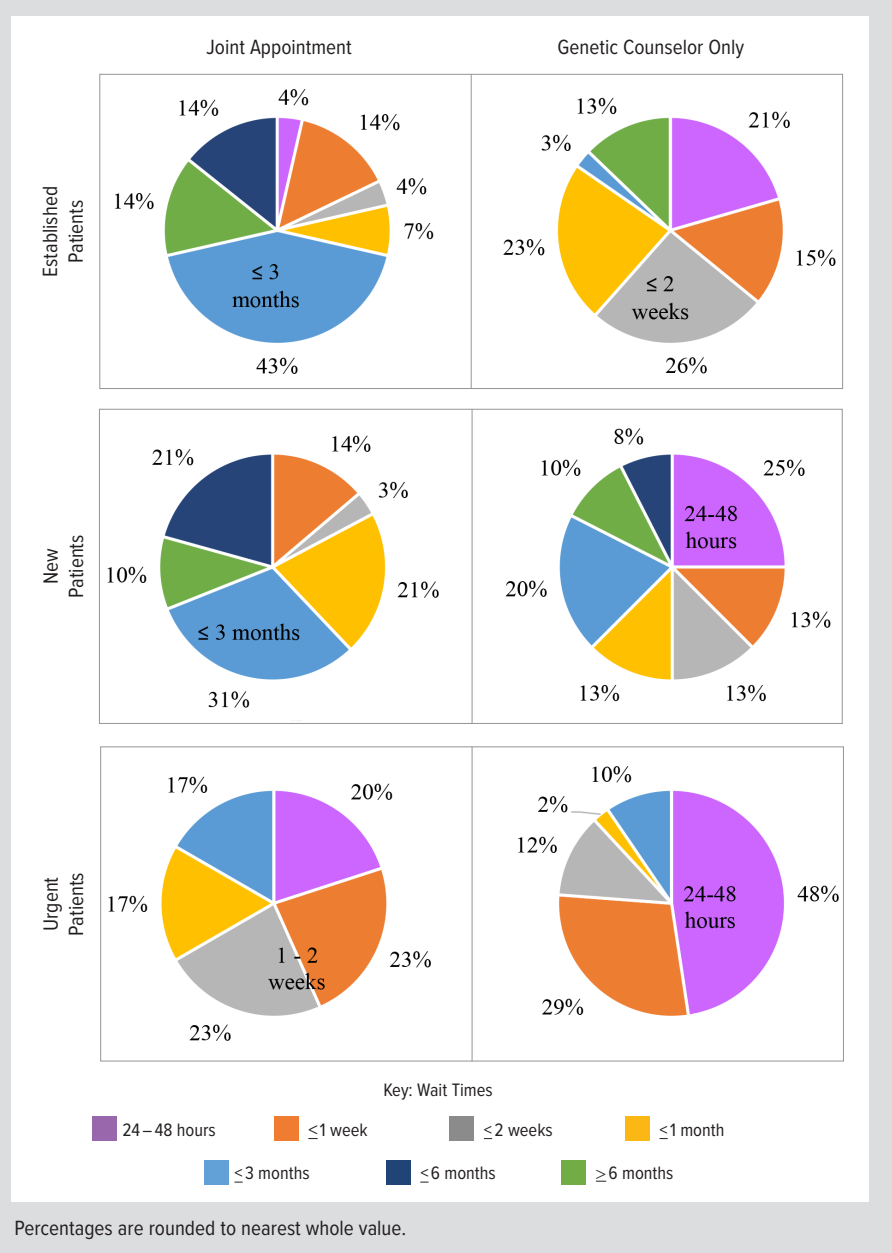
The time spent preparing for a patient’s visit by 64% of respondents (n=30/47), ranges between less than 15 to 30 minutes. The mode of genetic counselors spends 31 to 45 minutes in a patient session (41%, n=20/49). Lastly, respondents spend time on follow-up tasks that ranged from 15 minutes to 2 hours. Although all responses fell within a wide range, most responses fell within 31 to 45 minutes following up with a patient’s case (26%, n=11/43). Respondents were not able to divide their time if they provided care in multiple specialties; therefore, time spent on case manage-

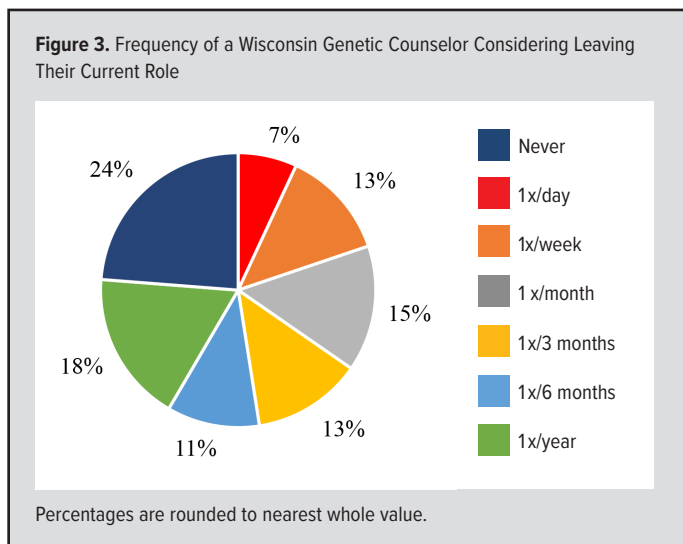
ment could not be divided by specialty and is generalized across all specialties.

Physician or Advanced Practice Provider Involvement and Appointment Wait Time Comparison

Respondents estimated appointment wait time across all visit types. Urgent visit types are for patients who may need testing to determine surgery, treatment, or have a rapidly developing condition. New patient visit types are for those seeking known family variant testing or genetic confirmation on a suspected diagnosis, risk assessment, and other routine indications. Established visits are for patients who seek additional testing, management, or follow-up. Summarized in Figure 2, appointment wait times

Figure 2. Appointment Wait Times for Genetic Counseling Only Appointment vs Joint Appointment With Physician/Advanced Practice Provider for Established, New, and Urgent Patients





decreased to 2 weeks or less when patients met with a genetic counselor only, instead of a joint appointment with a genetic counselor and a physician or advanced practice provider (APP). This was observed for established patients (62%, $n = 24/39$ vs 21%, $n = 6/28$), new patients (50%, $n = 20/40$ vs 17%, $n = 5/29$), and urgent patients (88% $n = 37/42$ vs 67%, $n = 20/30$). Fifteen percent of genetic counselors reported that their patient's appointments are always accompanied by a physician or APP ($n = 8/54$), whereas 37% ($n = 20/54$) never see patients with a physician or APP.

Changing Roles Within the Profession and Professional Satisfaction

Within the WIGCA workforce, 33% ($n = 24/73$) of genetic counselors have left DPC for non-DPC roles, with top reasons including a better salary, desire to change job responsibilities or roles, schedule flexibility, and job dissatisfaction. Only 5% ($n = 4/73$) moved from non-DPC to DPC roles, with the top reasons including desire to change roles, relocation, and job dissatisfaction. Figure 3 shows that 47% ($n = 34/72$) of Wisconsin genetic counselors thought about leaving their current position as often as once a day to once every 3 months, while 24% ($n = 17/72$) never thought about leaving. Survey respondents were asked to rate their stress level as never stressed, mildly stressed, stressed, or highly stressed. The highest percentage reported experiencing mild stress (46%, $n = 31/68$), while 10% ($n = 7/68$) were highly stressed, 40% ($n = 27/68$) were stressed, and 4% ($n = 3/68$) were never stressed. Respondents who chose highly stressed were also among the 48% who thought frequently about leaving their current position.

Support

Respondents reported access to a variety of support staff to assist in tasks, the most common being administrative/office staff (36%, $n = 37/104$). Of the support usage, 14% ($n = 15/104$) said they utilize a genetic counseling assistant, a role designed specifically to help with genetic counselors' administrative clinical tasks. Other

support included medical assistants (12%, $n = 12/104$) and graduate students/interns/volunteers (9%, $n = 9/104$). Another 13% ($n = 13/104$) had access to a medical geneticist for patient management, diagnosis, and treatment. This question allowed respondents to select all applicable support staff, which reflected a higher sample size. Overall, 60% of genetic counselors who responded to the survey are utilizing some form of support, while the other 40% ($n = 29/73$) declared they do not have support or did not answer the question.

DISCUSSION

To our knowledge this is the first comprehensive genetic counseling workforce study specifically completed for the state of Wisconsin. Results support evidence from previous literature that there is a deficit between the current supply of genetic counselors and the increasing demand for genetic counseling services. The number of respondents to this study ($n = 73/107$) exceeds the participation from Wisconsin genetic counselors in the national PSS ($n = 60$) and, therefore, provides a more comprehensive picture of genetic counseling services in the state.⁹ Collectively, the 73 individual respondents totaled a workforce of 67.85 FTE, with only 55% of the total FTE made up of DPC genetic counselors. This equated to being 55 of the 73 total genetic counselors offering DPC services; however, for some genetic counselors, the FTE was split with non-DPC time. The model provided by Dobson and DaVanzo suggests a need for 77 FTE DPC genetic counselors based on the 2018 Wisconsin population of 5.8 million.⁶ This estimate assumes that 1 FTE DPC genetic counselor is required to service 75,000 individuals. Based on the projected need, Wisconsin has less than 50% (37.18 DPC FTE) of the needed FTE DPC genetic counselors to meet the clinical demand. Thirty-four individuals did not complete the survey. Theoretically, even if those additional responses were counted as 1.0 FTE in DPC time, there would still be a shortfall in Wisconsin of 5.82 DPC FTE.

The DPC FTE values, combined with the location of genetic counselors across the state, confirm a shortage of genetic counselors in Wisconsin. There are concentrated locations of services across the state, with most counties not having access to a single genetic counselor. Distribution maps help patients and providers know where to locate a genetic counselor (see Appendix B).

Distributions from these data highlight increased expansion of cancer genetic counselors across the state. While the 2000 PSS reported prenatal genetic counselors as the most prevalent specialty workforce, these results had changed as of 2019, demonstrating cancer as the most prevalent specialty—and supporting findings reported in Wisconsin.^{4,10}

During the survey distribution in January 2019, only 8% ($n = 6/72$) of respondents reported using a form of telehealth. With the COVID-19 pandemic, however, many clinical services have implemented telemedicine to deliver direct patient care. A

follow-up survey could investigate access to genetic counseling across the state with recent expansion in telemedicine services.

Regarding wait times, the survey showed that appointment wait times decreased when patients visited with only genetic counselors instead of genetic counselors and a physician or APP. This finding identifies a potential opportunity to increase access to genetic services if there are patient types who can be served adequately with a genetic counselor-only appointment. Reasons for including a physician or APP in the appointment may have to do with scope of practice and patient need for clinical exam, diagnostic testing being ordered, and medical management. However, a potential justification for the combined genetic counselor/physician or APP visit may be due to billing and reimbursement concerns.^{11,12} As genetic counselors are not currently recognized as health care providers by US Centers for Medicare & Medicaid Services, reimbursement for services is a continuing issue. Many health systems bill for genetic counseling services under the physician's name using Evaluation and Management (E/M) codes, and often these billing practices require the physician to be present for a portion of the patient's visit.¹²

As genetic counseling becomes increasingly crucial to patient care across specialties, 55% of Wisconsin genetic counselors report being stressed or highly stressed, and many have considered or already have changed roles to non-DPC. Thus, the growing demand of referrals and stress are placed on the 55% of DPC genetic counselors in the state. There are many proposals on how genetic counselors can reduce stress and improve their services and efficiency. Capacity to increase patient volumes may be realized by having genetic counselors work to their highest scope of practice, which can be achieved by increasing support personnel to assist with case management.⁷ Pirzadeh-Miller et al first described the role of genetic counseling assistants as including administrative tasks, constructing pedigrees, completing test requisition forms, packaging genetic test kits, assisting with clinic flow, contacting insurance companies, and research activities; this allowed genetic counselors to increase efficiency and patient volume by up to 60%.¹³ Implementing genetic counseling assistants into the clinic workflow may decrease genetic counselors' case preparation and follow-up time, so that they are able to maximize their skill set, work to the top of their scope of practice, and also reduce stress.

To moderate the effects of a genetic counselor workforce shortage, partnerships between other medical providers and genetics providers are important for proper referrals and utilization of genetic information. Maise et al reported that patient wait times and patient caseloads have increased while the genetic workforce has not.¹⁴ Unmet demand impacts graduate programs lacking clinical sites for student practicum placement, thereby resulting in smaller class sizes and, overall, lower rates of workforce expansion. This is largely because there are not enough clinical genetic counselors to train graduate students, which 94% of program directors indicated is a barrier to expanding their class sizes.¹⁵ Currently in Wisconsin, there is only 1 Masters of Genetic Counselor Studies graduate

training program; it is located at the University of Wisconsin, Madison and accepts 8 students per year. The Medical College of Wisconsin plans to add a genetic counseling graduate training program in Milwaukee within 2 years.

A limitation to this study includes the incomplete response rate; not every Wisconsin genetic counselor responded to the survey. The survey structure also posed a limitation as answers were not required for every question. Therefore, although 73 individuals took the survey, not every question had a sample of 73 responses, resulting in the inability to fully capture the practice. Some respondents reported that they did not provide DPC but divided their FTE into DPC specialties. Those FTE divisions were included in the "other or unspecified" non-DPC specialty as their full FTE. In addition to FTE breakdown, some respondents divided their FTE into DPC and non-DPC time, but then reversed or changed those breakdowns in their specialty division. It is assumed that some respondents did not fully understand the difference in DPC and non-DPC roles and may have included non-face-to-face, patient care tasks as non-DPC time. Another limitation was the inability to efficiently break down themes by specialty to characterize the genetic workforce. Many genetic counselors divided their time between a variety of specialties, making it difficult to efficiently analyze specific patient volumes and time spent of patient-related activities for each specialty. For cancer, prenatal, and pediatric providers patient volumes were assessed for genetic counselors who provide DPC for only 1 specialty, their reported primary specialty. The remainder of the patient volumes were grouped into a category for providers who spread their time across multiple specialties. As a result, patient volumes for individual specialties were underrepresented, and patient volumes for providers in multiple specialties were overrepresented.

CONCLUSION

Our findings show a limited amount of DPC genetic counselors in Wisconsin. This workforce shortage results in long patient wait times and an inequitable distribution of services throughout the state. The data provided identifies and characterizes gaps in the current genetic counseling workforce, including the vulnerability revealed by the large percentage of genetic counselors who reported stress, changing to non-DPC, and the frequency they consider leaving their job. The data can be used to identify targets for increasing the number of DPC genetic counselors, maximizing time spent on patient care, and improving access to all genetic counseling specialties. In addition, this study may provide a template for other states to assess their own supply and demand needs for DPC genetic services.

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