

Practice Characteristics of Genetic Counselors Serving the North American Bleeding Disorders Community

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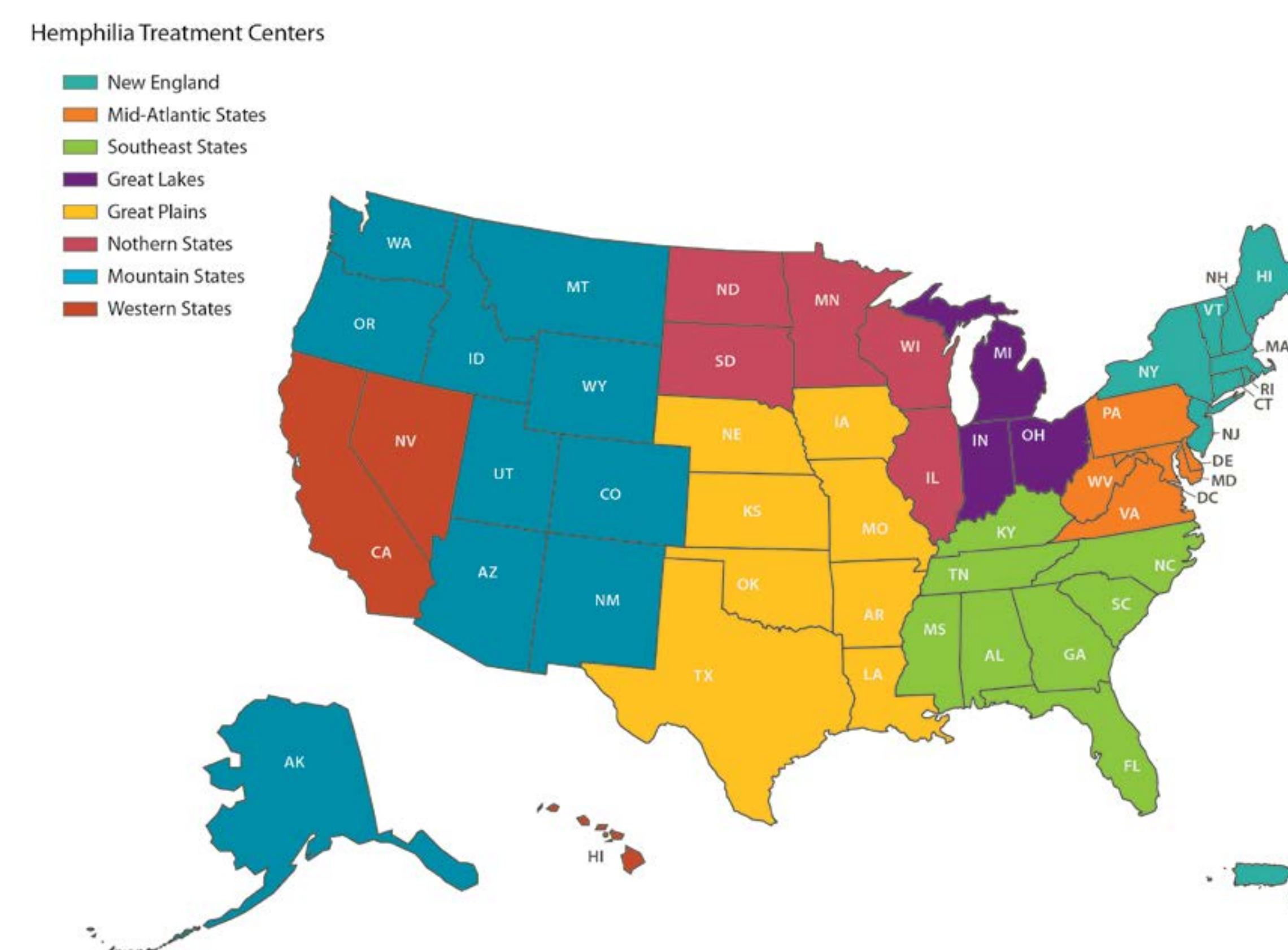
Introduction and Objectives

"Genetic counseling is the process of helping people understand and adapt to the medical, psychological and familial implications of genetic contributions to disease. This process integrates the interpretation of family and medical histories to assess the chance of disease occurrence or recurrence; the education about inheritance, testing, management, prevention, resources and research; and, finally, integrates counseling to promote informed choices and adaptation to the risk or condition" (2013). In the United States, genetic counselors receive a master's degree through an academic program that receives its accreditation through the Accreditation Council for Genetic Counseling. Graduates of an accredited program are required to receive certification through the American Board of Genetic Counseling, whose mission is "to protect the public by setting certification standards and providing leadership to promote the value of certified genetic counselors" and to "promote high standards in genetic counseling" (2013; 2016). Genetic counselors can practice in a wide variety of specialty areas. According to the National Society of Genetic Counselor's 2016 Professional Status Survey, the most common specialty areas are cancer, prenatal, pediatric and general genetics; only 2% of genetic counselors reported working in hematology (2016).

The Genetics Work Group of the National Hemophilia Program Coordinating Center (NHPCC) consists of a multidisciplinary team of genetic counselors, practitioners and consumers. The group was created to identify gaps and barriers to genetic services, to develop strategies to improve genetic services within the Hemophilia Treatment Center (HTC) network and to conduct outreach to genetic counselors not affiliated with HTCs. An HTC is a federally funded comprehensive care clinic serving patients with inherited bleeding disorders. HTCs are multidisciplinary teams, often including hematologists, nurses and social workers. Some HTCs have genetic counselors on staff to provide education to and address the health needs of patients with inherited bleeding disorders and their relatives, while many centers rely on referrals to genetic counselors in outside facilities. The HTC comprehensive care model improves patient outcomes, including improved health, decreased hospitalization and decreased cost of care (Smith and Levine, 1984). The NHPCC, funded by the Health Resources and Services Administration through the American Thrombosis and Hemophilia Network (ATHN), collaborates with regional leadership to support HTCs nationwide to identify gaps in services, barriers to care and national priorities to improve care.

The Genetics Work Group conducted a survey to better understand the practice characteristics of genetic counselors who see patients with a personal or family history of an inherited bleeding disorder at an HTC or other setting and to assess the comfort level of all genetic counselors in counseling individuals for this indication.

Figure 1. Almost 150 HTCs serve over 40,000 patients. The HTCs are divided into eight geographic regions



Materials and Methods

Genetic counselors were invited to participate in an online survey distributed through the American Board of Genetic Counseling listserv and during the 2015 annual education meeting of the National Society of Genetic Counselors. The survey questionnaire included 25 questions and was designed and executed using SurveyMonkey. Data collection occurred from August through October of 2015. Univariate and bivariate analyses were conducted.

Results

142 genetic counselors responded to the survey sent to 3,522 members of the ABGC listserv. Only 18% of the respondents reported counseling patients for inherited bleeding disorders while working within an HTC over the past year. Approximately 55% of respondents reported counseling patients for inherited bleeding disorders outside of an HTC. Of these external genetic counselors, 57% reported seeing these patients in a prenatal clinic, 18% in a genetic services clinic and 14% in a pediatric clinic; 57% have referred patients to an HTC, while 40% did not know the location of their nearest HTC; 77% reported these patients are being referred by obstetrician/gynecologists, 55% by primary care physicians and approximately 27% by hematologists. When asked to rate comfort level in counseling patients and families with inherited bleeding disorders, 19% felt somewhat or very uncomfortable. Approximately 75% of respondents reported interest in receiving further information from the NHPCC Genetics Working Group.

Figure 2. Frequency that genetic counselors reported directing patients seen with an indication of an inherited blood disorder to an HTC

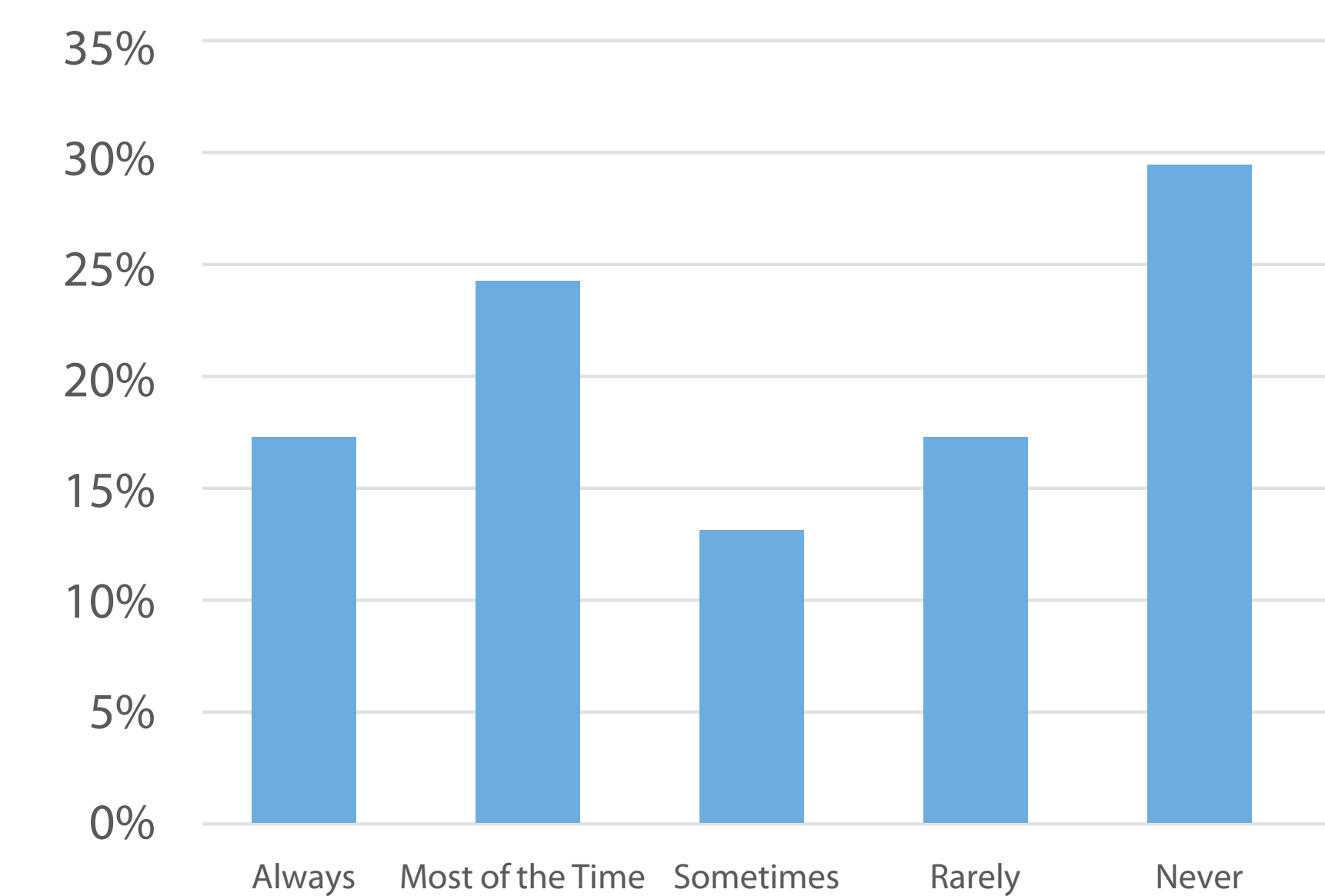


Figure 3. Primary sites outside of HTCs where genetic counselors see patients with an indication of an inherited bleeding disorder

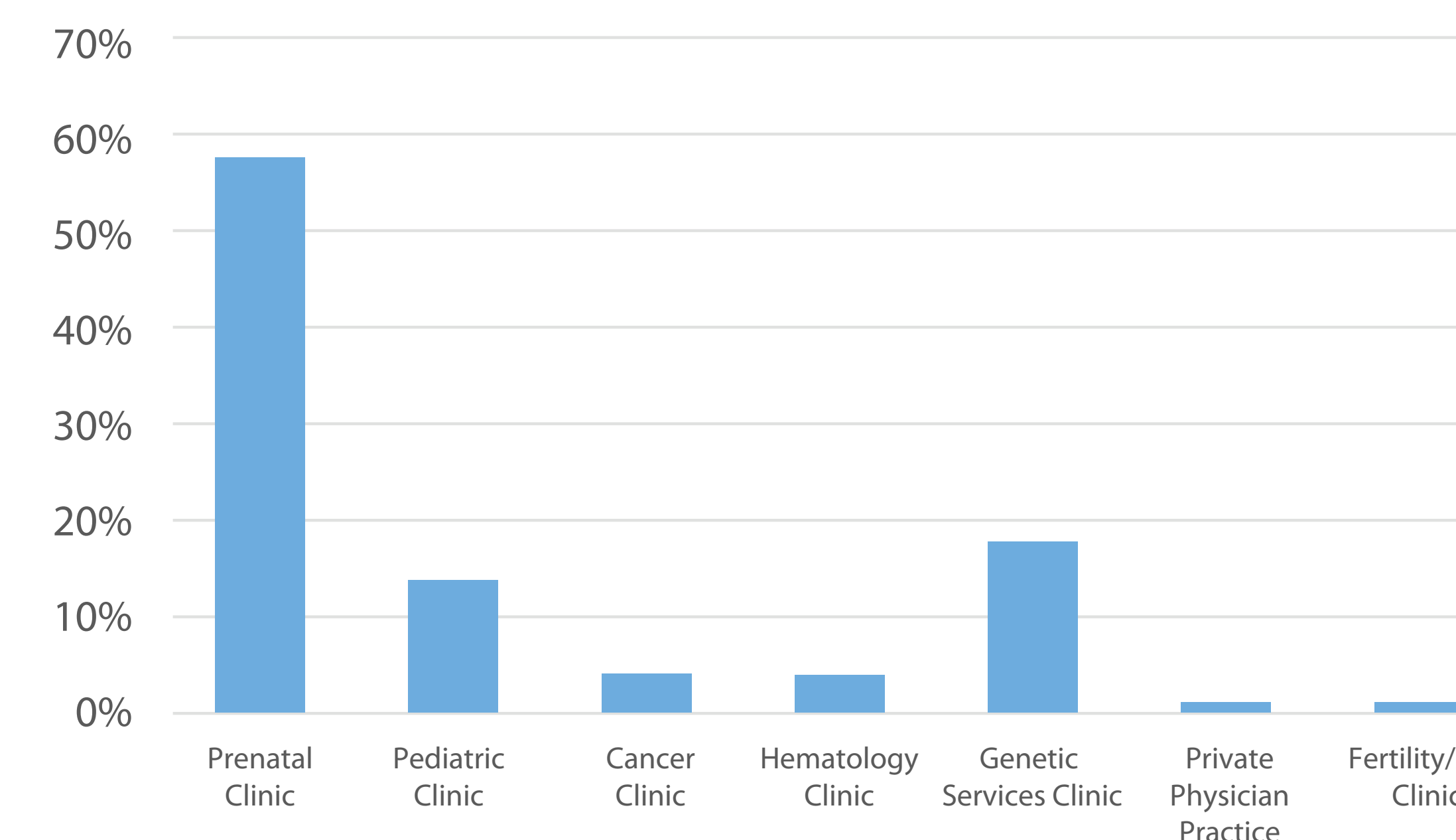
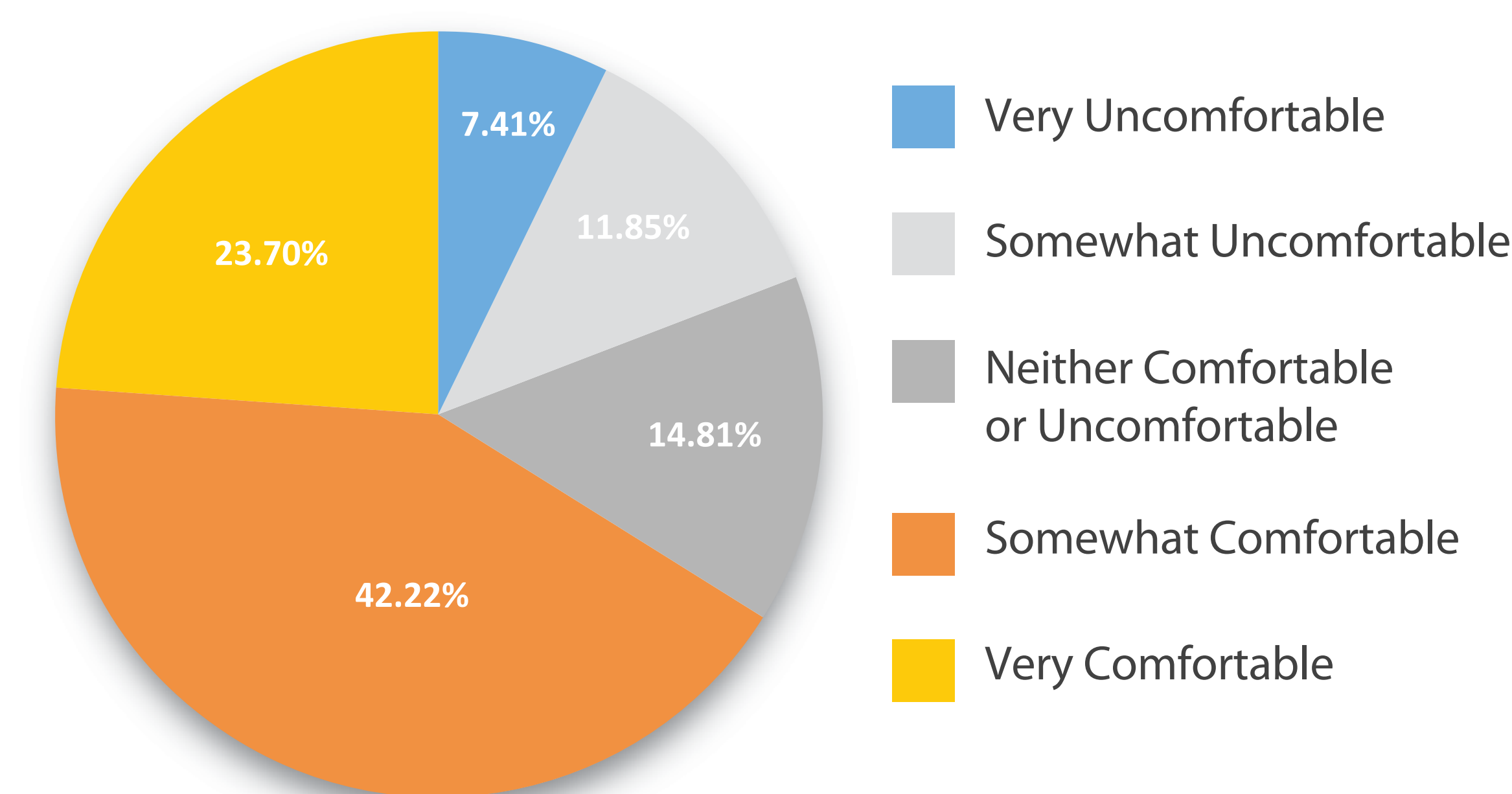


Figure 4. Comfort level rating in counseling patients and families with inherited bleeding disorders



Conclusion

Patients and families with inherited bleeding disorders are seeing genetic counselors outside of HTCs. Some genetic counselors are not comfortable with this indication and may facilitate less-than-ideal coordination of care with HTCs. Educational efforts from the bleeding disorders community should be aimed toward these external providers. In addition to continuing efforts to develop resources to educate providers and patients/families regarding genetic concepts relating to hemophilia, the NHPCC Genetic Work Group plans to take steps to educate the broader community of genetic counselors regarding current hemophilia information.

References

- American Board of Genetic Counseling, Inc. (2013). Retrieved June 6, 2016, from www.abgc.net.
- National Society of Genetic Counselors. (2013). Retrieved June 6, 2016, from www.nsgc.org.
- Accreditation Council for Genetic Counseling. (2016). Retrieved June 6, 2016, from www.gceducation.org.
- National Society of Genetic Counselors. (2016). Professional Status Survey: Work Environment, 1–75.
- Smith, P. S., & Levine, P. H. (1984). "The benefits of comprehensive care of hemophilia: A five-year study of outcomes." *Am J Public Health*, 74(6): 616–617.

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Care Delivery
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