Family Practice, 2025, **42**, cmae057
https://doi.org/10.1093/fampra/cmae057
Brief Report

Expanding the primary care workforce by integrating genetic counselors in multidisciplinary care teams

Rachel Vanneste[1,*,‡], Sasha A. Bauer[2,‡], Kennedy Borle[3], Erika Dreikorn[4]

[1]Division of Medical Genetics, Department of Pediatrics, University of Saskatchewan, Saskatoon, SK S7N 0W8, Canada
[2]Department of Medical Oncology, UW Health Northern Illinois, Rockford, IL 61114, United States
[3]Faculty of Graduate and Postdoctoral Studies, University of British Columbia, Vancouver, BC V6T 1Z4, Canada
[4]Clinical Translational Science Institute, University of Pittsburgh, Pittsburgh, PA 15213, United States

[‡]Both authors contributed equally and are considered co-first authors.
[*]Corresponding author. Division of Medical Genetics, Royal University Hospital, 103 Hospital Drive, Saskatoon, SK S7N 0W8, Canada. E-mail: rdw904@usask.ca

Abstract

Collectively, rare diseases are common, affecting approximately 8% of the population in Canada and the USA. Therefore, the majority of primary care (PC) clinicians will care for patients who are affected or at risk for a genetic disease. Considering the increasing ways in which genetics is being implemented into all areas of healthcare, one way to address these needs and expand the capacity of the PC workforce is through the integration of genetic counselors (GCs) into PC multidisciplinary teams. GCs are Masters-educated allied health professionals with specialized training in molecular genetics, communication, and short-term psychotherapeutic counseling. The current models of GCs in PC mimic other multidisciplinary models. Complex tasks related to genetics, such as pre- and post-test counseling, genetic test selection, and results interpretation, are conducted by GCs, which, in turn, allows physicians, nurse practitioners, and other PC providers to work at the top of their scope of practice. Quality genetics services provided by GCs improve clinical outcomes for patients and their families; the simultaneous provision of genetic education and psychological support by a GC is associated with an increase in patient knowledge, perceived personal control, decrease in distress, and can lead to positive health behavior changes, all of which are aligned with the goals of primary healthcare. With their extensive training in clinical care, medical communication, and psychotherapeutic counseling, integrating GCs into PC care teams will improve the care patients receive and allow PC clinicians to ensure their patients are at the forefront of the personalized medicine revolution.

Keywords: Genetic Counseling; Delivery of Health Care; Primary Health Care; Patient Care Team; Health Personnel; Allied Health Personnel

Introduction

Genetics is an area of healthcare that is ever expanding and is increasingly becoming a part of mainstream medicine [1]. Even though each individual rare disease affects few people in the population, rare diseases are collectively common; it is estimated that approximately 8% of people living in the USA and Canada have a rare disease and up to 80% of these conditions are genetic [2, 3]. As such, most primary care (PC) clinicians (which includes physicians and nurse practitioners in family medicine, internal medicine, obstetrics/gynecology, and general pediatrics) will care for several patients in their practice who either have a rare genetic disease, are at increased risk for health problems with a genetic etiology or are carriers for a genetic disease. To address this, alternative genetics-service delivery models are being considered and implemented in various genetics clinics, including efforts to provide more training and education for PC clinicians to provide genetics services. PC clinicians are often the frontline of healthcare access for many patients, making their offices the first place where patients present with questions or concerns related to genetics [4]. Due to increases in the availability and clinical utility of genetic information, the importance and promise of genomic medicine will continue to be incorporated into PC. Key components of genetics services, such as understanding and taking personal medical and family histories, conducting basic genetic risk assessments, and providing information and support around having a health condition, are important aspects of a PC clinician's role. However, some PC clinicians question whether the act of genetic counseling and ordering genetic testing falls within their scope of practice [5]. It has been discussed that the expansion of PC clinicians' role to include more components of genetics services may increase their medical liability risk [6]. Previous efforts have sought to increase education to address PC clinicians' objective and self-acknowledged lack of confidence and competence needed to implement genetics care into clinical practice [1, 5–7]. Although education can lead to short-term improvements in the appropriate use of genetic services, these behaviors are not typically sustained over time, leading to gaps in genetics care for patients and families [8]. PC clinicians have many competing demands on their clinical time and their continuing education priorities, and models of shared care that allow the formal delegation or allocation of complex and time-consuming tasks related to genetics healthcare to an expert in genetics can increase the quality of patient care while reducing burdens on PC clinicians [5, 7]. Other barriers to expanding the role of PC clinicians, with regard to genomic medicine, and more broadly, include the self-reported lack of time, resources, and support [4, 5]. Logically, there needs to be more support for PC clinicians to help them access quality

genetics services and genetic counselors (GCs) are ideal health professionals to fill this role.

Who are genetic counselors?

GCs are Masters-educated allied health professionals with specialized training in molecular genetics, medical communication, and short-term psychotherapeutic counseling. To work in Canada or the USA, GCs must attain certification by passing a rigorous exam administered by the Canadian Board of Genetic Counselling and/or the American Board of Genetic Counseling. Further, as of June 2024, 35 US states require GCs to apply for state licensure to provide care. Most GCs provide patient care in tertiary care settings, highly concentrated in departments of medical genetics, as well as in various specialty clinics, such as oncology, neurology, and maternal–fetal medicine [9]. In many genetics clinics, GCs are often the primary interaction with patients and frequently collaborate with specialist physicians to create medical management plans, within their scope of practice. The scope of GC practice goes beyond just genetic testing facilitation; GCs are well-versed in laboratory stewardship, to help prevent inappropriate genetic testing orders and the misinterpretation of genetic test results, both of which may lead to inappropriate or inadequate care [10–12].

Quality genetics services provided by GCs improve clinical outcomes for patients and their families; the simultaneous provision of genetic education and psychological support by a GC is associated with an increase in patient knowledge, perceived personal control, decrease in distress, decrease in anxiety during clinical decision-making and can lead to positive health behavior changes [13–15]. Studies have described how PC clinicians desire direct contact with a GC [1, 7] and the involvement of a GC might mitigate the previously mentioned legal risks associated with non-genetics professionals delivering genetics services [6].

PC clinicians already participate in multidisciplinary or team-based care, which involves the engagement of experts in the requisite specialties to support PC clinicians in providing quality care for patients. Such cooperation is already in place when prescribing medication (involving pharmacists) and optimizing patient care (involving nurses and other allied health professionals) [16]. In Canada and the USA, PC clinicians provide the majority (66%) of referrals to GCs; however, there are few GCs who work directly with a PC clinician [9].

Review of the literature

There have been a few examples of clinics integrating GCs into PC to increase access to genetics services. A non-systematic literature review using Medline and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases was performed by the first author (R.V.) in January 2024 to identify peer-reviewed articles (with an abstract) that described a GC performing genetic counseling duties in a PC setting. The search combined the terms ("primary care" or "primary health care" or "family physician" or "general practitioner") and "Genetic Counseling/ or Counselors/." The Medline search identified 470 items, 433 of which were excluded upon reviewing the abstract. Thirty-seven articles were more thoroughly reviewed and eight articles describing six clinics met the inclusion criteria. The CINAHL search used the terms ("genetic counseling" or genetic counseling") AND ("primary care" or "primary health care" or "primary healthcare" or "general practice" or "gp") identified an additional 48 articles, with none meeting the inclusion criteria upon review. One additional article not identified by these searches was provided by the co-first author (S.A.B.).

Across the nine articles, two models of GCs in PC are described: the hub-and-spoke and the embedded model. In both models, GCs participate in direct consultation with patients and provide real-time education and consistent support to PC clinicians. The hub-and-spoke model strategically integrates a GC within multiple PC clinics or a region. This model was first described by Westwood in their 2003 pilot project in the UK [17, 18], and is also used by the Primary Care Precision Medicine clinic at the University of Pittsburgh Medical Center Health System in the USA [19]. Conversely, the embedded model integrates a GC into a PC clinic within a health system. The first described example of this model was a two-year project in 2004 in North Kirklees, England [20], which integrated a cancer GC into a PC clinic to improve access for patients from a specific minority population. More recent examples of the embedded model include the Sanford Chip Program at Sanford Health, USA, which integrated a GC in 2014 [21], the one-year pilot study in 2020 at the Cool Aid Community Health Centre in British Columbia, Canada [22, 23] and a first-of-its-kind service in a student-run, free PC clinic at Vanderbilt University Medical Center, USA, where their GC training program integrates GC students into this clinic [24]. By having a GC integrated within the PC clinic, these models mimic other multidisciplinary models used in PC and GCs conduct complex tasks related to genetics such as pretest and posttest counseling, genetic test selection, and results interpretation to GCs, which, in turn, allows PC clinicians to work more fully at the top of their scope of practice. There are examples of clinics integrating a GC solely to educate and support PC teams regarding appropriate genetic referrals, family history taking, and risk assessments, including the North Kirklees clinic [20], and a 3-month pilot study in 2007 at the Family Medicine Mayo Clinic [25].

Genetics support in primary care

GCs who work in PC are similar to those who work in specialty clinics in terms of their general duties but do have some roles that specifically support PC clinics. In many areas, a number of patients who have genetic conditions, such as hypermobile Ehlers-Danlos syndrome, hemochromatosis, or other multifactorial genetic conditions are not accepted referrals to the local tertiary genetics center; however, all the patients could benefit from genetic counseling in the PC setting [26]. GCs could aid in the implementation and management of recommended screening and care protocols for patients with a variety of genetic conditions, such as hereditary cancer syndromes or other single-gene disorders. Due to the nature of genetics health, additional family members may also be at risk or affected by the genetic condition, so GCs in the community are able to help with the cascade of family care that can arise from a genetics diagnosis.

As genomic medicine becomes more widespread, and PC clinics move toward team-based care models, the expertise, skills, and knowledge of GCs are essential for maximizing the benefits of personalized medicine for patients, PC teams,

and the healthcare system. With their extensive training in clinical care, medical communication, and psychotherapeutic counseling, integrating GCs into PC care teams will improve the care patients receive and allow PC clinicians to ensure their patients are at the forefront of the personalized medicine revolution.

Conflict of interest

None declared.

Funding

None declared.

Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

References

1. Carroll JC, Allanson J, Morrison S, *et al*. Informing integration of genomic medicine into primary care: an assessment of current practice, attitudes, and desired resources. *Front Genet* 2019;**10**:1189. https://doi.org/10.3389/fgene.2019.01189
2. Canadian Organization for Rare Disorders (CORD). *Now Is the Time: A Strategy for Rare Diseases Is a Strategy for All Canadians*. 2015. https://www.raredisorders.ca/content/uploads/CORD_Canada_RD_Strategy_22May15.pdf (3 March 2024, data last accessed).
3. National Organization for Rare Disorders. *Rare Disease Facts & Statistics*. 2024. https://rarediseases.org/understanding-rare-disease/rare-disease-facts-and-statistics/ (28 June 2024, date last accessed).
4. Harding B, Webber C, Ruhland L, *et al*. Primary care providers' lived experiences of genetics in practice. *J Community Genet* 2019;**10**:85–93. https://doi.org/10.1007/s12687-018-0364-6
5. Fok RWY, Ong CSB, Lie D, *et al*. How practice setting affects family physicians' views on genetic screening: a qualitative study. *BMC Fam Pract* 2021;**22**:141. https://doi.org/10.1186/s12875-021-01492-y
6. Dauge A, Joly Y, Kaiser B, *et al*. General medical practitioners acting as geneticists, a risky business? *Lex Electronica* 2024;**28**:152–71. https://doi.org/10.7202/1108625ar
7. Chou AF, Duncan AR, Hallford G, *et al*. Barriers and strategies to integrate medical genetics and primary care in underserved populations: a scoping review. *J Community Genet* 2021;**12**:291–309. https://doi.org/10.1007/s12687-021-00508-5
8. Paneque M, Turchetti D, Jackson L, *et al*. A systematic review of interventions to provide genetics education for primary care. *BMC Fam Pract* 2016;**17**:89. https://doi.org/10.1186/s12875-016-0483-2
9. National Society of Genetic Counselors. *Professional Status Survey*. 2024. https://www.nsgc.org/Policy-Research-and-Publications/Professional-Status-Survey (27 June 2024, date last accessed).
10. Farmer MB, Bonadies DC, Pederson HJ, *et al*. Challenges and errors in genetic testing the fifth case series. *Cancer J* 2010;**1**:8–10. www.journalppo.com
11. Skinner SJ, Clay AT, Mccarron MCE, *et al*. Interpretation and management of genetic test results by Canadian family physicians: a multiple choice survey of performance. *J Community Genet* 2021;**12**:479–84. https://doi.org/10.1007/s12687-021-00511-w
12. Harding B, Webber C, Rühland L, *et al*. Bridging the gap in genetics: a progressive model for primary to specialist care. *BMC Med Educ* 2019;**19**:195. https://doi.org/10.1186/s12909-019-1622-y
13. Madlensky L, Trepanier AM, Cragun D, *et al*. A rapid systematic review of outcomes studies in genetic counseling. *J Genet Couns* 2017;**26**:361–78. https://doi.org/10.1007/s10897-017-0067-x
14. Wakefield E, Keller H, Mianzo H, *et al*. Reduction of health care costs and improved appropriateness of incoming test orders: the impact of genetic counselor review in an academic genetic testing laboratory. *J Genet Couns* 2018;**27**:1067–73. https://doi.org/10.1007/s10897-018-0226-8
15. Grzymski JJ, Elhanan G, Morales Rosado JA, *et al*. Population genetic screening efficiently identifies carriers of autosomal dominant diseases. *Nat Med* 2020;**26**:1235–9. https://doi.org/10.1038/s41591-020-0982-5
16. Mitchell JD, Haag JD, Klavetter E, *et al*. Development and implementation of a team-based, primary care delivery model: challenges and opportunities. *Mayo Clin Proc* 2019;**94**:1298–303. https://doi.org/10.1016/j.mayocp.2019.01.038
17. Westwood G, Pickering RM, Latter S, *et al*. Feasibility and acceptability of providing nurse counsellor genetics clinics in primary care. *J Adv Nurs* 2006;**53**:591–604. https://doi.org/10.1111/j.1365-2648.2006.03760.x
18. Westwood G, Pickering R, Latter S, *et al*. A primary care specialist genetics service: a cluster-randomised factorial trial. *Br J Gen Pract* 2012;**62**:e191–7. https://doi.org/10.3399/bjgp12X630089
19. Massart M, Berenbrok LA, Munro C, *et al*. A multidisciplinary precision medicine service in primary care. *Ann Fam Med* 2022;**20**:88. https://doi.org/10.1370/afm.2764
20. Srinivasa J, Rowett E, Dharni N, *et al*. Improving access to cancer genetics services in primary care: socio-economic data from North Kirklees. *Fam Cancer* 2007;**6**:197–203. https://doi.org/10.1007/s10689-007-9132-1
21. Christensen KD, Bell M, Zawatsky CLB, *et al*; Imagenetics Metrics Team. Precision population medicine in primary care: the Sanford chip experience. *Front Genet* 2021;**12**:626845. https://doi.org/10.3389/fgene.2021.626845
22. Slomp C, Morris E, Knoppers BM, *et al*. The stepwise process of integrating a genetic counsellor into primary care. *Eur J Hum Genet* 2022;**30**:772–81. https://doi.org/10.1038/s41431-022-01040-x
23. Carrion PB, Austin J, Elliott AM. A genetic counselor's reflections on lessons learned, challenges, and successes experienced during a one-year pilot integration in a primary care clinic. *Public Health Genomics* 2023;**26**:58–67. https://doi.org/10.1159/000530683
24. Jordano JO, Gallion T, Cevan C, *et al*. How the other half screens: a model for partnerships between student-run free clinics and genetic counseling programs to address disparities in hereditary cancer evaluation. *J Genet Couns* 2023;**00**:1–9. https://doi.org/10.1002/jgc4.1835
25. Bernard ME, Zabel CA, Rohrer JE. Improving risk assessment in family medicine through the family history. *J Prim Care Community Health* 2010;**1**:147–51. https://doi.org/10.1177/2150131910375841
26. Borle K, Michaels NJ, Evans DR, *et al*. Advancing the quintuple aim for health care improvement through the integration of genetic counselors into primary care. *Am J Med* 2023;**136**:1136–8. https://doi.org/10.1016/j.amjmed.2023.08.017