

A Genetic Counselor's Reflections on Lessons Learned, Challenges, and Successes Experienced during a One-Year Pilot Integration in a Primary Care Clinic

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Keywords

Access to genetic services · Cultural safety · Genetic counseling · Genomic medicine · Indigenous health · Mental health · Primary care · Trauma-informed practice

Abstract

This practice-related insight article describes the experience of a genetic counselor being integrated into a multidisciplinary primary care clinic that provides care for a predominantly marginalized patient population in Victoria, British Columbia, Canada. Reflections on the lessons learned, including challenges and successes during this 1-year pilot integration are shared by the genetic counselor in the context of exploring the potential value a genetic counselor can provide while embedded in a primary care clinic. The relationship between clinical genetic counseling practice and a culturally safe and trauma-informed approach in primary care is explored, and additional steps are described that can be taken to facilitate more equitable and inclusive access to genetic counseling services for underserved and vulnerable patient populations.

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Published by S. Karger AG, Basel

Introduction

Integration of medical genetic services within primary care is an emerging model with the potential to facilitate more equitable and increased access to genomic medicine. The challenges associated with integrating medical genetics into primary care, particularly for underserved communities, have been recently reviewed [1]. Barriers included, but were not limited to, a lack of genetic knowledge, appropriate training, and skills (including risk assessment) among primary health care providers. As described by Slomp et al. [2] (2022), part of a larger research project exploring innovative methods for effective genomic counseling in Canada (GenCOUNSEL) involved integrating a genetic counselor into a primary care clinic (<https://bcchr.ca/GenCOUNSEL>). The process of integrating genetic counseling (GC) into primary care, from the perspective of the existing team members has been described by Slomp et al. [2] (2022). In this practice-related insight article, we will focus on the experience and reflections of the genetic counselor embedded within the primary care clinic (P.C., the primary author), with the aim of highlighting key considerations to inform effective

primary care integration of genetic counselors. In particular, the challenges experienced, strategies applied, and lessons learned are described in each section of this article reflecting the genetic counselor's experience of progressing through the following steps in the primary care integration: establishing trust and increasing awareness of GC, integrating GC into the clinic workflow, engaging clinicians in considering the mental health of all of their clients, recognizing potential to partner in reinforcing protective strategies for mental health and other complex disease, and adapting to the impact of the COVID-19 pandemic on client and clinician access to the GC service. The genetic counselor also provides a narrative account of the experience of preparing to provide a culturally safe and trauma-informed practice, vicarious trauma, and establishing peer supervision and support. Notably, with respect to the embedded genetic counselor's positionality, P.C. is a cis-gender woman settler of mixed Filipino, Chinese, and Spanish ethnicity. In reflecting on the experience of providing GC for complex/multifactorial and rare conditions in primary care, she describes how she sees the potential role for genetic counselors in providing clients with a different perspective on their mental health and identifies the potential to fill an existing gap in GC services and client support.

Clinic Setting and Client Population

Identifying a suitable clinic for this genetic counselor integration proved challenging due to the infrastructure and operations of primary care (family medicine) individual and group practices (short appointment times, billing structure, and space restrictions). The infrastructure of the multidisciplinary Cool Aid Community Health Centre allowed for this integration. The Cool Aid Community Health Centre in Victoria, British Columbia, Canada, provides primary health care mainly to individuals who may be experiencing homelessness, mental health challenges, infectious disease, problematic substance use, and/or chronic illness (<https://coolaid.org>). They employ a multidisciplinary, team-based approach to primary care that includes physicians and other allied health care providers such as nurse clinicians and practitioners, registered clinical counselors, a physiotherapist, a dietician, as well as a pharmacy and dental health team. Through their partnership with the Victoria Native Friendship Centre, Cool Aid also provides primary health care to clients indigenous to Canada and living in southern Vancouver Island.

Establishing Trust and Increasing Awareness of GC

I began my first 2 weeks at the Cool Aid Community Health Centre by shadowing the staff and clinicians, exchanging questions, and building work relationships with each team member. Not surprisingly, many of my new colleagues were unfamiliar with the GC profession, and I had many one-to-one conversations and provided a presentation to the clinicians explaining what GC is about. Given that I was aware that most Cool Aid clients have mental health and/or substance use challenges, during my presentation, I included discussion of the potential application and utility of psychiatric GC in their context (for key points of this presentation, see online suppl. materials S1; for all online suppl. material, see <https://doi.org/10.1159/000530683>).

Initially, some clinicians expressed concern about what experience and training I had to provide culturally safe care for their Indigenous clients, many of whom had significant trauma history, including trauma resulting from the ongoing effects of colonization in Canada. Trauma is a term that encompasses a variety of experiences that overwhelm an individual's capacity to cope [3]. Among all Canadians, 76% of Canadian adults report experiencing some form of trauma in their lifetime [4]. Trauma disproportionately affects the most marginalized members of society, and accordingly, severe trauma disproportionately affects Indigenous populations [5]. Multiple research studies have demonstrated that within the Canadian health care system, Indigenous peoples' experiences are frequently negative, which can lead to adverse health outcomes [6]. The original, Indigenous inhabitants of what is now known as Canada collectively include the First Nations, Metis, and Inuit peoples [7]. The National Aboriginal Health Organization in Canada, NAHO (2008), adopted the following definition of cultural safety: "Cultural safety refers to what is felt or experienced by a patient when a health care provider communicates with the patient in a respectful, inclusive way, empowers the patient in decision-making, and builds a health care relationship where the patient and provider work together as a team to ensure maximum effectiveness of care [8]."

In particular, discussing family history was identified as a potentially triggering experience for clients who have experienced significant abuse and trauma. I reassured the Cool Aid clinicians that I had completed the Indigenous Cultural Safety training that was completed by all other team members, described the Rogerian, client-centered foundation of GC, and shared my experience in providing psychiatric GC for patients with treatment-resistant psychosis. I received feedback from the team that, through these conversations I was able to address many of their initial hesitations.

My previous experience showed me that although discussing family history was a vulnerable experience for some primary care clients, many expressed to me that they were interested in GC because of the opportunity to talk about family history and shared how the experience of reviewing the visual of the family tree was helpful for them to recognize the generations impacted by mental illness as well as intergenerational trauma, and connect with what strategies they have adopted or plan to apply to promote their recovery and protect their mental health.

Integrating GC into the Clinic Workflow

With respect to introducing me to their clients, clinicians who were familiar with GC were comfortable in introducing me as the “new genetic counselor at Cool Aid,” but others expressed concern about suggesting a service called “GC” to their clients, as they worried that it could be perceived as stigmatizing and/or intimidating (e.g., focused on “identifying genetic syndromes”). To address this, some clinicians simply introduced me to clients as a “counselor” and deferred to me to talk more about what would be involved in an appointment.

Initially, I shadowed physicians, and introduced myself to clients as the new genetic counselor on the team. Although this approach was very effective in leading to GC appointments, it was not sustainable from the physicians’ perspective given the time pressures of addressing many complex medical issues in an appointment. The physicians asked for a script with which to introduce the GC service to their patients. I provided them with a mental health focused document as well as one that outlined as to how I could discuss the role of family history/genetics in the development of certain illnesses/conditions (see online suppl. material S2). Each script outlined what clients could expect from meeting with the genetic counselor. In particular, how it could be helpful to them in gaining a better understanding of causes/contributing factors to mental and/or physical health conditions (including considering the role of genetics and family history) and strategies to protect against the development of these conditions and/or promote recovery and management. Although having their family tree drawn out when discussing family history is typically done in the first visit with the genetic counselor, it is highlighted in the scripts that having only a limited awareness of the health history of their family members, or not being interested in discussing their family history is not a barrier to clients participating in an appointment with the genetic counselor.

With the shift to remote work after the onset of the COVID-19 pandemic in March 2020, I transitioned from reviewing the patient bookings together with the physicians to reviewing their patient schedule independently each day and sending personalized electronic medical record (EMR) messages (addressing the potential role of GC for the individual patient, based on review of their chart summary) encouraging them to mention the GC service to clients I had flagged. Given the team’s expressed interest in what I could offer, I focused on flagging individuals with a history of mental illness and/or substance use, and also highlighted my ability to address the impact of COVID-19 on mental health. For example, I would explore with clients their perspective on the contribution of stressful and/or traumatic life experiences like the COVID-19 pandemic as well as genetic factors to their vulnerability to experiencing episodes of mental illness and substance use relapse and discuss ways to promote recovery and manage mental health. Ten months into the integration, I received the suggestion and support from the clinicians to shift to an “opt-out” approach to GC referrals for clients as a way to better integrate GC into the clinic workflow. Figure 1 outlines the evolution of the referral pathway over my time within the clinic. The majority of the physicians were keen to have me see their clients and would communicate on a case-by-case basis if there were clients that they felt would not be appropriate for GC for specific reasons.

Engaging Clinicians in Considering the Mental Health of All of Their Clients

We had imagined that appropriate clients to refer for GC would be best identified by reviewing charts for history of mental health and/or substance use disorders. However, while I was shadowing the clinicians, and introducing myself to all clients, some clients disclosed a personal and/or family history of mental illness that was not noted in their chart and expressed interest in a GC appointment. The clinicians told me that they appreciated this reminder to check in on the mental health of all of their clients, not just the ones with an established mental health diagnosis.

Recognizing Potential to Partner in Reinforcing Protective Strategies for Mental Health and Other Complex Disease

In my shadowing experience of the physicians, I noticed that many clients brought up how life stress

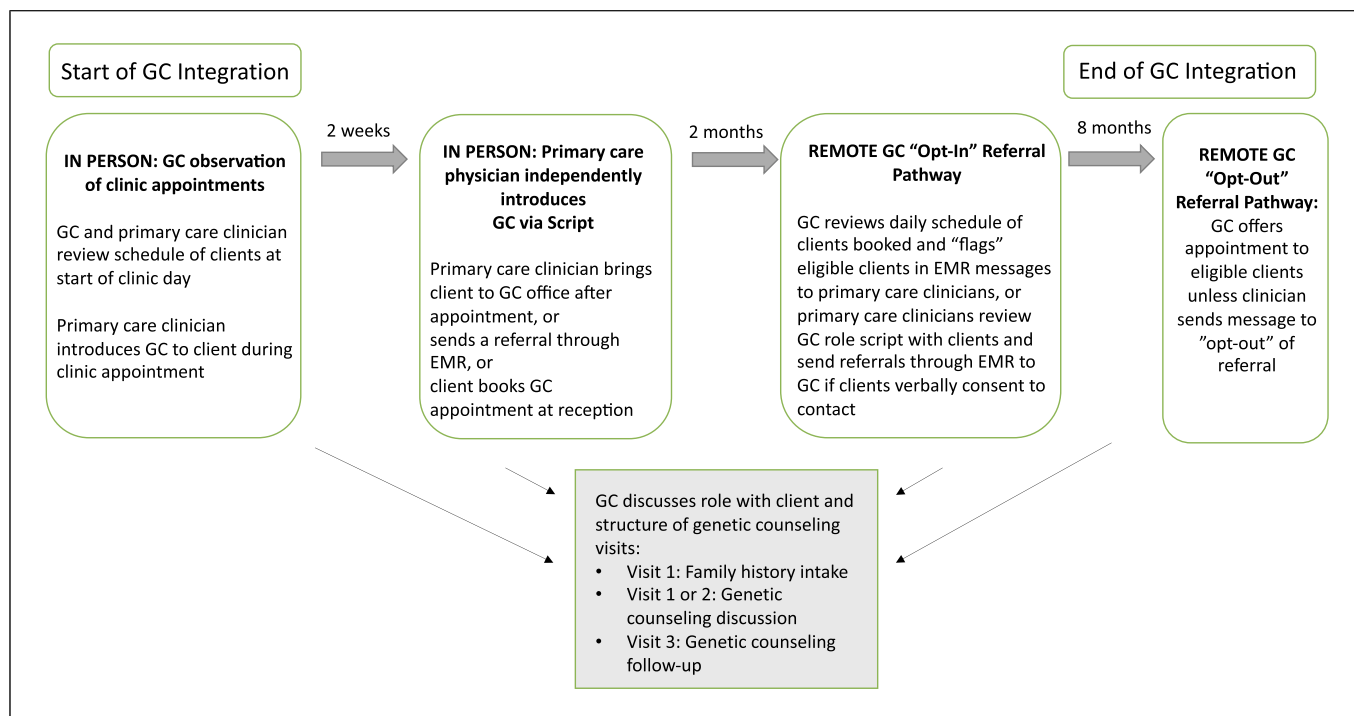


Fig. 1. Evolution of referral pathways to genetic counselor in primary care.

(e.g., relationships and financial stress) seemed to worsen their mental health problems and how – in turn – these would seem to trigger their physical health problems and vice versa. As well, though I observed physicians check in with their clients with respect to strategies to manage their mental health (exercise, nutrition, sleep, use of the clinic’s counseling service, and medications), this discussion was necessarily brief. A more in-depth exploration of other “protective factors” the client had in place was precluded by the time available in which many complex medical concerns and questions needed to be addressed. Thus, I felt able to build on the initial brief discussions the physician was having with their clients to further discuss the vulnerability factors (genetic and environmental) and protective factors for mental health and their complex medical health issues.

Adapting to the Impact of the COVID-19 Pandemic on Client and Clinician Access to the GC Service

Just over 2 months into the integration of GC at Cool Aid, the whole clinic team had to transition to providing services primarily online in response to the emergence of the COVID-19 pandemic. Removing the option for an in-

person GC appointment created an access barrier for some clients – primarily those with minimal resources who did not have a computer, phone, or a private and/or safe space to connect from. While virtual appointments can help with access for people of low socioeconomic status who may have transportation challenges or may not be able to afford to take time from work to attend an in-person appointment, some clients shared with me that phone and virtual appointments removed the barriers associated with having to attend in person that can be very challenging for people with (for example) severe anxiety and/or chronic pain.

While the trust-based relationships I had established with some of the clinicians remained intact through this transition, for those clinicians with whom I had not yet fully established a collaborative working relationship (as described by Slomp et al. [2], 2022), pandemic-induced remote work presented the additional challenge of the nascent GC component of the team being “out of sight, out of mind,” which acted as a barrier to further development of the relationship. I experienced the need to delicately balance strategizing and implementing creative ways to collaborate with clinicians while still respecting their focus on and prioritization of dealing with the immediate needs of clients in crisis and managing

complex medical issues in the context of a global pandemic. Prior to the pandemic, some clinicians would share their clients' reactions and experience with GC directly with me in person. With the pandemic, most clinicians shifted to noting any comments from clients about their experience of GC in their chart notes. I used these testimonials in my EMR messages to the clinicians with whom I was still trying to build relationships and consistent referrals.

Preparing to Provide a Culturally Safe and Trauma-Informed Practice

The most marginalized members of society are often profoundly affected by trauma, with Indigenous people being disproportionately affected by severe trauma [9, 10]. Among marginalized groups, medical distrust is significantly higher in health care in general and in genomic medicine in particular [11]. A trauma-informed approach has been proposed to help with mitigating the effects of medical distrust. Given that 20–30% of Cool Aid clients have First Nations, Métis, or Inuit heritage, it was clear that the GC service needed to apply a culturally safe and trauma-informed approach to care to build trust, engagement, and to promote clients' ability to process information. Cultural safety is an approach that acknowledges how the social and historical contexts, together with structural and interpersonal power imbalances, influence the health and health care of individuals from marginalized groups [12, 13]. In the Canadian context, a crucial consideration around cultural safety, is understanding of the how the health of Indigenous people and their experience of, and access to health care have been impacted by enduring institutionalized racism and trauma related to colonialism [6, 14]. Therefore, to provide trauma-informed, culturally safe care health care providers must practice self-reflection and self-awareness, particularly with respect to how power differentials can impact our clients and patients, and this has also been emphasized within the trauma-informed approach to care. However, there are limited studies relating to the implementation of trauma-informed practice in health care in general – and to our knowledge – there is still no published research on culturally safe and trauma-informed practice in the field of GC.

In preparing to provide GC services at Cool Aid, I reflected on the ways my client-centered psychiatric GC practice already incorporates cultural safety and the six principles of a trauma-informed approach to care are (1) safety, (2) trust and transparency, (3) peer support, (4) collaboration and mutuality, (5) empowerment, voice,

and choice, and (6) the importance of cultural, historical, and gender issues (as outlined by the Substance Use and Mental Health Services Administration, SAMHSA [2014]), and what strategies I could take to further augment my approach [15]. I sought out additional learning opportunities to increase my trauma awareness and facilitate and maintain an inclusive, culturally safe, and trauma-informed practice, including building my awareness of the utility of mindfulness in managing trauma. Further details of how I prepared for a trauma-informed approach to primary care GC are included as online supplementary material (see online suppl. materials S3). I summarize how I applied a trauma-informed approach to my GC practice in primary care in Table 1.

Addressing Vicarious Trauma and Establishing Peer Supervision and Support

Despite my preparation and awareness, 2 months into the integration and just before the onset of the COVID-19 pandemic, I came to recognize that I had started to experience the effects of vicarious trauma resulting from empathic engagement with clients who would sometimes share details of their traumatic experiences within their GC sessions. The registered clinical counselors at Cool Aid did not have a formal peer supervision group but would consult each other and provide support regarding shared clients experiencing trauma and other challenges. Connecting virtually with a registered clinical counselor colleague at Cool Aid was helpful in discussing shared challenges related to supporting clients with significant trauma experiences as well as allowing me to feel valued as a member of the Cool Aid team. However, I recognized that I needed more, and inspired by my involvement in a peer supervision group in my previous workplace, I led the development of a virtual peer supervision group that included genetic counselors working in patient facing roles as well as novel or emerging areas of practice. This provided me with a space to bring up the challenges I experienced and receive practical feedback with respect to the GC issues and emotional support from my colleagues.

Delineating the Potential Role for Genetic Counselors in Providing Clients a Different Perspective on Their Mental Health

Within the Cool Aid clinic, GC was considered part of the suite of counseling services. This required careful delineation of the differences between the registered clinical counseling and the GC. Although some clients were already seeing a

Table 1. A trauma-informed approach to engaging clients in primary care genetic counseling (GC)

Strategies to support the principles of trauma-informed practice ^{1,2}		Reflections from the primary care genetic counselor
safety and trustworthiness	choice and collaboration	
Consider all barriers to engagement	Work through the details together	I ensured clients were able to attend a primary care GC appointment in a way that promoted their safety and privacy, exploring communication options for clients (e.g., phone, virtual, or in person), and other potential barriers
Attend to immediate needs	Brainstorm ideas together to remove or reduce barriers to participation and attendance	During contracting at the start of the session, I explored with clients their self-care and coping strategies they could engage in if they were feeling anxious and/or triggered. I checked in with clients on whether they have a support person (e.g., case manager, family member, etc.) they would like to include in the appointment
Be transparent, consistent, and predictable as possible	Use statements that make collaboration and choice explicit	I would discuss with clients the goal for there to be bidirectional knowledge sharing, which can help with leveling the power differential and fostering collaboration and mutuality. In reviewing the family history with a client, it is important to recognize and acknowledge that it may be emotional or triggering for clients to talk about family history. I would let clients know they may choose not to talk about certain family members
Respect healthy boundaries and expectations by clarifying your role	Elicit individuals hopes and expectations for appointment and therapeutic relationship	I checked in on the client's understanding of what a primary care GC appointment involves and clarified how my approach is trauma-informed but GC is not a trauma-specific service (i.e., the intent of GC session is not to treat the trauma they have experienced). We would mutually agree upon an agenda for the appointment
Clearly outline expectations of the primary care GC service/appointment		We reviewed how GC is a short-term interaction over 2–3 sessions, in contrast to typically longer term supportive counseling with a registered clinical counselor
Obtain informed consent and explain how information will be shared and limits of confidentiality	I explicitly addressed with clients how only their health care providers (e.g., physician, nurse, and registered clinical counselor) will have access to the chart note summarizing our GC discussion. I also let them know that if there is any information shared that they preferred not to have entered into their medical record, that I can leave it out, but we can still include it in our discussion	
Collaboratively develop some grounding strategies	Working in a feedback-informed way: purposefully elicit from individuals and families their perspective of their overall experience	Midpoint check in: in addition to asking my clients to let me know if they need a break at any point during our appointment, I also let them know I would do a check in midpoint as well to explore how their experience of the appointment has been so far. After the family history intake, clients were offered the choice of engaging in the GC discussion in that same appointment or scheduling a second appointment End of the appointment check in: I have had clients share that they felt comfortable with me and would like to see me again for the next appointment. I have had some clients express

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Table 1 (continued)

Strategies to support the principles of trauma-informed practice ^{1,2}		Reflections from the primary care genetic counselor
safety and trustworthiness	choice and collaboration	
		<p>feeling anxious and with all my clients I would talk about a plan for self-care after the appointment (e.g., going for a walk, reading, and other culturally meaningful ways of coping like smudging and prayer)</p> <p>Follow-up phone call: for clients with a history of significant trauma, I have offered to do a follow-up phone call 1–2 days after our session to check in on how they are doing. This has been especially well received and viewed as helpful after initial family history intake with indigenous clients, as it is often after the appointment that these clients further process and experience the impact of our discussion</p>

¹Substance Abuse and Mental Health Services Administration (2014). *SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach*. HHS Publication No. (SMA) 14-4884. Rockville, MD: Substance Abuse and Mental Health Services Administration. ²Adapted from the BC Mental Health and Substance Use Planning Council (2013). *Trauma-Informed Practice Guide*. https://cewh.ca/wp-content/uploads/2012/05/2013_TIP-Guide.pdf.

registered clinical counselor at Cool Aid, they commented on the novelty of GC and the value of the difference in what a genetic counselor could offer, particularly the opportunity to review and discuss their family tree and how the mental health of their family members may have impacted on their own mental health. Within the feedback I received from Cool Aid clinicians on the GC integration, they shared how some clients appreciated gaining an alternative perspective on their mental health. Clients shared with me that having a safe space to talk about the guilt and blame they experienced about their mental illness and receiving confirmation of the contribution of genetics was validating – especially for those who felt like they had a “propensity to mental illness” in their family. The process of reviewing the family tree was expressed as a validating and empowering experience for many clients, who valued the discussion about ways to engage in strategies to promote their own mental health recovery and maintenance.

For many of the Indigenous clients I had seen for GC who had begun their healing journeys through trauma-focused counseling and/or cultural approaches, I experienced their openness to considering and engaging in GC. When asked by an Indigenous client if I was “one of those health care providers who encourages us to forget and move on from past pain and traumatic experiences,” I reassured them that my approach was about recognizing the impact of their painful and/or traumatic life experiences – including the ongoing impacts of colonization – as well as the contribution

of genetics on their mental (and often physical) health, and to explore ways that people can influence/lessen the associated stress and chronic effects on their health they experience (allostatic load/overload) [16]. In reviewing the visual of the family tree with Indigenous clients, I was able to highlight and encourage those who were able to identify and express how they were able to break the cycle of inter-generational trauma that has impacted them and their family members through their ongoing efforts to engage in strategies to promote their own mental health recovery and healing journey.

Identifying the Potential to Fill an Existing Gap in GC Services and Client Support

Some of the primary care clinicians were keen to refer their patients for nonpsychiatric reasons – for example, I received referrals for other complex conditions (e.g., nonalcoholic fatty liver disease and diabetes), a personal or family history of a diagnosed or suspected genetic syndrome (e.g., Ehlers-Danlos syndrome), family history of cancer or sudden cardiac death, and reviewing the results of direct-to-consumer genetic testing. I felt that I was able to provide value in GC in all of these contexts, but one of the most common physician-initiated referrals for GC at Cool Aid was for Ehlers-Danlos syndrome and deserves special mention.

Prior to my involvement in the team, the Cool Aid physicians had referred their clients with possible diagnosis of EDS for a medical genetics appointment at the provincial tertiary care clinic. But, while referrals were accepted for classical, vascular, or other types of EDS for which confirmatory genetic testing could be offered, hypermobile EDS referrals were declined. Therefore, when I arrived, these clients were referred to me. Much of the counseling I did for clients with hypermobile EDS was focused on clarifying misconceptions that were causing distress for them (for example, the vascular type of EDS is associated with a decreased life span, but the hypermobile type is not) and providing counseling around this. All of the clients I saw for GC expressed that the appointment was a validating experience for them (“it’s not all in my head”), especially given that their physical symptoms, particularly chronic pain and fatigue, were often dismissed by other health care providers, some only focusing on addressing their comorbid psychiatric illness. Clients with a diagnosis of EDS-hypermobile type who were referred to me for GC shared their guilt about the possibility of their children developing the same condition and expressed how helpful it was to be able to meet with a health care professional who could address the interconnectedness between their experience with physical symptoms of EDS and their mental health. All opted to engage in a psychiatric GC appointment for their diagnosed mental illnesses as well. When I would check in on social support and resources, some clients shared they had attended group medical visits as part of the “beyond pain group” at Cool Aid but felt like they had difficulty relating and connecting to group members who were typically considerably older than many of them and experiencing different life challenges. Some expressed interest in starting a support group and series of educational group medical visits targeted toward clients with hypermobile spectrum disorders and EDS, and the potential role for a genetic counselor as a co-facilitator was noted. There appears to be an important care gap for people with hypermobile EDS, which could be effectively addressed by a primary care embedded genetic counselor.

Summary of the GC Experience in the Primary Care Integration

A detailed summary comparing the challenges I experienced in the GC integration as well as solutions applied and lessons learned are included in the online supplementary material (see online suppl. material S4). As noted by Slomp et al. [2] (2022), from the perspective of the existing primary

care team members, the establishment of trust was critical to successfully integrating the genetic counselor into the primary care team. From my own perspective, I felt that building trust was the crucial component. Although I was able to establish this trust with many clinicians despite having to shift to remote work for the majority of the integration, there was a lack of opportunity for partnering with clinicians in appointments, which likely would have been a beneficial experience, as expressed by the primary care clinicians, that could have helped these clinicians to better appreciate the scope and skillset of the genetic counselor. In the context of the specific needs of this particular clinical setting, the most valuable skills I had to offer were in the domain of helping the team to address mental health and substance use concerns, but clearly this is going to differ according to different primary care practice needs. There are opportunities for genetic counselors to be identifying patients with rare syndromes, ensuring appropriate identification and follow-up for families with cardiovascular and cancer histories, and of course, as highlighted in this primary care integration, genetic counselors can play an important role in addressing common complex conditions. There is a need for research looking at outcomes of embedding genetic counselors into primary care practice settings in terms of access, equity, and patient outcomes. Conceptually at least, carefully delivered GC could be a good fit for integration within Indigenous healing approaches, especially regarding the opportunity for Indigenous clients to continue their healing journey through expressing, and gaining further insight into, the impact on their mental health of childhood pain and/or ongoing colonial and intergenerational trauma [17, 18]. Research evaluating the patient experience of a trauma-informed approach to GC could help with establishing a safe and optimal process, and particular attention to alignment with Indigenous healing approaches is potentially important.

Sustainability of the Primary Care GC Integration

Leadership changes within the Cool Aid Community Health Centre influenced the decision to discontinue the primary care genetic counselor integration at the end of the pilot study. The change in priorities that accompanies new leadership (the new leader had not been involved in the vision setting for the genetic counselor integration), combined with the lack of continued external funding, made it impossible to maintain the genetic counselor position in the team. The team is using the learnings from this experience to explore genetic counselor integration within other primary care practice settings.

Acknowledgments

The authors thank Dr. Morgan Price and the Victoria Cool Aid Community Health Centre clinicians, leadership and administrative staff, and clients for their engagement with the primary care integration of the genetic counselor. We also thank the members of the GenCOUNSEL team for their support, insight, and guidance. The GenCOUNSEL Study is led by Alison M. Elliott, Jehannine Austin, Bartha Knoppers, and Larry D. Lynd with project manager Alivia Dey, and includes the following co-investigators: Shelin Adam, Nick Bansback, Patricia Birch, Lorne Clarke, Nick Dragojlovic, Jan Friedman, Debby Lambert, Daryl Pullman, Alice Virani, Wyeth Wasserman, and Ma'n Zawati. The authors offer gratitude to the ɫəkwəŋən (Lekwungen) and W̱SÁNEĆ (Saanich) peoples of the Songhees and Esquimalt Nations as well as the Coast Salish Peoples, including the x̱m̱əθkwəy̱əm (Musqueam), Skwxwú7mesh (Squamish), and Səlilwətaʔ/Selilwitulh (Tsil-waututh) Nations, on whose traditional, unceded, and ancestral territory we have the privilege of working.

Statement of Ethics

Ethics approval for this practice-related insight article that is a narrative of the genetic counselor's experience of being embedded within a primary care practice was not required in accordance with local or national guidelines. Written or verbal informed consent from the individuals whose experiences were described in this manuscript to use this information for publication was not required in accordance with local or national guidelines.

Conflict of Interest Statement

Prescilla Carrion, Alison M. Elliott, and Jehannine Austin declare that they have no conflict of interest. After completion of the 1-year

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primary care integration at the Victoria Cool Aid Community Health Centre, Prescilla Carrion began working in a new position (independently funded and with no direct affiliation with the GenCOUNSEL project) as a genetic counselor at Medcan, providing proactive genetic services through integrated primary care.

Funding Sources

GenCOUNSEL was funded through the Large Scale Applied Research Project (LSARP) Genome Canada competition with co-funding from Canadian Institute for Health Research (CIHR), Genome BC, Genome Quebec, Provincial Health Services Authority, BC Children's Hospital Foundation, and BC Women's Hospital Foundation. The funding agencies had no role in the design and conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; or decision to submit the manuscript for publication.

Author Contributions

P.C., A.M.E., and J.A. made substantial contributions to the conception of the work. P.C. was responsible for writing the manuscript and all revisions. A.M.E. and J.A. were responsible for the critical review. All authors gave final approval for this version to be published and agreed to be accountable for all aspects of the paper.

Data Availability Statement

All data generated or analyzed during this study are included in this article and its online supplementary material. Further inquiries can be directed to the corresponding author.

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