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Who we are, what we do and how we add value: The role of the genetic counseling 'philosophy of practice' statement in a changing time

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Abstract

As genetics and genomics are integrated into healthcare and non-genetics health professionals deliver aspects of genetic counseling, it is increasingly important for genetic counselors to be able to define who we are, what we do and how we add value to client interactions, both on an individual and professional basis. In this paper, we argue that to understand ourselves as individual practitioners and as a profession, we each need to reflect on, write and constantly review our own philosophy of practice. A philosophy of practice is a dynamic, personal and reflective statement or narrative that captures the core ideas, values and beliefs of the individual about their chosen profession, including concrete examples of what this involves in practice. Here, we consider the nature, purpose and relevance of a philosophy of genetic counseling practice, drawing on examples from professions such as teaching and nursing, where the exercise of writing a philosophy of practice is more established. We demonstrate how and why we have introduced writing a philosophy of practice into our Master of Genetic Counseling program at University of Technology Sydney, and consider the possibilities for introducing such practice into professional registration or certification processes. Finally, we offer our own philosophy of genetic counseling practice as an example. As the roles and scope of practice for genetic counselors expand and diversify, it is increasingly important to understand, own and retain our core values and principles as individual practitioners and as a profession. Ensuring client-centred practice remains at the heart of genetic healthcare is vital. We encourage all genetic counselors to write, publish and share their philosophy of practice, adding to our collective professional identity in this time of change and opportunity.

Keywords

Genetic counseling, Genetic counselors, communication, philosophy of practice

Introduction

Genetic counselors are leading the implementation of genomics into healthcare, ensuring that client centred practice remains paramount. To fulfil this role, genetic counselors need to define who we are and what we do, both as a profession and as individual practitioners. We need to articulate what we do that is different from other health professionals and identify the added value we bring to clients and families who interact with genomic healthcare. The past few years have seen increasing efforts to describe and define the role of genetic counselors, with several leaders in the field challenging the profession to define genetic counseling as both an activity that contributes in a meaningful way to improved client outcomes, and as a profession with a unique and valuable skill and knowledge set (Austin, 2016; Middleton, Hall, & Patch, 2015; Patch & Middleton, 2018).

Austin and colleagues (2014) proposed conceptualising genetic counseling as a brief psychotherapeutic encounter, in which the value of the relational aspects of genetic counseling are upheld, centralised and celebrated. Models of genetic counseling have long recognised that the relationship between the client and counselor is central to clinical practice (Kessler, 1997; Veach, Bartels, & Leroy, 2007).

Establishing a therapeutic alliance within the time constraints of a clinical genetic counseling appointment requires establishing trust and safety, responding in ways that help clients make meaning of their situation, and facilitating cognitive, behavioural and emotional adaptation (Biasecker & Erby, 2008; Helm, 2015). The ways individual genetic counselors establish the relational elements required for a therapeutic alliance is not yet well understood, even though ‘the integration of the information provided in conjunction with establishing a counseling relationship makes

up the dance that is genetic counseling' (Biesecker, Peters & Resta, 2019, p.132). Here we argue that to truly understand what it is that genetic counselors 'do', each individual genetic counselor needs to develop their own philosophy of practice, constantly reflecting on the way they conceptualise genetic counseling as their practice evolves.

Developing and delivering a Master of Genetic Counseling program has contributed to our understanding of the place of a philosophy of practice as a guide to ongoing reflection and growth for students after graduation. The graduate framework in our university requires that each degree program articulate a set of graduate attributes and course intended learning outcomes. Graduate attributes provide a framework for what graduates will 'look like', while course intended learning outcomes are statements of what graduates can 'do'. The process of analysing and reflecting upon our years of clinical practice to write these statements and plan the detail of each subject and learning experience created an appreciation of the ways in which our philosophical and theoretical perspectives, life experiences, and interactions with clients inform the way in which we work. Over time we came to understand that our perspectives and experiences can be articulated in an individual philosophy of practice statement, similar to statements used by teachers and nurses.

In this paper we will (i) consider the nature, purpose and relevance of a philosophy of practice of genetic counseling, (ii) demonstrate how and why we have introduced writing a philosophy of practice into a Master of Genetic Counseling program and (iii) offer our own philosophy of genetic counseling practice as an example.

The nature, purpose and relevance of a philosophy of genetic counseling practice

What is a philosophy of practice?

In the broadest sense, philosophy 'is wondering and being curious about the "big" or fundamental questions that humans have grappled with throughout history' (Bruce, Rietze & Lim, 2014, p.67). Philosophy provides us with frameworks, or ways of thinking about the world, that can help to guide our actions and decisions.

Philosophical thinking and debate help us to understand how we know what we know (epistemology) and why we value certain things (axiology). The ethical training genetic counselors undertake is informed by the philosophical concept of axiology, so most genetic counselors will be familiar with philosophical constructs and use them regularly in their work.

A philosophy of practice is a personal reflective statement or narrative that captures the core ideas, values and beliefs of the individual about one's chosen profession, including concrete examples of what this involves in practice. A philosophy of practice is a fluid statement that changes and evolves over time as the practitioner matures and gains experience. The statement is, in effect, a promise that a practitioner makes 'about themselves and their professional practice' and enables them to hold themselves to account as they practice in their chosen profession (Alpers, Jarrell, & Wotring, 2013, p.163).

Articulating a philosophy of practice requires consideration of the core values, principles and ethical standpoints of the profession, fosters engagement with the professional literature, professional codes and scopes of practice, and helps us to

think critically and reflect on the ways in which our values, beliefs and life experiences influence our practice and our way of being (Bruce, Rietze & Lim, 2014; Denehy 2001). The process of writing a philosophy of practice requires the practitioner to spend time reflecting on the way they think about their profession (Gambescia, 2013; Kearns & Sullivan, 2011). A written philosophy of practice defines the individual practitioner and helps to get to the essence of how that practitioner thinks about who they are and what they do (Bruce, Rietze & Lim, 2014; Gambescia, 2013). Through each practitioner articulating their own philosophy of practice statement, the common values principles and goals of the profession can be identified as can areas of diversity, thereby enhancing the collective voice of a profession. The practice of writing and sharing an individual philosophy of practice statement provides a mechanism to collectively create consensus on the core values of a profession (Denehy, 2001). A philosophy of practice provides practitioners with 'a distinctive organizing vision — a clear picture of why you are doing what you are doing that you can call up at points of crisis' (Brookfield, 2006, p. 16).

Yet, whilst preparation of a philosophy of practice statement is wide-spread in nursing and teaching (Alpers, Jarrell, & Wotring, 2013; Behrens, 2008; Denehy, 2001; Gambescia, 2013; Kearns & Sullivan, 2011; Marchuk, 2014), a search of the internet and the literature did not yield examples in genetic counseling. We believe that there is tremendous power in the individual and collective practice of writing a statement of our beliefs and values about our chosen profession of genetic counseling.

Why do we need a philosophy of practice in genetic counseling?

Having a clear understanding of the principles and values that guide our own practice is important in helping us to understand, explain and define our role to clients, to other health professionals and indeed within our own professional group. Genetic counselors have grappled with defining the values, principles and goals of practice throughout the history of the profession, as evidenced by the wealth of literature and the evolving definitions of genetic counseling (Biesecker & Peters, 2001; Resta, 2006). Central to this debate is the question of whether information and education or counseling and empowerment are at the heart of genetic counseling as practiced by genetic counselors, a question which was initially raised over twenty years ago (Kessler, 1997).

Alongside discussion as to the central purpose of a genetic counseling encounter is consideration of the core principles and values underpinning genetic counseling, including client-centredness, autonomy, informed decision-making, privacy, confidentiality and the contested issue of nondirectiveness (Weil et al, 2006). These core principles, defined in our professional codes of practice, have been developed and revised as the profession has developed. The competency standards that inform our training and certification/registration/regulation processes speak to these principles and values, endorsing client-centred practice (Human Genetics Society of Australasia, 2019, Genetic Counselling Registration Board Code of Conduct, 2015, Accreditation Council for Genetic Counseling, 2019). These statements from Australasia, the United Kingdom and the United States of America all recognise that effective genetic counseling empowering clients and families who live with inherited conditions, occurs in a relationally sound environment, underpinned by the core

principles and values. In times of uncertainty and change, consideration of the core values and beliefs that underpin practice assist us to be clear about our professional identity as genetic counselors and builds resilience.

Increasingly, genetic counselors are called upon to succinctly state the value they add and to articulate the difference between genetic counseling as provided by genetic counselors and genetic counseling as provided by other disciplines. There is a growing need to be able to identify and measure the outcomes of genetic counseling in order to demonstrate the added value we bring to genetic healthcare (Athens et al, 2017).

As genetic counselors embrace the opportunities of increasingly diverse positions in healthcare systems, it is crucial that they are confident in their professional identity. We believe that through reading, discussing, writing and reflecting on what we do and who we are as we develop and modify our personal philosophies of genetic counseling, we deepen our understanding of ourselves and our roles as individual genetic counselors and our identity as a profession. For example, student genetic counselors could be encouraged to begin to think about developing their philosophy of practice early on, with the understanding this will evolve over time and with experience. Countries which require a portfolio of work for certification/registration could include a requirement for a philosophy of practice statement in the portfolio and require a review of the statement at each re-accreditation as part of continuing professional development. This personal and professional knowledge will in turn contribute to enhanced definitions, goals, and evidence-based outcomes for clients.

How and why we have introduced writing a philosophy of practice into the Master of Genetic Counseling program at the University of Technology Sydney

In Australasia, reflective practice is included as a core competency (Human Genetics Society of Australasia, 2019), acknowledging the responsibility we have as genetic counselors to continually reflect on our practice. Supervision offers a powerful opportunity for reflection for professionals working with clients who are facing significant life challenges. Regular, carer-long participation in supervision encourages and supports deep reflection, questioning and exploration of practice, enhances and enriches the work genetic counselors do with clients, builds resilience, and contributes to wellbeing and career longevity, all of which are vital elements of client-centred care. In addition, supervision and reflective practice is associated with a deepening understanding of our personal beliefs, values, and professional identity, assisting the evolution of the philosophy of practice over time.

We introduce UTS Master of Genetic Counseling students to reflective practice early and they participate in weekly small group supervision throughout their training. To encourage critical thinking and reflection on the values and beliefs they hold about the profession they are entering we also ask students to write a philosophy of practice at the end of their first year. We recognise that writing a philosophy of practice at this early stage of their career is an emergent articulation of students' thoughts and experiences.

In preparation for writing their philosophy of practice, we encourage students to engage with the literature that informs the ongoing evolution of the profession, identify role models and reflect on the way they practice and/or write about their practice, critically reflect on what they observe during clinical placements, and

interrogate their emerging conceptualisations of client centred genetic counseling practice. To assist our students, we have developed guidance about how to approach this task (see Figure 1) and a set of tasks and prompt questions (Figure 2).

Figure 1. Guide to writing a philosophy of practice

A philosophy of practice is a unique, fluid, individualised reflective statement conveying core ideas about being an effective person-centred genetic counselor. It is a succinct written articulation of the way that we each think about genetic counseling, and includes a consideration of the way in which our experiences inform our practice. It should include examples from practice to illustrate the way we enact our core beliefs. Each person will approach the development of a philosophy of practice in a different way. One of the challenges is to spend time crafting a written statement that clearly expresses the beliefs and values that inform practice. For example, many genetic counselors would identify with the statement 'I am a client-centred genetic counselor'. A written philosophy of practice provides an opportunity to make sense of a statement like this, giving the reader a 'picture in words' of what this looks like in practice, and at the same time ensuring that the genetic counselor who finds themselves stating this in a meeting about their role has a well thought out evidence-base for the statement.

Figure 2. Tasks and prompt questions for writing a philosophy of practice

Getting started	Prompt questions
<ul style="list-style-type: none"> • Start writing, using the prompt questions as sentence starters. • Take the prompt questions to supervision and talk them through. • Start a conversation on social media using one of the prompt questions. • Audio-record your responses to the questions and transcribe them. • Identify a quote that exemplifies practice for you. • Create an image, mind map or list that illustrates your ideas about practice. 	<ul style="list-style-type: none"> • What sort of genetic counselor am I? • Can I identify particular clients, moments or interactions that illustrate who I am as a genetic counselor? • Where have my ideas about myself as a genetic counselor come from? • How do my life experiences inform my work? • Who are my role models in life? • Who are my role models in genetic counseling? • What do I bring to my practice from these role models? • What is my theoretical perspective? • How does my theoretical perspective inform my thinking? • What are some of the elements of genetic counseling practice that resonate with me? • Can I identify examples when I have observed a genetic counselor

	<p>working with a family in ways that align with my beliefs about practice?</p> <ul style="list-style-type: none">• Can I identify a moment when I have thought 'this is how I want to be as a genetic counselor'? What was it about that moment that made me think this?
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Our philosophy of genetic counseling practice

'I've learnt that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.' Carl W. Buehner (1971)

In developing an assessment task for Master of Genetic Counseling students, we drafted our own philosophy of practice. This philosophy was developed over a two-year period, informed by our clinical experiences, life experiences, reading of the extensive literature regarding the core values, principles and definitions of genetic counseling, discussions with colleagues, students and each other. We include it here as an example, fully anticipating that it will evolve and change in the coming years.

Personal context

We acknowledge that our philosophical statement reflects our years of clinical practice in general and cancer genetic counseling in New Zealand and the United Kingdom, and our more recent experience as educators preparing the next generation of genetic counselors. We recognise and celebrate the many emerging opportunities for genetic counselors, including research and academic roles, laboratory genetic counselor roles, policy and leadership roles and roles that will use technology in new ways to provide genetic counseling care. We believe that a philosophy that holds at its heart the wellbeing, safety, care, and thoughtful consideration of the individuals and families who live with inherited conditions is directly applicable to all these roles, and to those roles that are yet to emerge.

Literature underpinning our Philosophies of Practice

Genetic counseling as practiced by genetic counselors 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 following: interpretation of family and medical histories to assess the chance of disease occurrence or recurrence; education about inheritance, testing, management, prevention, resources and research; counseling to promote informed choices and adaptation to the risk or condition’ (Resta, 2006, p.274).

Multiple definitions of genetic counseling can be found both in the literature and on the websites of the professional bodies. Biesecker and Peters (2001) proposed a working definition that captures the importance of the therapeutic relationship to ‘promote self-determination and to enhance their ability to adapt over time” (p.194). They define the goal of genetic counseling as facilitation of a ‘client’s ability to use genetic information in a personally

meaningful way that minimizes psychological distress and increases personal control' (p.194).

The values this definition privileges are those that place the client at the heart of the work.

Increasingly, other health professionals are required to communicate with clients about genetic and genomic issues, which may be termed the 'activity of genetic counseling'. This communication may include delivering information, obtaining informed consent, interpreting genetic or genomic information or planning clinical management based on the findings.

The key difference between genetic counseling as practiced by genetic counselors and genetic counseling as practiced by other health professionals is the focus on psychosocial issues and the therapeutic relationship that genetic counselors develop with clients and families with or at risk of genetic conditions (Resta, 2006). This therapeutic relationship is developed as a result of the distinct skills, qualifications, experience and expertise of genetic counselors (Middleton et al., 2015).

Our Philosophies of Practice

Within the Discipline of Genetic Counseling at UTS, we consider genetic counseling as practiced by genetic counselors to be 'a psychoeducational process focused on the communication of genetic information that is embedded within a therapeutic relationship' (Austin, Semaka, & Hadjipavlou, 2014, p.908). As such, it is our view that genetic counseling should be client-centred, with the goals of empowering the individual, fostering autonomy and promoting competency.

Through the process of developing our philosophy of genetic counseling, we have returned again and again to the relational aspects of the genetic counseling interaction. The

Reciprocal-Engagement Model of Genetic Counseling centralises the relational aspects of genetic counseling, reminding us that the outcomes of genetic counseling 'are only as good as the connection established between the counselor and patient' (Veach et al, 2007, p. 721). Genetic counseling has been characterised as a brief psychotherapeutic encounter (Austin et al., 2014). Counseling oriented genetic counseling practice 'positively influences knowledge-based outcomes' (p.905). Put more simply, people will remember more of the health and genetic related information that the genetic counselor provides if it is provided by a skilled counselor.

For us, attentive listening is at the heart of client-centred genetic counseling practice. We have reflected on the power of listening deeply to each individual client we meet, in order to understand where they are currently, and what they want, need and hope for in the interaction with us. If we truly listen, and support deep listening, with intention, appropriate questions or prompts and without judgement or reaction we can understand what is important for the client, develop an empathic connection and facilitate an interaction that will have a positive outcome for the client and their family (Donahue & Siegel, 2005; McCarthy Veach et al, 2003).

Clients seek genetic counseling to assist with integrating the news of an inherited condition into their lives, and the lives of their family members. While they may be currently experiencing a time of crisis or vulnerability, we do well to remember that the majority of the people we meet in clinics bring substantial life experience and competence to the situation in which they find themselves (Biesecker, Peters & Resta, 2019; Weil, 2000). Inviting clients to bring their competence and experience to their current situation requires us to spend time listening to their story and drawing out their skills and experiences of coping with adversity and making significant decisions, so they can apply the same skills to the current situation.

We also recognise that, while we may meet an individual or small group in the clinic, clients are part of a much broader system that includes family, community, ethnicity, culture, education, healthcare, and the broader institutional and policy structures these operate within. We draw on ecological theory to conceptualise and understand the clients we meet and the way that their lives are both supported and challenged by the layers of systems within which they live their lives (Bronfenbrenner, 1996). Understanding the broader structures and experiences, including fundamental human rights such as access to culturally safe healthcare and education, is central to the provision of competent genetic counseling care

An appreciation of the power of language informs our thinking about client-centred genetic counseling practice. The use of the word client rather than patient is deliberate and considered. The majority of people seeking genetic counseling are well at the time of referral and appointment so use of the word client suggests an autonomous and capable person seeking a service, rather than a person receiving medical treatment. We prioritise language structures that put the person, rather than the condition, first, again emphasising client-centred genetic counseling practice. For example, referring to a woman who carries a pathogenic variant in the *BRCA1* gene (rather than a *BRCA1* carrier) indicates that she is first and foremost a person just like the genetic counselor is a person, and then goes on to name the reason for seeking genetic counselling.

Examples from our own practice that exemplify the way we have developed and applied our personal genetic counseling philosophies

Alison: The centrality and power of the relational aspects of genetic counseling is typified for me by a client I met multiple times

Chris: During my practice, I was privileged to build therapeutic relationships with many clients and their families, often across several

<p>over ten years. Each time, the client was referred requesting presymptomatic testing for a familial neuro-degenerative disorder. We would sit together while he talked about the family experience of this condition, sharing the journey of another diagnosis, another death, and the fear of what the future might hold. Ten years after the initial appointment, this client chose to have presymptomatic testing. In the years leading to this decision, we had had four genetic counseling appointments, each of which I conceptualise as a brief psychotherapeutic encounter. Each encounter consisted of a conversation, during which I listened as this client made sense of their experience of a devastating familial condition. At times, I provided factual information regarding what was involved in genetic testing, however my primary role was to be the caring, empathic, listening human he needed during each encounter. As with each client I meet in clinical practice, my goal was for this client to feel empowered so that, ultimately, he would make the best decision for himself at that moment in his life. Three</p>	<p>generations. The relational aspects of my practice are exemplified by a family with familial adenomatous polyposis. I first met my client when she was newly diagnosed with colorectal cancer at age 31. For her, the decision to have a diagnostic test was straightforward, but her maternal protective instinct meant that whether, what, when and how to tell her two daughters, age six and 14, was much more difficult. I worked with my client in several face to face appointments and telephone calls - listening, reflecting, giving her time, helping her to work through and rehearse each communication, and providing support. I met her eldest daughter on several occasions, counseling her as she made the decision to undergo a predictive test, adapt to the positive result, have risk reducing surgery and come to terms with the impact of that surgery. When the youngest daughter was age nine, she attended clinic with her mother asking about testing. Drawing on the literature, my knowledge of the family, and my professional and life experience enabled me to work with the daughter to help</p>
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<p>times, the best decision for this client was to get on with his life without pursuing genetic testing. It is my hope that this client (and all clients) will remember how they felt during our brief encounters, and that their over-riding feeling is one of being truly seen and heard.</p>	<p>her to identify and name her fears, to find ways to adjust to the new reality in the family and to postpone testing until she was at an appropriate age, and later to counsel and support her through predictive testing. My philosophy of genetic counseling, helped me to remain client-centred, empathic and supportive and to facilitate autonomous informed decision-making across the generations for families such as this.</p>
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Our views of the elements of effective genetic counsellor practice

We consider that genetic counselors have a responsibility to educate, facilitate and support other health professionals to communicate with clients and families about genetics and genomics.

To practice effectively, we consider that genetic counselors need to:

1. Apply evidence-based genetic and genomic healthcare to practice across a variety of settings,
2. Develop a therapeutic relationship with clients from all walks of life and appropriately express empathy, collaboration, unconditional positive regard and goal setting,
3. Adapt and respond positively to change,
4. Recognise and work autonomously within their professional boundaries and collaboratively as part of a multidisciplinary team,
5. Practice within their professional code of ethics and scope of practice,

6. Apply professional self-awareness through self-reflection to enhance their practice and improve client outcomes,
7. Educate, facilitate and support health professionals who are not genetic counselors to deliver genetic counseling.
8. Use well-developed research skills to enhance clinical practice through an ability to critically appraise literature and to answer clinical questions

Conclusion

As advances in technology enable rapid and accessible genomic and genetic testing and other health professionals increasingly engage in aspects of genetic counseling, it is vital that clients remain at the very heart of practice. To achieve this goal, we believe that genetic counselors could draw on the example of other more established professions, such as teaching and nursing, to define and articulate as individuals and as a profession who we are, what we do, and how and why we add value to the clients and families who interact with genomic healthcare. We encourage all genetic counselors to write a philosophy of practice and to start publishing and sharing these, adding to our collective professional identity in this time of change and opportunity.

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