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The Greatest Priority for Genetic Counseling: Effectively Meeting Our Clients' Needs 2014 NSGC Natalie Weissberger Paul National Achievement Award

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Abstract

Receipt of the 2014 Natalie Weissberger Paul (NWP) National Achievement Award was a highlight of my career. Thank you to all who nominated me for this prestigious NSGC recognition. I am humbled to join past NWP award winners many of whom are admired mentors, treasured colleagues and friends. I would like to express what a privilege it is to honor Natalie Weissberger Paul for whom this award is named. Twenty-nine years ago I co-edited a volume of the Birth Defects Original Article Series with Natalie summarizing a conference co-funded by the March of Dimes and NSGC (Biesecker et al., 1987). Natalie demonstrated her devotion to children with special needs through her work at the March of Dimes. As such I believe she would concur with the focus of my remarks on the partners in our work: our clients.

Keywords

Psychotherapeutic genetic counseling; Client centered care; Paradigm shift in genetic counseling

Although in the early years of my career I served on NSGC committees, planning regional and national meetings, and held various Board positions including serving as President in 1988–1989, still I feel somewhat of a fraud in accepting this award. It came as quite the surprise! I will circle back to this perception at the end of my comments.

I love genetic counseling. The professional work is dynamic, challenging and captivating. It engages us in experiences of human suffering and resilience that we would otherwise not have the privilege of participating in. It is intimate work born of compassion and engagement with others at a meaningful level. Strangers admit us into their lives by sharing their narratives, including their thoughts and feelings about their greatest fears and hopes. We bear witness to optimism, compassion, grace and perspective that many of our patients and clients exude.

It is an exciting time in the profession that is very energizing for those of us training the next generations of counselors. There are more and varied positions as a result of the translational

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integration of genome sequencing and expanded testing options. And the number of genetic counselors has reached a mass to become more fully integrated into mainstream health care across the US and increasingly in other countries. Genetic counselors are more often participating in policy and practice conversations in Washington DC and quoted in national news articles addressing expanding clinical needs. Our graduates are accepting positions from a wider array of options with better compensation for their expertise.

Yet our profession is also alarmingly threatened by the variety of other clinical professionals assuming aspects of our work, the widespread integration of testing without involvement of counselors and the commercialization of genomics (Bob Resta, the Natalie Weissberger Paul National Achievement Award 2013 presentation). It is critical that genetic counselors remain at the forefront of delivering care to preserve informed choices for those undergoing testing and to facilitate effective coping for those at risk or affected with a genetic condition. To do so we need to promote our work and demonstrate its effectiveness using an evidence-based approach. This means advancing our research into interventions that enhance client outcomes. This expanded effort depends on our identification and use of optimal outcomes of genetic counseling. Given our client-centered model of care, these should be defined primarily by our clients.

I love genetic counseling because of our clients—our *raison d'être*. Genetic counselors are inherently curious to learn how our clients think and feel about their risk, conditions, options and decisions. Strangers bare their souls, trusting us to help them make decisions or join them for a leg of their journey to adapt to their risk or condition. Clients who present with fewer cognitive abilities are often remarkable in identifying ways to make meaning of their differences and to thrive in the face of adversity in social encounters. In these experiences there is wonder in our work.

Such praise of clients may leave you contemplating where all these remarkable people are and how you can recruit them to your practice! They are there in every clinic. As my colleague and friend Barb Bernhardt advised, “Find something you like about each client.” If you look you will find it. Even clients who are angry, sad or desperate for treatments or cures will often share the slivers of joy or hope they rely on to persevere. For one mother of several children affected by a genetic condition that leads to cognitive impairment, obesity and blindness, making beautiful meals for her children provided that glimmer of hope in spite of her children not being able to see the fruit of her labors.

Our lives are changed by our client encounters. We evolve in our understanding of what it means to be human when we are admitted to the inner lives of others that would otherwise be unknown to us. We are privy to their worries, secrets, dreams, faith, and love. What often shapes us is bearing witness to the strengths clients find; their resilience and hopefulness in the face of difficult circumstances. And the ways they use their strengths to help others even as they struggle themselves. We become better people as we open our minds and hearts to the ways that humans respond to health threat and suffering. It provides hope that future clients may find those resources as well.

We aim to effectively meet the needs of our clients clinically, cognitively and affectively. How they conceptualize their risk and feel about their risk influences what they do (or do not do) to minimize negative outcomes to their health. As such, we explore their perceptions: thoughts and feelings as they relate to their risk. Perceptions that may not be factually based or rational are real to our clients and determine how they make meaning of genetic information.

Upholding a commitment to high quality clinical work is essential to the future of our profession. Making the psychotherapeutic aspects of our counseling a priority gives us the greatest chance for more favorable outcomes for our clients. It is time to reassess our practice and realign our work with the goals outlined in the definition of practice and the reciprocal-engagement model (Resta et al., JGC 2006; McCarthy Veach, et al., JGC 2007).

In pursuit of a psychotherapeutic approach, we need to rethink our emphasis on information provision. Genetic counselors are enamored with genetics information. We became enamored with genetics in our pasts, which led us to the profession, and we want to share our affection for the science with our clients; share what we know and love with them. We regard it as our duty and primary responsibility. So it makes it challenging for genetic counselors to follow a relationally based model centered on how genetics affects our clients' thoughts and feelings, and ultimately behavior. For decades genetic counseling has prioritized information at the expense of the relationship with one's client (Roter et al. 2006, 2007, 2009). Seymour Kessler went so far as to claim that, "from the psychotherapist's viewpoint, the provision of genetic information in the absence of a growth-promoting therapeutic relationship would likely have harmful consequences for the counselees and for the persons around them" (Kessler 1979).

There *is* evidence for genetic counselors' prolific tendency to provide information without exploring client understanding or feelings, yet we have limited evidence for why it prevails. Likely information provision continues due to many converging factors, but ones we need to understand and resist in the interest of effectively caring for our clients. We know from education research that adults learn experientially rather than by listening to a recitation. Taking on new information is done in reference to what is previously known and experienced, and in relation to existing mental representations, biases and expectations.

Our sessions should begin by eliciting the client's narrative about her/his history and interest in testing or a diagnosis (this goes beyond contracting). We should carefully listen to the response and follow with conveying empathic understanding even if their response is that they have little idea why they are there or what to expect. New information can be effectively taught if it is personalized in the context of the client's narrative, building on prior knowledge, beliefs and motivations as elements that facilitate understanding. Yet genetic counselors routinely determine what information should be presented and how to present it. Rarely do we explore what our clients or patients already understand or value or what they would like to learn and how they would like to learn it, although evidence demonstrates that this is how adults learn (Roter et al. 2006, 2007, 2009).

I concur with President–Elect, Jehannine Austin’s plea in this journal (Austin et al. 2014) that the relational aspects of the genetic counseling profession are critical to our survival as a profession. We need to make a break from a practice of imparting information and embrace the working alliance based on eliciting, listening, inquiring and reflecting back to our clients our impressions of what they are thinking and feeling to ensure we understand them. This represents the essence of how we are able to help clients explore, react, deliberate, and use the information we aim to teach them. Such a partnership lays the groundwork for shared decision-making, a collaborative deliberation. (Elwyn et al. 2014).

We need evidence that what we are doing with our clients results in positive outcomes. What evidence exists, such as client benefits from anticipatory guidance in counseling (Bernhardt, et al. 2000) and attention to cognitive and emotional processing (Guan 2015), we need to integrate into clinical practice. For the many areas of genetic counseling for which there is insufficient evidence, research is greatly needed. To contribute to research in our profession, learn to design meaningful studies. It helps to collaborate with experts in social and behavioral science and psychotherapy research. If you are not motivated to collaborate with others in conducting research, read the professional literature voraciously and critically, and import ideas and interventions for which there is emerging evidence into your practice. Audiotape your sessions and assess client responses to your interventions. Present your findings at national meetings and publish what you learn. Our survival as a profession is keenly tied to generation and implementation of evidence.

Self-reflection is critical to assessing and improving our own practice. Routinely reviewing audiotapes of ones cases and listening to how our clients interact with us can help us to reflect on our style, content and response to client cues. We should all be presenting our work in peer or professional supervision where we can learn from others who we respect and have our best interests in mind. Embrace these ideas and find yourself rewarded with a more stimulating and illuminating practice model.

Strategies to enhance genetic counseling

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- Reflect critically on your practice; re-evaluate your model and engage in peer supervision
 - Use the relational aspects of genetic counseling to achieve beneficial client outcomes
 - Genetics education should be experiential: integrate novel information into the client’s existing mental representations
 - Facilitate preference-based decisions using a shared decision making strategy
 - Integrate emerging genetic counseling data into your work to promote evidence-based practice
 - Identify research from related fields that can be applied to your practice and appropriate it
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Nearly forty years ago Seymour Kessler called for a paradigm shift in the way that genetic counseling was being provided; towards a psychotherapeutic model of care (Kessler 1979). In 2014 we find ourselves not yet having made that paradigm shift from a predominantly information-oriented practice. There is much more work to do to help achieve this critical shift, and rapidly so that we can demonstrate our effectiveness before other providers absorb critical aspects of our profession. As stated previously, I feel undeserving of this award. As

of yet I have not reached my professional goal to see genetic counseling make this critically needed paradigm shift. I, and you, have much work to do!

One critical hope for our profession is the alumni of our program. I love genetic counseling because it is tied to my affection for our students. They are so eager, committed and hard-working and it is infectious. They trust us to serve as mentors, role-models and teachers to help them to address their worries and struggles to realize their dreams to practice effective genetic counseling. To witness them engaging, striving, evolving and working to meet their clients' needs is inspiring. Their self-discovery and professional development are transformative for them and all who have the privilege of working of them. We have a graduated a cohort of genetic counselors who realize that our work is not done...there is always something more to achieve, always something more to learn, always a better way to show our compassion for those we serve. This is one of my greatest sources of joy and investment in the future of genetic counseling.

I love genetic counseling because of the close colleagues I have worked with over the years who have taught me critical aspects of the work and who have helped me to recognize my weaknesses and strengths. Those who have significantly influenced my professional development and given their collegial friendship include; Jehnnine Austin, Barbara Bernhardt, Lori Erby, Don Hadley, Gillian Hooker, Lauren Kerzin-Storarr, Katie Lewis, Trish Magyari, Aideen McInerney, Holly Peay, Kathy Peters, Julie Sapp, Amy Turriff and my husband, Les Biesecker.

I love genetic counseling because of the fabulous mentors I have greatly benefitted from over the years. Their mentorship has been demonstrated by their own efforts to improve their work and their parallel expectations of their mentees. They motivate others and it is obvious that they care very much that we succeed. I have many mentors to thank as my career has been riddled with an embarrassment of riches. I am proud to be in a profession that has brought each of these mentors into my life and so grateful to have benefitted from their wise guidance and expertise. My life and work is all the richer from working with them. They include: Diane Baker, program director; Bryan Hall, first boss; Renata Laxova, second boss; Beth Fine, admired colleague; Jim Crane, third boss; Mason Barr, senior colleague; Francis Collins, later boss; Caryn Lerman, research colleague; Barton Childs, senior colleague; Bob Nussbaum, medical director; Bob Croyle, research colleague; Seymour Kessler, senior colleague; Shoshi Shiloh, senior colleague; Alan Guttmacher, medical director; Theresa Marteau, dissertation advisor; Colleen McBride, branch chief; Paul Han, senior colleague; and Bill Klein, senior colleague.

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As genetic counselors, let's focus our lens with greater clarity on our clients: our professional raison d'être.

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