

Defining Moments in Genetic Counselor Professional Development: One Decade Later

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Ten years ago we contacted then Editor of the *Journal of Genetic Counseling* (JOGC), Dr. Allyn McConkie-Rosell, to propose a series of “Defining Moments” essays. She encouraged us to “give it a try,” and the result was 15 essays from 17 authors [see *JOGC*, 2002, 11(4)] that illustrated numerous themes regarding professional development processes and outcomes. Because we so strongly believe practitioners grow professionally and personally when they have an opportunity to reflect upon their colleagues’ experiences, we decided to again invite members of the profession to “tell their stories.” The response was impressive—34 essays by 37 authors!

In 10 years, the number of essays has doubled and includes papers from around the world. We believe this expansion reflects the vibrancy of the profession and its increasing globalization. These stories also clearly demonstrate common experiences that further solidify our belief that genetic counseling is a unique health care profession. Once again there are defining moments that occurred in all phases of the authors’ professional development including

students, novices, and experts all providing genetic counseling services. There is even one “repeat author” [(Drake) Sebold] who wrote her first essay in 2002 while she was a genetic counseling student.

Format

To set the stage for the essays that follow, we first describe how we obtained these papers and then comment briefly on each one. Similar to the 2002 procedures, we invited proposals from all members of the National Society of Genetic Counselors via the listserv and published a “Call for Papers” in the *Journal of Genetic Counseling*. We used virtually the same definition of “defining moment” as in the first series (McCarthy Veach et al. 2002a): *Defining moments include any personal experiences or events that lead to realization about one’s self as a genetic counselor. Defining moments can come from all areas of one’s life, both personal and professional. They can be positive, negative, or “mixed” events that significantly affect a genetic counselor’s professional development.* As in 2002, we asked authors to describe the context of their defining moment (what happened), their reactions during and after the events (including their feelings, thoughts, and actions), how the events affected their professional development, and how the authors were able to resolve the events positively.

Themes

Similar to the 2002 series (McCarthy Veach et al., 2002a, b) the current defining moments include events that are random (e.g., diagnosis of a medical condition in one’s self), as well as events that an individual deliberately seeks

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(e.g., deciding to pursue a professional development opportunity). The authors play a major role in making these events influential in their professional development. The authors' readiness to learn from their experience, ability to engage in honest and often painful self-reflection, and their efforts to generalize their learning to their "personal" and "professional" selves give these experiences their defining power.

These essays illustrate that learning is a continuous, non-linear process (Note the number of authors who use the term "roller coaster" to describe their defining moments). Ultimately, however, through courageous self-reflection and the support of colleagues and loved ones, the authors progress in their development. The essays also demonstrate that development can occur from all sorts of personal and/or professional experiences, including BIG defining moments and smaller defining moments. You will notice a number of similar "lessons learned" by authors whose defining moments are quite different from each other. It seems as if *what* individuals choose to do with their experiences rather than the *type* of experience itself comprises the essence of the defining moment.

Three overarching themes characterize the nature of these defining moments: Patient Lessons (16 papers), Personal Life Events (12 papers), and Professional Milestones (7 papers). These themes are similar to those described in the 2002 series (see McCarthy Veach et al., 2002a, b). Nonetheless, the authors' unique stories reinforce important "learning points;" and they contribute richness and nuance to the lessons from 2002. The current series adds to a growing body of evidence demonstrating the importance of genetic counselor self-reflection, risk-taking, and translation of learning to professional practice (e.g., Anonymous, 2008; Abrams & Kessler, 2002; Runyon et al. 2010). In the following sections we offer you a glimpse of these stories and the lessons contained therein.

Patient Lessons: Learning What it Means to Help

Sixteen essays involve encounters with patients that resulted in qualitative changes in the authors. These essays demonstrate that *first-hand* experience is a powerful teacher. A number of authors describe the positive effects of moving from the relative safety of their typical *script* when interacting with patients to a riskier *improvised* approach. These experiences deepened the authors' affective empathy. They no longer primarily *thought* about how others feel, they *felt* how others feel.

Six individuals describe specific patient situations that allowed them to *learn to listen* in order to understand individual patient wants and needs. Consequently, they now have a deeper appreciation of what it means to help. They shifted from being counselor-focused (guided by their own

perceptions and desires) to being patient-focused (guided by the patients' wants and needs). For example, Freeman learned to put aside her own perception of what it means to help when she counseled a patient who expressed a desire to terminate a pregnancy if the fetus was a female carrier of hemophilia. Freeman was able to support the patient in important ways despite having to tell her the hospital would not terminate a female fetus.

Similarly, Chin learned to set aside her script when counseling a man with Klinefelter syndrome who wanted to believe in the possibility that his partner was carrying his biological child. Despite her repeated attempts to explain the connection between infertility and his condition, he persisted in expressing hope that he was the father of the baby. Chin learned that "...not everything in genetics is genetic" (in this issue). She now attempts to listen to and prioritize her patients' agendas. Lakhani similarly learned, through an international genetic counseling experience and the guidance of a mentor, to revise her script when counseling a couple in the Middle East. She learned that full disclosure of a person's genetic status might be more harmful than helpful. From this experience Lakhani realized that genetic counselors have to make "on the spot" decisions about what to say and how to say it—tailoring their counseling to the patient sitting in front of them.

Vanneste learned to more fully listen to her patients after she made a mistake with a prenatal couple and attempted to manage her guilt about it. Her defining moment occurred as she figured out how to distinguish her feelings and needs from those of her patients by listening "...to how I am feeling about a particular case..." (in this issue). Hopkins advocated with other care providers and a hospital ethics board in the case of a couple from India. The couple was deciding whether to withhold treatment from their newborn who had Down syndrome and a heart defect. Although Hopkins experienced value conflicts in this situation, she was able to put the couple and their baby first, by focusing on the importance of respecting their cultural beliefs and practices.

During a genetics rotation as a medical student, Bodurtha learned a valuable lesson about how to build relationships with patients. She interviewed Dr. J-H Tjio, the scientist "...who first counted the chromosomes under the microscope" (in this issue), about his asymmetric septal hypertrophy. His openness with her allowed Bodurtha to listen and appreciate the man behind the condition. Bodurtha states her experience with Dr. Tjio "...helped define my awareness that we are all more similar than different in our need to listen to one another as well as in our DNA" (in this issue).

Three authors learned to trust their intuition when moving beyond the traditional boundaries of a genetic counseling session. Infante describes how going beyond the

typical office boundaries is sometimes necessary to best serve patients and families. She learned this lesson through her experience providing information and emotional support to a pregnant adolescent whose baby was diagnosed with schizencephaly. Infante stayed with the patient and her family members through several difficult appointments, and she later followed up to support their efforts to cope with their situation.

Oswald also moved beyond traditional boundaries as she worked with “Mary,” a young adolescent diagnosed with Loey-Dietz syndrome, and her family. Mary died on Christmas day after undergoing heart surgery. Oswald stayed with the family that day and followed-up with them, going beyond her “routine” responsibilities as a genetic counselor. In doing so, she used her intuition and empathy to guide her actions. Referring to reliance on her intuition, Oswald realized, “I have to go where I don’t want to go” (in this issue).

Flynn similarly ventured beyond the genetic counseling room to provide ongoing support for a young couple. The husband was diagnosed with gastric cancer. Flynn describes the power of being able to listen fully and to maintain a connection even after the husband died. She learned that being a “counselor” is as vital as the information she provided to this couple.

Two authors, Burgess and Trepanier, write about finding and/or reaffirming their model of genetic counseling practice. As a novice counselor, Burgess was called upon to use his French to provide genetic counseling for a patient when an interpreter was not available. Although he did not feel as prepared as he might wish, he forged ahead, and the session went extremely well. His improvisation helped Burgess realize that the Reciprocal-Engagement Model of practice (McCarthy Veach et al. 2007) best fits his approach as a genetic counselor. Trepanier describes a genetic counseling relationship in which she focused a bit too heavily on information provision at the expense of considering a couple’s psychosocial circumstances. As a result, she reaffirmed that her model of genetic counseling must involve more than teaching. She writes, “It is not always (ever?) enough to just give people genetic information. It is so very important to consider the context in which patients receive the information” (in this issue).

Five authors describe general lessons they learned from patient interactions. Knutzen eloquently describes learning the meaning of hope for her patients and for herself as a result of giving *bad news* to a couple. She writes, “It is not our job to extinguish hope, but rather to dance the fine line between igniting the flames of unrealistic hope and smothering the flame of what little hope may remain.” Curnow similarly realized the power of hope and resiliency through her patient, Anna, who received a positive HD test result. Anna continued to be a tireless advocate for HD

research, even after learning of her test result. Curnow writes, “The result did not break Anna, but instead gave her further resolve” (in this issue).

With increased development comes less of a *self-focus* and more of a *patient-focus*, so well-described by Mathiesen whose defining moment involved counseling an angry patient. Mathiesen initially felt attacked and defensive. Through consultation with others and self-reflection she learned not to take patient anger personally. She writes, “... I was there to support the patient with her situation. Therefore I had to realize that if a patient is angry there is likely a good reason for this emotion” (in this issue). Sebold learned important lessons about recognizing and accepting her limitations as well as the value of social support through two defining moments. In one situation, she realized that by she admitting to herself and to a mother that she did not know what was wrong with her daughter, her authenticity built the relationship. In another situation when a patient who received a positive HD test result committed suicide, Sebold initially experienced a crisis of guilt and self-doubt. She turned to colleagues to help address her reactions and ultimately realized “...it is not only acceptable, but often necessary, to lean on colleagues and peers for support” (in this issue).

Walker connected two experiences involving suicide by individuals in her personal life with the experiences of members of a post-partum depression support group, thus realizing the profound nature of depression. Her realization prompted her to review research on post-partum depression and other mental health disorders. Walker now raises the topic of post-partum depression explicitly with prenatal patients she perceives as at risk, and she has become a more vocal advocate for mental health issues.

Personal Life Events

Ten authors describe defining moments that involved health issues in their personal lives. Their defining moments illustrate how one’s professional life affects one’s personal life, and vice versa, when the events involve a medical condition. These authors initially attempted to compartmentalize their personal life and their professional lives. Anonymous writes about her diagnosis of premature ovarian failure and subsequently learning she is a carrier of Fragile X syndrome. Although she initially needed to distance herself from her clinical work, she eventually was able to put the two pieces back together. As she so powerfully expresses, “I have learned it is not necessary to separate myself from my-counselor-self because ‘we’ are far stronger together than we could be apart” (in this issue).

Indeed, it seems impossible to completely separate these two parts of one’s self. McKanna describes a defining moment in which she realized that being a parent meant she

no longer wished to do pediatric genetic counseling. She offers a compelling metaphor regarding the extent to which genetic counselors can separate their personal and professional selves, "...it's like putting up a lane marker in a pool: on the surface you can appreciate the division, but everything underneath all swirls together no matter what you do. It doesn't matter which lane you are swimming in, it's all part of who you are" (in this issue).

Personal life experiences also have the potential to decrease genetic counselor judgmentalness while simultaneously increasing their empathy for patients. Jonas' defining moment involved challenges she and her husband experienced in coping with their infertility. She describes how this experience allowed her to decrease her assumptions about what patients want, what they are feeling, what they will decide, and how they will cope. Panchal describes how her husband's diagnosis of stage IV Non-Hodgkins Lymphoma enriched her understanding of her patients, including how their needs and feelings change at various points in their health situation. She also alludes to being denied the *blissful ignorance* many patients possess about their condition.

Similarly, Glessner writes about her diagnosis of and treatment for vocal cord cancer. Her perspective as a genetic counselor helped her cope effectively with her cancer, and her perspective as a cancer patient allowed her to realize the full import of psychosocial terms such as "empathy" and "self-disclosure" in her clinical work. She now approaches her patients differently [e.g., "no bad news given on a Friday" (in this issue)]. Gordon also describes qualitative changes in her empathy, and her increased appreciation for both her patients' and her own resiliency. These changes were precipitated by coping with her husband's diagnosis of a spinal cord tumor.

Bellcross's defining moment began with the birth of her first child, Connor, who has special needs. She learned that people have to work hard to develop resiliency (they don't automatically have it), and that coping is a never-ending process. Her experiences have qualitatively affected her empathy for patients. She writes, "Do I feel my patient's pain more deeply than other genetic counselors? I don't think so. I simply feel it differently" (in this issue). Bellcross also is vigilant about her countertransference ["We can never separate ourselves from our own feelings and emotions. We must simply be aware of what they are, and when they might prevent us from focusing on the needs and wishes of our patients" (in this issue)].

For two authors, countertransference is the essence of their defining moments. The reality that genetic counselors "bring their lives into the genetic counseling relationship" is apparent in Hyatt's defining moment. She describes how her fear of postnatal depression was triggered during a session with a prenatal couple who received a diagnosis of

a fetal abnormality. Hyatt sought consultation and her own personal counseling to address her feelings. Kinsley similarly writes about recognizing and managing her countertransference with an adolescent patient who was diagnosed with mosaic Turner Syndrome. The patient's questions about her sexual identity sparked Kinsley's own reflections about her inability to have children and its implications for her own gender identity. She writes, "This was not only her story, but mine" (in this issue).

The complex interplay of the genetic counselor as a "person" and as a "professional" is well-illuminated in two papers describing the authors' involvement in a loved one's cancer diagnosis. Matloff's defining moment occurred when her sister's close friend was diagnosed with Stage III breast cancer, and it came to light that the friend had a family history of a BRCA1 mutation. Matloff describes the ongoing information and support she provided her sister from the time of the friend's diagnosis to her death. Matloff's experience led to a *professional renewal*. She writes that despite the profession's lack of glamour and the frequent uphill battles to explain its importance, this experience helped her to reaffirm her commitment to genetic counseling and reinforced the importance of her work. Three colleagues, Mac Shane, Mountain, and Kiraly-Borri describe how they "struck a balance" in their workplace when Mac Shane's sister was diagnosed with breast cancer and a BRCA1 gene change. Mountain became her sister's genetic counselor, and Kiraly-Borri became her sister's geneticist. The authors found a way to manage their multiple relationships as colleagues, care providers, and friends. Their efforts resulted in the provision of needed information and psychosocial support to Mac Shane's sister and family, and to each other.

Professional Milestones

Eight authors describe professional transitions that affected their career satisfaction and overall professional development. Vogel experienced herself *running in place* when she took on too many additional professional responsibilities. This awareness allowed Vogel to give herself permission to say "No." Her ability to set reasonable boundaries allows her to maintain a standard of quality in her work.

By coping proactively with a failed board exam, Bradley learned that self-validation is every bit as meaningful, if not more meaningful, than external markers of one's competence. She learned her competence is more than an exam score. Bradley's story illustrates the value of positive self-talk and reaching out to others for support.

Two papers describe educational opportunities that became defining moments. In the paper by Paull and Lipinski, Paull describes how she *seized the day*, completing a fellowship in lysosomal storage disorders. Her

experience accelerated her professional development in ways she could not have imagined. Redlinger-Grosse removed the “routine” from her prenatal genetic counseling (said “routine” being herself) by beginning a doctoral program in Counseling Psychology. Her doctoral studies have renewed her commitment to actively engage in self-reflection and to consider her patients’ individual and cultural issues.

When Wessels took on the role of clinical supervisor/trainer/mentor, she evaluated her own genetic counseling as one method for providing supervision. In doing so, she realized she was overly-critical of her work; indeed her criticisms far outweighed her positive self-feedback. Wessels translated her realization of the necessity for balanced feedback to her work with students. She writes, “A non-judgmental reflective process in a supervision session allows not only learning, but also sharing, consoling and thinking, such as what occurs in the genetic counseling process” (in this issue).

Campion’s defining moment involves her courageous “leap into” the role of creating and directing a masters program in genetic counseling. She describes her hard work, willingness to take risks, and reaching out to others for guidance and support. Regarding the first incoming class of students, she writes, “As orientation approached, I realized that the curtain would rise, the show would start, and all of our lives would forever be different.” Sahhar’s defining moment began with an invitation to join a steering committee to develop genetic counseling in Australia. Her willingness to take on a complex task, despite working part-time and raising young children, places her among the founders of the genetic counseling profession in her country. In addition to the many professional opportunities her involvement has afforded her, Sahhar’s *voice* is evident from the early development of the field in her country to its current state.

Summary and Conclusion

The defining moments in this issue of the *Journal of Genetic Counseling* exemplify the powerful and on-going influence professional experiences and personal life events may have on development. The authors’ experiences provide valuable lessons about the power of human resiliency and hope. No matter how intensely these authors were challenged, no matter how much they risked losing, they moved forward. Every one of them ventured far beyond their comfort zones. Their defining moments

illustrate many of the personal qualities associated with professional development (Zahm, 2010), in particular: empathy, authenticity, honesty, self-awareness, resiliency, compassion, connection, courage, and commitment.

These essays contain a wealth of wisdom. They offer many insights about turning experiences into opportunities to learn, grow, and improve as professionals and as human beings. We thank the authors for sharing their defining moments. We believe you will be as touched by their stories as we were when reading them. Some will make you cry, others will make you smile. We are confident you will see yourself (or your potential self) in every one of them. We hope their stories will prompt you to reflect upon who you are, what you do, and why you do it, and help you appreciate what a privilege and challenge it is to be a practitioner in such a dynamic profession.

Caveat

Unless an author indicates having received permission to use actual names of patients or individuals who otherwise should remain anonymous, all names/initials are pseudonyms.

References

- Anonymous. (2008). A genetic counselor’s journey from provider to patient: A mother’s story. *Journal of Genetic Counseling*, 17, 412–418.
- Abrams, L. J., & Kessler, S. (2002). The inner world of the genetic counselor. *Journal of Genetic Counseling*, 11, 5–17.
- Defining moments essays. (2002). *Journal of Genetic Counseling*, 11 (4), 281–332.
- McCarthy Veach, P., Bartels, D. M., & LeRoy, B. S. (2002a). Defining moments: Catalysts for professional development. *Journal of Genetic Counseling*, 11, 277–280.
- McCarthy Veach, P., Bartels, D. M., & LeRoy, B. S. (2002b). Defining moments: Important lessons for genetic counselors. *Journal of Genetic Counseling*, 11, 333–337.
- McCarthy Veach, P., Bartels, D. M., & LeRoy, B. S. (2007). Coming full circle: A Reciprocal-Engagement Model of genetic counseling practice. *Journal of Genetic Counseling*, 16, 713–728.
- Runyon, M., Zahm, K., McCarthy Veach, P., & LeRoy, B. S. (2010). What do genetic counselors learn on the job? A qualitative assessment of professional development. *Journal of Genetic Counseling*, 19, 371–386.
- Zahm, K. W. (2010). Professional development: Reflective genetic counseling practice. In B. S. LeRoy, P. McCarthy Veach, & D. M. Bartels (Eds.), *Genetic counseling practice: Advanced concepts and skills* (pp. 353–380). New York: Wiley.