J Genet Counsel (2017) 26:195–198
DOI 10.1007/s10897-017-0080-0

COMMENTARY

Special Issue Introduction: Dealing with Psychological and Social Complexity in Genetic Counseling

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Received: 30 January 2017 / Accepted: 6 February 2017 / Published online: 7 March 2017

We are pleased to invite you to explore and celebrate this Special Issue of the *Journal of Genetic Counseling*, "Dealing with Psychological and Social Complexity in Genetic Counseling," with international submissions from the United States, Canada, United Kingdom and Australia. The volume of submissions we received shows how much interest there is in the topics reflected in this Special Issue. While there were many other worthwhile submissions, we selected the papers that follow because of their special relevance and creative approaches to the topic of psychological and social complexity in genetic counseling. We believe and hope that deep exploration of this Special Issue will stimulate at least as many questions as are answered.

We have organized this Special Issue as follows: First some background material, then several papers on genetic counselor training, genetic counseling in specialty practices of cardiovascular and cancer genetics, papers presenting legal and ethical issues, incorporation of new counseling models, and finally, consideration of similarities and differences of genetic counseling and psychotherapy.

As the practice of genetic counseling has grown over four decades, we are still asking the question "Can we define the 'counseling' in genetic counseling?" In this issue, we have been asked to consider genetic counseling as a form of psychotherapy. Our first response was surprise, but why should we be surprised when Seymour Kessler PhD in a seminal paper entitled "The Genetic Counselor as Psychotherapist" states "Genetic counseling has all the essential characteristics of a psychotherapeutic situation…" (Kessler 1979, p. 188). Early genetic counseling was based on Rogerian principles, as was much of psychotherapy. Rogerian counseling is an approach marked by therapist attitude of empathy, genuineness, and unconditional positive regard (often discussed in contemporary literature as non-judgmental attitude of acceptance). But the world changed, and so did genetic counseling. While Rogerian principles are still a cornerstone of all good counseling, we outlived the non-directive approach in certain situations (Weil 2003; Weil et al. 2006). Our profession has a long history of incorporating existing psychosocial theories to underpin our counseling such as object relations, self-psychology, attachment theory, various family therapy models, cognitive-behavioral therapy and a host of others. Recent research has also emphasized the addition of social psychological theories and shared decision-making models. Since its inception we have aimed to deconstruct the "counseling" in genetic counseling through a new definition [Resta 2006], defining training competencies (Ferrier et al. 2013; Fine et al. 1996), publication of peer-reviewed papers that offer insights into the counseling process and more recently defining and validating a proposed genetic counseling model, the Reciprocal Engagement Model (REM) (Hartmann et al. 2015; Mc-Carthy-Veach et al. 2007; Redlinger-Grosse et al. 2016).

The papers in this issue demonstrate that effective counseling is alive and well in the practice of genetic counseling. Two papers address facilitating the training of genetic counselors to be more psychosocially focused in their service provision (Eisler et al. 2016; Shugar 2016). One is a concept paper on teaching genetic counseling skills to genetic counseling students by incorporating the original Genetic Counseling

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Adaptation Continuum model to address psychological and social complexity (Shugar 2016). Original research on genetic counseling experiences are included in another paper which reports on the experience of training genetic counselors to deliver an innovative therapeutic intervention in multi-family discussion groups (Eisler et al. 2016).

Specialty practices in genetic counseling are continuing to grow, and as the genetic science advances, the need for psychological approaches to clinical translation become obvious. We have included a paper proposing a multi-disciplinary practice model to address psychosocial issues in genetic assessment of cardiovascular disease (Rhodes et al. 2016). Similarly, Corines et al. (2016) provide a paper on genetic counselors implementing informational workshops and psycho-educational support groups for families with Lynch Syndrome.

We include two papers focusing on parents talking to children about genetic testing, one from the UK and another from the US (Fenwick et al. 2016; Patenaude and Schneider 2016). This is a topic that has generated considerable professional soul-searching and ethical debate over the decades, especially during the period when genetic testing was considered research and there were few or no interventions that could be offered. However, times are changing, and the pendulum is swinging toward more testing. Fenwick et al., suggest reframing requests for testing from parents as a discussion about the optimal time of testing for adult-onset disease (i.e., asking "when" rather than "whether"). Patenaude and Schneider assert that there is no recipe for answering parents' questions but rather suggest that successful consultation requires tailored counseling incorporating relevant areas of family exploration.

Readers will undoubtedly find thought provoking several of the papers presenting ethical and legal dilemmas. One concerns identification and interventions regarding intimate partner violence (IPV), a social issue that is common but rarely raised in genetic counseling (Chen et al. 2016). Two are especially provocative. One addresses the effects on close family relationships of pre-symptomatic testing for Huntington Disease (HD) in an adult with intellectual disabilities whose guardian who is initially reluctant to discuss the testing and share the diagnosis with the person tested (Schilit and Nitenson 2016; Warren and Schak 2016). Another thought-provoking paper is a first person account of testing one of a pair of adult identical twins (Schilit and Nitenson 2016). We invited two commentaries on Schillit and Nitenson's narrative of adult twins using whole genome sequencing, as the authors present not only the dilemma of genomic testing of identical twins but also the broader issue of how genomic testing is being introduced to the healthy general population (Burke 2016; Suckiel and Zinberg 2017).

We include a paper highlighting a graded relational approach to genetic counseling for Hereditary Breast-Ovarian Cancer Susceptibility (HBOC) (Forbes Shepherd et al. 2016). In their qualitative study involving semi-structured interviews with 16 Australian genetic counselors, these researchers found the genetic counselors employ three escalating stages of relational approaches to encourage the disclosure of genetic testing information to relatives: 1) covert suggestion, 2) overt suggestion, and 3) authoritative statements about the benefits and obligations of disclosure. There were only rare circumstances where counselors took the proactive, authoritative stance to persuade a client that disclosure would be beneficial, often in extreme cases. This final approach was perceived as "the only remaining" option. Again, this paper raises new psychosocial and ethical questions. We wonder whether readers may agree or will perhaps recall other clients of their own who employed active or passive non-disclosure for a variety of reasons such as dealing with other demanding life crises, personality traits, ideological opposition to cooperating with medical advice, family estrangement, lack of easy opportunity, protecting others that they consider vulnerable, or other reasons. You may find yourself contemplating: "What approaches have worked for me?"

We hope that this Special Issue adds to the discussion about psychological and social complexities. Our genetic counseling profession has embraced its ethical responsibilities to ourselves and our patients per our Code of Ethics (NSGC 1992). If we are offering psychosocial interventions, we need to define our role clearly to our patients and get their informed consent to engage in these deeper psychosocial activities. To fully embrace psychosocially oriented genetic counseling, we also need post-graduate professional development training opportunities for clinical genetic counselors. This goes beyond individual workshops or talks at the annual educational conference; rather, we need continuity of continuing education experiences over years with facilitators returning year after year to help counselors refine their skills and develop the practice dexterity and confidence to have multi-session genetic counseling with participants who need and seek it. For example, psychotherapists offering group counseling in a particular approach usually attend annual professional meetings focused on skill development year after year, often with the same trainers and participants. In another example, one of the authors of a paper in this issue sought out multiple training opportunities in a related field of Motivational Interviewing, leading toward certification in that particular model of behavior change [Erin Ash, personal communication]. Redlinger-Grosse and the co-editors of this Special Issue have formally cross-trained in psychotherapy in addition to genetic counseling.

We include two papers attempting to integrate existing psychological and behavioral science theories, methods, and models into the published Reciprocal Engagement Model (REM) of genetic counseling. Both of these studies stretch the limits of traditional genetic counseling and deserve careful reading, deep inquiry and animated discussion. Our Australian colleagues report on a pilot study of an online

psycho-educational intervention about familial risk of depression for patients attending general medical practices (Meiser et al. 2016). In another example, Ash integrates Motivational Interviewing (MI) into the Reciprocal Engagement Model of Genetic Counseling (Ash 2016). It is interesting that MI seems to re-name and reframe many of the standard concepts, skills and practices that have long been part of both genetic counseling and psychotherapy (e.g., engage and bond with the participant, listen carefully for ambivalences, don't argue or coerce). Both of these papers borrow from psychotherapy theory and methods to enhance genetic counseling and demonstrate just one of the many phases of building an intervention to address emotional and informational needs of families facing hereditary conditions.

We are pleased to include a paper by three psychosocially skilled genetic counselors who use case examples to demonstrate how skilled genetic counseling can incorporate Fuzzy Trace Theory (FTT) and Cognitive Behavioral Therapy (CBT) (Biesecker et al. 2016b). We agree with the basic premise that the relational aspects such as establishing an effective working alliance, empathy, collaboration, positive regard and goal consensus are as essential to effective genetic counseling as to successful psychotherapy (Austin et al. 2014; Djurdinovic 2009). However, we especially wanted to address the tension between trying to encourage rich psychological encounters between genetic counselors and our clients and the need to clearly define and distinguish the professional roles of genetic counselors and psychotherapists. Therefore, in conjunction with this new paper, we have invited a commentary about the intersection of genetic counseling and psychotherapy (Redlinger-Grosse 2016). In response, Biesecker et al. have replied regarding their contention that genetic counseling is a form of psychotherapy (Biesecker et al. 2016a). They argue there is an historical precedent for considering genetic counseling to be psychotherapeutic, that there are overlapping theories, goals, skills, and research evidence, when available. The authors posit a continuum from educational genetic counseling through therapeutic genetic counseling to psychotherapy that may resonate with many genetic counselors. The Biesecker et al. response, however, does not address recognized differences between genetic counseling and psychotherapy in terms of patient contracting, academic degrees, training models, supervision, continuing professional education, state licensure requirements, malpractice insurance and practice models involving long-term care. Nor does the genetic counselor typically address deeper psychosocial issues such as entrenched defense systems, dysfunctional coping and adaptation, characterological disorders, marital discord, chronic anxiety, major depression or delusions that are usually addressed with psychotherapy with or without medications.

As an alternative, others may see a practice model where there is a discrete threshold demarking even the most psychotherapeutic genetic counseling from psychotherapy (Fraser 1982; Peters 1994). We wonder what those professionals who are cross-trained and credentialed in both genetic counseling and psychotherapy would say. What about the views of program directors- are genetic counseling programs preparing students to do psychotherapy? Perhaps this is all just semantics, as some have suggested. However, we believe there is opportunity for further debate to reconsider expanded roles in genetic counseling.

Finally, we close this issue with a paper that explores the interpersonal experience of several genetic counselors and their patients who maintained an ongoing personal connection after the completion of genetic counseling (Williams et al. 2016). We are reminded that we are witness to difficult life experiences and through our support and guidance; some of our patients can find comfort in remaining in connection with us. Our journeys with our patients with whom we have long term connections need to be examined by each of us to assure that our connections are genuinely beneficial for the patient.

We want to support the wish for a more psychologically-oriented genetic counseling that best serves the needs of counselees and counselors. To this end, we want to thank each of the authors for raising the issues and helping to set the stage for expanded opportunities for examination of the psychological and social complexities inherent to genetic counseling. We also thank them for describing potential ways to address the multiple challenges faced by individuals and families seeking genetic counseling.

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