



## Genetics and ethics

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The article “Ethics in Genetic Counseling” by Angus Clarke and Carina Wallgren-Pettersson in this issue of the *Journal of Community Genetics* opens a series of comprehensive reviews of topics central to community genetics. Genetic counseling is a central component within the practice of medical genetics, bridging the science and medical aspects of genetic illness with patient and family responses to illness and disability. While an important role of genetic counseling is to convey medical facts and facilitate patient understanding, genetic counseling goes far beyond that and raises issues of consent and autonomy, social views towards disability, personal and family adaptation to illness and impairment, individual perceptions of risk, communication within families, and the challenges in dealing with uncertainty. The abovementioned review article is based on a 3-day ethics course taught for more than 15 years in the UK to genetic counseling masters level students and genetics colleagues. Dr. Clarke himself has published more than 50 articles on genetics and ethics over nearly 30 years and brings his strong clinical background and experience to the discussion; we note that he co-founded the Genethics Forum in 2001, “...a well-established national ethics forum for genetics professionals in the UK” (Parker 2015).

Throughout the article, Clarke and Wallgren-Pettersson (2018) lead the reader through clinical scenarios across the lifecycle: prenatal genetics (including expanded carrier testing and the increasing future potential for prenatal genomic sequencing), diagnostic genetic testing in children and adults, and predictive testing in both adolescence and adulthood, as well as the impact of family communication and cultural issues. While framed as most relevant to the UK and Europe,

many of the topics presented in the article mirror those described in recent surveys of ethical challenges in the USA (Alliman et al. 2009), Australia (Alliman et al. 2009; McLean et al. 2013), and Spain (Abad-Perotín et al. 2012). Across the various examples, they briefly describe and advocate for the role of a clinical geneticist or genetic counselor to actively facilitate patient and family decision-making based on eliciting and understanding the values of the patient(s), as is described by Kessler (1997, 2001) and Weil et al. (2006).

Recognizing that many people struggle with developing a process for ethical reflection and analysis, they recommend that clinicians begin by identifying a problem is an ethical dilemma, and to then use a framework of identifying interests, considering solutions and the relationship with various interests. This mirrors aspects of relational ethics upon which the NSGC Code of Ethics was initially (Benkendorf et al. 1992) and is still based (NSGC 2018; Senter et al. 2018). Additional common approaches to ethical analysis include a principles-based approach, first described by Beauchamp and Childress (1979), and elaborated upon by Gillon (1994). The four-box approach to clinical ethics (Jonsen et al. 1982) is often used in clinical medical ethics consultation and considers relevant aspects of the medical indication, including its degree of certainty or uncertainty, which is increasingly critical as our genomic knowledge and testing capabilities expand. Also relevant are disability ethics models, including Rolland’s Family Systems Genetic Illness mode, which considers aspects such as clinical severity, onset within the lifecycle, type and impact of impairments, and treatment availability (Rolland and Williams 2005).

Finally, we want to remind readers that moral distress can occur in clinical geneticists and genetic counselors as a result of working in such emotionally charged situations, and there is an emerging body of literature that describes its occurrence both in clinic (Bernhardt et al. 2010; McLean et al. 2013) and in laboratory settings (Groepper et al. 2015; Balcom et al. 2016). Clinical genetics professionals are encouraged to identify resources to help when conflicts are identified—many hospitals are required to have an ethics board or committee, with trained biomedical ethicists, to help clinicians work

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through ethically challenging cases. Professional organizations also frequently have ethics committees that may even provide case consultation as needed. Peer support groups or supervision processes may also help clinicians process morally distressing cases in a supportive and confidential manner.

We hope that the article by Clarke and Wallgren-Pettersson (2018) encourages others to submit similarly extended reviews of topics central to community genetics as outlined in Ten Kate et al. (2010).

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