

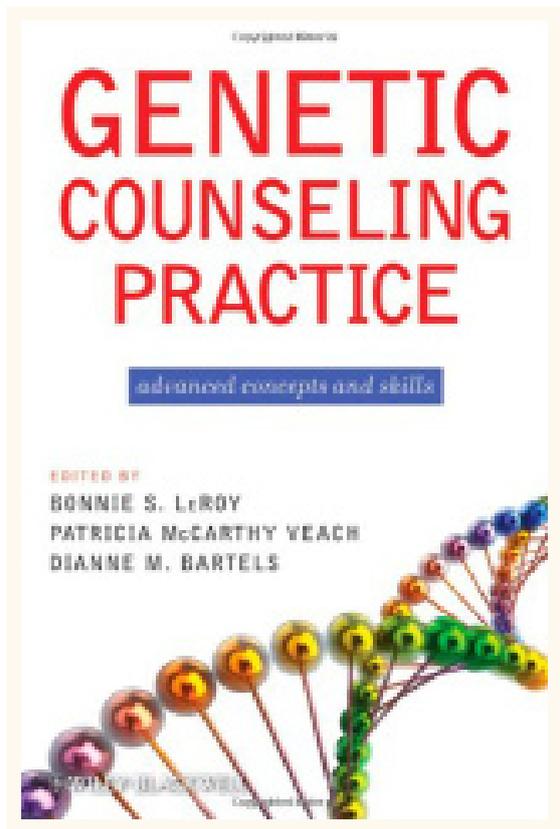
Genetic Counseling Practice Advanced Concepts and Skills

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ممارسة الإرشاد الوراثي مفاهيم ومهارات حديثة

المحررون: بوني لوروي ، باتريسيا ماكارثي فيتش ، ديانا بارتيلز .

مراجعة سمير العدوي



THE BACKBONE OF ALL SCIENTIFIC endeavours is either to employ a 'bottom-up' or a 'top-down' approach to understand our

natural world. The bottom-up approach is basically reductionist in outlook. The obvious candidates in this category include genomics and other molecular sciences. On the other hand, the top-down approach perceives content from the whole rather than from individual parts. In psychology, for example, top-down thinking holds the view that our habits are shaped by forces of socialisation and environmental factors. Bottom-up and top-down approaches represent diametrically opposing paradigms in the history of sciences; however, the wind of change is imminent. As if heeding the poem by T.S. Eliot, "we shall not cease from exploration and the end of all our exploring will be to arrive where we started and know the place for the first time", the bottom-up and top-down approaches are on the verge of reconciliation. In fact, with the birth of genetic counselling, it is becoming evident that these two seemingly opposing approaches, divided for so long by 'isms' and 'schisms', are in fact two sides of the same coin.

Forget eugenics where social control was meant to reduce the number of 'defective people' in order to achieve the goals of vanity. The marketing practice of using genetic information to discriminate against some people seeking medical insurance and employment is something that has little affinity with

the modern approach to genetic counselling. The new kid on the block mandates itself to dispense a dose of humanity. The central tenet of genetic counselling is to draw on evidence-based options in order to mitigate some of the vagaries of inherited diseases. The field prides itself on being in the vanguard in dispensing health education for people who have potential, or already evident, inherited disorders. This field has wide scope, including breaking the news to those who have been diagnosed with inherited diseases, providing family planning advice or charting out a meaningful existence for those who are prone to inherited diseases.

The inner workings of genetic counselling have received little attention despite its indispensable role in an age where the pendulum of science has swung towards genetic determinism. Despite its short but rapid growth, this field has yet to have its own 'classic read'. *Genetic Counseling Practice: Advanced Concepts and Skills* fulfils this role. The volume represents the synthesis of current knowledge and practice in the field of genetics as it applies to human diseases and its consequences in the social context. Editors Bonnie S. Leroy, Patricia McCarthy Veach and Dianne M. Bartels have invited a group of genetic counselor writers to synthesize fresh approaches to genetic counselling. The resultant volume has 15 chapters with 18 authors, mainly from North America and Minnesota in particular. The contributors have expertise in various fields including biology, genetics, nursing, psychology, public health and social work. Inclusion of perspectives from diverse disciplines gives testimony to the fact that genomic medicine has many repercussions and so requires a multidisciplinary effort. In many publications with multiple authors, repetitions are often inevitable. This volume has managed to avoid such pitfalls.

Proffered as an introduction to the field, the volume indeed lives up to expectations. The authors have laboured to include practical activities or scenarios to further consolidate the application of the concepts presented. The volume is not written on a 'Mickey Mouse' simplistic level, but the concepts presented can be grasped by anyone curious about the subject. There are many references that could be used for situations outside

the industrialised countries of the West. Two chapters entitled 'Client Cultural and Individual Characteristics' and 'Honoring Diversity: Cultural Competence in Genetic Counseling' bear witness to cross-cultural coverage. Such inclusions give strength to this book. In developing countries like Oman, genetic disorders are increasingly being recognised. One hypothesis is that such conditions are likely to be rife because of the cultural practice of consanguinity. If indeed culture contributes to the magnitude of inherited disorders, health education would be the best method to mitigate a rising tide of genetic disorders, since gene therapy has yet to find entrance into widespread clinical application.

In addition to being inescapably social, genetic counselling generally embraces a pluralistic approach. The volume has a chapter entitled 'Developmentally Based Approaches for Counseling Children and Adolescents' and 'Genetic Counseling for Women with Intellectual Disabilities'. These chapters represent another interesting facet of the work in accommodating even those who are often marginalised by society. As should be expected, genetic counsellors are the sole 'breakers of bad news' and must daily confront stark ethical questions. The coverage in this volume also leaves room for genetic counsellors to introspect. The chapters entitled 'Counter-transference: Making the Unconscious Conscious' and 'Genetic Counselors: Caring Mindfully for Ourselves' help inoculate genetic counsellors against events that could lead to occupational burnout. Additional tips for professional development are featured in a chapter entitled 'Professional Development: Reflective Genetic Counseling Practice' and 'Mobilizing Genetic Counselor Leadership Skills'.

Genetic counselors are purveyors of technical services relevant to genomic medicine. The purveyors of genomic medicine, on one hand, and the victims of inherited disease, on the other hand, are required to form a dyadic relationship. Such a relationship requires a genetic counsellor to be well versed in interpersonal and communication skills something akin to the skills needed in doctor-patient relationships in general medical settings. This book has vividly and succinctly captured such themes. However, on the less positive side, in tackling such

a complex issue, the authors of this volume have laboriously tried to revamp psychological concepts that are largely considered a relic of the past in modern mainstream psychological literature. For example, “grief work” was viewed as inevitable for people who are digesting bad news; however, although grief has been shown to be a universal phenomenon, it is often expressed in a socio-cultural context. The concept of “grief work”, as tackled on this volume, appears to rely on the predominantly western-centric perspective on human nature which has been largely discredited in the field of thanatology. Similarly, statements such as ‘making the unconscious conscious’ make the reader wonder whether Freud’s Vienna is being resurrected in Minnesota. What has been disappointingly overlooked in this volume is the acknowledgment that issues pertinent to genetic counselling are inescapably social in nature. Rather consider genetic counsellors as a modern day ‘priests of the psyche’, it would be more appropriate to assign them the role of ‘anthrotherapists’. From this perspective, genetic counsellors could be correctly seen as purveyors of technical expertise that requiring them to liaise between with social structures and genomic medicine. In a nutshell, their role would be to mediate between the bottom-up knowledge of genomic medicine and the top-down social forces that foster perceptions and attitudes towards and knowledge of inherited diseases.

Who should read this volume? As the mantra of the time is genetic determinism, literally everyone could benefit from this book. For genetic counsellors, this volume would be a valuable textbook for their shelf. For all other caregivers, this volume will open up new horizons in the appreciation of the much heralded communication skills and essential dynamism relevant for the doctor-patient relationship. It would be heartening if the publisher of this volume soon contemplated a second edition. Maybe this time inclusions should not just be limited to Minnesota.

REVIEWER

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