

## Psychological Aspects of Genetic Counseling. XIV. Nondirectiveness and Counseling Skills

SEYMOUR KESSLER

### ABSTRACT

The difficulties some professionals have in achieving nondirective goals is largely due to the inadequate and ineffective application of basic counseling skills. The "new genetics," with its emphasis on decision-making in association with genetic testing is among the most demanding forms of personal counseling, the effectiveness of which depends largely on the professional's human experience and counseling abilities. Examples are given showing inadequacies in professional responses to clients in genetic counseling which, in turn, defeat the achievement of a nondirectiveness that is helpful to clients, supports their self-directedness, and leaves them more psychologically prepared for quality decision making. Other models of counseling (e.g., shared decision making) will not fare any better than the nondirective one unless counseling skills of professionals in genetic services are upgraded in a significant way. Professional organizations need to give greater attention to the training and postgraduate supervision of all personnel involved in genetics services.

### INTRODUCTION

THE CONCEPTS OF DIRECTIVENESS AND NONDIRECTIVENESS (ND) illustrate the potential mischief caused by applying ideas from one discipline to another. In its original context—psychotherapy—ND was a technique used to foster free association whereas directiveness was one used to suppress such associations. Transferred to the field of medical genetics and genetic counseling, these concepts took on a different flavor and lost their connections to the clinical procedures that provided their foundation. In their new home, directiveness and ND gradually came to signify either an ill-defined association with(holding) advice-giving, a moral stance, or both. To confuse the situation further, the ND of genetic counseling was mistaken for the ND associated with the 'client-centered' psychotherapeutic procedures developed by Carl Rogers. The latter relied heavily on a reflecting-back technique as well as a dogma that clients, when given sufficient rope, would not hang themselves but would somehow find the inner courage, strength, and intelligence to make something positive out of their lives. In my opinion, Rogerian procedures were particularly ill-suited for genetic counseling, where client contact was frequently brief and where they had major needs for professional feed-back (e.g., diagnosis, risk figures), pertinent information, and active assistance in sorting out complex decisional options.

With the growing complexities imposed by the so-called

"new genetics," attention to the issue of giving advice began to be reconsidered and genetic counselors found themselves floundering in their attempts to remain neutral in their counseling and at the same time satisfy the needs of clients, employers, ethicists, and all the other constituencies currently involved in genetic services. A new look at the problems of directiveness and ND was clearly indicated. However, several obstacles to conceptual clarity stood in the way.

### CONCEPTUAL PROBLEMS IN GENETIC COUNSELING

The first obstacle involves the definition of genetic counseling itself. So long as practitioners persisted in thinking of genetic counseling as a 'process of communication', the essence of what was involved on human and practical levels could not be realized. To speak of a 'process' without first addressing the fact that human beings were involved in a give-and-take (an interaction or relationship) that transcended genetics, medicine, and biology relegated discussions of counseling to the realm of abstraction. This, in turn, tended to narrow the range of potential discourse to one representing the professional's interests and world-view and subordinated those of the client. The result often was, and continues to be, a lack of professional understanding of what transpires in the hearts

# Psyche And Helix Psychological Aspects Of Genetic Counseling

**Alexandra Minna Stern**



## **Psyche And Helix Psychological Aspects Of Genetic Counseling:**

**Psyche and Helix** Seymour Kessler, 2000-07-03 Genetic diseases affect the lives of millions of people regardless of age race religion ethnicity or social status Every day discoveries point to the complex role of genetics in common disorders such as cancer heart disease and Alzheimer s disease Experience and research have shown that being at risk for a genetic disease can have devastating psychological effects on patients and their families Genetic counseling helps families and patients cope with the medical psychological and social effects of genetic diseases It is to this end that genetic counselors must be sensitive to the needs of patients and families understand the psychological meaning of clients behaviors and communicate that understanding in ways that leave clients emotionally enriched psychologically stronger and more competent to deal with their own lives This insightful book covers topics such as Management of guilt and shame Roles of directiveness in patient care How a healthcare professional can expand counseling skills Understanding the distinction between education and counseling Detailed analysis of a genetic counseling session Providing practical and clinically meaningful ways to enhance counseling skills of genetic counselors physicians nurses social workers and other healthcare professionals *Psyche and Helix Psychological Aspects of Genetic Counseling* consists of essays compiled over two decades which will serve as a primary source of information for healthcare professionals who render genetic counseling     *A Guide to Genetic Counseling* Wendy R. Uhlmann, Jane L. Schuette, Beverly M. Yashar, 2011-09-20 The first book devoted exclusively to the principles and practice of genetic counseling now in a new edition First published in 1998 *A Guide to Genetic Counseling* quickly became a bestselling and widely recognized text used nationally and internationally in genetic counseling training programs Now in its eagerly anticipated Second Edition it provides a thoroughly revised and comprehensive overview of genetic counseling focusing on the components theoretical framework and unique approach to patient care that are the basis of this profession The book defines the core competencies and covers the genetic counseling process from case initiation to completion in addition to addressing global professional issues with an emphasis on describing fundamental principles and practices Chapters are written by leaders in the field of genetic counseling and are organized to facilitate academic instruction and skill attainment They provide the most up to date coverage of The history and practice of genetic counseling Family history Interviewing Case preparation and management Psychosocial counseling Patient education Risk communication and decision making Medical genetics evaluation Understanding genetic testing Medical documentation Multicultural counseling Ethical and legal issues Student supervision Genetic counseling research Professional development Genetics education and outreach Evolving roles and expanding opportunities Case examples *A Guide to Genetic Counseling Second Edition* belongs on the syllabi of all medical and human genetics and genetic counseling training programs It is an indispensable reference for both students and healthcare professionals working with patients who have or are at risk for genetic conditions     *Genetic Counseling Practice* Bonnie S. LeRoy, Patricia M. Veatch, Nancy P. Callanan, 2020-09-10 The second edition of Genetic

Counseling Practice Advanced Concepts and Skills provides in depth content regarding the advanced competencies for meeting patient needs across the changing landscape of genetic counseling practice The content aligns with the Reciprocal Engagement Model REM of practice which integrates the biomedical knowledge and psychosocial aspects of genetic counseling This edition has been revised and expanded to reflect advances made in the present day field Edited by a team two genetic counselors and a psychologist the chapters offer a holistic picture of genetic counseling Chapter authors are all recognized experts in the profession The chapters are grounded in evidence based practice and research Each chapter includes learning activities to help readers apply concepts and skills Featured topic areas include Meeting the needs of culturally diverse patients Addressing challenging patient dynamics Working with children adolescents and families Using emerging service delivery models for genetic counseling Engaging in self reflective deliberate practice Promoting genetic counselor professional development Genetic Counseling Practice is an indispensable guide to the complex and evolving field of genetic counseling and this updated second edition will help practitioners and trainees alike navigate its most pressing and practical challenges with skill and care

**Facilitating the Genetic Counseling Process** Patricia McCarthy Veach, Bonnie S. LeRoy, Dianne M. Bartels, 2006-05-04 Designed as an aid to students in Genetics counseling classes and professionals interested in honing their skills Facilitating the Genetic Counseling Process will guide the reader through the why s and how s of assisting clients with these complex issues The authors collective years of both teaching students and counseling clients is reflected in the clear practical approach of this manual

Practical Genetic Counselling Peter Harper, 2010-08-27 Easy to use and useful when kept close at hand in the room where you work The book is a pleasure to read the style elegant and authoritative Lancet this book is a wonderful reference to enable primary physicians to be informed about their patients Annals of Internal Medicine Universally used across the world by genetic counsellors medical

**Advanced Genetic Counseling** Barbara B. Biesecker, Kathryn F. Peters, Robert Resta, 2019-09-27 A CRITICAL NEW APPROACH FOR LEARNING AND THRIVING IN A FIELD OF CHANGE The scope and responsibilities of today s genetic counselors exceed the reasonable capacity of any one educational resource While the field s first year curriculum may be relatively fixed the landscape of what comes after that a dizzying mix of practice ethics research design and professional competencies is increasingly broad Advanced Genetic Counseling offers an overdue extension of the field s core curriculum From navigating ethical dilemmas and potential conflicts of interest to confronting the biases and patterns of thought that can limit counselors interactions with clients it prepares readers to face the profession s most challenging aspects with confidence Drawing on techniques from psychotherapy social psychology and health behavior Advanced Genetic Counseling is an essential resource for trainees and mid career professionals It offers a roadmap not just for addressing client needs but for the future of genetic counseling education

Telling Genes Alexandra Minna Stern, 2012-09-11 For sixty years genetic counselors have served as the messengers of important information about the risks realities and perceptions of genetic

conditions More than 2 500 certified genetic counselors in the United States work in clinics community and teaching hospitals public health departments private biotech companies and universities Telling Genes considers the purpose of genetic counseling for twenty first century families and society and places the field into its historical context Genetic counselors educate physicians scientific researchers and prospective parents about the role of genetics in inherited disease They are responsible for reliably translating test results and technical data for a diverse clientele using scientific acumen and human empathy to help people make informed decisions about genomic medicine Alexandra Minna Stern traces the development of genetic counseling from the eugenics movement of the early twentieth century to the current era of human genomics Drawing from archival records patient files and oral histories Stern presents the fascinating story of the growth of genetic counseling practices principles and professionals Troy Duster Chancellor Emery and Rimoin's Essential Medical Genetics David L. Rimoin, Reed E. Pyeritz, Bruce Korf, 2013-05-15 For decades Emery and Rimoin's Principles and Practice of Medical Genetics has provided the ultimate source for practicing clinicians to learn how the study of genetics can be integrated into practice Developed in parallel to the sixth edition and featuring 174 original contributions from the many authors of the full set this one volume work expertly condenses and synthesizes the most clinically relevant content for convenient desk reference Helping to bridge the gap between high level molecular genetics and individual application it follows the multi volume set in encompassing scientific fundamentals full spectrum discussion of major inherited disorders and actionable therapies Clinically oriented information is supported by concise descriptions of the principles of genetics research approaches and analytics to embrace the evolving population of students researchers and practitioners who are integrating their work to provide advanced diagnosis prevention and treatment of human disease This print volume is complemented and enhanced with online access to the complete text online only references and high quality illustrations on [www.expertconsult.com](http://www.expertconsult.com) Features 174 summarized contributions concisely discussing advances in cancer genetics genomic technologies and molecular genetics Contains hundreds of full colour illustrations supporting users with identification concept illustration and method processing Enhanced with full text online access high quality illustrations and online only references at [www.expertconsult.com](http://www.expertconsult.com) The Developing Person Through Childhood, Fifth Edition Kathleen Stassen Berger, 2002-10-15 New edition of Berger's acclaimed bestselling text for chronologically organized courses focus strictly on the childhood years **Genetic Testing** Michael Arribas-Ayllon, Srikanth Sarangi, Angus Clarke, 2013-03 Firmly grounded in empirical data this book critically engages with the relational moral and ethical issues surrounding genetic testing in contemporary society Competing accounts of autonomy responsibility and blame by families by professionals and in the public sphere are analysed rigorously within a discourse rhetorical framework paying particular attention to the situated management of risks of knowing and risks of disclosure *A Short History of Medical Genetics* Peter S. Harper, 2008-10-24 An eminent geneticist veteran author OMMG Series Editor and noted archivist Peter Harper presents a lively account of how

our ideas and knowledge about human genetics have developed over the past century from the perspective of someone inside the field with a deep interest in its historical aspects Dr Harper has researched the history of genetics and has had personal contact with a host of key figures whose memories and experiences extend back 50 years and he has interviewed and recorded conversations with many of these important geneticists Thus rather than being a conventional history this book transmits the essence of the ideas and the people involved and how they interacted in advancing and sometimes retarding the field From the origins of human genetics through the contributions of Darwin Mendel and other giants the identification of the first human chromosome abnormalities and up through the completion of the Human Genome project this Short History is written in the author s characteristic clear and personal style which appeals to geneticists and to all those interested in the story of human genetics      *The Developing Person Through the Life Span* Kathleen Stassen Berger, 2005 The *Developing Person Through the Life Span* Sixth Edition presents theory research practical examples and policy issues in a way that inspires students to think about human development and about the individual s role in the community and the world Review the new edition and you ll find Berger s signature strengths on display the perceptive analysis of current research the lively and personal writing style and the unmistakable commitment to students You ll also find a wealth of new topics plus a video based Media Tool Kit that takes the teaching and learning of human development to a new level

Genetic Testing Neil F. Sharpe, Ronald F. Carter, 2006-01-03 A complete review of the issues with specific recommendations and guidelines With over 1 000 tests commercially available genetic testing is revolutionizing medicine Health care professionals diagnosing and treating patients today must consider genetic factors the risks and limitations of genetic testing and the relevant law Genetic Testing Care Consent and Liability offers the only complete practical treatment of the genetic clinical ethical and legal issue surrounding genetic testing The authors present protocols policies and models of care that are currently in use and explain the legal framework for genetic testing and counseling that has developed in North America particularly with regard to the law of medical malpractice This essential book features an international roster of esteemed contributors including Nancy P Callanan Bonnie S LeRoy Carole H Browner H Mabel Preloran Riyana Babul Hirji Cheryl Shuman M J Esplen Maren T Scheuner Dena S Davis Jon Beckwith Lisa Geller Mark A Hall Andrew R MacRae David Chitayat Roxanne Mykitiuk Stephanie Turnham Mireille Lacroix Jinger G Hoop Edwin H Cook Jr S H Dinwiddie Elliot S Gershon C Anthony Rupar Lynn Holt Bruce R Korf Anne Summers S Annie Adams Daniel L Van Dyke Rhett P Ketterling Erik C Thorland Timothy Caulfield Lorraine Sheremeta Richard Gold Jon F Merz David Castle Peter J Bridge JS Parboosingh Patricia T Kelly Julianne M O Daniel Allyn McConkie Rosell Beatrice Godard Bartha Maria Knoppers David Weisbrot The coverage also includes Genetic screening including prenatal neonatal carrier and susceptibility testing Diagnosis risk assessment confidentiality and clinical legal issues related to follow up Interpreting test results and communicating them to patients psychological considerations Informed consent Family history evaluations Referral to medical geneticists and

genetic counselors Genetic Testing Care Consent and Liability is a must have resource for clinical geneticists genetic counselors specialists family physicians nurses public health professionals and medical students

**The Developing Person Through Childhood and Adolescence** Kathleen Stassen Berger,2005-10-19 This text presents theory research practical examples and controversial issues in a way that inspires students to think about development addressing the individual s role in both the community and the wider world This second edition contains revised chapters on adolescence and new research into brain development

**Genomic Medicine** Dhavendra Kumar,Charis Eng,2015 The first edition of Genomics and Clinical Medicine provided an overview of genomics based advances in disease susceptibility diagnosis and prediction of treatment outcomes in various areas of medicine Since its publication the science of genomics has made tremendous progress and exciting new developments in biotechnology and bioinformatics have created possibilities that were inconceivable only a few years ago This completely revised second edition of Genomic Medicine reflects the rapidly changing face of applied and translational genomics in the medical and health context and provides a comprehensive coverage of principles of genetics and genomics relevant to the practice of medicine

**Lessons Learned** Susan Schmerler,2007-11-15 No one wants to be sued A lawsuit is an assault on one s self image reputation and livelihood It is physically mentally and financially draining Professionals get sued because an individual believes she has been harmed or thinks there is enough evidence to convince a jury that she has been harmed An accusation of harm can be expressed in different legal terms such as breach of contract or negligence The profession of genetic counseling has developed within the field of medicine so that a medical model usually applies Therefore a formal complaint by a patient about a genetic counselor would come under the laws that apply to medicine as opposed to business Most commonly these complaints take the form of a malpractice lawsuit that claims malpractice or negligence The purpose of this book is 1 to provide genetic counselors with varying levels of experience and expertise with heightened awareness of the sources and processes of the law as it can affect their practice 2 to offer them strategies for minimizing the potential for their being named in a lawsuit and 3 to provide guidance for the management of current and emerging situations The book discusses the day to day practices of genetic counselors and identifies areas in which possible causes of liability can be found It looks closely at a negligence lawsuit as it would concern a genetic counselor so that readers may learn where the potholes hazards and how to avoid them

*Guiding Icarus* Rahul K. Dhanda,2003-03-31 There is a palpable need for business to explore the issues Dhanda raises Guiding Icarus offers a flight plan from the Foreword by Philip R Reilly Guiding ICARUS Merging Bioethics with Corporate Interests Rahul K Dhanda While bioethicists may enjoy the most thorough appreciation of both the promise and perils of new biotechnologies international corporations are in fact the entities generating these technologies and determining their application An industry insider versed in the language of bioethics Rahul Dhanda offers in Guiding Icarus Merging Bioethics with Corporate Interests a Rosetta stone to these two camps explaining why each needs the other why their disparate concerns often cohere

and why an ethical business is likely a successful one The author develops a dialogue between bioethics and corporate interests by examining case studies of several hot button issues including Genetically modified foods DNA data banking Personalized medicine Stem cell research In each instance he provides a treatment of the particular science under consideration a list of the benefits of the technology a description of the ethical issues involved an account of past industry response and recommendations for future action Given the expansive nature of biotechnology ramifications in the pharmaceutical and agricultural industries are covered in depth as well The book also features a Foreword by world renowned bioethicist and biotechnology CEO Philip R Reilly as well as a step by step discussion of the components of business and bioethical issues Written for a general audience Guiding Icarus will be particularly useful to biotechnologists regulatory affairs managers and corporate officers of biotechnology firms as well as bioethicists in the academic community Dhanda's peerless text provides a unique tool for understanding and addressing the ethical dilemmas confronting society in the 21st century

**The Developing Person Through Childhood** Kathleen Stassen Berger, 2005-10-14 A text on development through middle childhood This book uses theory research and practical illustrations to challenge students' conceptions of development

*Fabry Disease* Deborah Elstein, Gheona Altarescu, Michael Beck, 2010-08-02 Fabry disease is an X linked inborn error of metabolism wherein deficiency of a lysosomal enzyme results in systemic deposition of glycosphingolipids Storage deposition and hence pathological disease occurs preferentially in renal glomerular and tubular epithelial cells myocardial cells heart valve fibrocytes neurons of dorsal root ganglia and in endothelial smooth muscle cells of blood vessels Thus Fabry disease is a multi system disorder albeit with considerable phenotypic heterogeneity in onset and in severity however it is progressive exhibits extensive morbidity and is life threatening Within the past two decades there has been a radical change in the natural course of Fabry disease by virtue of the availability of specific enzyme replacement therapy Moreover there has been a concerted effort to better understand the underlying pathology and equally to identify patients prior to the onset of irreversible end organ damage It is to be hoped that the future for patients with Fabry disease can be viewed with greater albeit guarded optimism This state of the art textbook attempts to bridge the span of pre clinical studies clinical finding and management options in a readable but comprehensive manner for the medical practitioner as well as the interested non medical reader

**The Troubled Helix** Theresa Marteau, Martin Richards, 1996 This wide ranging and compelling account surveys the exciting opportunities and difficult problems which arise from the new human genetics The availability of increasingly sophisticated information on our genetic make up presents individuals and society as a whole with difficult decisions Although it is hoped that these advances will ultimately lead the way to the effective treatment and screening for all diseases with a genetic component at present many individuals are condemned to a life sentence in the knowledge that they have or will develop an incurable genetic disease



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