

Getting the Message Across

GETTING THE MESSAGE ACROSS COMMUNICATION WITH DIVERSE POPULATIONS IN CLINICAL GENETICS

Edited by
Jennifer Wiggins
and
Anna Middleton

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Foreword

Communication is a fundamental element of genetic counseling practice and requires particular skill because the information being conveyed by the professional is often both complex as well as laden with potential personal and familial significance for the client/patient and his or her family. When the genetic counselor is also faced with patients who, for sensory, cognitive, linguistic, or cultural reasons, present potential barriers, communication becomes an even greater challenge. Additional skills are also needed for particularly sensitive situations including consultations with the parents of newborns with indeterminate sex or those individuals as adults, the disclosure by patients of sexual abuse, or when discussing genetic testing with terminally ill patients. All too often, because of time and other resource pressures, or lack of preparation, as genetic counselors we are left with feeling that the consultation was less than satisfactory, that we have let these clients down. Although we may need to live with some of the institutional/structural limitations of the service we can provide, we have a professional responsibility to ensure that our practice is not poorer through lack of awareness or skill. For the first time, the editors of this welcome new text have consolidated specialist expertise so that we can work toward improving the quality of our communication with these specific client groups.

Each of the contributing authors give substantial background information, including research evidence where available, goes on to set this in the context of genetic counseling cases, and, perhaps most helpfully, gives very many specific suggestions for practice that range from practical arrangements in the clinic to the actual words that might be used to frame a particular intervention. In my own view, written accounts of counseling skills can often be too vague and generic, lacking clear detail. All of the chapters in this book avoid that pitfall, the topics being presented really come alive, and the pages are full to the brim with imaginative and helpful tips for practice.

I hope that this book enjoys the wide readership it deserves. Both genetic counselors and medical geneticists, whether in training or with years of experience, will find much to learn here, as I have done when privileged to be among the first readers. Many will want to read through the text in its entirety. Some sections, such as the chapters on talking to teenagers, working with particular cultural groups, and using interpreters, will be a great addition to the reading lists for postgraduate genetic

counseling training programmes. Trainee and experienced medical geneticists should find the chapters on talking to children and parents with learning difficulties, and parents of newborns with indeterminate sex very relevant. Individual chapters will also become useful for experienced clinical genetic professionals to refer to when seeing a client with communication needs not usually encountered in their practice, for example a deaf patient in a cancer genetic clinic, or a genetic counselor receiving the disclosure of sexual abuse in a consultation for the first time.

On a personal note, I am delighted to see the publication of this book, which indicates a further maturation of our profession. It is to the great credit of the two genetic counselor-editors that they have brought together contributions from a diverse group of experts (many of whom are genetic counselors themselves) to produce a text that contains thoughtful and in-depth coverage around many of the most challenging and complex counseling situations encountered in genetic practice.

Prof Lauren Kerzin-Storarr
Consultant Genetic Counselor (Head) and MSc Course Director
Genetic Medicine
Manchester Academic Health Sciences Centre/CMFT
St Mary's Hospital, Manchester, United Kingdom

Definition of Genetic Counseling

Genetic counseling is the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contribution to disease. This process integrates the following:

- Interpretation of family and medical histories to assess the chance of disease occurrence or recurrence
 - Education about inheritance, testing, management, prevention, resources, and research
 - Counseling to promote informed choices and adaptation to risk or condition
- Definition from the National Society of Genetic Counselors (Resta 2006)*

SCOPE OF PRACTICE OF GENETIC COUNSELORS

- Collect and interpret comprehensive client information, including medical, psychological, and genetic family history
 - Make appropriate and accurate genetic risk assessments
 - Use therapeutic counseling and communication skills with clients to help them:
 - comprehend medical facts about a genetic disorder
 - appreciate the way heredity contributes to the disorder, and the risk of recurrence in specific relatives
 - understand options for dealing with the risk of recurrence
 - choose the course of action that seems to them appropriate
 - make the best possible adjustment to the disorder in an affected family member and/or the risk of recurrence of that disorder
 - Make psychosocial assessments of client need, providing support and referral to other agencies as appropriate
 - Plan, organize, and deliver professional and public education in genetic healthcare
 - Serve as a genetic healthcare resource for professionals and the general public
 - Liaise with other members of the genetics multidisciplinary team to provide optimum services for clients
- Genetic Counselor Registration Board UK and ROI Code of Conduct (2012)

Preface

The two words “information” and “communication” are often used interchangeably, but they signify quite different things. Information is giving out; communication is getting through.

—Sidney J Harris

The idea for this book developed from a plenary session at the British Society of Human Genetics annual conference in 2008. This session was called “Getting the Message Across Communication Challenges in Clinical Genetics.” It had been organized by senior genetic counselors Jennifer Wiggins and Vicki Wiles on behalf of the Association of Genetic Counselors and Nurses (U.K.), and Dr. Anna Middleton was one of the presenters. There appeared to be a demand from the audience for practical tips that support cross-cultural genetic counseling. We wanted to build on the session by creating this book and invited genetic counselors with a particular expertise developed through research interests and/or clinical practice, along with experts from other disciplines to contribute the chapters.

GENETIC COUNSELING CAN INVOLVE ANYONE AND EVERYONE

Clients attending a genetics clinic may be any age, from newborn babies through to octogenarians. They may be affected with a genetic condition, or at risk of developing one when they are older or passing one on to children. Clients are often distressed, may be facing an uncertain future; they may be terminally ill or bereaved. Clients can be from any ethnic or social group. Some clients may have experience and knowledge of their family’s genetic condition; for others, the diagnosis will be brand new. The news of a genetic condition can impact many stages of a client’s life, so that the implications of the genetic condition are always with him or her—it is rarely considered “resolved,” even for those who test negative for a family condition.

Genetic conditions can be chronic, progressive, life-limiting; the effects of a genetic condition may be obvious at birth, or the onset maybe in young adulthood or middle age. The genetic condition may interfere with the functioning of any system in the body, causing physical and/or learning difficulties. Clients may have

dysmorphic features or physical impairments or learning difficulties. Information about genetic conditions is likely to change over time, for example, in terms of our understanding of the phenotype, in the type of molecular testing available, and the health screening and risk management options. Thus, uncertainty reigns for both the client and the genetic healthcare professional.

In reviewing the medical notes in preparation for a consultation, the genetic health professional may be able to check the latest medical literature to ensure that his or her knowledge of the condition is as up to date as possible, but until he or she meets the client, the professional cannot know how this information may be received and how it will affect the client's life.

Effective counseling requires effective communication: giving information that is relevant to patients' concerns, in a way that is easily understood. (Michie 1994)

“Success” in the genetics clinic is difficult to measure; recent research suggests this relates to the ability to empower clients so that they can make the decisions that are right for them. To achieve this, the genetic health professional should consider all aspects of the communication exchange the he or she facilitates, including recognizing and addressing barriers to communication.

PRACTICAL INFORMATION TO SUPPORT TRANS-/CROSS-CULTURAL COUNSELING

It is absolutely pivotal not to stereotype clients; everyone is different and there is more variation between individuals than among groups of individuals (Wang 2001). However, writers on transcultural counseling do advise that it is helpful to at least have some level of awareness of practical or cultural difference that may exist between counselor and client. Cultural difference can exist on many levels; this does not only relate to ethnicity or race. Healthcare professionals, as individuals, may be very different from the clients they see, and it is helpful to acknowledge rather than ignore this. For example, differences may exist within multiple planes: gender, age, educational background, sexual orientation, religious belief, politics, skin color, physical ability, fluency in language, cultural heritage, and beliefs about genetics. The list is endless. Although it is impossible to know prior to seeing a client what his or her perspective will be, it can at least be helpful if the health professional has given some thought to possible cultural and attitudinal nuances that the client may have.

To become a transculturally skilled counselor, students will need to...attain specific knowledge about the client group/s. (Lago & Thompson 1996)

WHAT IS DIFFERENT ABOUT THIS BOOK?

Numerous genetic counseling books describe the process and techniques of genetic counseling, along with hundreds that describe the specific features of genetic conditions. This book does not aim to delve into any of these issues. Instead, it aims to help genetic health professionals, indeed any health professional, improve their communication with clients by offering practical information and advice about working with specific client groups. Every health professional should already possess a toolkit of good communication skills; our book aims to add another level of awareness that can be incorporated into this toolkit.

We have asked each author, experts in the field, to view his or her chapter as a method for delivery of practical information—we wanted them to imagine they were passing on their worldly advice to another health professional who might, for example, be shadowing them in a consultation. What top tips would they want to impart? What would be considered a “do or a don’t”? We were particularly interested in the knowledge that comes from years of experience of working with a particular client group, the subtle cues, the pitfalls, the anticipated outcomes.

We have attempted to identify social and clinical scenarios that may inherently make communication more complex, perhaps due to the exaggerated difference between health professional and client. For example, a health professional who is young may have limited life experience or emotional cues to help him or her relate to a client who is elderly. By the same token, a health professional who is more mature may feel flummoxed by the idea of reaching out and engaging appropriately with a teenager. Due to the fact that genetic counseling may be relevant and appropriate at any stage of life and covers a vast array of different personal and clinical scenarios (as detailed above), it is to be expected that genetic health professionals cannot be expert in all. We have included clinical scenarios in which the genetic health professional might feel unsure of him- or herself or inexperienced in managing a taboo subject, such as talking to a patient who is dying about storing DNA for the future. We have also included cultural scenarios that the genetic health professional may not frequently encounter, for example, working with the Deaf community, Traveller community, or Orthodox Jewish community.

Readers of this book can be at any stage of their genetic counselor or health professional career. The information provided is relevant to students training to be genetic counselors and will also be useful for genetic counselors preparing for registration or certification. In addition, this book aims to be useful for health professionals who are unfamiliar with working within a particular client group and

who want to scan the text for some top practical tips. The book has been written in such a way that it can be dipped into and the salient points extracted when a health professional is doing preconsultation preparation. Each chapter is divided into four main sections: Background, Preparing for the Consultation, Communication in the Consultation, and the Summary. The chapter authors have also provided references and suggestions for further reading.

We sincerely hope that readers enjoy this book but, most of all, that they find it useful for their practice.

Jennifer Wiggins and Anna Middleton

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Contributors

**Mushtaq Ahmed, BSc, PGCE,
PhD, RGC**

Principal Genetic Counselor
Yorkshire Regional Genetics Service
Department of Clinical Genetics
Chapel Allerton Hospital

**Alison Clarke RN, RHV, RGC, BSc,
MSc**

Principal Genetic Counselor
St Mary's Hospital

Nicki Cornwell, BA, MPhil, CQSW
Private author

**Anna Gregorowski, BSc, MA, RSCN,
RGN**

Nurse Consultant, Adolescent Health
Great Ormond Street Hospital for
Children
NHS Foundation Trust

Georgina Hall, MSc, RGC

Principal Genetic Counselor and
Honorary Research Associate
Manchester Academic Health Science
Centre
St. Mary's Hospital

Kelly Kohut, MS, CGC, RGC

Genetic Counselor
The Royal Marsden NHS Foundation
Trust

Sara Levene, MSc, RGC

Principal Genetic Counselor
Clinical Genetics Department
Guy's and St. Thomas' NHS
Foundation Trust

Lih-Mei Liao, PhD, CPsychol, FBPsS

Consultant Clinical Psychologist &
Professional Lead for Psychological
Services

Institute for Women's Health
University College London

Anna Middleton, PhD, MSc, RGC

Ethics Researcher and Genetic Counselor
Wellcome Trust Sanger Institute
Cambridge

Kathryn Myhill, RN

Genetic Nurse
The Royal Marsden NHS Foundation
Trust

Christina Palmer, MS, PhD

Professor
Department of Psychiatry &
Biobehavioral Sciences
Department of Human Genetics
University of California, Los Angeles

Alan Phillips, BSc, MSc

Head, Psychosocial Services
Alder Hey Children's NHS Foundation
Trust

Margaret Simmonds, MA, MSc, PhD
UK Androgen Insensitivity Syndrome
Support Group

Anna-Marie Stevens, RN, MSc
Macmillan Nurse Consultant Cancer
Palliative Care
The Royal Marsden and Royal
Brompton Palliative Care Service
The Royal Marsden NHS Foundation
Trust

Rachel Taylor, RN, BSc, MSc
Consultant Nurse, Neurogenetics
University College London Hospitals
NHS Foundation Trust

**Jeremy Turk, MD, BSc, FRCPsych,
FRCPCH, DCH**
Professor of Developmental Psychiatry
Consultant Child & Adolescent
Psychiatrist

Institute of Psychiatry & St. George's
University of London
South London & Maudsley Foundation
NHS Trust

Jacqueline Turner, MSc, BA, RGC
National Centre for Medical Genetics
Our Lady's Children's Hospital

**Jayne Wood, MBBS, MRCP, BSc,
PgDip**
Consultant Palliative Medicine
The Royal Marsden and Royal
Brompton Palliative Care Service
The Royal Marsden NHS Foundation
Trust

Jennifer Wiggins, MSc, RGC
Senior Genetic Counsellor
The Royal Marsden NHS Foundation
Trust

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