


GENETIC COUNSELING IN PRACTICE



Genetic Counseling Research

A PRACTICAL GUIDE

IAN M. MACFARLANE

PATRICIA MCCARTHY VEACH

BONNIE S. LEROY

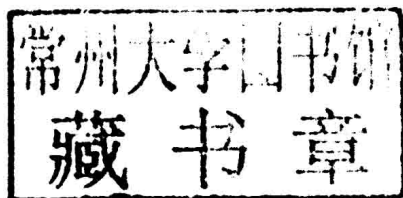
OXFORD

Genetic Counseling Research: A Practical Guide

Ian M. MacFarlane

Patricia McCarthy Veach

Bonnie S. LeRoy



OXFORD
UNIVERSITY PRESS

OXFORD

UNIVERSITY PRESS

Oxford University Press is a department of the University of Oxford. It furthers the University's objective of excellence in research, scholarship, and education by publishing worldwide.

Oxford New York

Auckland Cape Town Dar es Salaam Hong Kong Karachi
Kuala Lumpur Madrid Melbourne Mexico City Nairobi
New Delhi Shanghai Taipei Toronto

With offices in

Argentina Austria Brazil Chile Czech Republic France Greece
Guatemala Hungary Italy Japan Poland Portugal Singapore
South Korea Switzerland Thailand Turkey Ukraine Vietnam

Oxford is a registered trademark of Oxford University Press
in the UK and certain other countries.

Published in the United States of America by
Oxford University Press
198 Madison Avenue, New York, NY 10016

© Oxford University Press 2014

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, without the prior permission in writing of Oxford University Press, or as expressly permitted by law, by license, or under terms agreed with the appropriate reproduction rights organization. Inquiries concerning reproduction outside the scope of the above should be sent to the Rights Department, Oxford University Press, at the address above.

You must not circulate this work in any other form
and you must impose this same condition on any acquirer.

Library of Congress Cataloging-in-Publication Data

MacFarlane, Ian M., author.

Genetic counseling research : a practical guide / Ian M. MacFarlane, Patricia McCarthy Veach, Bonnie S. LeRoy.

p. ; cm.

Includes bibliographical references.

ISBN 978-0-19-935909-7 (alk. paper)

I. Veach, Patricia McCarthy, author. II. LeRoy, Bonnie, author. III. Title.

[DNLM: 1. Genetic Counseling. 2. Genetic Research. 3. Research Design. QZ 50] RB155

616'.042072—dc23

2013045531

9 8 7 6 5 4 3 2

Printed in the United States of America
on acid-free paper

GENETIC COUNSELING RESEARCH

GENETIC COUNSELING IN PRACTICE

Series Editor

Bonnie J. Baty, MS, CGC, LGC

Genetic Counseling Research: A Practical Guide

Ian M. MacFarlane, Patricia McCarthy Veach, and Bonnie S. LeRoy

Preface

This book grew out of our conviction about the necessity for genetic counselors to contribute to the research literature that directs their profession (LeRoy & McCarthy Veach, 2008). When genetic counseling research is conducted primarily by individuals outside the profession, there is a risk that clinical practice and, indeed, the field itself are defined by someone else's values, assumptions, and perspectives. We have argued elsewhere about the clinical wisdom that genetic counselors and genetic counseling students have to offer patients and other health professionals (cf. McCarthy Veach, 2004; McCarthy Veach et al., 2002). Dissemination of that knowledge through well-designed and executed studies will contribute to the growing literature on genetic counseling processes and outcomes, professional preparation, and service delivery.

Over 450 students are enrolled in American Board of Genetic Counseling (ABGC) accredited programs in North America. Many are actively involved in some type of research/capstone project as part of their master's degree requirements. These numbers are even larger when one considers students in genetic counseling programs in other countries. Thus, there are abundant research projects *in progress*, and they ultimately lead to papers that could be developed into manuscripts submitted for publication in professional journals. Many projects never make it to that stage, however, perhaps in part because students vary in their research knowledge, confidence, and experience.

Genetic counselors have data all around them in their work settings, and their firsthand experience in the profession makes them ideal individuals to pose meaningful research questions. Yet they may believe that they lack the necessary research knowledge to effectively and efficiently investigate those questions.

It is our hope this brief text, composed of practical information and resources, will assist students and their research advisors in completing master's papers. We further hope that this workbook will help to promote quality research by genetic counselors and to facilitate publishable manuscripts that increase the knowledge base for genetic counseling practice, other aspects of genetic counseling service delivery, and professional education. Much of this text deals with conducting quality research, regardless of the discipline. What makes this text unique is the use of genetic counseling-specific examples and discussion of how common research issues might arise in genetic counseling settings.

The 10 chapters in this book contain basic information and recommendations regarding the entire research process, from generating research questions to publishing your research. Chapter 1 focuses on developing and evaluating feasible research questions for your situation. Chapter 2 provides an overview of finding literature that will support the need for your research, including common issues encountered during literature searches. Chapter 3 identifies strategies for summarizing and critiquing research literature to create a quality literature review for your research proposal and manuscript. Chapter 4 guides you through the major ethical principles of conducting research, such as following Institutional Review Board guidelines and avoiding plagiarism. Chapter 5 introduces the distinctions between quantitative and qualitative research to help you select which paradigm will best help you answer your research question. Chapter 5 also includes an overview of sampling, an important concept to consider regardless of the paradigm you choose. Chapter 6 outlines the important decisions involved in designing a quantitative study, such as statistical power, common methodologies, and writing surveys. Chapter 7 walks you through the analysis of your quantitative

data by reviewing important terms, cleaning your dataset, dealing with missing data, and selecting appropriate descriptive and inferential statistics. Chapter 8 focuses on both the design and analysis of qualitative research, along with a discussion of issues unique to this type of research. Chapter 9 contains an overview of the publication process, tips for determining authorship order and journal selection, and common mistakes that authors make when writing for publication. Finally, Chapter 10 is written for those who direct research, either as research advisors in graduate training programs or leading research teams in applied settings. This chapter focuses on recommendations for effective leadership and learning activities based on the literature and our experiences working with numerous students.

To help you organize your project, we have supplied 11 worksheets scattered throughout the chapters. These worksheets pull important information from the chapter and get you thinking about critical questions at each stage of the research process. We have also provided an Appendix with additional resources that may be useful for researchers. These include a research idea log, an outline of a research report, and rubrics to evaluate your own or others' research proposals and manuscripts.

This book provides an overview of basic principles, but it does not provide in-depth coverage. We encourage readers who are interested in exploring certain topics in greater depth to refer to the literature suggested throughout the chapters.

This book was supported in part by an Audrey Heimler Special Projects Award. The Audrey Heimler Special Projects Award of the National Society of Genetic Counselors provides funding support for projects that focus on the future of the genetic counseling profession and/or the provision of genetic services.

Ian M. MacFarlane, PhD

Pat McCarthy Veach, PhD, LP

Bonnie S. LeRoy, MS, CGC

About the Authors

Ian M. MacFarlane, PhD, is an Assistant Professor of Psychology, Austin College, Sherman, Texas. He has taught courses in research design, measurement, and statistics at both the graduate and undergraduate levels, and supervised numerous student researchers. He has co-authored a number of research articles on genetic counseling and is an Associate Editor of the *Journal of Genetic Counseling*.

Patricia McCarthy Veach, PhD, LP, is a Professor of Educational Psychology at the University of Minnesota and has authored over 100 articles and book chapters. She co-authored *Facilitating the Genetic Counseling Process: A Practice Manual*, co-edited *Genetic Counseling Practice: Advanced Concepts and Skills*, and is Assistant Editor of the *Journal of Genetic Counseling*. She is a member of the University of Minnesota Academy of Distinguished Teachers.

Bonnie S. LeRoy, MS, CGC, is a Professor and Director of the Graduate Program of Study in Genetic Counseling at the University of Minnesota, has co-authored multiple articles and chapters on a variety of issues pertaining to genetic counseling, and is co-author of *Facilitating the Genetic Counseling Process: A Practice Manual*, co-editor of *Genetic Counseling Practice: Advanced Concepts and Skills*, and Editor of the *Journal of Genetic Counseling*. She is a member of the University of Minnesota Academy of Distinguished Teachers and past president of the National Society of Genetic Counselors and the American Board of Genetic Counseling.

GENETIC COUNSELING RESEARCH

CONTENTS

Preface | vii

About the Authors | xi

1. Developing Research Questions | 1
2. Finding Sources | 10
3. Writing a Review of Literature | 33
4. Ethics in Research | 81
5. Choosing a Paradigm | 94
6. Designing a Quantitative Study | 112
7. Quantitative Data Analysis: I've Got Data, How Do I Get Answers? | 138
8. Conducting Qualitative Genetic Counseling Research | 198
9. Preparing a Manuscript for Publication | 225
10. Guidelines for Directing Research | 242

APPENDIX: ADDITIONAL RESOURCES FOR RESEARCHERS
AND RESEARCH SUPERVISORS | 251

REFERENCES | 267

INDEX | 277

Developing Research Questions

How Do I Come Up with Research Questions?

The good news is you don't have to start from scratch. Ideas for potential research questions are everywhere! We believe that if you maintain a general state of "openness" to possible sources and ideas while in training as a student or practicing as a genetic counselor, your openness will lead you to the question(s) you wish to study. Pay attention to comments made by instructors in your courses and supervisors in your clinical rotations, ideas that arise in class or journal club discussions, ideas in your text or reference books, points made in a magazine or newspaper article, observations of patient and genetic counselor behaviors in clinic, and questions raised by patients and colleagues. Since good research questions build on prior theory and investigations, one excellent source is the "Research Recommendations" section of published journal articles. These sections often point out existing gaps and important next steps. Developing research questions is often most productive when done collaboratively with others. Whether collaborators plan to work on the research with you or not, getting outside feedback and suggestions typically leads to well-thought-out research questions.

We suggest creating a place where you can routinely jot down ideas for potential studies. Create a file on your computer and add to it as you run into new ideas. If you don't have a place like this already, we have provided an example format for a research idea log in the resource appendix at the end of this book. Even if you already have research questions in mind, our log will help you organize them and start thinking critically about the impact that the

research could have. Once you have a list of potential topics you can, in consultation with your research advisor and/or your colleagues, develop one of these ideas into a viable research question. Keep a list of all your questions in case you find that pursuing your top question is not possible due to practical considerations such as time, money, or other complications.

We'd like to offer one final suggestion for student researchers. Program faculty and clinical supervisors often have researchable ideas and may have ongoing projects in which you can participate. You can sometimes take on responsibility for one piece of a larger project. We encourage you to be open to those ideas for your study. Often students think they need to come up with their own "original idea" in order for the study to be valuable. Research is a collaborative effort. It is never done in isolation, and collaborations make for better studies.

What's the Difference Between a Research Question and a Hypothesis?

Research questions are just that—questions. Hypotheses, on the other hand, are specific predictions (i.e., statements) about a population you are going to investigate scientifically. Hypotheses should be responses to research questions. All research has research questions, but not all research has hypotheses. Hypotheses are used in studies when there is reason to believe the results will turn out a certain way (e.g., published theory, pilot studies, previous results giving an indication). Hypotheses can be used in either qualitative or quantitative studies, though they are more commonly found in the latter. In quantitative research, you will also have specific statistical hypotheses that are part of the statistical analysis (i.e., null and alternative hypotheses; we discuss this further in Chapter 7).

When there is not enough evidence or established theory to create a specific hypothesis, a researcher is left with only the research question. In these situations, the research is called "exploratory." Qualitative research is predominantly exploratory, while quantitative research more often contains hypotheses. In Chapter 5, we