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978-0-521-71823-3 - Undertaking Sensitive Research in the Health and Social Sciences:
Managing Boundaries, Emotions and Risks

Virginia Dickson-Swift, Erica Lyn James and Pranee Liamputtong

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Virginia

**For my mum who gave me an author's name in the hope that
one day I would write a book**

Erica

**For all the people who have ever shared a personal story with
a researcher**

Pranee

**To my two daughters, Zoe Sanipreeya Rice and Emma
Inturatana Rice, who always put up with my writing**

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Preface

The impetus for this book came from the experiences Virginia had while undertaking a small qualitative project that investigated the impact of gambling on spouses and partners (Dickson-Swift, 2000). Gambling is a sensitive topic, and undertaking research on sensitive topics raises a number of particular methodological and ethical issues for both the participants and the researchers. When Virginia began interviewing the spouses and partners of gamblers it became clear that many of the participants who volunteered to be interviewed had not told their spouse or partner about their participation in the research study. For many of the participants, this interview was the first time that they had spoken to anyone at length about their partner's gambling and the effects that it was having on both them and their families. Many reported that participation in the research interview had forced them to think about the consequences of their partner's gambling.

Undertaking gambling research in a small town proved to be quite challenging. Virginia was not immune from the stigma that is often attached to those who have partners or family members who gamble. Many people wondered how Virginia came to be interested in gambling research that focused on the issues for spouses and partners. After the advertisements for potential participants were printed in the local paper, people began to speculate about her interest in such a topic. Some members of the local community concluded that her husband (quite a well known person within the community) must have had a gambling problem and that this was the reason behind Virginia's interest in this topic. Despite this not being the case, this illustrates one of the tensions that may be faced when researching on sensitive topics, particularly in small communities. When designing the research Virginia had not thought about the impact it might have on her or her family. Another unexpected dilemma was raised when Virginia encountered research participants in her day-to-day life, for example in the local supermarket. This raised the tension of balancing participant confidentiality while also behaving in a socially appropriate manner.

During the research interviews some of the participants became quite emotional as they retold their stories; others expressed fear, frustration, anger and sometimes resignation to the hopelessness of their situation. They often

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asked Virginia for advice about what they should do. Should they take a break from the relationship with the gambler? Should they take the children and get out of the relationship? Should they be seeking help? Should they stay and try to deal with it? While research was the main purpose of the interviews, Virginia found that many participants were expecting some advice. The project had been granted ethics approval from an institutional ethics committee, and throughout the approval process Virginia had considered that the participants might become distressed by taking part and may require counselling or support after participating. There were protocols in place for referring people to other agencies that could help them work through their problems; however, very few people were interested in those referrals. After the interviews were over many of the participants spoke of a sense of catharsis from the interview. They said it was nice to talk to someone and to 'get it off their chests'. This raised a dilemma for Virginia. Was this therapy? Were participants being given more than an opportunity to tell their story? In telling their stories, were they somehow changed by the process and, in listening to it, was the researcher also changed? Many questions about the nature of doing research on sensitive topics began to emerge.

Searching for the answers to those many questions proved to be difficult. After much reading of the literature it appeared that the 'story' of what doing research on a sensitive topic was actually like was missing from the published books and research reports. Many of the papers and books focused on the ethical issues of informed consent, gaining access and dealing with gatekeepers, but very few authors were telling the story of how doing research on a sensitive topic is not as straightforward as methods books may have you believe. Frustrated by the lack of researcher accounts of undertaking research, we embarked on a project to talk to researchers and record their experiences of undertaking research on sensitive topics.

In this book, we aim to tell the 'story' of undertaking research on sensitive topics from the perspective of those who actually do the research. The accounts of 30 researchers provided the basis for this book. The researchers we interviewed had a range of research experience, but all had been involved in research on sensitive topics. We chose the Monarch Butterfly for the cover of this book as these butterflies embark on incredible journeys across the world and are faced with many challenges along the way. For us the butterfly represents the challenges these researchers take and the journey across the world that their stories will take via this book.

In addition to the researchers' stories, we bring together a range of issues highlighted in the published literature to build a picture of what the experience of conducting qualitative research on a sensitive topic is like. Quotes from the actual researchers involved in the interviews are used extensively throughout the text (*in italics*) to illuminate the issues researchers face. We also outline some of the possible implications for researchers working in

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sensitive areas and recommend some changes to policy and research practice that will assist in the protection of researchers.

This book is written for researchers (both novice and experienced), transcribers, research funders, research supervisors, university risk managers and anyone interested in undertaking a research project on a sensitive topic. It aims to bridge the gap for researchers and to provide them with a resource that will assist them in their preparation for undertaking research on sensitive topics. It is also valuable for the training needs of postgraduate students who wish to undertake qualitative research on sensitive topics, as it provides essential reading regarding the risks and difficulties associated with this type of research. We hope that the content of this book challenges, guides and inspires you to undertake innovative qualitative research on sensitive topics.

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We wish also to acknowledge that earlier versions of the following chapters have been published elsewhere. Chapter 3 (Doing sensitive research: what challenges do qualitative researchers face? *Qualitative Research*, **3**(7), 327–353, Sage Publications), Chapter 4 (Blurring boundaries in qualitative health research on sensitive topics. *Qualitative Health Research*, **16**(6), 853–871, Sage Publications), Chapter 5 (Researching sensitive topics: qualitative research as emotion work. *Qualitative Research*, in press, Sage Publications) and Chapter 6 (Risk to researchers in qualitative research on sensitive topics: issues and strategies. *Qualitative Health Research*, **18**(1), 133–144, Sage Publications).

Finally, to our families and loved ones, we thank you for your encouragement and patience.

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About the authors

Virginia Dickson-Swift has a PhD in public health and is a Lecturer in Public Health at the School of Public Health, La Trobe University, Bendigo, Australia. Virginia has taught across a range of units within both the undergraduate and postgraduate programmes. Virginia has particular interest in the role of emotion in qualitative research, and the use of qualitative methodologies in health research. She has published a range of papers based on this work internationally and presented her work at a range of conferences.

Erica James is a behavioural epidemiologist and a Senior Research Academic at the Centre for Health Research and Psycho-oncology (CHeRP), which is funded by The Cancer Council NSW and situated at the University of Newcastle, Australia. Erica's research programme emphasizes lifestyle behaviours and cancer control, including both qualitative and quantitative research with cancer survivors. She has published numerous papers and book chapters on various aspects of health promotion, methodological issues and teaching research methods.

Pranee Liamputtong is Personal Chair in Public Health at the School of Public Health, La Trobe University, Melbourne, Australia. Pranee has previously taught in the School of Sociology and Anthropology and worked as a Public Health Research Fellow at the Centre for the Study of Mothers' and Children's Health, La Trobe University. Pranee has particular interests in issues related to cultural and social influences on child-bearing, child rearing and women's reproductive and sexual health. She has published several books and a large number of papers in these areas.

Pranee has written and edited a number of research method books including *Qualitative Research Methods: A Health Focus* (with Douglas Ezzy, Oxford University Press, 1999, reprinted in 2000, 2001, 2002, 2003, 2004) the second edition of this book is titled *Qualitative Research Methods* (2005, reprinted in 2005, 2006 twice), and *Health Research in Cyberspace: Methodological, Practical and Personal Issues of Researching Online* (Nova Science Publishers, 2006). Her most recent method book is titled *Researching The Vulnerable: A Guide to Sensitive Research Methods* (Sage, 2007). She is now preparing three books: *Knowing Differently: Arts-Based and Collaborative Research Methods* (Nova Science Publishers), *Performing Qualitative Cross-Cultural Research* (Cambridge University Press) and *Doing Cross-Cultural Research: Methodological and Ethical Perspectives* (Springer).

Scientific research work, as all human activities, is governed by individual, community and social values. Research ethics involve requirements on daily work, the protection of dignity of subjects and the publication of the information in the research. However, when nurses participate in research they have to cope with three value systems; society; nursing and science.Â In situations that are particularly complex, sensitive, and in which the participants are extremely vulnerable, a Certificate of Confidentiality issued by the U.S. Department of Health and Human Services (DHHS) may be useful to help ensure the privacy of research participants especially in studies in which participants and researchers may be exposed to compelled legal disclosure of research data. Undertaking qualitative research on sensitive topics often raises a variety of ethical problems. Based on empirical research, this book documents experiences throughout the entire research process: from conceptualization, ethics approval, fieldwork, to analysis and publication. It presents readers with stories from the researcher's perspective and synthesizes these experiences into a conceptual framework that will assist researchers to undertake qualitative research. Each section discusses potential pitfalls, provides quotes and stories and reviews the relevant literature and theory, prov