EDITED BY PAUL M.W. HACKETT
AND CHRISTOPHER M. HAYRE

HANDBOOK OF ETHNOGRAPHY IN HEALTHCARE RESEARCH

ROUTLEDGE

HANDBOOK OF ETHNOGRAPHY IN HEALTHCARE RESEARCH

This handbook provides an up-to-date reference point for ethnography in healthcare research. Taking a multi-disciplinary approach, the chapters offer a holistic view of ethnography within medical contexts.

This edited volume is organized around major methodological themes, such as ethics, interviews, narrative analysis, and mixed methods. Through the use of case studies, it illustrates how methodological considerations for ethnographic healthcare research are distinct from those in other fields. It has detailed content on the methodological facets of undertaking ethnography for prospective researchers to help them to conduct research in both an ethical and safe manner. It also highlights important issues such as the role of the researcher as the key research instrument, exploring how one's social behaviours enable the researcher to 'get closer' to his/her participants and thus uncover original phenomena. Furthermore, it invites critical discussion of applied methodological strategies within the global academic community by pushing forward the use of ethnography to enhance the body of knowledge in the field.

The book offers an original guide for advanced students, prospective ethnographers, and healthcare professionals aiming to utilize this methodological approach.

Paul M.W. Hackett is professor in ethnography at Emerson College, Boston, USA, a visiting professor in health research at the University of Suffolk, UK, and a visiting scholar at the Royal Anthropological Institute in London. He has developed the declarative mapping sentence out of his research which is concerned with the categorial understanding that humans have of their world and how such understanding underpins and facilitates behaviour, drawing upon several branches of psychology, philosophy, anthropology, and research methods. His publications include around 20 books and articles in leading journals.

Christopher M. Hayre is a senior lecturer at Charles Sturt University in New South Wales, Australia. He has published both qualitative and quantitative refereed papers in the field of medical imaging and brought together several books in the field of medical imaging, health research, technology, and ethnography.

Taylor & Francis
Taylor & Francis Group
http://taylorandfrancis.com

HANDBOOK OF ETHNOGRAPHY IN HEALTHCARE RESEARCH

Edited by
Paul M.W. Hackett, PhD, and
Christopher M. Hayre, PhD

Routledge
Taylor & Francis Group
LONDON AND NEW YORK

First published 2021
by Routledge
2 Park Square, Milton Park, Abingdon, Oxon OX14 4RN

and by Routledge
52 Vanderbilt Avenue, New York, NY 10017

Routledge is an imprint of the Taylor & Francis Group, an informa business

© 2021 selection and editorial matter, Paul M.W. Hackett and Christopher M. Hayre; individual chapters, the contributors

The right of Paul M.W. Hackett and Christopher M. Hayre to be identified as the authors of the editorial material, and of the authors for their individual chapters, has been asserted in accordance with sections 77 and 78 of the Copyright, Designs and Patents Act 1988.

All rights reserved. No part of this book may be reprinted or reproduced or utilised in any form or by any electronic, mechanical, or other means, now known or hereafter invented, including photocopying and recording, or in any information storage or retrieval system, without permission in writing from the publishers.

Trademark notice: Product or corporate names may be trademarks or registered trademarks, and are used only for identification and explanation without intent to infringe.

British Library Cataloguing-in-Publication Data
A catalogue record for this book is available from the British Library

Library of Congress Cataloging-in-Publication Data
Names: Hackett, Paul, 1960– editor. | Hayre, Christopher M., editor.
Title: Handbook of ethnography in healthcare research / Edited by
Paul M.W. Hackett and Christopher M. Hayre.
Description: Abingdon, Oxon; New York, NY : Routledge, 2021. |
Includes bibliographical references and index. |
Identifiers: LCCN 2020028624 (print) | LCCN 2020028625 (ebook) |
ISBN 9780367336332 (paperback) | ISBN 9780367336349 (hardback) |
ISBN 9780429320927 (ebook)
Subjects: LCSH: Medical anthropology–Research. |
Medical anthropology–Moral and ethical aspects. |
Medical anthropology–Social aspects.
Classification: LCC GN296.5.B47 H36 2021 (print) |
LCC GN296.5.B47 (ebook) | DDC 306.4/61–dc23
LC record available at https://lccn.loc.gov/2020028624
LC ebook record available at https://lccn.loc.gov/2020028625

ISBN: 978-0-367-33634-9 (hbk)
ISBN: 978-0-367-33633-2 (pbk)
ISBN: 978-0-429-32092-7 (ebk)

Typeset in Bembo
by Newgen Publishing UK

Dr. Christopher M. Hayre would like to dedicate this book to his supportive wife Charlotte
and his daughters Ayva, Evelynn, and Ellena. Love to all.
Professor Paul M.W. Hackett would like to thank Jessica whose support makes it all possible.

Taylor & Francis
Taylor & Francis Group
http://taylorandfrancis.com

CONTENTS

List of contributors *xii*
Acknowledgements *xv*
Foreword by Shane Blackman *xvi*

PART I
Introduction **1**

1 Introducing ethnography and its rationale for healthcare practitioner use 3
Christopher M. Hayre and Paul M.W. Hackett

PART II
Ethical considerations **9**

2 Ethical considerations in ethnography 11
Jessica Schwarzenbach and Paul M.W. Hackett

3 Ethics of online research with human participants 23
Jeff Gavin and Karen Rodham

4 Cultural variation in informed consent for clinical research participation 33
David Resnik and Julia Hecking

5 Encountering hostility in ethnographic research 47
Christopher M. Hayre and Paul M.W. Hackett

PART III
Design and planning **55**

6 The door-to-door ethnographer: recruiting patients and healthcare providers for ethnographic research 57
Melinda Rea-Holloway and Steve Hagelman

7 Ethnographic research design 67
Ruth Montgomery-Andersen and Michelle M. Doucette

8 The declarative mapping sentence as a framework for conducting ethnographic health research 80
Paul M.W. Hackett

PART IV
Interviewing in ethnographic research **95**

9 Getting deep in the pain: understanding people through ethnographic research 97
Antonella Fabri

10 An ethnography of a universally designed play environment 107
Hira Hasan and Susan Squires

11 To be on a diet: ethnography of weight loss between beauty, food, and violence 128
Martina Grimaldi

12 The clinician-patient interaction: crossing the chasm of expectations 141
Gillie Gabay

13 Constructing ethnographic data in medical education 153
Jonathan Tummons

PART V
Visual/sensory ethnography **165**

14 Visual ethnography in health and healthcare: concepts, steps, and good practices 167
Laura Lorenz and Bettina Kolb

PART VI
Auto/ethnography **181**

15 Institution(alization), bureaucracy, and well-being? An organizational ethnography of perinatal care within the National Health Service 183
Tom Vine

16 Critical autoethnography and mental health research 197
Stacy Holman Jones and Anne Harris

PART VII
Observational methods in ethnographic research **211**

17 Ethnographers in scrubs: ethnographic observation within healthcare 213
Melinda Rea-Holloway and Steve Hagelman

18 Ethnographic investigations of a diagnostic imaging department 224
Ruth Strudwick

19 The ALIVE! Project: understanding the intersection between faith and soul food using ethnographic methods 234
Deirdre Guthrie and Elizabeth Lynch

PART VIII
Note-taking and writing up **257**

20 Fieldnotes in ethnographic research 259
Ruth Strudwick

21 Writing and representation 264
Michael Klingenberg

PART IX
Journals and diaries **275**

22 Ethnographic diaries and journals: principles, practices, and dilemmas 277
Graham Hall

PART X
Narrative analysis **291**

23 Narrative ethnography: how to study stories in the context of their telling 293
Ditte Andersen

24 In the quest of resilience in elder patients: solutogenics 301
Gillie Gabay

25 And the anthropologist made the "emotional note" 313
Haris Agic

PART XI
Projective techniques 327

26 Projective techniques in health research 329
Taylor Malone and Paul M.W. Hackett

27 Being creative using projective techniques 341
Paul M.W. Hackett

PART XII
Focus groups 351

28 Using focus groups in healthcare research 353
Alicia Carlson and Paul M.W. Hackett

29 Focus group research in healthcare 364
Immy Holloway

PART XIII
Multiple methods 375

30 Becoming a physician of the people in a rural mountain community in Mexico 377
Deirdre Guthrie

31 Breaking down silos: the value of interdisciplinary production of knowledge for (health) innovation 388
Tamira Snell

PART XIV
Analyzing data 401

32 Analyzing the data: conditions, meanings, and reasonings analysis 403
Tine Aagaard

33 Computer-Assisted Qualitative Data Analysis Software (CAQDAS) and ethnographic health research 414
Áine M. Humble

34 Ethnographic and qualitative data analysis 425
Immy Holloway

35 Ethnographic creative non-fiction: the creation and evolution of *Lily's Lymphedema* 438
Elise Radina

PART XV
Novel approaches **453**

36 Mapping network disturbances: case studies that demonstrate the use of an ethnographic approach to health and well-being research 455
Maria Louise Bønnelykke

37 Why happiness studies ought to include qualitative research components 467
Cathrine V. Jansson-Boyd and Anke Plagnol

38 A whole-school approach to health and well-being: an auto-ethnographic account of a primary school 481
Jonathan Glazzard

PART XVI
Conclusion **491**

39 Conclusions and the future of ethnography in health-related research: challenges and innovations 493
Paul M.W. Hackett and Christopher M. Hayre

40 Coronavirus and COVID-19: qualitative healthcare research during and after the pandemic 503
Paul M.W. Hackett and Christopher M. Hayre

41 Black Lives Matter: birdwatching in Central Park and the murder of George Floyd 513
Paul M.W. Hackett and Jessica Schwarzenbach

Index *522*

CONTRIBUTORS

Tine Aagaard, University of Greenland, Greenland.

Haris Agic, PhD, in Medical Anthropology Health and Society, Development Leader for Society, Culture and Arts at Study Promotion Association, Studiefrämjandet, Stockholm, Sweden.

Ditte Andersen, Senior Researcher at VIVE, The Danish Center for Social Science Research, Copenhagen, Denmark, den@vive.dk.

Maria Louise Bønnelykke, Department of Culture and Learning, Aalborg University.

Alicia Carlson, Video Production Manager, Office of Marketing, Emerson College, Boston, MA, USA.

Michelle M. Doucette, Independent Public Health Researcher, University of Greenland.

Antonella Fabri, Business Anthropologist, Caleidoscopio Ethnographic Research, University at Albany.

Gillie Gabay, College of Management Academic Studies, School of Behavioral Science and Psychology, Israel.

Jeff Gavin, Senior Lecturer in Department of Psychology at the University of Bath.

Jonathan Glazzard, Professor of Inclusive Education, Carnegie School of Education, Leeds Beckett University, Leeds, UK.

Martina Grimaldi, Lecturer in Cultural Anthropology and Ethnology, University of Bologna, Alma Mater Studiorum, Italy.

Deirdre Guthrie is an ethnographic consultant and research advisor for the Wellbeing Project based in Paris.

Paul M.W. Hackett, Visiting Professor of Health Research Methods, School of Health Sciences, University of Suffolk; Visiting Scholar, Royal Anthropological Institute; Professor of Ethnography, School of Communication, Emerson College; Honorary Fellow, Department of Philosophy, Durham University.

Steve Hagelman, Ethnographic Research Inc.

Graham Hall, Professor of Applied Linguistics, Northumbria University, UK.

Anne Harris, VC Principal Research Fellow, RMIT University, Melbourne, Australia; ARC Future Fellow School of Education, Australia; Director, Digital Ethnography Research Centre, Melbourne, Australia; Creative Agency Research Lab, Melbourne, Australia.

Hira Hasan, Department of Applied Anthropology, University of North Texas, USA.

Christopher M. Hayre, Senior Lecturer, Diagnostic Radiography, Charles Sturt University, New South Wales, Australia.

Julia Hecking, Mount Holyoke College, South Hadley, Massachusetts, USA.

Immy Holloway, Professor Emeritus of Health Research, Bournemouth University, UK.

Áine M. Humble, Professor, Family Studies and Gerontology Department, Mount Saint Vincent University, Halifax, Nova Scotia, Canada.

Cathrine V. Jansson-Boyd, Anglia Ruskin University, Cambridge, UK.

Stacy Holman Jones, Professor and Director in Centre for Theatre and Performance, Monash University, Australia.

Michael Klingenberg, Senior Lecturer in Adult Nursing, Leeds Beckett University, UK.

Bettina Kolb, Lecturer, Department of Sociology, University of Vienna and Department of Health Science and Social Work, Carinthia University of Applied Science, Villach, Austria.

Laura Lorenz, Visiting Research Scholar, Heller School for Social Policy & Management, Brandeis University, Massachusetts, USA. llorenz@brandeis.edu.

Elizabeth Lynch, Associate Professor, Department of Preventive Medicine, Rush Medical College, Chicago, IL, USA.

Taylor Malone, School of Communication, Emerson College, Boston, USA.

Ruth Montgomery, Andersen Independent Public Health Researcher, University of Greenland, Greenland.

Anke Plagnol, Senior Lecturer in Behavioural Economics City, University of London, UK.

Elise Radina, Professor of Family Science and Social Work, Miami University, Oxford, OH, USA.

Melinda Rea-Holloway, Ethnographic Research Inc.

David Resnik, National Institute of Environmental Health Sciences, National Institutes of Health, National Institutes of Health.

Karen Rodham, Professor of Health Psychology, Staffordshire University, UK.

Jessica Schwarzenbach, Independent Researcher, Massachusetts, USA.

Tamira Snell, Insights Lead at Nordic Health Lab and Associated Partner at Copenhagen Institute for Futures Studies.

Ruth Strudwick, is a diagnostic radiographer and an associate professor in Diagnostic Radiography, University of Suffolk, Ipswich, UK.

Susan Squires, Professor, University of North Texas, USA.

Jonathan Tummons, Associate Professor and Deputy Head of School, School of Education, Durham University, UK.

Tom Vine, Associate Professor, University of Suffolk, Ipswich, UK.

ACKNOWLEDGEMENTS

The editors would like to thank all of the authors who have contributed to this book for their commitment, hard work, and determination. It has been a pleasure to work with you and to bring together this collection of chapters. We believe that these demonstrate the continued importance of conducting ethnography for health research. We have personally found this to be an exciting and enriching project, which we hope readers will enjoy and utilize.

FOREWORD

Ethnographic vision

Professor Shane Blackman

Ethnography has become more popular as a research method and research councils such as the ESRC and AHRC, and government departments including Health and Social Care, Work and Pensions, and Education have actively sought data from ethnographic studies. This is evident from the varied contributors within this Handbook. Increased popularity, of course, does not mean increased acceptance. The *Handbook of Ethnography in Healthcare Research* does not set out to replace, oppose, or critique positivism in healthcare, or to demonstrate that ethnography has the answers. It explores new agendas in ethnographic research in healthcare. The chapters highlight that qualitative methods are both exploratory and produce outcomes which are generalizable and of high value for patients, doctors, nurses, and all professionals within healthcare. Ethnography seeks to be inclusive through access to experience to offer rich data both inside and outside clinical settings, through participant observation, conversational interviews, personal documentary evidence, digital ethnography, and the researcher themselves.

The ethnographic studies here reveal that fieldwork can be dynamic yet also boring; the accounts bring forth a range of contradictory, oppositional, and pleasurable experiences through encounters with anger, frustration, guilt, irony, and humour. Recognition of these different lived experiences of people of different ages, social classes, sexualities, and ethnicities enable us to address healthcare issues from a variety of stand points, where ethnographic interventions deliver positive results in understanding and through sharing knowledge. A number of the chapters here recognize that ethnographic studies may be positioned in opposition to the dominant positivist model operated within health sciences. There is also recognition that the rise of ethnographic studies, to some extent, has been held in check by the status of biomedical science and its hegemonic position. Yet during the Coronavirus pandemic of 2020 we have seen research uncomfortably coexist between science and politics, delivered online as a daily furor defined by accusation, blame, censorship, and lack of transparency. Science has been used for political purposes whether it has been allowed to offer answers or not permitted to speak. Ethnography is familiar with politics, decolonization, critical questioning, and "fired up" accusations; throughout its long history ethnography has sought out what is uncomfortable to enhance the understanding that all research depends on the subjective understanding of trust.

Ethnography is established though relationships and it can fall apart quickly when respect is not its top priority. This approach is more than a research method used to collect qualitative empirical data, it is about empathy, conflict, and interpretation, and as Clifford Geertz (1973) explained, ethnography is where the researcher and the researched are engaged in applying imagination. In this book we see that ethnographic studies are achieved through relationships and intimacy—there is care and sensitivity both in the research practice of fieldwork and in the writing of the research itself as a publication. The attraction and value of the ethnographic studies in this book is that they are personal stories of journeys lived through fear, shame, anxiety, self-realization, triumph and disaster, and even laughter.

What marks ethnography out as a research method is usage of the field diary, whether hand written or electronic, audio or visual. From the moment they are in the field the researchers are actively recording, interpreting, writing, and constructing the text. From its beginning, ethnography has been understood as both interdisciplinary and beholden to no discipline. All ethnographers know that they are standing on the "shoulders of giants." Over a hundred years ago, the method was first used in the discipline of anthropology by key figures such as Franz Boas (1858–1942) and Bronislaw Malinowski (1884–1942). In (1916: 418) Malinowski said that, "I found the lack of philosophical clearness on matters connected with ethnographic and sociological field work a great setback." In 1915, Robert Park set out the urban fieldwork manifesto of the Chicago School of Sociology and from the 1920s ethnographic research techniques to collect and analyze data were professionally taught and systematically organized at Chicago, for example, Palmer's (1928) *Field Studies in Sociology: A Student's Manual*. Pre-dating such academic development was Harriet Martineau (1838), who could be considered an ethnographic primer and who not only prioritized first-hand observation but also teaching ethnography when she said in the Advertisement of her book, "The best mode of exciting the love of observation is by teaching 'How to Observe.'"

Ethnography is both a method and research technique, and a methodology that is a philosophy of method. Ethnographic methods are focused on being open and sharing experiences. This can advance knowledge. Ethnographers enable the data to speak back, to question the research and the researcher. This may mean allowing the participants to collect data, do analysis, and take part in coproduction of texts. Within qualitative research the researcher is always part of what is happening. Sometimes the researcher tries to minimize their involvement, but at other times they may guide participants to engage with ideas. Trying to pigeonhole ethnography is not what ethnographers do.

Speaking on fieldwork, Malinowski (1926: 127) states: "Open air anthropology, as opposed to hearsay and note-taking, is hard work, but it is also great fun." The assertion that research can be fun still remains a taboo topic because an ethnographic approach involves immersion within, and an investigation of, a social world which can be painful and emotionally upsetting for all. Self-awareness is important in ethnography because, as the researcher, you are directly learning about people's experiences and feelings. Formally this is described as reflexivity, where you show sensitivity towards your research subjects and also reflect on what is your role in speaking with them. In all the chapters of this book, we see that in order to conduct successful ethnographic fieldwork, the researcher is required to be responsive and flexible to the needs of the research subjects and to build positive contact on a constant basis to enable data to be forthcoming.

The aim of ethnography in healthcare is to observe behaviour within a clinical, natural, and everyday setting or context to discover the meaning and value people put into their actions and ideals. Ethnography is alive to the real opportunities of dynamic fieldwork encounters and experiences: we see here that researchers need to be prepared for surprises! An ethnographic vision enables research to offer something new, alternative, or different from what was anticipated or expected, so the researcher should be prepared to improvise. Therefore, flexibility within research design and fieldwork management are the markers of a sophisticated and receptive researcher who is aware of the changes within the setting at the level of theory and methodology.

References

Blackman, S. (2010) 'The Ethnographic Mosaic' of the Chicago School: critically locating Vivien Palmer, Cliff ord Shaw and Frederic Thrasher's research methods in contemporary reflexive sociological interpretation. In Hart, C. (ed), *The Legacy of the Chicago School of Sociology*. Kingswinsford: Midrash Publishing: 195– 215.

Geertz, C. (1973) Thick Description: Towards an Interpretive Theory of Culture. In *The Interpretation of Cultures*. London: Hutchinson, pp. 3–30.

Malinowski, B. (1916) Baloma; The Spirits of the Dead in the Trobriand Islands. *The Journal of the Royal Anthropological Institute of Great Britain and Ireland*, 46(Jul–Dec): 353–430.

Malinowski, B. (1926) *Myth in Primitive Psychology*. London: Kegan Paul.

Martineau, H. (1838) *How to Observe Morals and Manners*. London: Charles Knight.

Palmer, V. (1928) *Field Studies in Sociology: A Student's Manual*. Chicago: University of Chicago Press.

Park, R. E. (1915) The City: Suggestions for the Investigation of Human Behavior in the City Environment. *American Journal of Sociology*, 20(5): 577–612.

PART I

Introduction

Taylor & Francis
Taylor & Francis Group
http://taylorandfrancis.com

1

INTRODUCING ETHNOGRAPHY AND ITS RATIONALE FOR HEALTHCARE PRACTITIONER USE

Christopher M. Hayre and Paul M.W. Hackett

Introduction

This introductory chapter sets the scene for this book volume and introduces ethnography as a methodology to the reader. As we will come to acknowledge, the use of ethnography is well-established for researchers within a range of health settings. For example, in the author's own discipline, diagnostic radiography, the rise of ethnographic approaches is providing greater clarity into the professional practices of diagnostic radiographers and the care experienced by patients undergoing medical imaging examinations. Whilst the prospective chapters in this book are from experienced researchers and academics who have undertaken ethnographic studies within health settings, there are also examples outside the healthcare setting, which provide unique contexts that can be transferred into clinical environments. In this introductory chapter, we begin by discussing what ethnography is, focusing on its methodological purpose and how, for healthcare professionals, it can uncover central phenomena previously undocumented. Next, the authors reflect on the virtues of undertaking ethnography as experienced researchers, whilst importantly reflecting on our own journeys of pursuing ethnography as both a research methodology and an enlightenment in our own professional conduct.

What is ethnography?

Ethnography is regarded as a methodological tool that "gets close" to a particular group and/or sub-group to uncover cultural phenomena. Historically, it has its roots in British social anthropology, whereby researchers went out to study foreign cultures, and in American Sociology (from the Chicago school), whereby observation was used to explore urban industrial society. These schools of thought aimed to provide an overarching objective: that of cultural description (Brewer, 2000). Since then, the rise of ethnography has been identified in many academic disciplines, notably business, sociology, criminology, education, politics, and healthcare. In short, it is generally accepted that ethnography offers exploratory researchers an opportunity to uncover the social reality of individuals and groups in order to better enhance our understanding of their social world (Hammersley & Atkinson, 2007).

In Chris Hayre's work, the rationale for using ethnography was due to an immediate disconnect in diagnostic radiography practice. For example, the pedagogical principles and practices offered at his higher education institution (as an undergraduate radiography student) were seen to be dichotomous with what was practiced in the clinical setting. Looking back, he remained inexperienced as a student radiographer. He was "learning by doing," and as he continued to observe the clinical environment, he would replicate the social practices by conforming to cultural norms. As he developed and became more competent as a student radiographer, leading to gradation and then becoming a practitioner, he began to appreciate the complexities around the diversity of diagnostic radiography practice, but importantly, how this disconnect was also influenced by workplace cultures.

Deciding to embark on a PhD remained a key driver for the first author in order to enlighten his own practice and understand the observed behaviour of clinical work. In response, ethnography provided an opportunity to study a culture (of radiographers in this case) within their own settings (Hobbs & May, 1993; McGarry, 2007) and, not forgetting the primary purpose, in order understand why a dichotomy existed between principles professed within the higher education setting when compared to the day-to-day practices of diagnostic radiographers. Hobbs and May (1993) agree, stating that ethnography enables researchers a way of telling it like it is, by learning and then describing the culture observed and looking at the actions of individuals. Further, Denzin (1997) reminds us that researchers aim to unveil the participants' interpretation and then draw from their own conclusions by using many alternate incidences in order to understand the cultural perspective. These former tenets remained high on the agenda of uncovering radiographic practices.

For prospective ethnographic researchers reading this book for the first time, we firmly acknowledge that in order to document/uncover findings, researchers need to become part of the culture being studied in order to gain understanding and insight. This typically involves observation, which remains a key method for ethnographers, both historically and contemporaneously. There are alternate forms of observation, which is beyond the scope for this introductory chapter, but we direct readers to the following texts (see Roth, 1962; Spradley, 1980). Looking back, participant observation remained an important method in the first author's own research, enabling him to observe and listen to what was being said and ask questions as an insider (as a diagnostic radiographer himself) (Hayre, 2016). This is important when it comes to utilizing ethnography as a methodology of choice because it is the observed behaviour that should be examined in its natural state and undisturbed by the researcher as much as possible (Hammersley & Atkinson, 2007). We also suggest that when considering ethnography, observation is carried out over a period of time that not only meets the aims and objectives of the study but also ensures that the behaviour of others is not linked to the researcher's presence in the field. For example, Wolcott (1999, p. 49) reminds us that "people can sustain an act or maintain their best image only so long." This is commonly regarded as the Hawthorne effect, whereby the presence of the researcher alters the behaviour of those studied. It is, however, accepted that over a longer period of time this fades, and thus the "real" behaviour begins to emerge (Nieswiadomy, 2002). In short, for the first author, ethnography offered a valued insight into a specific culture underexplored within his own profession, diagnostic radiography, which subsequently expanded the evidence base and at the time of writing this chapter influenced transnational policy for the radiographic profession. In short, our view is that ethnography has the ability to add value to all healthcare disciplines and expand the existing body of knowledge and, importantly, challenge commonly held beliefs and viewpoints of practice.

What is ethnography? Ethnography is a methodological tool that can offer prospective ethnographic researchers the opportunity to critically engage with contemporary healthcare practices and also provide the opportunity for innovation and change within a health discipline, which is well evidenced in this book volume.

The virtues of ethnography in healthcare settings

The editors will now comment on the virtues ethnography offers when it comes to researching within the healthcare environment. Because of its increasing use amongst healthcare practitioners to gain deeper insight of either practitioners' or patients' perspectives, Hammersley (1992, p. 35) terms it "practitioner ethnography" following its recent uses amongst vocationally based disciplines, such as practicing healthcare professionals. Further, as a healthcare professional, reflection remains an essential tool. Reflection is often used to gain perspective on a clinical situation, patient interaction, and the practice/application of new knowledge, for instance. It is also central when renewing our professional registration in order to demonstrate continuous professional development as healthcare professionals. In addition, the methodological practice of ethnography is not wholly dissimilar: the engagement of reflexivity enables ethnographers to critically reflect on their interactions with peers, participants, colleagues, the research environment, and the generation of new knowledge when in the field. Further, the association between reflection (as a healthcare practitioner) and reflexivity (as an ethnographer) offers similar opportunities and virtues whereby the unification of such practices can help develop a greater appreciation and understanding of self-management. For example, by undertaking and pursuing ethnography as a research methodology, we are not simply implementing a research strategy that ends upon leaving the research field, but instead one that continues and develops, involving workplace interactions coupled with the management of potential hostile situations, while we, importantly, remain ethically mindful of our own positionality within the context of the social world around us.

When ethnographic researchers consider their methods in healthcare contexts, with the overarching aim of ascertaining "what people say they do and what they actually do," researchers typically align to social constructionism and interpretivism in order to help obtain new knowledge and understanding through cultural exploration of a particular context (Brewer, 2000). For example, interpretivism identifies and searches for patterns of descriptive meanings, helping to understand the participants view. Constructionism is a form of interpretive research (Taylor, 2002), which states that meaning is not discovered but constructed (Crotty, 2005). Constructionism can be formed from our everyday experiences, our history, our use of language, our knowledge, and our social action, which are all interconnected and, over time, lead to shared meanings (Brewer, 2000). Whilst these are commonly utilized and generally accepted as ethnographic norms, we urge ethnographers to critique whether positivist methods can be used to help uncover the social world, depending on the research questions posed. For instance, Hayre and Blackman (2020) recently identified the combination of both interpretivist (observation) and positivist (X-ray experimental) methods within a single ethnographic methodology. After philosophically grappling with the ideological disconnect, the emergent discourse presented offers what the authors term "an umbrella strategy." The acceptance and/or acknowledgement of positivism within ethnography is rarely discussed nor evidenced within healthcare literature. Further, for Hayre and Blackman (2020), there was a genuine recognition and acceptance of the philosophical challenges (and even juxtaposition) for the healthcare professional and the researcher. However, after critical reflection, discussion, and recognition of what the purpose of ethnography is (ethnos – "a people" and -graphy, meaning "writing"), this reminded us that ethnography focuses on writing about a group and/or a sub-group of individuals being studied, regardless of philosophy. Thus, because positivism remains central to the practices of optimizing X-rays clinically, it was helpful to include positivist approaches as part of the culture being researched.

Thus whilst for most ethnographic researchers there remains firm use of qualitative methods, which typically involves observation, interviews, focus groups, and examination of written documents and/or diaries (and remains the general consensus throughout this book), we do welcome the utilization of positivist approaches, which can draw on a range of research philosophy within contemporary ethnographies. Chapters 8 and 11 in this book recognize the integration of quantitative methods in order to support or refute phenomena. In order to provide an example of the aforementioned approach, the following was deemed appropriate in the work by the first author:

1) Participant observation: Used to observe contemporary radiographic practices and note "what the radiographers did."
2) In-depth semi-structure interviews: Explored key themes derived from the clinical observations and uncovered deeper meanings into "what had been seen."
3) X-ray experiments: To reflect on specific radiographic phenomena observed and contribute X-ray findings with "what had been seen" and "what had been said" regarding specific phenomena.

The above methodological strategy arguably demonstrates an emancipation of research methods and philosophy within the diagnostic radiography setting. Inductive and hypothetical-deductive approaches are becoming well-established in health disciplines (Henwood, 1996) in order to study the effectiveness of clinical and person-centredness (Mellion & Tovin, 2002). This remained central to the ethnographic journey of the first author, which may resonate with authors transnationally in their respective health disciplines. In short, one of the key virtues of ethnography resides in its versatility to be applied in a number of health contexts and to encompass an array of research strategies depending on what the research seeks to uncover.

Summary

This chapter sought to provide two key introductory messages. First, we provide a definition to ethnographic research and explore how the first author came to consider and adopt this methodological approach for his own research. As identified above, a key driver behind this selection resulted in the dichotomy of pedagogical principles and the observed behaviour of healthcare professionals as a student radiographer. These experiences help contextualize the utility in which ethnography offered a professional community the ability to uncover professional practices that resonated with the discipline as a whole. Second, we sought to provide some key attributes that ethnography offers. For example, not only do we feel that ethnography provides a toolkit for researchers, but it can also provide academics with the virtues of upholding professional excellence throughout an academic career. Finally, we have argued that whilst qualitative methods are typically aligned to ethnographic approaches, the health disciplines offer a wide range of methodological (and philosophical) opportunity that engages positivist traditions in order to help discern the social world around us.

References

Brewer, J.D. (2000) *Ethnography*. Buckingham: Open University Press.

Crotty, M. (2005) *The Foundations of Social Research – Meaning and Perspective in the Research Process*. London: Sage.

Denzin, N.K. (1997) *Interpretive ethnography*. Thousand Oaks: Sage.

Hammersley, M. (1992) *What's Wrong With Ethnography*. New York: Routledge.

Hammersley, M. and Atkinson, P. (2007) *Ethnography Principles in Practice,* 3rd Ed. New York: Routledge.

Hayre, C.M. (2016) Radiography Observed: An Ethnographic Study Exploring Contemporary Radiographic Practice. PhD Thesis. Canterbury Christ Church University.

Hayre, C.M. and Blackman, S. (2020) "Ethnographic mosaic approach for health and rehabilitation practitioners: an ethno-radiographic perspective." *Disability and Rehabilitation*: 1–4**.**

Henwood, S. (1996) "Managing quality in diagnostic imaging departments." *Radiography,* 2 (2): 111–117.

Hobbs, D. and May, T. (1993) *Interpreting the field – Accounts of ethnography*. Oxford: Oxford University Press.

Mellion, L.R. and Tovin, M.M. (2002) "Grounded theory: a qualitative research methodology for physical therapy." *Physiotherapy Theory and Practice,* 18 (3): 109–20.

McGarry, J. (2007) "Nursing relationships in ethnographic research: what of rapport." *Nurse Researcher,* 14 (3): 7–14.

Nieswiadomy, R. (2002) *Foundations of Nursing Research*. 4th Ed. Prentice Hall: Upper Saddle River, USA.

Roth, J.H. (1962) "Comments on secret observations." *Social Problems*, 9 (3): 283–284.

Spradley, J.P. (1980) *Participant Observation*. New York: Holt, Rinehart & Winston.

Taylor, S. (2002) *Ethnographic Research*. London: Sage.

Wolcott, H.F. (1999) Ethnography – A Way of Seeing. Altamira Press: Oxford.

Taylor & Francis
Taylor & Francis Group
http://taylorandfrancis.com

PART II

Ethical considerations

Taylor & Francis
Taylor & Francis Group
http://taylorandfrancis.com

2

ETHICAL CONSIDERATIONS IN ETHNOGRAPHY[1]

Jessica Schwarzenbach and Paul M.W. Hackett

Introduction

Other chapters in this book address aspects of ethics which apply to the practice of qualitative research within a healthcare setting. However, this chapter utilizes a slightly different approach by containing largely anecdotal reports from the authors' personal experiences. In this chapter the term *consideration(s)* signifies the application of continuous and careful thought. As a consequence of this perspective, the chapter addresses many ethical features of the actual practice of qualitative interview research and constructs a body of cautionary advice for future investigators.

The healthcare industry embodies a unique set of power differentials between medical researchers and those who seek medical assistance. Often research is conducted in a situation where outcomes are uncertain and patients are especially vulnerable to feelings of fear and confusion. Medical care professionals are often perceived by those undergoing physical and mental care as experts who inherently possess greater knowledge (and thus power) as well as influence due to their familiarity not only with the illness itself but with the language and operations of the healthcare establishment. Ethical awareness of this power differential between researcher and patient is codified through written laws and regulatory bodies such as institutional review boards (IRBs), the Belmont Report, the American Psychological Association (APA), the British Psychological Society (BPS), the British Medical Association (BMA), etc., but even when following ethical guidelines and with the best of intentions, well informed researchers may cause unwitting discomfort to subjects through naïve or careless behavior. Although participants must review and sign informed consent documents before interviews, situations may develop that the researcher and the participant do not anticipate. This chapter offers some insight into how notions of trust as well as the researcher's honesty regarding his or her own biases are paramount when negotiating with a participant regarding the sharing of information and some of the unexpected emotional responses that may affect the research findings.

Ethicality

The term ethics is a complex concept, yet it is often oversimplified through definitions referring to notions of right and wrong behavior. The Ancient Greeks used the word *ēthikos* to pertain to moral character, which was interrelated with the term *ēthos,* a reference to custom. Thus, ethics encompassed the moral principles of an individual or group. As a qualitative researcher, numerous choices must be made. We must attempt to understand our motives and prejudices, how our backgrounds affect our decisions, and what information we retain and what we disregard. We must also respect and protect the participants' trust in us whilst safeguarding the use of their information in a way that transcends desires for sensationalistic data. Consequently, researchers must proceed cautiously. Often what seems to be an intuitive and sensitive research methodology may develop into a complex process imbued with difficulties that could affect the credibility of the research project.

Research design

The success of an ethically sound qualitative research project rests upon the strength of its research design. The research design refers to the process of managing all aspects of the study including the context, materials, and procedures and how these will be utilized to potentially answer the research question(s). In qualitative research the investigator constructs the research design after assessing various arrangements of the investigation's components in an attempt to generate the most informative responses from participants. Many inaccurate outcomes in otherwise well thought out research projects arise through design flaws, tempting some researchers to conceal these imperfections in their final results and reports.

Within the authors' experiences, ethnographic or qualitative researchers sometimes value the significance of good research design less than quantitative researchers. Research design is central to quantitative enquiry as quantitative researchers choose appropriate experimental designs in order to allow identification of the effects of specific experimental (independent) variables upon other specific outcome (dependent) variables (or combinations of these variables) whilst reducing the effects of background confounding variables. The authors believe that qualitative researchers would benefit by spending as much time and effort upon the careful study of research design as their quantitative counterparts. In qualitative research, attempts are not made to partition the effects of independent variables upon dependent variables as interest lies in how respondents experience events and understand the circumstances that impact their lives. However, methodically designed qualitative research may help the investigator avoid unreliable conclusions.

Emergent design model

In contrast to following a clearly organized guideline, the researcher, when utilizing the emergent design model, is allowed the flexibility to respond to what *emerges* from the data as the research progresses. Emergent design originated within grounded theory and with its open-ended format has become popular among novice qualitative researchers. However, the emergent process is difficult to undertake successfully. To understand the complex aspects of human experience, investigators must be able to assemble evidences and descriptions from participants' actions and interactions while they are discussing the situation/phenomenon being explored. Often inexperienced investigators embrace emergent design as they enjoy the excitement of not knowing in what direction unexpected data will lead them.

One of the defining tenets of emergent design is the permission given to the investigator to ask diverse questions of participants during the interview process, resulting in the collection of dissimilar data from participants in the same study. The second author experienced an example of an unheeded emergent design flaw when he was recruited into an ongoing longitudinal medical research project. This study had been running for a number of years when several questions were added to the research instruments. Unfortunately, none of the investigators had considered how these additional questions related to the instruments previously employed in the study. The new questions were developed from the results of the questionnaires' previous administrations and were thus assumed legitimate. Therefore, the responses to the new questions were thought to be directly commensurate with the old information, presupposing a continuity of understanding to develop from the study's different phases. However, the new questions and procedures differed from previous stages in subtle ways and the new responses, whilst yielding interesting information, were distinct enough from the earlier research to be noncomparable. For example, a question asked during the later phase of this study inquired how youth respondents felt about the importance of family in their health regimens. This question had been developed because during the initial research stages a question had requested respondents to talk about the people they considered to be important to them. All respondents mentioned their families, whilst some respondents also mentioned people outside their families. However, in the new round of the research, questions were not asked about non-family members. Thus, the results from different stages of the research were neither cumulative nor directly comparable. Conclusions from the different stages of the research made only partial sense in regard to the investigation of the importance of families.

Without doubt, different questions asked at different times to the same people or to different persons within a particular time frame may become problematic. Sometimes an interviewee will present unforeseen information that may perturb the investigator who had not thought to include this type of data. This situation may confuse the examiner as to what to do next. Sometimes unique and serendipitous data may prompt the researcher to re-contact participants to gain further information about unanticipated developments. Yet reconnecting with former interviewees may strain the trust between respondent and researcher. These previously interviewed participants have already given precious time to help answer your research questions. Creating extra demands upon participants in order to make newly discovered data more comparable may aggravate the researcher/subject relationship and affect the quality of a study's results. Unfortunately, even for the seasoned researcher, emergent design with its tangle of unique and incomparable data may become exasperating and disorderly.

The lack of regulatory codes of practice within emergent design may create additional hardship for the inexperienced investigator. If in-depth interviews are employed, the researcher may have trouble controlling the amount of information contained within the myriad of responses from new participants. Furthermore, novice researchers may have difficulty ignoring data that could uniquely inform dissimilar features of the research questions. An investigator new to this research approach may thus become overwhelmed by the amount of cumbersome and confusing data. A methodology that helps keep a research project on course amongst the multiple opportunities and ambivalences of the emergent design model is a mapping sentence. A mapping sentence is a tool used in Facet Theory that offers an adaptable framework in a declarative mapping sentence format (See Chapter 8, The Declarative Mapping Sentence as a Framework for conducting Ethnographic Health Research). The declarative mapping sentence provides a structure within which the interaction between researcher and participant may be defined and also offers a method for interpreting subjects' responses.

Interviews

Central theories inherent to qualitative inquiry recognize that all research is value-laden, that the research context is shaped by the research project, that multiple realities need to be taken into account, and that investigators explore their frequently unrecognized personal biases. Thus, qualitative research can be rife with ambivalence and uncertainty. Another fundamental aspect of qualitative methodology is the desire to explore the "why" underlying quantitative studies.

Researchers who are new to qualitative research often assume that talking to people and writing up results is a more personalized and sympathetic way to understand human complexity than other research designs. However, neophyte researchers are often unaware that talking intimately with people about their significant concerns may generate complicated relational issues that require a sense of moral responsibility. Respondents' viewpoints, fears, and opinions must be treated with utmost consideration whether you concur with them or not: trust between researcher and participant is of the utmost importance.

There is an assortment of interview techniques available to qualitative researchers, yet interviewers must be aware that their chosen style may affect the quality of the interview process. The most commonly utilized types of interviews are structured, semi-structured, and unstructured formats. A structured interview, with questions organized beforehand, is the least complicated procedure for the investigator to code and write up as the exchanges with respondents can be more easily arranged for comparison. However, all interview styles, along with the technology used (telephone, recording, video, Skype, in-person, etc.) influence the interview data. Even the inclusion of props or the setting in which the interview takes place (the participant's home, your office, an institution, a café, etc.) may affect the data emerging in the conversation.

The second author has experienced uncomfortable situations while collecting healthcare data, i.e., receiving verbal abuse from bystanders or from the subjects themselves. He was verbally attacked by an interviewee who used expletives to state the uselessness of healthcare research. The author had to make a great effort to continue the interview to its useful conclusion. He has also been bitten by an aggressive dog and another time had a trouser leg torn. Whilst these situations may be unpleasant, they are fairly easy to cope with and may be considered learning experiences behooving greater care in the future. However, the second author questions the value of data gathered in these sorts of situations. For example: how much rapport was established with the respondent after her dog bit through his trousers; how much was he able to focus on the content of the interview; and how trustworthy was the information produced by the interview?

Generally, qualitative researchers feel there is more rapport established when conversing face-to-face with a participant, using eye contact and body language to help develop a better understanding of the interview content. However, some participants may feel more at ease when answering questions on written questionnaires or telephone interviews than when meeting a stranger in real time to discuss personal material. The interviewer may also be more comfortable with less direct contact but must be aware that a participant who feels confident and safe is more likely to share information.

An interesting, though challenging, interview style is the *active interview.* Here, the interviewer and respondent are encouraged to co-construct meaning through the creation of a joint narrative. The investigator does not seek impartiality in this style but takes an assertive role to actively stimulate responses from the participant. Both the interviewer and interviewee are considered equal partners in the conversation, which can be liberating but also intrinsically problematic and difficult to accomplish. Conversely, this unconventional interview format may generate data that otherwise would not have emerged.

Data collection

Qualitative and ethnographic researchers are often concerned with the quantity of data their study will require: how many interviews or sort procedures they should conduct. In contrast to the power calculations used in quantitative research, the qualitative researcher has no fixed methodology to establish sample size. The reader must be aware that all types of research have functional restrictions which determine data collection, such as money, time, or other resources available for the project, and most importantly, the interviewee's desire to cooperate.

To avoid some of the errors associated with questions of quantity, the eager qualitative researcher must learn to establish a balance between gathering too much and too little data. Inexperienced researchers must pay attention to tiring participants who may start to repeat themselves during an interview. This is often a symptom of an overlong data gathering session, as are the times when respondents are no longer able to offer novel interpretations to questions. On the other hand, data quality may decline when the researcher hurries through the interview, attempts to adhere to too rigid a time schedule, ends the session before data saturation has been reached, or uses identical criteria to specify the amount of data to be gathered from all participants. A better choice is to realize that different amounts of meaningful information are supplied by different individuals. The researcher must be finely attuned to how long and in-depth a procedure the respondent will accept: the goal is to finish the interview when saturation has been achieved.

The researcher's lack of focus may also negatively impact the amount of interview data collected due to nerves, personal issues, or divided attention while taking notes, etc. Absolute concentration is necessary, and if the plan is to write up the data post-interview, the researcher must be confident about the accuracy of his or her memory. The authors, however, recommend the use of audio and/or video recordings, although such implements in themselves may disrupt the construction of rapport in the research environment. Whilst mobile phones have become ubiquitous, many respondents may feel uncomfortable having their exact words chronicled by these devices. Oftentimes, participants will hesitate to sign their names to the informed consent document which is a necessary part of their agreement to take part in any research project. If the respondents sign but do not consent to the utilization of audio/visual recordings, then the researcher must rely upon note-taking during the interview and post-data gathering recollections. Although video and aural recordings may increase the veracity of what emerged during the conversation, both authors have encountered the capriciousness of recording devices and advise the use of a backup instrument to document a participant. On the other hand, both authors have also experienced occasions when both instruments were unreliable, causing sections of data on a series of interviews to be unintelligible. The most effective protection against these types of difficulties is to take the time to write up your impressions of interviews immediately after each data collection session. If the recorded material is examined promptly and poor-quality data is discovered, researchers may be able to retrieve some of the missing information by writing up the conversation while the dialogue is still fresh in their memory. If more than one researcher is involved, then discussions immediately after an interview may reveal important insights.

Research materials

When conducting an in-depth interview or focus group in qualitative research, the investigator may introduce supplementary objects to generate dialogue and allow participants to experience a hands-on understanding of the topic. There is also the belief that initiating projective stimuli may elicit subconscious responses from the participant to visual or textual materials related to the area of study. The reactions of the participant to the introduced objects may disclose a valid indication of the participant's comprehension or, contrarily, misunderstanding of the research question. The timing of when and by what means auxiliary objects are introduced in an interview may affect the ensuing data collection. Often when researchers use supplementary materials, they believe they are employing similar data gathering procedures with all participants. However, minute irregularities in the researcher's delivery may lead to dissimilar experiences for the respondents.

Research respondents/participants/subjects

When conducting an ethnographical study, researchers carefully choose participants for their specific knowledge (experience or understanding), engagement in certain activities, or relationship to the subject matter of the investigation. In quantitative research, a researcher most commonly selects participants randomly or proportionately to represent a specified population. If an interviewee ceases to participate in a quantitative project, the researcher must be concerned about the non-representativeness of the remaining sample. The missing person's data may distort the ability to generalize from the results (i.e., the sample may become skewed). The lack of a sample's representativeness in ethnographical research is of less concern, yet the loss or absence of a participant will affect the results: the missing data (the singular details, involvement, expertise, understanding, etc.), will be unavailable to the findings. Even if the participant completes a few interviews or activities from a series before disappearing, all data gathered from this participant must be discarded.

Some of the greatest sources of error and concern in qualitative research are issues to do with respondents who wish to create a positive image of themselves. This often subconscious desire to be well regarded by the investigator (and future public) may produce atypical behaviors that may affect the research's validity. The investigator must make great efforts to dispel any doubts regarding the representation of respondents by ensuring the subject's anonymity (if desired) and the confidentiality of the study results. Nevertheless, participants may withdraw from a research project for numerous reasons: being troubled by their interview performance, feeling uncomfortable with the topic of investigation, reappraising what they said, or having doubts about how their thoughts and feelings are going to be used by the researcher. The rapport between participant and researcher often determines the trustworthiness of the data, its interpretation, the results, and the relevance of conclusions. Frequently, while disclosing information during an interview, participants will request that the material discussed be placed "off the record." This is completely permissible, and "off the record" information can still enlighten the researcher's understanding of the situation at hand. The investigator should make every effort to create an interview environment that is pleasant and comfortable: a relaxed and trusting participant discloses more information than a defensive and suspicious participant.

As stated above, healthcare professionals, due to their expertise and medical knowledge, usually possess greater authority than those they attempt to help. However, sometimes when professionals are questioned about their own field, they may perceive an inquiring researcher as intimidating and a power reversal may develop. Therefore, the researcher must always consider the pressures, often unacknowledged, of power relationships influencing a study. Differences between respondent and researcher in age, education, race, areas of knowledge, class, gender, professionalism, etc., may affect how research questions develop, how the interview is conducted, and how the final write-up is assembled. Investigators must realize that what may seem to them a common place matter could appear highly charged to the interviewee. One respondent may find certain questions relevant while another may be affronted by them. Using a field journal is sometimes helpful to record emerging conflictual conditions in order to avoid potential friction.

We, as investigators, must be conscientious about representing participants honestly and respondents must have confidence that we will represent them accurately and in a way with which they are comfortable. Participants generally receive little or no recompense for giving us their time and efforts and are central to qualitative investigations: they must not be used instrumentally. Researchers must cultivate a trust-based relationship with participants and resist misrepresentation that may be construed as harmful or untrue. In attempting to consider all the options discussed above researchers may realize that responsible research means facing difficult conflicting ethical responsibilities.

Anonymity

Participant anonymity, if requested, requires discretion which the neophyte researcher may readily give, especially in sensitive circumstances, however, the investigator must be aware that respondent anonymity means that none of the respondent's expertise, background information, or related primary data (artifacts, images, written material, etc.) will be available for inclusion as the material may hold clues to the participant's identity. To wit, background characteristics of the respondent, including the bases for their comments to be seen as authoritative, will have to be omitted, even when providing verbatim quotations from the transcript. Furthermore, one participant's request for anonymity may affect how all the other respondents in the study are presented. In some studies, named contributors may put at risk the anonymity of those participants who wish to remain unnamed. Thus, when offering anonymity, the researcher must consider that he or she may end up with an entirely anonymous sample.

Sometimes, the assigning of pseudonyms will alleviate respondents' concerns about too extensive a scrutiny into their personal perspectives or public representation. Yet, removing all recognizable attributes in the write-up are not always sufficient anonymity for some participants. Another alternative to soothing a concerned participant about the way he or she will be represented is for the researcher to explain to participants at the commencement of the interview that before the completed report is finalized, subjects may read and edit their own transcriptions to check for data accuracy. This process is called a member-check and is a way for researchers to establish their intentions to represent subjects honestly and to verify the accuracy of the information presented in the study.

Trustworthiness: biases and the member-check

Ethnographers accept the notion of the subjectivity of the researcher and thus the influence of a researcher's bias. Each investigator brings his or her own distinctive experiences, preconceived ideas, and personal outlook to collecting and interpreting data. *Bracketing* is the name given to a method used in qualitative research that strives to reduce these inherent individual biases. As investigators commence a project, they must reflect and declare all the features of their identity that may impact the collection and analyses of data. In contrast to quantitative research with its quest for validity, qualitative enquiry seeks to establish the trustworthiness of the data presented.

A researcher may also attempt to improve trustworthiness through the above-mentioned strategy of the *member-check*. The respondent is given the option to edit the material and return the revised version to the researcher. This process can continue until both researcher and respondent concur that the interview data is represented accurately. Often respondents produce thoughtful corrections that clarify misconceptions. However, participants may discover they no longer support their documented statements and wish to either remove those comments or completely change their stated positions. Some participants told the authors that they wanted to replace ambiguous statements with more confident terminology, others wished to edit their statements such as "It is" to "It might be" to sound less peremptory. Another unintended predicament developed when a respondent perceived a bias in the manner in which the first author represented him in the final report. He challenged the style in which the researcher had documented their conversation. He noticed the interviewer's dialogue was summarized, thus appearing succinct and word perfect, whilst his language was captured verbatim, incorporating all of his grammatical flaws and idiosyncrasies. He believed this manner of presentation could be understood as a strategy to promote the interviewer's point of view over his own. This unintentional effect of the style of her report was a complete surprise to the author. She believed the goal of the report was to present the respondent's thoughts in his very own words and not those of the researcher's. The collected data in her study had been extensive and substantial editing was necessary to make a readable account for publication. The author made the decision to condense her own talk in order to be able to use direct quotations from the participant, thereby capturing the most authentic portrayal of his viewpoint. Sometimes inequity is attributed to interviewers because their language may appear more eloquent than participants due to their understanding of the research topic and their reading of pre-written questions. Yet in this case the author had to acknowledge the respondent's complaint: her representations of interviewer and interviewee were not portrayed in an equivalent manner. Thus, without changing the participant's actual words, a researcher may construct an account differing from what an interviewee might expect: any selection or elimination of data could adjust the perspective of the completed document.

The consideration at the center of the previous example is one that reflects how a recording of ordinary speech differs from participants' expectations of language based upon their experience of novels, films, theatre, etc. Everyday conversation includes all types of utterances, yet eliminating any expression from a transcript may be deemed an alteration of what took place during the interview. For example, even deleting pronouncements such as "you know" which may convey solidarity (Are you with me?), or "ah-huh" an affirmation (I know), or "hmmm," hesitation (I need to think about that) along with any other vocal sounds, repetitions, pauses, etc., may reshape the nature of the dialogue. These types of utterances may communicate mutual understanding, eagerness, doubt, incredulity, reassurance, misgivings, indecision, hostility, acceptance, etc., and are all indicators of researcher and participant rapport.

The inexperienced researcher is best to be apprised of these difficulties associated with the in-depth interview. The authors reiterate that respondents may like to revise data to complement their role in the dialogue. What was intended as a joint scrutinization of the accuracy of particulars may become "participant profile-management" effecting the significance of the collected material. On the other hand, if a researcher declines to offer a *member-check,* the truthfulness of his or her interpretation of the discussed issues may not be supported by the respondent. Not only could the data's credibility be disputed but the study may also lose the benefit of the participant's continued cooperation and insight.

Another difficulty with the *member-check* may occur when a respondent wishes to exit a study after reading the report and that person's data is uniquely significant to the research. The first author experienced this distressing situation in an investigation in which all of the other study participants had enthusiastically examined her interpretations and provided useful criticism. She found the other participants' scrutiny of the data and comments had improved the trustworthiness of her study, confirming to her the positive value of the *member-check*. However, in this case, she was obliged to withhold one participant's unique information from the final report. Thus, when addressing contentious ideas or circumstances, a researcher must realize that an investigation could be compromised if data important to the study cannot be represented due to the concerns of even one participant.

In an attempt to avoid some of these ethical quandaries, a reciprocal agreement between respondent and researcher may be constructed prior to the interview. This contract might specify the sorts (and quantity) of alterations the participant will be permitted to carry out and also state the limits of the role of the researcher. However, being asked to sign this sort of contract before an interview might suggest to respondents that they may not approve of the final presentation of the research: a feeling of suspicion may be introduced and hinder the desired rapport between researcher and participant. If trustworthiness is not achieved, the study will suffer. Qualitative research strives to challenge the participants' thinking in unusual ways through the interview process and to enhance their understanding of the research topic and of themselves. How an investigator emends a written representation ought to be determined by the research questions and the topic of study whilst respecting all participants.

A final *member-check* consideration worthy of mention is again related to contributors' concerns about how they will be regarded by their peers, culture, and families if identified within a study. Most often, providing anonymity assuages these fears, yet allocating false names and removing distinguishable characteristics may not be sufficient. One participant wanted to review how his responses contrasted with the other cases in the study. one requested a gender alteration to further obscure recognition, and one contributor asked for all of her negative statements to be removed so that she would be regarded in a more positive light. Consequently, when a researcher employs the *member-check,* she or he must be mindful that any study, but especially one that could be controversial, may be compromised due to altered or eliminated data affecting the trustworthiness of the results. Another difficulty influencing rapport is that contributors may not understand that some privacy will be sacrificed when permitting an interview. Also, novel topics may emerge in an interview and the respondent may be confronted with unexpected questions about (uncomfortable) issues. Another strain on rapport is when an investigator decides to "go native" (identifying with some, or all, of the cultural traits of the participant) during the interview period, but upon returning to an academic environment, reshapes his or her position with a more scholarly viewpoint.

As the *member-check* may be fraught with difficulties, how else might a qualitative researcher establish trustworthiness in a study? *Triangulation* is a process that attempts to supplement the validity of an analysis, in which at least two other researchers examine the raw data of a study and conduct a separate analysis in order to reconcile or invalidate the researchers' initial conclusions. *Triangulation* may be utilized to decrease inaccuracies, challenge misleading information, and actually produce more in-depth data. However, *triangulation* is not considered to have standardized protocols that reliably test subjective assessments. Moreover, other researchers may have their own agendas when assessing your data, which may, consciously or sub-consciously, influence their evaluation of your interpretations. The difficulty here is to find other investigators with an interest in your topic who have the proficiency and time to make a comprehensive assessment of your findings.

Data conversion, interpretations, and meaning-making

Other significant areas in need of consideration in qualitative research become evident after the completion of the data gathering process. This data may materialize in the form of written notes, video recordings, still images, and audio accounts, etc., all of which must address the research questions and be converted into information that is comparable between data collection approaches. This conversion process is often more difficult than at first thought and may result in multiple inaccuracies. In qualitative research, collected data is usually transcribed into written text through reduction, summarization, and interpretation—all processes which create opportune conditions for making mistakes (especially when a neophyte researcher strives to make the data "fit" the research questions).

Interpretation of a body of material begins with data coding which involves recognizing and extricating the important words, phrases, and significant groupings of text from the transcript. Researchers must analyze the components of data through direct impressions in order to make meaning of the respondent's utterances. However, any process involving interpretation, modification, explanation, reduction, etc., may produce errors in meaning as perspectives of respondent and researcher may differ. To make sense of data requires a particular type of artful interpretation founded upon diligent and methodical inspection. The examiner begins the meaning-making process by citing multiple references within the recorded dialogue, etc., while also noting a participant's intricate efforts and strategies to make sense of the issues addressed by the research questions. The analyst must document characteristics of the interviewee's lived experiences as well as particulars of how his or her reactions were formed within the context of the interview.

There are multiple approaches available when undertaking analyses of textual data, including: discourse analysis, narrative analysis, content analysis, thematic analysis, and grounded theory. A popular method for examining qualitative data is a combination of content and thematic analysis: *content-based thematic analysis*. This procedure is utilized to determine the elements of analysis in the data/content (understood as a participant's explicitly stated narrative in terms of what happened and to whom, when, where, etc., along with attributes of the underlying conceptualizations implicit in the text). These elements arise from the comments, opinions, and ideas recorded in the conversation, as well as the emerging patterns (themes, and subthemes) found in the more descriptive data.

Analysis begins through a close examination of the interview story and a selection of words, sentences, or short paragraphs (sometimes known as *chunks*). The researcher then assigns these *chunks* to specific categories in an attempt to understand and organize the meanings communicated through them. However, the term *meaning* carries multiple levels of understanding. The first author favors a description of the nature of meaning defined in Webster's Seventh New Collegiate Dictionary:

1a: *the thing one intends to convey especially by language:* PURPORT; b: *the thing that is conveyed especially by language:* IMPORT; 2: INTENT, PURPOSE; 3: SIGNIFICANCE; 4a: CONNOTATION b: DENOTATION.

The above definitions illustrate how the term "meaning" can be associated with conveyance, intention, purpose, significance, implication, indication, etc., and can be understood to make known, signify, bring out, suggest, represent, etc. a message of importance, most commonly through language. To construct such an understanding, the researcher must decide how to identify the components or word *chunks* in a text that elucidate that which is important to the respondent. However, there is no one correct way of assigning meaning to significant components of an observation, narrative, etc.

Qualitative research is unique in the research field in that investigators are expected to utilize their intuition and propose knowledgeable impressions when making meaning from research data. Moreover, qualitative research does not consider the researcher's subjective and essential understandings as inaccuracies. Intelligently designed research protocols that are clearly identified and abided by are capable of proffering set limits upon research while curtailing error, misinterpretations, and value judgments. Such protocols include the declarative mapping sentence.

Below, we provide characteristic difficulties confronting a qualitative researcher when making meaning from research data. These details are based upon an analysis conducted by the first author. Her study comprised six in-depth interviews with the resultant audio recordings converted into 140 pages of written text. She went over and over the transcripts to give shape to a working summary of their content. She jotted down comments about each interaction and when she found parts of the dialogues unclear or questioned her own inferences, she asked for advice from another researcher. Ambiguous elements were underlined and annotations reflecting her impressions, interpretations, and revelations were scribbled in the text's margins. Each interview was read once again along with another round of note-taking in order to clarify contrasts and similarities between participants' points of view. She also examined these notes for evidence of whether her interview style had influenced the dialogues. Finally, she developed category headings that seemed to produce a logical and consistent structure to the interviews and placed data under these headings, especially noting both recurrent and uncommon remarks. Despite following a thorough protocol, the first author could not claim unbiased analyses. She also bore in mind that most respondents had talked about their complaints about the service being examined. She realized her efforts to encourage participants to divulge more in-depth particulars about the research question had developed into an underlying feature of the interview process. Furthermore, she was unsure that she had mined all significant messages and meanings from the data. Only after her analyses had been perused by other researchers did she become confident about her interpretation of the data.

Context and external influences upon the research findings

The concept of *context* and its effects upon the research findings is extensive within a qualitative study. The notion includes: the choice of the physical setting of the investigation; the researcher's quest for understanding; broad issues of identity, i.e. the relationship between interviewer and interviewee (their values and thoughts); as well as wider events occurring during the data collection period (the interface between historical, economic, political and cultural forces). Further external influences to be addressed by an investigator include: time of day, time of year, or variations of these; other persons present during data collection; the length of the data gathering period; atmospheric effects (temperature, lighting, noise, etc.). All these features and circumstances may have some impact upon the research findings.

Generalizing from your data

Another ethical consideration bearing scrutiny is when qualitative researchers attempt to use conclusions from a specific project and make these findings relevant to persons other than those investigated in that study. This is applying the process of *generalization* which may be the explicit or implicit aim of practically all research writing. Nevertheless, the qualitative investigator must be reminded that small non-random samples are not representative of a greater population. While conducting qualitative investigations within the medical care industry, researchers may be confronted with circumstances in which a single person alone possesses the knowledge or experience to answer specific research questions. In this type of situation, the in-depth study is the most comprehensive research method available as it allows the investigator to vigorously examine the life story/biography of the selected participant. However, despite the fact that narrative is a formidable agent for substantiating a theoretical standpoint, studies comprised of only a few individuals and their stories are not representative of how other people think, feel, and act. Investigators must be mindful of these sorts of limitations and intelligibly portray these restrictions within the research report.

Conclusion

In this chapter we have attempted to create a conversation around the various ethical concerns relevant to qualitative/ethnographic research. We aspired to draw the reader's attention to numerous and diverse sources of inaccuracies that may complicate the conduction of a rigorous ethnographical investigation. The series of ethical considerations described above are not intended to be an all-inclusive inventory but mere suggestions to kindle interest and understanding of the difficulties inherent within ethnographic inquiry and to encourage discussion among medical care researchers.

Note

1 This chapter is based on a previous chapter, Ethnographic Caveats, Hackett, P.M.W. & Schwarzenbach, J.B., (2015). In P.M.W. Hackett (Ed.), *Qualitative research methods in consumer psychology: Ethnography and culture*. New York, NY: Routledge.

3

ETHICS OF ONLINE RESEARCH WITH HUMAN PARTICIPANTS

Jeff Gavin and Karen Rodham

Introduction

In 2017, we wrote a short think piece on research ethics in the digital age (Gavin & Rodham, 2017). We had been invited to write that article for two reasons. First, our experience of conducting research in the online world. Between us we have worked on projects ranging from: online support for eating disorders, self-harm, and persistent pain to studies exploring dating, sexting, online intimacy, and revenge porn. We have also collected data using various online sources such as public forums; private bespoke forums; social media such as Facebook, Instagram, and Twitter; online dating sites; as well as traditional "pen and paper" surveys disseminated and completed via online platforms, such as Qualtrics. And second, when we first began to use the online world in our research, we quickly realized that ethics panels were (in our opinion) overly anxious about the ethics of doing so. They seemed to struggle to understand this kind of research, not just from a practical but also an ethical point of view. As a consequence, alongside our research, we decided that we ought to write about the ethics of conducting research on (and in) the online world.

What is online research?

Put very simply, we define online research as research which is conducted in or by the Internet or in or by digital social media. The British Psychological Society (2017, p. 3) uses the term "Internet Mediated Research", and broadly defines it as "any research involving the remote acquisition of data from or about human participants using the internet and its associated technologies". So, a researcher may decide to conduct an online study – perhaps running a survey using the online survey platform Qualtrics. Maybe they will prefer to run focus groups with people from all over the world joining in. Maybe they will collect data that they can subsequently analyze – for example, Instagram posts, Tweets, snapchats and so forth. Indeed, the Internet and digital social media present researchers with myriad opportunities to recruit and collect data from a diverse range of participants (e.g. Brownlow & O'Dell, 2002; Roberts, 2015; Skitka & Sargis, 2006), in ways that are often cheaper than traditional methods (e.g., no travel costs, no postage costs). The online environment also allows researchers to observe behaviour and communication (e.g. Kraut, Olson, Banaji, Bruckman, Cohen, & Couper, 2004).

Box 3.1 Illustration of the multi-layered online world, example adapted from Alexander (2008)

A YouTube member uploads a video. Others comment on this video, which is subsequently discovered by other Internet users through social aggregators and search services. These people add comments to the original video entry (which they might link to from their own YouTube, Facebook or Twitter accounts via "liking" or "sharing" the video or "following" the original poster), view the video, and add further comments on YouTube, thus intensifying and contributing further to a networked discussion across multiple sites, with multiple authors and with new text, hypertext, and audio-visual content.

What is wrong with existing research ethics guidelines?

The online world is continually evolving and has multiple layers which bring the potential for unintended consequences. This means that it is impossible for there to be a clear set of all-encompassing rules. Think for a moment about fake news (the intentional presentation of misinformation) and the more recent "deep fake" video examples. A deep fake video consists of manipulated videoclips in which someone else's face is inserted into pre-existing videos frame by frame. As a short aside, the videos are called deep fakes after the Reddit user called "deepfake" who first created them (Guera & Delp, 2018). It is not always easy to recognize fake news and deep fakes are, as is suggested by their name, deeply hidden and almost impossible to determine as "fake". As such, this creates a challenge for future researchers in the form of a philosophical and ethical question: "What is real?" We do not intend to answer this complex question here. Instead we have argued (Gavin & Rodham, 2017) that researchers need to accept that ethics for our digital age requires the development of a different mindset, one that maintains the central ethical mantra of "do no harm" – but does so not through traditional clear cut "if-then" rules and regulations but through the process of solving puzzles. Indeed, just as in "real life", we cannot control for all eventualities; in the multi-layered online world we need to think about different questions: What counts as data? Whose permission do we need to seek to use the data? What data, even if we can see it, might be considered private? How do we define open access? What happens if someone who is a private user links and contributes to a multi-site discussion? Does this then render his or her contribution public? (See Box 3.1) Whose permission do you need to seek? How would you solve this ethical puzzle?

We have already mentioned the difficulties ethics panels have had when assessing our applications for ethical approval. It is also clear that our professional bodies have grappled with similar dilemmas. They have struggled to produce ethical guidelines that can keep abreast of the fast-changing online world. In 2002, the British Sociological Association (BSA) decided that it was more appropriate to put the onus on the researchers themselves, as part of their professional competence, to keep abreast of developments in online research:

> Members should take special care when carrying out research via the Internet. […] Members who carry out research online should ensure that they are familiar with ongoing debates on the ethics of Internet research and might wish to consider erring

> on the side of caution in making judgements affecting the well-being of online research participants.
>
> *(BSA, 2002)*

More recently, the British Sociological Association (2017) published their "Statement of Ethical Practice" which has a separate annex entitled "Ethics Guidelines and Collated Resources for Digital Research". Both documents can be downloaded from the Association's "Guidelines on ethical research" website. These two documents, and particularly the annex, offer a more in-depth exploration of the possible ethical issues surrounding online research. But the conclusion is very similar: that the field is fast moving and that there are likely to be unintended, and possibly currently unimaginable, consequences of researching in and on the online world. And, as a result, the researchers themselves, need to be willing and able to engage in an ethically appropriate manner:

> […] we should remember that 'the fields of internet research are dynamic and heterogeneous [as] reflected in the fact that as of the time of this writing, no official guidance or 'answers' regarding internet research ethics have been adopted at any national or international level' (AoIR, 2012: 2). Aside from ever-changing technological contexts, and the unstable public/private distinction, the AoIR [Association of Internet Researchers] also identifies the complex and unresolved relationship between data and persons: 'Is one's digital information an extension of the self?' The data/person relationship is a central issue for research ethics, as ethics aim to minimise harm, and harm is typically understood in relation to 'persons' (2012: 3, 6–7). This all leads back to reiterating a dynamic, situational, process-based and dialogic approach to ethical digital research; where you anticipate that unforeseen situations, issues, and technologies may arise, and you are prepared to engage in an ongoing way.
>
> *(BSA, 2017, p. 8)*

Similarly, the British Psychological Society's (BPS) second edition of the Internet-Mediated Research Guidelines (2017) recognized that as technology advances, changes, and grows, it extends the opportunities for research whilst at the same time, introduces extra complexities in ways that might not at first be obvious. The second edition BPS Internet-Mediated Research Guidelines (2017) highlight the issues facing researchers and the need for ethical guidelines *not* to be used as a rule book, but as a set of guiding principles. In short, it is not possible to have a set of ethical rules that can deal with all situations. How then, as researchers, do we uphold the essence of our ethical principles when conducting research in and on the online world?

In this chapter we set out to address this question by returning to the three universal principles that underpin the notion of "do no harm" with respect to how we go about conduct ethical research:

- respect for the autonomy, privacy, and dignity of individuals and communities;
- scientific integrity;
- maximizing benefits and minimizing harm

We will structure our chapter according to these universal principles and will share good and bad practices to demonstrate how we can work towards maintaining the overarching goal of ethical research: do no harm to your participants.

Respect for the autonomy, privacy, and dignity of individuals and communities

In the online world, working out what is public and what is private is not straightforward. How do we label different types of information that could become data if we collect it? How can we be sure that someone posting information online knows or expects it to be public? Does it matter if information is posted (and collected for research) on discussion forums, Twitter, YouTube or Facebook? Should researchers be asking themselves the following question: just because we *can* collect online information, *should* we? For example, at the time of writing, the default setting on Qualtrics (a simple-to-use, web-based survey tool) is set to collect data on the precise location of respondents. This is not unique to Qualtrics; many data harvesting software packages for collecting Tweets have the same default setting. Failure to turn off such features means that it is possible to conduct analyses which may reveal people's personal characteristics and potentially their identity, which they may have assumed to be private.

In the UK, the recent introduction of the General Data Protection Regulations (GDPR) published by the Information Commissioner's Office (2018) has highlighted the problem related to collecting data "just because you can". In essence the GDPR is Europe's new framework for data protection laws. The UK Research and Innovation organization (UKRI) has a very useful summary for how the GDPR impacts researchers. One of the requirements of the GDPR is that researchers must have a clear rationale for collecting different types of personal data. Personal data is described as information that relates to an identified or identifiable individual. This could be a person's name or might include other identifiers such as an IP address or a cookie identifier. The key issue here is that if it is possible to identify a person directly from the information being collected and analyzed, then that information may be personal data.

In addition to ensuring that we consider carefully what counts as personal data, the GDPR also introduces the notion of data minimization. This refers to the expectation that only data which is relevant to the research in question will be collected. In other words researchers need to be able to demonstrate that they have appropriate processes in place to ensure that they only collect and hold the personal data they need. In other words, gathering or collecting information just because you can access it is not permissible unless you have clear rationale that links back to your research question. In the same way that researchers must, in effect, seek consent from their ethical bodies to collect data, so too should they seek informed consent from their participants.

Under GDPR, even data collection methods that may previously have seemed straightforward, quite rightly require further thought. For example, if we choose to collect data by means of a quantitative online survey, how can we be sure that a participant who shuts down their web browser has simply decided that they no longer wish to participate or that they have decided to withdraw consent? How can we be sure it is still okay for us to use the data we collected before they shut down their web browser? The BPS (2017) suggests that these kind of potential issues should be anticipated and withdrawal procedures made as clear and robust as possible. One example offered is to display a clearly visible "exit" or "withdraw" button on each page of a survey. If participants were to click on this button they could then be taken to a debrief page and a tick box section asking participants to confirm they are still happy for their data to be included in the study.

For qualitative research there are different considerations. If a member decides they no longer wish to participate and withdraws from the discussion in the same way those participating in a face-to-face focus group have the option to do, what should a researcher do with the data? Omitting that person's contributions is likely to render the other participants' words meaningless. A focus group is, by its very nature, interactive; what one member of the group says will build on the contributions of others. Removing one voice can mean that the whole group discussion is unusable. However, as long as an information sheet is explicit about the process of withdrawal, this issue can be prevented. For example, it is common for those being invited to take part in face-to-face focus groups to be told that they can withdraw from the group discussion itself, at any time, *but* that all contributions they have made up to that point *will* be included in the analysis. The same clause could easily be included in information sheets for online focus groups.

Ethical concern about consent in the context of online studies is illustrated well by the following study where researchers had sought consent from what they considered appropriate sources. In 2008, a team of experienced researchers in the USA published a study based on data taken from the Facebook profiles of the entire cohort of a U.S. university (Lewis, Kaufman, & Christakis, 2008, see Zimmer, 2010 for review). Their focus was on how friendships and tastes develop over time. The researchers had permission from both Facebook and the university in question and had also received ethical approval from the relevant boards. They downloaded each student's name, gender, major, and their network of friends, including who was tagged in their photos. They collected information on tastes, political views, and romantic interests, and inferred students' race from their photos and group membership. Students from the same university were used as research assistants to access this information because, in 2006, Facebook privacy was predominantly based on university networks, and only those in the same network could see your profile. This meant that these research assistant-students had access to the profiles that the researchers themselves could not access.

In accordance with ethical guidelines, permission to use the data was not sought from the users, but the data were anonymized and all identifying information (such as names and identification numbers) removed from the published data. Unfortunately, as regular social media users know, it is not difficult to use indirect means to find somebody on Facebook. In this case the university was identifiable by its unique characteristics (e.g., the number of students, the combination of degrees offered), and from here individual students could easily be identified, particularly if they were in some way unique (such as the only female Latvian law major, to take a hypothetical example). The net result was that participants did not consent to their data being used, and worse, their anonymity was not protected.

Scientific integrity

Ensuring research maintains the principle of scientific integrity means that it "should be designed, reviewed, and conducted in a way that ensures its quality, integrity, and contribution to the development of knowledge and understanding" (British Psychology Society, 2014, p. 9). If a research study is not designed well or is conducted poorly then it is effectively a wasted opportunity. A poorly designed or implemented study will not collect high quality data. As such, it wastes resources (financial, equipment, time) and more importantly devalues the contribution of the participants and, in so doing, affords them a great lack of respect. At worst, such research may lead to inaccurate or misleading information being shared or influencing subsequent research, policy decisions, and so forth, and as such, it can have the potential to cause harm. Researchers must therefore ensure that their work meets high quality, robust scientific and scholarly standards.

Scientific integrity vs participant safety

The underpinning principle of scientific integrity is very clear and unambiguous. However, scientific integrity can conflict with the need to keep participants safe. For example, when conducting qualitative research the actual words used by participants are important. How people say things, the words *they* choose to use when talking about things are important. However, unlike face-to-face interviews or focus groups, collecting text from online sources brings the potential that the extracts could be placed into a search engine and the original interaction or posting identified and with that identification comes the risk that the person's identity could be traced and revealed. For example, the BPS guidelines note that:

> On a legal note, should a person find out that their online posts or traces of activity have been accessed, stored and used as research data, they are likely to have rights under the Data Protection Act to stop these data being processed if they could be linked to them personally. In many cases it is very unlikely that a person will ever find out that their online posts have been used for research purposes. However, this does not preclude the responsibility of the researcher to ensure that maximal anonymisation procedures are implemented (for example, researchers may consider paraphrasing any verbatim quotes so as to reduce the risk of these being traced to source, and participants identified). Here again, the principle of proportionality becomes pertinent: considerations of the level of risk/harm must be weighed up against scientific value, the quality and authenticity of reports of research findings, and possible practical issues too.
>
> *(BPS, 2017, p. 14)*

This then provides us with a clear example of a time when scientific integrity – using the data as it was collected – may be outweighed by the need to ensure participants' confidentiality is maintained. This might well involve paraphrasing verbatim quotes in order to reduce the risk that what someone said online can be traced back to them. The paraphrasing would be completed post analysis and so would not impact on the researcher's ability to interpret the data they have collected; it may however, render the report of the study less convincing to the reader (and journal reviewers), perhaps even undermining the epistemological and ontological bases of the study (for example, in the case of Foucauldian discourse analysis or narrative analysis where it is language and the way in which language is used which is central to the analysis).

The decision to paraphrase (or not) also has consequences for replication. We are thinking here of the fact that there is currently a drive towards ensuring research is both open and transparent. As such, it is becoming more common for researchers to be expected to deposit their data in an open science repository. What then should we do with qualitative data collected from the online world? If we need to paraphrase it in order to protect anonymity and confidentiality of our participants (who, by the way, if the data was collected from a publicly accessible site, may be unaware that their words have been used in research), should we deposit the paraphrased text or the original text? If we do the latter, we are potentially opening up the possibility that our participants may be identified. If we do the former, the data available for other researchers to analyze is not the actual data that was collected, which defeats the purpose of open science.

A solution used by one of the authors of this chapter (JG) in disseminating his research on online dating is to illustrate his arguments with screenshots of his own (mock) online dating profile (Gavin & Griffin, 2012). Similarly, in a series of recent studies examining the perceived attractiveness of autistic males' online dating profiles, the same author and his colleagues first analyzed the actual profiles of autistic male online daters, and then used this analysis to create a prototypical profile to use (and manipulate) in a number of online experiments (Gavin, Rees-Evans, Duckett, & Brosnan, 2019). As it was considered ethically impossible to use profile photos of real online daters, the researchers used an "average" face comprised of a composite image created by averaging and then combining the shape and colour information of a number of individual facial photographs using specialized software.

In contrast, for our research on images of self-harm posted on a public forum (Rodham, Gavin, Lewis, St Denis, & Bandalli, 2013), creating "mock up" images would have been inappropriate. The images *were* the data, therefore we needed to analyze the images themselves. We took two approaches to maintaining the scientific integrity of our data whilst also ensuring participant safety. During the dissemination phase of this study, we only used images of self-harm that contained no identifying information such as faces or a distinctive background. This rendered them privately public; that is, private in the sense that they contained no identifying information, but public in that anyone could see them (Lange, 2007). Our second strategy was to publish a content analysis of the images without including the images themselves. In each of the cases cited above, ethical and methodological compromises are made in consideration with the specific research questions, type of analyses, and social context of the online site in/on which the research is conducted.

Maximizing benefits and minimizing harm

Maximizing benefit and minimizing harm refers to the aspiration that the research conducted brings the most benefit it can without harming, or, at the very least, minimizing the risk of actual or potential harm as a consequence of data collection, analysis and publication. In short, this process is about "ensuring scientific value (maximizing benefits) and taking steps to protect participants from any adverse effects arising from the research" (BSA, 2017, p. 18).

In whatever social context we as researchers work, we should be mindful and respectful of social structures. The BPS code of human research ethics (2014, p. 10) states: "unwarranted or unnecessary disruption should be avoided unless the psychologist judges that the benefits of intervention outweigh the costs of such disruption". This holds for online research and comes back to the difficulty that sometimes arises in distinguishing between what is considered a private or a public online space by users. It is not necessarily the interventions themselves that are potentially harmful, but their possible scope for compromising the anonymity/confidentiality of participants. Researchers should consider such potential unintended consequences. For example, if researchers enter open access online spaces that are considered private by their users, their presence is likely to be unwelcome, their arrival considered invasive and potentially socially irresponsible. To mitigate this, if the proposed research is highly valued in terms of scientific integrity and potential benefits, then a researcher might feel that joining a group without disclosing that they are a researcher is an appropriate course of action. Doing so will enable them to undertake undisclosed observation and data collection whilst avoiding disrupting the space and causing potential harm perhaps to group cohesion. However, this strategy is not to be taken lightly, for it brings with it potentially serious negative consequence for those being studied. For example, Roberts (2015) shared an example of what happened when an online community learned later that they had been the focus of a research study. One community member commented:

> When I joined this, I thought it would be a support group, not a fishbowl for a bunch of guinea pigs. I certainly don't feel at this point that it is a safe environment, as a

> support group is supposed to be, and I will not open myself up to be dissected by students or scientists.
>
> *(King, 1996, p. 122)*

The expectations of those being researched must be considered, anticipated, and taken into account when planning research. This in itself is not straightforward:

> Defining a space from the 'outside', based on access, and from the 'inside' based on participants' experience of the social activities taking place … are two different positions that do not necessarily correspond.
>
> *(Bromseth, 2003, p. 73)*

Whose perspective about access is correct? How do social media users feel about researchers lurking and gathering data? Hudson and Bruckman (2004) showed that users' expectation of privacy often conflicts with the public setting in which their interactions take place. While they may be interacting in a public space, they behave (and it seems, expect to be treated), as if this is a private space. Conversely, Hargittai and Marwick (2016) have explored the 'privacy paradox' from another angle: when individuals claim to be concerned about privacy whilst their behaviour, especially online, runs counter to these concerns. From this point of view, there is a recognition that even if you personally have concerns and do all you can to maintain your privacy, once something is online it can generate a life of its own. One of their participants sums this up neatly:

> On Facebook, I think it's been drilled into me that you just have to assume anything you post is public. You can set your privacy settings at the strictest you want, but you just have to assume that anything you put out there can be made public to the world.
>
> *(Hargittai & Marwick, 2016, p. 3746)*

What, then, are we as researchers to do about this paradox? As with much of this multilayered online world, there is no straightforward solution. How do we as researchers do the right thing without inadvertently doing the wrong thing? If a researcher announces their presence overtly, it is likely that how that group interacts may change. If a researcher lurks and, in effect, surreptitiously collects data, they run the risk of compromising the group if their presence is subsequently recognized.

Conclusion

At the start of this chapter we posed the question: if it is not possible to have a set of ethical rules that can deal with all situations, how then, as researchers, do we uphold the essence of our ethical principles when conducting research in and on the online world? This is an important question for us as researchers to consider, for the online world has made it both easier and harder than ever to conduct research. The landscape of the online world changes so rapidly that the British Sociological Association (2017) clearly stated that it was not possible to create guidelines that would be able to address all current and future forms of digital research that may become possible. This is an issue picked up by Kosinski, Matz, Gosling, Popov, and Stillwell (2015) who noted that when they were writing their article, the American Psychological Association's website only listed three documents containing guidelines relating to research on the Internet, all of which had been written before Facebook came into being. This inability to keep up with the fast-changing online world means that the onus is on both ethics committees and researchers to approach online research with an open, curious, and pragmatic mind, that at all times has the phrase "*do no harm*" at its centre. In other words, the basic ethical principles underpinning research remain universal: 1) do no harm, 2) respect the autonomy, privacy, and dignity of participants, 3) maintain scientific integrity, and 4) maximize the benefits and minimise the harm of research. What is different is how these principles might be applied in a fast changing, multi-layered context with the high risk of unintended consequences. How the principles are applied and how unexpected happenings are dealt with will rely on the researchers' and ethics committees' ability to act carefully with due diligence with the information they have at that time. In summary, as far as researchers who conduct online research are concerned, we feel that they would do well to heed the words that have been ascribed to Maya Angelou:

> Do the best you can until you know better. Then when you know better, do better.

References

Alexander, B. (2008). Web 2.0 and emergent multiliteracies. *Theory into Practice*, *47*(2), 150–160.

AoIR, (Association of Internet Researchers) (2012). *Ethical Decision-Making and Internet Research*. Available at: http://aoir.org/ethics/

British Psychological Society (2014). *BPS Code of Human Research Ethics*. www.bps.org.uk/news-and-policy/bps-code-ethics-and-conduct

British Psychological Society (2017). *Ethics Guidelines for Internet-Mediated Research*. www.bps.org.uk/news-and-policy/ethics-guidelines-internet-mediated-research-2017

British Sociological Association (2002). www.britsoc.co.uk/media/24310/bsa_statement_of_ethical_practice.pdf

British Sociological Association (2017). Statement of Ethical Practice. www.britsoc.co.uk/ethics

British Sociological Association (2017). Ethics Guidelines and Collated Resources for Digital Research. www.britsoc.co.uk/ethics

Bromseth, J. (2003). Ethical and methodological challenges in research on net-mediated communication in a Norwegian research context. In M. Sorseth (Ed.), *Applied ethics in Internet research* (pp. 67–85). Trondheim, Norway: NTNU University Press.

Brownlow, C., & O'Dell, L. (2002). Ethical issues for qualitative research in on-line communities. *Disability & Society, 17,* 685–694.

Gavin, J., Rees-Evans, D., Duckett, A., & Brosnan, M.J. (2019). The attractiveness, trustworthiness and desirability of autistic males' online dating profiles. *Computers in Human Behavior, 98,* 18195.

Gavin, J., & Griffin, C. (2012). The technological affordances of online dating sites: A comparative study. 10th Asia Pacific Conference on Computer Human Interaction (APCHI2012), August 28–31, Matsue, Japan.

Gavin, J., & Rodham, K. (2017). Ethical research in the digital age. *Psychology Review,* 2–5.

General Data Protection Regulations: https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/

Guera, D., & Delp, E.J. (2018). *Deepfake Video Detection Using Recurrent Neural Networks*. 15th IEEE International Conference on Advanced Video and Signal Based Surveillance (AVSS). DOI: 10.1109/AVSS.2018.8639163

Hargittai, E., & Marwick, A. (2016). "What Can I Really Do?": Explaining the Privacy Paradox with Online Apathy. *International Journal of Communication, 10,* 3737–3757.

Hudson, J.M., & Bruckman, A. (2004). "Go away": Participant objections to being studied and the ethics of chatroom research. *The Information Society, 20*, 127–139.

King, S. (1996). Researching internet communities: proposed ethical guidelines for the reporting of the results. *The Information Society*, *12*(2), 119–127.

Kosinski, M., Matz, S.C., Gosling, S.D., Popov, V. & Stillwell, D. (2015). Facebook as a research tool for the social sciences: Opportunities, challenges, ethical considerations, and practical guidelines. *American Psychologist*, *70*(6), 543–556.

Kraut, R., Olson, J., Banaji, M., Bruckman, A., Cohen, J., & Couper, M. (2004). Psychological research online: report of Board of Scientific Affairs' Advisory Group on the conduct of research on the internet. *American Psychologist*, *59*, 105–117.

Lange, P. G. (2007). Publicly private and privately public: Social networking on YouTube. *Journal of computer-mediated communication*, *13*(1), 361–380.

Lewis, K., Kaufman, J. & Christakis, N. (2008). The Taste for Privacy: An Analysis of College Student Privacy Settings in an Online Social Network. *Journal of Computer-Mediated Communication*, *14*(1), 79–100.

Roberts, L. (2015). Ethical Issues in Conducting Qualitative Research in Online Communities. *Qualitative Research in Psychology*. *12*(3), 314–325.

Rodham, K., Gavin, J., Lewis, S., St Denis, J., & Bandalli, P. (2013). An investigation of the motivations driving the online representation of self-injury. *Archives of Suicide Research, 17*(3), 173–183).

Skitka, L.J. & Sargis, E.G. (2006). The Internet as psychological laboratory, *Annual Review of Psychology*, *57,* 529–555.

Zimmer, M. (2010). "But the data is already public": On the ethics of research in Facebook. *Ethics and Information Technology, 12*, 313–325.

4

CULTURAL VARIATION IN INFORMED CONSENT FOR CLINICAL RESEARCH PARTICIPATION

David Resnik and Julia Hecking

Introduction

Informed consent is one of the cornerstones of ethical research with human subjects and has occupied a prominent place in numerous guidelines, regulations, and laws ever since its appearance in the *Nuremberg Code* in 1947 (Resnik 2018). Although most people living in Western countries are familiar with the concept of informed consent and would not question its importance, this was not always the case. Indeed, informed consent did not become a standard part of medical practice in the U.S. and other Western nations until the 1960s (Berg, Applebaum, Parker, & Lidz 2001). Also, in some parts of the world the idea that an individual has the right to give his or her informed consent for medical care or research participation is a foreign notion (Macklin 1999). In this chapter, we will examine the ethical and legal basis of informed consent and review the published research on cultural variation in informed consent for clinical research participation.

Brief history of informed consent

For many years, medical practice in Western nations was paternalistic insofar as doctors often made decisions for patients without presenting them with information they needed to know about their condition or their options for treatment. Even when patients were presented with information and options, they often deferred the decision to the doctor. This paternalistic ethic was based on the Hippocratic Oath, which instructs doctors to benefit their patients and protect confidentiality but says nothing about the patient's right to make medical decisions. Informed consent started to become incorporated into clinical practice during the 1960s and 1970s as a result of the Patient's Rights Movement and some influential court decisions related to medical malpractice (Faden & Beauchamp 1986. In *Canterbury v. Spence* (1972), for example, the Federal Appeals Court for the District of Columbia held that physicians have a legal duty to provide their patients with the information that a reasonable person would want to know.

Informed consent for research participation was also not part of standard medical practice in Western nations before the mid-20th century. Doctors often experimented on their patients without telling them that they were conducting research, and they did not clearly distinguish between medical therapy and medical research (Resnik 2018). A notable exception to this norm occurred when U.S. Army physician Walter Reed conducted experiments to determine the cause of yellow fever in the early 1900s. Reed's experiments involved exposing human subjects to mosquitos thought to carry the disease. 33 people participated in these experiments and six died from yellow fever. Reed asked the volunteers to sign an informed consent document prior to participating, which was translated into Spanish for the Cuban participants who did not speak English. Volunteers received $100 in gold for their participation, free medical care, and free burials (if they died). This is thought to be the first instance of the use of an informed consent document in biomedical research (Resnik 2018).

Although the Nuremberg Code, adopted in 1947, emphasized the ethical necessity of informed consent for research participation, many investigators continued to study human subjects without obtaining their consent. For example, participants in the Tuskegee Syphilis Study (1932–1972), which was sponsored by the U.S. Department of Health, Education, and Welfare, were not told that they were in a research study. They were told only that they were receiving treatment for "bad blood." Likewise, subjects in the U.S. Department of Energy's secret human radiation experiments, which took place from the 1930s to the 1960s, were not told that they were participating in research or that they were receiving radiation. Human subjects in the Jewish Chronic Disease Hospital Experiments, which took place in 1963, were not told that they had been injected with liver cancer cells as part of a study of the immune system's response to cancer (Resnik 2018).

Informed consent became a widely practiced standard for research with human subjects in Western nations (e.g. U.S., Canada, U.K., Europe, Australia) in the 1970s, when the National Institutes of Health (NIH) and the Food and Drug Administration (FDA) revised their regulations for the protection of human research subjects (Resnik 2018). In 1981, 16 U.S. federal agencies adopted the revised NIH regulations, which became known as the Common Rule (45 CFR 46). The revisions were based in part on an influential document, *The Belmont Report*, which was written by the National Commission for the Protection of Human Subjects in Biomedical and Behavioral Research (Resnik 2018). *The Belmont Report* articulated three ethical principles for research with human subjects: respect for persons (which requires that informed consent be obtained prior to research), beneficence (which requires minimization of risks and maximization of benefits), and justice (which requires equitable distribution of risks and benefits) (National Commission for the Protection of Human Subjects of Biomedical or Behavioral Research 1979). Other Western nations soon developed laws, regulations, and policies based on NIH and FDA rules. Today, over 130 countries have enacted laws, regulations, or policies for research with human subjects (Office of Human Research Protections 2019).

U.S. human research regulations

The Common Rule requires that informed consent "will be sought from each prospective subject or the subject's legally authorized representative" and "appropriately documented" (Department of Homeland Security et al. 2017 at 45 CFR 46 111a). The Common Rule describes 16 types of information that should be conveyed to subjects during the consent process, including the nature of the research, risks and discomforts, potential benefits, alternatives to research participation, confidentiality protections, additional costs to the subject (if any), the right to refuse to participate or withdraw without reprisal, how to withdraw from a study, and the length of the subject's participation (45 CFR 46.111b and 111c). The Common Rule also requires that consent take place under conditions that minimize the possibility for coercion or undue influence, that subjects receive information that a reasonable person would want to know, that information be conveyed in a language understandable to the subjects, and that subjects not be asked to waive legal rights (45 CFR 46.111a). The Common Rule includes exceptions to the informed consent requirements. An institutional board review (IRB)[1] can waive or alter the informed consent process if it determines that risks to subjects are minimal and it would be impractical to conduct the research without a waiver or alteration (45 CFR 46.111e). An IRB can waive documentation requirements if it determines that risks are minimal and the only record linking the subject to the research is the consent document, or if the risks are minimal and the subjects belong to a cultural group in which signing forms is not norm (45 CFR 46. 117c).

The Common Rule and the FDA regulations are very similar in content and scope. The main difference between these sets of rules is that the FDA regulations include exceptions to informed consent requirements for emergency research in which the subject faces a life-threatening condition for which there is no effective treatment, an experimental treatment is available, the subject is unable to consent, and a legally authorized representative (such as parent, guardian, or next of kin) is not available (Resnik 2018).

International guidelines on consent

The *Nuremberg Code*, which was promulgated by the Council at Nuremberg as a means of judging Nazi doctors and scientists for war crimes, was the first international guideline for research with human subjects. The first principle of the Code states that "[t]he voluntary consent of the human subject is absolutely essential (Nuremberg Code 1949)." The Code also states that the subject must have the legal capacity to give consent and should be able to exercise the "free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion" (Nuremberg Code 1949. The Code states that the subject should have enough knowledge and comprehension of the research to make a responsible choice concerning participation. The Code does not include provisions for allowing a legally authorized representative to consent for the subject (Nuremberg Code 1949).

In 1964, the World Medical Association adopted the *Declaration at Helsinki*, which has been revised nine times, most recently in 2013 (World Medical Association 2013). The *Helsinki Declaration* states that physicians have a duty to "protect the life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information of research subjects" (World Medical Association 2013). One of the chief ways of meeting this obligation is to ensure that human subjects participate in research only if they (or their legally authorized representatives) have given consent. Consent should be voluntary and free from duress. Subjects should be informed about the "aims, methods, sources of funding, any possible conflicts of interest, institutional affiliations of the researcher, the anticipated benefits and potential risks of the study and the discomfort it may entail, post-study provisions and any other relevant aspects of the study" (World Medical Association 2013). Consent also should be properly documented in writing and witnessed. Subjects should be told that they can refuse to participate or withdraw without fear of reprisal. An ethics committee, such as an IRB, can approve research on identifiable human biospecimens or data that does not involve consent if consent would be impossible or impractical (World Medical Association 2013).

The Council for International Organizations of Medical Sciences (CIOMS), a group established by the World Health Organization (WHO) and United Nations Educational, Scientific and Cultural Organization (UNESCO) in 1949, adopted its *International Ethical Guidelines for Biomedical Research Involving Human Subjects* in 1993. The CIOMS Guidelines were revised in 2016 and renamed the *International Ethical Guidelines for Health-related Research*

Involving Humans (Council for International Organizations of Medical Sciences 2016). The CIOMS Guidelines, like the *Nuremberg Code* and *Helsinki Declaration*, include rules for providing and documenting informed consent. The *Guidelines* also address other relevant consent topics, such as essential information that should be conveyed to the subject, the voluntary nature of consent, freedom of choice, deception, comprehension of information, the capacity to consent, consent by a legally authorized representative, and procedures for modifying or waiving consent (Council for International Organizations of Medical Sciences 2016).

Moral basis for consent

Informed consent is based on three moral principles. The first is the obligation to allow autonomous (i.e. competent) individuals to make their own decisions. This fundamental moral principle, known as respect for autonomy, is supported by several Western moral theories including: natural rights theory (as developed by John Locke and others), Immanuel Kant's moral theory, and John Stuart Mill's harm principle (which says that liberty should be restricted only to prevent harm to others (Faden & Beauchamp 1986; Resnik 2018). Respecting autonomy is also part of what it means to respect persons, according to the authors of *The Belmont Report*. Informed consent enables individuals to make their own decisions concerning research participation. Providing individuals with relevant information about the research helps them to make autonomous decisions pertaining to the participation. Coercion, undue influence, duress, and deception are unethical because they interfere with or compromise autonomous decision-making (Faden & Beauchamp 1986).

The second moral principle is the obligation to avoid harming other people, also known as the principle of non-maleficence (Resnik 2018). The three moral theories mentioned above, as well as numerous others (including natural theory and utilitarianism), the Hippocratic Oath, and *The Belmont Report*'s principle of beneficence imply ethical duties to not harm others. Consent enables researchers to avoid causing harm by helping individuals to protect themselves from harm. If an individual decides not to participate in a study because he or she deems it to be too risky, the potential harm to the individual will not occur, and the researcher will avoid causing harm (Resnik 2018).

The third moral principle is the obligation to promote and maintain trust when engaged in relationships that depend on trust, such as the relationship between a physician and a patient or an investigator and a human subject. Trust is an essential component of research with human subjects since subjects must trust that investigators will protect their rights and well-being. If subjects do not trust investigators, they will not participate in research or they will withdraw from research. Informed consent helps to build and maintain trust by respecting the participant's autonomy and dignity. Informed consent also helps to promote honest and open communication between investigators and subjects, which is also essential for trust. When researchers do not obtain consent, as has happened in abuses of human subjects like those discussed above, trust breaks down. Obtaining consent irresponsibly (e.g. by not following consent requirements) can also undermine trust (Resnik 2018).

Although informed consent has widespread support from different Western moral theories and traditions and is required by various national laws, regulations, and guidelines, disputes still arise pertaining to various topics related to consent, such as: how to obtain consent, what types of information to convey to subjects, how much information to share, the degree of comprehension required for consent to be valid, how much decision-making capacity is required for consent, what constitutes coercion or undue influence, whether people can be involved in low-risk research without consent, and whether opt-out consent procedures are acceptable (Resnik

2018). Many of these disputes stem from underlying disagreements about how to prioritize conflicting moral values or principles, such as the obligation to respect autonomy vs. the obligation to benefit society by advancing human knowledge through scientific research.

Cultural variation in informed consent

While U.S. clinical research informed consent policies emphasize protecting individual rights and autonomy, other countries place more emphasis on community and family-unit decision-making. In these cultures, the concept of "autonomy" is seen in a relational rather than an individual context, meaning that an individual's sense-of-self is influenced by his or her social roles, responsibilities, and connections to the community or family (Clough, Campbell, Aliyeva, Mateo, Zarean, & O'Donovan 2013; Frimpong-Mansoh 2008; Pratt, Van, Cong, Rashid, Kumar, Ahmad, Upshur, & Loff 2014; Sariola & Simpson 2011). In cultures that define their members by their relations to others, the Western formal practice of autonomous informed consent process is viewed as a foreign concept (Cook 2015). This is because the decision-making process usually involves the family and community, not just the individual, and because medical practice may place a higher emphasis on values other than individual autonomy or privacy, such as physician loyalty or compassion. In such cultures, if a patient is invited to participate in a clinical trial, it would be customary for the family to be involved in the decision, while in the U.S., the family or community would not be involved unless explicitly called upon for input (Cook 2015; Macklin 1999; Ruiping 2015). As there has been a significant increase in the last twenty years in international research projects and multinational clinical trials, researchers are increasingly being challenged to adopt new clinical trial procedures that may create a conflict between the investigators' research standards and the ethical values of the culture in which the trial is being conducted.

Methods

To better understand this conflict and how to manage it, we reviewed the literature on cultural variation in informed consent for clinical research. We defined "culture" broadly to include characteristics such as religion, nationality, geographical location, and ethnicity that influence the informed consent processes. To obtain articles for our review, we used an institutional resource that provided access to 268 databases, including Elsevier ScienceDirect, EBSCOhost Premier, SpringerLink, ProQuest Sciences, JSTOR Life Sciences, and MedlinePlus (PubMed).

We conducted our search using the terms, "human subjects," "clinical research," "informed consent," and "nationality." We refined our results year (1990 or later), subject (informed consent), language (English), publication type (academic journals), and availability (full text online). This search identified 1168 results. Results were excluded if they were not clinical research studies (i.e. letters or short commentaries) or not an analysis of a clinical research study, and if they explicitly discussed research in vulnerable populations (prisoners, children, pregnant women, neonates, etc.).

Results

When the Western, individualistic concept of informed consent is applied in non-Western settings, participants may experience confusion and distrust because this concept may be inconsistent with their community values and because they may not be accustomed to making medical decisions without the input of community/familial leaders (Kumar, Mohanraj, Rose,