Chapter 5

Ethical Issues in Qualitative Data Collection Among Vulnerable Populations in Healthcare Setting

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ABSTRACT

The chapter aims to highlight the ethical issues in qualitative data collection among vulnerable populations. Among the ethical issues are the conflict role of interviewers, adverse impact on future patient-therapist relationship, and emotional trauma both during and after data collection. The interviewers, usually healthcare providers, may subconsciously assume the role as a therapist during the interviews. Furthermore, the interviewers may encounter the participants (patients) in future clinical consultations; hence, information exchanges during the interviews could influence the therapeutic relationship. Recollection of experiences with an illness during the interviews can be a painful experience for patients. These ethical dilemmas can be addressed with appropriate sampling of participants and constant awareness of the researcher roles and relationships with the participants. Debriefing the participants with support is important to handle emotional upheavals.

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INTRODUCTION

Qualitative data collection is an interactive process between the interviewers and the participants. Although interviewers appear to play a passive role in some data collection processes, their mere presence, interest and rapport, often actively influence participants in sharing their life experiences and thoughts (DiCicco-Bloom & Crabtree, 2006). Therefore, acquiring high quality data requires interviewers to play an appropriate active role in the process.

This is particularly the case for in-depth interviews (IDIs) and focus group discussions (FGDs) conducted for the patients in health care settings where thought-provoking conversation, sharing of living experiences, and disclosure of sensitive issues often occur. Thus, participants potentially expose their “weaknesses” or trauma and life issues to the researchers. These vulnerable moments can be detrimental to both participants and researchers (Parnis, 2005). The potential negative impact of the data collection process on participants begins with participant recruitment, setting the venue for data collection, to conducting the interviews and thereafter.

The objective of this chapter is to highlight the ethical issues in qualitative data collection, related to health care settings, where patients who participate in research are vulnerable as they are health compromised (Latvala, Janhonen & Moring, 1998; Paavilainen, Astedt-Kurki & Paunonen, 1998; Stroebe, Stroebe & Schut, 2003). The interviewers may also be participants’ health care providers, which can have further ethical implications. Strategies to address the ethical challenges will also be discussed.

UNFOLDING THE ETHICAL ISSUES IN VARIOUS STAGES OF THE DATA COLLECTION PROCESS

In qualitative data collection, incidences that present an ethical dilemma occur when there is tension between the benefits to researchers (the need for data) and benefits to participants (the need to have confidentiality preserved and fulfill participants’ own agenda). Setting rules and guidelines in relation to ethical issues in qualitative data collection can be a challenging task because of unanticipated incidences in the data collection. The planning for recruitment of participants and the venue are often tentative. The researchers may need to collect further information, either from the same participants, or from new participants. During the IDIs and FGDs, researchers may also need to deal with unanticipated stories revealed by participants. They may also encounter issues that are unrelated to the topic of the study, for instance, participants taking the opportunity to fulfil their own agenda from the interviews.
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