ETHICAL TENSIONS IN GENETIC COUNSELLING RESEARCH

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Ethical tensions are recognised as part of the everyday practice of conducting research and practising genetic counselling. What are the conceptual frameworks that can assist researchers and genetic counsellors to deal with ethical tensions when conducting research? How might the overlap that arises from being a researcher and clinical genetic counsellor be dealt with? This article uses a case study to consider the ethical tensions between conducting research in genetic counselling and maintaining a clinical practice as a genetic counsellor. It examines the reconciliation of the dual roles of researcher and genetic counsellor. It explores conceptual frameworks that can combine the needs of ethical research practice, while maintaining ethical clinical practice.

INTRODUCTION

It is well known that ethical dilemmas may arise during all kinds of research — as a social researcher I am aware that ethical dilemmas are inherent in the conduct of qualitative research. As an experienced genetic counsellor, I am accustomed to considering and dealing with ethical dilemmas in day-to-day practice. A challenge for me has been the management of ethical tensions that have arisen while practising as a genetic counsellor and undertaking qualitative research. I was forced to consider these issues in detail following an incident where I consciously breached confidentiality and used information obtained in a research interview to inform a clinical discussion.

As interaction is at the core of social research, it seems inevitable that issues and dilemmas will arise. Qualitative researchers often talk about day-to-day dilemmas and Guillemin and Gillam described these as ‘ethically important moments’ — the difficult, subtle and often unpredictable situations that arise as a result of undertaking research (Guillemin and Gillam 2004). This article examines the ethical dilemmas I faced while practising as a cancer genetic counsellor and undertaking qualitative research in cancer genetics within the same discipline. In particular, I examine the conceptual frameworks that assisted me in the ethical conduct of concurrent genetic counselling research and
practice as a genetic counsellor. Initially it was helpful to me to separate the domains of researcher and clinician to prevent role confusion, but the ethical dilemma that resulted in my breaching confidentiality challenged me to reconsider these domains, and to ultimately see them as overlapping and complementary. Finally, this article proposes that genetic counsellors have ethical expertise as a result of their training and practice and, as such, are well placed to undertake qualitative research in genetic counselling.

**RESEARCH PROJECT**

As a genetic counsellor with many years of clinical experience, I became interested in understanding the decision-making processes of women considering predictive genetic testing for BRCA1/BRCA2 mutations. Women who, through predictive genetic testing, are shown to carry a mutation in BRCA1 or BRCA2, have a significantly increased risk over their lifetime for the development of breast and/or ovarian cancer. The average cumulative risks for breast cancer in women known to carry a BRCA1 gene mutation is 65 per cent by age 70 years and 39 per cent for ovarian cancer. For women carrying a BRCA2 gene mutation the risks are 45 per cent for breast cancer and 11 per cent for ovarian cancer (Antoniou et al. 2003).

During genetic counselling, women who are identified as carrying a BRCA1 or BRCA2 mutation are told that they are at high risk over their lifetime to develop breast and/or ovarian cancer. This allows them to consider risk management options. Risk management is a medical term used to describe a number of strategies to manage or reduce ongoing lifetime cancer risk. It includes cancer surveillance and/or prophylactic surgery.

In my practice, I observed a mismatch between women’s expectations of genetic counselling and what genetic counsellors understood their role in the decision-making process to be. It seemed to me and many of my colleagues that most women attending genetic clinics to explore predictive testing for BRCA1/BRCA2 mutations had already decided to undergo testing and some seemed affronted when asked by a genetic counsellor to reflect on their decision.

This is in keeping with Sarangi et al., who showed how counsellors use reflective questions in an attempt to draw out moments or events that explain a client’s decision to present for predictive testing for Huntington’s disease (Sarangi et al. 2005). They found that genetic counsellors often look for causal and prevailing factors to validate the client as being appropriately engaged. When clients appear disengaged, counsellors tend to explore the decision-making process, which may be interpreted by some clients as a requirement to demonstrate that they are ‘psychologically competent’ to undertake testing. This, coupled with clients’ perceptions about the gate-keeping role of the genetic