



DOCTORATE IN CLINICAL PSYCHOLOGY

Major Research Project

**The experience of prophylactic bilateral mastectomy in women to reduce the risk of
breast cancer: An interpretative phenomenological analysis**

Katharine Jones

This manuscript has been submitted in partial fulfilment of a Doctoral Degree in Clinical
Psychology
with revisions 26 August 2013

Word count (exc. tables): Manuscript: 8000

Main Supervisor: Dr Phil Yates, University of Exeter

Secondary Supervisor: Dr Janet Smithson, University of Exeter

Field Supervisor: Elaine Vickers, Clinical Psychologist, Devon Partnership NHS Trust

Field Worker: Sandra Cookson, Breast Care Nurse Specialist, Royal Devon and Exeter NHS
Foundation Trust

Nominated Journal: British Journal of Health Psychology

Manuscript

Abstract

Objectives: Increasing knowledge of genetics has found that a mutation to the BRCA 1 or 2 genes are associated with a high risk of developing breast cancer throughout the lifespan. A woman with this genetic mutation may consider preventive surgery to reduce the risk of breast cancer. This involves a prophylactic bilateral mastectomy to remove the breasts when there is no cancer present and may be followed by breast reconstruction. This study aimed to explore the lived experience and psycho-social impact on women of this surgery.

Design: Interpretative phenomenological analysis was employed in an in-depth study of a small sample of eleven female patients with BRCA 1/2 genetic mutations who had undergone preventive surgery of prophylactic bilateral mastectomy.

Methods: Semi-structured interviews were carried out. The transcripts of those interviews served as the data for an interpretative phenomenological analysis.

Results and conclusions: Three themes were identified from the Interpretative Phenomenological Analysis to convey the lived experience of participants. These were (1) focus on reduced risk of cancer; taking control, relief and benefit finding, (2) a focus on relationships; family life, medical professional and BRCA support group and other women with lived experience, and (3) Focus on experiencing surgery and impact on self; the importance of reconstruction, loss of sexual attractiveness, impact on self from negative reaction of others and adjusting to surgical results. The implications are discussed in relation to the current literature and clinical practice.

Keywords: Preventive medicine, prophylactic surgery, genetic mutations, female

Table of Contents

Manuscript	4
Abstract	4
Introduction.....	5
Method.....	10
Results.....	17
Discussion.....	26
References.....	34
Appendices.....	41
Appendix A: Ethics documentation	41
Ai Letters of ethics and NHS Trust approval	41
Aii Consent Form	47
Aiii Letter to GP	48
Appendix B: Participant Information Sheet.....	49
Appendix C: Semi-structured Interview Schedule	53
Appendix D: Extended Method.....	56
Di: Plan of Dissemination of Results.....	56
Dii: Reflexivity statement	57
Diii Extended description of data analysis.....	58
Appendix E: Example of transcript coding (Claire)	60
Appendix F: Instructions for authors	61