

MSc Nutrition and Dietetics

**Health beliefs and behaviours amongst women at high
risk of breast cancer**

An in-depth interview study

Cheryl Barlow

0303478

October 2009

Acknowledgements

I would like to thank the following people for their assistance during this project; Claire Wright, Dr Michelle Harvie and Professor Kinta Beaver for their valuable advice and guidance.

Participants who took part in the study and The Genesis Appeal who provided funding for the transcribing of audio recordings.

Advisors, Mr A. Shenton, Professor A. Howell, Professor G. Evans and Dr P. Hopwood.

Abstract

Aims: This study aims to explore the health beliefs and the reasons for these beliefs amongst BRCA mutation carriers.

Design: This study used a qualitative research design through one to one interviews. A semi structured interview guide was developed around the phenomenon being investigated. Data collection was through audio recordings of interviews. Tapes were transcribed verbatim. Transcriptions were coded for emerging themes using Framework Analysis. Elements of Discourse Analysis were also applied.

Subjects: 20 women either BRCA1 or BRCA2 mutation carriers, affected or unaffected by breast cancer, or at a 50% risk of being a BRCA carrier.

Findings: Genetic factors are perceived to be the strongest element when assessing breast cancer risk. Secondary factors quoted included a wide variety of other causes, environment, stress, diet, exercise and smoking. Participants were aware of their raised breast cancer risk. The majority of the group had made changes to their behaviour. The perceived benefits of these changes were, improved outcome if they did develop breast cancer in the future, positive effects on general health and ensuring that they had done whatever they could to reduce possible causes. Belief that a behaviour was a risk factor in the development of breast cancer was not always correlated with changes in that behaviour. Some individuals did not believe particular behaviours were risk factors yet still made changes to those behaviours. The majority of the group were willing to join future lifestyle based trials but were generally reluctant to be involved in drug based investigations.

Conclusions: Despite the wide spread belief that their breast cancer risk was largely predetermined by genetic factors the group displayed strong motivation to find other ways to exercise control over their breast cancer risk and the possible outcome if breast cancer did occur. If clear causal links between behaviour and breast cancer occurrence can be proven for this specific population group, it may be expected that the group's strong motivation to affect some control over their increased breast cancer risk would lead them to engage in this protective behaviour.

Declaration

“I hereby declare that work contained herewith is original and is entirely my own work (unless indicated otherwise). It has not been previously submitted in support of a Degree, qualification or other course.”

Signed:**Date:**

Contents

1. Introduction	11
2. Literature Review	13
2.1 Factors influencing risk	13
2.2 Attitudes to risk modifiers	18
2.3 Theoretical models	19
2.4 Health beliefs of those with genetic predisposition	21
2.5 Summary of relevant published work	25
2.6 Key interview objectives	26
3. Methods	27
3.1 Study design	27
3.2 Sampling	27
3.3 Sample size	29
3.4 Recruitment and consent	30
3.5 Ethical issues	31
3.6 Data collection	32
3.7 Analysis	35
3.8 Validity and reliability	36
4. Findings	38
4.1 Quantitative statistical data for participants	38
4.1.1 Study Participants	38
4.2 Qualitative Analysis of interview data	41
4.2.1 Theme 1. Perceived causes of breast cancer	42
4.2.1.1 Uncontrollable	43
4.2.1.2 Controllable	44

4.2.1.2.1	Lifestyle	44
4.2.1.2.2	Environmental	45
4.2.1.2.3	Hormones	45
4.2.1.3	The relative strength of various causes	46
4.2.2	Theme 2. Perceived risk of breast cancer for the participant....	48
4.2.2.1	Awareness of risk	49
4.2.2.2	Coping with risk	52
4.2.2.2.1	Risk reducing surgery	52
4.2.2.2.2	Acceptance	54
4.2.2.2.3	Ignore	54
4.2.3	Theme 3. Control of risk of developing breast cancer	56
4.2.3.1	Increased Control	58
4.2.3.1.1	Monitoring	58
4.2.3.1.2	Psychological	59
4.2.3.1.3	Lifestyle	59
4.2.3.2	Reduced control	65
4.2.3.2.1	Genetics.....	65
4.2.3.2.2	Barriers to control	66
4.2.4	Theme 4. Behaviour changes made or considered.....	67
4.2.4.1	Long term	69
4.2.4.1.1	No change	69
4.2.4.1.2	Ongoing.....	70
4.2.5	Theme 5. Attitudes to future trials	72
4.2.5.1	Motivations	73
4.2.5.2	Barriers.....	74

5. Discussion	76
5.1 Risk dominated by genetics	76
5.2 Strong desire to find ways to exert control	78
5.3 Application of diet and exercise.....	80
5.4 Future research	82
5.5 Limitations	83
6. Conclusions	86
7. References	88
8. Appendix 1 - Information sheets	107
8.1 Patient invitation letters	108
8.2 Patient information sheets	110
8.3 Patient consent forms	114
8.4 GP letter	115
9. Appendix 2	116
9.1 Original semi structured interview guide.....	117
10. Appendix 3	118
10.1 Details of the analysis approach used	119
10.2 Initial theme tables	121
10.2.1 Perceived causes of breast cancer	121
10.2.2 Perceived risk of breast cancer for the participant.....	122
10.2.3 Control of risk of developing breast cancer	123
10.2.4 Behaviour changes made or considered.....	124
10.2.5 Attitudes to entering future breast cancer trials	125

Tables

Table 1. Semi-structured interview guide	34
Table 2. Response rate	38
Table 3. Demographic information of study participants	39
Table 4. Participant's genetic status.....	40
Table 5. Cancer burden	40
Table 6. Perceived causes of breast cancer	42
Table 7. Quotations on the causes of breast cancer	43
Table 8. Language used in response to the causes of breast cancer.....	47
Table 9. Perceived risk of breast cancer for the participant.....	48
Table 10. Quotations on awareness of risk	51
Table 11. Quotations relating to uncertainty about cancer risk	52
Table 12. Control of risk of developing breast cancer	56
Table 13. Control and lifestyle factors.....	63
Table 14. Reduced control of breast cancer risk.....	65
Table 15. Behaviour changes made or considered.....	68
Table 16. Attitudes to future trials	72

Abbreviations

BMI Body mass index

BRCA 1 Breast cancer gene 1

BRCA 2 Breast cancer gene 2

CB Cheryl Barlow

DCIS Ductal carcinoma in situ

EMBRACE Epidemiological Study of Familial Breast Cancer