

Traditional acupuncture: exploring the rationale and theory of change in the specific context of early breast cancer and chemotherapy in research and practice

Sarah Price

Submitted in accordance with the requirements for the degree of
Doctor of Philosophy

The University of Leeds

School of Healthcare

September 2012

The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

This copy has been supplied on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

The right of Sarah Price be identified as Author of this work has been asserted by her in accordance with the Copyright, Designs and Patents Act 1988

Acknowledgments

My thanks go firstly to the two acupuncturists and fourteen women with breast cancer who took part in this study. Thanks also go to the oncologists and specialist nurses who were open to the idea and made it happen most especially Professor David Cameron who opened the doors of possibility onto this study. This study would also not have been possible without the British Acupuncture Council who funded the acupuncture treatment.

My special thanks go to Andrew Long and Mary Godfrey at the University of Leeds and also to Kate Thomas who have supervised this project and have given so generously of their time and their ideas. They have shown extraordinary patience and kindness as I have travelled this long road. George Lewith also gave helpful advice and support in the early days.

Lastly my thanks go to friends and family in Edinburgh especially Georgia and Lauren and my two colleagues Trina Ward and Andrew Flower for their helpful advice and comments and Wendy Faulkner for the same.

Abstract

Acupuncture is an increasingly popular complementary therapy. Acupuncture research, however, leaves uncertainty as to its effectiveness and raises question about what traditional acupuncture (TA) is. This thesis aims to examine what acupuncture is, by using the Theory of Change (ToC) as a novel approach to elucidate the pathways for change. Early breast cancer (EBC) is used as a complex exemplar providing the TA practitioner with the opportunity to utilise TA in all of its complexity.

A ToC framework was developed from the professional accrediting body of TA. This ToC framework was applied to two sets of literature: firstly acupuncture research where validated outcome measures were used; secondly research on the exploration of practitioner and patients' perceptions of TA. A longitudinal study was constructed to examine change over time during the EBC experience. This study entailed interviewing 14 women before, during and after chemotherapy while they received up to ten sessions of TA. The two practitioners were also interviewed; they kept diaries and treatment logs of the process creating additional data. Grounded theory methods were used to analyse the data.

The ToC was refined after analysis of all the data to provide a comprehensive insight into the components of TA providing further weight to the idea that it is a complex intervention. Treatment entails a continuous process with multiple pathways to change. TA offers great flexibility in addressing chronic illness with acute features or daily fluctuations of a range of problems. The concept of outcome patterns arose from this which is ripe for further exploration. The therapeutic relationship is part of the intervention, used to engage the individual with new insights into health and changing behaviour as well as to enable disclosure leading to person-centred goals of treatment. Therapeutic befriending emerged as a notion suitable for further exploration within CAM.

Table of Contents

ACKNOWLEDGEMENTS	I
ABSTRACT	li
TABLE OF CONTENTS	lii
LIST OF BOXES, FIGURES AND TABLES	X
GLOSSARY OF CHINESE MEDICINE TERMS	Xiii
CHAPTER ONE	1
INTRODUCTION TO THE STUDY	1
Acupuncture in Practice.....	2
Different Theories Underpin Practice.....	2
Acupuncture in Research – model validity.....	4
Acupuncture – a simple or complex intervention?.....	5
Finding Appropriate Methods of Evaluation.....	7
Early Breast Cancer as a Complex Exemplar.....	7
Theory of Change.....	7
Research Aim.....	9
Research Question.....	9
Structure of Thesis.....	9
What might this PhD add?.....	10
CHAPTER TWO	12
EARLY BREAST CANCER AS AN EXEMPLAR	12
Introduction.....	12
Background.....	12
Early Breast Cancer as a Complex Medical Condition.....	14
<i>Cancer Related Fatigue</i>	14
<i>Symptom Clusters</i>	15
Exploring the Experience of Breast Cancer.....	17
Summary of Findings from the Qualitative Literature.....	17
Time and the Illness Trajectory.....	29
Concluding Comments.....	32

CHAPTER THREE	34
METHODOLOGY	34
Introduction.....	34
Theory of Change.....	34
<i>Applying the Theory of Change Approach</i>	37
A Longitudinal Study Using a Broadly Interpretative Approach.....	38
<i>Interpretive Naturalistic Approach</i>	38
<i>Qualitative Research</i>	39
<i>Rigour</i>	39
<i>Reflexivity</i>	40
<i>Researcher's Epistemological Position</i>	41
<i>Ethics</i>	42
Concluding Comments.....	42
CHAPTER FOUR	43
METHODS	43
Introduction.....	43
1. Exploring Two Models of Acupuncture Comparing Theory, Practice and Research	43
Developing a Framework that Articulates the ToC	43
<i>Textbooks for Cross Reference</i>	46
2. Applying the ToC Framework to the Clinical Acupuncture Research Literature	50
Search Strategy.....	50
Sampling Strategy.....	50
3. Exploring the Literature for Patient and Practitioner Experiences of TA.....	52
Search Strategy for the Qualitative Literature Review.....	52
4. A Longitudinal Qualitative Study.....	54
<i>Inclusion and Exclusion Criteria</i>	54
<i>Sampling</i>	54
<i>Acupuncture Treatment and Setting</i>	54
<i>Access to women with EBC (participants)</i>	54
<i>Access to acupuncturists</i>	54
<i>In-depth Interviews</i>	54
<i>i) Topic guides for interviews with EBC participants</i>	55
<i>Interviews with breast cancer participants</i>	57
<i>ii) Topic guides for interviews with the Acupuncturists</i>	57

<i>Interviews with acupuncturists</i>	58
<i>Reflective Diaries</i>	59
<i>Acupuncture Treatment Log</i>	59
<i>Safety Data and Satisfaction with Treatment</i>	59
<i>Demographic Data</i>	60
<i>Ethical Approval</i>	60
<i>Funding for the Study</i>	60
<i>Analysis for the Longitudinal Qualitative Study Using Grounded Theory</i>	60
<i>Managing data</i>	61
<i>Process of analysis</i>	64
i) <i>Open coding and memo writing</i>	64
ii) <i>Focused coding</i>	65
iii) <i>Vignettes</i>	65
iv) <i>Developing categories</i>	66
v) <i>Time</i>	67
<i>The Inclusiveness and Consistency of the Data</i>	68
<i>Reflexivity and Grounded Theory</i>	68
<i>Sensitising Concepts</i>	68
<i>Theoretical Sampling</i>	69
5. <i>Analysis of Acupuncture Data Using the ToC Framework</i>	70
<i>Interpretation of the Data</i>	70
<i>Concluding Comments</i>	70
CHAPTER FIVE	72
THEORY OF CHANGE IN CLINICAL TRIALS OF ACUPUNCTURE FOR	72
SYMPTOMS COMMON DURING BREAST CANCER TREATMENT	
Introduction.....	72
Aim of this Review.....	72
Results.....	73
<i>Adherence to a Theoretical Model</i>	73
<i>TA Model</i>	73
<i>MA Model</i>	74

<i>Unclassifiable</i>	76
<i>Exploration by Symptom</i>	76
<i>Vasomotor Symptoms</i>	76
<i>Fatigue</i>	77
<i>Depression, Anxiety, Insomnia Symptoms</i>	78
<i>Nausea and Vomiting</i>	78
What are the Gaps in the Knowledge?.....	78
Concluding Comments.....	79
CHAPTER SIX	81
SURFACING THE THEORY OF CHANGE: TA PRACTITIONER AND PATIENT PERSPECTIVES	81
Introduction.....	81
Practitioner Perspectives and Theory of Change.....	81
Patient Perspectives on Experiences of TA.....	85
Theory of Change.....	96
Concluding Comments.....	99
CHAPTER SEVEN	101
EXPLORING EXPERIENCE AND CONCERNS: A MAELSTROM OF CHANGE	101
Introduction.....	101
1. Before Chemotherapy.....	102
<i>Shock of Diagnosis</i>	102
<i>Keeping Everything Normal</i>	102
2. During Chemotherapy.....	110
<i>Carrying On As Normal</i>	111
Consequences of 'keeping everything normal'.....	115
<i>i) Limiting Support</i>	115
<i>ii) A Limbo State</i>	115
<i>iii) Suffering and Isolation</i>	116
3. Looking Back.....	116
4. Meaning and Significance of EBC.....	119
5. Suffering.....	121
<i>Physical Suffering</i>	121
<i>Emotionality</i>	123

<i>Mental Anguish</i>	124
<i>Loss</i>	125
<i>i) Loss of the independent self</i>	125
<i>ii) Loss of the confident self</i>	126
<i>iii) Loss of intimacy</i>	127
<i>iv) Loss of peace of mind</i>	127
Concluding Comments.....	129

CHAPTER EIGHT 132

OUTCOMES 132

Introduction.....	132
1. Practitioner Perspectives.....	133
<i>Treatment Logs</i>	133
<i>Diaries</i>	135
<i>Practitioner Intended Outcomes</i>	135
<i>i) Fortify and Strengthen</i>	137
<i>ii) Pre-empt Side-effects</i>	139
<i>iii) Resolve Outcome Patterns</i>	140
<i>iv) Enable Coping and Wellness</i>	142
2. Women's Perceptions of Perceived Benefits and Valued Outcomes.....	144
<i>Perceived Benefits</i>	144
<i>General Benefits</i>	145
<i>i) Feeling more relaxed</i>	145
<i>ii) 'It made me more open'</i>	146
<i>Specific Benefits</i>	146
<i>Anticipatory Benefit</i>	147
<i>Enabling Coping</i>	148
Therapeutic Relationship and Therapeutic Befriending.....	150
Concluding Comments.....	154

CHAPTER NINE 157

TRADITIONAL ACUPUNCTURE: THEORY OF CHANGE IN PRACTICE 157

Introduction.....	157
Information Gathering.....	158

<i>Signs and Symptoms</i>	158
<i>History of the Person</i>	159
<i>Silent Information</i>	159
<i>Continuous Process</i>	160
<i>Individualised Treatment</i>	162
Root and Branch.....	165
Treat According to the Zang Fu and Balance of Qi.....	166
Therapeutic Relationship.....	168
<i>Building Rapport</i>	168
<i>A Warm and Genuine Attachment</i>	169
<i>Mutually Enhanced with Acupuncture</i>	169
Whole Person Approach.....	171
Concluding Comments.....	171
CHAPTER TEN	173
REFLEXIVITY	173
Introduction.....	173
My Standpoint.....	173
My Journey from Practitioner to Practitioner-researcher.....	174
<i>Reflections on the Nature of the Encounter with Participants</i>	174
<i>Reflections on the Discussion of the Therapeutic Relationship</i>	178
<i>Reflections on the Encounter with Practitioners</i>	179
<i>Reflections on Methodology</i>	180
<i>Reflections on Methods</i>	180
Case Studies.....	181
<i>A counter case</i>	181
<i>A case to demonstrate ToC and the outcome of changing perspectives</i>	182
Concluding Comments.....	186
CHAPTER ELEVEN	187
DISCUSSION	187
Introduction.....	187
1. Meeting the Objectives of the Thesis.....	190
2. Intended Effects, Perceived Benefits What to Measure.....	191
<i>Whole Systems Research</i>	192
<i>Symptom Clusters and Outcome Patterns</i>	192

<i>Whole Person Effects</i>	193
<i>Enable Coping</i>	194
<i>Participants' Seeking Meaning</i>	194
<i>From Therapeutic Relationship to Therapeutic Befriending</i>	196
<i>Summary of Intended Effects and Goals of Treatment</i>	199
3. Refinement of the Theory of Change.....	200
4. Strengths and Limitations of the Study.....	205
What This Study Adds.....	208
Recommendations for Future Research.....	209
Conclusion.....	210
BIBLIOGRAPHY.....	211
APPENDIX I.....	226
APPENDIX II.....	227
APPENDIX III.....	232
APPENDIX IV.....	236
APPENDIX V.....	239
APPENDIX VI	241
APPENDIX VII	247

List of Tables, Figures and Boxes

Boxes

Box 1. Theory of Change Framework for Two Contrasting Models of Acupuncture....	49
Box 2. Revised Theory of Change for TA.....	204

Tables

Table 1.1 Differentiating the concept 'holistic' between TA and MA models.....	3
Table 1.2 Researching Acupuncture as a Simple and Complex Intervention.....	6
Table 2.1 Selected studies, phenomenon and evaluative summary.....	19
Table 2.2 Quality appraisal of included studies.....	28
Table 4.1 Examples of differentiation of the core curriculum of two professional bodies	45
Table 4.2 Refinement of the Traditional Acupuncture topics.....	46
Table 4.3 A sample of the pro forma guide to the overview of each study.....	51
Table 5.1 Classification of included studies according to model such as TA, MA or 'unclassifiable'.....	74
Table 6.1 Studies on the Practitioner Perspective.....	83
Table 6.2 Summary studies exploring patient perceptions of TA.....	89
Table 6.3 Outcomes (and Processes) of TA from within all the studies.....	98
Table 8.1 Summary of main and secondary complaints recorded in Treatment.....	134
Table 8.2 General Benefits.....	145
Table 8.3 Specific Benefits.....	147
Table 8.4 Characteristics of Relationship.....	154
Table 11.1 Theory of Change Framework mapped to themes emerging from the longitudinal study.....	200

Figures

Figure 2.1 Order of treatment of early stage breast cancer patients.....	14
Figure 2.2 Time span of studies for the qualitative literature review.....	31
Figure 4.1 Excerpt from fields notes of second participant interview.....	62
Figure 4.2 Excerpt from fields notes of second participant interview.....	62
Figure 4.3 Excerpt from 'contact summary sheet'.....	63
Figure 4.4 Excerpt from field notes of the second participant follow-up interview.....	63

Figure 4.5 Example of early memo writing.....	64
Figure 4.6 Development of the theme of therapeutic befriending.....	65
Figure 4.7 Example of vignette for Julie on her first interview.....	66
Figure 4.8 Example of gathering data over time to capture the process of change.....	68
Figure 7.1 Shock of diagnosis resulting in disruption.....	104
Figure 7.2 Disruption during chemotherapy.....	113
Figure 8.1 Outcomes the practitioners intended to achieve.....	136
Figure 8.2 Pattern and Symptom.....	141
Figure 9.1 Themes from the practitioner data regarding Theory of Change.....	157
Figure 9.2 Diagram to demonstrate the continuous processes in TA.....	161
Figure 9.3 Examples of treatment logs demonstrating variation in treatment.....	163
Figure 9.4 Treatment logs for Mary (1 st and 2 nd treatment).....	165
Figure 10.1 Scale to illustrate differences in my experience of women with EBC.....	175

Glossary of Chinese Medicine Terms

Sources: A practical dictionary of Chinese medicine second edition Nigel Wiseman, Feng Ye 1998 paradigm publications. A Manual of Acupuncture, Peter Deadman, Mazin Al-Khafaji, Kevin Baker 1998 JCM publications. The Practice of Chinese Medicine. Giovanni Maciocia 1994 Churchill Livingstone.

Bian Zheng (zang fu) – pattern differentiation

The processing of information derived from examinations to determine which zang fu are affected by disease and identify changes in their qi-xue and yin-yang aspects. The first step of pattern identification involves identifying the affected zang fu based on the signs and symptoms eg. Heart – the heart governs the blood vessels and stores the Shen (mind-emotion) therefore palpitations or emotional disturbance point to a disease in the Heart-Zang. Once the affected Zang fu has been identified the relative states of yin, yang, qi and xue can be determined from the eight-principles and ten questions. This is of vital importance in treatment. The zang fu are closely related to each other and also to other organs and soft-tissue of the body, understanding the development of the disease or patterns, making a correct diagnosis and determining appropriate treatment are all dependent on a holistic approach. For example, once insomnia has been identified as the result of Heart Xue or Heart Yin xu it is important to determine whether the Spleen or Kidney is also affected since this involvement may give rise to more complex patterns such as Heart-Spleen Xue xu or Heart and Kidney Disharmony.

Biao Ben (Root and Branch)

Primary and secondary aspects of a disease. Root refers to a) the essential nature of the disease, when branch is the signs; b) the cause of the disease when the branch is clinically observable changes in the body.

Disharmony

A function disturbance of any of the zang fu, qi, xue etc. For instance Disharmony of the Stomach Qi - mild upset of the stomach characterized by aversion to food, nausea (rebellious Qi), sleeplessness and abnormal stool.

Eight Methods ba fa

A classification of medicinal treatment methods by Cheng Zhong Ling of the Qing dynasty

Sweating; Ejection; Precipitation; Harmonization; Warming; Clearing; Supplementation/tonification; Dispersion.

Jing-Shen – Essence and Spirit

The Jing-shen is the manifestation of the life-force or a person's vitality in mind and body.

Kidney Qi Deficiency (Kidney Qi Xu) shen qi xu

Weakness of the Zheng qi in the Kidney due to congenital ('pre-heaven') deficiency, or over work or chronic illness characterised by low back and knee ache and weakness and lack of vitality in the essence/spirit of the person. There are other signs as well. Hilary and Debra talk about Kidney deficiency generally as well, this covers Kidney Qi xu, Kidney Yin xu, Kidney Yang xu all suggesting different aspects of a lack of vitality associated with different symptoms all of which will be chronic.

Liver Zang

The Liver Zang governs the free flow of Qi and the making of strategies, or planning. The vitality of the Liver Qi is manifest in the eyes, both in terms of healthy vision to see and to mentally see. The free flow of Liver Qi ensures the free flow of normal mental and emotional activity.

Liver Qi Stagnation (gan qi yu jie – trans. liver qi bound and stuck)

The Liver Qi's function to flow freely is interrupted. This happens when there is frustration or qi is obstructed by damp-heat or there is yin or xue xu. There is a range of signs (mental depression, oppression in the chest and frequent sighing) and symptoms of Liver Qi Stagnation including nausea and vomiting, pain and distension, abnormal bowel movements, pre-menstrual syndrome and menstrual irregularities and it can manifest in as well as being caused by emotional disturbance such as anger, frustration, agitation and impatience and also depression. Over time Liver Qi stagnation will give rise to heat.

Liver and Gall bladder damp-heat (gan dan shi re)

A pattern arising when the Liver's free flow of qi function is impaired owing either to internal damp-heat stemming from excessive consumption of fatty or sweet foods or to externally contracted damp-heat. The main signs are alternating heat and aversion to cold, bitter taste, rib-sided pain, abdominal pain, nausea and vomiting, distension, aversion to food and abnormal stool.

Lung 7 (acupuncture point)

Luo-connecting point of the Lung channel

Confluent point of the Ren channel

Gao Wu point

Ma Dan-yang point

This point has several physical functions such as for acute virus affecting the nose and chest and allergic rhinitis; headache etc. But Debra was referring to using it for someone with grief and another use is that of a releasing effect on the emotions (especially sadness, worry and grief) where there is constraint in the chest.

Qi

There are 12 aspects of Qi definition in the Wiseman dictionary including ‘anything of a particular nature’ such as Yin Qi or ‘any various dynamic of the body’ which could be Zheng Qi, Xie Qi, Shi Qi, Qi of the Zang fu etc. It is also ‘Activity – Qi is highly active; human growth and development as well as all physiological activity and metabolism are manifestations of the activity of Qi’.

Qi Deficiency (Qi Xu)

Weakness of qi, is associated with poor zang fu function, general weakness through illness or overwork, poor diet or damage to yin or xue and in the case of this study, from shock (diagnosis) and chemotherapy. General signs include fatigue, lack of strength, easily sweating for no reason, dizziness, weak voice, breathless and signs on the pulse and tongue. Because Qi is very closely related to Xue, Yin and Yang, there may be more complex patterns than simply Qi Xu. Qi Xu may be related to a particular organ such as Heart Qi Xu or Spleen Qi Xu giving rise to additional signs and symptoms.

Shen (spirit-mind-consciousness)

The Chinese concept of Shen is what makes us conscious and alert during the day and what becomes inactive during sleep – it is the mental capacity to think, the emotional capacity to feel. When there is Shen disturbance the person will not be able to sleep, concentrate, they will have feelings of anxiety or restlessness and may suffer palpitations. All depending on what other concurrent patterns there are.

Spleen (pi)

The spleen has the function of assimilating nutrition from food in the stomach to make Qi, Xue and vital fluids and governs the transformation and transportation of fluids and nutrition. Thus it plays an important role in the formation of qi and xue.

Spleen Qi Xu

This pattern arises from irregular eating or excessive worry or over work and a pattern involving spleen and stomach disharmony would manifest as lack lustre complexion, pale lips poor appetite, abdominal distension after eating, dizziness, quiet and low voice, breathlessness, fatigue and lack of strength, loose stool, and signs on the tongue and pulse. A common symptom of chemotherapy is nausea and vomiting involving patterns of the spleen-stomach disharmony; these participants also suffer from excessive worry and loss of peace of mind.

Spleen 6 (acupuncture point)

Meeting point of the Spleen, Liver and Kidney channels

Tonifies/fortifies the spleen and stomach, resolves dampness, harmonises the Liver and tonifies/supplements the kidney qi, calms the Shen plus more.

Stagnation of Qi (Qi Zhi)

Decrease in the normal activity of qi that is attributed to the obstructive effect of mental and emotional problems, or externally contracted pathogens, xue stasis or qi or xue xu. It is characterised by distension, fullness and oppression in the affected area

Supplement/tonify (bu) – Strengthen (qiang) – Fortify (jian)

To increase or strengthen (yin, yang, qi or xue). Supplement is one of the eight methods and it is used where there is deficiency (xu). It is also a method to restore Zheng Qi so that Zheng Qi can expel Xie Qi – part of the harmonising method in the theory of TCM. There are specific dimensions to Bu fa such as Fortify the Spleen Qi (jian pi); Support (fu) Zheng Qi; Enrich (yu) Yin; Boost (yi) Qi; Strengthen (qiang) Yin; Invigorate (zhuang) Yang;

Xue (blood)

Xue is as important a substance as Qi, Yin and Yang. Xue has additional qualities than what could be described if just saying blood, as it has the nature of Yin.

Xu and Shi (emptiness/weakness and fullness/excess)

Xu is weakness of Zheng Qi, that is the forces that maintain the health of the body and fight disease, whereas Shi is strength of Xie Qi (pathological Qi) or accumulation of substances in the body such as Qi stagnation and Xue stasis or due to something from outside the person such as a virus or in this case chemotherapy (externally contracted disease). Xu (empty) patterns may be due to such causes as weak constitution or damage to the Zheng Qi through chronic illness or repetitive patterns of behaviour and lifestyle (for instance excessive worry or alcohol or over work). Distinction is made between general xu of qi, xue, yin and yang and since these frequently affect specific zang (organs) further distinction is made such as Heart Qi Xu, Heart Xue Xu, Heart Yin Xu, Heart Yang Xu. Mary was cited as having Heart Xue Xu explaining her insomnia and Anne as having Heart Yin Xu to explain her insomnia.

Shi patterns vary according to the location and zang affected thus when there is for instance excess heat a hot pattern emerges; pathology involving heat can be xu or shi (empty heat or full heat) giving rise to different signs and symptoms. In the study Lena is described as having both Xu and Shi heat which Hilary expected the chemotherapy (which generally gives rise to an imbalance of either xu or shi heat because it is experienced as a hot pathogenic influence) to make worse. It was made worse again by the wig, which made her head very hot.

Yin and Yang

Two complementary and opposing principles in Chinese medicine theory that categorise phenomena of like quality and relationship eg. the light and dark side of the mountain – light is associated with heat and dark with cold; daytime is the time of activity and night time of rest. Yin and Yang are interdependent and an ebb and flow relationship is observed eg. day fades into night and night into day so there is a spectrum of relative yin or relative yang.

Zang Fu (organs of the chest and abdomen)

The five Zang are the heart, lung, spleen, liver and kidney. The six fu are the stomach, small intestine, large intestine, gallbladder, bladder and triple burner. The function of the Zang is to produce and store Jing (essence); that of the fu to decompose food and convey waste. Elementary Questions (Su Wen) states: “the so-called five zang store essential qi and do not discharge waste thus they are full but cannot be filled. The six fu process and convey matter and do not store. Thus they are filled but are not full”. The Zang-fu have functions that are physiological and active and metabolic as well as cognitive functions such as the ability to think and concentration or process information. In addition other functions such as the ability to feel or express emotion appropriately. These categories of function were first translated

by the Jesuits, which due to the historical-contextual factors of the time chose words that best summed up meaning then such as words for organs rather than functions.

Chapter One

Introduction to the Thesis

Acupuncture is an increasingly popular complementary therapy widely accessed by people for a wide range of reasons and ill-health symptoms and conditions; at the same time, there remains uncertainty about what it is, how it works and how it might be researched. As a practitioner over this time period I have gone from feeling I have to justify what I do and fend off charges of quackery to realising it rouses fewer derisory stories than being a physics teacher! The main and faintly damning question from interested parties remains the same, '*does it work?*' This of course is a really good question. If only it could be answered to a satisfactory level for all the stakeholders. Other common questions are '*what is it exactly?*' and '*how does it work?*' Having equipped myself with an MSc in Epidemiology I found the methodology to address the effectiveness of '*does it work?*' appealing; the methods and research design offered what appeared an objective and 'scientific' approach to a simple question. However, as was found by other researchers, the question was more problematic than it looked. After venturing even a little way down this path it became clear that it was not possible to start to answer it without first considering the prior questions, '*what is it?*' and '*how does it work?*'

In reflecting on a suitable topic for the thesis I thought about the clients that most moved me in my private practice; and I chose women with breast cancer for a variety of reasons. There was the shock of diagnosis and I wondered if some suffered a mild form of post-traumatic stress disorder. Then there was the battery of problems resulting from chemotherapy and adjustment as many continued treatment with me on and off over a period of years. These women not only moved me, but made me wonder how much the acupuncture really helped and in what ways. It was not known to me how much the breast cancer experience varied, as in private practice it was likely I was only witnessing certain aspects of it, or possibly a limited cohort of women motivated to seek out help and support. Spending time and resources exploring the experience of breast cancer diagnosis and treatment seemed a worthwhile task; especially if it would be possible to illuminate what the main needs and concerns of women are at this time.

In starting to examine what acupuncture is difficulties revolve firstly around what is defined as acupuncture: is it a needle technique or a complex whole system approach where the individual is seen in the context of their life and their history (Paterson and Britten 2004, Wayne et al 2009)? A second set of issues relates to whether the research reflects the

theoretical model of healing, that is, model validity. Does the research into acupuncture take the theories underpinning it into account, and what are the different theories? A common grumble amongst practitioners is that the research conducted bears virtually no resemblance to what they do in practice. If acupuncture research bears little resemblance to practice, there is a risk that any output from acupuncture research cannot be rolled out as a service, or inform practice and findings on effectiveness will have less relevance. Expanding the question from *does it work?* to *what is acupuncture? how does it work? with what effect and for whom?* may aid clarity on how to improve on research done so far.

Acupuncture in Practice

Acupuncture is a diverse and global practice. Originating in China approximately 2,500 to 3,000 years ago, its use has spread geographically and over time. Inevitably as a practice it becomes imbibed by each culture that embraces it. This thesis is concerned with acupuncture as practised in the UK.

There is a formal industry of acupuncture education and professional practice that exists in the UK, with variations in the education of practitioners, in how it is practised and in the theory of healing underpinning the practice (Paterson and Britten 2004, Hughes et al 2007). One approach to addressing the question '*what is acupuncture?*' is to examine how it is understood in theory and practice as explicated by the professional organisations that establish educational standards and regulate practice. Acupuncture in the UK operates within a self-regulatory system and there are several professional associations or registers of acupuncture practice including: the British Acupuncture Council (BAcC), the largest, whose members primarily practice a type of acupuncture called by the BAcC 'traditional acupuncture' or TA; the British Medical Acupuncture Society (BMAS) whose members have a biomedical approach (MA); the Acupuncture Association of Chartered Physiotherapists (AACCP) whose focus is on muscular-skeletal problems; and the Association of Traditional Chinese Medicine (ATCM) whose members are comprised mainly of ethnic Chinese trained primarily in China. The thesis addresses acupuncture as practised by the first two professional organisations as the two dominant groupings in the UK.

Different Theories Underpin Practice

One scientific approach is to examine the theory of acupuncture and how it is hypothesized to effect change. Acupuncture is frequently discussed in the literature as being a single, simple intervention, with a single theory underpinning it. However the various professional bodies representing acupuncture practice suggest otherwise. Each of the associations represents members drawing on different theoretical and philosophical commitments

underpinning their practice of acupuncture. One part of the underlying theory relates to how it is expected to effect change, and how points are selected. For instance, the BMAS adopts a biomedical approach and uses this in the rationale for choosing acupuncture points for specific outcomes. Its form of acupuncture, medical acupuncture (MA), is practised exclusively by those with a biomedical training such as doctors and nurses. The theory underpinning practice will inform not only how to practise, how the practice effects change, and also what kind of change is hypothesised to occur.

In contrast, members of the BAAC draw on a traditional acupuncture (TA) model. This adopts a whole person approach, where treatment is focussed on the person within their own personal, social and cultural context and not the disease (Paterson and Britten 2008). The BAAC accreditation board lists and defines seventeen 'statements of professional values', some of which may be considered exclusive and meaningful only in the context of BAAC members practising TA. Others of these values may be common across professional bodies, for example, the adherence to, and monitoring of personal and professional boundaries which frame 'what is ethical'. And yet others have a similar meaning but are labelled differently. To illustrate this last point Table 1.1 displays the ideas on what 'holistic' means in the TA and MA models, even though holism as a concept is not explicitly described within the BMAS statement, its constituents being implied only.

Table 1.1 Differentiating the concept 'holistic' between TA and MA models

BAC values statement (TA)	BMAS Statement of specific knowledge (MA)	Comment
<i>Holistic - because treatment is based on an understanding that mind, body and spirit are integral, acupuncture can offer the possibility for (re)discovering what it might mean to be fully oneself.</i>	Health, effective functioning and wellbeing. <i>How the psychological and emotional balance of the client may affect their health, effective functioning and wellbeing; the nature of illness and the impact this may have on a client's effective functioning and wellbeing.</i>	Both organisations describe something that could be interpreted as 'holistic'. The BAAC suggest that mind, body and spirit are interrelated and form a whole; whereas the BMAS suggest that health and wellbeing are influenced by the emotional balance of the person.

Table 1.1 illustrates the subtle but essential difference in the approach to treating the person. For the TA approach, there is a direct interrelation of mind and body demonstrated within the theory. Because the TA approach addresses issues of imbalance for the mind and the body simultaneously one effect of acupuncture treatment could be to restore a sense of wholeness to the person. The MA approach is that a knock-on effect of improving physical functioning is an improvement in well-being.

This thesis focuses primarily on aiding understanding of TA as practised by members of the BAAC. Differentiating the theory of TA with another model of acupuncture, in particular MA is used to clarify its definition and expose what the theories of change might be. Defining both the TA and MA model is one essential step in addressing the question of '*what is acupuncture?*'

Acupuncture in Research – Model Validity

Differentiating the detail in the bodies of theory within TA and MA more clearly may contribute to defining each model enabling discussion on what good model validity in acupuncture research would look like. Model validity addresses the issue of the closeness, or otherwise, of the intervention used in research to that delivered in acupuncture practice. The greater the closeness, the greater the potential applicability of acupuncture research to practice. Hence any conclusions that answer the question '*has acupuncture as practised been tested?*' would likely be both more reliable and more valid.

Literature on the issue of model validity for acupuncture (Verhoef et al 2005; Cassidy 2009a, Cassidy 2009b) coupled with the conflicting evidence for effectiveness suggests there is a gap between research and practice. This literature raises questions as to whether acupuncture research design pays attention to the underlying philosophy and theory of healing for the acupuncture intervention being tested. A second aspect is whether the studied intervention is consistent with current practice. In consideration of '*what is acupuncture in practice?*' an understanding of what the professional bodies consider good practice as well as exposure of the theory of change underpinning the practice is necessary. This will also shed further light on the relationship between research and practice for different models. Other questions regarding model validity ask whether the explanatory model is credible.

- Is it reasonable that treatment based on this explanatory model could have the intended effects?
- Do the treatment procedures reflect what is done in practice (Cassidy 2009b, Jonas et al 2005)?

- Does practice flow from the theory of change that underpins the model? Are the outcomes used in the study able to capture the range of effects of the intervention (Long 2002, Mason et al 2002, Paterson et al 2009)?

Ensuring model validity is essential in assessing whether the intervention has had the expected effect in a clinical trial. In order to understand further the theory of how acupuncture effects change, as interpreted and implemented in research and in acupuncturists' practice, making explicit the link between theory and outcomes will allow a better insight into what in the explanatory model is working. Asking the question '*does it work?*' cannot be addressed without understanding what is it that makes it work and to what effect. To answer this question, it is necessary to consider what all the possible component parts to the explanatory model are.

Acupuncture – A Simple or Complex Intervention?

Many resources have been expended on acupuncture trials that still leave an unacceptable level of uncertainty as to what acupuncture is and how effective it is (Smith et al 2000; Verhoef et al 2005; Shekelle et al 2005). This problem is evidenced by the output of systematic reviews that are attempting to evaluate the evidence of efficacy of acupuncture for the treatment of particular symptoms (Birch 2004). The key issue according to Birch lies in the quality of the studies available citing inclusion criteria, adequate treatment, the quality of the control intervention and as mentioned already model validity.

The premise of much of the acupuncture research conducted to date implicitly perceives acupuncture as being a simple intervention. Acupuncture in research tends to take the form of a fixed-point prescription, akin to a recipe, which stays the same at each treatment, and if successful, produces change in the single outcome measure. Given the desire to reduce non-specific effects, agency on the part of the practitioner is deemed to be negligible. Building on Rogers (2008) helpful differentiation of the notions of simple, complicated and complex in the wider context of evaluation, Table 1.2 aims to demonstrate the difference between acupuncture as a simple (akin to a recipe) and a complex (akin to raising a child) intervention.

Table 1.2. Researching Acupuncture as a Simple and Complex Intervention

<i>Simple: following a recipe</i>	<i>Complex: effecting change in a complex outcome</i>
<i>Using acupuncture as a simple intervention: Acupuncture treatment as a recipe for acute back pain</i>	<i>Using acupuncture as a complex intervention: Doing pragmatic research on TA for chronic fatigue</i>
The acu-point recipe is essential (and could be drawn from different theoretical approaches i.e. MA or Trigger* point work)	Formulae have a limited application as with a whole person, individualised approach with a multi-dimensional outcome, treatment will vary
Recipes are tested to assure easy replication	The process of approach can be replicated but the choice of points will vary according to a differential diagnosis
No particular expertise is required but experience of point location increases success rate	Expertise can contribute but is not a guarantee of success as other (unknown) variables may effect change
Recipes produce standardised results	Each treatment is unique and individualised producing variable results
The best recipes give good results every time for relief of acute back pain	Uncertainty of outcome remains

*Trigger point acupuncture is mainly used for musculoskeletal complaints

Different theoretical models of acupuncture may lie at different points on this spectrum of simple to complex. For instance, as in the 'simple' column, treating acute back pain may have a more simple approach whatever the acupuncture model. This may in part be because the ways that acupuncture may bring about change in acute back pain is much more straightforward than for something multi-dimensional such as chronic fatigue. The above table does not preclude the TA approach from being useful for treating acute back pain, but it suggests that the MA approach is much simpler to follow through, both in research and practice. The TA approach has the capacity to treat acute and chronic conditions as the focus is more on the person where the signs and symptoms of illness are reflections of imbalances within the whole person. For an individual with a multi-dimensional problem such as chronic fatigue, multiple outcomes with the TA approach are in theory possible. In research, the MA model has appeal because it is more easily reproducible, as its validity depends on the plausibility of the theory of change. Much of current research already purports the notion that TA is a complex intervention (Paterson et al 2004, Hughes et al 2007, MacPherson et al 2006). This is reinforced by my personal experience in encountering medical professionals both informally and in giving talks on acupuncture, namely, that the idea that TA is a complex intervention is not a given.

Finding an Appropriate Methodology

Whether TA is a complex intervention or not is important when thinking about what the appropriate criteria and methods to evaluate it and what the appropriate outcome measures to assess change are. If there is a desire to test a causal hypothesis as in an explanatory trial then that causal hypothesis has to be laid bare including the possible ways that may bring about or can explain change. If there are multiple components to an intervention, and multiple outcomes and other contextual factors that are unpredictable or uncertain, it becomes much more difficult to isolate causal relationships and test them. Regarding TA, if a whole person approach leads to a range of outcomes the question arises of how it is possible to attribute change to the intervention and what defines the intervention?

Early Breast Cancer as a Complex Exemplar

The focus in this thesis is to attempt to uncover what acupuncture, most especially TA, is and what its component parts are. To take this forward in a feasible manner, it is important to select an illness where patients may experience multiple or complex outcomes. Early breast cancer (EBC) is one such case. It was chosen as an exemplar for two reasons. Firstly diagnosis of EBC generates a complicated scenario, as other illness and/or 'side effects' may be more induced by treatment at the early stages than by the disease. This complexity is added to by the introduction of a life-threat. EBC as an exemplar provides the backdrop to explore the full capacity of TA as a whole person approach where there are likely to be multiple and complex outcomes. Secondly, this work provides a starting point to explore whether acupuncture is a suitable and acceptable supportive intervention for EBC. As mentioned earlier, beginning an examination of any possible value to women with EBC to receive TA is part of the purpose of this thesis.

Theory of Change

The argument for TA being a complex intervention is important when designing research trials. The Medical Research Council's (MRC) updated guidelines (Craig et al 2008) for the evaluation of complex interventions are helpful in delineating the issues of complexity regarding TA. The MRC guidelines argue that *'the greater difficulty in defining precisely what exactly the "active ingredients" of an intervention and how they relate to each other, the greater the likelihood that you are dealing with a complex intervention'*. Questions include *'how does it work?' 'what are the 'active ingredients'?' and 'how are they exerting their effect?'*. These questions are raised in the guidelines as part of the process of developing and evaluating complex interventions in health care. They provide a departure from the gold

standard of randomised controlled trials which assume there is just one active ingredient that causes change and all other non-specific effects can be isolated, discounted and controlled.

The MRC guidelines suggest that developing or understanding the '*likely process of change*' is a key task and that being able to describe this theory to allow for replication of the study is important. Different theoretically driven approaches to acupuncture are experienced differently by participants with different outcomes (Paterson and Britten 2008). The context, that is, the setting of the delivery of the intervention plus the life-world for the individual and other socio-economic factors will affect the outcome. During a treatment that takes place over time, it is inevitable that accumulated change will be wrapped up in these contextual factors as well as other processes such as the therapeutic relationship (Oakley et al 2006).

One approach to developing an understanding of how a complex intervention might work is to uncover the underlying or implicit '*theory/theories of change*' over how the intervention might work and in what circumstances. The theory of change approach to evaluation, developed within the context of community change initiatives, focuses on understanding the way an intervention works and how it might bring about change (Weiss 1995, Anderson 2005). Applying the theory of change approach, as presented in programme theory, to acupuncture may aid clarity on the causal pathway - from underlying theory, to theory as practised within the client-practitioner encounter and desired and achieved outcomes. For MA the causal pathway is presented as if it were linear, with a direct link from needling to outcome for example: changes in pain levels are brought about through stimulation of acupuncture points in order to increase endogenous endorphins (White 2009). In TA, the causal pathway is non-linear with degrees of uncertainty at each stage of treatment. A fundamental question is thus whether research on acupuncture is predicated on the understanding of these different theories of change?

Research Aim

The overall purpose of the thesis is to deepen understanding of the theory and practice of TA and the ways in which TA may affect change, using EBC as an exemplar

Research Question:

What is the theory of change for TA, as articulated in the professional training, explored in research and as experienced by women with EBC?

Specific Objectives:

1. Map out the current knowledge of the experience of EBC.

2. Explicate the theory underpinning models of good practice of TA in contrast to MA by exploring the professional theoretical framework.
3. Draw out the theory of change for published clinical studies of acupuncture for selected outcomes by applying the framework of the TA and MA models.
4. Provide background detail to the thesis by reviewing the literature on TA regarding processes and outcomes as reported or experienced by patients and practitioners.
5. To undertake an intervention study:
 - i) To explore women's experiences of EBC and provide some context within which the TA is introduced as an intervention.
 - ii) To understand how practitioners theorise TA and what their intended outcomes are.
 - iii) To gain insight into how women experience TA and explore outcomes as experienced or valued by the women participants.

Structure of the Thesis

This thesis is exploring TA as a complex intervention. In order to establish the theory of change for TA, it needs to be studied in practice, where a whole person approach is utilised. Prior to that, further light will be shed on the theory of change by exploring existing research literature on TA.

The first step in this thesis is to establish EBC as a complex exemplar. Chapter Two will focus on both the medical view of EBC; firstly a summary of the epidemiological data is provided to examine what outcomes are considered relevant by the research community. These outcomes are later used to further explore published studies of acupuncture. A review of the qualitative literature is then presented to scrutinize further the idea of EBC as a complex mixture of problems for the individual. The methodology employed in this research needs to be able to expose the theory of change for TA. The methodology also needs to be able to observe change over time, and to explore what effects the TA approach is intended to have and how these are experienced by recipients. The methodological approach and methods employed are outlined respectively in Chapters Three and Four. Chapter Four relates the initial development of the theory of change (ToC) framework using information from the professional accrediting body of the British Acupuncture Council (BAcC) and, by contrast, the Medical Acupuncture Society. It also describes the methods used in conducting the two literature reviews and the longitudinal study. Grounded theory methods are used to analyse the data from the longitudinal study and this process is described in detail.

Two theoretical models (TA and MA) will be examined in detail in Chapter Five with a view to illuminating their contrasting theories of change and hypothesized causal pathway. This is done by applying the ToC framework developed in Chapter Four from the theory to selected research studies of acupuncture and symptoms that are commonly experienced by women with EBC, as outlined in the epidemiological findings in Chapter Two. Chapter Six reports on the second literature review of TA using qualitative methods to discover further the patient and practitioner perceptions of TA. Consideration is also given to the possible implications for the thinking within the ToC framework when discussing the findings from this literature.

The complex EBC experience of sudden change and illness through treatment, taking place over time is described in Chapter Seven; this chapter provides the contextual background within which the acupuncture intervention is delivered. Chapter Eight presents the findings on outcomes from the longitudinal study both outcomes that the practitioners are trying to achieve and perceptions of benefit experienced by the EBC participants. Chapter Nine extrapolates further the ToC for TA, by offering the analysis of the triangulated data from the practitioners, including treatment logs, diaries and in-depth interviews.

A reflexive approach is essential to aid rigour if using an interpretive research design and this is detailed in Chapter Ten. The journey from practitioner to practitioner-researcher is outlined with examples taken from the interviews with participants. This chapter also includes a counter case. Finally, Chapter Eleven provides discussion on the thesis, reflecting on the research question and the degree to which it is addressed by the findings; what further research might be necessary or useful. Strengths and shortcomings in the design and deployment of the thesis are offered. A refined theory of change for TA is presented after discussion regarding all the findings from the literature reviews and the longitudinal study.

What might this PhD add?

This thesis will contribute to the debate on what traditional acupuncture is in research and practice; and for this purpose at times TA will be usefully contrasted with MA. Using the theory of change is a novel approach and provides deeper understanding of what research designs are suitable for different models of acupuncture and for different outcomes. This in turn may improve model validity in acupuncture research where findings are made more valid and reliable. Doubts still exist regarding whether acupuncture can be considered a complex intervention, this approach it is hoped will illuminate it as such further. Examining the practice of acupuncture for a complex condition, at an acute stage, may enhance

understanding of the processes involved and what the theory of change is in a real world setting. Using EBC as an exemplar will provide an opportunity to further expand knowledge on the experience of women as they undergo diagnosis and treatment. This will also illuminate what the outcomes, needs and concerns are of women at this time and whether acupuncture might be considered an acceptable supportive intervention.

Chapter Two

Early Breast Cancer as a Complex Exemplar

Introduction

This chapter sets out to provide the rationale for the use of early breast cancer (EBC) as an exemplar for the exploration of the theory and practice of TA. The chapter begins by providing a brief explanation of what EBC is, drawing attention to it both as an acute and chronic condition, and its existential implications, in that it poses a life threat; and the different forms of treatment for EBC. The chapter continues by showing how EBC is a complex medical condition. There is a wealth of literature about not only the multiple symptoms that characterise it but the fact that these also occur in clusters or combinations that vary over the illness course and of which some also are a consequence of the treatment. This literature search points to cancer related fatigue (CRF) as being the most prevalent and problematic symptom.

EBC is additionally complex due to little understanding of any physiological mechanism for CRF thereby making treatment for it elusive. Other symptoms, including emotional distress, hot flushes, night-sweats and insomnia, are frequently clustered together creating a situation that is universally regarded as complex. EBC has impact on the psychological, emotional and physical health of the person and these aspects are interrelated in complex ways and they interact. To further illustrate the complexity of EBC, the next and final section explores an additional, qualitative literature about the meaning, significance and consequence of EBC as illness that also encompasses social, psychological and existential dimensions that vary depending on the stage in the illness trajectory. The unfolding process of change in time is an important consideration at this stage of the illness trajectory and thought is given as to how time is used as a heuristic within the qualitative literature.

Background

Breast cancer is by far the most common cancer in women, accounting for nearly a third of all new cancers for women; a woman has a one in eight chance of a breast cancer diagnosis in her lifetime. The stage of breast cancer takes into account the size of the tumour, whether it has spread to the lymph nodes or other parts of the body (metastases). Other factors will influence treatment, for instance, if a tumour is rich in Her2 protein this will make it potentially receptive to biological treatment such as *Herceptin*. This study is focused on non-

metastatic, early breast cancer where adjuvant chemotherapy is recommended after surgery. Needing adjuvant chemotherapy for EBC means one or some of the following:

- The lymph nodes under the arm contained breast cancer cells
- There is a large primary cancer in the breast
- The breast cancer cells were high grade (grade 3)
- The cancer cells did not test positive for hormone receptors and so are not likely to respond well to hormone therapy

Within the literature breast cancer is argued to be a chronic illness, with acute episodes (Tritter and Calnan 2002), but it has existential features due to the diagnosis often being interpreted as a death sentence. It is a generic label and can mean different courses of treatments, outcomes and experiences. There is a wealth of literature on cancer survivorship, and as new treatments continue cancer is increasingly viewed as a curative condition with chronic features. EBC as an acute illness is less reported and despite new treatment, the path of disease is uncertain as is the potential for disablement or even death; in 2011 there were 11,556 deaths from breast cancer (Cancer Research UK, 2011).

Early treatment involves firstly surgery to remove the tumour, (a lumpectomy or mastectomy depending on the size and position of the tumour), then chemotherapy with or without radiotherapy, followed by adjuvant hormonal therapy, such as *Tamoxifen* or biological treatments such as *Herceptin*. This means that treatment for breast cancer can last in total for four or five years. A common chemotherapy regime for women in routine practice is Epi-CMF. Epirubicin is given for three or four cycles of chemotherapy and then Cyclophosphamide, Methotrexate and Fluorouracil are given together for the second half of treatment. The whole chemotherapy treatment cycle can last approximately six months. The course of breast cancer treatment likely to be experienced by women recommended to have adjuvant chemotherapy (non-metastatic) is pictured in figure 2.1. Treatment from diagnosis including surgery, chemotherapy and radiotherapy usually takes about one year. Additional treatments such as *Herceptin* and *Tamoxifen* will continue for a further three or four years; meaning that some women will experience a daily reminder of their diagnosis for five years.

Figure 2.1 Order of treatment of early stage breast cancer patients

Time point →	< 4 weeks after diagnosis →	Up to 24 weeks →	Usually for 6 weeks →	Usually for 3 years →	5 years after diagnosis
Diagnosis	Surgery	Chemotherapy	Radiotherapy	Endocrine therapy	Survivor
←— Approximately one year —→					

Early Breast Cancer as a Complex Medical Condition

Within the medical focus, having a diagnosis of EBC and in need of chemotherapy means several things. As a result of diagnosis and surgery an individual will likely have many hospital visits, frequent blood tests, anxious waiting for results or for chemotherapy treatment to begin. With chemotherapy there is also an increased risk of infections as the immune system is compromised. The focus of a considerable section of the research community is on the symptoms and side-effects of treatment for women during this time phase of the illness. To gain insight into the nature and form of these side-effects, a scoping search (Davis et al 2009) of the literature was undertaken, exploring three databases (EMBASE, OVID and PSYCHOinfo) from 1990 to 2008, along with a further search on individual outcome measures commonly used in trials (see Appendix I for search terms).

As mentioned in the introduction, the literature search revealed that the most prevalent symptom appears to be cancer related fatigue (CRF). A description of the literature relating to CRF and other symptoms commonly clustered follows. This provides an overview of the symptom experience for a large proportion of women at some point during the first year after diagnosis. It reveals the interconnectedness of symptoms or symptom clusters.

Cancer Related Fatigue (CRF)

CRF has been best described by Mock *et al* (2000, page MS-2) as a '*persistent, subjective sense of tiredness related to cancer and cancer treatment that interferes with usual functioning*'. Currently, there is agreement in the literature that it is the most prevalent and important symptom for cancer patients. Although CRF is multi-dimensional, the mechanisms of CRF are unknown (Ryan *et al* 2007) and there is a dearth of ideas on what to do about it. There is no doubt that a significant proportion of breast cancer patients report an unacceptable level of fatigue which impacts on quality of life.

Two important qualitative studies that have contributed to the debate on CRF are Glaus *et al* (1996), who interviewed 20 cancer patients and 20 healthy volunteers, and Richardson and Ream's (1996) study of over 100 cancer patients interviewed before and after a cycle of chemotherapy. Glaus *et al*'s (1996) study helped define CRF, finding a difference between physical, cognitive and affective fatigue that were worse in the cancer group, 85% of whom were undergoing active chemotherapy (but not necessarily for breast cancer). Glaus *et al* (1996) identified that physical fatigue was worse than cognitive and affective fatigue in this group of patients, a finding repeated in subsequent studies. Richardson and Ream (1996) were able to demonstrate differences in feelings of 'tiredness' which were considered normal from feelings of fatigue ('*absolutely exhausted and absolutely drained*'), and that fatigue did not abate with sleep or rest, a feature (or phenomenon) that has been reported frequently since; 89% of the sample reported fatigue during chemotherapy.

A number of studies have measured the prevalence of CRF prior to chemotherapy, usually after diagnosis and surgery (Cimprich *et al* 1999, Jacobsen *et al* 1999, Kumar *et al* 2004, Bower 2005, Andrykowski *et al* 2005). These studies enabled examination of how CRF changed during treatment (it got worse and was experienced by more people), and that not all CRF was attributable to chemotherapy. CRF was also worse for women due to receive chemotherapy and radiotherapy rather than radiotherapy alone suggesting a mechanism associated with the diagnosis more than treatment (Donovan *et al* 2004).

During chemotherapy the amount of time each day patients experienced fatigue increased over time (Jacobsen *et al* 1999, Kumar *et al* 2004). Jacobsen *et al* (1999) study showed that just as pain, sleep problems and emotional upset continued to be strongly associated with CRF during chemotherapy, additional symptoms of nausea/vomiting, mouth sores, and chills were added to the list. Longman *et al* (1996) found 83% of the large sample describe CRF as being the most problematic with pain (60%) and difficulty sleeping (59%) following closely behind. As several of these studies indicated, CRF does not occur singly or in isolation, rather it occurs as one component of a cluster of symptoms that together exacerbate distress.

Symptom Clusters

It is apparent from exploring the literature on breast cancer that symptom clusters emerge that are difficult to understand or separate out. Jacobsen *et al* (1999) as with several other studies found no associations between CRF scores and type of surgery or stage of disease, or necessarily age; but pain, sleep problems, psychological distress and difficulty concentrating were strongly associated with pre-treatment CRF. These symptom clusters

loomed again in other studies (Bennett *et al* 2004, Fleishman 2004, Bender *et al* 2005). It is perhaps not surprising that strong correlations between CRF and sleep problems have been found (Carpenter *et al* 2001, Roscoe *et al* 2002, Haghghat *et al* 2003, Schultz *et al* 2005, Berger *et al* 2007). Although CRF is related to sleep/wake cycles (Ancoli *et al* 2001), the length of time in bed did not reduce fatigue. By measuring circadian activity, Berger *et al* (1999) were able to show an association between disrupted sleep and increased CRF. An interesting finding (Berger *et al* 1999, Ancoli *et al* 2010) was that sleep was already disturbed and CRF already present prior to chemotherapy. All studies that measured sleep patterns found a strong association with CRF, and a substantial proportion of breast cancer sufferers reported disturbed sleep. Roscoe *et al* (2007) provided a review of papers that discussed the association of sleeplessness for cancer.

Patients with measurable CRF were more likely to report psychological distress (Bennett *et al* 2004); but although other studies also showed an association, CRF was not explained by psychological distress (Jacobsen *et al* 2003, Bower 2005). Haghghat *et al* (2003) found in their sample that more patients were anxious (32%) than depressed (16%) despite reporting high levels of insomnia, pain and CRF. In Ferrel *et al*'s (1996) study, anxiety and psychological distress were reported as being of more importance than physical concerns. Hoskins *et al* (1997) also described CRF and psychological distress as being the most pressing issues. In Okuyama *et al* (2000) although depression and anxiety were associated with CRF, mental adjustment to cancer was not. In seeking somatic symptoms to diagnose depression (Akechi *et al* 2003), CRF and sleep disturbances were found to be poor guides. While Bower *et al* (2006) found that pain and depression could predict CRF, only 45% of the variance in CRF could be accounted for with all the predicting variables, including treatment. In an attempt to unearth any link between depression and CRF, two studies found that when groups were randomly assigned to placebos or anti-depressants depression scores reduced but CRF did not (Morrow *et al* 2002, Roscoe *et al* 2005). This suggests that the mechanisms linking CRF to other cluster components are not understood, and the relationships are neither clear nor straightforward.

These studies have so far involved symptom clusters of CRF, insomnia, psychological distress and depression. Several of these studies also mentioned additional symptoms such as sore mouth or nausea increasing the suffering for women with EBC. Inevitably many women experience an increase in vasomotor symptoms as chemotherapy will often bring forward or worsen the symptoms of the menopause and the mean age in many of these studies is the prime menopausal age. Fan *et al* (2005) found that menopausal status increased in the chemotherapy group from 30% to 84% compared to age-matched controls (32% to 46%) during the 2-year time period of treatment. Several studies reported clusters

of vasomotor symptoms, disturbed sleep and CRF (Stein et al 2000, Fan *et al* 2005, Downie *et al* 2006). Comparing cognitive function with pre-chemotherapy and post-chemotherapy groups and healthy controls revealed that cognitive deficits were worse during treatment and remained compromised after completion of treatment compared to the control group (Wieneke et al 1995, Schagen *et al* 1999, Brezden *et al* 2000, Janelins *et al* 2011). Two longitudinal studies also suggested a decline in cognitive function due to chemotherapy (Wefel *et al* 2004 and Shilling *et al* 2005) and for a subgroup of survivors the effect was long-term (Ahles *et al* 2002).

This summary of a review of the epidemiological literature reveals key gaps in understanding and demonstrates that EBC is a complex medical phenomenon. The major symptom is CRF, especially during chemotherapy but as CRF is multi-dimensional and the biological mechanisms are unknown finding interventions to prevent or ease CRF are problematic. Symptom clusters are an even greater problem as multiple strands of side-effects and symptoms create multi-dimensional effects for the individual. More understanding of symptom clusters may lead to outcome measures that capture the totality of the experience.

Exploring the Experience of Breast Cancer

So far, focus has centred on exploring EBC from a medical perspective where experiences are intended to be captured by validated, simple outcome measures. This has shown that women experience a range of problems; but problems are unlikely to be confined to purely medical symptoms. Aside from the life-threat of cancer, diagnosis comes suddenly and out of the blue. The qualitative literature, can offer a broader understanding of the lived experience of EBC from the perspective of women themselves: in its meaning, significance and consequences as expressed through women's narratives; and in how researchers theorise it. Moreover, given that this stage in the illness trajectory from diagnosis and through treatment proceeds at a rapid pace, the process whereby women make sense of the experience in time, as they journey through this early stage in the illness trajectory, requires attention. This has implications for method (how and at what critical time points do studies capture the process of change); and theorising the dynamic nature of the experience.

To explore these issues, a systematic search of the literature for qualitative studies focussing on the first year after diagnosis, including chemotherapy, is reported here. Studies were included if they used qualitative methods, included data collected within the first year following diagnosis, for women with EBC who also were receiving chemotherapy (see Appendix I for search terms). Selected papers were examined using an evaluation tool purposefully designed for qualitative studies (Long and Godfrey 2004). Data were extracted

and described according to categories such as 'phenomena under study' or 'data collection' and evaluated according to the appropriateness or validity or other quality markers. Table 2.1 displays the included studies, phenomenon and an evaluative summary.

These eleven published studies display a range of key findings. They had different aims which directed data collection and analysis and varied also in their conceptual clarity and methodological quality. For instance, Beisecker et al (1997) set out to explore coping strategies immediately after chemotherapy but coping as a concept was not discussed at all. In addition grounded theory was described as being used half way through the study and little information was offered on negative cases. Moch (1990) stated at the outset that illness was an opportunity for growth but the cases where this did not appear to happen were not discussed; it appears for this study that the findings were used to confirm the theory of *expanding consciousness* rather than employed as a point of discussion. Another example of failing to comment on a primary aim was Browall et al (2006) where age was not discussed explicitly as part of the context even though the focus was on post-menopausal women.

Overall, most of the studies offered a descriptive analysis; very few developed a discussion on concepts and consequently failed to draw on what is already known in both the cancer and chronic illness literature. McCann et al (2010) discussed in detail *biographical disruption* as the frame for analysis and *transition* as the key finding but provided little detail on the analytic process or disconfirming cases. Most importantly, time as a factor in the experience and analysis is largely ignored with the exception of Richer and Ezer (2002) who offered an insight as the participants moved through a process in time; and with Frith and Harcourt (2007) who used photography as a method to capture change.

Table 2.1 Selected studies, phenomenon and evaluative summary

Study	Phenomenon	Theoretical Context	Analysis	Key Findings	Evaluative Summary
<p>Moch 1990</p> <p><i>Health within the experience of breast cancer</i></p>	<p>To explicate the concept of health within illness by describing the experience of women diagnosed with breast cancer. Illness is an opportunity for growth therefore it is called '<i>health within illness</i>' or '<i>expanding consciousness</i>'</p>	<p>Phenomenology and emerging methodology.</p> <p>Crises brought about by an illness provide an opportunity for growth and development. Moch used Newman's theory of health as expanding consciousness as a framework.</p>	<p>Thematic analysis using constant comparative methods. Participants were asked to offer feedback during the analysis process.</p>	<p>Three themes are described: <i>a) changing relationships with others b) identifying meaning in the illness, c) adding new perspectives about life.</i> Moch suggests there is a shift of emphasis from '<i>fighting the enemy of illness</i>' to '<i>learning about oneself through the illness experience</i>'</p> <p>Expanding consciousness was the concept through which the analysis was framed; essentially health and continuing health is viewed as a process of '<i>expanding consciousness</i>'</p>	<p>The author explained the research process and rationale in detail and reflexively accounted for the analysis. It is possible that there is greater emphasis on perceived positive findings: for instance expanding on the theme of '<i>increasing richness in relatedness</i>' but saying very little about '<i>increasing distant/disconnectedness and fear from others</i>'. This suggests the author was looking for evidence of '<i>expanding consciousness</i>' or some kind of positive benefit.</p>

Study	Phenomenon	Theoretical Context	Analysis	Key Findings	Evaluative Summary
<p>Hilton 1996</p> <p><i>Getting back to normal: the family experience during early stage breast cancer</i></p>	<p>The process of normalisation and the challenges and problems faced by families</p>	<p>Explicating the meaning of normal for families with a member who has cancer, and managing getting back to normal. This paper could have offered a more detailed review of the ideas around 'normalising' illness</p>	<p>Five semi-structured interviews with 45 women and their families. Data analysed using grounded theory.</p>	<p>The author wanted to establish how important getting back to normal was for families; including what challenges and aids the families experienced in this process of normalisation. There is a discussion on trajectories. The author considers that for those families successful in returning to normal, Dorsett's recovery trajectory better fits the findings. Corbin and Strauss' (1992) illness model more accurately encompasses the experience of those that were not coping. <i>Transition</i> is also mentioned.</p>	<p>A major finding is that keeping things normal helped families maintain a positive outlook. In order to 'keep things normal', women sometimes did not seek support; keeping things normal may interfere with adjustment. The author discusses the illness trajectory (Corbin and Strauss 1992) and recovery model (Dorsett 1992).</p>
<p>Beisecker et al 1997</p> <p><i>Side effects of adjuvant chemotherapy: perceptions of node-negative breast cancer patients</i></p>	<p>To explore the side-effects and coping strategies of node-negative women with breast cancer immediately after chemotherapy and six months later.</p>	<p>No theoretical framework is reported.</p> <p>Chemotherapy appears to present problems and may continue to do so long after it has finished.</p>	<p>Analysis was initially started using coding according to various theories of coping but this changed to grounded theory. 3 researchers conducted the analysis and report that '100% consensus' was reached regarding any discrepancies on coding.</p>	<p>Side effects are ranked by patients. Emotional problems are ranked high but are not evident to women during treatment. Fatigue and weight-gain continue to be a problem and experience did not match expectation of recovery at time 2. Authors consider that emotional problems due to chemotherapy may be independent of emotional problems due to diagnosis. The central frame to this study is decision-making.</p>	<p>There may be some reservation regarding the findings as the methodology was not made explicit. Coping strategies were part of the research question but no detail is offered in the paper on coping theories and it is not developed as a concept. The authors report that the coping strategies used by participants 'were not innovative or creative' suggesting that there was an implicit expectation of the participant experience.</p>

<p>Charles et al 1998</p> <p><i>Doing nothing is no choice: lay constructions of treatment decision-making among women with early stage breast cancer</i></p>	<p>Shared-decision making is explored as a phenomenon.</p>	<p>A qualitative descriptive case study. Data collection and analysis cites several authors including Charmaz. 'Meaning-seeking' is described. The theory maybe more in the doing than in the description.</p>	<p>Described in detail and based on grounded theory. Some data was compared to a second study being undertaken by the same team with a different cohort of patients (and different aim). Audit trail of data and coding transparent. Use of raw data</p>	<p>Explores decision making and concludes that '<i>doing nothing is no choice</i>' in relation to choosing whether to have treatment and these decisions were framed as right or wrong. Some women felt they could beat the odds; or compared themselves with friends/relatives with the same disease. Participants wanted shared decision-making with their oncologist. The central theme is <i>decision-making</i></p>	<p>This study is a qualitative exploratory study, the framework for which is grounded theory. The framing of the question, data collection and analysis all appear to be done to a high standard; there is no reflexivity but a secondary analysis by a co-investigator and discussion with the research team contributes to rigour.</p>
<p>Landmark et al 2002</p> <p><i>Breast cancer and experiences of social support</i></p>	<p>How BC women experience '<i>social support</i>' (sources of emotional, practical help and information from professionals and personal relationships at work or home)</p>	<p>A description of what social support means and how it might be relevant to BC sufferers is offered. Social support 'strengthens the individual' and may help in 'coping with cancer'</p>	<p>Grounded theory was used to conduct in-depth interviews with 10 women and the topic guide is described. Analysis is described in detail by two researchers</p>	<p>Social support and relationships are described in positive or negative terms; women who have a stronger social network are more able to cope.</p> <p><i>Social support</i> is framed as being present or absent and is related to how women <i>cope</i> but <i>coping</i> as a concept is not explored. Maintaining identity is mentioned as being dependent on informal social support</p>	<p>Social support is given added depth to its definition; the authors link the lack of it to less coping with cancer. The authors report both negative and positive experiences, from all aspects of social interactions for the BC sufferer. They discuss the reactions of others to the individual more than the other way round. This is a relevant study in that it relates the quality of support to the self-esteem and coping ability of the individual.</p>

Study	Phenomenon	Theoretical Context	Analysis	Key Findings	Evaluative Summary
<p>Richer and Ezer 2002</p> <p><i>Living in it, living with it, and moving on: dimensions of meaning during chemotherapy</i></p>	<p>To explore the meanings assigned to the experience of receiving chemotherapy</p>	<p>This is a descriptive exploratory design.</p> <p>The concept of meaning is explicated</p>	<p>Analysis was reported to have been conducted using grounded theory by two researchers. Categories were corroborated with both participants and nurses in the oncology clinic.</p>	<p>The authors report on three dimensions or stages of living with cancer with sub-categories within each dimension: <i>'Living in it a) side effects make the cancer real, b) my body – friend or foe? c) applying things learned in the past.'</i> The data supports both negative or difficult experiences as well as positive ones.</p> <p><i>Meaning</i> as a concept is explored. The data is collected over time, and <i>time</i> as a concept is present as the findings give a sense of participants moving through their experience as a process</p>	<p>This study is valuable because of regular interviews conducted with participants during the course of chemotherapy. Reservations include a lack of a reflexive approach given that nurses in an oncology setting conducted the interviews with participants while they were receiving chemotherapy.</p>

<p>Boehmke and Dickerson 2006</p>	<p>The authors raise two questions: what are the common experiences, and how do perceptions of diagnosis and treatment affect the symptom experience.</p>	<p>This is described as an '<i>interpretive phenomenological approach to uncover common meanings in narratives.</i>' The rationale is that nurses interpreting the narratives of women will gain insight and understanding of their experience.</p>	<p>Analysis is described as a seven-stage hermeneutical process by the research team. This is a secondary analysis of recorded interviews of women receiving their last cycle of chemotherapy; this secondary analysis was undertaken once the first was complete when the research team realised that symptom distress was affected by individual perception.</p>	<p>Four themes a) <i>changing health overnight</i>, b) <i>erasing of a former self</i>, c) <i>appraising of illness</i>, d) <i>approaching the future – now what?</i> The authors report that women experience a dramatic change after diagnosis; how they are mentally affected by this in turn affects how they experience symptoms and side-effects.</p> <p><i>Transition</i> is in the title - the critical point of change is seen as diagnosis: participants are looking back as the single interview point is at the end of chemotherapy.</p> <p>The authors report that <i>uncertainty</i> is also present because of the surprise of cancer and how the body had '<i>betrayed</i>' them but this link between the concept and the data is not explicated deeply.</p>	<p>This is a good quality study in terms of the relevance of the question, the data collection methods and analysis. The study raises important issues regarding the needs of this group. This study is based on secondary analysis – a reflection on how the interviews might have been different with a different topic guide is not offered.</p>
<p>Browall et al 2006</p>	<p>To explore the experiences of post-menopausal women who undergo chemotherapy treatment for BC.</p>	<p>Older women may experience BC treatment differently. The authors justify the use of qualitative methods to '<i>capture what is unique in patients' experiences</i>'.</p>	<p>Content analysis is used by two researchers of the 20 open interviews conducted and is described in detail. The authors use raw data to offer examples of themes.</p>	<p>Four themes are described: <i>fear of the unknown; effects on body and mind; to get by; a transformed life</i>. The authors conclude that women experience a journey from fear of the unknown to a transformed life with a straight path from negative to positive experience.</p>	<p>This is an interesting study but the discussion suggests a linear process of moving from negative through to positive (transformative) experiences. The interviews were conducted once yet the results suggest the description of a process through time. The authors barely refer to the effect of age, which was part of the primary question.</p>

Study	Phenomenon	Theoretical Context	Analysis	Key Findings	Evaluative Summary
<p>Frith and Harcourt 2007</p> <p><i>Using photographs to capture women's experiences of chemotherapy: reflecting on the method</i></p>	<p>Examines the value of using photographs as a method for generating health-related narratives. This is in relation to women's experiences before and after chemotherapy regarding how they felt about their physical appearance.</p>	<p>Photo-elicitation as a method to access accounts of 'psycho-social phenomenon'. No other detail is given as to the methodological framework for the question or data collection.</p>	<p>There was no detail given on any analysis of the process; the bulk of the study is a descriptive account of the method but includes some raw data. Participants were interviewed before and after chemotherapy and in between given a camera to take photos of anything that might mean something to them in capturing their experiences.</p>	<p>Using photography as a medium of expression and exploration is a useful method and enables the capturing of events over time. It also provides women with a sense of control during the research process</p> <p>This study is primarily about the method of using photography and in part, to capture change. Although the study is about the method, capturing change over time and the temporality of the experience is part of the findings.</p>	<p>This is an interesting study that uniquely captures changes over time by providing the participants and researchers with photographs as points of interest or resources for recall in the follow up interviews. The researchers are frank in reporting that the study may only appeal to a select group (those interested in taking photographs). It is lacking in detail regarding approaches to data collection and analysis, which renders it less valuable than it might otherwise have been. The authors also report that photographs could not capture the emotional distress experienced by women in their study.</p>

Study	Phenomenon	Theoretical Context	Analysis	Key Findings	Evaluative Summary
<p>Ching et al 2009</p> <p><i>Reframing: psychological adjustment of Chinese women at the beginning of the breast cancer experience</i></p>	<p>Coping process in Chinese women. 'The purpose is to explain the process of psychological adjustment of Chinese women to breast cancer.'</p>	<p>The authors explain in detail what is known about coping and cancer; and state they wish to explore what cultural differences and other context factors might exist</p>	<p>Grounded theory is used and explained in detail. This is the only study that offers a substantive theory as a result of using grounded theory.</p>	<p>Women were considered as four 'types', and those that coped well had '<i>underestimated</i>' the impact of cancer and '<i>overestimated</i>' their ability to cope with it, and this enabled them to sustain hope. The authors also consider that there might be cultural differences in how women manage information and the degree of trust in health care providers.</p>	<p>This paper offers substantial information regarding the core concept of coping and methods and analysis. The authors go further than all the other papers by going beyond description and offering substantive theory</p>
<p>McCann et al 2010</p> <p><i>Transitional experiences of women with breast cancer within the first year following diagnosis</i></p>	<p>To explore the experiences of 12 women with breast cancer over time</p>	<p>Exploring the idea of breast cancer as chronic illness meant using the concepts of biographical disruption and embodiment. This is a longitudinal prospective qualitative study</p>	<p>A constant comparative method was used for analysis with a descriptive and thematic approach.</p>	<p>Two key themes emerged: '<i>identity transition moving from health to illness</i>' and '<i>making the transition to the future?</i>' Women had to make changes as a result of the diagnosis and <i>transition</i> is a consequence of these challenges.</p> <p><i>Biographical disruption</i> and <i>embodiment</i> are concepts used to frame the analysis.</p>	<p>Using biographical disruption, embodiment and concepts of identity the findings suggest a shift in identity captured over time moving from health to illness which challenges both the body and the self and that a cancer diagnosis affects many dimensions of a person's life.</p>

Summary of Findings from the Qualitative Literature

Adding further support to the argument for the choice of EBC as a complex exemplar, no one clear picture emerges from this review of the literature. These selected papers focussed on different aspects of the EBC and chemotherapy experience and are summarised as: how families cope (Hilton 1996), the process of adjustment and coping (Besiecker et al 1997, Ching et al 2009), the disruptive impact of diagnosis and uncertain future (Boehmke and Dickerson 2006, McCann et al 2010), meaning (Richer and Ezer 2002, Frith and Harcourt 2007); transition from health to illness (Boehmke and Dickerson 2006, McCann et al 2010), and illness as transformative or opportunity for growth (Moch 1990, Browall et al 2006). Some of these aspects overlap and for some of the studies, the reporting of the analysis makes trustworthiness of the findings problematic. Some studies emphasised how women found positive meaning over time following on from the cancer diagnosis and treatment. However, Moch (1990) offered very little information on those in her study that experienced *'increasing disconnectedness and fear from others'* and rather more that fitted her frame of crises bringing opportunity for growth and development. Browall et al (2006) likewise concluded that women underwent a journey from fear of the unknown to a transformed life, yet proffered not a single negative case to contradict this linear, transformative journey.

In contrast, Boehmke and Dickerson (2006) and McCann et al (2010), took the diagnosis as their point of departure and marker of the transition from health to illness. For Boehmke and Dickerson (2006) diagnosis marked a *'precipitous'* change in women's lives, as they reflected back over their experience at one single time point at the end of chemotherapy. Here too, symptom distress was mediated by the individual's *'sense of self'*. They described a major theme as *'erasing of a former self'*. McCann et al (2010) conducted serial interviews but did not report on the process of change as it unfolded over time through successive interviews. There was still a sense of a shift in identity over time whereby the cancer diagnosis affected many dimensions of a person. Bodily changes and hair loss impacted on the sense of self and disrupted identity. Focus was on women who continued daily treatment such as hormone treatment keeping the traumatic experience of cancer more alive. The authors discussed the multiple transitional experiences during and post treatment.

Although all of the studies focus on early stage breast cancer, the time point in the illness trajectory during which data is collected varies in these studies and this is likely to impact on the findings. Although researchers used words like 'transition' or 'journey', they did not all reflect on the dynamic nature of the process of change over time. Richer and Ezer (2002) explored the unfolding meanings ascribed to the treatment experience by conducting serial

interviews at different time points. In contrast to other studies, these findings give a real sense of participants moving through their experience as a process. Findings included side-effects that gave women a sense that the cancer was real, and a loss of trust in the body with the diagnosis. Hilton (1996) used Dorsett's 'recovery trajectory' (1992) as a way to describe families that successfully returned to normal, and the illness trajectory (Corbin and Strauss 1992) for those that were less successful. Women coped by playing down their difficulties for the sake of others, a finding echoed by Richer and Ezer (2002). This strategy led to a sense of isolation, which Landmark et al (2001) found in their study on social interaction in the first year of diagnosis. Ching et al (2009) examined coping strategies amongst Chinese women categorising four sub-types; the authors discussed cultural and contextual factors that influenced the way in which and the degree to which women adjusted to cancer.

Table 2.2 displays a brief resume of the quality of these studies; this frame is inspired by one found in Smithson et al (2010). It is possible that word restrictions of journals limit the detail that can be provided to assess quality. The majority of the studies were published in nursing oncology journals with the exception of Charles et al (1998), in *Sociology of Health and Illness*, on decision-making – a descriptive study that offers detail regarding data analysis and rigour. Frith and Harcourt (2007) published in *Qualitative Health Research* focussed on photography as a method of data collection but lacked detail on methods and analysis. Lastly Ching et al (2009) also published in *Qualitative Health Research* offered a substantive theory of coping for Chinese women living in China. Only one of the papers (Landmark et al 2002) discussed a reflexive approach; and although Table 2.2 suggests that many of the studies did report detail on analysis, this is not necessarily reflected in the quality or depth of the findings.

Although several of these studies suggested that the diagnosis and changes resulting from treatment disrupted identity, only one study (McCann et al 2010) discussed the concept of biographical disruption. Biographical disruption (Bury 1982) is one of the defining concepts in understanding illness that has an impact on the biographical self, as well as consequences for daily living. Biographical disruption is a concept that can provide insight into the way in which people make sense of and adapt to illness. The dimensions of biographical disruption have been developed and refined as it has been applied in a wide variety of conditions, illnesses and characteristics of sufferers. McCann et al (2010) used biographical disruption as a way of understanding transition but did not develop the concept further.

Table 2.2 Quality appraisal of included studies (table frame taken from Smithson et al 2010)

Article	Is there a clear statement of research?	Is the qualitative methodology appropriate?	Is the theoretical perspective explicit?	Is sampling strategy clear?	Did the researcher consider reflexivity?	Is data analysis rigorous?	Are there negative or contradictory cases?
Beisecker et al	Y	N	N	Y	N	N	N
Boehmke and Dickerson	Y	Y	Y	Y	N	Y	Y
Browall et al	Y	Y	N	Y	N	Y	N
Charles et al	Y	Y	Y	Y	N	Y	Y
Ching et al	Y	Y	Y	Y	N	Y	Y
Frith and Harcourt	Y	Y	Y	Y	N	N	N
Hilton	Y	Y	Y	Y	N	T	T
Landmark	Y	Y	Y	Y	Y	Y	Y
McCann et al	Y	Y	Y	N	N	N	N
Moch	Y	Y	Y	Y	N	Y	N
Richer and Ezer	Y	Y	Y	Y	N	Y	Y

Several of the studies mentioned change over time or even overnight but offered no expansion of the concept of transition. Transition was cited as a major theme in McCann et al (2010) but there was no definition and they cited three other papers all by the same author

(Kralik 2002; Kralik et al 2006; Kralik and van Loon 2007). One other paper in the qualitative literature review explicitly described changing from health to illness (Boehmke and Dickerson 2006) and although the word 'transition' appears in the title, no definition, discussion or references to the concept were made. Hilton (1996) discussed the term "transitions" in her discussion and uses it to describe families adjusting to major events. Adjustment and transition are two separate concepts; transition is change over time (Liddle et al 2004) or discontinuity in a life course and is often discussed in the health and illness literature in terms of how people cope with change. There is some evidence that transition as a concept could be better defined. Kralik et al (2006) in a literature review on the concept concluded that it is '*the way people respond to change over time*' rather than it being about change per se. Given that this chapter is focussed on outlining EBC as a complex exemplar, further discussion on the relationship of the concepts of transition to coping and adjustment may be beyond the remit of this thesis.

Time and the Illness Trajectory

This thesis is focussed on a very specific point in time as demonstrated in Figure 2.1; data is gathered at specific points along the illness trajectory. As developed by Corbin and Strauss (1992), the concept of the illness trajectory refers to the physiological unfolding of the disease process and the multi-dimensional nature of the illness experience in time. This includes the meaning, significance and consequence of illness on the lives and self-images of sufferers and their families and the organisation of illness work. As interest lies in the process of change, critical in capturing that change is awareness of the analytical significance of time. The closer in time to the immediate experience, especially when the experience is imbued with shock and emotion such as diagnosis, the more likely the data collected will reflect the kaleidoscope of emotions and confusion experienced. The further the distance from the experience when it is collected, the more likely that some adjustment and processing has taken place so the experience is presented in more coherent terms.

A second critical factor is the need to develop a descriptive and explanatory account of the process of change as it unfolds over time, and within the moving illness trajectory. Time is used analytically to explore the unfolding process. Exploration of process has implications for method and in terms of developing explanations. Multiple interviews facilitate looking backwards and forwards but from a standpoint that does not remain still. Figure 2.2 displays the studies according to time point during treatment. The illness context of these studies was at specific point(s) along the illness trajectory, after diagnosis, during or after chemotherapy. The time point at which data was collected within this illness trajectory stage is likely to affect the nature of the data generated but for several of these studies, this was

not explicitly addressed in the conduct of the analysis. Hilton (1996) and McCann et al (2010) conducted multiple interviews over a longer period of time. Both studies discussed transition and adaptation, with Hilton's (1996) study discussing the factors that made it more difficult for some families to make adjustments to cancer and McCann et al (2010) describing challenges to identity and reinforcing the point that diagnosis and treatment affect multiple domains of life. McCann et al (2010) like Hilton (1996) and Richer and Ezer (2002) did not report and possibly analyse the data according to time which may have resulted in a missed opportunity for deeper insight and understanding of the experience.

The concept of trajectory (Corbin and Strauss 1992) is about the daily flow of change in the relationships between the disease process, treatment regimen, what it means to the individual and its impact on identity and living. The time point in this temporal flow of EBC is critical to understanding women's experience because there are many complicated factors; time is a dynamic with focus on change and continuity. The initial diagnosis and treatment for breast cancer appears to be intense with much sudden change from experiencing symptoms, and shock through to potentially reconstruction of the ideas of self-concept. Much of the breast cancer literature reports this period retrospectively, with less focus on time points in the treatment journey, which may result in a loss of insight and understanding of the experience as findings become generic. For this reason, the selected studies were examined in more detail to see what insight they might provide regarding change over time. For Beisecker et al (1997), chemotherapy side-effects lasted long after chemotherapy had finished and they changed over time. Moch (1990) did not illuminate on the effects of change over time as the follow-up interview was very soon after the initial interview. Richer and Ezer's (2002) study did not explore change over time, or include any comment on time, even though the data was collected during a course of chemotherapy, with participants being interviewed on average five times. Frith and Harcourt (2007) made valuable use of their methods using photography the results of which acted as points of interest in the follow-up interview; how participants used the camera was entirely up to them. Participants used the photographs to tell a '*chronological story*' akin to diary keeping and enabled participants to '*relive their experiences*' and thus gave a clear reconstruction of events as they relived them. The focus of the study was on appearance and how women felt about their bodies.

Figure 2.2 Time span of studies for the qualitative literature review

Pre-Treatment	During Chemo	Within 1 year of diagnosis	Within 2 years of diagnosis
			<p>Moch SD (1990) 2 interviews (within a week of each other) in the first 2 years since diagnosis</p>
<p>Hilton BA (1996). Five interviews conducted with families from diagnosis to within a year</p>			
		<p>Beisecker A, Cook AR et al (1997). Two interviews within 7 months of chemo finishing.</p>	
	<p>Charles C, Redko C et al (1998). Single interviews just before or during chemo.</p>		
	<p>Landmark BT, Strandmark M, Wahl A (2002) Single interview</p>		
	<p>Boehmke MM, Dickerson SS (2006). Single interview during last cycle of chemo</p> 		
		<p>Browall M, Gaston-Johansson F, Danielson E (2006). Single interview within 1 year of having chemo.</p>	
<p>Frith H, Harcourt D (2007). One or two interviews before and after chemotherapy</p>			

	<p>Richer MC, Ezer H (2002) Several interviews during chemotherapy</p> <p>→</p>	
		<p>McCann L, Illingworth N et al (2010) 3 interviews during the first year since diagnosis</p> <p>→</p>
		<p>Ching et al (2009) The number per participant and frequency of intervals is not clear</p>

The fact that none of these studies utilise the data taken over different time points is an interesting methodological point as qualitative methods are aiming to provide understanding of phenomena in dynamic, holistic terms. Although context was provided in terms of who was sampled and when, little attention was paid to the experience in terms of the temporal flow of the illness trajectory. This is especially important when taking into consideration the dynamic of change and self-concept, biographical disruption, transition and adjustment.

Concluding Comments

This chapter has laid out the argument for EBC as a complex exemplar with which to examine the ToC for TA. Firstly EBC was demonstrated to be a complex medical condition, with still much to discover regarding the inter-relationships of symptom clusters. For women with EBC, neither the qualitative or quantitative literature offers direct knowledge about what support might be valuable to women during treatment nor what might be acceptable. Clearly there is a need for support, with symptom clusters centring around CRF and for some women a clear struggle to cope with all the demands on them.

One outstanding feature in this literature is the absence of any sense of the suffering that women endure during this time, even though there are clear references to women experiencing both diagnosis and treatment as a threat to self. Arman and Rehnsfeldt (2003) conducted a meta-synthesis on the hidden suffering of breast cancer, concluding that not only is it under-reported, but that researchers wilfully ignore it. Their work focussed on different time points than this review, but clearly the absence of this concept in the first year since diagnosis is also very telling. There is literature that suggests (Arman and Rehnsfeldt 2003; Charmaz 1983; Frank 2001) that, during suffering, individuals are not able to articulate

their difficulties, and only when time has passed by, when they are through difficulties can they start to make sense of their story. If studies only focus on general, final findings at a later time point the exploration of concepts such as suffering or transition or changes to self-concept will be limited. Having a proper understanding of the potential suffering women experience and how they experience threats to self and biographical disruption may also guide and give weight to appropriate supportive interventions.

For the purposes of this thesis, EBC is a complex exemplar; it has social, psychological and existential dimensions in addition to the symptom-based experience outlined earlier. The combination of these strands calls forth the need for an intervention that has potential to address the whole person. This chapter has demonstrated the usefulness of EBC as a complex exemplar with which to explore the ToC of TA. The following chapter discusses finding a suitable methodological approach with which to meet the research aims and objectives regarding the theory of change for TA.

Chapter Three

Methodology

Introduction

This chapter reports on the guiding methodology that informed the research design. This thesis is concerned with what TA is and how it works in relation to the complex problem of EBC. Chapter One postulated that there are problems with acupuncture research and implicit within that are the assumptions made about what it is and how it works. This chapter considers what logic of inquiry might best address the aim of the thesis. It is important to find methodology that is able to penetrate deeper into meaning and go beyond a descriptive account especially given the complexity of the intervention and exemplar. In this light, two broader approaches are adopted. Firstly, the *'theory of change'* (ToC) approach is proposed as a research framework to examine this complexity. It is used to aid drawing out the theories underpinning different models of acupuncture. A methodology used in the evaluation of social programmes, for complex social problems, the ToC approach can be usefully applied to acupuncture when considered as a complex intervention with unpredictable elements and emergent properties. Secondly, an interpretive approach is employed within a longitudinal study, exploring the practice and experience of acupuncture, in order to gain insight into meaning and valued outcomes. Choice of a longitudinal study is important. Interest lay in uncovering participants' experiences from receiving a set of acupuncture treatments (the acupuncture 'intervention') within the wider ill-health context of early treatment for breast cancer and its impact on participants' lives. 'Time' thus becomes a key feature of interest. Finally, in order that research is conducted that has relevance to practice regarding model validity, a pragmatic study was conducted with emphases and commitments to ethical principles, rigour and reflexivity.

Theory of Change

A Theory of Change approach is one way of exploring TA and how it brings about change. It embraces the idea that whether an outcome is achieved or not is dependent on several factors that need to be identified. It is a critical thinking process that starts with the long term goal and works backwards to consider and/or uncover the steps needed to achieve that goal.

The Theory of Change (ToC) aims to make explicit underlying assumptions about how an intervention is meant to work (Anderson 2005). First expounded by Connell and Kubisch (1998) for evaluating social policy programmes, interest is not just in whether an intervention

works, but how and why. It was developed as an approach to evaluate and assist in developing solutions to complex social problems. Surfacing and articulating a ToC aims to expose assumptions and reveal causal links.

The ToC approach is one of several utilised in programme evaluation. Problems of evaluating interventions for complex social problems have led to different ideas about how to understand what works and what fails to work. Chen and Rossi (1980) argued that a 'black box' exists where input enters and output emerges and it is what is in the black box that evaluators need to assess. Weiss (1995) argued that within it potentially lie many theories or 'theories of change'. Divergent ideas about programme theory place different emphasis on what is key within the black box but the basic idea is that it needs to be made into a clear, Perspex box. Weiss continued by suggesting that *implementation* theory describes the steps within a programme, within a real life setting and context of an organisation, and that *programmatic* theory provides insight into the ways in which a programme intervention is meant to work. The ToC encompass both, as both together relate to programmes, a focus on both the content of the intervention and the process of implementation are of interest. The ToC approach continues to evolve within the Aspen Institute Roundtable on Community Change. Furthermore, Stame (2004) suggested that many programme theories fail to articulate the politics that heavily influence development of the programme; that theories need to be made explicit, assumptions exposed leading to the revelation of causal chains. The ToC is chosen for use within this thesis because of the thesis' central focus on making explicit underlying assumptions about how an intervention (TA) will work.

The ToC approach has been used in multiple areas within community and social change initiatives with users and organisations having many different kinds of problems, contexts and goals. A logic framework (LF) is another method of mapping the processes of change for a complex situation that was considered. There are important differences between the two approaches. For instance, LF's tend to illustrate a programme's components in terms of activities and inputs that leads to certain outcomes. A LF usually starts with a firm idea of what the intervention is whereas ToC is focussed first on the long term goal. ToC is also interested in mapping the relationships between different 'pre-conditions' necessary to effect the change. In addition ToC has interest in the causal pathway(s) of change and aims to produce a plausible and testable causal model. LF can thus be characterised as being more descriptive and ToC as more explanatory (www-theoryofchange.org), thus reinforcing the latter's potential value within this thesis.

The ToC approach was also chosen after consideration of pursuing a realist evaluation approach (Pawson and Tilley 1997). Realist evaluation focuses on trying to identify the

mechanisms responsible for bringing about certain outcomes in a (or these) particular context(s). One example is the IMCO (Intervention, mechanism, context and outcome) model, developed by Launsø and Skovgaard (2008) in the context of research for persons with multiple sclerosis (MS). They used it as a team based tool to enable discussion with practitioners from different backgrounds, for instance, a neurologist and a homeopath, to develop mutual understanding of each other's treatment approaches and to develop a programme theory of a team-based intervention. Practitioners had to articulate the mechanism and context connecting to their particular intervention and outcomes, a task all ten participant-practitioners found 'unusual'. These ideas were further developed in a critical analysis of the outcomes concept (Paterson et al 2009) creating IPCOE (Intervention, processes, context, outcome and experiences). They are also in keeping with Whole Systems Research (Verhoef et al 2005) which will be discussed in light of the findings of this thesis in the final chapter. Within this thesis, the intention is more limited than that advocated by Launsø and Skovgaard (2008). The aim is centred on trying to uncover or surface possible theories of change for TA, drawn from a range of sources, as, for example, professional accreditation boards, within relevant literature, and perspectives arising from participants within a longitudinal study of a TA intervention.

Applying the theory of change approach to acupuncture may aid clarity on what the pathway of change is. Connell and Kubisch (1998) identify three stages for the evaluation of community change initiatives:

1. Surface and articulate a theory of change
2. Measure the initiatives activities and intended outcomes
3. Analyse and interpret the results of an evaluation, this includes the possibility of adjusting the theory of change amongst other things

The ToC itself has been discussed and debated as different types of communities and institutions have used it. Critics have identified several potential problems or limitations in the thinking, for instance, the assumption that if the planning is good enough the intervention will succeed (Reeler 2007). ToC advocates though argue that one purpose is to identify why and how an intervention succeeds or fails. ToC may also assume that problems are easily articulated, can be identified and turned into pre-determined outcomes. What is clear is that the ToC may lack space for emergent influences or outcomes; even though it seeks to take account of human agency there maybe multiple feedback loops that alter what happens and that are unpredictable. The ToC is concerned with causal pathways, but these may be elusive. Ortiz Aragón and Giles Macedo (2010) argue that the simple cause and effect

thinking within ToC is insufficient to take account of the complexity of social change. They thus propose use of 'soft systems thinking' in their critique of ToC; that is that 'systems and processes are flexible, emergent, iterative and learning based' (p88). Furthermore, it may be that the ToC aim of measuring processes is influenced by grant makers need for value for money.

Given the problems outlined in Chapter One regarding the evidence for acupuncture's effectiveness, the ToC approach has thus been chosen as a useful way to assist in unpacking and gaining insight into what TA is in theory and in practice. Acupuncture trials produce variable results that are sometimes difficult to interpret. How acupuncture works is often a matter of conjecture. Theory explaining hypothesised mechanisms expounded in published trials may be different from the theory-based practice used in real world settings (Verhoef et al 2005) which in turn may vary. Moreover, the model validity of the acupuncture intervention in clinical trials has been questioned (Birch 2004) and the human element present in practice is often ignored in the trial context. In other words, acupuncture research may bear little resemblance to practice. By getting underneath the intervention, and exposing the theory and rationale and linking this to outcomes, it may be possible to shed light on what the gap is between acupuncture as it is theorised to work, and in research and in practice.

Applying the ToC Approach

The ToC approach is used in the subsequent thesis in the context of providing TA, a complex intervention, to women recently diagnosed with EBC, a complex (emergent) and complicated (multiple components) condition or illness, as a critical case study. The focus is to expose the component parts of the intervention, including the process of delivery; each stage will result in reflection and possibly revision of the ToC for TA.

1. A mapping of the theory of TA into a ToC framework (theory)
2. An application of the ToC framework to published clinical studies of acupuncture and qualitative exploratory TA studies from the participant and patient perspective (research)
3. A focus on the intervention in practice via interviews and other data sources with two practitioners of TA and subsequent analysis using the ToC framework (practice) including an outcome map of what the practitioners were trying to achieve
4. Final reflection and revision of the ToC for TA.

A Longitudinal Study Using a Broadly Interpretative Approach

In an effort to answer the research question, a longitudinal research design, exploring a TA intervention, provides a setting to examine change over time and practitioner/participants' Theories of Change. In addition it provides the opportunity to identify valued outcomes from both the practitioner and recipient viewpoint. The study, as befits an emphasis on model validity, takes a pragmatic approach, to replicate real-world practice and yet to be conducted within a research setting. It is intended to provide insight into what is important to women at this time, and what kind of outcomes a supportive intervention like acupuncture might achieve. This stage of treatment for women with EBC, within a year of diagnosis, provides the context for explicating the ToC within the acupuncture intervention from the perspectives of the acupuncturist delivering treatment. Specific time points in the cancer treatment trajectory may reveal that individual women's needs vary depending on specific points in time, and other contextual factors such as life stage. Using a broadly interpretative approach will enable an attempt to go beyond description in order to gain insight and understanding into how an intervention brings about change. As the focus is on recipients and practitioners of acupuncture in a real life setting, the naturalistic inquiry of qualitative methodology is highly appropriate.

Interpretive Naturalistic Approach

Naturalistic inquiry offers a rationale for non-positivist approaches to research; it seeks to describe, interpret or understand human experiences in depth. Qualitative methodology is a diverse field with debate regarding how much it can convey reality as oppose to rhetoric (Hammersley 2008 p.147). Much health research has its roots in positivism. Emphasis is on positive facts that can be constructed and tested according to scientific methods. Although health research utilises both quantitative and qualitative methods, positivism is rejected by some as misleading because it encourages a superficial understanding of 'facts' with absence of insight into the underlying mechanisms involved or the meanings attributed by individuals. Positivism fails to take account of context and meaning and that facts are theory laden or that knowledge and truth is historically or socially conditioned (Kuhn 1962). Qualitative research attempts to make sense of or interpret the meanings individuals bring to phenomena in their real life setting. Although critics of qualitative approaches may argue that what is produced reflects more the characteristics of the researcher than the researched, providing a reflective account of the research process and being explicit about how the research is done (Lofland and Lofland 1995) allows the reader to make a fair judgement of what is generated.

This thesis is concerned with trying to uncover assumptions rather than testing a hypothesis. It is necessary to have an open and exploratory stance in order to discover new insights. The output from naturalistic inquiry is description and understanding of whole complex phenomena rather than reducing them to single discrete variables. Rather than trying to control for contextual variables, naturalistic inquiry seeks to find out what they are in a real-world setting, that understanding is context bound. Interpretive methods offer subjective meaning and values. In contrast to seeking objective knowledge that is *uncontaminated* by human agency as in quantitative approaches, the qualitative inquirer is both actively engaged in generating data and her perceptions are part of the findings and the necessary trade-off for deeper understanding.

Qualitative Research

Qualitative research is an inductive and emergent methodology used typically for exploring human behaviour in the context of individuals' lives in a natural setting. The researcher is the instrument of data collection (Creswell 1998 p.14). This interpretive approach offers no firm guidelines, and entails walking an unknown path necessarily suggesting uncertainty and ambiguity. The exploratory nature of the PhD research question dictates that this is the right approach because of its focus on the '*what*' and the '*how*' of acupuncture and EBC rather than the '*why*'. An exploratory and interpretive approach will enable insight into what all the issues and concerns are and the processes and context. The significance of process, which relates to social life as dynamic, interconnected, changing and not static, encourages a longitudinal approach. Context for this thesis is multi-dimensional. It relates to: context in the life of the individual; context in terms of the illness trajectory; and context in relation to change over time. The process is inductive and orientated towards generating a hypothesis rather than testing it. As Creswell (1998) comments, drawing on Ragin's useful summary of differences in methodology, quantitative methods are interested in a few variables but many cases, and in qualitative methods it is the opposite – a small number of cases but with many 'variables'. Limitations of qualitative research can be the lack of generalizability of findings; these limits can to a degree be overcome through detailed description of the context and transparency of the process of data collection and analysis to allow the reader to extrapolate to other groups and situations.

Rigour

Ensuring rigour is a basic necessity in naturalistic inquiry to establish trust in the findings. In research designs using qualitative methodology, the researcher is the primary research tool. The ability of the reader to interpret the value and quality of the research depends largely on the transparency of the reasoning and methods used to conduct it and a helpful description of the lens through which the researcher sees the world. Reflexivity regarding this standpoint

is necessary throughout the research process. A reflexive approach assumes that data generation involves a co-production between the researcher and the researched and focusses on how this occurs; as well as what the researcher makes of it. A degree of self-consciousness is required whilst valuing a developing sensitivity and responsiveness (Guba and Lincoln 1982 p.129).

Ideally, detailed description of methods, including sampling, and analysis should be good enough as to be reproducible and for findings to generate points of discussion. Conducting the research in a systematic way using a broadly interpretive approach appropriate for the research question is essential. Triangulation enhances rigour where data is collected from different sources as it allows a fuller understanding of phenomenon. Examples of triangulation used in this thesis include examination of contrasting information about acupuncture from text books, research studies, practitioners and recipients of it. In addition, data came in the form of in-depth interviews, treatment logs and diaries and raw data is provided in the findings. Seeking out contrasting cases within the data to capture the range of experience is also an aspect of rigour.

Reflexivity

...in continuously interacting with those being researched, (the researchers) inevitably influence and structure research processes and their outcomes-through their personal and professional characteristics... (Mruck and Breuer 2003 p1)

Reflexivity is a very important component of rigour in interpretive models of research. Reflexivity is about critically examining one's effect as researcher on the research process (Hall and Callery 2001). However skilled the researcher is at entering into the other's world, and absorbing understanding and perspective of the other, the analysis still relies on interpretation. Meaning and experience are to a degree negotiated between two people, and some would argue that the output from the research encounter is unique to that encounter. As the participant talks, she may also evolve her own understanding of her experience even as it is shaped and moulded by the questions being asked of her. Epistemological reflexivity requires assumptions to be uncovered about how the research question and design has been defined and may limit the answers. Thus there are several strands of influence on the final analysis and making these strands as explicit as possible is one of the ways weight is given to the quality of the research.

Reflexivity is used by qualitative researchers from differing methodological backgrounds, grounded theory, phenomenology or ethnography for example and is considered vital for rigour (Hall and Callery 2001). One of the concerns is the impact the researcher has on the

research. This takes a number of forms. It relates to the interaction between the researcher and the researched, the influence of the researcher not only on the construction of meaning within the process, interviews, and observations but also in the design and construction of the research. It challenges the concept of objectivity in the research process, that it is impossible to remain outside of the subject matter while engaged in the research.

A reflexive approach can take the form of descriptions of the data collection and use of field notes that capture happenings before, during and after the data collection. The reflexive process for the intervention study is explored in Chapter Ten. In my daily practice I see women with EBC who are also having chemotherapy; the in-depth interviews with participants are different from how I conduct myself as a practitioner and this needs a special amount of reflection. Similarly, in interviewing colleagues, individuals I already know professionally where we are assumed to have a shared culture of practice brought its own particular difficulties and advantages.

The Researcher's Epistemological Position

Any research study is based on the researcher's own epistemological approach. As a practitioner of acupuncture I have a certain subjectivity that I bring to this study, I have a *priori* knowledge. As the research design uses a broadly interpretive approach it is essential to be explicit about my position.

One core feature is the practitioner-researcher's experience and knowledge of the subject area. I have been practising acupuncture for 26 years. The process of being reflexive involves generating questions to challenge assumptions about how values and experiences are framed and constructed – from the research question itself, the design used to arrive at answers, how interviews are approached and conducted and how the data is analysed. Being a practitioner-researcher demands an even greater account of myself in the research process and an awareness of myself as a practitioner conducting research. In addition, my MSc in Epidemiology had a stronger focus on quantitative methods which is in direct contrast to the qualitative methodology used in this thesis. Even if this background has not unduly influenced the methods, it means a specific journey has had to be made to develop understanding of the research question. This background in epidemiology reflected my starting point: a desire to explore the effectiveness of acupuncture for women with EBC. The way in which the question has changed from one of evaluation to an examination of the intervention itself reflects how my training has shaped the way I frame questions. The nature of grounded theory means a constant re-examination and reflection on what one knows and this is reflected in the evolving objectives.

Ethics

This study was mindful of certain ethical values in qualitative research:

- Participation was voluntary and participants were told verbally and in writing that they could leave the study at any time
- No harm must come to participants as a result of the study. The researcher is essentially passive and should not intervene or interrupt any health intervention.
- Privacy, anonymity and confidentiality would be upheld at all times.
- Awareness of the nature and boundaries of the relationship. As the participant is sharing her story, it is important to find a balance between empathy and sympathy against becoming too supportive and involved.

As this research involves human subjects, obtaining ethical approval for the study and signed, informed consent was essential. As the study takes place at two NHS trusts, seeking ethical approval from their administrative bodies was necessary. Dissemination of the results of the study is also an aspect of ethical practice and every effort will be made to make the findings known.

Concluding Comments

This chapter set out to present and provide a rationale for the methodology underpinning the exploration of the thesis research question. It is essential that the thesis is based on choice of both a methodology and methods that are appropriate to explore and address the research question and objectives. Three key guiding approaches were explored. Firstly, the rationale for choice of a ToC approach was presented, as a way to gain insight into the underlying theory of how acupuncture might bring about change. Secondly, the rationale for choice of a longitudinal design, using an interpretive qualitative approach and based within a pragmatic framework, was outlined. Thirdly, the area of rigour was explored, drawing attention in particular to issues involved in the researcher's epistemological position and underlying ethical principles. Attention now turns in Chapter Four to the methods employed in the thesis and thus how the methodological principles were followed through in practice.

Chapter Four

Methods

Introduction

This chapter explores the methods used to meet the second, third, fourth and fifth objectives of the thesis. The chosen methods comprised secondary analysis of selected research literature and an empirical study. The chapter begins in Section One by presenting the way that a framework was developed to articulate the ToC for two models of acupuncture, TA and, by way of contrast, MA (objective 2). Section Two then presents the methods used to undertake a novel literature review of clinical acupuncture studies using validated outcome measures (numerical data), in which the developed ToC framework is applied, the findings of which appear in Chapter Five (objective 3). Section Three extends the work in a further direction, by examining a set of literature on TA which reported on the experiences and perceptions of TA from both a patient and practitioner perspective, the results of which are provided in Chapter Six (objective 4). In the final Section Five, insight is provided into the design, undertaking and analysis of data arising from a longitudinal qualitative study (objective 5). It is important to point out that the development of the ToC acupuncture framework and methods used to explore its application draws on a joint publication with the PhD supervisors (Price et al 2011).

1. Developing a Framework that Articulates the ToC

The second objective outlined in Chapter One is to explicate the ToC that underpins the theory of TA. In order to aid the delineation of theory and to provide a contrast, the theory of MA was explored at the same time. As explored in Chapter Three, a first step in developing a ToC is to uncover or identify the essential or implicit theory or theories that underlie an intervention, that is, how the intervention is thought or meant to work and its expected impacts and desired outcomes; and what the long term goal is. In the current context, this is akin to clarifying the underlying therapeutic rationale that guides and lies implicit within the acupuncture intervention. The development of this framework was a process of critical thinking; the evolution of the framework and then its application and, in effect testing on the data gathered for this thesis is in keeping with the ToC approach, where a range of ToC may emerge and/or a core ToC be modified and refined.

The first stage was to gather information on the theories of the two approaches. In consideration of *a priori* knowledge (Department of Health 2008), the educational content and guidelines of two professional bodies for acupuncture (British Acupuncture Council and

the British Medical Acupuncture Society) were examined and a framework developed from these. These two bodies represent, though not necessarily exclusively, TA and MA practitioners and act in an accreditation role. In a national postal survey of acupuncture practice in the UK undertaken in 1995, Dale (1997) reported that 85% of BAacC responders depicted their style of practice as 'wholly' or 'mainly' traditional; in contrast, 83% of BMAS responders described their style of practice as 'wholly' or 'mainly' Western. Acupuncturists that practise TA use primarily traditional Chinese medicine theory (TCM) but this framework does not exclude variations of other traditional East Asian medical approaches. MA uses 'neuro-physiological principles' based on evidence that acupuncture alters brain function through stimulating nerve pathways (Han 1982); the principles of treatment are based on scientific knowledge of a known *physiological* mechanism.

In developing the framework, only areas that were deemed to be distinct from either group were included. Any values or guidelines that might be considered as shared, such as '*ethical – where personal and professional boundaries are monitored and maintained*' were excluded. Aside from different theoretical commitments, these two approaches are differentiated in terms of the nature and length of education and training required for their practice (Paterson and Britten 2004, Hughes 2007). Examples of the consideration of some topics which are excluded or included from both groups are shown in Table 4.1.

Table 4.1. Examples of differentiation of the core curriculum of two professional bodies (BAcC and BMAS) - (values in bold and italics are extracted directly).

BACc values statement	BMAS Statement of specific knowledge	Comment – topics
Holistic <i>because treatment is based on an understanding that mind, body and spirit are integral, acupuncture can offer the possibility for (re)discovering what it might mean to be fully oneself.</i>	Health, effective functioning and wellbeing. <i>How the psychological and emotional balance of the client may affect their health, effective functioning and wellbeing; the nature of illness and the impact this may have on a client's effective functioning and wellbeing.</i>	Both organisations describe something that could be interpreted as 'holistic'. The BAcC suggest that mind, body and spirit form a whole; whereas the BMAS suggest that health and wellbeing both influence and are influenced by the emotional balance of the patient. Holistic is used as a topic.
Patient-centred – <i>patients are at the centre of the therapeutic process and their individual experiences of health and illness are acknowledged and respected.</i>	No information on being patient-centred is offered.	Although the BMAS makes no comment about being patient-centred, it would be unreasonable to think this concept is exclusive to the BAcC; comment will be made in the summary for each paper regarding this concept.
Responsive – <i>the practitioner engages with, and responds to, the changes in the patient's condition over time, and integrates the patient's evolving priorities and choices.</i>	Treatment is fixed and focused on symptoms.	A core element of traditional acupuncture is that the focus of treatment is on the individual and the signs and symptoms present therein – treatment approaches and strategies will change as the individual changes. This topic is used in the framework.
Therapeutic – <i>acupuncture acts as a catalyst for change and self-healing.</i>	No description is given of acupuncture as a catalyst for change and healing	The idea that acupuncture is a catalyst for change and self-healing suggests something akin to a mechanism, and appears unique to the BAcC and therefore is used as a topic.

As the next step in developing the ToC framework, the TA topics were distilled further. As several aspects of TCM theory co-exist and only make sense when used together, it was felt that putting these into one category of pattern differentiation (Bian Zheng) would sufficiently sum up a large body of TCM theory; other aspects of theory such as *Wu Xing* were added. Traditional East Asian medicine theory encompasses more than TCM and it was important that the framework was broad and general enough to encompass other approaches whilst still retaining its validity. Table 4.2 demonstrates this paring down TCM theory into topics distinct from MA.

Table 4.2 Refinement of the Traditional Acupuncture Topics

Core Content	Topic for framework	Comment
<p>Understanding health and harmony: <i>including: yin/yang, wu xing, qi, xue, jin ye, zang fu, jing luo, and all their relationships</i></p>	Differential diagnosis	As working knowledge of concepts such as yin and yang is necessary to identify and differentiate patterns, 'differential diagnosis' becomes a summary of a much bigger body of knowledge
<p>Understanding causes of disharmony: <i>internal causes, external causes, miscellaneous and secondary causes</i></p>		
<p>Patterns of disharmony: <i>to identify, differentiate and interpret the patterns of disharmony using the following: yin/yang, wu xing, ba zang, qi xue, jin ye, zang fu, liu yin or liu xie, zang fu bian zheng, jing luo, san jiao, wei qi ying xue bian zheng, liu jing bian zheng</i></p>		
<p>Principles and priorities for treatment: - <i>interpret the overall signs and symptoms including the cause, the nature and the location of the patient's condition according to the principles of traditional acupuncture.</i></p> <p>- <i>Identify the principles of treatment which includes an assessment of the balance of excess (shi) and deficiency (xu), and the emphasis of treatment directed towards the root (ben) or the branch (biao); and the theory of Wu Xing where appropriate.</i></p>	Principles of treatment	Principles of treatment encompass five specific ideas in traditional acupuncture (two are described in the left column) and are summarised simply here by the title.

The BMAS does not publish a core curriculum but educational guidelines are currently being developed and an outline of these was made available. Principles of treatment are based on the '*Western understanding of acupuncture mechanisms*'. Holism was not mentioned but lifestyle factors that may hinder progress are considered and there is an emphasis on wellbeing '*consistent with the practice, principles and theory underlying your discipline*' that is, biomedical discipline. Students receive a brief introduction to some of the concepts of Chinese medicine (such as qi, yin, yang), but they appear to in no way inform treatment. The principles of treatment are based on '*the Western understanding of acupuncture mechanisms.*'

Textbooks for Cross Reference

Further development of the ToC necessitated an exploration of the main standard textbooks for each professional body, as a cross reference check against the model being created, although this is not considered to be a validation of the model. The books recommended by the BMAS (Stux et al 2003; Campbell 2001) broadly expound the idea of using only the

biomedical mechanism as a guide to treatment; although some exceptions may apply: *'because some Westerners wish to use the traditional system of points without immersing themselves in the full complexity of traditional theory, there exist 'cookbooks' that contain lists of sites to needle in different disorders'* (Campbell 2001, page 56). In contrast, two recommended texts from the BAcC (Maciocia 2005, Maciocia 2008) are large compendiums of Chinese medicine theory. The Practice of Chinese Medicine (Maciocia 2008) does include pattern differentiation (Bian Zheng) according to disease or symptom and this is representative of the integration of Chinese medicine into biomedicine. For instance, tiredness is described as coming under the category of *xu luo* or *'tiredness from deficiency'* but additional explanation reveals that tiredness is not always from deficiency but can be caused by a *shi* condition or a mixture of *xu* and *shi*. Reference to the Su Wen or "Classic of Difficulties" (a chapter from an ancient Chinese text, from the Han dynasty and the foundation stone of all Chinese medicine theory) is the basis for the differentiation. The aetiology and pathology of tiredness according to TCM is set out in detail and lastly all the possible patterns that could be responsible for the tiredness, of which there are nineteen. Given the nature of the TA approach to address the whole person, tiredness in an individual will not be the only symptom; other symptoms and signs will be present (using the four diagnostic methods) leading to an even more complex combination of patterns of disharmony. Writing this detail is necessary to explain that in the TCM textbooks, even though diseases and symptoms are differentiated, it is not possible to address them without going through a process using Chinese medicine theory and diagnosis that is there are no shortcuts from symptoms to points. Incidentally, only exhaustion is mentioned in one BMAS textbook (Stux et al 2003) as opposed to tiredness, with a short descriptive paragraph and a list of eleven points to use.

A further round of reflection and critical thinking ensued. Five key components of potential difference were identified: 1) theory (for aetiology, diagnosis and treatment); 2) the rationale offered for how the treatment is expected to work; 3) the practice of the intervention; 4) the implied or assumed causal pathway for change; 5) the desired outcome of treatment. While these five components are interrelated, the underlying theory of acupuncture underpins them all. For example, the theory of Chinese medicine talks in terms of the balance of *Qi*, embracing how to diagnose, and how to formulate a treatment strategy. The practice should embody the theory; for instance in Chapter One it was reported that TA holds to the idea of holism, then its practice must reflect the understanding that mind, body and spirit are integral. The ToC framework was then 'tested' by using data from selected published clinical trials (details of the selection of which are below) which were sifted through the framework and topic areas that overlapped or gave no additional meaning to the data were revised.

Topic areas that seemed relevant and core to either professional body, but for which the literature provided no data, were kept in as gaps in information are seen as being relevant and revealing.

The final version of the framework is displayed in Box 1. This framework makes explicit the differentiating features of a TA or MA model. Features of both systems that were about values rather than principles of theory were not included. Two points are noteworthy. Firstly, the heading '*aetiology of the symptom as integral to the treatment*' is considered exclusively a TA feature; how a symptom starts provides diagnostic information for this type of acupuncture. Secondly, the heading '*responsiveness*' is important as patient responses and changes provide new diagnostic information that may modify the treatment approach (iterative treatment). This is a feature that orientates the TA model to the individual over and above the symptom. In contrast, the MA model focus stays fixed on the symptom. Although the outcome is displayed at the end of the box, in ToC it is the point at which the thinking process starts. This shows that, for TA, the outcomes from the intervention include changes to the whole person, mind and body and any symptoms. For MA, the outcomes are much narrower and specifically related to the symptom(s).

Box 1. Theory of Change Framework for Two Contrasting Models of Acupuncture

TA	Component	MA
Approach is orientated to the whole person based on an understanding that mind, body and spirit are integral	Theory	Approach is focused on the symptom
Aetiology of the main complaint: a detailed history of the main complaint is integral to the diagnosis	Theory (Aetiology)	Aetiology of the symptom is prognostic only and does not affect process of treatment.
<ul style="list-style-type: none"> ▪ Differential Diagnosis: summary of the core curriculum theory of TCM encompassed by Bian Zheng or pattern differentiation; and <i>wu xing</i> where appropriate ▪ Diagnostic Methods: principles of looking, listening, asking, touching (tongue and pulse) are part of differential diagnosis 	Theory (Diagnosis)	<ul style="list-style-type: none"> ▪ Symptom based diagnosis ▪ Diagnostic Methods: concerned with nature and location of symptom
<ul style="list-style-type: none"> ▪ Treatment Principles: understanding of main complaint in terms of context, nature and location including concepts of <i>xu</i> and <i>shi</i>, and <i>ben</i> and <i>biao</i>; (specific CM terminology) ▪ Responsiveness: diagnosis and treatment change in response to patient reported changes 	Theory (Treatment)	<ul style="list-style-type: none"> ▪ Treatment Principles: the symptom and its underlying biomedical mechanism have a linear path ▪ Constant: treatment approach stays focussed on the principle of affecting change in the biomedical mechanism of the symptom
<ul style="list-style-type: none"> ▪ Mechanism of change is dependent on affecting the balance of Qi, Yin and Yang and other defined substances of the person as decided by the differential diagnosis ▪ Acupuncture works by affecting change in the balance of Qi, Yin and Yang and other imbalances as defined by the differential diagnosis. 	Rationale	<ul style="list-style-type: none"> ▪ Mechanism of change is based in biomedical science and is linked to a direct expected action of acupuncture ▪ Biomedical mechanism of acupuncture whether hypothesised or tested is linked to the symptom
An iterative, individualistic and interactive approach - At each session the practitioner uses the principles of looking, listening, asking, touching (tongue and pulse) to make a differential diagnosis and to formulate a new treatment.	Practice	At each session, the selection for the formulae of point's remains fixed on the biomedical mechanism of the symptom.
Non-linear, with degrees of uncertainty at each stage of treatment	Possible Causal Pathway	Linear, from acupuncture needling to symptom
Desired changes in the balance of Qi, Yin and Yang and other imbalances as defined by the differential diagnosis which will manifest in various aspects of the person in mind and body, in addition to any specific symptom changes	Outcome	A change in dimensions of the symptom, for example, hot flushes, a change in the intensity and frequency.

2. Applying the ToC Framework to the Clinical Acupuncture Research Literature

This second section explores both the process of gathering the research literature of published clinical trials of acupuncture and also the way in which the framework was used as a data extraction tool. The selected studies form the data set on which the ToC framework was applied; the findings of the application are detailed in Chapter Five.

Search Strategy for the Literature Review

The subject of this review are clinical trials of acupuncture for the symptoms commonly experienced by breast cancer patients undergoing adjuvant treatment, specifically: fatigue, depression, anxiety, insomnia, vasomotor symptoms, nausea and vomiting. These include, but not exclusively, all studies involving breast cancer. Published clinical trials of acupuncture tend to involve single outcome measures; and as the brief resume of the epidemiological data revealed in Chapter Two, this is also a common approach in seeking out the goals of intervention studies for EBC. An initial search of acupuncture for symptoms suffered by breast cancer patients, conducted in 2006, produced very few studies and so widening the search to studies on these symptoms generally produced more material to work with. As the point of the review was not to find evidence for efficacy but to surface the theory, it was appropriate to widen the search criteria. The following databases were searched using the symptoms mentioned above and search terms 'acupuncture' or 'acupuncture therapy' from 1986 to 2008: Major biomedical databases: Medline, Embase, CINAHL, PsychInfo and the Cochrane database of systematic reviews; specialist databases: AMED, CISCOP, Acubriefs, Cochrane Complementary Medicine Field Registry. A hand search of English language Chinese medicine journals: Journal of Chinese Medicine, European Journal of Oriental Medicine was also undertaken.

Sampling Strategy

Purposeful sampling was used to ensure a variety of quality studies measuring the range of symptoms. All randomized controlled trials (RCT's) and quasi-randomized trials comparing acupuncture with a control group (described as placebo, sham or usual care) that used validated outcome measures as primary or secondary outcomes were included. In addition, some uncontrolled studies were included if they appeared in key journals and were subsequently cited by other included studies. Other inclusion criteria were all studies had to use needling, be originally in the English language, and to include patients. Exclusion criteria were: healthy subjects, pregnancy and fertility trials, interventions for auricular acupuncture alone, laser therapy, acupressure, TENS.

The papers were looked at initially with a summary pro forma taken from Long and Godfrey (2004) including the purpose, key findings and an evaluative summary. The citations of each paper were also searched to examine how the thinking had been developed from the literature. An example of this section of the critical thinking behind the developing framework is given in Table 4.3.

Table 4.3 A sample of the pro forma guide to the overview of each study (taken from Long and Godfrey 2004)

Study Overview	
Bibliographic Details	Wyon Y, Lindgren R, Lundeberg T, Hammer M. Effects of acupuncture on climacteric vasomotor symptoms, quality of life and urinary excretion of neuropeptides among postmenopausal women (1995); Menopause (US). Study located in Sweden
Purpose	To study if and to what extent two different kinds of acupuncture affected postmenopausal hot flushes, urinary excretion of neuropeptides and QoL
Key Findings	Acupuncture significantly affects vasomotor symptoms with effects persisting at least 3 months after the end of treatment; CGRP* was also significantly decreased with treatment.
Evaluative Summary	21 women completed the study. Outcomes other than change in symptom must have been anticipated judging by the outcome measures. The acupuncture consisted of a fixed-point prescription for dysmenorrhea; the theory was focussed entirely on hypothesised mechanisms of acupuncture and disease and not on TCM theory. The superficial needle insertion (SNI) was considered (by the authors) a poor control method and the results for both groups were very similar; two styles of acupuncture were used that bear little resemblance to what is done in real practice – firstly using a needle technique (SNI) usually seen in Japanese acupuncture (though it seems unlikely the authors knew this and thought they were just using a weak form of acupuncture), and secondly using a fixed-point prescription for a syndrome not associated with the main symptom to be addressed (hot flushes). The acupuncture is described as ‘classical acupuncture’; and as with other studies, it is possible the authors are considering that the needle technique is the dimension of the intervention that makes it ‘classical’ or traditional. The authors hypothesize that beta-endorphins are the link between acupuncture and effects on outcome measures.
Context I <i>aims, rationale, setting</i>	Comparing the same acupuncture points with different needle techniques chosen for a symptom other than the primary target but with a similar hypothesized mechanism; in a gynaecology and obstetrics outpatient clinic administered by a physiotherapist The group acknowledged that there is no inert placebo for acupuncture, so creating two different styles of acupuncture (different only in needle technique) and comparing them seemed like a reasonable option; but cannot be said to be what is done in every day practice.
Context II <i>publication, department and funding</i>	Menopause is the journal of the North American Menopause Society and the study was located in Sweden and was funded by two Swedish foundations for scientific research The study will be geared towards the outcomes and finding a scientific rationale for

Citations On finding the cited article (the reference given was incorrect) for the point-prescription this article in turn cites a Chinese medicine text book

*CRGP - calcitonin gene-related peptide

3. Exploring the Literature for Patient and Practitioner Experiences of TA

This section provides insight into the methods used for a further elaboration of the potential theories of change of TA, undertaken through exploration of selected published research on patient and practitioner experiences of TA (the fourth objective). A literature search for studies using qualitative methodology was conducted: For clarification, a qualitative study is defined here 'as one that uses qualitative methods in both gathering and analysis of the data, that is visual and verbal (conceptual or thematic) rather than numerical data manipulation' (Long and Godfrey 2004 p.183). This provides a contrast with the clinical trials based, literature review. Moreover, it is likely to offer different kinds of insight and information on potential ToC and also outcomes valued by patients and those sought by practitioners, these themselves being a core part of a ToC model; it will thus further expand the ideas around potential theories of change for TA.

Search Strategy for the Qualitative Literature Review

The subject of this review is traditional acupuncture, and search terms included 'traditional acupuncture', 'acupuncture' and 'qualitative'. Studies that were about CAM in general were excluded because the focus within these papers was not on the theory of TA *per se*, and some aspects appeared to be assumed to be generic to TA from other CAM, for instance homeopathy. In order to make this review replicable it was therefore considered better to have a narrower rule of inclusion. Accordingly, other relevant papers on CAM and cancer regarding patient and participant perspectives and experiences are drawn on as appropriate in the final Discussion chapter of this thesis. The following databases were searched from 1986 to 2010: Medline, EMBASE, PsychInfo, and AMED. A hand search of English language Chinese medicine journals: Journal of Chinese Medicine, European Journal of Oriental Medicine was also undertaken. A citation search was also conducted.

Each selected study was then examined carefully and read for explicit or implicit ideas about the ToC. For instance, practitioner focused perspectives were more likely to have detail regarding why they did what they did and what they were intending to happen. Similarly the

patient focused perspectives were more directed at exploring the perceived benefits from TA and what aspects patients valued. Both sets of information fit with the ToC approach, as this starts with the endpoint by thinking about what the 'long term goals' are and working backwards to map out what the 'pre-conditions' for change are. The findings of this literature review are reported in Chapter Six.

4. A Longitudinal Qualitative Study

This fourth section explores the methods used to address the fifth objective of the thesis, that is, to undertake a longitudinal qualitative study. This study aims: firstly, to provide insight into how women experience TA and explore outcomes as valued by the women participants whether or not they were able to attribute them to TA; and secondly to gather data from TA practitioners who are involved in providing these women with TA on how practitioners theorise TA and what their intended outcomes and long term goals are (and thus to clarify their own ToC of TA). The qualitative study is described first, followed by the process of data analysis using grounded theory.

A longitudinal qualitative study was set up to offer women who had recently been diagnosed with EBC the opportunity to access, via their oncologist, up to ten sessions of acupuncture while they underwent chemotherapy. Exploring change over time and the processes of treatment over time meant that looking at practice as it happened would more likely capture these aspects of treatment and experience.

Inclusion and Exclusion Criteria

Inclusion criteria for the study were developed with a medical oncologist. We decided that the sample would be homogeneous in terms of gender, disease pathway, and spread. For instance, as men can get breast cancer the study explicitly stated that only women were to be included; and inflammatory breast cancer can have a different pathway of disease and treatment from most other breast cancers. Keeping the criteria for inclusion in the study simpler, that is, including women who were advised to have chemotherapy but who did not have metastasis would keep the cohort more homogenous. Once cancer has spread to other parts of the body, different treatments are advised and a different prognosis might affect the outlook of the individual.

Inclusion Criteria: female, 18 years and over; early stage breast cancer; due to receive chemotherapy; no previous chemotherapy (although they could have a history of cancer); no metastatic cancer; no inflammatory cancer;

Exclusion criteria: Needle phobia

Sampling

Aside from the inclusion criteria, funding limited the numbers to fourteen women. The decision on who was invited into the study rested with the oncologists although in theory they were meant to invite anyone who fitted the inclusion criteria; in practice this may not have happened, which is in keeping with the pragmatic design of the study.

Sampling for the acupuncturists was purposive. It was important to have two experienced and local practitioners who were willing to participate.

Acupuncture Treatment and Setting

Acupuncture treatment took place at a cancer support centre or private acupuncture clinic that is registered with the local authority. The participants remained under the care of the oncologist at all times. Individuals were offered up to 10 sessions of acupuncture over a period of 14 weeks, starting within a week of their first chemotherapy treatment cycle. The acupuncture was provided by one of two members of the British Acupuncture Council (BAcC), both with over ten years clinical acupuncture experience. Members of the BAcC require a minimum/equivalent of 3 years full time training, and are trained to identify symptoms that might indicate serious pathology. No acupuncture was attempted on the ipsilateral arm in patients who had undergone axillary dissection to avoid any risk of swelling and lymphoedema. The acupuncturists were instructed 'to do what they normally do', in keeping with a pragmatic study design.

Treatment details, responses to treatment, and adverse events were monitored by the acupuncturist using schedules, or a treatment log, based on those developed for use in a recent UK trial of acupuncture care for patients with low back pain and are provided in Appendix II. Details of acupuncture care will be reported according to the Standards for Reporting Interventions in Controlled Trials of Acupuncture (STRICTA).

Access to Women with EBC (participants)

The study was located in two sites: a large district teaching hospital with a team of oncologists and nurses referring patients; and a regional hospital where the access to patients was via a single oncologist and his personal assistant. These two sites represented quite different pathways into the study. The recruitment design was developed in an attempt to keep to the minimum any effort on the part of the oncologists and their team in recruiting participants. There is a very short time between women having surgery and meeting the medical oncologist for the first time. The medical oncologist has a lot to discuss in that first meeting and it was likely that an invitation to the acupuncture study could easily get missed

off the list. Chemotherapy usually starts within a week to ten days of the meeting with the medical oncologist. During this time, the potential participant was informed of the study, signed consent was obtained and the first interview conducted. A study pack is included as Appendix II. This contains a letter of invitation into the study which concurrently asks for participant approval for the researcher (SP) to contact them, the participant information sheet, and consent form. Participants were informed on consent that they were free to withdraw from the study at any time. Written signed consent was obtained by the researcher (SP). In this thesis, women with EBC are referred to as participants rather than patients except when reporting the acupuncturists' data.

Access to Acupuncturists

The two acupuncturists were invited to participate, both of whom had been members of the BAcC for over ten years. They have both lectured at an accredited college of acupuncture, a university course affiliated to the BAcC, and been clinical supervisors there for the professional acupuncture course at degree level. They were both willing to participate and they were the only acupuncturists approached to be involved. They were also prepared to act as co-supervisors for each other should difficulties arise professionally. In this thesis the acupuncturists are referred to always as the acupuncturists.

In-Depth Interviews

In-depth interviews with both sufferers of breast cancer and with practitioners were used to allow a thorough exploration of individual's perspectives on the acupuncture experience. Interest lay in exploring the practitioner perspective on what she hoped to achieve with the acupuncture and how it might work in relation to their experience of treating this particular group of women. For the participants receiving the acupuncture, the in-depth interviews were used to explore the needs and concerns of individuals and how they experienced the acupuncture care. The topic guide for the interviews are described first, and then more detail is given about the nature and setting of the interviews. The topic guides can be found in Appendix IV.

i) Topic Guide for Interviews with EBC participants

The topic guide was developed after an examination of the literature outlined in Chapter Two. The first step was in creating a draft of ideas especially in consideration of the qualitative literature and the sense of an erased identity. It was decided to start with an open question '*how are things for you just now?*' and follow-up questions were similarly open such as '*What would you most like help with?*'. On conducting the first interview it was decided to change the questions more specifically to allow the participants to tell their story from the point of diagnosis and to go from there; thus the opening question became '*Tell me about*

how you first discovered you had breast cancer? The focus of the interview was attempting to understand how have EBC sufferers experienced the impact of diagnosis and treatment and in what way has it changed them: their whole self.

The topic guide for the second interview was developed after several, but not all, of the first interviews had been conducted, transcribed and the process of analysis begun. The interview started with an open question *'How are you and how have things been in the last three months?'* Within the framework of the topic guide, specific features of the individual participant's life were picked up on as the conversation flowed. Further questions related to what participants had found most challenging about the process up to then including their experience of chemotherapy, with an aim to understand the significance of the treatment and its effects. This was followed by what they had been seeking from the acupuncture treatment in this context. The key to the interview was what this experience of breast cancer meant to the individual at this point in her life, and in relation to her specific circumstances. Finally the participant was asked *'What is important to you now? Is this different from before'* to gain insight into any sense of change in perspective on values and what was meaningful.

A topic guide for the third interview was developed in consideration of the need to examine time as an analytical category in the study. As in the second interviews, the guide was tailored for each individual and even more than the previous interviews the conversation was allowed to flow with the initial opening question: *'how are things feeling for you just now?'* It was not always possible to even get this question in as some participants started talking before the audio recorder had started. Prompts if they were used at all included *'getting back to normal has been very important to some women in the study, has it been so for you?'* Other questions focussed on the acupuncture, and whether and in what ways they had found it useful or supportive. This was asked in an open way *'what is you're feeling about the acupuncture looking back now?'* and *'was it offered at the right time?'* A sense that had emerged from the second interviews was that the acupuncture had somehow offered support to the whole person, and exploring whether they felt the acupuncture care helped them maintain a sense of self or *'get them back on track'* was part of the ethos for the guide.

Interviews with breast cancer participants

In-depth interviews with the selected participants allowed a thorough exploration of what individual's perspectives were on the acupuncture experience. The in-depth interviews were used to explore the needs and concerns of individuals and how they experienced the acupuncture care. In-depth interviews are appropriate because of the complex and potentially sensitive nature of the subject. The interviews were conducted at two time-points

for all the participants and at a third time-point for half of the women. The first interview took place between the meeting with the medical oncologist and the start of chemotherapy; this was usually a space of less than ten days; and usually within three months of either discovering a lump or having a routine mammogram that led to diagnosis. Three participants had a mastectomy; another had a serious wound infection that kept her in hospital for three weeks but this was discovered the day after she had her first interview with me. The second interview took place approximately 14 weeks after the first. The third interview was within six months of the finish of chemotherapy, although nearly all women were still having some kind of treatment, radiotherapy or medication and this was also within a year of the diagnosis of breast cancer. Interviews took place at the local cancer support centre; in Site One there was a choice of two - one being within the hospital grounds, and a separate centre in the town centre. Interviews lasted approximately 35 minutes to over an hour. Three of the third interviews were conducted over the telephone, bad weather inhibited one face to face interview, one participant had returned to work and was only available during her lunch hour and the third was having to travel for daily radiotherapy in another town and was too tired to consider meeting up. Given these circumstances I did not wish to press further for face to face interviews with these three participants.

ii) Topic Guides for Interviews with the Acupuncturists

The topic guide for the first acupuncture interviews took some time to develop. The desire to explore the ToC initially informed the overarching ethos of the guide, that is exploring why they do what they do and for what purpose:

- Outcomes *What are you trying to achieve for this patient?*
- Treatment *How is this outcome going to be achieved?*
- Theory *Why is this treatment going to work?*

The aim in the interview was to move beyond an articulation of professional practice to how the acupuncturist had internalised practise. There was an attempt to explore values: '*what is important to you in how you practice*'; and expose theory: '*what procedures do you go through to arrive at a treatment plan?*' and '*What has to change in the patient for you to change your treatment strategy?*' The interview also attempted to gain insight into how the practitioner thought acupuncture worked: '*What do you believe the catalyst for change is in patients?*' This topic guide was then used as a pilot on an interview with several colleagues. These interviews were transcribed and the questions analysed and reflected on to further develop the guide. Two further pilot interviews were conducted going through a similar process.

The final version of the topic guide started with an opening question: *'When someone comes to your practice for the first time – can you describe to me how you go about getting the information you need in order to treat them?'* There are further prompts delving into the detail of practice as mentioned before. At the end of the interview the acupuncturist was asked to read a short vignette of the experience of a breast cancer patient soon after diagnosis and to comment on it. This vignette was an attempt to get more directly at the practice of acupuncture as described by the practitioner. The vignette was developed from a collection of stories and experiences from my practice as an acupuncturist.

The topic guide for the second interview was very open starting with *'how did you find treating this group of patients?'* The aim was to gain insight into the way in which the acupuncturists had engaged in practice in respect of this patient group and with particular individuals. The conversation was allowed to flow; other prompts included *'What kind of things do you think the acupuncture helps with?'* and *'What do you think you are trying to achieve?'* After interviewing one acupuncturist the second time, questions that had arisen in that talk were included for the second acupuncturist for instance, *'Do you think that the therapeutic relationship is a by-product of that process of discovering about them in order to treat them?'* and *'Just talking generally now, and thinking about these patterns say for instance Qi stagnation – a lot of anger or a lot of stress, or trauma from the past or emotions that haven't been processed, do you think then that we should in some way facilitate some processing of those feelings or...do you think this happens just with the actual acupuncture?'* The interview was partly attempting to establish how the practitioner saw themselves in relation to the acupuncture treatment, what did they attribute change to.

Interviews with acupuncturists

The interviews with Diane were at her clinic and with Helen in her home. The interviews lasted between 45 minutes to over an hour. The acupuncturists were contacted again after the second interview for further discussion and to clarify some points.

Reflective Diaries

It was important to attempt to capture the dilemmas of practice or the rationale for decision making or other moments in time that might reveal how the practitioners went about their practice. These diaries were then used in the follow-up interview with the practitioners as aids to gaining understanding about what they were trying to achieve, in keeping with the ToC. The acupuncturists were given a notebook each and were requested to keep reflective diaries on their experiences of treating individuals during the study. The diary had written inside it:

This diary is for your personal reflections and emerging understanding as you treat this patient group. Your reflections can be general in relation to two or three specific cases that you follow during the study. Think about:

- *What are you trying to achieve?*
- *How is it going to be achieved?*
- *Why is it going to work?*

The diary is aiming to capture some of your emerging understanding and ways of managing and treating women with breast cancer – your developing knowledge.

Think about 'how is my understanding of the way I am managing patients developing over time'? The diary is not a case history; it is about emerging understanding and thoughts.

Acupuncture Treatment Log

The practitioners did not write extensively in their diaries, but the diaries did include personal reflections on specific participants within the study. Practitioners were asked to complete a treatment log after each session in addition to their records that they normally kept. The treatment log contains details for the reporting of trials according to STRICTA (MacPherson et al 2010), and provided space for reflective comments on the rationale for the diagnosis and treatment. These comments were useful additions to the diaries to understand the practitioners thinking process. A copy of the log is provided as Appendix II. The treatment logs were collected at the second interview.

Safety Data and Satisfaction with Treatment

The women participants were asked to complete at the second interview two forms for satisfaction with treatment and reporting of any side-effects or adverse events. These forms were used in a large back pain trial (Thomas et al 2003) and are provided as Appendix V.

Demographic Data

It is appropriate to collect a small amount of demographic data in order to be able to place this data in the context of other studies. This data included age, occupation, marital status, whether there were dependents and menopausal status of the women participants.

Ethical Approval

Ethical approval was given from the Site One Research Ethics Committee in August 2007 and a substantial amendment was approved in September 2008 to have a second site. Approval for the study was given by the Site One Teaching Hospital NHS Trust Clinical Trials Research Approval Board (CTRAB) in June 2008. Research Governance approval from the Site Two NHS Institute for Health Research was given in January 2009. The start of the study was delayed in Site One and that led to another substantial amendment being approved in June 2008. Recruitment started in Site One in November 2008 and in February

2009 at Site Two. The only changes the ethics committee requested initially were that the patient information sheet included more detail on the style of acupuncture delivered i.e. traditional acupuncture. The patient information sheet is attached within Appendix III.

Regarding the development of the topic guide for the acupuncturists' interviews written consent was obtained from the pilot acupuncturists. Ethical approval for interviewing health professionals both within and outside the NHS regarding their views on acupuncture had been discussed at a NREC to establish whether approval was needed. It was decided that obtaining signed consent was good practice even though full ethical approval was not required.

Funding for the Study

Funding was received from the BAAC to cover the cost of the acupuncture treatments, after a competitive round of funding applications. Funding was available for twelve participants. During the study, a further funding application resulted in money for two more participants.

Analysis for the Longitudinal Qualitative Study Using Grounded Theory

Grounded theory offers a systematic approach to the analysis of the data. The focus of grounded theory lies in developing deeper understanding of concepts and generating theories from the data to explain what is happening. An assumption of grounded theory is that social phenomena are complex and dynamic (Strauss 1987). Grounded theory provides a method to explain this complexity. Theory is generated from within the data - '*Generating a theory from data means that most hypothesis and concepts not only come from the data, but are systematically worked out in relation to the data during the course of research*' (Glaser and Holton 2004). Grounded theory aims to capture the relationships between concepts that may explain variation in the object of study. Attention is paid to processes, context and relationships. It involves both an inductive and deductive process, and data gathering, analysis and theory have a reciprocal relationship. The nature of grounded theory for the researcher is their being *involved*, as Strauss put it, '*in the work* – emotionally as well as intellectually' (Strauss 1987, page 10). Glaser and Strauss articulated a grounded theory approach in their *The Discovery of Grounded Theory* (1967) drawing on their research on how patients and health care professionals approached dying in hospitals (Awareness of Dying 1965). They developed a set of analytic procedures to develop a more systematic approach to analysing data and further elaborated and developed their ideas in subsequent work. Over time, their formulations of grounded theory diverged. Others have expanded and refined its use (Charmaz 2006). Here the focus lies on the approach portrayed by Corbin and Strauss (2008). Data collection and analysis are thus seen as continuous processes

that overlapped each other. The formal process of analysing data collected at interview and in other forms is described below.

Grounded theory was chosen over thematic framework analysis for two reasons. Framework analysis seeks to classify and organise data according to themes, generally relies on answering specific questions and relies on *a priori* knowledge (Ritchie and Lewis 2003). Although it is the case that TA has a well-known body of knowledge, the main thrust of the argument for developing the research aim within this thesis is that many assumptions are made regarding what it is. As grounded theory is abductive, incorporating what is already known within the data analysis, for example, judicious use of sensitising concepts explored below, is part of the process of analysis and allows revision of theoretical assumptions. Grounded theory thus provides a more open way of exploring what may be implicit as well as more obvious. Secondly, the output of this thesis aims to provide fresh understanding of TA in terms of a theory of change. Using an analytical technique that aims to generate theory thus seemed most appropriate.

Managing Data

Field notes were made immediately after each interview, with a brief summary description from memory of the main impressions of the interview. A contact summary sheet (Miles and Huberman 1994) detailed the main issues raised in the interview including methodological, observational and reflexive notes. Questions and areas that I wanted to talk about meant that some issues that went unexplored were noted, and any comments on the setting or the interview generally. Finally there was a section on salient points of the interview and my general observations which was an opportunity to explore my position at that moment to reflect on later after transcription. The field notes were an attempt to make explicit my assumptions about the person to reflect on later, by writing an honest account of my initial impressions.

A selection of the field notes are displayed in Figures 4.1 to 4.4, they were made after seeing Lindsay, the second participant on her first interview, and effectively my second interview in this role of practitioner-researcher.

Figure 4.1 Excerpt from fields notes of second participant interview

A section taken from the general notes: *'Lindsay arrived with her partner whom I called her husband and was corrected. He was happy to stay in the waiting room and she told me he came on all of her health appointments – he wanted to “be supportive”. Lindsay was well dressed and made-up. She drove the car to the appointment. She at first introduced herself as ‘Mrs D....’ and I asked her if it was alright if I called her by her first name. She seemed to require some formality. She seemed reasonably comfortable talking her about her cancer, she gave an impression of being strong and capable – a woman who had lived through life experiences and knew how she was going to manage this one. On the other hand, it occurred to me that she was unaware of some of her feelings – she alluded to this with the alopecia saying she didn’t know how it had happened but she thought it must have been a sign of stress – she didn’t report feeling stressed. She had recently had a very difficult time and it sounded like her difficulties were on-going regarding her divorce from her husband – she felt she couldn’t possibly tell anyone about the cancer because he might find out and would most certainly use this against her when it came to dividing assets. This seemed awful to me. I didn’t feel it appropriate to ask her about her divorce. She had one close friend.'*

The feeling for me at this point in the process was that I was not getting the same sense of openness and connection that I get so easily in my practice. Initially, I was struggling to see if this was me doing a poor job as practitioner-researcher or this particular individual. Almost certainly it is a combination of both, my slight lack of ease in my new role being detected by someone who is usually very guarded. At this second interview (Figure 4.2) though it causes a reflection on identity and changes to the self, which unbeknown to me at this stage, is a major theme for this group.

Figure 4.2 Excerpt from fields notes of second participant interview

Reflections on the general impression: *'She described herself as fit and healthy (although she didn’t look too fit and healthy) and that she was super-active, and skied and exercised, that she was sociable and life-and-soul type of person- I felt that this was the part of herself she was used to inhabiting for the rest of the world – the front she put on, and that other parts of herself were more hidden certainly to others and maybe to herself. She was keen to get it (the treatment) over and done with, to get on with it, so that she could then resume her life again. – is this a common theme? Does one resume oneself again?'*

Detail extracted from the contact summary sheet is shown in Figure 4.3 for Lindsay reflecting on what I had not managed to explore, for whatever reason and any salient points.

Figure 4.3 Excerpt from ‘contact summary sheet’

Questions to explore further: ‘*What are her needs now? Can she recognise her needs?*’

Salient points: ‘*She talked a lot about being upset but didn’t get upset. A strong private character, she wanted to busy herself and get on with it.*’

The field notes from the follow-up interview (Figure 4.4) reveal that I was more comfortable with Lindsay, possibly reflecting my own growing experience in the role of practitioner-researcher but Lindsay was not necessarily more ‘open’ as a result and my increased confidence may not have meant I was doing a better job.

Figure 4.4 Excerpt from field notes for the second participant follow-up interview

Excerpt from general notes: ‘*She is a very strong, mature woman used to coping alone and getting on with it. She said that the most taxing thing had been to keep mental strength – she felt she had been much stronger than her breast cancer friends and I asked her what she meant by strong – I think I may have tried to answer this for her because she really was lost for words- it was an awkward moment, and here because I am so habituated in keeping people comfortable I still step in too quickly, but anyway, her answer involved ‘not breaking down’ and staying positive.*’

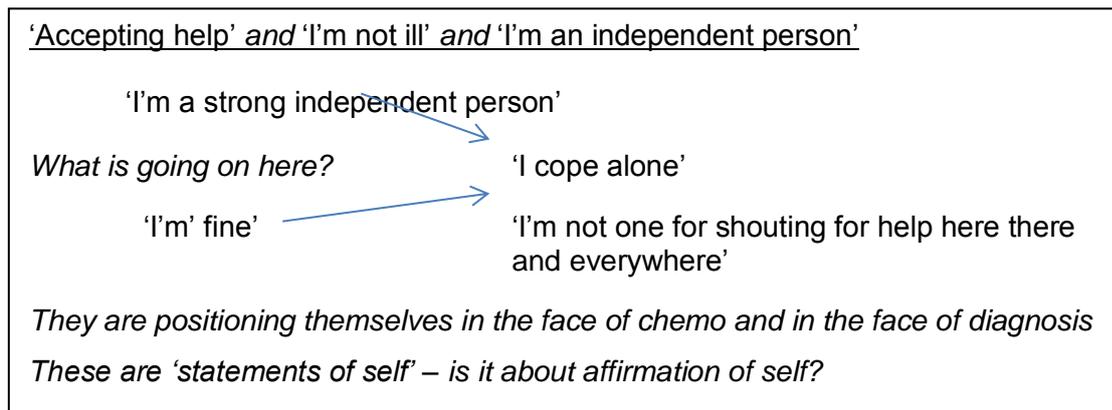
Field notes towards the end of the first interviews included headings on ‘normalising’, ‘identity’ and ‘emotional distress’ reflecting the developing ideas from the data, as well as personal reflections on how well the interview had ‘flowed’, and judgements about how comfortable talking and being open with individuals had seemed.

Process of Analysis

i) Open coding and memo writing

Following Miles and Huberman’s (1994) example, the first step was familiarization with the data. Re-reading transcripts and listening again to recordings and making notes and developing memos was a continuous process along with reference to field notes. Over time core ideas were noted, and the data was re-read and considered with these in mind. As is typical in open coding, the aim was to uncover all possible codes. Ideas and themes that seem to overlap were re-examined and considered. Data was then examined systematically line by line as described by Charmaz (2006 p:50) and in detail asking ‘*what is really going on here*’. Figure 4.5 is a typed example of a handwritten memo written after open coding of the first five interviews.

Figure 4.5 Example of early memo writing



The sub-theme of *accepting help* serves as a useful example of the process of analysis. It was women's difficulty in accepting help that made it a theme as all the women reported that they did not need or want help at the time of their first interview. It also served as a useful example of shifting experiences when this approach of not *accepting help* became problematic during chemotherapy when they needed it. Not *accepting help* was intricately tied up with the women's universal need to be seen to be coping and to '*keep everything normal*', that is, for both themselves and for relationships with others to be as they were before.

ii) *Focused coding*

The data was re-examined for codes that were separate and stand-alone. A constant comparative method was used (Glaser and Strauss 1967). These codes were documented in the language of the data (in vivo codes), that is, phrases or words that captured the essence of what was being experienced or expressed. Sometimes these codes were in the language close to what was expressed. Questions were asked of the data such as '*how do these themes relate to each other?*' and '*what do I see going on here?*' Different contrasting codes were looked at together for differences; and participants experiencing or expressing different things were compared and contrasted together as were codes in subsequent interviews of the same person. Codes were then compared with data. The headings were developed as they became overarching themes. One such theme is reported in Figure 4.6.

Figure 4.6 Development of the theme of therapeutic befriending

1. Constituents of therapeutic relationship	
<i>Participants' data</i>	<i>Practitioners' data</i>
<ul style="list-style-type: none"> • being 'outside of it all' • time to talk • friendly, like a friend • age and experience • apparent mutuality • signs of care • knowledge • acupuncture facilitates relaxation 	<ul style="list-style-type: none"> - creating a relaxing safe space - time to talk - providing an opportunity to open up - attachment and concern - make it friendly - person centred care - explanations - acupuncture facilitates relaxation
2. Therapeutic Befriending	
<p>Participants talk of a mutual relationship but they do not have to be concerned with burdening the practitioners as they might if they were a friend, or for the consequences of a changed relationship or loss of reciprocity. Practitioners say they are a <i>'friend for while they are there'</i>; that is they mimic friendship. The intention of the practitioner is to be friendly to gather information; therefore their focussed attention and memory of detail feels the same as friendship does. Practitioners share a limited amount of their experiences to aid mutuality and rapport. Participants contrast this attention with that of the nurses, who are only making conversation to pass the time. The intention on the part of the practitioners changes the quality of the interaction and participants can detect it. In addition, the effect of the acupuncture means that participants 'open up' during treatment possibly aiding trust and openness and this is reported by both practitioners and participants.</p>	

iii) Vignettes

Each interview was reduced to a short vignette using nearly all the participants own words; thus for each individual participant it was easy to access a brief narrative of the three time points before and during chemotherapy and for half the group, after chemotherapy. This was done to assist in looking at change over time for each individual, a within case analysis, and to compare the stories for different stages with different individuals. It also enabled the identification of contrasting experiences to better sensitise particular areas of difference as described by Strauss (1987). This process assisted the management of the data. An example of a vignette is given in Figure 4.7. The vignettes for all the participants are provided in Appendix VII.

Figure 4.7 Example of vignette for Julie on her first interview

I found the lump in the shower – the doctor and the hospital were very quick with all the tests and I was prepared in my mind, I knew it was cancer. I then had a mastectomy and reconstruction and this was all fine and I didn't need chemo. But then very shortly after I found another lump - I wasn't prepared for this second time, I was absolutely floored because I wasn't ready for the diagnosis, and I have to have chemo. And that has really knocked back my confidence, I can cope but it was a big shock. The anxiety – I feel like a coiled spring, and I can feel calm but then suddenly the apprehension... it is so annoying; and because of this I can't relax, I keep thinking well if it can happen like that, what else can happen? But I have lost my confidence of wondering what is going to happen. What I want is peace of mind – it's always on my mind, I want to be able to put things to the back of my mind. I'm worried that it might come back and I'm worried about the chemotherapy, I feel well, I always feel well, and I can cope with pain but I can't cope with feeling unwell, I don't want to feel sick and unwell for weeks and weeks and weeks.

I don't like being treated like an invalid because I feel fine, I don't like people asking me how I am – I always say 'fine thank you how are you?' My son, he keeps phoning me and asking me if I am all right and I want to say don't ask me. I just try to lead as normal a life as possible. I just don't like being fussed over, thinking people are talking about me and feeling sorry for me. My husband has always been thoughtful and kind, and he has found the right balance for now, not too much fuss, he knows I don't like that.

Feeling well is very important to me; I can cope with anything if I feel well. I want to feel fine and calm and this anxiety – I want to feel in control, because it is at the back of your mind you start getting anxious again and it is annoying. I know longer worry about insignificant things. I can cope with anything if I feel well maybe the acupuncture will help with that. Hair loss comes after the sickness and anxiety in terms of worry.

iv) *Developing categories*

Codes were organised temporarily together as Lincoln and Guba (1985 p:347) suggest where chunks of data appeared to relate to the same idea or concept. This is also about defining categories where initial codes are considered for differences or similarities; to consider whether they are expressing the same thing or whether there is nuance that can be identified. Codes were further interrogated to create higher order categories using the method of constant comparison and search for negative cases. Memos were written during this phase of analysis to assist explanations of the differences and similarities in the data and to develop rationales for coding (Lofland and Lofland 1995) to see if the analysis was making sense.

v) *Time*

Time in the sense of temporal flow was an important analytical category in that focus was on processes of continuity and change as women progressed through the breast cancer trajectory – from diagnosis, through surgery and chemotherapy. Attention was on capturing shifts of nuance of meaning and experience over time as participants proceeded through

stages in the illness trajectory. Initial codes and categories developed were interrogated to explore both the dynamic of change and develop an explanatory account of the process. An example of this as raw data is given in Figure 4.8 where Lena is expressing various perspectives on losing her breast that change over time. Other developing ideas were mapped out in diagrams, to further examine the data. For instance, there appeared to be a struggle with most participants to hold on to a sense of themselves and to keep everything 'normal' and yet at the same time they experienced suffering and loss. The themes were mapped out at three time points to look at changes over time. This gave an overview of the subtle shifts over time for some themes.

Figure 4.8 Example of gathering data over time to capture the process of change

“Losing that breast to me is not a big deal. It’s not stopping me, it’s not keeping me to hide inside and not go out. To be honest, I’m out and about more now than before...”

Lena (1st time-point)

“Because losing a breast that is part of you, it’s a limb! It’s losing a limb...And my self-esteem has hit rock bottom with losing one breast, because I’m right, what you call it – well getting undressed now in front of my husband, whereas before I wasn’t bothered but now I am. You know, and he is noticing that – I’ll turn my back, I’ll go in the bathroom, I’ll switch lights off sort of thing – that side of it has been hell, and it still is.” Lena (2nd time-point)

“I can’t help it – the thought being there at the back of my head you know, or well, with what I have been through, it is like a scar I look on it as a scar on me emotionally as well as physically. And I’ve got to live with it every day.” Lena (3rd time-point)

The Inclusiveness and Consistency of the Data

A further round of analysis was undertaken to look at how consistent the categories were and whether they tell the whole story of the data. The data was examined for negative cases, and to look at outliers and extreme cases. The question ‘*what is this specific thing an instance of?*’ was used for each instance.

Reflexivity and Grounded Theory

The place of the researcher and how she shapes the data is a vital consideration in grounded theory and all qualitative research. As researchers, we are both active in the construction of knowledge through our engagement with participants in the process of data collection and in making sense of it through the development of codes, categories and concepts that are refined through collection of further data. We cannot separate who we are from what we do as researchers, from the formulation of the research question, through data

collection, analysis and interpretation of the resulting data the researcher is central to generating and making sense of it. Being self-reflexive about how we shape the research process and product and how it in turn influences us, enables the reader to identify with and account for how process and product has been generated. In the analysis stage examining the data for solicited material, or reflecting on my presence in the process and how the participant (whether acupuncturist or breast cancer sufferer) might relate to me as well as actively detecting assumptions on my part is part of the reflexive process. In order to achieve this and have a reflexive stance, I made memos and notes and regularly took time to consider my standpoint. The most typical times for me to do this were immediately after an interview with a participant or after I had seen a woman with EBC in my acupuncture practice.

Sensitising Concepts

In approaching the data and asking questions of it, my starting point was the 'sensitising' concept as discussed by Blumer (1969, p148) i.e. concepts that provide a general sense of reference and guidance in approaching empirical instances. Thus, whereas definitive concepts place emphasis on constraining empirical data to fit them, the sensitising concept directs attention on what is distinctive about the specific empirical instance and not just on what it has in common with other instances covered by the concept. As I examined the data and sought to make sense of it through coding to developing categories and creating memos, I explored some key concepts from the chronic illness literature not as definitive concepts but as sensitising concepts, that is, as 'stepping off point' questions to aid analysis (Strauss and Corbin 1998). It was this literature that articulated such concepts as *biographical disruption*, *transition* and *suffering*. This in turn led me back to re-examine the early breast cancer qualitative literature as outlined in Chapter Two; where there was very little use of these concepts. This was also the point in which the synthesis of the qualitative literature was finalised. McCann et al (2010) who used biographical disruption as a framework for analysing their data was published almost at completion of the analysis and was included at the tail-end of the qualitative synthesis. The concept of biographical disruption had already been used as a sensitising concept in the analysis of the data from this thesis prior to this publication.

Theoretical Sampling

Theoretical sampling regarding participants occurred at two points. Firstly, as in keeping with grounded theory, data collection, and analysis can occur simultaneously. As the analysis progressed with the first and second interviews, in thinking about and making sense of the data, it became clear that a third interview would be highly appropriate to develop emerging ideas. Some second interviews were being conducted while women were still

being recruited into the study. The chemotherapy was very demanding and women found it difficult to get perspective on what was happening to them as the majority seemed overwhelmed by the experience. The speed of the treatment trajectory since the first visit to the GP and including the chemotherapy treatment meant women had little time to take in what was happening to them. It was discussion of the data coming out of the first interview which appeared at odds with what might be expected having had a diagnosis of breast cancer that led back to exploring the chronic illness literature. It was the presentation of self as *'normal'* and the cancer excised that was perceived as a puzzle. And while the effects of chemotherapy began to challenge that, it did not completely reverse this notion, leading us to consider whether it was the speed of the treatment process that contributed to this and therefore the need for a third interview to see how women progressed with their adjustment. The participants at the second time point were still struggling to assimilate the shock of the diagnosis. Limited resources meant that choices had to be made regarding who to interview for a third time. It seemed that ensuring inclusion of women at different life stages would enable testing out of the ideas about the impact of diagnosis and treatment over time. The participants were selected for these third interviews according to life stage. Secondly, as recruitment progressed, and life stage was a possible factor in how women experienced chemotherapy treatment, it was felt that the last participant should be pre-menopausal.

Theoretical sampling also occurred within the data analysis process; for example after the first five interviews had been analysed with open and then focussed coding a new question was added to the topic guide. The topic guide was there to explore ideas if they had not emerged naturally in the conversation. The new question was - *'is there anything about the diagnosis and this process of treatment that has had any positive effects?'* This question reflected the idea that the previous participant (Lena) felt her perspective on life had been altered positively as a result of her diagnosis. During the interview with the sixth participant the idea of positive change had not come up so the question was put directly. Another example is as the interviews progressed; the desire to *'get back to normal'* and the broad theme of normalisation was very present, during the latter first interviews. Theoretical sampling of the PhD data was used as the interviews progressed and concepts such as disruption and normalising emerged; questions such as *'do you think you will ever return to normal'* and other similar notions if they had not come up in the interview were posed. During the third interviews the conversation was brought round to this theme to explore change and adjustment over time.

Analysis of Acupuncture Data Using the ToC Framework

The interviews with the two acupuncturists were firstly analysed using a grounded theory approach. There emerged two stages ‘*intentions*’ of treatment and ‘*reflections*’ on treatment given that the interviews were conducted before and after they had completed seeing all the breast cancer participants. Included in this analysis is data from the treatment logs and diaries. A further analysis was conducted using the ToC framework (Box 1) as a way to examine critically the ToC as expressed by the practitioners. The findings from these phases of analysis are reported in Chapter Six.

Interpretation of the Data

Wolcott (1994) expresses the process of analysis as description (what is happening, staying close to the empirical data), analysis (key factors and relationships between them are identified from the data) and interpretation (generating understanding and explanations that contain the analysis but go beyond the empirical referents) and locating them within a wider body of knowledge. Wolcott’s work on transforming data was influential at this final stage. Time was spent thinking about the data, and re-reading transcripts, codes and memos. Ideas were sketched out in diagrams and eventually important themes were generated and were tested against the data. Discussion in supervision of these themes and diagrams aided the interpretation of the data.

Concluding Comments

This chapter has outlined the detailed methods used to address the research question and to realise the objectives of the thesis, following through the methodological issues discussed in Chapter Three. The first three sections of this chapter have explored use of the ToC approach in order to enable exposure of the TA theory in different kinds of research. This approach is novel and experimental, relying on the use of the ToC framework or the thinking therein as a way to articulate assumptions about the process through which change will occur. The fourth and final section expounded the approach adopted and followed through in a longitudinal qualitative study, based on a pragmatically-designed set of TA acupuncture sessions offered to a small number of women with EBC. This aims to add yet further insight into the theory and valued outcomes of TA, core aspects of any ToC model. Inherent is the assumption that the data generated through interaction with the participants relates to ‘real’ experiences that are not simply a product of the research encounter. A reflexive approach ensures that ideas are checked constantly against what was already known and assumed by me. Detailed insight was also provided into the process of data analysis and movement from data to interpretation.

The thesis now turns to present the findings, both from the literature reviews and the empirical study. The next chapter reports on the application of the ToC framework to the selected published clinical studies of acupuncture that have used validated outcome measures.

Chapter Five

Theory of Change in Clinical Trials of Acupuncture for Symptoms Common during Breast Cancer Treatment

Introduction

This chapter directly addresses the third objective of the thesis outlined in Chapter One, to explicate the theories of change (ToC) that underpin acupuncture in clinical trials for common symptoms experienced by women with breast cancer, with a focus on TA and MA. The ToC of these two models was exposed by the process of applying the framework which appears as Box 1 (page 49) in Chapter Four. This framework outlined in the methods chapter was developed with a view to surfacing the ToC in TA and MA. A literature search was conducted, as described in the methods chapter, and the ToC framework was then applied to the included studies. The results of this application are reported below. They appear first via each model that is TA, MA and 'Unclassifiable' and then each outcome is discussed in turn. This chapter draws on a joint publication with the supervisors of this thesis (Price et al 2011). The rationale for the methods and the development of the framework was reported in this paper, and the results included two of the four symptoms detailed here, namely vasomotor symptoms and fatigue. This chapter reports on the explicit or implicit ToC for acupuncture studies with these outcomes and extends that discussion to explore nausea and vomiting and signs of emotional distress (anxiety, depression and insomnia).

Aim of This Review

The aim was to aid the identification of the ToC underlying acupuncture interventions within clinical trials by applying an analytical framework to differentiate two contrasting approaches to acupuncture (TA and MA). In order to fully research this, studies of acupuncture for symptoms commonly experienced by breast cancer patients were systematically selected. Including a range of outcome measures enabled a broader exploration of this subject; these studies were used to examine what the theory is, and whether there is more than one theory evident in these clinical trials of acupuncture. This review is not attempting to quantitatively synthesise evidence for effectiveness or efficacy but unpack or identify the implicit theory behind the intervention using a ToC approach. The first step in this approach is to uncover or identify the essential or implicit theory or theories that underlie an intervention, that is, how the intervention is thought or meant to work and its expected impacts. In the current context,

this is akin to clarifying the underlying therapeutic rationale that guides and lies implicit within the acupuncture intervention.

Results

2297 papers were examined and 27 met the inclusion criteria as at September 2008; some of these papers used several outcome measures e.g. depression and fatigue, in these cases, only the main outcome measure was examined. Appendix VI lists all the papers, their aims and outcomes. The results suggest that studies could fit into one of three models or categories, TA, MA, and 'unclassifiable', that is, where there is insufficient information to identify a fit to either model. Table 5.1 provides detail for studies fitting the TA or MA model including the rationale for the categorisation of each study.

Adherence to a Theoretical Model

For fourteen studies information is either missing completely or is justified by suggesting that 'experts' chose the points. No clear rationale links the intervention to the outcome, and there is no discussion of how change would be brought about. These studies may imply that acupuncture is a fixed, homogenous intervention and there is no reference to the possible inter-linking between symptoms or what might be changed by the acupuncture. It is thus hard to ascertain what the researchers think might be 'working'. One common problem with these studies is that some suggest by description that they are using a TA model while they are actually using a fixed-point prescription, a common feature of a MA model. Use of a fixed-point prescription invalidates a description of the study as adhering to a TA model. It is, however, possible that authors have described a needle technique using the language of a TA model and omitted to provide a rationale for their point selection.

TA Model

Four studies are characterised as TA (Allen et al 1998, Dong et al 2001, Wayne et al 2005, Huang et al 2006). They use defining aspects as described on the left-hand side of Box 1. The language used is embedded within Chinese medicine. For example, Allen et al (1998) referenced their book, which describes all possible variations in treatment and uses a 'manualised' method to enable a more explicit and therefore replicable pathway for how the acupuncturist arrives at a selection of points. Although two studies (Dong et al 2001, Wayne et al 2005) also offer a medical rationale, in addition to a TA one, as to the causal link between acupuncture and vasomotor symptoms this does not dictate how the treatment is carried out. Huang et al's (2006) study used a 'placebo needle', which involved plastic rings and tape. This procedure was repeated for the 'real' acupuncture group and practitioners complained of it altering their practice. More problems in definition emerge as the studies

use the language of a single homogenous intervention such as ‘standardized’ or ‘replicable’ which seems at odds with the individualised and flexible approach described.

MA Model

Nine studies were characterised as MA, in particular because of their description of a biomedical rationale or mechanism as justifying the use of acupuncture and hence the theory underpinning the intervention was rooted in biomedical science. However there are problems in characterising these studies. Three have a tenuous adherence as the acupoints are not described at all (but the biomedical rationalisation is strong). That is, the theory for why it might work is good but the rationale for treatment is poor (Rorsman and Johansson 2006, Kim et al 2004, Spence et al 2004). The other six studies (Wyon et al 1995, Hammer et al 1999, Sandberg et al 2002, Wyon et al 2004, Nedstrand et al 2005, Cohen 2003) use an acupuncture point selection for a symptom (dysmenorrhea) other than the outcome measure (vasomotor symptoms and depression).

Table 5.1 Classification of included studies according to model such as TA, MA or ‘unclassifiable’

Authors	Outcome Measure	Authors’ description of acupuncture treatment	N	Rationale for classification (how the acupuncture points were selected)
TRADITIONAL ACUPUNCTURE				
Allen et al (1998)	Depression		38	The approach used pattern differentiation based on presenting signs and symptoms; and other theoretical frameworks inherent within Chinese medicine
Wayne et al (2005)	Depression	‘TCM style acupuncture’.	33	‘Each patient received a TCM evaluation at each visit based on the ‘4 examinations’, interrogation, looking, smelling, listening and palpitation.’
Dong H, Ludicke F et al (2001)	Vasomotor	‘Classic manual acupuncture (based on the principles of TCM)’	11	Diagnosis and treatment was given based on the interpretation of symptoms and signs of based on TCM; treatment was individualised.
Huang MI, Nir Y et al (2006)	Vasomotor	Based on ‘the principles of TCM’	29	Points were selected from a group that were selected according to TCM <i>patterns</i> but the authors mention elsewhere ‘based on their ability to target hot flashes’. There was a degree of interpretation, and an individualised approach on the part of the practitioner.

MEDICAL ACUPUNCTURE

Sandberg, Wijma et al (2001)	Anxiety	'The choice of points was based on a previous study on vasomotor symptoms in postmenopausal women. Thus the acupuncture points were not specifically intended for psychological symptoms.'	75	This study is the same as Wyon et al 2004 but with a different outcome measure. It is included because the rationale for the mechanism of acupuncture is slightly different to justify an effect on mood. This however was not related to the treatment, which was the same as for the other Swedish vasomotor studies. The authors do not discuss the mechanisms underlying the main outcome measures (either hot flushes or mood); and therefore the link between the rationale for treatment and outcome is very weak.
Spence, Kayumov et al (2004)	Anxiety/ Insomnia	'...the study investigated the use of traditional (symptomatic) acupuncture...'	18	This study successfully links the mechanism of the symptoms and the hypothesised mechanism of acupuncture – that acupuncture can influence melatonin production and endogenous opioid production.
Kim, Lee et al (2004)	Insomnia	'In oriental medicine, acupuncture has been frequently used for insomnia. Recent studies show that acupuncture can control the autonomic nervous system and Shen-Men and Nei-Kuan acupuncture can reduce sympathetic activity.'	32	There is a clear link between the rationale for the mechanism of the symptom (stroke-induced insomnia) and mechanisms for the acupuncture points chosen (based on several cited studies for these two points). This design is similar to the P6 for nausea studies except that the citations to back up the ideas, and the exploration of mechanisms are more thorough
Rorsman and Johansson (2006)	Depression	'...to assess the effects of different types of sensory stimulation...'	54	The rationale for the point choice appears in a previous publication. The authors were clear and stated this 'should not be considered a study on acupuncture consistent with traditional Chinese medicine.'
Wyon Y, Lindgren R et al (1995)	Vasomotor	'classical acupuncture'	24	No rationale given as to why choosing points for a different syndrome/disease (dysmenorrhoea) except that they didn't know what else to do. As the rationale for treatment is based on matching the mechanism of disease with the mechanism of acupuncture – this group have rationalised that beta-endorphins are the key link.
Hammer M, Frisk J et al (1999)	Vasomotor	-	9	These were male participants given a fixed-point prescription chosen for dysmenorrhoea because the mechanism of vasomotor symptoms is hypothesised to be linked to the production of beta-endorphins.

Cohen SM, Rousseau ME, Carey BL (2003)	Vasomotor	'Within Eastern thought, acupuncture is viewed as a holistic approach grounded in Chinese medical philosophy.'	18	Much TCM language is used in the paper but the points were the same fixed prescription as the other MA vasomotor papers, the rationale for treatment is based on matching the mechanism of disease with the mechanism of acupuncture – this group have rationalised that beta-endorphins are the key link.
Wyon Y, Wigma K et al (2004)	Vasomotor	-	45	As the rationale for treatment is based on matching the mechanism of disease with the mechanism of acupuncture – this group have rationalised that beta-endorphins are the key link and have used the same fixed-point prescription as the other vasomotor studies.
Nedstrand E, Wikma K et al (2005)	Vasomotor	-	38	As the rationale for treatment is based on matching the mechanism of disease with the mechanism of acupuncture – this group have rationalised that beta-endorphins are the key link and have used the same fixed-point prescription as the other vasomotor studies.

Unclassifiable

All the nausea and fatigue studies fit into this category. The nausea studies in particular offer very little in the way of rationale at all, and these research designs are the most similar to a classic RCT, as if one acupuncture point (P6) is equivalent to an anti-nausea pill. The rationale for effects on fatigue is recognised to be poorly understood. Some authors allude to its being multi-dimensional (Vickers et al 2004) and this may explain why in the research studies the acupuncture offered is not recognisable as either MA or TA. What is curious is the degree to which the authors suggest that it is 'traditional' or 'classical' and may signify some lack of knowledge or due diligence on the part of the authors.

Exploration by Symptom

Examining the studies by symptom provides additional insight into how certain approaches have evolved. The vasomotor and fatigue category were reported in the publication informed by this thesis (Price et al 2011) and the results are reproduced here.

Vasomotor Symptoms

Five of the nine vasomotor studies are arguably in the MA category (Wyon et al 1995, Hammer et al 1999, Wyon et al 2004, Nedstrand et al 2005, Cohen et al 2003) and four of these come from one group of Swedish researchers. Their description of a biomedical mechanism as justifying the use of acupuncture and hence the theory underpinning the intervention was rooted in biomedical science. However there are possible problems in characterising these studies due to the fact that they use acu-points for a symptom other

than the outcome measure. The rationale for point selection is reported in Wyon et al (1995) and similar language is used in the other four papers:

“As there was very sparse experience of acupuncture therapy for climacteric symptoms, the choice of acupuncture points was a modification of points used in previous studies on acupuncture treatment of dysmenorrhoea.”

The authors describe the effects of acupuncture in biomedical terms and match acupuncture's effects to a possible biomedical mechanism underlying the symptom:

“acupuncture could decrease hot flushes by regulating temperature control through increasing beta-endorphin levels and subsequent inhibition of GnRH.”

As this is suggestive of a very general effect, it raises the question of how specific does the understanding of the biomedical mechanism of the symptom have to be to justify an effect and how strong does the link need to be between theory, anticipated mechanism and actual point selection to ensure a robust model. In addition there is the problem of the hypothesized mechanism of hot flushes and Deng et al (2007) are upfront about this:

“it has been hypothesized that acupuncture regulates neurotransmitters involved in thermoregulation. Few data currently support this contention.”

Of the other four studies, two follow a TA model (Dong et al 2001, Huang et al 2006) describing some of the defining aspects for TA displayed in Box 1 but some are assumed; for instance, offering individualised CM treatment it is likely to include a differential diagnosis. The other two are unclassifiable (Deng et al 2007, Frisk et al 2008).

Fatigue

None of the five fatigue studies could be classed as either MA or TA [26-30] and all studies had a weak rationale for the chosen treatment. Some studies allude to a more 'traditional' model. Vickers et al (2004) describe their selection of acu-points as:

“these points typically are used in Chinese medicine to treat fatigue,”

citing in support a widely used textbook [39] that is more focussed on point location than theory of CM. An examination of the referenced textbook for one of the chosen points (Spleen 9) does not refer to tiredness or fatigue but rather to

“abdominal distension, cold and pain of the abdomen, cutting pain in the middle of the intestines, no desire to eat... “. [p194]

In addition there is no explanation as to why the authors modified the points used during the research study. The absence or weakness of a rationale for the chosen treatment in all five

studies may be partly due to the possibility that no biomedical mechanism associated with fatigue has yet been discovered.

Depression, Anxiety, Insomnia Symptoms

Of the eight studies that examine the impact of acupuncture on these various symptoms, two are TA studies (Allen et al 1998, Wayne et al 2005), four studies of the MA type (Sandberg et al 2002, Rorsman et al 2006, Spence et al 2004, Kim et al 2004) and two cannot be classified (Roschke et al 2000, Paraskeva et al 2004). The study by Rorsman et al (2006) illustrates the issue where the authors are not explicit about the acu-points chosen, referring to their having been used in an earlier study. Rorsman et al (2006) carefully state that the acupuncture used:

“(this) should not be considered a study on acupuncture consistent with traditional Chinese medicine. Treatment was standardized and electro-stimulation was used with the purpose of producing broad physiological changes. The chosen outcome measures are behavioural and activity-orientated rather than organic.”

The theoretical basis for choosing the points is unclear and whether or not a different set of points would have made a difference.

Nausea and Vomiting

Five studies met the inclusion criteria with this outcome measure; three of them (Dundee et al 1988, Aglietti et al 1990, Streiberger et al 2003) cite Dundee et al 1987 as the justification for the single acu-point P6 used symptomatically. These authors offer no theory for why this treatment would work, or why this point is chosen. Only Shen et al (2000), attempts to describe the biomedical mechanism behind the effect of acupuncture on nausea and vomiting and describes the intervention as a ‘common symptomatic approach.’ Due to the known effect of anti-emetic medication it is perhaps surprising that for this symptom more biomedical justification for this P6 acu-point treatment is not offered.

What are the Gaps in Knowledge?

There is evident uncertainty regarding the efficacy of acupuncture and this novel exploration of the literature offers some clues as to why. Certainty and conviction in acupuncture could be increased if authors were able to offer a good enough reason as to why particular acu-points were chosen over others. If the MA approach is operated, then linking acu-points with a plausible anticipated effect on biomedical mechanisms would increase confidence. Some authors cited lack of knowledge for choosing acu-points for symptoms other than the outcome measure based on a supposition that the two might be linked; for instance

dysmenorrhea and vasomotor symptoms. There is a large body of knowledge available in China accessed through different branches of science and history that may give ample argument for certain approaches to treatment. It is possible that the desire to avoid the taint of traditional medicine by ignoring these sources overrode the search for them.

Concluding Comments

This chapter has begun the process of drawing out 'what TA is' and how change is brought about by applying a model of TA, developed from the professional content and guidelines of its main professional accrediting body (BAcC), as outlined in Chapter Four, to research in the form of clinical trials on commonly experienced symptoms for women with breast cancer. The chapter applied the ToC framework (see Box 1, page 49) for the two models of acupuncture, TA and MA, to these studies. The framework was applied to systematically selected studies to critically appraise their model validity and the ToC.

The framework was helpful in identifying the explanatory models used and exposing how acupuncture as it is researched may differ from the theory espoused by the accredited professional governing bodies. The ToC of TA developed from the professional educational material only matched four of the twenty seven studies. Given that for several of these symptoms the biomedical mechanism is unknown, making a case for using MA is also difficult but this did not stop some authors offering a hypothesised ToC in keeping with the biomedical model.

A major finding of the analysis of this selected literature is that more than half of the studies had no identifiable ToC as to how the acupuncture might work or why certain acu-points were chosen. This helps to partially explain why there is so much uncertainty around whether acupuncture 'works' or what works. Although it is important to reflect on whether the ToC framework actually worked as suggested in a paper, the fact that there was no alternative rationale presented in a paper to the reader suggests potential flaws in the thinking behind the intervention.

The ToC is concerned with the long term goals. Within the TA model this tends to mean or be expressed in terms of multiple outcomes in the mind and body of a person. In contrast, clinical trials tend to restrict the goal of the acupuncture intervention to single outcome measures which fit more comfortably with the MA model where only changes in dimensions of symptoms are aimed for, whether or not other changes are reported or measured.

A final point to note from this examination of the selected studies is that none offered additional insight into further aspects to add to or refine the ToC as outlined within the framework presented in Box 1 (page 49). The next chapter takes the analysis and discussion a stage further and looks at a different set of research literature, that is, studies of TA which have sought the practitioners' and patients' perceptions of it, its delivery, benefits and modes of working. This is with a view to, as appropriate further refine the ToC for TA, a process undertaken in the final chapter of this thesis.

Chapter Six

Surfacing the Theory of Change: TA Practitioner and Patient Perspectives

Introduction

This chapter directly addresses part of the fourth objective of the thesis, namely to cast additional light on the ToC of practitioner and patient perspectives on TA. As indicated in Chapter Three, a ToC centres on how change might be brought about and intended outcomes (in the sense of long term goal(s)). As explained in Chapter Four, this chapter examines two sets of systematically selected literature: qualitative studies that report on practitioner perspectives of TA, so as to provide insight into TA's potential outcomes and into practitioner perspectives of how TA might work; and qualitative studies which directly report on patient experiences and perceived benefits of receiving TA, thereby offering insight into factors facilitating change and perceived value and beneficial outcomes. The aim of this review of the literature was to explore the ToC for systematically selected papers on the patient and practitioner experience of TA. Each set of literature is considered in turn. The critical thinking employed to develop the ToC Framework (Box 1, Page 49) was used as the guide in the appraisal of these papers as well as the critical appraisal evaluation tool for qualitative research (Long and Godfrey 2004).

Practitioner Perspectives and Theory of Change

The literature search identified three papers (Macpherson et al 2006, Hughes et al 2007, Jackson and Scambler 2007) that met the inclusion criteria. Each used interviews with practitioners regarding their views on acupuncture and all the participants in the studies were reported to be members of the BAAC and practising TA. Hughes et al (2007) also interviewed practitioners of '*western acupuncture*' as the aim of this work was to explore contrasting approaches to practice. MacPherson et al (2006) employed a nested qualitative study within a large RCT for chronic low back pain; as the focus of this study was expanding what TA means '*beyond needling*', it provides much more relevant information regarding the ToC than the other two studies. The focus of Jackson and Scambler (2007) study was on practitioners attitudes to scientific evidence and whether it influenced their practice.

Table 6.1 provides an overview of each study, including the study aim, a brief overview of the methods and an evaluative commentary. In addition, given the focus of the chapter, the fourth column of Table 6.1 draws out key findings or comments in the papers about '*how TA*

might work'. The focus in examining each paper was to draw out what practitioners might do to bring about intended outcomes, in other words, to answer the question '*what are they trying to do and why?*' It is important to note, as was ruminated in Chapter Five for the clinical trials papers, that there may be many reasons why a theory of change is not made explicit within a published study.

Achieving longer term goals was dependent on engaging the patient with the treatment process. Long term goals were achieved through bringing about insight into health and illness and changes in lifestyle with a whole person focus (Hughes et al 2007). All three studies described to different degrees that TA worked through regulating or assessing the strength of the individual's *Qi*, regulating *Qi* and addressing energetic imbalances. All emphasised the holistic nature and individual focus within treatment. MacPherson et al (2006) were most explicit about the ToC and suggests this as involving multiple causal pathways.

Two studies (Hughes et al 2007, MacPherson et al 2006) emphasised the central role of the therapeutic relationship in both facilitating treatment and to engage with individuals sufficiently to empower them to make changes in their lives. Changing behaviour was seen as the lynchpin in obtaining long term goals of improvement in the various parameters of chronic illness.

The papers show that practitioners used the explanatory model of TCM to link the illness experience to other broader life experiences both in terms of understanding illness onset and in what might contribute to improvement or deterioration (MacPherson et al 2006) as treatment progressed. This was in part what was meant by '*helping patients make sense of their condition*', but also in using Chinese medicine theory as an explanatory model of how treatment might work or ways in which they had become ill. Direct examples of this were reported from practitioners. According to the practitioners some patients wanted to be 'fixed' whereas others were appreciative of a more engaged experience; being person-centred is about gearing the treatment to what the patient want (Hughes et al 2007, MacPherson et al 2006). MacPherson et al (2006) concluded that both the relationship and individualised treatment worked together to reinforce increased agency in self-care. Hughes et al (2007) found that the intentions of the practitioner and their theoretical framework changed the goals of treatment.

Table 6.1 Studies on the Practitioner Perspective

Authors	Study Aim	Methods Overview	How TA might work	Evaluative Summary
MacPherson et al (2006)	To characterise the treatment process in a trial of TA for chronic low back pain	6 acupuncturists were interviewed after participating in a trial for low back pain	Practitioners aimed for long term improvement in back pain. They worked to engage with their patients understanding and attitudes to effect change in self-care for instance a) meaning in linking the illness experience to broader life experiences b) lifestyle factors that made things better or worse c) using the explanatory model of TCM to gain new insight. Practitioners reported that it took time to get some patients to engage with this process and some did not at all. Practitioners felt it was the combination of acupuncture treatment and engagement that facilitated changes in behaviour and increased care in self-agency. Building a good therapeutic relationship was an important factor in attaining the long term goal.	This is a descriptive interview-based study where a-priori and emergent themes are merged. Interviews were conducted by an acupuncturist who was then himself interviewed by the co-researcher. A thematic framework approach was used to analyse the data. Raw data was included and a range of patient/practitioner experience reported. No reflexive account is given.
Hughes et al (2007)	Exploring the impact of practitioner affiliation to a traditional or western theoretical base	19 practitioners were interviewed, 9 of whom were members of the BAAC and practising TA. They were interviewed about the treatment of rheumatoid arthritis.	This summary relates to the 9 TA practitioners - treatment goals included improvement in symptoms, improved general physical and mental health, increased emotional wellbeing and healthier lifestyle changes. 'Treatment' was seen as the entire process and experiences all having the potential to impact on the outcomes. Treatment was iterative with patients themselves inducing change as a result of earlier changes. The therapeutic relationship was seen as important and goals of treatment were achieved in partnership.	Analysis used grounded theory and is described in detail. Convenience and purposive sampling is used although the authors called it theoretical sampling. Data collection is described. Written accounts were sent to participants for feedback; a reflexive approach was adopted.
Jackson and Scambler (2007)	Practitioners' perceptions of evidence and evidence based medicine in relation to their practice of TA. Consideration is	Semi-structured interviews with 10 acupuncturists to explore their perceptions of how TA works and the value of evidence of	Practitioners understood TA to work through regulating Qi or harmonising the five elements. Their goals of treatment were to see broader effects in addition to reductions in symptoms. Focus was on treating the individual and the whole person. They had no explanation of how it worked 'scientifically' and were ambivalent about this and EBM in general.	Although the sampling and interview were described, no information was given on the analysis of data. Both authors examined the transcripts. This study explores a small sample of TA practitioners' attitudes towards EBM but does not make comment

	given to the cross cultural divide between biomedicine and CAM	efficacy		on different kinds of evidence.
--	--	----------	--	---------------------------------

In summary, these three studies drawing out a practitioner perspective on TA provide insight into the importance of engaging with individuals in different ways to bring about long term goals. These long term goals were not specific, except in the case of chronic back pain (MacPherson et al 2006), but intended outcomes included both improvement in symptoms and in the whole person such as changed behaviour and new insight. How TA works is in part through addressing energetic imbalances, including strengthening and regulating or balancing the *Qi*; and in engaging the individual with her health trajectory. As a consequence there are multiple causal pathways to change.

Patient Perspectives on Experiences of TA

The literature search identified fifteen papers relating to fourteen different studies (Cassidy (1998) Alraek and Barheim (2001), Gould and MacPherson (2001), Paterson and Britten (2003, 2004), Walker et al (2004), Griffiths and Taylor (2005), Paterson (2006), Paterson and Britten (2008), Alraek and Malterud (2009), Hughes (2009), Hervik and Mjaland (2009), Evans et al (2011), Rugg et al (2011), Huang et al (2011)). Not all the searched qualitative studies were included in the analysis as findings provided no relevant data. Schroer et al's (2009) study, which explored views regarding depression for effectiveness trials, was not included. Although both patients and practitioners were interviewed, the findings did not differentiate the views of other participants, such as GPs and shed little, if any, light on why patients sought TA or how they benefitted or what practitioners did. Bishop et al (2011) and Barlow et al (2011) were also not included as both studies had a focus respectively on NHS care compared to private practice or differences in cohorts in research trials. Neither study added any detail given the focus of this review. Some studies are included even if there is doubt as to whether the acupuncture offered was individualised or 'traditional' (for example, Hervig and Mjaland 2009); if the intervention might have used a semi-standard protocol (Walker et al 2004); and whether the methods were mixed and the qualitative element was minimal (Gould and MacPherson 2001). Smithson et al (2010) was not included as it was a meta-synthesis of CAM studies for cancer. Upon examination, there was not enough differentiation of TA specifically to warrant inclusion given the aim of this review.

All of the studies reported on the use of TA for chronic illnesses and a broad range of perceived benefits. There are important methodological considerations. Studies in this review include a range of sampling (prospective and convenience) which means a spread of views was explored. Most of the patient participants were paying for treatment themselves and had sought out TA. Rugg et al (2011) is one of the exceptions and the authors made extensive comment on the implications of this. Four papers had less to offer the focus of this review because interest lay more on whether treatment had worked or not, or levels of

evidence (Walker et al 2007, Jackson and Scambler (2007), Hervik and Mjaland (2009), Huang et al (2011)). Most but not all the studies included a negative case analysis.

In contrast to the previous section, interest here lies in understanding the experience of TA as perceived by patients and its impact on them. As a ToC starts with the long term goals, exploring patient perspectives on these goals, what patients' value and the perceived benefit may further elucidate the ToC of TA. All the included studies are summarised in Table 6.2, including aims of the study, methods and brief evaluative comments on the study. The third column of Table 6.2 draws out key findings or comments on the desired outcomes and perceived benefits and any other insight into factors that might have facilitated these outcomes or brought about such a change.

Following a review of these studies, consideration is given to material within them as a contribution to the ToC for TA. Some of the perceived benefits or outcomes are grouped together under headings for the purposes of this review, for instance, 'changes in self-concept' includes studies that described changes in personal confidence, ability to cope, self-awareness and personal or social identity. These headings are used later in this chapter in further consideration of the ToC of TA.

Cassidy (1998), in a large survey which included opportunity for participants to write in their own experiences, had many findings that were echoed by subsequent studies. Broadly in all of these papers, there were two layers of change, those related to symptoms and changes to the whole person. Gould and MacPherson (2001) described how their findings had concordance with Cassidy (1998) including new holistic understandings. Participants appreciated an '*educative*' style of treatment, meaning practitioners relating experiences to a TA explanatory model, even though, like Cassidy (1998), individuals found their own language to describe this such as '*balance*', '*well-being*' and '*self-awareness*' in relation to their new insights, rather than the technical language of TCM. Participants valued all aspects of change to their mental, emotional and physical health. Two of the included papers are from the same single prospective study (Paterson and Britten 2003, Paterson and Britten 2004) each paper focusing on different aspects of the findings. Both papers provided information about valued outcomes from treatment and ways in which the process of treatment was linked to these changes. Changes in energy were described as '*feeling stronger including an increase in physical and emotional strength*'. Changes in the presenting problems resulted at times in changes to lifestyle changes and self-awareness. One of the papers (Paterson and Britten 2004) provides insight into patient perspectives over how the treatment might work. For example, participants discussed their treatment not just in terms of needling skills but also with regard to the therapeutic relationship and '*new*

understanding of the body and self as a whole being'. New insights into health and illness fed into changes in treatment.

Griffiths and Taylor (2005) is valuable because it is set in Australia (all the other included studies are from within the UK, aside from three from Norway (Alreak and Barheim (2001), Alreak and Malterud (2009), Hervik and Mjaland (2009)) and uses a different methodology (phenomenology). Twelve participants were recruited using purposive sampling and they described the differential diagnosis including observing the tongue and pulse and a detailed history. Participants expressed a sense of being cared for because of the multiple questions and a sense of real interest in them as an individual. This study also provides interesting data on the experience of the treatment itself; participants described '*energy running*' and '*energy flow*'. In another study, Paterson (2006) used interviews with patients of TA between three to five months after treatment to explore changes in self-concept. Self-concept is defined as an expression that can mean changes in self-esteem and self-respect and the paper cited findings from other studies in support of these outcomes of TA (Cassidy 1998, Gould and MacPherson 2001, Paterson and Britten 2003). This study contributes to understandings of ToC because of the findings that more than half the participants did experience changes in self-concept. In summary seven of the included papers (two from one study) report changes in self-concept as well as other benefits.

Hughes (2009) explored patient experiences of two different types of acupuncture, '*western acupuncture*' or TA. The patients of the TA practitioners were more likely to describe the treatment as encompassing more than needles and experienced whole person effects which enabled them to regain their lives. It is important to note that 3 of the 13 participants had received on different occasions TA and 'western' types of acupuncture, yet the findings included comparisons of one style over another.

Rugg et al (2011) sampled a cohort of prospective patients from a much wider socio-economic group who did not pay for their treatment in contrast to most of the other studies. These participants had medically unexplained symptoms and the majority experienced wide-ranging benefits from this treatment. Participants attributed being actively engaged in the process to the practitioner listening and responding to them and they interpreted the explanatory model of TA in layman's terms - in keeping with several other studies. They also saw themselves as actively seeking understanding and discussion about treatment. They felt involved because the practitioners asked them lots of questions. They followed or negotiated or considered changes to their diet, relaxation, exercise and other social activities. Acupuncture was seen in relation to 'personal energy' and how this was balanced, or moved or regulated. An outcome of this whole process was that they had increased self-

awareness and reflected on how they managed their problems outside in their general life. They liked the whole person approach because they were asked about physical, emotional and social dimensions of health. An additional outcome suggested by the authors was that patients felt more able to cope as a result of being more engaged and more empowered. They described their practitioners as *'warm, open minded, trustworthy and knowledgeable'*. Participants who experienced wide ranging changes were not always able to attribute it to the acupuncture.

An important value highlighted by seven of these studies is changes in self-care or as expressed by Evans et al (2011) as *'increased agency in self-care'*. Evans et al (2011) used novel methods to gather data regarding self-care in TA consultations, and then interviewed patients of four practitioners after they had listened to the audio recording of their treatment session. This gave unique insight into the interaction between practitioners and their patients and the way in which self-care talk was initiated. The findings show that several kinds of talk are inter-woven in self-care talk, and that sometimes this talk is initiated by the patient, and it has an air of mutuality about it.

Most importantly in thinking of the ToC, self-care talk is individualised by embedding it into the particular patient's TCM diagnosis. For instance in one patient interview, the participant described thinking that the concept of *'damp'* was *'nonsense'* until she began to relate her experience of heavy legs (she had a medical diagnosis of MS) being worse under certain conditions; or behaviour relating to the concept of *'damp'* as explained by her practitioner. A similar example is given in MacPherson et al (2006), who focus on self-care from the practitioners' perspective (reported above), in relating a patient's back pain to feeling tired, and *'overdoing it'* as not having enough *Qi*. It is valuable here to reflect that one goal in TA is to bring about improved health and wellbeing in the long term. In consequence, an important part of the ToC is to change lifestyle and behaviour to enhance health and make this long term goal more likely.

Table 6.2 Summary studies exploring patient perceptions of TA

Authors	Aim of Study	Methods Overview	Desired Outcomes Perceived Benefits	Evaluative Summary
<i>Cassidy (1998)</i>	To explore what users of TA value about their treatment	Analysis of 462 handwritten stories of TA patients, collected as part of a survey of 6 acupuncture clinics in 5 states in the USA. Participants were given questionnaires within which there were 'spaces' to write their own experiences. This paper reports on the answers to one question 'now tell us your story'. A fictional story was provided as a guide of what might be written. A total of 575 questionnaires were completed.	A range of emotional and physical benefits were reported including increased energy and relaxation, faster healing and recovery. In addition patients reported new insights into health, new guidance and responsibility for health. A quarter of the sample mentioned the relationship with their practitioner as being pivotal to the success of the treatment.	The findings are limited by the methods; the analysis is not described and no reflexive account is given despite the author being a practitioner-researcher. Although the findings can be described as descriptive, there is a degree of unquestioned interpretation apparent. Some of the findings relate to answers to fixed questions such as offering a choice of nine words to describe the relationship with their practitioner. Cassidy situates the findings within a definition of holism as the guiding framework; included within this is some definition of Chinese medicine theory. The paper presents a substantial amount of raw data. Although this is a very useful study, it is difficult to judge the value of the participants' comments, as there is little detailed analysis and question marks over the study's rigour and thus reducing the trustworthiness of the findings.
<i>Alraek and Barheim (2001)</i>	To explore health changes experienced by women after acupuncture treatment for recurrent cystitis	46 women of the 67 participants in a RCT of TA for recurrent cystitis completed and all returned an open-ended free-text questionnaire, sent out 2 weeks after the end of treatment. The text was analysed with a phenomenological approach.	Women experienced improvement to symptoms of cystitis plus more energy, better sleep, improved bowel function and reduced stress. The authors comment that this range of outcomes matches with TCM patterns of diagnosis.	The text was analysed by the two authors separately. Useful reflective comments are offered by the authors on the strengths and limitations of the study. Methodological limits include lack of follow-up questions to explore meaning which might have been possible in an interview. In this way, the analysis remains at a more descriptive level.
<i>Gould and MacPherson</i>	To explore patient	4 acupuncturists offered questionnaires to all 132 of	A range of outcomes were reported from physical and emotional change	This paper reports predominantly on a seeming pre-coded questionnaire (thus, not

(2001)	perspectives on outcomes while having TA	their patients in a two-week period, 72 responded; 11 of these, selected by purposive sampling (experienced 'substantial change' and attributed this to the TA), were interviewed.	through to wider benefits involving the patients' lifestyle, outlook, and attitude toward their health. Patients report changing their priorities during treatment; the authors suggest this is in response to interest in their whole health. Authors argue that existing outcome measures are not adequate to assess these wider benefits.	qualitative); the authors supplement these data (which were reported only in a Master's thesis) within the discussion section. These latter quotes help to illustrate the issues surrounding their experiences and changes. This is problematic, as little insight can be gleaned into this interview data, nor the way that this was analysed.
<i>Paterson and Britten (2003)</i>	To explore problems and benefits deemed important for individuals with chronic illness receiving TA	8 practitioners informed prospective patients of the study. 23 patients with chronic illness receiving TA for the first time were interviewed three times over a 6 month period. Prior to each interview (exploring their experiences of illness and treatment) participants also completed three health status questionnaires and cognitive interviews used to discuss their questionnaire responses. Grounded theory was used in the analysis.	This paper focussed on insight into the whole-person effects experienced from TA and also the value or otherwise of the three health-status questionnaires to capture these experiences. This paper is one of two papers reporting on this study (see also Paterson and Britten 2004). Whole person effects such as changes in self-awareness, self- confidence, self-acceptance and self-help captured in interviews were not necessarily reflected in the questionnaires. Other perceived effects were changes in strength and energy and personal and social identity.	This is a rigorous study with detailed description of the process of analysis using grounded theory and a reflexive approach. Other strengths include a variety of data gathered including both interviews and questionnaires at three time points enabling a look at the process of treatments and outcomes over time. The practitioners were also interviewed but there is no detail available from this data or published elsewhere which might have offered further valuable insight into the TA intervention.
<i>Paterson and Britten (2004)</i>	To explore how the experience and the effects of a course of acupuncture evolved over time	8 practitioners informed their patients of the study. 23 patients with chronic illness receiving TA for the first time were interviewed three times over a 6 month period. Grounded theory was used in the analysis	This paper is one of two papers reporting on this study (see also Paterson and Britten 2003), focusing on the experiential data. This study explored the idea that TA is a complex intervention and offers a holistic model. Treatment effects included a) changes in symptoms b) changes in energy c) changes in personal and social identity. Insightful vignette portrayals of three participants are provided. The TA was characterised	This is a valuable and rigorously executed study. Detail was provided on recruitment, interviews and analysis of the data. Reflexive and analytical memos were written during data collection. Vignettes are also used to provide a summary overview of the cases. Findings were sent to six of the acupuncture practitioners who were then interviewed and content analysis was used for the resulting data; this was done 'for rigour' and to check 'emerging hypotheses'. How these interviews influenced the analysis is not clear except that

			by the practitioner's needling and diagnostic skills, the therapeutic relationship and new understanding of the self as a whole being. The authors offer insight into the complexity of TA in that components of process are entwined with effects leading them to conclude that TA is a complex intervention.	separately the practitioners describe the diagnostic process is 'on-going' and other detail. Negative cases were included.
<i>Walker et al (2004)</i>	To evaluate the experience of women with breast cancer receiving TA for menopausal like symptoms associated with Tamoxifen	Focus groups – 4 discussions. 50 women who had had TA were invited 16 of which came to the groups. At least nine months had elapsed since their last acupuncture treatment. Grounded theory was reported to have been used but not described in detail.	Women reported relief from menopause-like symptoms plus they felt more able to cope. TA was relaxing and enjoyable and they valued the therapeutic relationship. Other benefits were improved sleep, relief from aches and pains; women felt that both the therapeutic relationship and the actual needling were important	Although a range of perceived benefits from receiving the TA are reported, the lack of detail regarding the methods, and especially the analysis, makes judgements about the rigour of the findings problematic.
<i>Griffiths and Taylor (2005)</i>	To describe the lived experience of acupuncture (to enable nurses to inform their patients more accurately)	A phenomenological study using unstructured interviews asking about their experiences of having acupuncture involving 12 participants already receiving TA.	Participants described the differential diagnosis phase of treatment, including interest in the history and being treated as a whole person, tongue and pulse taking; their understanding of how acupuncture works (as 'energy flow' or similar); immediate experiences post-treatment (including feeling relaxed); and successful treatment outcomes (changes in symptoms).	A clear definition of TA is provided and rationale for use of Van Manen's phenomenology focused on the meanings and lived experiences of participants. Methods of accessing participants, data collection and analysis are well described. There is less detail reported on outcomes, which are more limited as to whether the TA 'worked' or not.
<i>Paterson (2006)</i>	To identify outcome measures suitable for quantifying changes in the self-concept	Following a literature search, three questionnaires suitable for assessing changes in the self-concept were evaluated. A convenience sample of 23 patients of 5	The interview data point to changes across a range of areas: self-awareness, self-acceptance, self-confidence, self-responsibility and self-help. 15 participants (half the sample) were considered to have experienced changes in self-concept.	In the search for outcome measures that reflect what patients value about TA, this study explores three possible questionnaires relating to well-being and enablement. The definition of self-concept is that a dynamic component is self-esteem which itself has two dimensions (self-efficacy and self-respect).

	while receiving TA	acupuncturists completed two sets of questionnaires and a semi-structured interview (including cognitive interview in relation to the questionnaires). The interview data were coded, reflexive memos written and within case analysis undertaken via vignettes.		Sufficient detail is provided about the way the study is done and the methods seem appropriate. Given use of a convenience sample, care must be taken in generalising from the study, treating the findings as indicative rather than definitive.
<i>Paterson and Britten (2008)</i>	To characterise the diverse nature of experiences of acupuncture treatment for chronic health problems	Secondary analysis of 5 studies of either TA (3), Western Acupuncture (WA) (1) and TA as the intervention arm in a research trial (1). The secondary analysis used the constant comparative method to develop a theoretical understanding and patient's perspective of holism, and the use of vignettes drawn from the patients' experiences.	Holism in the sense of 'being treated as a whole person' was a common feature of TA. This was rarely mentioned by patients receiving WA, where focus lay more on a single symptom. A model of factors affecting patients' experience of their care as holistic, including the therapeutic theory underlying the treatment and practitioner and patient intentions (and needs). Holistic care is argued to be good for complex health problems and emotional upset.	Sufficient detail is provided on the process of analysis, a constant comparative method, with varied cases adding rigour to the findings. The use of vignettes adds depth and detail to the findings. Of the five included studies, two are Paterson and Britten's work from the same study published as separate papers (2003, 2004), one appears to be about patients turning to CAM after feeling dissatisfied with general medicine (Paterson et al 1999) and does not detail the number of patients who used only TA.
<i>Alreak and Malterud (2009)</i>	To describe changes in health experienced by women of TA for hot flushes.	127 women who had received TA in a trial for hot flushes were asked, after a course of 10 TA treatments, to write, in their own words, about changes they perceived were related to the TA. 112 statements were provided. The text was analysed using systematic text condensation, including identifying units of meaning and leading onto	83 (74%) described positive changes. A range of changes (in addition to reduction in hot flushes) were noted, included improved sleep, energy levels, relaxation and feeling less stressed.	The authors provide valuable comments on the study's strengths (e.g. evidence of saturation) and limitations (e.g. opportunistic sample, limited transferability due to cultural Norwegian-specific dimensions). Overall, the study's approach is well outlined and findings are well presented.

<p><i>Hughes (2009)</i></p>	<p>To outline rheumatoid arthritis (RA) patients' experiences of receiving acupuncture, from either a TA or WA theoretical base</p>	<p>generalised descriptions and concepts.</p> <p>A convenience sample of 13 patients of either TA or WA practitioners were interviewed using in-depth semi-structured interviews and field notes taken. Data analysis used grounded theory. -10 had treatment within 2 years and 3 had none for 2 years. 2 patients had received TA for longer than a year.</p>	<p>Looking across all participants, acupuncture was experienced as eliciting a range of effects, irrespective of theoretical framework, with greater effects for those receiving TA. Patients who had TA were more likely to describe the treatment as encompassing more than just needling. The therapeutic relationship ('affiliatory relationship') was seen as important and as part of the treatment (with differences noted by acupuncture style). The setting and relaxed demeanour of practitioner made it more enjoyable. More mobility, less pain, improved sleep and more energy, increased wellbeing and reduced stress were other perceived benefits. All these effects helped them to feel normal again and regain their lives.</p>	<p>The methods and analysis are described in detail. This convenience sample appeared to provide enough rich data to easily detected differences in the two approaches as well as the impact of the setting on perceptions of treatment. It is not always clear whether benefit is ascribed to one style of acupuncture or another or in general.</p>
<p><i>Hervik and Mjaland (2009)</i></p>	<p>To examine the quality of life for women two years after receiving TA for hot flushes on oestrogen antagonists for EBC</p>	<p>82 women who had been in an RCT two years previously either to receive 'TA' or sham acupuncture were asked to write their thoughts and experiences 'related to you breast cancer diagnosis, treatments or anything else' (61 completed statements were received). Data was analysed using systematic text condensation.</p>	<p>About half (33) of the women had received TA, the remainder (28) sham acupuncture. 28 of the 61 spontaneously mentioned either hot flushes or acupuncture (the open question referred to neither). 15 of the TA group mentioned its positive effects during and after treatment. Other comments related to their experiences of breast cancer and health services and the way they had come to terms with their situation.</p>	<p>The methods used in the study are well described and appropriately conducted. The mode of data collection is very unstructured enabling the women to write whatever they would like, though this limits insight into whether or not any changes they reported they also linked to their acupuncture. Useful illustrative findings are presented in relation to quality of life and EBC. The authors also point to the limited transferability due to cultural Norwegian-specific dimensions. However, it is important to note that the 'TA' intervention in the original study (Hervik and Mjaland 2009) consisted of 8 pre-selected points; this does not fulfil common criteria of TA, nor as</p>

<i>Evans et al (2011)</i>	To explore how practitioners communicate with their patients about self-care and lifestyle. (Note: the study was also looking at new methods for gathering data by audio-recording treatment sessions)	Audio-recorded 21 consultations with 18 patients of 4 BAcC practitioners followed by a sub-set of patient telephone interviews. A group of research minded practitioners developed the study giving it added authenticity. A framework analysis was used as well as content analysis and the constant comparative method.	The findings suggest a trajectory of talk with 8 categories, each interwoven with each other and periods of physical examination. Focus in the paper lay on 'self-care' talk its content and who initiated it. The findings demonstrate how the therapeutic relationship and communication facilitates increased agency in self-care. The TA construct was considered 'more holistic' providing new understandings of self-care and agency. The study revealed that self-care talk is embedded within the theory and practice of TA and is person-centred and individualised.	depicted within this thesis. This is a well-designed and executed study and constructively provides insight into the types of talk employed and illustrative examples. Rigour was increased by an external researcher conducting the qualitative research allowing data to be anonymised from the practitioners as they discussed and developed the findings. The authors discuss the study's strengths (e.g. co-operative enquiry, insight into process of consultation) and limitations, including the potential inhibiting effect of audio-recording consultations and patient sample (known to practitioners, thus not first users; limited sample size). Although patients reported being happy with audio-recording, the practitioners expressed unease and felt some patients reported less when the recorder was on. Convenience sampling was used.
<i>Huang et al (2011)</i>	To investigate the treatment of chronic stress using TA as compared with attention time (AT) and a waiting list (WL) control group and explore the similarities and differences between individuals' experiences	18 persons with chronic stress were randomised into one of three groups (TA, AT, WL). Two focus groups were conducted for the 12 participants who had either received 5 sessions of TA or AT. The data was analysed using thematic content techniques. (Note: AT patients saw the same practitioner providing the TA, who asked similar questions; then the patient lay on the couch for 20 minutes.	Only 7 patients took part in the focus groups (4, TA; 3 AT). Four main themes are presented, two each for the separate groups. For the TA group, these relate to experiences of using TA for stress, expectations of acupuncture for the AT, experiences of attention and expectations of something to do with stress.	This is a problematic study report, due to the very small number of participants. The findings cannot be extrapolated. Talk in the focus groups seemed to be focussed on whether there was any benefit rather than any other detail.
<i>Rugg et al 2011</i>	To ascertain how individuals with	20 of 80 patients in a RCT of TA for MUPS were	Physical, mental and social changes were experienced but not always	Good detail is provided on the data collection and analysis including reflexivity The findings

<p>Medically Unexplained Physical Symptoms (MUPS) experience five element acupuncture.</p>	<p>interviewed, using a semi-structured format, twice before and after TA. Patients were 'frequent attenders' at GP practices. . Analysis involved use of the constant comparison method involving identification of cross-case themes and within-case vignettes.</p>	<p>attributed to acupuncture. Participants valued the whole person approach and the therapeutic relationship. Both of these meant that participants engaged in a more active role leading to increased agency. They enjoyed the time to talk and also the interactive nature of the sessions. Participants did not talk of acupuncture or self-care advice in terms of any theory of TA but instead used words such as 'energy' 'balance' 'whole person'.</p>	<p>are also well presented, illustrating the themes emerging (but despite the indicated use of vignettes none are presented in this paper) and negative cases were reported. All patients were recruited before their first treatment and returned for the follow-up interview – an important difference with some of the convenience samples of other studies. Comparison of findings with other literature is limited. It is important to note that five element acupuncture is a specialist branch of TA; there is a differential diagnosis which has important differences to a TCM diagnosis but the process is individual, on-going and iterative.</p>
--	---	---	--

The therapeutic relationship is described in nearly all the studies as being of value or worthy of special mention. It is characterised in various ways but one attribute that does stand out is its mutuality. Although most studies reported how patients really enjoyed being listened to and understood it is the notion that engagement with the process of treatment is facilitated by the relationship that has significance for the ToC, including the use of the explanatory model of TA.

In summary, a number of the studies build on the findings of Cassidy (1998) and Gould and MacPherson (2001) and develop ideas especially with regard to two valued outcomes, changes in self-concept and increased agency in self-care. Additional benefits that are perceived and valued by patients include changes to physical symptoms, increased emotional wellbeing, and changes in energy. These combinations of changes link in with each other and sometimes are linked to the therapeutic relationship (especially regarding increased agency in self-care), the explanatory model of TA and patients being able to relate changes they experience directly from the acupuncture treatment. Other important outcomes are new holistic insights, and the valued focus on the whole person. These outcomes are tabulated in Table 6.3 below, which presents the outcomes of all the included studies, with the practitioner perceptions in blue.

Theory of Change

Looking across both sets of selected literature, one can then ask, in what way does this literature review contribute to further understanding of the ToC for TA? Change in a sense snowballs providing weight to the idea that there are multiple causal pathways in TA. These multiple pathways include experiencing direct benefit from treatment that increases confidence in the practitioner and belief in the explanatory model of TA. This increases motivation to make lifestyle changes. The nature of the therapeutic relationship also increases agency in self-care; responding to the multiple questions of the practitioner causes patients to reflect on their illness experience. Feeling more energised, more relaxed and calm, seemingly common effects of TA, also contributes to change. For some patients, being able to make reductions in medication and decreasing visits to their doctor leads to increases in self-confidence and self-responsibility. Nine studies show self-care talk is embedded in the TA diagnosis (see Table 6.3 below). Patients also 'translate' the specialist terminology of TA into their own lay terms and metaphors as a way of relating to them (Cassidy 1998, Gould and MacPherson 2001, Paterson and Britten 2004, Rugg et al 2011).

Multiple causal pathways make the division between process and outcome more blurred, as suggested by some of the included studies (for example, in particular, Paterson and Britten

2004 and Macpherson et al 2006). Valued processes integral to the theory of TA include the whole person approach and the therapeutic relationship. In Table 6.3, the heading for the therapeutic relationship signifies one specific aspect of it, that is, whether it is considered integral to bring about change. Many of the participants enjoyed and appreciated their relationship with the practitioner for other reasons too.

An important long term goal of the practitioners was to bring about change in behaviour using the explanatory model of TA. This may also be considered an outcome that patient/participants cited as being of value to them to enable them to find new meaning. Holistic insights are about new ways of seeing health and the body; an outcome that may in itself lead to change. Increased agency in self-care includes all the notions of increased motivation and empowerment resulting from multiple changes occurring within the time of treatment and having a path to change that makes sense or that the individual can related to.

One part of the ToC that the three practitioner studies mentioned and was alluded to in some of the patient perceptions was that an important component bringing about change is addressing imbalances in the *Qi*; this is, according to these studies, difficult for practitioners to articulate in any language other than TCM. This aspect of the ToC is not included in Table 6.3, as it is a more obtuse but, at the same time, is an essential cog in the wheel of change which many practitioners might argue is the central driver. Without it, it would not be TA.

Table 6.3 Outcomes (and Processes) of TA from within all the studies.

Authors	Therapeutic Relationship: interactive engagement enabled change	Increased Self-care and using the TA explanatory model	Changes in Self-concept	Holistic Insights	Physical/ Emotional/ Mental Changes	Whole Person Focus
Cassidy 1998	X	X	X	X	X	X
Alraek and Barheim (2001)					X	
Gould and MacPherson (2001)	X	X	X	X	X	
Paterson and Britten (2003 and 2004)	X	X	X	X	X	X
Walker et al (2004)				X	X	
Griffiths and Taylor (2005)					X	X
Hughes et al (2007)	X	X	X		X	X
MacPherson et al (2006)	X	X		X	X	X
Paterson (2006)		X	X			
Jackson and Scambler (2007)					X	X
Paterson and Britten (2008)		X				X
Alreak and Malterud (2009)					X	X
Hughes (2009)					X	X
Evans et al (2011)	X	X	X			X
Huang et al (2011)					X	
Rugg et al (2011)	X	X	X	X	X	X

Regarding the ToC Framework (Box 1, page 49) as developed in Chapter Four, the studies explored in this Chapter provide less detail regarding the substance of the process of treatment with TA; a TA diagnosis is alluded to in some studies or in more depth in others; change is brought about by the balancing of *Qi*. Certainly the whole person and individualised approach is clearly present in these studies as are the long term goals of

bringing about change and balance to the whole person, in mind, body and emotionally. Causal pathways are multiple as well as non-linear.

Concluding Comments

This chapter has continued the process of drawing out 'what TA is' and how change is brought about by applying the critical thinking of the ToC, as outlined in Chapter Three and Four, to research in the form of qualitative studies exploring the patient and practitioner perspectives on TA. These studies were systematically selected but not all of them provided material with which to consider what the ToC of TA might be.

The main finding of this review is the way several of these papers demonstrate the multiple pathways of change inherent within TA treatment. Some aspects of the process of treatment are also important outcomes of treatment. In addition, new insight and belief in the acupuncture leads to more change. Patients valued different kinds of change including those that allowed them to gain new insight into their health, and ways of managing their problems better. There is evidence to suggest that this was by design on the part of the practitioners. Long term goals of the practitioners were to bring about lasting change through the acupuncture treatment, through engaging the patient with the explanatory model of TA to help explain and find meaning in their illness and to enable change in behaviour, insight and lifestyle. All the studies reported physical, emotional and mental changes to health and some reported that being treated as a whole person was important. The two studies that explored more closely the emphasis in TA on increased agency in self-care and improving lifestyle changes, reveal both that the long term goals of treatment are partly intended to be obtained through the individual's own agency and that the skill of the practitioners in engaging patients with the TA model of health is a factor in inspiring patients to change.

With regard to the ToC framework developed in Chapter Four (Box 1, page 49), these studies elaborate on the complexity of change in several ways, for instance, in the acupuncture treatment itself, engaging the individual in the process of change and using the explanatory model of TA as a tool for patients to relate to their illness. What is to a degree missing from these studies, and thus what this literature review can add to the refinement of the ToC for TA, is detail regarding '*what is done*' in the treatment. What is missing from the ToC framework in Box 1 is the pivotal role of the therapeutic relationship in engaging the individual in the process of change.

This review of the qualitative literature on practitioner and patient perspectives perhaps adds extra insight to the multiple causal pathways. In the previous chapter (Chapter Five) that looked at a range of clinical studies of acupuncture, many gaps were found in the rationale for how the treatment was expected to work, and there are several possibilities for this. The methods used in the studies in this chapter provided more opportunity to explore the ToC for TA. It becomes increasingly evident that the single outcome measures that tend to be assessed in clinical trials do not reflect the whole person approach or multiple outcomes aimed for in TA.

An additional key point is that all of these studies were revolving around patients with chronic illness. Some of the patient participants were already very experienced in managing their illness (Rugg et al 2011). They were already familiar with the impact of their problems on their lives and consequently potentially more attune to what they wanted to change. Several of the studies reported that the relationship had a mutuality, and air of team work to attain the goals of treatment.

Taken together, the findings from Chapter Five and this chapter provide insights into the ToC within TA from a range of published studies against which to compare the data from the longitudinal study. Findings from this study are now reported in the following three chapters. This begins in Chapter Seven through providing background and context to the women's experience of EBC. It will demonstrate that understanding what women value and what they need at this time is heavily imbibed by the sudden change and turmoil induced by the diagnosis and chemotherapy.

Chapter Seven

Exploring Experience and Concerns:

A Maelstrom of Change

Introduction

This chapter sets out to contextualise the findings in Chapters Eight and Nine which respectively explore perceived and intended outcomes of practitioners and patients, and the way in which practitioners theorise change to occur with TA. Thus it aims to provide insight into the women's experiences of EBC at a critical stage in their illness trajectory, namely following diagnosis and surgery, and through chemotherapy; and their receipt of TA treatment (prior to, during and subsequent on TA). In so doing, it is explicitly addressing the first sub-objective (5) relating to the longitudinal qualitative study (see page 9, Chapter One). It is argued that this 'time' dimension is significant in aiding understanding of the shaping of needs and concerns of the women which were addressed within the acupuncture treatment.

Much of the published research on practitioner and patient perspectives of TA, as reported in Chapter Six, was concerned with on-going chronic illness conditions. As was argued in Chapter Two, there are likely to be important differences when TA is utilised in addressing the needs and concerns for people at the point of onset of illness with a chronic or life threatening course. EBC is more than a complex medical exemplar, it also has acute, chronic and life threatening dimensions. The qualitative literature reviewed in Chapter Two enabled a wider understanding of this experience. This chapter offers further insight into this complexity and why it was not necessarily straightforward for women to articulate their needs and concerns. This must be taken into account when thinking about the goals and outcomes valued by these women regarding the ToC for TA. In order to ensure the complexity is conveyed, a full picture is provided with detail as to their experiences.

The data drawn on in this chapter, and reported in this order, arose within the first, second and, for a subset, third interviews with the women. At the first interview, a few days prior to chemotherapy and acupuncture, participants were recovering from surgery following diagnosis only weeks previously. At this time, women viewed EBC as an acute condition (and their breast cancer, in the form of the tumour, expunged with surgery); and, although highly disruptive, the on-going implications of EBC were only revealed to them over time. The second interview took place after completion of the acupuncture but with one more chemotherapy treatment to go. At the third interview, women had completed chemotherapy

and were beginning to address the longer term consequences of EBC. Seven women were selected for the third interview for being at different stages of life. Of these seven women, five were receiving radiotherapy and two Herceptin which meant continuing regular visits to the hospital; one had no further treatment. Interviewing women after chemotherapy provided an opportunity for reflection on the whole experience of diagnosis and treatment so far, and the ways in which the TA had been helpful.

Biographical disruption was used as a sensitising concept. According to Bury (1982) chronic illness involves a disruption of taken for granted assumptions and behaviours (relating to the embodied self), requires a fundamental re-think of the person's biography and involves the mobilisation of resources at multiple levels (e.g. individual, social, practical, cultural) to cope with and develop strategies to manage it. Moreover, the meaning of chronic illness for sufferers can be seen in terms of its practical consequences or its impact on day to day life (meaning as consequence) and has also symbolic significance (meaning as significance). Different conditions, he argues, carry with them different symbolic connotations with impact on how they see themselves and how others see them. For women, here, the symbolic significance of the diagnosis as potentially life threatening was immediately apparent as was its potential to question the taken-for granted. However, their desire as reflected in how they presented themselves, was to keep everything 'normal' as a way of managing their response to the diagnosis, a form of coping that was slowly eroded as the consequences of the cancer and treatment in terms of side-effects took their toll. Women sought to cope with their shock and dislocation by pushing away help and the attempt to keep things as they were led to increasing isolation and suffering. Suffering and biographical disruption are discussed towards the end of this chapter.

1. Before Chemotherapy *'I don't want anything to change' Kathy*

There are two overriding themes from the analysis of the interviews at this point in women's illness trajectory. First, women conveyed the shock of the diagnosis, still raw several weeks later, both in terms of its profound impact on them and the disbelief provoked: *'is it real?'* was a common question posed. Second, simultaneously, they presented a picture of themselves as unchanged, affirming themselves as strong and independent. The interviews had an almost visceral tension of women wanting to convince me and possibly their own self that they were their pre-diagnosis *'normal'* self; but then feelings that challenged this notion would bubble up, puncturing this conception of *'normality'*. There was a sense of paradox within each interview; individuals were not only describing a kaleidoscope of feelings from *'I'm happy'*, to *'I'm devastated'* as they talked through their story, but they also became very

emotional as they spoke. The themes from this first interview are displayed in Figure 7.1; sub-themes are underlined within the text.

Shock of Diagnosis

All the women experienced the shock of diagnosis; at this time point, they did not appear to have assimilated what it meant. Natasha, the youngest participant at 26 years, talked of the shock and how *'everything came crashing down'*.

'It just feels like you are walking, or running through life and a wall stops you. That is what it feels like.' Natasha

Natasha continued: *'it has only been three months. Which I suppose... it might hit me later'*. Similarly, for Lynne, the moment when she received the diagnosis was etched in her mind, and like others described how there was a clear before and after.

'So I had a really good carefree Christmas, and a carefree new year but on January 2nd I got a phone call from my GP asking me to go and see her and my world just came to a crashing halt. It was like a train, a fast moving train just stopped on January 2nd... Oh yeah. I remember that day – I'll never forget it – the day, the year... that was the start of

SP: yeah

my life – the second part – I've got my life before the cancer and my life with cancer and that was the second that life started.' Lynne

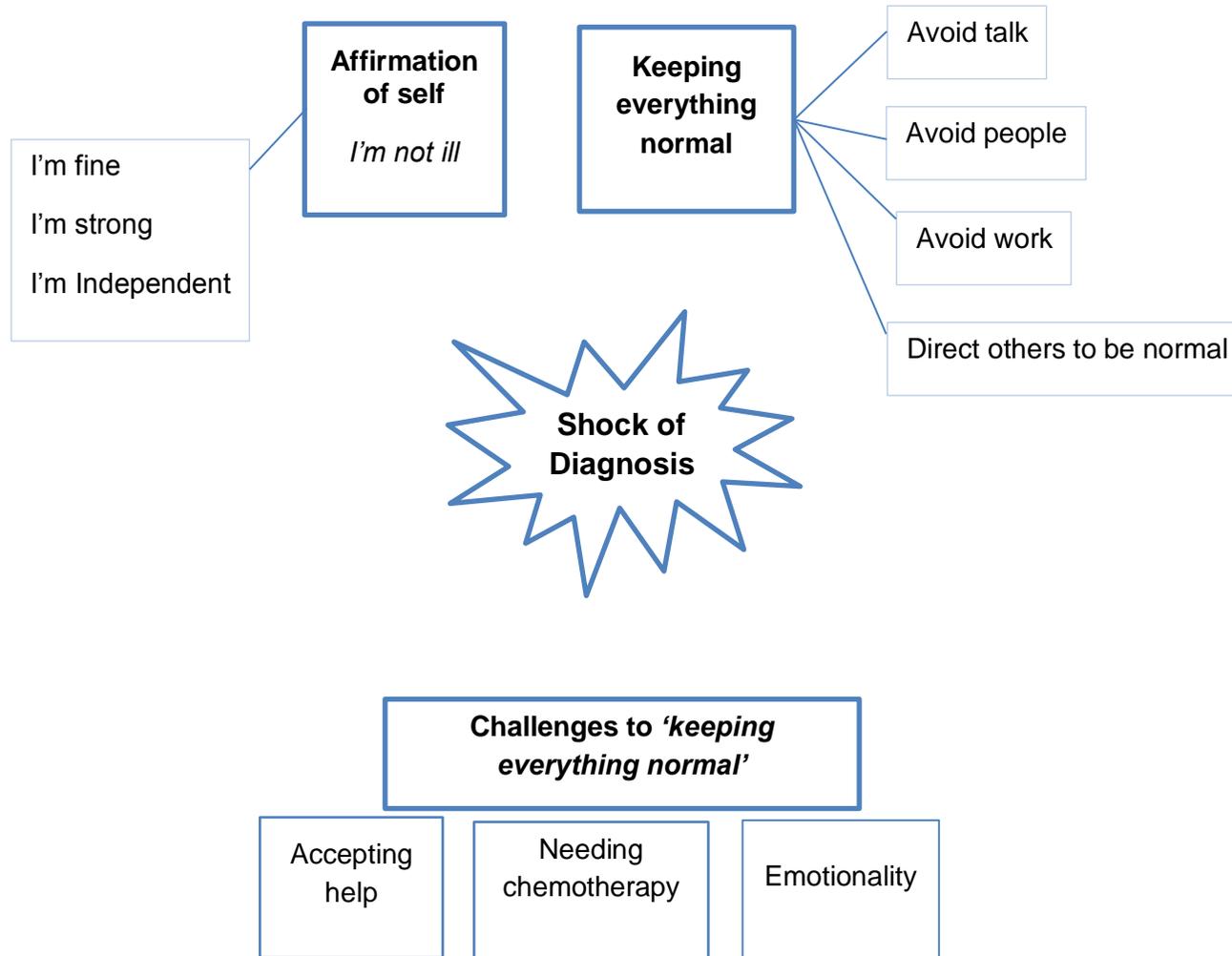
Reactions to the diagnosis were also confusing - Mary described the shock she experienced while expressing surprise that she could not cry. The shock made her numb.

'I went back a few days later, and was told that it was cancer, which was a huge, huge shock. It was... I was told it was cancer, it's invasive and it's the fastest growing type. So that was a massive shock...but I haven't cried. I haven't cried once. Which I don't really understand' Mary

Because there were no prior warning signs of illness or symptoms, the idea that cancer could have formed without an individual knowing compounded the shock.

'So when they did give me the diagnosis, because I was feeling so well, I thought to myself they must have the wrong person (laughs) come back because I just couldn't believe it.' Lena

Figure 7.1 Shock of diagnosis resulting in disruption



There was a gap, a chasm, between hearing the news and processing it into something meaningful for the individual. The diagnosis was felt as disruptive, in that it challenged who they thought they were but shock, disbelief and numbness were the primary emotional responses at this point. Women were unable to recognise cancer, or relate to it as something to do with them. Recognition and validation had been external only; by the GP, the surgeon and the medical oncologist. Its potential to impact on their lives was implicit in their experience of shock but at this point it was not thought through and indeed as they subsequently conveyed, their assertion of 'normality' seemed to indicate that they were not going to allow it to impact their lives and relationships.

Keeping Everything Normal - 'I'm not ill so I just want everything to be normal' Mary

Women conveyed a picture, unwittingly, of utter confusion and emotionality and yet spoke as if it was possible to keep everything as it was. This was an expression of desire, they wished to remain their pre-cancer selves, and not be defined by the cancer. Liz, like many participants felt she was coping with the diagnosis until she started talking about it and then oscillated, like others, between feeling okay and feeling emotional and dumbfounded.

'I feel as if I have accepted it, until I talk about it and then it's like I can't go back to see the girls at work because I know I will be too upset. (weeping)... It's just if I stop and think I get upset. It's like I've just pushed it, and think I'm dealing with it and I'm ok, and then like now, I haven't got upset about it for several weeks. But because I'm talking to you I'm feeling it again. So it just brings it back, the shock, the devastation, just this – bolt out of the blue. How did it happen? So it was a great shock yeah.' Liz

If talking about it, made it 'real', a strategy employed by many of the participants was to avoid talking about it

'But I don't really want anybody to talk about it because we keep going... everybody goes on don't they especially when it's cancer it's like god, and everybody's got a friend that's so they are all telling you all their tales, some tales are good and some tales are bad and I think, well I wish they would all stop talking about it.' Anne

Avoiding talk impacted on how participants related to others. Lindsay did not tell anyone except for her partner, so her children and her mother and other friends never found out

'Yeah and I just don't feel that, you know, I just want to get on with it and I've hardly told anybody other than my immediate people I have had to tell because I just want to get on and be normal and get back to where I was before hopefully.' Lindsay

That women did not wish to be seen as ill, or changed or defined by the cancer meant that they valued interactions that supported this conception

'I mean when I was in hospital, I mean, I had about 15 friends come and visit all within the space of... and they didn't you know, they didn't want to make me feel like I was ill, it was just you know, talking about, you know what you would normally speak about. Which is good.' Natasha

Sustaining *'keeping everything normal'* relied on people around women also *'being normal'* and what was clear from the narrative was that women either had to direct others to be so, or persuade others; or limit information such as telling children or elderly parents only partial truths or avoiding situations and people. Another example of this was that none of the women who mentioned in the interview that they had been told they had an aggressive form of breast cancer shared this information with their partners. Avoiding people, situations or talk was done to protect themselves and others from what it might mean.

Much of the talk involved *'carrying on as before'* in the face of a life threat. The diagnosis brought in to sharp relief the confusion over feeling well and yet being told they had a chance that the cancer might kill them.

'I said (on the phone to her sister in America) I'm not dying (pause) we all have to die someday but I said but I'm not dying you know, I'm still carrying on as normal you know.'
Lena

Later Lena said how calm she felt.

'As I said, I feel alright, I feel good within myself, you know. Yeah, and even my children doesn't understand why I'm so calm, and as normal, and carrying on as normal.' Lena

Every participant wanted life to be as it was, to carry on as before, to ignore what had really happened; the women strongly affirmed that they do not wish to be defined by it.

'Well, just trying to live life as normally as possible around everything else. I don't want to be an ill person, I just want to be normal I suppose, so that is what I am trying to do.' Mary

This was confirmed by much of the interview taken up with talk of being strong, healthy and independent, and for several of the participants stories of previous adversity that they had overcome; an affirmation of self.

'I'm a strong independent person' Kathy

Women affirmed feeling well, or fine, or even happy which contrasted with the shock and disbelief of the diagnosis. The strong aspiration to hold on to their sense of themselves and their lives pre-diagnosis resulted in a struggle when it came to accepting help. Women affirmed that they were strong, independent and liked to cope alone. Many of the participants had had adverse life events in the past such as Liz whose husband died leaving her with two small children to raise alone, or Vera who despite co-morbidity nursed her dying husband for years; two of the participants experienced bitter divorces at the time of diagnosis and faced financial uncertainty and changed relationships with children.

'I've always been quite a strong person, and I always think life throws things at you and you deal with them, and you just get on with it, you know.' Liz

Anne, who not only experienced violence and trauma in her past also lost her beloved brother suddenly and traumatically which led to a period of severe depression, defined herself by her independence:

'I'm not one for shouting for help here, there and everywhere.' Anne

Similarly Sue:

'I don't do fuss...you know, I've never had fuss, I've just got on with it, brought the boys up and... I think you know because I've gone through a bad divorce, I think I can do it all on my own.' Sue

The implications of this 'assertion of wanting to be normal' were that women found it difficult to accept help. Accepting help challenged the idea that they were coping as before. Trying to keep everything as it was meant avoiding talk about cancer, refusing help and cutting off from the potential comfort of sharing difficulties and receiving assistance. Accepting help at this stage was only to make others feel better, so Jane let her 13 year old son do some washing up; or as Vera said it was forced on her

'I'm in a flat you see, so I don't have no stairs or anything, and it only takes me like an hour to go round it to clean, but she's prepared to give her house up and come and live with me. But as I say, that is her way of paying me back for what I have done for her over the years. But I don't rely on anybody. It's forced on me.' Vera

The majority of the women only needed help at the time of this interview because they had had breast surgery. But it was clear that they fought it, and regularly pushed away offers of assistance. This also reflected their discomfort with other people's reactions to their diagnosis. Similar to Lena quoted above talking to her sister, they spent time discussing

with people that they were not dying; that they were not even ill and that they certainly did not need any help.

Needing chemotherapy provided the second challenge to keeping everything as it was. All the participants had experienced disfiguring surgery, and three had had a mastectomy but all described a sense of tremendous relief that, from their perspective, the cancer had been removed and they no longer had cancer.

'Well it was like I had won the football pools it was like I had won the lottery because I was so – I thought if it's got to the lymph nodes it could be anywhere. But they said, no it's not in the lymph nodes, so my daughter was with me again for the results and Ray, you know came. But we were both so relieved, I came out and I phoned work and you'd think I had won the lottery I was just so – I said it's not spread you know, that was a lovely feeling. That was good, to know that it hadn't gone any further.' Liz

But as chemotherapy had been offered, doubts emerged about both the cancer, and whether it really had been excised; that they were perceived as needing chemotherapy added to the array of emotions already being experienced.

'At that point, I think what I had got confused about was because they had told me that the lymph nodes were clear the whole idea of chemotherapy and it spreading anywhere was still a little bit confused. Because you kind of think well if the lymph nodes are clear then it means it hasn't moved anywhere but at that point she said no it can still have moved within your blood system or some other way. So I think that was then probably the lowest point that I got to. We were actually in Morrison's when she rang me as well which didn't (laughs) help sort of being in a corner by the baked beans being told 'well yes actually you could still have cancer and it could still be somewhere else in your body, that was the worst point.' Kathy

It was bewildering because on the one hand they described how well they felt, and used phrases such as *'I'm not ill'* while simultaneously being told that if they did not have chemotherapy they might die. It challenged their initial idea that surgery had excised the cancer, and that they could get back to life as it was. There was a visible struggle within these women as they battled over their need to believe nothing had really changed and life could carry on, with what needing chemotherapy meant. Several women cited needing chemotherapy as the worst of all the things that had happened so far. This first stage was characterised by the utter shock of diagnosis that made people think that there was a break with who they were while simultaneously not only thinking it could not be happening to them but that by blocking it out and struggling to keep things with others the way they were, would

make the reality of the cancer go away. The reality, however, kept breaking through as expressed through emotionality (breaking down in tears), a signal that needing chemotherapy had dented the armour of 'normal'.

All participants aside from Mary reported feeling emotional at times, most often unexpectedly. Jane, like several other participants was unable to return to work because she kept crying for no obvious reason. Others conveyed an overwhelming difficulty with their situation, and despite wanting to hold on to how things were, were clearly struggling to articulate or make sense of all the changes. Sue, having described the loss of her breast as a bereavement that she had yet to accept went on to describe her recent feelings

'I just keep thinking, I mean at the beginning I just you know, I did cry a lot, and I thought I wish I had died. I did.' Sue

She went on to talk about what was happening for her now and she reflected on moving house

SP: 'Have you just moved out of the family home?

I'm moving out at the weekend

SP: So that is again, another terrible thing

I know

(pause)

SP: A very emotional time.

And I think... blimey...(tearful)

(pause)

SP: What's keeping you going Sue?

(big sigh) – my family and my partner.

(pause)

SP: yeah

(pause)

SP: here have a tissue Sue.' (Sue is crying)

Her level of grief and emotion meant she avoided people; she could not bear to talk or risk breaking down. She refused offers of emotional comfort.

At this time before the start of chemotherapy and acupuncture, women were in shock, they were struggling to make sense of their diagnosis and what it meant to them, they were universally fearful of the chemotherapy and how they might cope and were still recovering from surgery. Their impulse to hold on to life as it was before was strong as was their desire to assert themselves as independent and affirm their sense of self. This resulted in avoiding people and old routines such as work and friends and even family or anything that might challenge the idea that things had changed. The emotionality that women displayed is illustrative of the disconnection between the shock of diagnosis and its disruptive meaning, and not wanting to consider its implications.

In struggling to keep everything as it was women had to alter their relationships and control the ways in which they accepted or asked for help; they experienced increasing isolation by avoiding offers of emotional comfort. Figure 7.1 attempts to capture this struggle and displays the themes in relation to each other. Regarding the ToC, this first stage provides insight into why women may find it difficult to identify their needs and source appropriate support. A fundamental feature of biographical disruption is that it involves a disruption of taken for granted assumptions and behaviours; and that such disruptions necessitate a fundamental re-thinking of the person's biography; there is a disjuncture between the person as they were before and after the event. The shock of diagnosis resulted in profound disruption in terms of meaning as significance but at the time, its meaning in terms of its consequences for self and others was both minimised and not understood. This resulted in increased suffering as women closed off support. This suffering increased as women started chemotherapy and the routine of hospital appointments, blood tests and side-effects took their toll.

2. During Chemotherapy – *'It's turned my world upside down'* Lena

At the second interview, with one more chemotherapy treatment still to go, there were increasing nuances in participants' subjective experiences of illness, health and well-being. Individual women simultaneously reported within the same interview that they felt very well and very poorly; and although all of them experienced adverse effects of the chemotherapy, half the group considered that they had coped very well, and the others that they had not coped well at all. As in the first interviews, an overriding theme again was one of struggle to understand what it all meant with some participants still expressing directly *'is it all real?'*

It is the processing of the meaning of the diagnosis that this analysis focuses on, because much of how both the physical and emotional challenges are mediated depends on the degree to which the significance of the cancer and treatment is acknowledged or played down. Figure 7.2 displays these themes with a disrupted life at the centre as women struggled and went to lengths to keep everything as it was whilst experiencing a more hidden suffering and loss. There was less talk affirming the strong, independent self as there was before chemotherapy; this could in part be due to the fact they had met me once before. My impression partly gained through the physically changed appearance of nearly all the participants, and partly through what they said was that the absence of this talk was more due to their overwhelming difficulties. The chemotherapy and its effects were beginning to drive home the fact that the cancer was real in terms of its consequences.

Carrying On As Normal

Almost all participants talked about '*carrying on as normal*' as they did in the first interview. '*Normal*' in this context meant both attempting to keep things as they were and holding on to their pre-diagnosis self, that is, unchanged. There are subtle nuances to this theme as some started to question whether they could consider that things would not be the same, that there were fundamental consequences to the diagnosis and treatment.

Women hoped to *carry on as normal* in order to curtail any change in their sense of themselves or how others treated them; they did not want to be different and expressed a strong desire that this should not affect their lives or their relationships. Lindsay talked about not having told people because '*I just wanted to carry on as though things are normal*'; she wanted to avoid being 'labelled' as a person with cancer. She explained:

'I didn't want to feel any different, I didn't want to feel isolated in any way, I didn't want to be treated differently...' Lindsay

What is different from the first interview is that the women had an additional burden of the side-effects of chemotherapy. Time had gone by since the diagnosis stretching out the mental and emotional resources for these women as they attempted to continue to fend off support or negotiate help. Several participants talked about those close to them, especially children, demanding that they continue as they were; women '*carry on as normal*' for others. This is a complicated scenario because it is also mixed up with how women played down their symptoms, which backfired when they really needed some support and had to ask for it. Kathy having discussed the fact that '*I don't do ill*', talked about her grown-up daughter who kept nagging her to resume cooking in the kitchen:

'She hasn't changed towards me, no, she still tells me to get my arse out the door! In fact she said to me "when are you going to start doing things again!"' Kathy

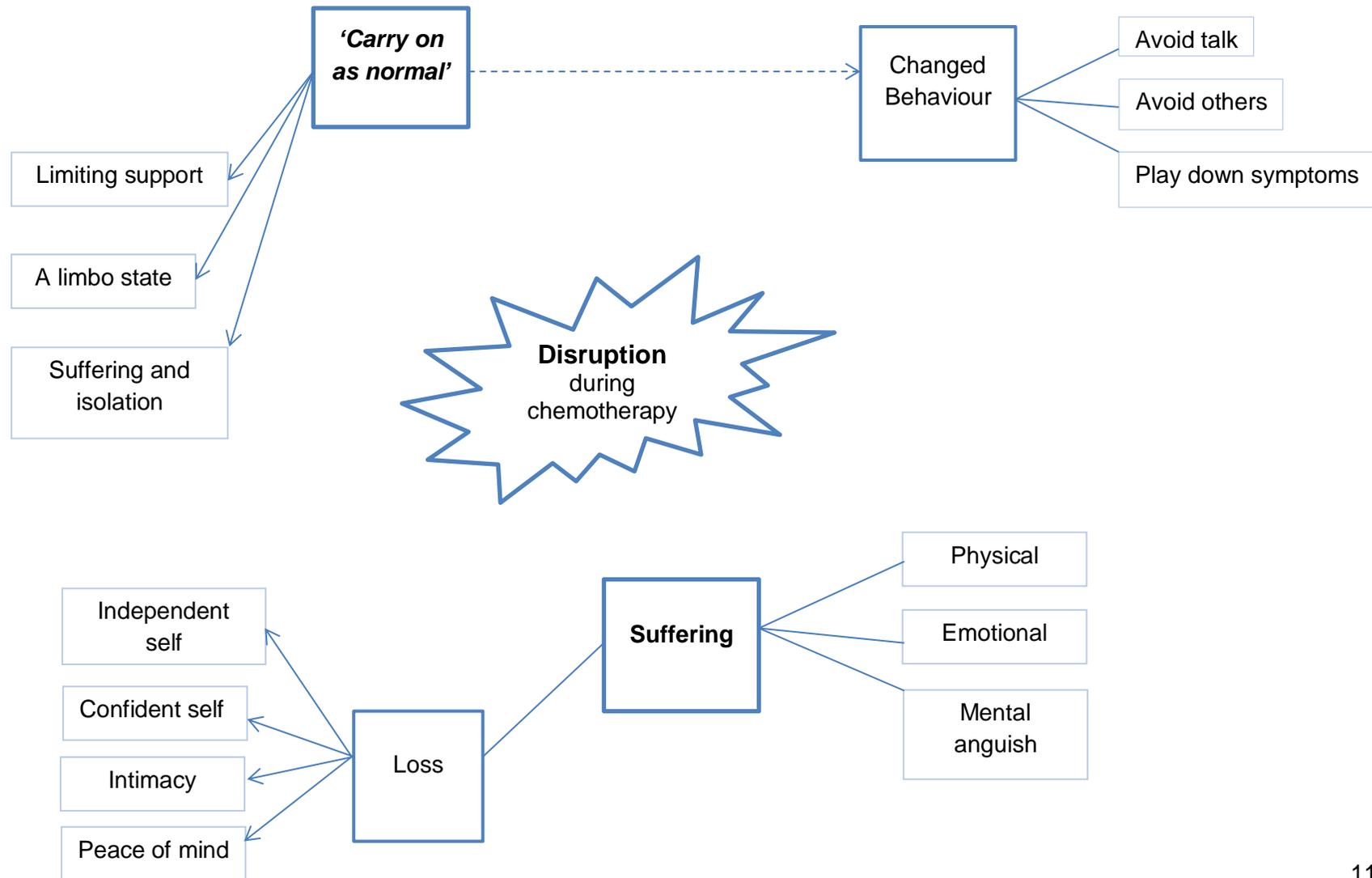
Later Kathy described her tiredness as just feeling 'lazy'. *Carrying on as normal* was conducted as a way of reducing the impact of the significance of the diagnosis, but women had to find a way of accommodating side-effects and illness resulting from chemotherapy into this strategy. Mary's talk was littered with examples of carrying on as normal and suggested that making a drama out of it was not something she needed to do:

'I feel this is an incident in my life which I have to get through... I don't want to get embroiled in this whole breast cancer business really. I want to put it behind me I suppose... I'm quite busy anyway, I don't need anything else to fill my life, maybe some of those people do but I don't need that.' Mary

The need to carry on as normal led to changed behaviour. Anne had to tread a fine line due to her fear of returning depression. She stayed indoors most of the time and wore headphones in the waiting room to avoid any cancer talk but then she found she had to switch off the TV.

'I had to switch telly off, it were going on for that much (about Jade Goody), because you always think, because you have cancer, you think it's going to happen to you, do you know what I mean? And you don't want to hear about dying, because you think well I've looked on my cancer, not a cold, but you know like a cold, you are getting treated and you are going to get better, but when you start hearing things about all terminal, and it's gone to this person and it's gone to her liver, you think, oh god is that going to happen to me then, so I prefer not to hear it.' Anne

Figure 7.2 Disruption during chemotherapy – diagram to display the relationships of themes contained within overarching concept of biographical disruption



Playing down the impact of symptoms also helped keep things as they were. It was in fact the symptom of fatigue that most betrayed this urge. The example given here for Mary is interesting not only because it demonstrates this, but also reveals her own determination to avoid facing how different her life had become. At the start of the interview Mary carefully told me that she had had no real side-effects due to *'out of date perceptions'* of chemotherapy and how bad it could be. During the interview she mentioned several fairly severe symptoms such as waking several times a night due to thinking about the cancer and also night sweats, but it was fatigue that was the worst:

'It's really difficult to describe because it is not tiredness that I have ever had before. It is your whole body is drained and literally just walking around the house, when it is at its worst, is an effort. And really I'm the sort of person who is busy all the time, but you can't force yourself to do things because you feel much worse if you try to work through it – it's just not possible. The nurse told me that to begin with, and I thought well maybe I'll be able to but really you can't. You just have to stop, and you have to sit down, because otherwise you feel worse, and it is just the whole body is just exhausted. And the couple of times when it's come over me a week after I have got over the worst again, you just – the whole body seems to tremble, you just have to sit down, you just can't do anything, and that is really awkward if you are in, well I was in the middle of town, and it's just such an effort to get back to the car. I was really astounded at how bad I felt.' Mary

As it turned out, Mary, like Julie, never went out by herself anymore. She talked about *'playing down'* how she felt because everyone wanted her to be okay and so did she. Later, I probed her again about not really having any symptoms and listed the ones she had mentioned.

'But I suppose not sleeping well and hot flushes are sort of fairly normal. So they haven't impacted so much on my life. The exhaustion, well you just have to get through that really; and because I haven't had a lot of time to dwell on things either...I just haven't had time to dwell.' Mary

Mary was both in the process of fighting to keep everything as it was, by not talking and by playing down her symptoms and yet at the same time, normalising her experiences into a new way of being. Other participants revealed similar changes in behaviour, including avoiding the mirror. Julie said *'it helps me to look as normal as possible'*, and like several other women she wore a scarf in bed and did not let her husband see her without it and avoided the mirror. Liz commented:

'I hate it when I see myself... It's not me. It's not me this person in the mirror now is not me.' Liz

All of these changes in behaviour added up to a startling picture of women blocking out support, feeling increasingly isolated and alone while also not being able to acknowledge how different their lives had become. As will be seen in Chapter Eight, they experienced a range of symptom clusters and continued to feel very emotional as well as being emotional during the interview.

Consequences of 'keeping everything normal'

Participants aspired to keep everything as it was, even with the debilitating effects of chemotherapy and disguised their needs and concerns, not wanting to change actions and interactions. Understanding the consequences of this aspiration, to keep everything as it was, will help to elaborate the experience of EBC and treatment, most especially when thinking about what kind of support might be helpful and acceptable at this time.

i) Limiting support

Playing down the impact of symptoms and the anxiety of the diagnosis had the consequence of individuals not being able to recognise their needs and not wishing to seek help and support. In turn, it meant that those close to them sometimes failed to offer support and there were several examples of this. The urge to keep everything as it was mediated the participants' experience of diagnosis and treatment. It seems that this urge was not helpful and yet it was almost universal, and resulted in a struggle within, the need to ask for or accept help was pitted against the desire to *'not give in'* (Liz) or worry others. Two problems betrayed this monumental effort to keep things *'normal'* – fatigue and emotionality which are considered as aspects of suffering discussed later.

ii) A limbo state

A second consequence appeared to be a kind of limbo state where women were not who they were - in how they looked (Sue described herself as having been in a war, with a war wound, her scar), how they felt with uncontrollable emotion, and what they were able to do. The timing of the interview caught a process in time of not yet coming to terms with dramatic change from health to illness where the self had yet to catch up. The self they thought they were, that they took for granted, no longer existed – the essence of Bury's disrupted biographical self (1982). Kathy talked about this process as being in the past tense, yet it had not become apparent during the interview where she currently was:

'I felt like another person. I felt like I'd lost me. I'd disappeared somewhere. The me that is confident and independent and gets on with stuff had disappeared into this timid little person who was completely dependent on John to sort things out for me. And...umm... that was difficult because that wasn't me. And I couldn't figure out where I had gone.'

Kathy

Women were in the process of shifting from their perceived normal biographical trajectory (Bury 1982) into something new, and as yet unknown. If it was not physical symptoms that kept women away from work it was emotion, they felt unable to rely on not crying and several never returned to their old jobs; there was an inability to bridge their old selves prior to diagnosis with the emerging new '*normal*'.

iii) Suffering and isolation

Several participants described the consequence of hiding physically and emotionally with increased isolation which compounded suffering. Julie described lying on the bed for days, unable to even listen to the radio, cut off from people, too tired to talk. Suffering existed at the first interview, but it was articulated more fully as women experienced the side-effects of chemotherapy whilst continuing to block off support or acknowledge their needs. Suffering was increased as women continued to attempt '*normality*'. Suffering is a concept that is discussed below as an overarching theme for these participants.

So far this chapter has described women's shift from feeling very shocked and thereby revealing the diagnosis had had huge significance to them to slowly experiencing the consequences of the cancer diagnosis on their physical and emotional health and changed relationships and behaviour. Women reported both coping and yet feeling emotional and altered by it all whilst desperately trying to hold on to life either being normal or returning to normal. At the third interview, it was clear that women accepted that life would not return to what it was prior to the diagnosis, and they were in the process of accommodating changes to their lifestyles and health.

3. Looking Back

This section reports from the third interviews that were conducted between two and six months after the last chemotherapy session. At the initial stages after diagnosis, women were struggling to hold on to the idea that nothing had really changed as a result of diagnosis and that they would not be defined by the cancer. During chemotherapy the majority of participants started to question whether life would be the same as they became subsumed by suffering and loss induced by what the diagnosis might mean and the effects of the chemotherapy. At this third time point six of the seven participants clearly felt that life

had changed irrevocably; although they asserted that they were fundamentally the same person, physical effects and lifestyle adjustments were some of the ways in which this change was demonstrated. Reflecting back over time provides perspective on the experience.

Liz having discussed and reflected on how *'I held on to that thinking life will be as normal'* had come to accept that too much had changed, and that it had gone on for too long for this to happen. She responded to the question of whether she had changed saying that:

'I still feel the same person, and no... apart from thinking, the only thing that it's made me realise is that you don't know what is around the corner and make the best of things and enjoy your life but don't put things off.' Liz

The nature of the adjustment was one of reordering priorities and coping with new physical changes to health. Women reflected back on their working lives and realised that work was the least important priority compared to time with family and loved ones. A new priority emerged though and that was creating time for herself. Lena talked about having much more time for her family, her grandchildren and her elderly father and how much she enjoyed just being with them and reflected on how she had missed out on so much by working so hard all her life. But most importantly she talked of how good it felt to have time for herself and to pamper herself. Jane talked about becoming more *'selfish'* and putting herself first more.

'I certainly think more about me than I would have done before and in and I think about me before I have even thought about the kids...' Jane

This reflective process was assisted by several things two of which are discussed here. Firstly, women had time out from work and busy lives to reflect on their priorities and what was important. This time out was cited as a big influencing factor. In asking women why it was possible to take this time, the seriousness of the diagnosis had given permission, even indirectly, in a way that nothing else would ever have done. For Jane it was forced, as she reflected that her normal coping strategy throughout her life had been to work and keeping going which failed during this period because she was too emotional to go to work or distract herself.

'My family is more important to me than my work, which it never has been. Now that sounds dreadful doesn't it, but I never took time off with the children. Well I so wish I had now.' Jane

Participants still became emotional when thinking of the diagnosis suggesting that there was still a way to go to process the feelings of loss and suffering so acutely felt at the first and second time point. A second influence was an altered outlook brought about by life coming into sharp focus when threatened by a cancer diagnosis. As Liz reported thinking she would live at least as long as her parents she was suddenly confronted by the idea that she might not. This sharpening of focus on what really mattered had not faded for these participants as they experienced new intense pleasure at being in the company of their loved ones and for being alive.

'It doesn't matter if it is raining or dark or cold, to me every day is a blessing, you know, and I make use of that day, and I'm grateful for that day.' Lena

The combination of time out and an altered outlook resulted in a more relaxed way of life. Lynne described how she put a huge effort into keeping things normal and relaxed at home because she had three children at school, one of whom was in her exam year. The cancer experience for her led to a renewal and strengthening of family relationships as her family and friends rallied round to create for her a very positive experience.

Adjustment occurred in pragmatic ways as women learned to live with the physical effects of treatment. This was clearly a process in time as the participants were demonstrably not comfortable with the changes even as they accepted that they had happened. Julie suffered from physical stiffness and fatigue and discussed how carefully she planned her time even to the point of becoming *'obsessive'* about it.

'I feel as though when I'm going up the stairs, I never run up the stairs now and I think well if I do, it will take away some of my energy... I'm happy the way I am now, but get annoyed with the way I am because I'm slower and it's difficult to relate to that.' Julie

Life style changes occurred; Liz chose not to return to work, a very reluctant decision but one which she eventually accepted as she felt too much had changed for her. Sue was in the process of selling her business; it reminded her too much of the moment of diagnosis, and the loss of her sister (please see the vignettes in Appendix VII for more details on the individual participant's stories). Mary and Lena chose early retirement, and Jane was still on sick leave at the time of this interview.

Within this small group there is a range of experience. Unlike the other participants Mary said it had not been difficult to get back to normal. She knew something *'really huge'* had happened but she would not accept it, or believe it had happened and just wanted to get on and not talk about it.

'I know in my mind it's huge but I suppose because I didn't have a lot of physical effects it hasn't really felt as huge. And I tend to not make a fuss about things any way so, that may be helps me to think it's not so huge.' Mary

It was difficult for her to talk to anyone because she did not want to worry her family and friends. Despite suffering from fatigue to the degree that she did not leave the house on her own, she continued to report that the symptoms she still had, she had had before anyway. Mary did not want to make a fuss, but a consequence was one of confusion around identity, as she said *'I suppose I haven't found that self yet'*; she had not assimilated the experience into herself.

Lynne reported no longer feeling excessively emotional, and had a real sense of achievement in returning to work. She felt like her old self aside from being more relaxed within herself and with those around her. She felt that having very few physical symptoms and no hair loss helped her to recover more quickly. She had an altered outlook not only from her own experience but also from knowing two other women with breast cancer, one of whom had died the previous week.

All seven women at this third time point reported a continuing of the mental anguish regarding the fear of the cancer returning. Two concepts are now discussed in more detail as the concept of suffering is extrapolated through the rich data provided in this study along with the use of the concept of biographical disruption as a way of understanding the experience for women.

4. Meaning and Significance of EBC

In examining the meaning and significance of EBC, biographical disruption was used as a sensitising concept. Developed by Michael Bury in a series of papers (1982, 1988, 1991), 'biographical disruption' has been pivotal in theorising chronic illness. A wealth of subsequent research has, as Williams (2000:62) suggests, affirmed its analytic value albeit eschewing its use as a definitive concept. Rather, as with sensitising concepts developed through lived experience, focus is more appropriately placed on extending their applicability by directing attention at the conditions in which they apply. Thus, Williams argues that in respect of developing a theory of chronic illness, focus needs to be on the "*timing, context and circumstances* in which illnesses are 'normalised' or 'problematized' and the manner in which identities are threatened or affirmed..." However, this also poses a methodological issue, namely, the point in the illness trajectory at which data about the experience is generated.

For women with EBC in this study, the diagnosis of EBC at first interview was simultaneously presented as profoundly life changing and as an acute illness which could be treated, and in part contained or excised. Changes to behaviour in order to manage and cope were considered temporary until things return to as they were. As suggested what was distinctive in women's narratives at this point in the illness trajectory was the way they conveyed the significance of the meaning of the diagnosis of breast cancer while 'normalising' its consequences on lives and relationships. While women struggled to process what was happening to them, they strove to present themselves as 'normal', the breast cancer as acute and its consequences as transitory. Evidently, the diagnosis and surgery had a huge impact, but women struggled to recognise what was happening, that is, its significance, or acknowledge it. This process was compounded by not being able to make sense of how and why cancer had occurred. The diagnosis was disruptive of who they were; but they also sought to 'normalise' it through their overwhelming effort to present themselves as the same as before including to others. That it was a struggle is also revealed in the strategies they employed to avoid talking about it or avoid entering into situations in which they might have to explain what had happened to them. In part this was reinforced by the fact that prior to diagnosis they had not felt ill. The full import of EBC emerged over time both in terms of its significance and consequences particularly through chemotherapy.

A crucial feature of biographical disruption is the disjuncture between the person they were before and after the event – there is a disruption of the taken for granted assumptions. There has been an extension of the empirical referents beyond Bury's (1982) original work in rheumatoid arthritis, to other illness conditions including sudden onset illness conditions with on-going impairment such as stroke (Faircloth et al (2004)) or spinal injury (Dickson et al (2008)) and conditions with insidious onset. In this body of work, there has been an unstated assumption that the meaning as consequence and the meaning as significance occur in tandem and flow from one another.

There are variations to this, for instance, in illness that has a slow insidious onset there is no sudden disruption (Pinnock et al 2011, Williams et al 2000); and some conditions that typically occur in older age like osteoarthritis, might be "biographically anticipated" albeit having major consequences for managing daily life (Sanders et al 2002). In this EBC study, diagnosis resulted in profound disruption in terms of meaning as significance but at the time, its meaning in terms of its consequences for self and others was both minimised and not understood. This exacerbated suffering (the struggle to keep everything normal resulted in a shutting off of support). Only later, in time, with the impact of treatment, did the

consequences become apparent with increased suffering as women held on to their desire to keep everything as it was.

McCann et al (2010), whose work was part of the literature review reported in Chapter Two, used the framework of biographical disruption to explore the notion of transition regarding self and identity; transition from health to illness and transition to the future for women with breast cancer. McCann et al (2010) cited continued medication and other threats to identity from physical changes as being factors that stopped women 'moving on' successfully. Aside from McCann et al (2010) two other studies have used biographical disruption to explore experiences within the first year of diagnosis of cancer (colorectal and prostate cancer). Hubbard et al (2010) like McCann et al (2010) employed three interviews over a year for 18 people with colorectal cancer and like McCann et al (2010) did not use time as a way of analysing the data. Hubbard et al (2010) described two types of disruption experienced by their participants: those that adapted to a new normal that might be described as moving from 'health to illness' similar to McCann et al (2010), and those that maintained their pre-illness selves. Hubbard et al (2010) put forward the notion that biographical disruption could be temporary.

Cayless et al (2010) adopted a very similar design to Hubbard et al (2010), in that three interviews were conducted with sixty six men within the first year of a diagnosis of prostate cancer; although the authors reported findings as at diagnosis and treatment phases, there was no discussion of change over time. Cayless et al (2010) concluded that disruption was 'punctuated' by complex and chaotic factors. Although the authors did not express their findings in terms of meaning as significance and meaning as consequence, some of the participants were reported as attempting to minimise the impact of the diagnosis on their sense of self with consequent limiting support. A second contrast to the findings in this EBC study is that the authors concluded that as prostate cancer occurs in clusters in families, many participants had anticipated a diagnosis of cancer as being not unexpected; it did not have the same devastating impact as the women in this breast cancer study.

5. Suffering — *'I feel weak, and tired, and ugly'* Lilly

Suffering emerged more clearly as a theme during the second interviews while the participants were in the maelstrom of chemotherapy. The shock and emotion displayed in the first interview was also an expression of suffering. It is important to explore the concept of suffering in relation to these participants because the needs and concerns of women at

this time are a major consideration in the ToC and in what the practitioners were presented with when thinking about their approach and intended outcomes with TA.

Attempting to convey the experience of suffering at the stage in which the acupuncture care was offered is necessary both to grasp what outcomes might be important to this group and also to understand that supportive interventions might appear a mere drop in the ocean of the difficulties and challenges experienced.

Dimensions of suffering are shown to be a sense of loss, physical and emotional pain, mental anguish and threats to self. Suffering as a concept is difficult to define and articulate and as Frank (2001) says *'our suffering is what we cannot say'*. What makes something an experience of suffering is the depth and breadth of pain and distress? The concept as developed here is then discussed with regard to the relevant literature.

Physical Suffering

The suffering experienced by individuals has already been hinted at as a consequence of avoiding or hiding both emotional pain and fatigue in order to keep things *'normal'*. Mary's description of fatigue was detailed earlier. Several participants described being in a state of near physical collapse, and used the word *'collapse'* several times, particularly in the context of the effects of chemotherapy. Lena talked about her extreme experiences of chemotherapy

'The first lot, I felt as though I was dying, I'm not joking... That is all I could describe it as. I felt as though I was going to die... Like I was in a collapse'. Lena

Several participants talked about exhaustion or weakness leading to a sense that they were going to collapse, that they would lose control of their body. Worse, this came out of the blue; they could no longer rely on their body. Lena also described her fatigue.

'I would be at home, sat down in the sitting room with the rest of the family and I just had to go back up stairs and lie down. Because I feel that if I didn't lay down I would just fall down. That is how bad I felt sometimes'. Lena

In addition to fatigue, it was the collection of other symptoms that added up to a sense of the suffering. Restless sleep experienced by most contributed to tiredness.

'I often wake up two or three or four times a night. Not to stay awake, but I'm obviously not getting a proper restful sleep because it is disturbed. The last few months, I've had that, waking two or three or four times a night, but I have also had nights when I have found it difficult to go to sleep.' Mary

Hot flushes and night sweats were a nuisance for some and for others extremely so. For instance Anne who did not sleep at all and Lena who described her head at one point as literally 'steaming'. Wearing a wig was a problem when there was such heat and meant missing out on important occasions. The accumulating effect of several symptoms took its toll

'The feeling ill – the nausea is a big part, and the tiredness does drag – I asked the chemo nurse why my mouth was so bad and if that would have big effect on the rest of my bowel, because my tummy has been so bloated... and constipation - bloated-ness is really bad. Skin condition – I got an infection in my fingernail, I pulled a fingernail and had to have antibiotics for that. You just feel so low.' Jane

The inter-relation between the mind and body was expressed by Jane; the accumulation of symptom clusters had an impact on the emotional and physical energy and wellbeing of the person. Feeling low at some point or another was described by all participants, and fear of depression was there for some. For many of the participants, feeling low was a consequence of the physical effects of the chemotherapy especially fatigue as they were unable to deploy their normal coping strategies such as 'keeping busy' or 'going out'. The range of physical symptoms is extrapolated in the next chapter on outcomes.

Emotionality

The emotionality present for all the participants may be taken as a sign of suffering. Emotions ranged from feelings of anger at the diagnosis, and frustration and anger at having to ask for help and being dependent, the low mood brought on by physical discomfort and fatigue and the tension induced by hospital visits, waiting for results and the actual process of receiving chemotherapy (*'taking myself to have it done was the worst thing'* Jane). But in addition, all participants, with the exception of Mary, talked about being unable to control being tearful, often at inappropriate times or unexpectedly. It was the single biggest reason, aside from fatigue, for not even popping in to work to see colleagues and friends, or for hiding from friends and family. This expression of emotion betrayed the idea that they were coping normally as they so wished to.

'I want to try and carry on my life as normal, work was the one thing I didn't want to do...It was too emotional.... I mean I haven't even been back into see the girls because I don't want to.'

SP: Why don't you want to?

I don't know. They come to see me (laughs). I can cope, you know like they will come and see me and they will come for their lunch or and I can cope on a one to one, but I just wouldn't want to go and see them on masse. You know, and going back in, and it's the confidence as well now. I've just not got that you know... yeah. The sympathy, I would get upset. Because you know... they would all be how are you doing and feeling, and I wouldn't want that'. Liz (weeping)

Being emotional could not necessarily be linked to what women were feeling and it left them disconcerted.

'Well I just find myself bursting into tears, and for no reason at all these tears would be here, and I just couldn't... I wasn't aware that at that time I was feeling sad or anxious or anything, where were these tears coming from?' Lynne

This emotionality displayed the confusion and struggle continuing within, and also during the interviews themselves revealed a palpable sense of grief and loss.

Mental Anguish

Like a weevil burrowing holes in wood, worry about cancer returning was forever plaguing the mind. If emotionality was crying and weeping uncontrollably about anything, mental anguish was the inability to stop intrusive and unwanted thoughts. Participants frequently used the words '*on my mind*' or talked about trying to push it to the back of their mind. All the participants spoke of this worry, and it led to daily examinations or interpretations of new signs or feelings. Kathy summed up what others said:

'Obviously that it happens again, that is the major, that is the one that sits at the back of your mind and gnaws away at you like biting a nail and having a ragged nail that you keep going back to, and until you make it sore, and you know you are making sore but you can't stop yourself and that is one of the things that will, there will probably always be a little worm at the back of your mind that says, what is that ache, what is that pain, I'm not sure what that is, why have I got that pain, and that is going to be the one thing that is going to be I suppose the final battle to get over – is not to let it take over.' Kathy

In fact, Kathy said at one point that it had been finding mental strength to deal with this that had been the most important and also most difficult thing. Stopping the idea of the cancer and the treatment regime from taking over was cited by others as a major reason for trying to keep things normal; it was about trying to keep the mental anguish under control.

Participants were frequently exposed to others whether friends or acquaintances talking about their experiences of cancer or stories they had heard, which induced fear and anxiety.

In addition they came across women while waiting in the hospital for whom cancer had returned or found themselves obsessively reading the obituary column in the local paper to see how and at what age people had died. This mental anguish expressed the degree to which women felt the uncertainty of their future, and threat to their self.

Loss

Loss is a dimension of suffering and is an experience of emotional pain. In the interviews, there was a palpable sense of loss and grief in the room with all except Mary weeping quietly at times either while talking, or when they could not find words to express what they felt. This experience of loss pervades different themes, as it is about the loss of their old lives, and their old selves, even how they used to look, and while they were trying to keep everything normal at the same time, they were feeling the loss of what was.

i) Loss of the independent self (or fear of becoming dependent)

Many participants in the first interview were keen to affirm how independent they are, and this continued to a degree in the second interview but the reference points had changed to having lost something.

'What does it mean to feel ill? Oh as you said, it takes so much away, because you don't want to do anything – you don't want appear ill, in front of the family, you just don't want the family to know how bad it is. But you can't help it. (weeping gently)' Jane

It was the changes in relationships that occurred through becoming dependent as well as the loss of control. Vera who was so robust before chemotherapy was a shadow of her former self.

'My daughter has moved in this last month, she's lived with me, she is my full time carer... I have to have someone do for me. (weeping...) (pause). No, when you are used to doing everything for yourself, it is a bit hard to accept that someone else will do it for you. I'm so used to doing my own shopping, my own washing, my own cleaning. I mean I'm not even able to put a pair of pants on. It's awful, what it's taken away from me.' Vera

Loss of the competent self was also revealed by the careful management of relationships; other people appeared to lose normal courtesy and sensitivity regarding the subject of cancer and offered unwelcome advice or told negative stories.

ii) Loss of the confident self

'I don't like being this weak person yeah. It has affected my, not personality, but it has affected my confidence, it has knocked my confidence.' Liz

The experience for Liz had affected her confidence, she had become *'this weak person'* yet affirmed that her personality had not changed, resonating with earlier discussions on biographical disruption as women attempted to articulate what had or had not changed. For many women in this culture, confidence was in part dependent on how they look. For half the participants, how they perceived their appearance had a direct and powerful effect on how they felt and their confidence. They also expressed embarrassment that appearance should be so important to them. At the first interview Lena was very upbeat about her mastectomy but later she expressed thoughts very similar to Sue who also had a mastectomy:

'Because losing a breast that is part of you, it's a limb! It's losing a limb. And for married women, like myself with husbands, I suppose, my husband I would say is ok. I cannot fault him but to my mind I keep thinking oh is he going off me sort of thing. That part does come into it with me, you know, and I joke with him and he'll laugh about it, you know. He has never one day yet ridiculed me or anything like that, but to my mind, I'm thinking oh my god to myself, what is he thinking, you know? And my self-esteem has hit rock bottom with losing one breast, because I'm right, what you call it – well getting undressed now in front of my husband, whereas before I wasn't bothered but now I am. You know, and he is noticing that – I'll turn my back, I'll go in the bathroom, I'll switch lights off sort of thing – that side of it has been hell, and it still is.' Lena

It was the combination of physical effects and feeling unwell, plus hair loss, scars that took their toll

'Yeah... my confidence – yeah the chemo has brought me down a lot, not just by strength, I don't like to see myself in the mirror, I think I look horrible...I am weak and tired, and ugly' Lilly

Hair loss for half the group was described as the most difficult thing to get over and *'devastating'*. It was the visible evidence of cancer, and meant not going out in case people spotted the wig, or because they were uncomfortable or because they were too hot. For working women, loss of confidence emerged from not working or from not being able to be successful at work. Having energy and vitality and a positive outlook also contributes to confidence, and the sense of fatigue and un-wellness in turn added to negative feelings.

iii) Loss of intimacy

Several of the participants talked about the effect of the surgery and chemotherapy affecting their confidence in their relationships, hiding their hair loss or their scars from their partners. In addition, they did not share all of their feelings or concerns because they felt they were already a burden and did not want to cause further worry. Sue used to love hot baths with her partner, but after her surgery, she showered carefully with her back to him and never let him see her naked, as with Lena above. Other participants' only took their head wear off when the light was out.

'I don't even let Ray see me... he hasn't even seen my bald head (laughs). I won't let him see me without my wig or my hat on at night, you know, I wait until the light goes out and then I will take this little hat off and put it at the side of the bed first thing in the morning it goes back on. I won't let him see me with a bald head. Silly isn't it, especially at my age...' Liz

Participants who had been told their cancer was 'aggressive' did not communicate this to their partners and were therefore unable to share the burden of this news. It was a loss of both physical and emotional intimacy.

iv) Loss of peace of mind

From the mental anguish and worry described above, participants had lost their peace of mind. Lacking in energy they found it difficult to distract themselves from their worry making them tense and anxious in addition to the ordeal of going through chemotherapy.

Suffering in the overall sense was reduced at the third interview as women also felt relief that the worst part of the treatment was over, and for Lena all treatment had finished. Only Jane and Liz had to return regularly to the hospital to receive Herceptin for a year. Although six of the seven women became emotional during the interview, there was a general sense of less emotional distress compared to the previous meeting. Mental anguish, and physical symptoms continued to a degree and four of the women continued to feel unhappy with their physical appearance. Mental anguish seemed more pronounced at the third interview, possibly because other problems had diminished and participants talked about worrying daily over every lump and bump. Partners had got used to the breast cancer and were not willing to entertain talk about uncertainty or worry for the future. There was a clear sense that women worried a lot but did not share their worries because they tried not to worry others.

Regarding the concept of suffering, there is no literature on the experience of suffering for women with EBC before and during chemotherapy. Given the large amount written about suffering in chronic illness (for instance Charmaz) the lack of it in breast cancer is surprising. This chapter is attempting to describe how experiences of EBC shape the needs and concerns for women at this time. Understanding suffering as a concept, and in light of what is already known, forms part of the developing picture of the needs and concerns of these women. Attention has been drawn to the lack of discourse on suffering for women with breast cancer (Arman and Rehnsfeldt (2004), Thomas-Maclean (2004)) who cite that the experience of breast cancer and treatment is rarely told from the woman's perspective. Suffering as a result of diagnosis and healthcare is neglected and this is borne out by the literature review in Chapter Two.

Thomas-Maclean's (2004) phenomenological study on the everyday experiences of women with breast cancer and embodiment attempted to draw out experiences including suffering and the way in which women dealt with the medicalised view of their bodies. Having developed topic guides from focus groups, Thomas-Maclean (2004) interviewed twelve women twice, seven of the twelve women were survivors of breast cancer with at least five years since diagnosis and for the study as a whole the number of years since diagnosis ranged from one to twenty-four. Memories of suffering relating to treatment and physical pain were still fresh years after treatment had ended. But Thomas-Maclean's paper (2004) did not reveal the depth of whole-person suffering that this thesis does. In this study, women experienced physical suffering, emotional distress and mental anguish and uncertainty combined with an intense experience of loss.

Sandaunet (2008) explored shared experiences for women with breast cancer in an on-line support group of 40 women over an 18 month period and included interviews with individuals. She started with the idea that women with breast cancer were culturally confined to only have socially acceptable stories of their experiences, similar to Frank's (1995) restitution narrative of things being difficult but they will get back to normal soon. This is certainly reflected in this thesis with women both expressing a strong desire to '*get back to normal*' and offering a chorus of '*I'm fine*' to all others. The experience of loss and isolation and managing fear were major emerging themes. One major difference with Sandernaut's study is that the majority of her participants had experienced a spread of their cancer to other sites. Sandaunet concluded that although the website created a space where women could reveal difficulties they could not share elsewhere, their behaviour was still modified to make it 'considerate' of others in the group; or reflected Frank's (1995) 'quest' narrative of finding good in difficulty. In Fernandas et al (2006) interviewing women with a range of

problems including breast cancer, the authors conclude that suffering is a combination of loss, isolation, loneliness, anger, and emptiness.

Suffering from this study emerged as a consequence of the impact of diagnosis and treatment. Suffering as a concept is expanded by this thesis as key links between experiences of loss, and how loss (which is more than the loss of a breast) relates to suffering are made. Suffering for the women in this study had several dimensions manifesting in moments of sadness and weeping during many of the interviews, especially during chemotherapy. As Cassell (1982) and Corbin (2003) suggest, it is an experience of the body and self, the whole person. Just as Arman and Rehnsfeldt (2003) and Frank (2001) report, suffering is often '*silent and unarticulated*' or can be assumed from the accumulation of difficulties experienced by each individual. Isolation as a result of fatigue or not being able to share is echoed by Sandaunet's study. For this group, aside from physical suffering, it meant loss of the normal, threatened changes to self-concept, and loss of the taken for granted future (Charmaz 1999).

Concluding Comments

This chapter has described the participants' experiences of EBC and how these shaped their needs and concerns at this stage in their illness trajectory. It is possible that these experiences may vary from that of others reported in the social science literature because the women had the additional supportive intervention in the form of the acupuncture care. Women experienced a maelstrom of change, so overwhelming at times that any supportive intervention seemed like a drop in the ocean. Through the use of serial interviews with these fourteen women, the fluctuating experience is laid bare, including paradoxical experiences of coping and suffering.

These women had gone from a state of wellness, to illness (diagnosis) to '*I'm not ill*' (post-surgery) to illness (chemotherapy) during the space of a few months. Given these experiences of women with breast cancer, outcomes that were apparently valued by them were ones that enabled coping, relaxation and involved some kind of talking or sharing of experiences. This becomes more apparent in the following Chapter. Women clearly experienced symptom clusters and feeling unwell. Suffering was most acute during chemotherapy but did not abate totally within this time frame; it was certainly present at the first interview expressed through tears, silence and emotional numbness. Suffering as a concept was explored, and dimensions of loss, physical and emotional pain, and mental anguish emerged. The diagnosis and subsequent treatment had a huge impact on women's lives and their sense of themselves. The methodology used enabled an insight into change

over time as women struggled to hold on to their old selves and lives; they failed initially to acknowledge or recognise the significance of the diagnosis and only as treatment brought about physical consequences such as hair loss and scars or fatigue, and also uncontrollable emotion were they forced to start to consider that things may not return to as before. This also has implications for the interventions that women might value or find acceptable at this time.

Time as an important dimension as noted in the introduction is clear early on in the analysis; it became apparent that a third interview would allow further exploration and development of ideas emerging from the data. Time had importance in different ways. Firstly, the speed of the treatment trajectory and management of diagnosis and treatment meant that time is potentially an explanatory factor in the need for women to 'normalise' their experience. Secondly, time had significance as an analytical concept; with the focus on the dynamic of change over time as women journeyed through the EBC experience and its interaction with the treatment regimen. Thus time was important in terms of the process of illness and treatment, and also in terms of the normalising, disruption and continuity which were visible through the prism of time.

The first hint that time impacted on the experience was with the speed of the treatment trajectory. Although women welcomed this speed (it was discussed in nearly all of the interviews) because waiting for results was always a worry; it resulted in women never quite catching up with themselves or what was happening to them. Jane had a delay to her chemotherapy commencing (of several weeks) as she was hospitalised the day after her first interview with me due to an infection. This delay for her meant she had time to come to terms with the diagnosis and ready herself for the chemotherapy. The speed of the treatment trajectory had a significant impact on how women experienced and managed their diagnosis. Treatment and recovery from it took time, symptoms and side-effects meant important life events were missed, for instance, Lena missed a family wedding, Jane the birth of her first grandchild.

The effect of change and time is seen in the fluctuating emergence of concepts such as normalisation and disruption. At first, with the almost universal desire to keep everything unchanged, the disjunction between the person they were before and after diagnosis, conveyed through the concept of biographical disruption, was largely absent in how women vocalised their experience. Women did not want to take on the significance of the diagnosis and this desire was expressed by them emphasising that they were still the same and that nothing had changed. Yet the diagnosis clearly had significance. Corbin and Strauss (1985) argue that when illness is out of control there is likely to be more biographical disruption; this

may help explain the aspiration to *keep everything normal* as one way women managed their diagnosis. It brought women time while they attempted to process what it meant. Women did not want anything to be different and that meant that they could not recognise or acknowledge the *significance* of the diagnosis.

This chapter has attempted to convey the complexity of EBC and the confusion practitioner's would have encountered with regard to clarifying the needs and concerns of these women. Problems were inter-related, with accumulating symptom clusters and fatigue impacting on the women's usual coping strategies such as keeping busy or going to work. This resulted in a whole person experience of suffering which was made worse by difficulties in accepting help and support. The next chapter explores the intentions of the practitioners regarding outcomes of TA, and the perceived benefits the participants valued.

Chapter Eight

Practitioner Desired Outcomes and Outcomes the Women Participants Valued

Introduction

As outlined in Chapter Three a core part of elucidating a ToC is clarity over the (long term) goals on the intervention under study, in the context of this thesis, TA. Clarification of such goals is critical in order to help elucidate and understand how in theory or as perceived by those providing the intervention, the intervention itself (here, TA) might then lead to change, and thus the ToC itself. Accordingly, this chapter explores findings from the longitudinal qualitative study which focuses on the goals of TA. The next Chapter then takes the data analysis and interpretation onto the ToC as perceived by the practitioners. This work fulfils the objective of this thesis relating to outcomes (objective 5). Consideration is given towards the end of the chapter on how these findings contribute to the ToC for TA. For the purposes of this thesis, 'long term goals' are followed through by a focus on shorter and longer term desired outcomes and perceived benefits.

The reader may find the glossary of Chinese medicine terms (on pages *xiii* to *xix*) helpful here. The practitioners use common words such as '*heart*' with the Chinese medicine meaning and it therefore appears in italics and is underlined such as *kidney qi deficiency*. The practitioners talk about the *ten basic questions*, *root and branch theory* and the tongue and pulse. It is worth noting that a fundamental concept in TCM or TA is *Qi* (*pronounced chee*); there is no equivalent concept in western culture (see the glossary for a definition).

The chapter draws on three sets of data generated within the longitudinal qualitative study: treatment logs maintained by the practitioner, practitioner diaries and in-depth interviews with both practitioners and the women. Treatment logs and diaries offered the opportunity to explore TA as it was happening; interviews located accounts of the rationale of treatment by practitioners and women's retrospective reflections on what they derived from it as they transitioned through this initial illness phase. For practitioners, the goals of treatment were to address problems that the women brought with them, both chronic and acute and including emotional distress and difficulty coping. Toward this end, ascertaining the women's needs, that is, disclosure, was seen as an important intermediate goal for practitioners; although this was potentially complicated as women had not themselves sought out TA (it was offered to

them) and they were still in shock. This is a very different situation from many other studies on TA that focus on chronic illness where participants have sought out TA.

The chapter has two main sections. The first section draws together findings on the practitioners' perspectives on the outcomes they sought to achieve. Findings from each set of data (treatment logs, diaries and interviews) are presented separately. Attention then turns in the second section to examine the findings arising from the interviews with the women participants. It draws attention to the broad and specific expressed benefits they received from TA; and both the end valued outcomes of TA and process outcomes, namely the benefits resulting from treatment that they valued. It also draws attention to the value, and thus outcome, of the therapeutic relationship and its emerging conception as 'therapeutic befriending'.

1. Practitioner Perspectives

This section includes both the expressed intentions of the practitioners and what they were focussing their treatment on as recorded by the practitioners in their treatment logs and diaries. The analysis of the practitioner data includes material from the treatment logs, interviews and diaries, enabling a deeper exploration of the practitioners' approach to their patient's treatment. The practitioners sought to achieve broad outcomes such as enabling coping; whilst alleviating particular problems raised by participants during each treatment.

Treatment Logs

Due to the complex experience of chemotherapy, some problems varied from treatment to treatment, such as headaches or blepharitis (redness and soreness on the eyelids) while frequent, underlying, and more sustained problems were addressed at the same time. Following the format of the treatment logs, Table 8.1 provides a summary of all the main and secondary complaints recorded in the treatment logs that the practitioners were seeking to address. Some participants had suffered from hot flushes or night sweats for several years prior to the diagnosis. Sometimes the practitioner recorded as '*nothing*' in either the main or secondary complaint box, suggesting that things were not too bad. It is important to note that the treatment logs alone do not necessarily reveal all that was presented to the practitioner on that day, rather the problems that the practitioners chose to record, possibly after discussion. The practitioner sometimes made a note regarding the impression of tension or tiredness even if this appeared not to have been vocalised.

This data reveals the range of problems presented that the practitioner attempted to address, including chronic long-standing problems and acute infections. The main backdrop was one of fatigue and emotional upset with both sleep disturbance from heat and night

sweats and distress or anxiety. These combinations appeared to come and go in order of importance for individuals and at different stages of the treatment trajectory.

Sometimes individuals appeared to have more extreme fatigue manifesting as exhaustion and '*disorientation*' with weakness and consequent emotional upset. Sometimes they had a good week and had nothing major to complain about. This data does not record the intensity of complaints, for instance, nearly all the nausea was written as '*mild*' even when it was recorded as a major complaint; and sometimes the night sweats were '*severe*', '*mild*' or '*much better*' but still recorded as the major complaint.

Table 8.1 Summary of main and secondary complaints recorded in Treatment Log (n)

Main Complaint	Secondary Complaints
Tiredness/Fatigue/Exhaustion (27)	Night sweats/Hot flushes (29)
Emotional (stress/distress/anxiety) (18)	Fatigue/Tiredness/Weakness (22)
Night sweats/ Hot flushes (12)	Emotional (stress/distress/anxiety) (17)
Nausea (11)	Poor Sleep (19)
Pain – gastric, arthritic, tension (9)	Heartburn/Gastritis (10)
Depression and feeling low (7)	Aches and pains including pain in chemotherapy arm, pain due to tension, chest pain (10)
Ear problems (pain and deafness, tinnitus, infection) (6)	Eyes – Blepharitis (dry/pain/infection/red/inflamed) (7)
Anxiety/Fear (5)	Sore mouth/throat (7)
Poor Sleep (4)	Nausea/poor appetite (7)
Migraine/Headache (4)	Breathless/ tight chest (5)
Sore throat/mouth (3)	Disorientation/"spaced out"/ feeling disconnected (4)
Head cold/ cough (2)	Headache (4)
Constipation (2)	Breast pain or tenderness or infection or fluid (5)
Disorientation/"spaced out"/ feeling disconnected (1)	Diarrhoea (5)
Fluid around wound (1)	Oedema (5)
	Back pain (4)
	Blood glucose erratic (4)
	Tinnitus (3)
	Constipation (3)
	Low white cell count (1)
None (17)	None (27)

Diaries

The practitioner diaries reported the dilemmas of treatment such as whether to address the overall *pattern* of imbalance or specific complaints. Helen, for example, reflected in her diary how to approach treatment with Vera who had chronic pain from arthritis and neck trauma: would she treat the pain or offer protective treatment directed at Vera's whole system to better withstand the effects of chemotherapy. She choose the latter approach yet Vera's pain improved so much that she was able to come off her pain killers which in turn increased her energy and appetite (according to both Vera and Helen in their interviews).

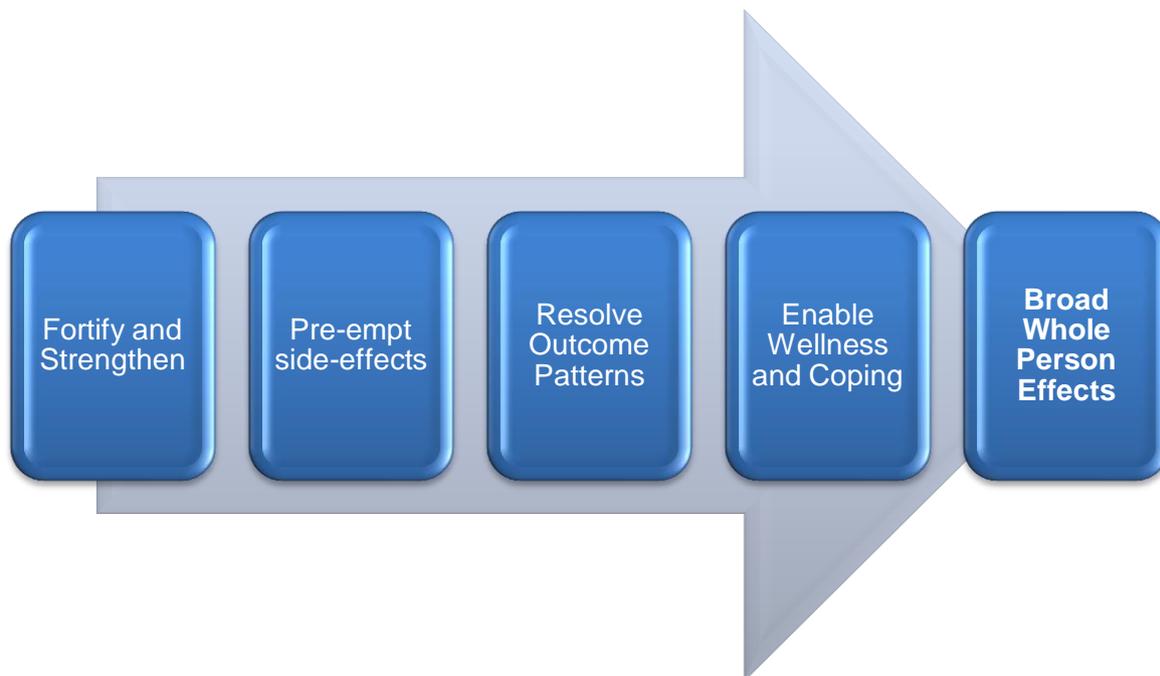
Looking further at the treatment log for Vera, '*arthritic pain*' was recorded seven times as the main complaint and the primary syndromes or *patterns* recorded were *Kidney Yin and Yang Xu* and *Spleen Qi Xu*. Other main complaints recorded were an ear infection (twice) and '*soapy taste/stomach heaviness/belching*'. Quite frequently Helen addressed '*Spleen Qi Xu and damp*' in what she wrote and the acu-points she choose; as she said in her interview and discussed in the diary, the goal was to '*pre-empt*' the effects of the chemotherapy on Vera's erratic glucose levels and the fact that she had chronic gastritis and a history of duodenal ulcers.

This single case analysis of the triangulated data both gives a flavour and demonstrates the level of complexity the practitioners were addressing on a treatment by treatment basis in order to secure what they considered the best outcomes. As Vera reported in her second interview, she had never been better than when she was receiving the acupuncture.

Practitioner Intended Outcomes

The in-depth interviews provide more detail on what the practitioners intended to happen with TA, while they addressed the complaints listed in Table 8.1. Rather than list each of the outcomes that practitioners deemed important, sets of related outcomes have been brought together and the identified sequencing drawn out and are presented in Figure 8.1. This diagrammatic portrayal is attempting to understand how the practitioners pragmatically addressed multiple problems that were both acute and chronic, and may help in understanding the ToC for TA. There is a multi-strand approach rather than a linear, step by step one, to achieve broad effects relating to the whole person, and longer term outcomes such as 'enable coping'.

Figure 8.1 Outcomes the practitioners intended to achieve



The following example illustrates and demonstrates how practitioners, by focussing on *patterns*, were able to address multiple problems. Helen orientated herself towards the individual and expanded on the whole person approach as she talked about a heart and spleen pattern in relation to insomnia. The patient wanted to sleep better, and Helen understood the sleep problem in relation to a TCM *pattern*, which related to a bigger picture than just the symptom of poor sleep:

Helen: 'So if their priority is to sleep better, I need to have a working diagnosis, whether that is Heart related, Spleen related, whatever it is related to, I need to have the diagnosis that is making them sleep poorly. Their goal is to sleep better and that is what I want to achieve.

SP: And how does that fit in with treating holistically? You know with that model you just described.

Helen: Because in that case, insomnia could be due to, in TCM terms could be due to lots of different causes, or lots of different inter-relationships that are out of balance in the body. So if I am identifying those in a wide holistic diagnosis that is my view of treating that person holistically. I suppose, in terms of the insomnia, but I suppose, there are lots of different elements to that. They may be presenting with other symptoms that you feel are that they might not feel are a priority but you feel may become a priority. And that has to be a fluid negotiation with the patient. And you already have got that in your diagnosis

because they have already told you about their hot sweats that they are not really bothered about but you know that kidney yin xu might be part of their insomnia, so it is relevant. It may not be their priority.'

Helen was reflecting on signs and symptoms that were inter-related demonstrating how in TA theory, because all the component parts are connected, multiple outcomes are possible. It is an approach that can address complexity. Helen was addressing complexity and anticipating what might become a problem in the future from her use of *pattern differentiation*. This is an important detail that has not been reported hitherto in the published TA literature. It is also a demonstration that practitioners have their own agendas regarding outcomes and long term goals and have their eye on a bigger picture of health including projections into the future as a result of the theory of TA. With this information as a background to the approach of the two practitioners, the main outcomes portrayed in Figure 8.1 are now discussed in turn.

i) *Fortify and Strengthen*

This is an important outcome to discuss as not only was it reported as an outcome by patients in the TA literature (see Chapter Six and Paterson and Britten 2003 and 2004) no peer-reviewed published accounts of TA have considered what it means to the practitioner. For EBC sufferers where fatigue and tiredness are daily experiences, increasing vitality is of paramount importance. 'Strength' to these practitioners was about the whole person, and not just physical strength; it included, for example, emotional strength to deal with difficulties. Addressing the fear and anxiety from the life threat were seen as the target for strengthening the woman emotionally.

'So I think if you can help with the emotional side it is going to give them the strength to deal with the physical aspects of what is happening. So that would be my first thought, with a woman like this, umm... because if you can help with the emotional side, then you can help with the confidence and they are going to be much stronger because there is nothing more dis-empowering than being frightened or anxious – it is just the most awful feeling for whatever reason, and this is a serious reason isn't it. You lose your ability to cope if you're emotionally distressed. So to me to help her feel stronger would help her to deal with the chemotherapy and whatever life is going to throw at her with the treatment.'
Diane

The practitioners considered how they achieved this with acupuncture and it is clear that they believed this was achieved mainly through the acupuncture and only partly through talking. *Fortifying* and *Strengthening* (tonifying) are also key concepts or methods in Chinese medicine theory (please see CM glossary).

Earlier in the interview with Helen, I asked what she had meant by asking people about their energy and she replied that it was about an individual's overt stamina and continued further:

'So whether their energy keeps going during the day or whether they are extra tired after meals or whether they would have a snooze in the afternoon if they can you know! Umm... you know whether they are tired in the morning, you know just the pattern of their energy generally. Stamina -throughout the day or over time.' Helen

Later she explained during her response to the vignette that coping was linked with tiredness and that the breast cancer sufferer's 'energy' was of principle importance

'You know whatever else is going on in her life I think that would be one of my main worries really (energy); you know can I get to grips with the tiredness, because it will be a principle issue because she can't cope if she is tired and not sleeping.' Helen

Fortifying and increasing vitality in theory seems to be about both increasing the *energy* of the individual and resolving emotional distress. By strengthening and fortifying the *Qi*, the person is more able to withstand emotional distress and also manage physical discomfort. The acupuncturists used the language of *fortifying, increasing the vitality and tonifying* the *Qi* of the person and this was a key part of the process of strengthening and balancing the whole person. The practitioners discussed the effect of shock on the *Qi*. Both practitioners described women as being overwhelmed with anxious thoughts and being unable to think clearly.

'...so if you can use the acupuncture to clear the mind, to ground the Qi, to get it circulating properly, then physically they are going to feel stronger, mentally they are going to feel stronger, they are going to be able to focus more on what is important, or what is the priority at that time rather than looking six months into the future and is there any point planning for Christmas...' Diane

Helen also spoke in this way, and about her belief that acupuncture treatment could increase confidence and courage and therefore self-esteem

'Yeah I did wonder towards the end, I've just done it with Sue, whether I should have been looking at the gall bladder more in terms of courage, I have just done that with Sue because her self-esteem is really low.' Helen

Gallbladder Patterns: the ‘Gallbladder governs decision making – the ability to maintain balanced judgement in the face of adversity is attributed to the gallbladder. When gallbladder qi is weak, fear, fright and timidity may lead to more disease.’ Wiseman and Feng Practical Dictionary of Chinese Medicine p.234

ii) Pre-empt Side-effects

One area identified by the practitioners was the potential of TA to pre-empt, as well as alleviate, the side-effects arising from the chemotherapy (in particular, to address Qi imbalance) that the women were receiving. This was important to the practitioners and they talked about it extensively. The practitioners gave examples of individuals and their *patterns* linked with symptoms that might typically get worse with chemotherapy such as nausea or night sweats, relating their examples to individuals.

‘So for someone like Vera I would expect her, because she was spleen knackered anyway, obviously they were all kidney affected to a certain extent but she was majorly spleen and stomach problems so I would have expected the chemo to go for that and for her to be very nauseas and her diabetes to get worse and her blood sugar levels to get out of control that kind of thing so I think the acupuncture by tonifying the spleen and stomach for that person helped prevent those complications. Her blood sugar did go up but it didn’t get out of control. She wasn’t overly nauseous at all I don’t think.’ Helen

Certain *patterns* (here *spleen and stomach qi xu*) might predicate certain symptoms to manifest with the chemotherapy, for instance, a worse experience of nausea and vomiting. Diane explained that making the Qi stronger would pre-empt some symptoms and that having an understanding of both what the chemotherapy might do and as previously mentioned an understanding of the past *patterns* of the person allowed the acupuncturist to anticipate the needs in terms of acupuncture treatment

‘And support them through the chemotherapy and have an understanding of what the chemo is going to do to them and almost pre-empt the side-effects that I would say 99% of the women are getting with chemo, so you can start to work on nausea before they get the nausea so that the Qi is strong enough to deal with that – Qi deficiency is quite common as well – so if you are aware of what the majority of women are experiencing without having acupuncture, you can pre-empt what is going to happen and hopefully put the Qi in a better position to cope with it before it happens.’ Diane

This is illustrative of the rationale for strengthening the *Qi*, before it becomes eroded by the chemotherapy; once *Qi* is *deficient* symptoms in addition to tiredness such as nausea can result.

iii) Resolve Outcome Patterns

An emerging idea is that outcomes are linked together to loosely reflect the *patterns* of imbalance perceived during the differential diagnosis. In asking Helen what kinds of things acupuncture helped with she responded:

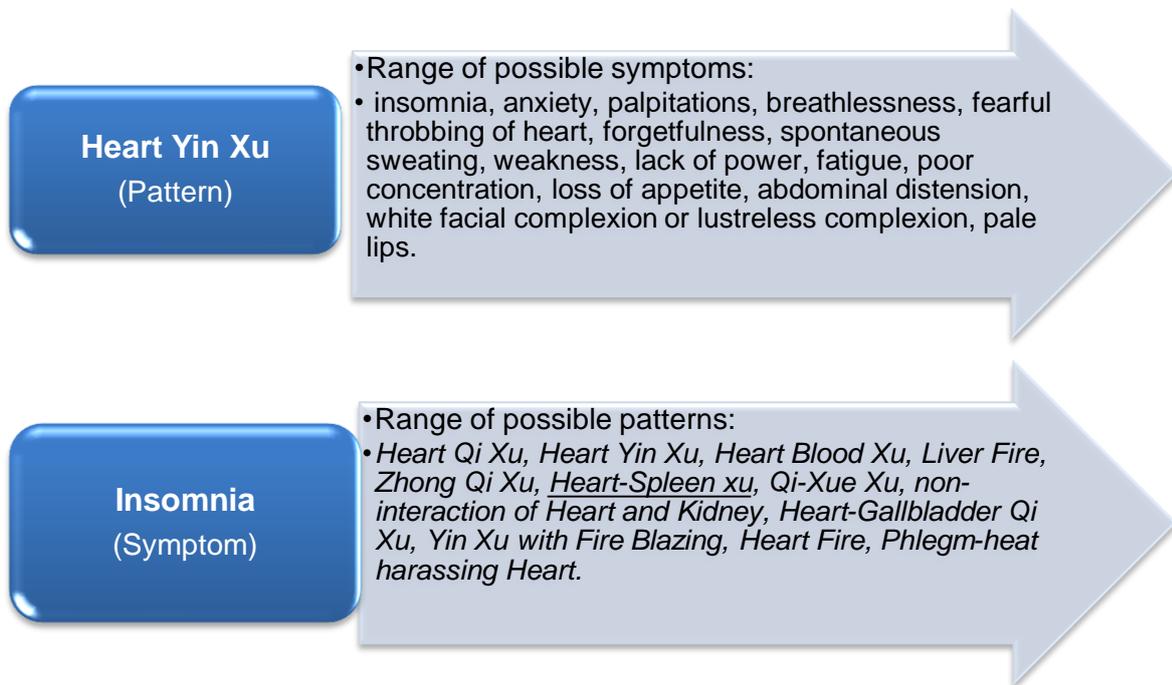
'Everything. I think the emotional level and the physical level. I do think we have pre-empted chemo symptoms – I think we have controlled past patterns and therefore pre-empted worsening chemo states.' Helen

Helen stated that acupuncture was preventative and that by addressing *patterns* a range of symptoms could be minimised or avoided. The word *patterns* has specific meaning in TCM theory, *patterns* are a set of specific collections of signs and symptoms one of which is illustrated in Figure 8.2. Helen went on to articulate the complex process of the experience of a cancer diagnosis and how both the acupuncture and the care helped the person

'I think it is difficult to be specific but I think any illness brings up the previous emotional patterns, it's not just the emotions about the cancer – it's about you know "is my husband being supportive" or for some "I have been looking after my father for all that time and rushing here there and everywhere" and how much has that contributed. So I think it helps the person – the cancer has catalysed their mind so that they can express that, the sessions help them express it more and the acupuncture helps them deal with it I think.'
Helen

Here there are different influences at work within a person: firstly the way a person is (in the past and now) in their *patterns*; secondly the cancer diagnosis has a profound effect, the acupuncture sessions provide an opportunity for an expression of all of these things and then the acupuncture treatment has an effect that helps them deal with it all. One point that Helen made here was that in treating the person, it was not just about the cancer, but about life before the diagnosis and how the diagnosis might focus past issues. By addressing *patterns* in TCM theory, and addressing different dimensions of health at once, both Helen and Diane spoke consistently of effecting change on different '*levels*' - physical, emotional and mental. An example of the difference between *pattern differentiation* and symptoms are shown in Figure 8.2. This also relates back to earlier discussion regarding how Helen focussed on improving insomnia by having a '*good working diagnosis*'.

Figure 8.2 Pattern and Symptom: relationships according to TCM using insomnia as an example. (Information taken from Wiseman and Feng 1998)



Diane mentioned the experience of a participant, Kathy, who was astonished that her anxiety had vanished after the first treatment; she was ironically concerned that the acupuncture could have had such an effect, because she was so altered.

'And what had happened so I explained how the acupuncture had worked because it had obviously just smoothed things out grounded her and she was sleeping and she was really quite chilled out about the whole cancer problem in a way to how she had been. She had not been sleeping, she had been having sweats – sweats because of her anxiety nothing else, so she was really disconcerted as to what on earth had happened and I was just - great... fantastic!' Diane

In this example, it is not just Kathy's anxiety that had improved so quickly, but her sleep and her night sweats. It is possible to see, from Figure 8.2, how by treating the pattern of *Heart-Spleen Xu*, which is what Diane did according to the log, she was able to achieve this range of outcomes. It is important to emphasise here that Diane believed this was an effect of the acupuncture treatment itself. The collection of signs and symptoms in a *pattern* of imbalance can result with treatment in changes in outcome patterns; outcome patterns are collectively inter-related according to this theory and not discrete as so often suggested by or reported in research on acupuncture. Outcome patterns reflect the whole person approach

in treatment; in other words, having a framework with which to relate different aspects of the person results in patterns of change to the whole person. Desired changes are identified via the differential diagnosis and interpreted as *patterns of imbalance*, treatment effects changes to these patterns and results in a pattern of outcomes linked together.

iv) *Enable Coping and Wellness*

For the practitioners, enabling coping and wellbeing or wellness were important outcomes. Both enablement and increased wellbeing are significant outcomes reported by patients in the TA literature (Chapter Six), but few studies have demonstrated that they are outcomes actively pursued by practitioners. Diane talked about dealing with the issues that were important to the person but, in addition, to get them to a point where they were strong enough to cope; problems had been worked on and changes had been made both physically and mentally.

'Well to deal with again, what they are actually presenting with. But to put them in a better place to cope after they have decided that they have had enough of the acupuncture. Or it's taking them to a place where actually they can coast along quite nicely, because you have unravelled the issues for them, and they are able to get on with their lives and maybe if they have done the changes, so... yes. Yes I think that is what I am trying to achieve with the acupuncture so it is again, for me it is on a physical and mental level as well.' Diane

These underlying outcomes were viewed by the practitioners as additional to the specific concerns of the patient. In order to achieve broad outcomes, enabling coping was also about helping the person process all that was happening to them too. Diane viewed this in terms of the acupuncture treatment rather than as an effect of the relationship. She perceived being able to cope as having something to do with both removing emotional distress and anxiety and assisting in the processing, or '*unravelling*', of all their issues and concerns.

'So going back to the first one then "with this patient – what would you be hoping to achieve?" - is to help them through their priority symptoms – and those symptoms may not be just the physical symptoms but about their anxiety and their fears for the future so to help them cope more with that.' Helen

Helen indicated that by supporting the person through easing of their main symptoms or concerns that they were more able to cope. From this perspective enabling coping was both a result of strengthening and fortifying the person's *Qi*, but also through alleviating other

signs of imbalance whether this was pain, or insomnia or anxiety. Diane returned to the idea of addressing both specific concerns but also enabling the person

'I see the acupuncture as supporting what is happening with the chemotherapy for the sickness and the nausea and maybe the hair loss. But just to make them, to empower the woman really – to make her feel that she is in control of what is happening to her as well as the doctors telling her what she is going to have to have done.' Diane

Coping in the cancer literature has links with self-esteem, self-efficacy and well-being; coping is commonly understood as meaning a demonstration of surviving and managing in daily life (Epping-Jordan et al 1999). These aspects have also been captured in studies using TA (Cassidy 1998, Paterson 2006) and Price et al (2006) in their exploration of patient enablement. Coping is an outcome for the practitioner, but it is an outcome that is affected by strengthening and fortifying the person and increasing vitality. There is a recursive feedback loop as the more the person is enabled to cope, the more balanced they will be in TA terms, and therefore the closer they approach to a place of wellness.

Enabling wellness according to Diane was about the attitude of mind as well as the body, and that someone might not be physically well but could still have a sense of wellness.

'If you wake up in the morning and you feel you are a bit rough then the whole day can be spoilt, because you feel so miserable and fed up and that is not wellness to me. Having a positive attitude is wellness. Again thinking of a patient of mine who is blind and is heavily disabled and he never really leaves the house but he is the most dynamic person. He is just absolutely brilliant. And although physically his life is hopeless, he is just such a wonderful man and he is an inspiration and he's got so many friends, because you just feel great being with him. Now to me that is a lot to do with wellness. If your mental attitude isn't there, then you are physically not going to feel well.' Diane

Wellness as described here suggests that there is an extra dimension to the person in addition to emotional or physical expressions of health or ill health. This extra dimension is about an expression of vitality or, in TCM terms, the balance and quality of Qi within the person. Consequently, a person can have limitations to their lives whether they are physical or emotional but still feel well. Being able to cope is an element that contributes to this experience of wellness.

All of these (desired) outcomes described by the practitioners are centred on *'broad whole person effects'*. Together they offer an insight into the whole person approach and effects of TA. More hidden desired outcomes such as pre-empting side-effects are facilitated by

balancing the *Qi* and *resolving outcome patterns*, as well as *fortifying and strengthening*. This leads to the individual being more able to cope and achieving a sense of wellbeing in the face of adversity. Implicit within these outcomes are two other outcomes, both discussed by the practitioners: acupuncture as being aimed and about facilitating changes in perspective or clarity of thought; and that, ensuring the process of treatment itself facilitates building a good relationship and rapport with patients, as patients relax and gain confidence as a result of the effects of the treatment. This latter dimension, relating to the therapeutic relationship and the emerging concept of therapeutic befriending, is explored in Chapter Nine with its focus on the process for achieving the desired outcomes.

So far this chapter has discussed desired outcomes, in the short and longer term, as perceived or recorded by the practitioner. In terms of the ToC, the outcomes are multiple and are inter-related, specific and broad. Problems according to the diaries and treatment logs were chronic and acute and the practitioners had in mind the whole person when addressing multiple problems. Attention now turns to examine the perspectives of women as they experienced TA, the outcomes and those that they valued.

2. Women's Perceptions of Perceived Benefits and Valued Outcomes

The women participants perceived both broad and specific benefits; they attributed change to the acupuncture because it was felt immediately; but also in looking back months after the chemotherapy had finished, they had a sense of a longer term effect. Nearly all the women felt they have coped well, despite their problems. At the same time, some of the women also found it difficult to attribute benefit directly to the TA; this was sometimes expressed explicitly because they did not know how acupuncture could work.

Perceived Benefits

While the women felt better in ways that seemed difficult for them to articulate fully, a number of benefits from acupuncture were reported and could be discerned. These have been categorised into general and specific benefits as well as the anticipatory effect of receiving an intervention, the individual believed was beneficial. When it came to discussing the acupuncture during the interview, all the participants conveyed enthusiasm for the experience.

General Benefits – 'I have felt the benefits of it'

Women reported feeling better generally, and also immediately after the acupuncture in a variety of ways. The practitioners had spoken substantially about using acupuncture to

increase vitality and fortifying and strengthening the person to enable them to cope better. This *'feeling better'* could be about symptom relief, as was reported by most of the participants, combined with inducing a sense of calm or feeling more relaxed. Women talked about feeling more composed, balanced, lighter, energised and good in themselves as well as more peaceful.

'I don't know what you are supposed to feel from acupuncture, because it is the first time I had ever had that, but I know that when I used to leave from the session, I used to feel good in myself. Like, feel good about myself, and feel like I'd got energy, and I didn't feel tired.' Anne

This general benefit may be an important outcome to women who are receiving medical interventions that are in some way reducing their wellbeing and vitality. All the participants reported that they looked forward to each session, regardless of what they felt the acupuncture was doing for them. Table 8.2 displays the list of *in vivo* codes under the heading of 'General Benefits' to demonstrate the range of experiences under this theme. Two aspects to general benefit are discussed in more detail: *'feeling more relaxed'* which was a universally perceived benefit, and being made *'more open'*.

Table 8.2 General Benefits (in *in vivo* codes)

<ul style="list-style-type: none"> • I have felt better generally • I looked forward to it • Happier • Lighter • More energy • Spring in my step 	<ul style="list-style-type: none"> • Relaxed • More open • Balanced me up • Calm, peaceful • Relaxing made it easier to chat
--	---

i) Feeling More Relaxed

As participants looked back having finished the chemotherapy, they described acupuncture as being very relaxing during what was a frightening time

'I found it very peaceful, very relaxing, very calming, and as I say it was just a great help to know that on a weekly basis I could go to that lovely quiet room, and talk to somebody and have treatment that I feel was helping with the side-effects of the chemo. ' Liz

'It helped me relax, I always felt much more relaxed after I had been with her. Yes I mean I'm thinking back now because it does seem quite a while. Yes, at the time, even when on

the day when I had the chemotherapy when maybe I felt really horrible I still wanted to go to Diane and have the acupuncture.’ Julie

Sue also described the acupuncture as relaxing and helping her through a very difficult time. She continued to have acupuncture through her radiotherapy up until her sister died. The third interview took place just a month later and she was still clearly in shock.

ii) *‘It Made Me More Open’*

In the second interviews, four participants talked about the acupuncture helping them to open up to accepting help or pamper themselves more. In addition, Jane, Julie and Lena reported this in the third interview and Mary hinted at it.

‘I think with having it and making me more relaxed, I would say it made me feel – it made me feel more at ease within myself as well. As I say speaking to the acupuncturist I felt ok about it – I felt more open as well.’ Lena

Being more open was also about putting themselves first or looking after themselves more and reflected changes in perspective; some participants clearly felt that the acupuncture had had a direct effect. This effect can be contrasted with the difficulty these women had in accepting help. A case example of this is given in Chapter Ten.

Specific Benefits – ‘It helped with lots of different things’

Table 8.3 displays a list all the symptoms that, at various times in the interviews, the participants reported the acupuncture helped with. This list complements the data recorded in the treatment logs in Table 8.1 above. Some of the participants described feeling very unwell at times often with a combination of extreme tiredness, nausea and a disorientated feeling that came on unpredictably; this may reflect the symptom clusters concept reported in Chapter Two although that data lacks the vivid sense of un-wellness that women described in this study. It was the immediate relief of these symptoms that convinced women that acupuncture worked. Some women suffered from extreme night sweats and reported the frequency and intensity reducing immediately. Night sweats went hand in hand with disturbed sleep which in turn contributed to fatigue. Several women reported their sleep was improved and that they felt more relaxed at night. Symptoms that seemed unrelated were reported as having being eased and resolved. An illustrative example is Jane’s reported combination of fatigue, joint pain, digestive discomfort and bloating as well as: *‘I know I have gone away and felt less boggy and my head hasn’t been as pitted’*.

Table 8.3 Specific Benefits *'It helped with lots of different things'* (in vivo codes)

• Bloating	• Watery eyes
• Pitted oedema	• Constipation
• Headaches	• Sore throat
• Eye pain	• Nausea
• Hot flushes, night sweats,	• Tight chest
• Tiredness	• Reflux
• Anxiety	• Insomnia
• Depression/low mood	• Restless legs
• Feeling emotional	• Achy joints
• Kept me bubbly	• It helped me relax

Several participants talked about help with headaches and eye pain, and others about help with emotional problems, or fear of not coping emotionally. Reduction in anxiety levels was dramatic for two participants, Lindsay and Kathy, almost immediately on starting acupuncture and for Anne, her fear of depression returning was managed she felt by the acupuncture

'It's kept me bubbly. Yeah it's kept me bubbly because otherwise I would have been down... Because I have suffered with depression quite badly. So I don't want to go down that road. Because it's like a no return sometimes, you can get that far down, so I prefer to stay at the high notes, and be all bubbly-bubbly... So I never got down, I never got depressed.' Anne

Anticipatory Benefit – 'I looked forward to it'

There was a high attendance for the acupuncture treatments, despite the effort of going in addition to the numerous and lengthy hospital visits. Because women knew they would come out of the session feeling in some way better, it was not an additional burden for them to attend and they reported making great efforts to do so. All participants enjoyed the whole experience of the acupuncture treatment, the interaction with the practitioner and the immediate benefit most of them believed they would get. They had the opportunity to share their worries or take the wig off; women valued being 'themselves' with the practitioner – but a self that was not only strong and coping but was weak and vulnerable as well, that is, containing the turmoil, fear and ambiguity – in contrast to how they sought to present themselves to others including protestations that everything was 'normal'. What was known about the contexts of their lives was problematic, for instance, the roller coaster pattern of the illness trajectory; becoming a cancer patient overnight, having challenging treatment, the

diagnosis and complex relationships with others. In the acupuncture session, they could both talk about ordinary things where the cancer did not define them and express their fears and vulnerabilities. For the participants, the acupuncture session was both light relief and a safe haven. In addition they could get '*topped up*' with something enabling them, as several participants reported, in having enough energy after the session to go into town and shop or be alone.

It should be noted that participants had access to other free CAM treatments, such as massage, counselling and reflexology, in the same location as the acupuncture but most did not use any services, aside from Kathy and Lynne who both had one session of counselling each.

'I mean I've made lots of appointments here at the Centre for various things, to see the nutritionist, the herbalist, when it actually comes to it I've often cancelled. With counselling I've tried it, but I've cancelled the second one, but I wouldn't have dreamt of cancelling the acupuncture.' Lynne

Lynne was not able to fully explain why this was except that she '*instantly liked it and instantly liked her*' (the acupuncture and the acupuncturist) and as she noted, the two things were important. There is no doubt that the ability of the acupuncturists to strike up rapport and relationship was part of the whole experience valued by all fourteen women. Vera, for instance, reported that she did not really need to see Helen for talking but found the acupuncture so helpful, and the conversation was conducted accordingly:

'She's a great lass is Helen. We always used to have a laugh' Vera

Anticipatory benefits are about the whole experience, and to participants being open to the idea of benefiting and being supported. Anticipatory benefits may also have contributed to women feeling that they were coping, as they were able to do something for themselves at a time when the ground had shifted under their feet with the cancer diagnosis.

Enable Coping – 'It would have been harder to cope without it'

Enabling coping emerged as both a broad and possibly long term valued effect of the acupuncture care. Several participants reported this effect at both the second and third interview. According to these women, the acupuncture seemed to be able to treat different symptoms in one session, and also produced whole person effects such as feeling stronger, feeling healthier and feeling more able to cope. Coping could result from an alleviation of symptoms as well as improved well-being. For instance, Vera who had co-morbidity and chronic pain, was able to stop taking painkillers and reduce other medication during the

period of time that she had acupuncture. She felt a new lease of life and reported that she had never felt better, and this was while she was having chemotherapy. Acupuncture seemed to lead to an improved mental outlook which made other symptoms feel more bearable.

Participants cited evidence that acupuncture had helped them, when they were talking about before and after changes. Experiencing these changes added weight to their belief in it and increased their sense of being supported, which in turn enabled them to cope better.

'I think because I believed it was doing me good, because I would come in and say you know, one day... What was that now... I came in once and I think I was having digestive problems or I was feeling really sick I wasn't feeling very good at all... and I came for the acupuncture and I went out, and we went to Morrison's for a cup of tea and a scone or something, and the problem I'd had had just disappeared. It had! And I said, that's all down to, I can't remember what my problem was – oh that is annoying – but I come in feeling really bad, and within a couple of hours of having the acupuncture I was completely different. And that really... I said to Mark (her partner), I feel fantastic, I said that's Helen, whatever she has done, it's worked. Yeah, I did feel the benefit, it did benefit me. Yeah.'
Liz (second interview)

Coping involves the ability to deal with something difficult and participants felt that the acupuncture care had made it more possible to cope. This could be because they felt they were doing something positive, or because they felt better for it or other reasons. Several participants talked about how the routine and continuity of seeing Diane or Helen helped 'keep them going'. Several participants vocalised directly that they felt the acupuncture had helped them to cope better.

For Liz, like others, it was the structure and routine of the sessions, her relationship with Helen and the acupuncture that she found so supportive. Despite suffering emotionally during the process of diagnosis and treatment, the whole experience of seeing Helen had helped her to cope. Being able to cope was very important for these participants as it chimed with their talk of remaining independent, and putting on a brave face for the sake of others so that they could buy time and space while they made their own adjustments.

'I liked the, I felt as though I could rely on Helen. She was always there, she is a lovely person and like I say I did feel that the acupuncture helps I had that structure you know, going every week, and I felt that kept me going, having that structure, during and with the chemo.' Liz

In the third interviews, where the women looked back over their experiences, of the seven participants interviewed, six reported directly of the overall benefit they experienced and how it helped them to cope. Liz talked about how the acupuncture helped her to feel stronger and more able to cope after the acupuncture had stopped

'When I started my new course of chemo, the side-effects were different, and I was able to cope with them, and I didn't feel... I wanted to do it on my own as well, I appreciated Helen very much, that first part because it is all so new and frightening so it was nice to have Helen there in the beginning but then as it went on, and I was half way through the chemo I felt stronger and able to do it on my own.' Liz

For this group, being 'able to buy' space and time to process the meaning of the diagnosis meant having the resources to put on a brave face for others and carry on as normal or, in other words, find a way of coping. Lena went through a lot of difficulties with the diagnosis and surgery and experienced debilitating fatigue at times. But she felt the whole experience of acupuncture helped her to cope, and part of what made her believe in it was she felt a lot worse when she stopped having it.

'I think from the – I think comparing when I was having it plus the chemo and then after stopping it, well whilst I was having it I think it helped me looking back, I think it has helped me a lot, to keep all the symptoms at bay – you know all that I complain of. Although it was there and I felt sick, and I felt tired, and I was able to cope because after the sessions of acupuncture finished I suffered badly and I put it down to not having the acupuncture to help me.' Lena

Like the practitioners, some of the women also felt that acupuncture facilitated the relationship as they described lying on the couch and feeling relaxed, and being more open to talking and sharing.

Therapeutic Relationship and Therapeutic Befriending

The therapeutic relationship formed a substantial amount of the talk of the women participants and is discussed here as a valued outcome or benefit of receiving TA as perceived by the women. For the practitioners the therapeutic relationship was an important process outcome and this is further explored in Chapter Nine.

The therapeutic relationship was highly valued. It is important to explore this experienced 'treatment process' outcome of care more deeply in this group not only because of the

complex nature of the context of this acute phase of EBC but also as few studies have provided data from both the practitioner and (women) participant perspectives in a longitudinal study of TA. In Chapter Six, the review of the TA studies involving chronic illness revealed that the therapeutic relationship was valued by participants. This study data provides a very different circumstance within which participants received TA, as the nature of the illness was acute and life-threatening.

Mary was very reluctant to attribute how well she coped with the chemotherapy to the acupuncture, but she went for all ten sessions and looked forward to them:

'But the big advantage and really its nothing to do with the acupuncture was coming here, sitting down, and talking to somebody about how I felt and it... because she is not part of the family or a friend, I could just say exactly how I felt, whereas to other people sometimes I would think twice about how I said something or whether I said something. Everybody wants me to be ok, and you want to think that you are ok, so to some extent you sort of play down I think, well I do, how I feel.' Mary

All the participants enjoyed seeing Helen and Diane, and found benefit from (just) being able to talk:

'In your mind, you think I don't need counselling. I'm coping, I'm doing ok, I can manage on my own, but yet when you come to someone like Helen, and you are just chatting and things come out in conversation, that is lovely, that is helpful.' Liz

Nearly all participants used the word '*friendly*' or '*friend*' when discussing the relationship with Helen or Diane, and much of the talk was about the nature of this relationship; it was of significant value to the participants. The following three pieces of narrative demonstrate how strong this '*friend*' theme was:

'I felt she was more of a friend while we were doing... obviously there is still a professional basis, whereas with the nurses they are smashing but it is all part of their chat of helping you through the chemotherapy and once you've gone you are gone and that is it.' Julie

'Talking to Helen and having the acupuncture sessions, I would say it helped me to not feel as depressed. Because I used to look forward to going for my weekly sessions. And I thought oh I will have a word with Helen about that so did enjoy talking with her, it did help me to keep my sanity really yeah. I would say that yeah.' Lena

Because it were just like talking to a friend. It was just.... It wasn't like you were going to the doctors or you were going to see a consultant if you like, to see whatever. It was just... like going to see a friend, but at the same time she's helping you.' Natasha

The women did not have to worry how the expression of their fears would affect the practitioner (unlike a 'friend'); and of course the friend relationship was bounded by the therapeutic encounter. Participants did not say explicitly that the relationship was formally therapeutic, such as in counselling, but they differentiated it from the chat with the nurses. This difference detected and discussed by the participants in the interviews, may be due to the purpose or function of these different kinds of treatment interactions. The purpose of and focus of the communication for the TA practitioner, in the main part, was to make a differential diagnosis according to TA theory; it provided a particular texture to the encounter. For the women participants, it had its own meaning, as therapeutic befriending, and it had importance for these women in this particular context of EBC. As reported in the TA literature in Chapter Six, the therapeutic relationship had an air of mutuality about it, or sharing of personal information. The topics ranged from light and chatty such as gardening to deeper and wider ranging topics.

'We have quite an open topic, and we have talked over so many things over the past few months, umm... yeah she has helped, she is just so supportive... We haven't always talked about the cancer, or the acupuncture, so maybe it is more about the whole life. We have talked about everything from babies to being babies. So, yeah, it has been a whole thing, even when we were off on a tangent completely, yeah, because she's not only a good listener and she doesn't impose her advice upon you but she will share her experience.' Jane

In contrast, nurses were available to talk and certainly had time because they often sat with women while they received chemotherapy. But for these women, it was perhaps that time and nurse availability was not sufficient to encourage them to open up and share their worries. It also may have been important to talk with someone separately from the cancer and medical community, or as Kathy said '*outside of it all*'; in addition to the experience that Diane and Helen cared in a personal way

'Because I mean, they chat to you, but I know it's part of what they've got to do while they're sitting. I felt as though Diane and I could have a dialogue, and we were interested on catching up on things, and she was genuinely interested as a secondary thing I suppose, I mean her main thing is the acupuncture, where with the nurses and that, they

are smashing and that obviously when they are sitting with you all of the time, they've got to chat, but they're not really interested.' Julie

Julie went on to say that the nurses chatted to pass the time of day; there was little personal interaction. In contrast, the acupuncturists were able to convey that they cared and were interested, and the women in consequence perceived the encounter as more meaningful. The participants reported that they did not rely on the nurses in the same way; but it may be that this was due to the fact they had the acupuncturists to talk to. But it was also all too easy for these women to brush off interest from the medical staff and respond with the usual '*I'm fine*'.

The data in this PhD study seemed to differ when compared to the findings of several other studies described in Chapter Six as there was virtually no self-care talk on the part of the women participants. There was no use of the theory of TA being used as an explanatory model, nor talk of '*new holistic insights*', despite the relationship being clearly strong and valued by the women; these encounters with the practitioner were perhaps for a different purpose, in contrast to individuals with chronic illness. Relationships with partners, friends and family had become by and large, complicated for women, as they negotiated help, whilst trying to not be defined by the cancer. Many people were keen to share cancer stories with them, both positive and negative, which were mostly not welcomed by these participants. In the TA treatment room, women were able to express different aspects of themselves not just the 'strong' or 'independent' aspects they projected to others.

For the women, the therapeutic relationship in this study was a valued outcome. In contrast to the practitioner and its importance to maximise disclosure, for the women it meant a variety of things, including light relief away from all other aspects of life which reminded them they were a cancer patient; being free to discuss fears and worries and explore what they might need. It also had the connotation of 'being' or 'acting as a friend'. These findings suggest a notion a little different to the connotations of a therapeutic relationship, to embrace the sense of 'becoming like a friend', albeit based and founded within the developing therapeutic relationship with the practitioner. The emerging concept can perhaps be best characterised for these women in terms of a notion of 'therapeutic befriending'. Befriending means to stand side by side with someone; it is a supportive relationship akin to but different from the notion of 'connections' expounded many years ago in the medical literature by Matthews et al (1993). The inter-relationship between the notions of the therapeutic relationship and therapeutic befriending is discussed further in Chapter Eleven. Here the

text returns to draw out the multiple features of the emerging concept of therapeutic befriending.

As a group, the women in the study found it difficult to accept help as they struggled to process what the diagnosis meant to them. They accepted the invitation to acupuncture treatment not knowing that it might involve in-depth conversation about how they were as a person, but they appreciated it and valued it as time went on. For many of the women, the conversation appeared to be light and chatty including topics such as cake-baking or past experiences. Women described being able to also share difficult feelings and traumatic past experiences. It appeared to these women to have a degree of mutuality about it because the acupuncturists would sometimes share their experience. Laughing and joking added to a sense of mutuality. Mutual warmth is also a signature of a good therapeutic relationship (Blow *et al* 2007). Trust was built not just by the Rogerian person-centred characteristics of the encounter (1951) but by the acupuncture helping with signs and symptoms. Acupuncture also relaxed women and made them more open. The characteristics of this 'befriending' relationship, as displayed by the women, are displayed in Table 8.4 below.

Table 8.4 Characteristics of Relationship Therapeutic Befriending

Characteristics of Relationship	Therapeutic Befriending
• Genuineness, unconditional positive regard, empathy	X
• Friendly	X
• Apparent mutuality	X
• Attachment and warmth	X
• Orientated towards the patient	X
• Supportive	X
• Nature of talk – light to deep	X
• Informal	X
• Focus is on acupuncture rather than relationship	X
• Acupuncture facilitates openness	
• Information gathering is purposive	

The women recipients talked about being 'free' to share their feelings because they knew they would not burden the acupuncturist. The relationship was still asymmetrical in keeping with all therapeutic relationships. Women were able to benefit from this supportive relationship without it appearing to challenge their desire to appear independent and that they were coping. As the women described, the practitioners were able to offer all the hallmarks of friendship: genuine care and interest, warmth and empathy, time to listen and

respect and the recipients recognised these qualities and found therapeutic benefit from talking and sharing during what was a very difficult time of their lives.

Concluding Comments

This chapter has explored the outcomes of TA, in terms of what the practitioners indicated as the short and longer term goals or desired outcomes they wanted to achieve, and in terms of the women's perceptions of benefits from receiving TA and outcomes that they valued. There are several findings from this chapter that need to be drawn together, some of which will be explored further in Chapter Nine and/or discussed further in the final chapter of the thesis (Chapter Eleven).

Building on material discussed in Chapter Two, the concept of symptom clusters within TA has been further validated by the triangulated data; combinations of symptoms added to up a feeling of disorientation and un-wellness. As perceived by the women, TA appeared to have great flexibility in addressing symptom clusters involving chronic and acute features, whilst from the practitioners' perspective staying focussed on the whole person. Goals of the treatment for the practitioner were articulated as addressing specific complaints and fortifying and strengthening the person to better withstand the onslaught of chemotherapy and the shock of diagnosis resulting in better coping. The practitioners used the theory of TA to attain change in multiple ways and the theme of *outcome patterns* emerged.

While the women in the study on the whole felt they had coped very well with chemotherapy despite lots of ups and downs, women were able to be certain of the benefits of TA when they were felt immediately. Desired outcomes for the practitioners and perceived and valued (achieved) outcomes for the women participants were frequently expressed as 'adding something to the (whole) person' rather than reducing frequency or intensity of a symptom. The therapeutic relationship was highly valued by the participants. As noted above, in keeping with other studies of TA, this relationship may be used for different purposes by the practitioners; this is discussed further in the next chapter. On further close analysis of the data the concept of therapeutic befriending, as depicted by the women, emerged as a valued outcome. As is explored more in the next chapter, this may be from both from the women's and the practitioner's perspectives an essential lynchpin in successful treatment especially where goals of treatment are complex or obtuse and involve emotional distress.

This chapter demonstrates that the multiple effects of TA are by design and strategy on the part of the practitioner and not a fortuitous side-effect of acupuncture treatment. In terms of the ToC, broad outcomes relating to the whole person are the overall long term goal of practitioners, as well as keeping the whole person, mind, body and spirit strong and whole to

better withstand the effects of chemotherapy. Attention now turns in Chapter Nine to explore the ways in which practitioners bring about their intended outcomes, thus enabling further extrapolation of the ToC for TA.

Chapter Nine

Elucidating the TA Practitioners' ToC in the Treatment of EBC

Introduction

This chapter reports on the findings from the longitudinal study regarding how the practitioners' employ TA constructs in practice to establish and work towards the goals of treatment. This will elucidate the ToC for TA in a real world setting using EBC as a complex exemplar. The chapter draws on data collected in three different ways from the two TA practitioners: in-depth interviews, one occurring with the practitioner before TA treatment and the other after all treatments had been completed; practitioners' diaries; and the logs they kept after each treatment. The final thesis chapter (Chapter Eleven) will bring all the elements of the ToC for TA unveiled at each stage of this thesis together including relating this chapter to the ToC framework (Box, 1 page 49) and the work already published regarding TA and patient and practitioner experiences as reported in Chapter Six. The glossary of Chinese medicine terms (on page xiv) is helpful in defining some of the specialist lagnuage and terminology of TCM reported in this chapter..

The methods used in this study provide important and comprehensive detail about the ToC of TA in the context of EBC. Before and after interviews offered rich data as the practitioners thought about how they would approach treatment and then discussed how they did it, relating some explanations to specific patients. In the logs the practitioners did not offer explicit rationales as to why they changed their treatments; rather they recorded what they did and any new problems experienced by their patients which reflected in altered treatment priorities. The diaries provided the practitioners with opportunities for reflection and were more personal.

Figure 9.1 displays the themes and sub-themes from the data analysis. Three main themes emerged: information gathering; individualised treatment; and the therapeutic relationship. Each is considered in turn. The therapeutic relationship was discussed in the previous chapter from the women's perspective and their perception of it as a valued benefit. In this chapter, the therapeutic relationship is discussed in relation to how and why it was used by the practitioners to facilitate the treatment and achievement of their desired outcomes.

Figure 9.1 Themes from the practitioner data regarding Theory of Change

Information Gathering (Differential Diagnosis)	Signs and Symptoms
	History of Person
	Silent Information
	Continuous Process
Individualised Treatment	Root and Branch (Surface and Underlying Issues)
	Treat According to the Zang Fu
	Treat Imbalances in the Qi
Therapeutic Relationship	Build Rapport, Feel Empathy, Make Time, Really Listen, Enable Trust
	Develop Warm and Genuine Attachment
	Mutually Enhanced with Acupuncture

Information Gathering

This theme centres on the process of gathering information. It has four sub-themes: signs and symptoms; the history of the person (not just the history of the disease); silent information about the person from close observation; and the fact that information gathering is a continuous process. These four dimensions of the diagnostic process reveal the steps required to make a *differential diagnosis* in TA and are now described.

Signs and Symptoms

Signs as well as *symptoms* were important to the practitioner because this information provided ballast to the *differential diagnosis*. Signs could be any experience that was not interpreted as being *balanced*, for instance, being very thirsty, or excessively warm. Helen and Diane both talked of gathering a lot of detailed information about the person over time. Firstly they asked about things that were important to the patient, knowing that more information might come later, possibly in future sessions since disclosure was contingent on trust. But within the first session, the practitioners would then ask the questions they needed to in order to treat.

'I get to the nuts and bolts at the very end. So once I have elicited the information I want, then I just say well let's just start from the top and I will ask about headaches, and chest problems and work through the system like that.' Diane

History of the Person

Both acupuncturists were certain that understanding the person's history was an important key to doing a better treatment. Diane explained why:

'If someone came with, well say breast cancer because that is what we are discussing, and I just treated the fact that they had got breast cancer on a physical level, that is not going to help them because I do believe that it is things that have happened in the past that has brought them to this point. Everything that has happened in their life has brought them to a certain point so I think that by helping maybe with all the personal information allows me to do a much better treatment.' Diane

Helen also affirmed that it was '100 per cent important'. To understand the history of the issue and of the person meant that establishing a rapport was vital to get the necessary information. Having insight into that history would shed light on underlying imbalances that might be more obtuse than the presenting main complaint. The diaries also provided information about individual history. Diane commented in hers that *'It strikes me more and more that the women I see have had immense emotional traumas in their lives, above what most people would have.'* She later wondered if this was a factor in getting breast cancer. Helen also recorded this in her diary *'the main issue that strongly connects them is that they all had extremely stressful lives for several years prior to their diagnosis of breast cancer'*.

Silent Information

The acupuncturists spoke about starting assessing the person's Qi as soon as they walked in the door, Helen referred to this as 'silent information', that is, non-verbal information that could be *interpreted* according to TCM theory.

'I think from the minute I see them; actually, I am starting to create a picture. As soon as they walk in,.... You can tell by the way someone stands, if they make eye contact with you, or if you shake their hands, and I often do, you can tell the feel of the skin, or what sort of handshake they have got, so immediately or I guess within the first ten seconds you have got a snapshot picture of what their eyes are like, what the Shen is like, you know if they are looking at you; just the whole way they carry their body – their skin tone, the way they are dressed.' Diane

I asked Helen to expand on 'silent information'.

'Because I find in when I am teaching in the college in supervision sometimes we will come out of a room with a new patient, we have done all the questioning, and we leave the patient with a drink and we come out and have a chit chat about what we think is going on,

umm... and sometimes I will have a feeling that damp-heat Liver and Gallbladder men are clammy – because they can be quite difficult to diagnose. You know, they don't come with a heaving chest and all the rest of it usually (laugh) and sometimes I will feel 'this person is....' And I will have to rationalise that to the students, you know, because we might not have hard evidence on it.' Helen

Thus, practitioners use all of their senses to gather information about the individual's *imbalances*. There was further evidence of this in the treatment logs, in how the practitioners described taking the pulses, noticing the weight and size and general impression of the individual, including the volume of their voice. The observationally derived or silent information deemed important by the practitioner appeared to go above and beyond the simply defined concerns of the patient such as '*I can't stop worrying*'. It seemed vital to the practitioner because it gave her clues about what might underlie expressed concerns or symptoms. Everything about the person was *interpreted*, by the practitioner, according to the theory of TCM, that is signs, symptoms and silent information.

Continuous Process

Both practitioners talked about taking their time with women, knowing that important information would not necessarily all be delivered in the first session. But this continuous process of information gathering related to time in an interesting way. It was both a looking back and a looking forward. Looking back through the history of the person (practitioners gave examples of trying to assess what *imbalances* might have already been present prior to diagnosis of EBC); and looking forward to what their health trajectory might be, with or without chemotherapy to anticipate needs both of the individual and also in terms of the differential diagnosis. Change was anticipated by the practitioners from the acupuncture treatment, from talking, from reflection on the part of the individual over time. Building rapport and trust and having a framework for enquiry was viewed as giving rise to more in-depth disclosure; the acupuncture treatment itself facilitated relaxation and trust. Over time, and with each treatment, more in-depth knowledge of the individual was discovered by the practitioner. This did not preclude new insights coming from the patient too. This continuous circular process is displayed in Figure 9.2. Disclosure and reflections with new insight are process-outcomes for the practitioners and feed into new information and new treatment. Disclosure is an outcome of the therapeutic relationship, discussed below.

Figure 9.2 Diagram to demonstrate the continuous processes and outcomes in TA



What is asserted from the ToC Framework (Box 1, page 49) and the general literature, and evident in these data, is that TA is not a fixed, repeated treatment. I asked both practitioners what has to change in order for them to change their treatment:

'I suppose it is on different levels all the time. Part of it is just hopefully a progression you know, you've made a decent diagnosis, you've done the decent treatment, and the person is progressing so the treatment has to follow the patient's progression and will change as the person's symptoms change.' Helen

Treatment changed because the person changed, or their priorities altered or they revealed information that changed how the practitioner made the diagnosis or the practitioner has new insight. Both Helen and Diane experienced this, and it was another element in the drive to quickly establish rapport and trust so that they could find out early on what the real issues were; aiding disclosure was a priority.

'The medication... the really easy one that I am careful with now is indigestion ' no I don't have any indigestion, no I'm not taken any drugs' and then you find out they have been eating Gaviscon for years. That is why they don't have any indigestion! That is quite more simple stuff. But there may be more serious stuff that you don't have the information about.' Helen

Diane records in the treatment log for Lindsay that her pulse is 'wiry' and that her treatment strategy is to 'sooth the liver'; by the fourth session and from then on Lindsay is much more open with Diane and reveals much more of her difficulties (according to the log).

The treatment process is thus demonstrated as a continuous dynamic of new insight, understanding, interpretation and progression. The practitioners spoke extensively about the process of making a differential diagnosis, through gathering a range of information about the person, their past, their current and future concerns, their relationships, and daily life and health. They employed the methods of listening, both to the quality of the voice, as well as what was said, asking appropriate questions to help them understand and diagnose, and as seen from the treatment log, they took the pulse and looked at the tongue and other notes about their *jingshen* or *silent information* as described above; that is they used different senses to absorb information. The information gathering and interpretation continued regardless of the content of the conversation, although the content was important for understanding what the individual's needs and concerns were and how to prioritise those through discussion and negotiation. The process of the diagnosis consisted of the *silent information* and assessing the *jing-shen* of the person, and the taking of the pulse and touching the skin, and looking at the tongue and asking the basic questions.

Individualised Treatment

The acupuncture treatment itself involves technical TCM language in describing the individualised treatment. This second theme shows how practitioners relate and draw on the body of the TCM theory in treating individuals (*BenBiao, Zang Fu* and *Qi*). Both practitioners spoke of individualised treatment; not only in the person-centred approach to caring and listening written about in the *therapeutic relationship*, and in prioritising, but also in how they needed the person and how many and which acupuncture points they selected. The strength of the treatment was also adjusted to the person

'How do you judge what is a heavy treatment? So part of it is just common sense, you know too many needles, part of it is judging how the person is operating, and then trying to fit your treatment to that. So in that latter case it would be releasing them maybe gently hopefully, they maybe have some deficiency that you are going to look at as well.' Helen

Diane explained that she was working out her treatment plan during the detailed diagnostic process and she, like Helen would then adjust each treatment depending on how the individual was at the time

'It's their feedback on the second treatment, how they have felt, if they have felt nothing fine then I can really start to do a bit more. But yeah, it is really their feedback.' Diane

The treatment logs and diaries also provide evidence for individualised treatment. Both in the *differential diagnosis* reported at each session, in the taking of the pulse and looking at the tongue each time and also the comments made by the practitioner. Using EBC as a

complex exemplar provides the opportunity to demonstrate the person-centred nature of TA as women go through a continuous roller-coaster both physically and emotionally with constant new challenges. For instance, Vera, after her third session, discussed with Helen the fact that her daughter who smoked was coming to stay, and Vera had managed to give up smoking. She talked through with Helen how to deal with this and thereafter Helen made notes about how Vera was getting on with her daughter. Lynne, as she did in the interviews with me, presented two sides to Diane. In the diary Diane reflected on how Lynne would say she was fine, but then burst into tears. In the treatment log, she always focussed on *calming the shen* regardless of how Lynne described how she was. She partly made this judgement through her experience, and partly on what the tongue and pulse told her about Lynne's *imbalances*.

Examples of the treatment logs are provided in Figure 9.3. In all, 129 acupuncture treatments were conducted in this study. Looking at the first and last treatment log for the third patients that Helen and Diane each saw (Anne and Liz) demonstrates the variation within treatment. At the third treatment, Anne disclosed to Diane her traumatic past which involved a violent relationship and separately, the murder of her brother. Her sleep and flushes, problems she had prior to diagnosis having come off HRT, were much improved after two sessions (although they continue to be problematic through chemotherapy). At her last acupuncture treatment (she still had one session of chemotherapy to go) the log records that her sleep was good and she only had mild flushes.

Figure 9.3 Examples of treatment logs demonstrating variation in treatment (Anne and Liz)

Practice	Anne (1 st treatment)	Anne (10th treatment)
Concerns	1. Night sweats. 2. Arthritis in right hip	1. Slight flushes
Primary Syndrome	Kid Yin Xu	Kidney Yin Xu
Secondary Syndrome	-	-
Pulse	Slow	Less rapid
Tongue	Purple, redder tip	Pink (slight scallops)
Strategy	Nourish Yin, clear heat, regulate sweating	Nourish Kidney Yin, clear heat, regulate sweating, tonify Qi
Points	Kid 7; Kid 6; St 36; Sp 6; LI 4; He 6; LI 11; Lu 7	Liv 3; He 6; Kid 6; P 6; Kid 7; Lu 7; St 36; LI 4; Du 20

Practice	Liz (1 st treatment)	Liz (10th treatment)
----------	---------------------------------	----------------------

Concerns	1. Queasiness. 2. Night sweats	1. Strong metallic taste. 2. Low level nausea. 3. Constipation. 4. Minor night heat.
Primary Syndrome	Rebellious Qi due to Liver Qi stagnation with heat	Rebellious Qi due to Liver/Gallbladder heat and stagnation
Secondary Syndrome	Kidney Yin Xu, Liver Blood Xu	Kidney Yin Xu
Pulse	Tense, flooding, excess	Tense. Resilient. Variable intensity
Tongue	Purple, redder tip	Pale purple with white coat
Strategy	Regulate Liver Qi, clear heat, subdue rebellious Qi, Tonify Qi and Xue, Nourish Kidney Qi	Clear Liver and GBL heat and regulate Qi; nourish Yin, Qi, Bld, descend rebellious Qi; keep channels on right eye.
Points	GB 34; LI 11; Ren 14; St 36; Liv 8; Sp 6; Kid 3	Lu 7; Kid 6; P 6; Ren 22; Ren 14; Ren 12; GB 34; GB 43; Liv 3; Sp 6; St 36; Bl 12 ®; Yuyao ®; St 2 ®

Four of the participants had blepharitis in one eye during this time and both practitioners treated it as Liz in treatment 10 above. Blepharitis is a common side-effect of chemotherapy due to loss of eyelashes. This is an example of practitioners focussing on specific symptoms, whilst still treating the *Qi*. If patients reported more nausea the practitioners included this in their diagnosis and treatment strategy without necessarily abandoning old complaints such as fatigue or night sweats.

An example of a different kind of change is given for Mary in figure 9.4 where between her first and second treatment her father's Alzheimer had become much worse and she needed to find him a home. She was consequently very upset in addition to the discovery that her sister-in-law was diagnosed with breast cancer (something she did not mention in her interviews with me). The treatment log revealed how Helen had re-diagnosed Mary with additional syndromes (*Spleen and Heart Xu*) having taken her pulse, listened to her and observed her. In her comments in '*just allowing Mary to talk*', Helen revealed how talking in itself was therapeutic in this circumstance aside from providing essential information for Helen's diagnosis.

Figure 9.4 Treatment logs for Mary (1st and 2nd treatment)

Practice	Mary (1 st treatment)	Mary (2 nd treatment)
Concerns	1. slight tiredness (no real complaints)	1. Tiredness – physical and emotional Very stressed – trying to find nursing home for father
Primary Syndrome	Kidney Yin Xu	Kidney Yin Xu
Secondary Syndrome	Liver Blood Xu	Spleen Xu (Yi) Liver Blood Xu Heart Yin Xu
Pulse	Flooding, deficient, tighter at Qi	Tense to tight, flooding deficient
Tongue	Slightly swollen, pale body, thick white coat, redder tip	Swollen pale body, small tooth marks, redder tip
Strategy	Nourish Kidney Yin, tonify Qi and Blood	Nourish Kidney Yin, Heart Yin, Calm Shen, Nourish Liver Qi and tonify Spleen Qi
Points	Ren 12, Liv 8, St 36, Sp 6, Kid 3, Kid 6.	He 6@, Kid 6, Sp 3, Sp 6, St 36, Liv 3, LI4@, Shenmen
General Support	Discussed some strategies for coping with phobia about vomiting. Gave her time to talk about worries re: her father's health.	Just allowing Mary to talk re: father but also sister-in-law diagnosed with breast cancer

Root and Branch

The *root and branch* approach is part of the theory on TCM and Helen and Diane used this language to describe what they were doing when they talked about '*different levels*'. It is an important part of the ToC for these practitioners and what they treat, that is, what is happening now or long standing imbalances. This again involved a judgement. Helen or Diane explained how they tried to assess the level at which the underlying imbalance is manifesting on, whether it was emotional or physical or at the *Qi* level or whether it was acute or chronic.

'But I always refer back to what they have actually come for because I think as an acupuncturist you often see what is underlying. Well for the patient you have got to treat what they have come for rather than working on the root of it. Because then they come back and they don't really know what you have done so I try and make the first treatment a

really obvious benefit to them and then I can start to explain, well dealing with what I think is causing the problem in the first place.’ Diane

There is a hint in this talk of the difficulties of treating imbalances for problems that had not been yet identified either by the patient or with the patient. I asked Diane to explain to me what she meant by treating the root.

‘The actual basis of where the manifestation of the problem has come from. So when I mentioned grief before, if someone has been grieving for ten years, they maybe manifesting with something completely different and physical but it is actually the grief in the first place that has caused it. She has got stomach pains, and she gets palpitations, and she has been treated by western doctors for the palpitations as angina but actually, I think it is because of grief, and actually we have been working upon that with acupuncture and she is just so much better.’ Diane

Helen explained too that there were different approaches to treatment, but that whatever the style, the result was that you treated the whole package.

‘You know, I think people have different styles. Some people will want to treat the root cause for them, some people will want to remove excess first, before they tonify, some people will want to do all of those things at the same time. That is going to be individual clinical judgement about how you approach it but most practitioners I think however they approach it, will have the thought that eventually they are treating, they are trying to treat that whole package so...’ Helen

This theme offers insight into how there can be several different approaches to treatment but they can all be reasonable. It adds to the argument that the TA approach is multifarious; it seeks to address the underlying cause of a problem, resolve the manifestation of it and as Helen said *‘treat the whole package’*.

Treat According to the Zang Fu and Balance of Qi

These two sub-themes are taken together given their close interconnections. In asking both practitioners how acupuncture worked their answers were relayed in terms of the *Qi* and *Zang Fu*. Treatment was about the balance of *Qi*, and according to imbalances in the *Zang Fu*. *Qi* was discussed in terms of soothing, smoothing, circulating, and unblocking or grounding. I asked Diane what she meant by *‘grounding the Qi’*

‘Well when they come in and they are talking 20 to the dozen, and they can’t get hold of a thread to have a conversation through so we can go from a to be to c, they are all over the

place, very head stuff – very agitated, physically agitated, can't sit still, and I find that after a session of acupuncture, if they are like that, and you can use some points just to smooth the liver out, to tonify the kidneys so they are feeling more – I can't say better than grounded – instead of the Qi all whizzing around in their head, all head stuff, not knowing what to do with it, it gives them some breathing space, so it gets the Qi circulating, nice and calmly, grounds them so that they can actually get some space in their head, to be logical again, so that it is not just a big ball of wool that is going round, and I think the acupuncture just unblocks that ball of wool and re-circulates it gain, so that they step back a little bit and be more rational again I think.' Diane

Balancing the Qi could result in improvements in all kinds of ways, including being able to stand back and have space to reflect. Helen and Diane mentioned directly that treating according to the *Zang Fu* will bring about the changes for health, both to prevent chemotherapy symptoms and still treat holistically:

'So going back to how it works I mean you know without going in to all the different patterns that is how I think it works, I am a great believer in TCM... In this group to prevent chemo symptoms. And to obviously by doing that and by treating them holistically according to the zang fu then you are improving their general wellbeing and hopefully if they were coming to the end of the chemo then I would be saying hopefully, fortifying them for that new stage of life, you know strengthening their kidney deficiency or whatever it is.' Helen

From the practitioner perspective, imbalances resulting in illness were corrected to enable a return to health, righting excess or deficiency, moving stagnation of Qi, and fortifying or strengthening deficiency of Qi. Getting the acupuncture to work then was reliant on their interpretation of the information available to them according to TCM theory, and choosing the right treatment strategy, which included acupuncture point selection and needling strength.

Helen and Diane related their talk to specific individuals and their problems, and the predominance of certain clusters of symptoms and patterns they saw in this group. The acupuncture working was dependent on affecting a change in the person and Helen and Diane believed that this was what they were doing by making a *differential diagnosis*, upon the information they had interpreted, and treated accordingly. They gave examples of both immediate and obvious changes such as anxiety disappearing immediately after treatment and not returning and of the slow reduction of symptoms or prevention of worsening symptoms such as nightsweats and hot flushes during the duration of the chemotherapy. How change occurred for Helen and Diane primarily related to the acupuncture affecting the

balance of the *Qi* and *Zang-fu*. As this was perceived as *individualised treatment* that was directed at particular imbalances of the person, using acupuncture to *facilitate changes in perspective* and the *relationship* was also part of how change was effected. These three sub-themes all involve the concept of balancing or treating the *Qi*.

Therapeutic Relationship

'They need much more time than the treatment of "run of the mill" acupuncture patients.' Diane

The third theme, the therapeutic relationship, emerges in this data as being of central importance as it is the trust and empathy that enables disclosure which allows the practitioners to focus on what is really important to these women, and thus to individualise their treatment. Although the literature on TA (for instance, MacPherson et al 2006) also suggested that the relationship was critical, but in a different way as it was part of the means through which TA empowered participants to take charge of their own recovery itself key to effecting long term benefits. Thus the weight of different explanatory accounts can be tested against existing literature and the data. This may also partly reflect a difference between a) women who seek out acupuncture as opposed to those that are offered it as part of a trial and b) recent diagnosis of a life threat compared to chronic illness.

Building Rapport

There was a lot of talk in the interviews about how and why the practitioners built trust, rapport, empathy, taking the time to really listen and sharing parts of their own experience. Helen described how she tried to make people feel comfortable, and how she would be careful not to repeat anything so that patients knew she was paying attention and *'they feel heard'*.

'You know you have got to get to know the person. But if they are not comfortable, if they feel threatened, then it is going to interfere with the whole consultation process and the treatment. It is more for the person to feel relaxed, especially if they are coming out of western medicine to feel that this is slightly different. They have got more time. There is a more relaxed atmosphere. We are going to be able to talk in detail. Where some people feel that they have never been able to do that before. You know, they have been rushed.' Helen

Building rapport and trust was viewed as a process that for some people would take time, and the practitioners did not expect to get all the information at first. Important detail that might only emerge after a few sessions helped the practitioner to orientate the treatment to

the goals of the patient. Helen and Diane reported that they worked hard to enable disclosure.

A Warm and Genuine Attachment

Both diaries recorded feelings of warmth, concern and attachment to individuals, feeling concerned for them, worried for them and being sad at the end of treatment to say goodbye and consequently wondering how they were. The patients' stories led the practitioners to reflect on their own lives. During the study, Diane's father died after a stroke and within weeks Natasha's father was hospitalised with a severe stroke. When Lindsay at the initial treatment expressed so much anger about getting breast cancer again, Diane took extra time to let her talk and at the end of each session thereafter they hugged. Here is an extract from one day in Diane's diary

'It's Anne's last treatment next week so I have encouraged her to get involved with (local cancer centre where Diane works). Partly for my benefit, as I don't want to leave her without support. We've talked a lot throughout these sessions and I'm sure I have helped her. I find it quite difficult knowing our sessions are nearly finished. I will miss her! I am very disappointed that her flushes have returned because she was doing so well with them. I suspect that she uses up any energy boosts she gets – she's a hard task master to herself!' Diane

It is interesting to note that the women commented on and were able to detect a difference in the nature of care received from Diane and Helen compared to other health care workers they came into contact with and this may not have been to do with just time to listen. One difference may have been how the practitioners themselves felt about their patients.

Mutually Enhanced with Acupuncture

Diane and Helen were certain that the therapeutic relationship while facilitating appropriate treatment was also assisted, in terms of disclosure, by the acupuncture treatment. As reported in Chapter Eight, this was described as a perceived benefit by several of the participants that as they relaxed during treatment, they became more open to talking. For the practitioners, the therapeutic relationship was both a process, to enable and facilitate TA treatment; and the level of disclosure was affected by the TA treatment itself. This is a complex association which contributes to the emerging idea that there are multiple pathways to change. According to the practitioners, it was accounted for by more than the treatment setting where lying and relaxing on the couch enhanced talk. Diane used her experience with Jane to argue that acupuncture facilitated the relationship. Having described Jane as

'angry' underneath, Diane reported that Jane felt although she had coped with a lot of difficulties in her life, the diagnosis and treatment brought up a lot of emotion.

'She didn't want to go to counselling or anything because she didn't feel she needed it because she knew exactly why she was feeling the way she did but I think the acupuncture did help to put her in a calmer place where she wanted to be, and she was aware of why she wasn't in a calmer place but I do think that the acupuncture did help get her out of this cycle that she had been in. So I worked a lot through liver, she had a lot of liver Qi stagnation, very nice and calm lady but underneath she was angry, so I think it helped with the liver Qi stagnation I remember working on that with her, definitely spleen, and Qi deficiency.' Diane

Diane went on to explain that she witnessed a shift in how Jane expressed herself, being more honest and open about what she wanted and needed. When I asked her if this was due to talking she was adamant it was the acupuncture as Jane was not much of a talker about painful emotions and memories

'It's the acupuncture. I'm sure it is. Unblocking circles, I think the acupuncture – the actual sticking needles in somebody precipitates the therapeutic relationship – because I think she was so used to putting on a brave face and well "this I what happened to me but it happens to everybody" and I'm thinking oh my god I don't think it does... some of the things that happened, so I think the acupuncture released enough in her for her to start to express and to actually recognise that actually these were big issues.' Diane

It may be difficult to unpick how and what causes a reflective process. Here the acupuncturist believed it was the way she did the acupuncture that achieved that. She had a rationale as to why emotional resolution had been lacking, namely, that the individual may have had a particular '*pattern*' that made insight and healing difficult. But in the women's own accounts, they drew attention to the value they placed on experiencing time and space inside the cocooned treatment room to think and feel and talk about themselves and their lives. Diane described this in terms of TA theory too:

'Because if you can actually talk about it, what is happening for you, then that itself releases Qi, and moves emotions and that itself can make you feel better.' Diane

Trust also evolved out of women feeling better after a treatment, a finding reiterating other research on TA as reported in Chapter Six, and the women's enthusiasm for TA after experiencing immediate benefit was reported in Chapter Eight.

Whole Person Approach

The overarching theme from this data is that the approach, in order to achieve the practitioners' goals of broad, whole person effects, is related to the whole person - their physical and emotional and mental condition, their history, the context of their home life and work and other demands. For example, in the treatment logs, diaries and interviews, practitioners talked about the three women who had dependent parents and what extra difficulties were caused when they are unable to care for them in the usual way (one was hospitalised, one went into a home). All of this information fed into the overall diagnosis and expectations of treatment. In the diaries practitioners reflected on what aspect of the person to focus on. The whole person approach in this study is about the interdependence of mind and body, and the inter-relatedness of the systems within the body and that everything about the person, past, present and feelings regarding the future has relevance to the practitioner and is woven into the diagnosis. This approach is in part, dependent on the therapeutic relationship, and the degree of disclosure. It is largely only possible to know and act on what the person is willing to reveal. The whole person approach is deeply embedded in the ToC of TA and gives it particular meaning. All aspects of the person are *interpreted* in the language of TA, for instance in their *Jing Shen* or their *Qi* and can be categorised into patterns, an example of which was given in Chapter Eight (Figure 8.2, page 141). The treatment logs recorded the tongue and pulse, along with the patterns of imbalance for instance '*Spleen Qi Xu*', or '*Liver Qi Stagnation*' along with the treatment strategy such as '*smooth the Liver Qi*' or '*Calm the Shen*'.

Concluding Comments

This chapter has shed light on the ToC of the two practitioners as they went about providing the acupuncture treatment, and thus how they perceived TA as leading to the achievement of their desired outcomes. It drew attention to the three themes. The findings have shown a dynamic process involving information gathering, individualised treatment and the establishment of a therapeutic relationship. These three themes together form the whole person approach which enables potential change to the whole person.

This study provides comprehensive detail on the ToC for TA, in the context of EBC, in a way that most other studies only offer partial insight into. In contrast to the studies reported in Chapter Six, here TA is applied to an acute stage of illness, which involved for the women unique aspects such as shock and emotional distress. These findings are able to demonstrate the characteristic parts of TA related directly to theory as opposed to incidental

aspects. There are several aspects of TA that chime with the existing literature such as the idea of non-linear and multiple causal pathways and that processes and outcomes of treatment are not divisible. The findings from this chapter are discussed in Chapter Eleven with regard to the ToC framework (Box 1, page 49) and the findings from the literature review in Chapter Six.

This study is unique in providing data from practitioners and patients in a longitudinal study. Moreover, since the study focused on the acute phase in the women's breast cancer trajectory (EBC diagnosis and treatment) it identified issues pertinent to the experience and management of this phase that are different to those experienced by people with a chronic illness. This is reflected in the different kind of outcomes and the orientation of the practitioners compared to the chronic illness studies. The therapeutic relationship has a different emphasis from these studies suggesting that it is a flexible tool in the repertoire of skills of the TA practitioner. In addition, this study provides significant detail regarding the role of the therapeutic relationship from the practitioners' perspective and from the need for its quality. From the data provided in the diaries and interviews, the practitioners form a warm and genuine attachment which, as reported earlier, was highly valued by the women participants. The important differences between the significance of the therapeutic relationship for practitioners in assessing and treating people, and the specific concept of therapeutic befriending as women articulated it are discussed further in Chapter Eleven.

The rigour of this study is strengthened by the use of treatment logs and diaries in addition to the descriptive data of interviews. The next chapter (Chapter Ten) will report on the reflexive approach used in this study as the researcher was also a practitioner. These findings and those from the previous chapter will be drawn together at the end of this thesis to provide a finalised view of the ToC for TA.

Chapter Ten

Reflexivity

“The posture of the naturalistic inquirer gives rise not to neutrality, but to a profound responsiveness and interactivity”

Guba and Lincoln (1982 p.130)

Introduction

This chapter describes the reflexive approach used in relation to the thesis. Reflections follow on my own experience as I have made the journey from practitioner to practitioner-researcher. The data from this thesis is largely made up of in-depth interviews and the degree to which this data reflects the participant’s reality can be more accurately judged with a reflexive approach. The process of being reflexive involves generating questions to challenge assumptions about how values and experiences are framed and constructed – from the research question itself, the design used to arrive at answers, how interviews are approached and conducted and how the data is analysed; that is epistemology, methodology and methods (Carter and Little 2007). In this chapter attention is drawn to different aspects that have resulted from this reflexive approach, most especially on the reflexive journey from practitioner to researcher, including influences on me as a practitioner. This examination is illustrated as a reflection on where I stand in terms of being practitioner-researcher and the journey I have undertaken. This includes examining more closely my choices as a researcher. Lastly two case studies, one a counter case and the other to illustrate a general perceived benefit of feeling *more open*, are provided to add rigour to the analysis.

My Standpoint

The first thing to make explicit is my standpoint as a practitioner-researcher (Frank 2000). This will hopefully aid in interpreting how I have coloured this research. One assignment for my MSc required a research design and funding application the subject for which I chose EBC with quality of life (QoL) as an outcome measure. I wanted to show that newly diagnosed women had complex needs and improvement of which could be demonstrated in a QoL measure and that acupuncture can address multiple problems contributing to an increase in a sense of wellbeing. As a practitioner I saw women recently diagnosed and identified them as by and large a vulnerable group but I was not able to articulate why I thought of them as vulnerable. They had lots of concerns which appeared to be compounded by receiving chemotherapy. It was difficult for me to know what value acupuncture added to the situation. In addition, I wanted to provide opportunity for women

who would not normally have access to acupuncture to try it; in turn I could reflect on comparisons within my own private practice. The intervention study within this thesis reflects my needs as a practitioner, I wanted to help and I wanted to care; I don't have any personal history of breast cancer with my friends or my family.

My Journey from Practitioner to Practitioner-researcher

Conducting this research has influenced me rather than changed me in that I am not aware of obvious changes in my practice. I have reflected in how I am with my patients, I am mindful to give them space and time to respond to my questions. Witnessing the excellent standards of practice offered by both Helen and Diane instilled a sense of respect for them; their confidence in their work sprang from their own experience. Talking with the oncologists and their difficulty in administering toxic drugs and their wish to offer supportive treatments moved me. In giving talks to practitioner-colleagues nationally on some of this work, it is clear that other practitioners are very glad to have this topic researched and are eager to discuss the findings.

Reflections on the Nature of the Encounter with Participants

“What on earth am I doing?” (field notes after the first interview)

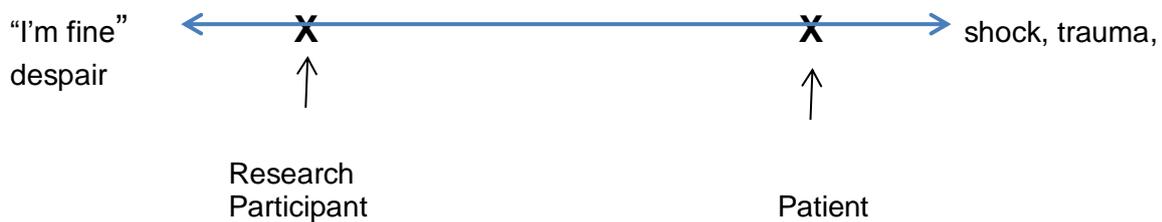
This section on the interviews with women with EBC discusses three questions

- How far can I go?
- What differences in disclosure are there for different types of interviews?
- How do we build rapport as interviewers?

As a practitioner of acupuncture my focus is on the whole person, whatever the problems of the individual. The focus on the whole person requires skills in developing rapport, empathy and trust, to enable me to see as much of that person as they will let me and is appropriate to enable improved health and wellbeing through acupuncture care. Together with the individual we work out a plan as to how things have come to be and how they can be resolved. Ultimately this relationship is person-centred, where sensitivity is required to ensure the individual although challenged at times remains comfortable with the process. Conducting this research has made me more mindful of my values regarding this approach that mind and body are integral and that outcomes of treatment should reflect changes in the whole person. The therapeutic relationship is central to my work, and I assumed that when it came to interviewing the breast cancer participants, these skills would be transferable. It was quite a shock initially when I realised that it was a very different encounter and I found myself floundering.

Women I see for acupuncture appear to disclose many difficult things almost immediately (within the first treatment). They will tell me what their immediately pressing problem is when I ask ‘*what is it that you would like me to help you with?*’ This may change as they get to know me, or as they reflect through talking, but in that moment, they are telling me what their most pressing concerns are. This experience meant I went into the interviews with participants with some kind of knowledge of the depth of difficulties that this patient group sometimes plunge to. Figure 10.1 illustrates the feeling I had that on the scale of disclosure, acupuncture patients share much more from the beginning about how they are really feeling than the participants in this study.

Figure 10.1 Scale to illustrate differences in my experience of women with EBC



Participants seemed to experience a difference between how they wanted to be (to have control over how they presented themselves to others) and how they are in this moment of their life (recently after diagnosis and surgery, and facing chemotherapy). They presented contradictory information. For example, Lena talks of horror and shock, and depression, and fear of losing her sanity but also reports that she has only had her normal ups and downs; Lindsay describes not suffering from nausea and vomiting but is violently ill during the interview; Jane says her energy is returning to normal, but she has spent the previous five days in bed. This resulted for me, during each interview, in feeling unsure about how far I could intrude into that individual’s awareness of their contradictions. Do I dismantle and deconstruct this contradictory view of themselves through asking challenging questions, as I might do if in a practitioner role? Is it ethical to demand an openness which might result in emotional distress for the purpose of research (Hewitt 2007)? As a practitioner, my authority to challenge their view would be to get a clearer picture in order to be able to do a good acupuncture treatment; but what was my authority as a researcher? The fact that participants were frequently offering up a confusing picture is in fact the story but I felt I needed to explore to a degree whether or not I had understood as much as I could. Examples of this are provided here via my second interview with Mary. At the outset of the interview she felt she had coped so well with the chemotherapy probably because the ideas about chemotherapy were out of date. During the interview it emerged that she slept terribly, that her mind was active at night often with worry, that she had fairly severe night sweats

and fatigue so bad she never went out on her own. I could have taken what Mary said at face value but I felt it was important to expose this contradiction and see what she said about it

SP: *'It's also interesting hearing you talk about that you haven't got many symptoms, but you don't sleep very well, you have got hot flushes and night sweats, some anxiety... you know, and also the tiredness – you actually have quite a cluster there.'*

Mary explains that these symptoms are normal and therefore not to worry about it, and that regarding 'the exhaustion well you just have to get through that really' and keeping herself busy meant she did not dwell on things, it was her strategy for not worrying. If Mary had come to me for treatment my very next question would have been 'so what can I help you with then' – I would have spent time coaxing out of her what she really wanted, which would also have potentially forced on her some reflection about how she honestly felt about things.

This suggests to me that there are two, possibly more, fundamental differences at play. Firstly, disclosure varies according to how I am seen on the part of patient/participant – it suggests that researchers get a different kind of information to practitioners; and that practitioners are privy to the more painful and difficult aspects of experiences more immediately. Patients have a powerful incentive to tell it how it really is because they are directly asking for help. Secondly, as a practitioner I have the authority to clarify what an individual is really feeling about something, while hopefully retaining a sensitive and person-centred approach, because I believe it will impact directly on the quality of treatment and success of the outcomes. These reflections revealed my epistemological position, that individuals share different parts of themselves for different reasons with different people. As a researcher, I was aware that careful and sensitive probing might be important if I was not to take everything at face value.

Having a whole person approach means also being mindful that this is contextual and contingent on what an individual will share with you. The experiences I have had as a researcher and as a practitioner included in this thesis add weight to the argument that there is a direct relationship between what people experience and what they share with an interviewer. This is in contrast to the more constructionist idea that the output from an interview between two people is a product of that interview.

The encounter as a researcher was different in the nature of the questions I was able to ask, in terms of the disclosure on the part of the participant and also in terms of their expectations, compared to women I saw for acupuncture. I started my interviews with participants making the assumption that it would be similar to my experience in practice. It

caused me to reflect on my practice, and how focus on the treatment meant that sometimes my questions were not as open as I thought; that maybe some women might need more time and space to find out what they really wanted or what was important to them. This also makes me wonder that without this long habit of questioning as a practitioner, that as a researcher I could have been more open, giving people more time to answer in their own way. My habit is to echo back to people what they have just said in order to confirm that I have understood them and there is the possibility that I did this too quickly or I changed it in a way that it was no longer open. This is intended to be a rapport building skill, that is, if you echo back to people what they have just said they feel you have really heard them, even by ensuring you have used the same language. An example is my second interview with Natasha when she is telling me about being hospitalised:

Natasha: 'Yes, because it might just be the steroids, and then I might be able to control it with diet afterwards, but we don't, they don't know yet. I went round for 3 days with an insulin pump because they just couldn't control the blood sugars at all. And then trying to fight a chest infection at the same time.'

SP: So you were feeling really low at that point?

Rather than echo back to Natasha her experience I re-phrased it and wrapped it up. Another example is Brenda told me during the first interview that she was going on holiday with five friends, as she did every year although one friend had died the year previously from cancer. Instead of asking her in an open way how it was for her, I asked her: '*was it good fun?*' If I had paused and waited and then asked her how it was for her, the nature of the interview may have changed.

These two encounters demonstrate the fact that although I got more comfortable as all the interviews progressed at challenging contradictions, there were still plenty of moments where I closed the interview off more quickly than was necessary. Rapport building as practitioners may be different to researchers who have only ever conducted qualitative in-depth interviews in that context. From this experience I feel my interview skills as a researcher have plenty of scope for improvement.

Skills in developing rapport are partly dependent on knowing what the boundaries of the relationship are and feeling relaxed and familiar within those boundaries as a consequence. During the first interview I was not relaxed when I realised I had before me a participant and not a patient. I am certain, however, that personally feeling empathetic yet relaxed in the face of an individual's emotional distress, that being upset is natural, normal and healthy, is the key to developing deepening empathy and trust and that only comes with experience, for

me, the years of experience as a practitioner. Despite the floundering I experienced at first when I was unsure about how far I could probe, having before me an emotionally distressed person is something I am very used to and relaxed about. Consequently, rich data was gathered in terms of nuances and contradictions within the interviews notwithstanding the shortcomings already discussed.

Reflections on the Discussion of the Therapeutic Relationship

As the therapeutic relationship is of importance to me as a practitioner, it seemed appropriate to look critically at how I explored participants' views regarding Helen or Diane. To this end, I extracted from all the second interviews any question relating to Helen or Diane. With one exception this subject was introduced by me, rather than participants, between half way and three quarters of the way into the interview, after questions and discussions about acupuncture. The exception was Anne, who talked immediately about Diane. In nine of the fourteen interviews, I introduced the topic by asking '*How was it for you talking with Helen/Diane?*' for the other four, aside from Anne, three had been talking about their emotional distress (Mary, Kathy and Julie) and it led in from there, and one mentioned seeing a counsellor once who she did not like (Lynne). Examining how the topic of the therapeutic relationship changed over time, given some of the responses, by the fifth (of the second) interview (Lena) I started to explore, during the course of our talk, how this relationship compared to others:

SP: '*Different from friends and family, what about other health professionals – how you spoke with Helen was it different from how you might speak with a nurse or...?*'

By the seventh interview (Kathy) I introduced the possibility of whether she felt spoken to as a cancer patient or a person as questions regarding the therapeutic relationship seemed to open up associations with setting and '*being outside of it all*'. For Vera and Sue the relationship was very much about accessing acupuncture, even though Sue was very distressed so this further exploration had less meaning for these participants. For three interviews within the last five (two of these were with Vera and Sue), the exploration had extended to asking whether if they had a choice, they would choose counselling, and if they would choose it over acupuncture. On reflection my approach regarding the therapeutic relationship was by and large led by the topic guide and the interview as it unfolded and only took up more time if it was important to the participant. Otherwise, exploration was limited after the initial question.

This reflexive approach enabled me to subtly respond to the subject, in this instance the therapeutic relationship, as the meaning of it emerged. I was able to explore it a little further and deeper as a result of this reflexivity.

Reflections on the Encounter with Practitioners

I already knew Diane and Helen through working at the same professional educational establishment although they taught acupuncture and I taught Chinese herbal medicine. I would describe them as friendly colleagues rather than friends. They were very generous with their time on this project, especially Diane because the project was delayed by almost a year before Helen became involved. The interviews with them were relaxed and informal and as they are both confident and experienced practitioners, their relaxed posture indicated to me that they felt very happy to share their experiences in this study and it caused them no angst.

The danger is of course that I made assumptions about what they were talking about because we took a level of the shared knowledge of TCM for granted in our conversations. To be mindful of this I consciously tried in the interview to ask them what they meant by, for instance, *Qi*; I made field notes after each interview and cross checked these against the transcribed interviews. I returned to Helen after her second interview with more questions, having asked her permission for more time. We talked on the phone which I recorded and transcribed. It was difficult for Diane to articulate what she meant by *Qi*, and for both practitioners to explain how they thought acupuncture worked until they realised they could talk just in the language of TCM. Being a practitioner-researcher made this kind of conversation much more possible than it might have been if they were explaining ideas from scratch. The three of us trained at different colleges, so I was interested to see some of their language coming through which seemed their own but also appears as important concepts in TCM for instance the idea of *fortifying and strengthening*. It is so long since I trained that I had not realised it was a straight translation of a process found in the Wiseman and Feng (1998) TCM dictionary. I had coded it first then found it in the textbook. I am not sure whether Helen and Diane were also using this word naturally to them or it was a label of the concept they taught at their college. Clearly the process is familiar to all three of us as practitioners but the label describing the process was a formal one as well as being one that naturally articulated the process.

I piloted the acupuncture interviews with several local colleagues before seeing Helen and Diane; these pilot interviews were recorded and transcribed and gave me the opportunity to reflect on my approach prior to the interviews proper. In order to aid this I reflected on the

nature and intent of the questions I had asked and how I had led the conversation by extracting all the questions I had asked at each interview. This increased my self-awareness during my interviews with Helen and Diane.

Reflections on Methodology

My initial intention was to conduct a quantitative study to test the hypothesis that having acupuncture during chemotherapy enables women to bear the impact of it more comfortably. Initial exploration of the subject and discussions during supervision caused a re-orienting of the research question and consequently the methodology changed. The difficulties I had making the transition from practitioner to researcher were possibly partly reflected in the methodology. Using quantitative methods may have enabled a more seemingly 'objective' stance or rather allowed my assumptions to go unchallenged. I was surprised when participants completed a small number of questionnaires at the end of each interview how very different their answers seemed to what they had just shared with me. As has been reported above, there was a great deal of contradictory information within each interview, and it seems that when it came to circling a number on a form, participants erred towards a more positive tone and the more difficult experience was missing from these questionnaires. It is consequently more appropriate to say that the journey from practitioner to researcher is more about a transition from practitioner to *qualitative* researcher, as the roles of open interviewing may have looked similar but were experienced so differently by me depending on which hat I was wearing.

This experience reinforces the comments made in the research literature that suggests that the research design and question does define and limit what can be found; not only in terms of questionnaires or interviews as above, but in the setting too. The lens adopted matters and may make a difference. The participants were glad that the setting of the study was '*outside of it all*'; they had limited contact with nurses despite the latter's apparent availability. This information coupled with my own experience of differences in disclosure depending on practitioner or researcher suggests that the setting has the potential to influence how much women who are traumatised will share and with whom.

Reflections on Methods

It was important for me to go beyond a descriptive account of the data and grounded theory was an obvious choice of method to attempt this. An important question in a reflexive approach is to ask '*what do I want this research to achieve?*' The choice of methods suggests something of what I wanted to achieve; my sense as a practitioner was that acupuncture and what it can do, and how it does that in the context of the treatment

encounter is a complex subject. Much of this complexity has been reduced in clinical trials to 'white noise' to be disregarded, whereas in my experience this white noise seemed to entail vital components to aiding healing and whole health. Regarding acupuncture and research, there is not enough of the whole problem of acupuncture on the discussion table and I hope in this small study to contribute to this discussion by providing evidence for what it is; and that it is more than just a needle technique; especially where complex conditions or co-morbidity is present.

Case Studies

Two case studies are provided to add rigour to the analysis. Firstly a counter case and secondly one to demonstrate changing perspectives illustrating the ToC. Mary and her experience of EBC and acupuncture care from Helen are offered as a counter case. Jane's story demonstrates a physical complexity and her changing sense of perspective and becoming *more open*, which both she and Diane attribute in part to the acupuncture treatment.

A Counter Case

Mary was someone who disliked making a fuss and felt she had to protect her family and husband from her fears, which kept her awake at night, and her symptoms, including her fatigue which was debilitating and stopped her from going out alone. She had still not gone out alone by the third interview three months after chemotherapy had finished. She had not told her husband she had an aggressive form of cancer and he was unable to have an open conversation with her about her prognosis. Mary had a range of symptoms but she 'normalised' them by saying she had them before the diagnosis and that her life was 'carrying on as normal'.

Mary felt she had coped really well with the chemotherapy and that this was due to '*out of date perceptions*' of how terrible chemotherapy could be. She found it difficult to credit acupuncture with a beneficial effect. This may have been partly because she did not have a sense of how it could work and also partly because she found it so difficult to acknowledge her problems. In one episode she suffered acute back pain, which Helen treated and it resolved immediately after the acupuncture. The back pain had caused her untold anxiety, as reported in Helen's treatment log and her diary. Helen described taking time to talk through her fears as Mary was convinced it meant the cancer had metastasised. Mary was unable to credit the acupuncture helping her back pain and considered that it might have gone away anyway. Despite all of this, she really enjoyed going to have acupuncture, she attended all ten sessions and she found great benefit in talking with Helen. At our final

meeting she said she was glad she had the acupuncture and that she would say yes to it again.

Mary was not open to change in the way that other participants were; she refused to take on board what the diagnosis might mean and said she would only really believe it had happened if she had a recurrence. Her need to keep the significance of the diagnosis at bay was her way of coping. As a consequence she described herself as *'being in limbo'* and that she had yet to find *'her new self'* and she may have denied herself much needed support. She found seeing Helen very supportive and her justification for it was that she was helping others by contributing to research in being a participant.

A Case to Demonstrate the ToC and the Outcome of Becoming More Open

Jane is used as a case study to demonstrate changes Diane believed were due to the acupuncture, and experienced by Jane. Jane also discussed her treatment and how she had changed in our interviews both during chemotherapy and afterwards in looking back at the third time point. Diane used the example of how she perceived and approached treatment with Jane that is her ToC for TA, which is reproduced below.

'What did she get from the acupuncture? I think it just supported her physically, emotionally she was very together on one level, and she was aware of her issues in the past, I won't go into it. More problems than most people would experience in a lifetime, but she had processed it on an intellectual level and she was aware of what was going on but on an emotional level it was still messing her up and I like to think that the acupuncture helped her release some of that on a deeper level. She didn't want to go to counselling or anything because she didn't feel she needed it because she knew exactly why she was feeling the way she did but I think the acupuncture did help to put her in a calmer place where she wanted to be, and she was aware of why she wasn't in a calmer place but I do think that the acupuncture did help get her out of this cycle that she had been in. So I worked a lot through liver, she had a lot of liver Qi stagnation, very nice and calm lady but underneath she was angry, so I think it helped with the liver Qi stagnation I remember working on that with her, definitely spleen, and Qi deficiency – she was really she was saying what she thought she should say, and I think within the treatments when I saw her she started saying what she wanted to say which was a big change for her.'

Diane talking about Jane

Diane talked about how Jane's *Qi* was *blocked* and the unblocking of *Qi*, especially *Liver Qi* would result in a change of perspective. Diane made a judgement that Jane had a hidden level of anger. The glossary of Chinese medicine terms gives a definition of *Liver Qi stagnation* which also amplifies this link with vision and being able to perceive more clearly and being more open and relaxed. It is reproduced here for convenience.

Liver Qi Stagnation (*gan qi yu jie* – trans. *liver qi bound and stuck*)

The Liver Qi's function to flow freely is interrupted. This happens when there is frustration or qi is obstructed by *damp-heat* or there is yin or xue xu. There is a range of signs (mental depression, oppression in the chest and frequent sighing) and symptoms of Liver Qi Stagnation including nausea and vomiting, pain and distension, abnormal bowel movements, pre-menstrual syndrome and menstrual irregularities and it can manifest in as well as being caused by emotional disturbance such as anger, frustration, agitation and impatience and also depression. Over time Liver Qi stagnation will give rise to heat. *Glossary of Chinese medicine terms.*

This extract does not express what it means to have balance in the *Liver Zang (Gan)* rather the imbalance of it. Much of the talk of the practitioners, in this PhD study, was taken up with creating balance and strengthening and fortifying as the theory of TA provides a vision of what healthy and balanced is. Below is another extract from Wiseman and Feng (1998) that discusses what the functions of the *Liver Zang* are. In these extracts (original translations from texts are in italics) vision is mentioned and as in keeping with the whole person emphasis, vision means both literally the health of the eyes but also the ability to see things in perspective. When *Liver Qi* is depressed, a lack of hope for the future is a common feature.

"The Liver governs free coursing means that it makes qi course freely round the body, ensuring normal mental and emotional activity. Impairment of this function leads to binding depression of Liver Qi."

"Liver Qi stagnation can cause rashness, anger and impatience"

"The Liver opens at the eyes stresses the important connection between the state of the eyes (and vision) and the state of the liver."

"The statement that the liver governs the making of strategies comes from a statement in Elementary Questions (Su Wen, Ling Lan, Mi Dian Lun) "the liver holds the office of general, whence strategies emanate" which means that the ability to make plans is related to the state of the liver."

Extracts from Wiseman and Feng (1998)

The treatment log for Jane reported that she had a history of grinding her teeth and had recently broken her teeth as a result of this. At the first treatment she was very anxious about her health and a recent wound infection (she was hospitalised and had the chemotherapy delayed as a result) and was generally 'very stressed' (*treatment log for Jane*). Jane had a history of fatigue and co-morbidity but had held down a full time job as a nurse while she had three children. The treatment log reported two main *patterns of imbalance* – Spleen Qi Xu and Liver Qi Stagnation. Jane also had headaches that went into her right eye; she suffered with bloating, constipation and a sore mouth but her main complaint was tiredness. At every single treatment the first acu-point that Diane needed was *TaiChong* (*Liver 3*). A detailed description of this point from the recommended textbook for TA is provided below.

TaiChong (Liv 3)

Principal point for promoting the free-flow of Liver qi in the head, eyes, throat, chest, Heart, breasts, epigastrium, abdomen, lateral costal region, uterus and genitals.

Subdues Liver Yang and pacifies Liver Wind: headache, dizziness...

Treats eye disorders: blurred or failing vision, red swollen and painful eyes...

Treats constipation and difficult defecation as well as diarrhoea due to Liver-Spleen disharmony

A Manual of Acupuncture – Deadman et al (2007)

In my conversation with Jane, she became very upset as she described to me her purchase of an old post office van to travel around with on her own. After becoming upset she confided that she becomes upset when talking about the subject of putting her needs first:

SP: *And so you are going to go somewhere in your van?*

Jane: *I'm going to go to Scotland. I've always wanted to look at the Scottish coast, and the kids have been too young. You can't drag them all over and I've been working. And I've got a chance to do it...I wouldn't have done this six months ago. So...*

SP: *What does that represent for you? Getting in your van by yourself, and going somewhere you want to go? What is that about?*

Jane: *Freedom.*

SP: *Freedom!*

Jane: *Yeah. Yeah. I don't think it's a case of if I don't do it now I never will but I need to do it now.*

SP: *You need to do it now. Why do you need to do it now?*

Jane: *I need to do something for me. I've spent so much time doing things for other people.'*

This was a very moving exchange because of how emotional Jane became in talking about her need for freedom and how difficult she found it. Diane attributed this change in perspective and behaviour to the acupuncture which she saw as a result from unblocking Jane's *Qi* and making her '*more open*'.

This change in perspective which other participants reported, for instance, for the first time doing things for themselves rather than everyone else, may have been brought about by several factors most importantly the life-threatening diagnosis, but also time to reflect from being off work. But it is also possible that the acupuncture somehow facilitated this process, making the actual acknowledgement of it more concrete and possibly sooner than it might otherwise have been made. Diane and Helen in their talk made it clear that it was not so much talking about any issues but an effect of the acupuncture that brought about greater reflection and clarity within the person. Diane and Helen were both certain that change in outlook was brought about by the acupuncture treatment itself. Becoming more open was brought about through participants talking and reflecting, but also from the effects of the acupuncture; participants talked of the acupuncture as making them more relaxed and more open to things. It is possible that this is related to '*new holistic understandings*' as outlined in Paterson et al (2004) and other TA literature in Chapter Six. In this PhD study, the practitioners provided very little information about the theory of TA to the participants, probably due to the acute nature of the illness both in terms of participants having had very little time to create their own understanding of it and also because they frequently were just managing day to day.

Concluding Comments

This chapter aimed to demonstrate my stance as a practitioner-researcher, and how and in what ways I may have coloured the research with my beliefs and values. Two case studies demonstrating two aspects to the thesis were presented to aid the reader to judge more carefully the quality of the research process and findings. The advantages and limitations to researching the subject of one's own profession were also presented. This demonstrates,

as Strauss (1987) reported, my and the participants' emotional as well as intellectual stake in the research. The next and final thesis chapter brings all the findings together and discusses the contributions they make to a revised Theory of Change for TA as well as strengths and limitations of the study.

Chapter Eleven

Discussion

Introduction

This thesis set out to deepen understanding of the theory and practice of TA, using EBC as an exemplar. It has sought to answer the research question namely: 'what is the theory of change for TA, as articulated in professional training, explored in research and as experienced by women with EBC?' Using a complex exemplar, EBC, provided the opportunity to lay open TA both as a complex intervention and to gain insight into its underlying theory as demonstrated in its practice.

There is difficulty in defining acupuncture resulting in problems interpreting the results of research trials. What constitutes model validity may depend on whether the different theories underpinning acupuncture are properly taken into account. In addition not all stakeholders buy into the idea that acupuncture is a complex intervention; despite traditional acupuncture having a documented whole person approach. I was inspired to undertake research in the area of early breast cancer because, in my private practice, women often seemed to experience a paradox of feeling healthy and well but being told they have a life threatening illness. The complexity of this scenario seemed to provide the right exemplar with which to explore TA. Finding a methodology that would help explicate what TA is led to the use of the Theory of Change (ToC) as an approach.

In wanting to implement the objectives and answer the research question, it was necessary in Chapter Two to explore the complexity of EBC. A detailed review of both qualitative and quantitative research on EBC and chemotherapy was undertaken. Aside from clear evidence that EBC is a complex medical condition with women experiencing debilitating symptom clusters, EBC has social, psychological and existential dimensions. In reviewing the literature in Chapter Two, gaps were found in understanding what the real needs of women were at this time and a sense that their suffering was not fully acknowledged (or understood or conveyed). The methodological challenges to depicting the tumultuous and rapidly moving nature of the experience for women before, during and after chemotherapy were apparent by the lack of detail regarding the process of change over time.

Establishing EBC as an appropriate exemplar led to the need to find methodology and methods suitable for answering the research question: "*What is the theory of change for TA, as articulated in the professional training, explored in research and as experienced by women with EBC?*" An argument for the ToC approach was presented in Chapter Three and details regarding the development of a framework (Box, 1 page 49) from the

professional guidelines of the major accrediting body for TA (BAcC) were set out in Chapter Four. This ToC framework acted as a guide to appraise the different data relating to TA explored within this thesis. Applying this ToC framework to two different sets of literature would, it was envisaged, surface different aspects of the ToC of TA and highlight gaps in the knowledge. A longitudinal qualitative study was performed, generating data about women's experience of TA and what practitioners did to effect change over time, as women underwent chemotherapy for EBC. This offered further opportunity to explore the ToC for TA and the findings of the deployment of these methods were reported in the subsequent four chapters.

Chapter Five reported on the first stage of drawing out 'what TA is'. The ToC framework was applied to systematically selected studies to critically appraise their model validity. The framework was helpful in identifying the explanatory models of acupuncture in clinical trials: significantly, less than half of the 27 selected studies had any ToC as to how the acupuncture might work or why certain acu-points were chosen. One of the criteria for selecting studies was that they employed outcome measures reflecting symptoms relevant to the EBC experience. Research already suggested that these symptoms might be multi-dimensional, that is, have more than one mechanism of dysfunction. The main finding from the application of the ToC framework (Box 1, page 49) to the research literature was that research in acupuncture more often than not fails to acknowledge fully and properly the different theories underpinning it. Where research is designed along pragmatic lines, that is, designed to explore effectiveness (Thorpe et al 2009), the closer the model in research replicates what is done in practice the more relevant the results. The large gap between acupuncture theory and acupuncture as researched (Chapter Five) may provide a major reason why so often results from acupuncture trials are deemed inconclusive. There is not a close enough fit between the models researched and good TA practice, and as these findings show quite often there is no explicit theory whatsoever as to how acupuncture might work.

Chapter Six continued in the process of drawing out 'what TA is' by applying the critical thinking of the ToC framework to a different kind of literature to that in Chapter Five; that is the patient and practitioner perspectives on TA using qualitative methodology. A significant finding is that several of these papers demonstrate the multiple pathways of change inherent within the TA approach. Processes of treatment for the practitioners are also valuable outcomes of treatment or process-outcomes; and new insight and belief in the acupuncture increases change in a snowball effect, for the patients. Patients valued different kinds of change including new insights into their health and the use of the explanatory model of TA

as a way to understand and manage their problems better. One of the longer term goals of the practitioners was also to bring about change *inter alia* in symptoms, ways of coping and to help their patients to find understanding and insight into illness leading to changed behaviour and lifestyle, thus empowering their patients to take charge of their own recovery. This relied on the skills of the practitioner in building a good therapeutic relationship and was cited by two of the practitioner studies as a primary purpose of it. Increased agency in self-care was of major importance in several of these studies, all of which were focussing on chronic illness. A range of perceived benefits were reported relating to mental, emotional and physical health and in self-concept; patients also appreciated the whole person approach. The single outcome measures common in clinical trials thus do not reflect the whole person approach or multiple outcomes aimed for in TA. One omission from this literature, however, was detail regarding '*what is done*' in the treatment although practitioners described individualised treatment and conducting a differential diagnosis.

Chapter Seven was the first to report findings from the longitudinal study that took place under the auspices of two NHS hospital trusts. As qualitative methods were employed it was imperative to contextualise the patient experience of EBC and how this shaped the fourteen women's needs and concerns at this stage in their illness trajectory. Through the use of serial interviews insight was gained into the maelstrom of change brought about by diagnosis and chemotherapy as women desperately tried to hold on to themselves and their lives pre-diagnosis. Light was cast on the depth of suffering; women's suffering was compounded by their reaction to the shock of the diagnosis firstly in their struggle to keep everything unchanged and their continued pushing away of support as a way of limiting the impact of the significance of the cancer diagnosis. Employing Bury's distinction between meaning as significance and meaning as consequence, its consequences were slowly but inevitably felt as side-effects and/or symptoms; the strain of trying to carry on as normal were palpable in the women's narratives. Mental anguish, loss of intimacy, isolation and emotionality were some of the expressions of this suffering. Paradoxically half the women considered that despite their suffering, they had coped very well during chemotherapy.

Chapter Eight reported on the outcomes of TA as explored and arising in the longitudinal qualitative study, both in terms of what the practitioners intended to achieve with their treatment (desired outcomes) and the perceptions of women participants and what they valued. As perceived by the women, TA appeared very flexible in addressing symptom clusters that varied daily along with enabling coping and relaxation. Practitioners wanted to address specific complaints and achieve broad outcome such as strengthening and fortifying the person in the face of the chemotherapy as well as enable coping and improve wellbeing. The triangulated data demonstrated that the multiple effects of TA come about by design

and are inherent within its theory of change, rather than just fortuitous side-effects. The therapeutic relationship was highly valued by the participants and the emerging concept of therapeutic befriending was tentatively developed.

The findings regarding the two practitioners' theory of change for TA in a real world setting were discussed in Chapter Nine. Three themes, information gathering, the therapeutic relationship and individualised treatment together formed the whole person approach. Treatment was a dynamic process of continuous information gathering dependent on several things including increased disclosure (Figure 9.2 page 161). This demonstrated one way in which the causal pathways are multiple. The study focussed on the acute stage of EBC, in contrast to much of the TA literature on chronic illness which revealed a different emphasis regarding the therapeutic relationship. This suggests the therapeutic relationship is a flexible tool used in different ways by TA practitioners to enable the achievement of long term goals; in this instance to enable coping and improve wellbeing.

Finally Chapter Ten addressed rigour and reflexivity; having and reporting a reflexive approach is one aspect of increasing trustworthiness of data. I describe my standpoint, what I sought to achieve within the research and the ways in which my outlook may have coloured it, offering illustrations of subjective twists and turns that the data collection and analysis also took.

Against this background, this final chapter aims to draw together, discuss the findings and draw out the implications of the study for theory, method and practice. It begins in Section Two by exploring the way the findings meet and address its five research objectives and how they contribute to existing knowledge. This is followed in Section Three with a focus on the intended or perceived outcomes of TA from both the literature in Chapter Six and the longitudinal study in keeping with the ToC attention to outcomes and long term goals. This includes what the practitioners were trying to achieve and participants' perceptions of benefits as well as discussion on what criteria and measures of outcome might best reflect these. Section Four draws together the material relating to the theory of change for TA, building on the initial framework as explored in Chapter Five, refining this framework in relation to the literature explored in Chapter Six and the findings from the practitioners in the longitudinal study. Finally, Section Five discusses the strengths and limitations of the study, indications of the thesis' contribution to knowledge and suggestions for further research.

1. Meeting the Objectives of the Thesis

The first objective of this thesis was to demonstrate EBC as a complex exemplar. Chapter Two demonstrated that EBC is best understood as both medically complex with a range of symptom clusters, and also complex in relation to the individual's life experience. Both the

speed of the diagnosis and treatment trajectory and the sense of threat to life add to the melting pot of difficulty and suffering.

The second objective was to explicate the theory of change underpinning models of good practice of TA in contrast to MA by exploring the professional theoretical framework. This was achieved in Chapter Four, where the framework was developed. Applying the ToC framework to published clinical studies of acupuncture with selected validated outcomes helped to meet the third objective of starting to draw out the theory of change. This process of surfacing the ToC was continued in reviewing the qualitative literature on TA regarding the perceptions of patients and practitioners of what TA is and perceived benefits or goals. Thus the fourth objective was accomplished.

Realising the fifth objective relied on the analysis of data generated from the longitudinal study. Firstly, Chapter Seven described in detail the women's experiences of EBC and how these shaped women's needs and concerns at this stage in their illness trajectory. Insight was gained into how women experienced TA and perceived benefits that the women valued were reported in Chapter Eight. Included in this section was understanding of the practitioners' intended outcomes and long term goals regarding the ToC. Finally, how practitioners' theorised about TA was reported in Chapter Nine in order to further extrapolate and refine the initial ToC. The ToC for TA, including how it is intended to work and the perceived benefits are now discussed in the following two sections starting with a look at intended and perceived outcomes.

2. Intended Effects, Perceived Benefits What to Measure

The first step in developing a ToC is to consider what the long term goals are, and work backwards making explicit the steps necessary to achieve these goals. A focus on this thesis is on outcomes; in Chapter Five single outcome measures were included in a review on acupuncture studies with frequent lack of detail on how the intervention might bring about change, for instance, in the five fatigue studies. Chapter Six reviewed qualitative studies on practitioner intended outcomes and patient perceived benefits. The outcomes from these chapters are now discussed in relation to the findings from Chapter Eight on the intended outcomes of the practitioners (based on triangulated data from interviews, treatment logs and diaries) and perceived benefits reported by the women. Comment is made on these outcomes and the ToC for TA before the subsequent fourth section of this chapter which presents a refined ToC for TA.

Whole Systems Research

In the majority of CAM effectiveness research, despite the allusions to a whole person approach, outcomes in clinical settings are often measured as single end points using a quantitative indicator (Reilly et al 2001, Khorsan et al 2010). In cancer care, patients can feel frustrated at the lack of support for CAM from their medical practitioners and do not require the same level of evidence for its use (Verhoef et al 2007). Researchers have highlighted the need for whole systems research (WSR) (Verhoef et al 2005, Verhoef et al 2006, Sutherland et al 2009) and outcomes (Long 2000, Sutherland et al 2009) to reflect the whole person approach common to CAM. WSR advocates finding measures for both outcomes and processes and recently more complex approaches have been advocated to capture change such as non-linear dynamical complex systems (NDS) (Bell et al 2012). WSR assumes that causal pathways are non-linear, that there are several causes of change that spread and are emergent (Bell et al 2012) a finding that chimes with this EBC study. This EBC study has used qualitative methodology to explore links between processes and outcomes and the ToC was found to be flexible, iterative and emergent with multiple causal pathways. Using quantitative methods, as WSR advocates, may be problematic but early attempts have been made in healthy student populations to explicate more what predicts flourishing and resilience within individuals when seen as complex systems (NDS) (Otto et al 2010).

Symptom Clusters and Outcome Patterns

The concept of symptom clusters was supported by the triangulated data reported in Chapter Eight. Combinations of symptoms added up to, at times, a sense of total unwellness and collapse. TA appeared to have great flexibility in addressing symptom clusters that had both acute and chronic features. This is problematic for finding single outcome measures as a primary outcome in research trials, as this perceived benefit and this valuable flexibility will not be captured. The notion of outcome patterns emerged where collections of signs and symptoms in a *pattern of imbalance*, identified in a differential diagnosis, were changed by treatment into *outcome patterns*. Treatment effects changes in these patterns and results in a pattern of outcomes linked together. Outcome patterns reflected the whole person approach in treatment and changes were experienced in the whole person. Moreover, outcome patterns are collectively inter-related and loosely fitted with theory of TA. Finding outcomes that capture all the inter-related changes also tied up with the process of care resonates with discussion surrounding the development of whole systems research discussed above. The findings of Chapter Eight thus demonstrate a more complex picture than that evident in Chapter Six. In the literature reviewed there, the notion of outcome

patterns does not emerge from the literature except in a more generic way such as improvement in physical and emotional wellbeing.

Whole Person Effects

Intended outcomes of practitioners in the EBC study were expressed as 'to strengthen and fortify'. Several studies in Chapter Six reported perceived benefits by patients as being increases in personal energy, and increases in emotional and physical strength. Other literature on CAM also points to perceived/reported changes to energy and strength (Verhoef et al 2006, Otto et al 2010).

TA has a central focus on *Qi*; looking at the Wiseman and Feng (1998) translation of this concept it is more easily related to in terms of the lack of it such as general weakness, fatigue and poor physical functioning. In TA theory, strength is not just reliant on having enough *Qi*, but is a reflection of the whole person being balanced and the vital substances such as *Qi, Xue, Yin and Yang* being in harmony.

It was possible through looking at the detail within the treatment logs to see that focus was on bringing about change in relation to these Chinese medical terms. According to Diane wellness included having personal energy and a positive outlook and both practitioners worked to strengthen and fortify the *Qi* and address side-effects and symptoms. This echoed with the findings of several of the Chapter Six studies which recorded perceived benefits such as an increase in personal confidence and changes to personal and social identity and self-concept including self-awareness. Where the daily ups and downs of problems are routine and familiar, as in chronic illness, attributing these kinds of change to TA may be more straightforward. In the EBC study, despite the very confusing and overwhelming picture for women, some participants did report shifts in their perceptions and focus as a result of the TA, most especially in making more time for themselves and appreciating their needs more.

In this EBC study, there was a range of problems cited as the main complaint in the treatment log (Figure 8.1) and the practitioners appeared flexible in their approach to treatment. In a study of people using CAM while suffering from cancer (Polly et al (2006)), the concerns ranged over thirty categories, and using the Measure Yourself Concerns and Wellbeing (MYCaW) instrument a significant improvement was shown overall. Finding ways of capturing change where problems range from symptom clusters to changes in self-concept is not easy but the MYCaW instrument may be a useful way of capturing a range of changes important to the person and provides also opportunity to collect some narrative.

One proviso might be that when patients have a recent diagnosis and rapidly undergo treatment, needs and concerns will fluctuate wildly and may also be difficult to identify.

Enable Coping

A broad intended outcome of the practitioners in the EBC study was to enable coping. This was brought about by using acupuncture to reduce the impact of symptoms both directly and through *strengthening and fortifying*. These two intended outcomes fed into one another; as the women reported feeling more able to cope, their sense of wellbeing and confidence increased. From findings reported in the literature explored in Chapter Six it was evident that practitioners went about achieving long term goals of improvement in health and coping with illness through several pathways including engaging the patient with the explanatory model of TA. The therapeutic relationship and the TA explanatory model were being used in combination by the practitioners, to provide additional insights to their patients and to enable them to make changes in lifestyle by linking their health experiences with their environment or via *new holistic insights*. In contrast to the studies' findings, the approach adopted by the practitioners in the EBC study did not appear to include references to the TA explanatory model and the practitioners reported that, to a degree, this was because many problems were fluctuating and acute and their focus was on supporting women through their daily struggles. This thesis has thus provided the opportunity to show that although the long term goals of practitioners may be the same for acute or chronic illness, different skills and tactics may be utilised according to the practitioner's perception of the personal resources available to the individual at the time, the health problems experienced and other factors in the life-world of the person, including social support.

Participants' Seeking Meaning

Some of the studies in Chapter Six suggested that outcomes from acupuncture care can include '*new holistic understandings*' (Cassidy 1998, Gould and MacPherson 2001, Paterson and Britten 2004) of the person in relation to their health or illness. For individuals with a chronic condition, who have had time to understand what their illness means to them, less value and time may be placed on the importance of unravelling with the practitioner what the needs and concerns for the individual are. In real life, where people have co-morbidity, it is likely that needs and concerns will vary with changes resulting from treatment and other context factors. For the women in this study, the experience of illness was dominated by shock initially, more than seeking meaning in the transformative sense. They were battling to make sense of what was happening to them. By the second interview there was a struggle to find meaning but at this stage women were mostly trying to manage the effects of medical treatment. By the third interview, life changes that had been made, such as retiring, were

described as more forced than chosen, in that they wished the diagnosis had not happened. It is possible there was less focus, within the acupuncture sessions, on finding meaning and understanding of the illness with the practitioner and more focus on managing and coping with daily living.

This difference in attitude towards what might be gained from the TA treatment, that is, new holistic insights, could be attributed to differences particular to this group of women; as noted earlier, that people who seek out TA have a different kind of commitment and purpose to their approach compared to those who take an opportunistic option such as signing up to free treatment in a clinical trial (Barlow et al 2011). To counter this argument, Rugg et al (2011) reported findings for participants receiving TA for 'medically unexplained symptoms' akin to 'new holistic understandings' even though recruitment was of the latter kind, that is free in a clinical trial. This also contrasts to some findings of outcomes of other complementary medicine studies (Verhoef et al 2005b, Koithan et al 2007, Smithson et al 2010b) which found personal transformation a key outcome. This does suggest that although pathway to treatment may be a factor in what people gain from treatment, the chronicity or familiarity an individual has with their health and illness is an important consideration. It is possible that, as found in the qualitative studies on EBC in Chapter Two, where authors focus on illness as transformative, they may discount negative cases. In contrast in this PhD study, at this early stage, the participants without exception wanted to move on with their lives, wished the breast cancer had never happened and were explicit in their expression that nothing positive had resulted from it.

Although new holistic insights were missing from the EBC study, the empirical findings and findings from the TA literature indicated that people perceived changes to mind, body and emotion and they also appreciated the whole person approach. It is possible that the TA offered in this EBC study assisted women as they adjusted to their diagnosis and treatment; due to the nature of the diagnosis and treatment there were real and legitimate *threats to self* and biographical disruption manifesting in different ways. Women found the TA helped them to manage all of these changes. In this sense it would be reasonable to say that TA contributed to changes in self-concept, an outcome defined in Chapter Six and as discussed above, and reported by seven of the studies (Cassidy (1998), Gould and MacPherson 2001, Paterson and Britten 2003/2004, Hughes et al 2006, Paterson and Britten 2008, Evans et al 2011, Rugg et al 2011).

From Therapeutic Relationship to Therapeutic Befriending

The therapeutic relationship was found to be both a 'process outcome' (for the practitioners) and an outcome (for the participants) thus having a different significance and meanings for the two groups. For the practitioners, developing the therapeutic relationship was a central intended outcome, and perceived as necessary to enable effective treatment. For the women, all of whom really enjoyed their acupuncture treatment, the therapeutic relationship was a desired and achieved outcome and had several perceived benefits. For many of them, it '*kept them going*' through difficult times. This finding coheres with findings reported in several of the studies in Chapter Six where participants highly valued the therapeutic relationship with the practitioner. It was found to be comforting, and in several of these studies participants commented on the caring nature of their practitioners.

Howe (1993) has argued that what people in a clinical relationship want is human friendliness and warmth rather than receipt of care from a cold, technical expert. The different dimensions of the concept of therapeutic befriending, discussed below, found in this study included, having the time to talk, in a space and setting that felt person-centred and safe. Being able to talk contributes to adjustment (Cordova et al 2001; Mehnert and Koch 2008), an idea particularly pertinent to this group of women, most of whom reported that they only shared their difficulties with the acupuncturist. The concept of a kind of '*friendship*' emerged strongly from the women participant data and was affirmed, to a degree, in the diaries and in the talk of the practitioners, demonstrating their care and attachment.

The acupuncturists were interested and concerned and were able to convey a caring approach to the individual; they demonstrated sensitivity allowing topics to range from light to deep. The practitioners wanted to know about the lifeworld of the individual to understand the context of their lives and problems. For the practitioners, developing a therapeutic relationship was an important 'process outcome' with their wanting to have a deep understanding of the person in order to do a better treatment and achieve a range of outcomes. The practitioners gave signs of caring and engendered trust by remembering detail, taking an interest, being concerned and using techniques to build rapport such as sharing experiences. The practitioners sought to form a warm and genuine attachment, something that their patients could detect. The two practitioners in this study found all aspects of information gathering useful in doing this and consciously worked to enable disclosure. The content of the talk, although crucial, was valued alongside how participants expressed themselves, as different kinds of information were important. Thus it was possible to retain, if appropriate, a friendly and light quality; clearly the participants valued this. This picture coheres with evidence from research on other CAM modalities. For

example, disclosure was seen as an important part of the process of homeopathic consultations (Thompson and Weiss 2006); furthermore, disclosing traumatic events has been found to have therapeutic value, changing perspectives and resulting in a more 'resilient self-concept' (Hemenover 2003).

The nature of the talk was described by most of the women participants as being '*friendly*' with a range of subjects discussed, and for many of them the experience was one of lightness and humour as well as sharing of the suffering reported in Chapter Seven. The participants describe trust being established quickly, where they felt they could '*rely*' on the practitioners for help, support, caring and sharing of difficulties. An important value for these women was that the relationship although highly supportive and caring did not result in them feeling less of a person, such as being a patient. Rather there was equality and mutuality to it, aspects that have been reported in several of the Chapter Six studies. In this study the relationship was perceived as having elements of friendship (openness and sharing) but not quite friendship (not having to be concerned about the impact of their suffering on an intimate/close other) in the particular context of women struggling to present themselves as strong and coping. This finding thus led to the description of the emerged concept of therapeutic befriending.

According to Carl Rogers (1951), all helping interventions can achieve a relationship with therapeutic benefit. Its impact on outcome has been demonstrated amongst a wide range of healing professions measured by both patients and practitioners. Most of the discussion regarding the nature of the relationship and befriending *per se* has, however, occurred in psychological therapies, where the relationship between therapist and client is central to effective therapy (Gelso and Hayes 1998). Indeed, much research has explored the potential of purposeful befriending (by a therapist or another) as an intervention in its own right in mental health (for example, Mead et al 2010). In that research though, befriending has a different meaning to the concept emerging from the women in this PhD study. In their meta-analysis, befriending relates to an intervention aimed at providing '*... the client with additional social support through the development of an affirming, emotion-focused relationship over time*' (Mead et al: 2010: 96 italics added).

Another dimension of the therapeutic relationship has been described as the therapeutic alliance (Bordin 1975) and has three aspects: bonds (mutual trust and liking), tasks (consensus on how the therapy will work and negotiation on what needs to be done) and goals (agreed short and long term outcomes of therapy). As reported in Chapter Six, receiving TA appears to lead to increasing agency in self-care which suggests that the tasks aspects, mentioned above (Bordin 1975), are well negotiated and successful. Different

kinds of talk were analysed in Evans et al (2011) study to gain insight into what enabled this increase agency in self-care and has been discussed already. Bordin (1975) argues that the therapeutic relationship due to its collaborative nature is bidirectional (Horvath 2000). Matthews et al (1993) also found that with proper 'connexion', experiences of sharing and understanding, were mutually therapeutic. This idea of connection was further explored in a study of homeopaths (Eyles et al 2012).

In this EBC study, the interaction was always orientated towards the patient/participant and her needs, but unlike in psychological therapies, there was little pressure on the relationship itself. Differences with homeopathic consultations may also result in a different kind of relationship, as acupuncture treatment is given more regularly and the treatment process involves the practitioner being present. Relational empathy has been found to contribute to therapeutic outcome in acupuncture (Price et al 2006) but not always in homeopathic treatment (Bikker et al 2005, Thompson and Weiss 2006) suggesting key differences in the relationship. One possible explanation is that engagement with the explanatory model of TA leading to changed behaviour and new holistic insights, two process-outcomes cited as the reason for building empathy and rapport by TA practitioners, results in more long lasting health changes.

In summary, therapeutic befriending has emerged as a new concept, based on the data collected in this EBC study. As evident from Table 8.4 (page 154) its characteristics share overlaps but are also different from that of the therapeutic relationship. It is based on a central perception of the women about the therapeutic relationship and arose both from their interactions with the practitioner and, by implication, the practitioner seeking to develop a strong and therapeutic relationship with the women. For the practitioners the therapeutic relationship was purposive. But within its development, they were able to successfully convey the idea of *friendship* because they wanted information; the participants gladly received this *friendship* without being burdened with the worry of the impact of their suffering on the other. The significance for women of this notion of therapeutic befriending also lay in the specific context of their stage of the illness trajectory: a point at which 'normalising' the diagnosis and illness meant that that they were reluctant to acknowledge it with close others and were therefore dealing with its emotional impact on their own.

This suggests the importance of recognising therapeutic befriending as a novel, valuable additional concept, and potential facet, for further clarification in other research and exploration of ways that it may occur, or not, in other TA and client-practitioner relationships more generally. Importantly, this new concept is separate but at the same time closely linked to definition of the characterisations of the therapeutic relationship found within TA and

literature on the therapeutic relationship more generally. Therapeutic befriending is an important concept because it was so highly valued by the women ; its uniqueness may lie in the fact that the practitioners were not trying to befriend the women, for example, to offer social support, particularly, but were seeking to gain understanding and to insight into their needs and thus to provide effective treatment.

The setting outside of the medical community may also have significance for the development of a therapeutic relationship and emergence of therapeutic befriending. In a study exploring the characteristics that generated satisfaction different criteria were applied by participants to CAM and medical practitioners (Kelner 2000). The informal setting of the CAM practitioners was cited as aiding a sense of collaboration and mutual respect, qualities similar to the therapeutic alliance concept. The CAM relationship was signified by partnership, the medical relationship by expertise. Other research shows that the effect of good therapeutic relationships can be diminished in settings that did not adhere to a person-centred philosophy (Horvath 2000). The informal nature of the encounter in this EBC study may relate to both the setting and the ability of the practitioners to create a friendly and enjoyable ambiance.

This comment is further reinforced by findings from Smithson et al's (2010b) meta-synthesis of 29 CAM and cancer studies to explore patient experiences. One key concept was *polarisation* reflecting the division between CAM and conventional medical care whereby although patients did not express this as a therapeutic problem it was identified as a barrier by many of the authors within the studies to a more positive experience of CAM care. Detail is not provided by Smithson *et al* (2010b) as to how patients entered CAM care; but in this EBC study, women were invited to the study by their medical oncologist suggesting *integration*, another important theme in Smithson *et al* (2010b) and clinician approval. Moreover, the women positively appreciated having their TA outside of the medical setting with its emotionally challenging associations of diagnosis and treatment.

Summary of Intended Effects and Goals of Treatment

The outcomes and long term goals are considered the first stage in inaugurating a ToC. The practitioners had their own ideas of outcomes and goals they wished to achieve as well as developing the therapeutic relationship to help women uncover what their needs and concerns were. In the chronic illness TA studies, the therapeutic relationship is commonly depicted as being used to engage the patient in finding meaning, understanding their illness and find new insights as well as the primary function of enabling change in behaviour and increasing agency in self-care. For recipients of acupuncture, changes to health were perceived to be physical, emotional and mental as well as changes in perspective and new

ways of understanding their health. Outcome patterns in the theory of TA suggest that symptoms and problems are linked together and are changed together via treatment. The ToC for TA relating to the findings in Chapter Nine, and earlier work from the literature reviews will now be discussed all together.

3. Refinement of the Theory of Change

The focus of this thesis lay in uncovering the ToC for TA; this process started with the development of the framework in Chapter Four, based on professional training documentation, and applied to selected literature in Chapter Five, and to the qualitative literature in Chapter Six. All the data reported in the subsequent chapters from the thesis' empirical study relevant to the ToC are now brought together and a composite, refined ToC presented a process in keeping with developing a ToC. The practitioner data as reported in Chapter Nine provided important detail about what their perceptions of component parts to TA are for a complex exemplar and, in contrast to other published studies on TA, for an acute stage of illness. The data here were also collected during the process of actual treatment so the practitioners were talking from experience and not just hypothetically, and reinforced data taken from their treatment logs and reflective diaries.

As the first stage in this thesis was the development of the ToC framework (Box 1, page 49), the themes and sub-themes which evolved from the practitioner data are now matched against this framework and presented in Table 11.1.

Table 11.1 Theory of Change Framework mapped to themes emerging from the longitudinal study

TA – Theory	Component	TA – Practice (the longitudinal study)
<p>1. Approach is orientated to the whole person based on an understanding that mind, body and spirit are integral</p>	<p>Theory</p>	<p>Whole Person Approach</p> <ul style="list-style-type: none"> ▪ It is everything about the person ▪ Treating holistically according to the <i>zang fu</i> <p>Therapeutic Relationship</p> <ul style="list-style-type: none"> ▪ Find out about the person to do a better treatment ▪ Build trust and rapport to enable disclosure

<p>2. Aetiology of the main complaint: A detailed history of the main complaint is integral to the diagnosis</p>	<p>Theory (Aetiology)</p>	<p>Diagnostic Process</p> <ul style="list-style-type: none"> Information gathering – History <p>Therapeutic Relationship</p> <ul style="list-style-type: none"> Disclosure and depth of understanding
<p>3.</p> <ul style="list-style-type: none"> Differential Diagnosis: Summary of the core curriculum theory of TCM encompassed by Bian Zheng or pattern differentiation Diagnostic Methods: Principles of looking, listening, asking, touching (tongue and pulse) are part of differential diagnosis 	<p>Theory (Diagnosis)</p>	<p>Diagnostic Process</p> <ul style="list-style-type: none"> Information gathering (looking, listening, asking, palpating) Signs and symptoms Tongue and pulse Silent information Continuous process
<p>4.</p> <ul style="list-style-type: none"> Treatment Principles: Understanding of main complaint in terms of context, nature and location including concepts of <i>xu</i> and <i>shi</i>, and <i>ben</i> and <i>biao</i> (specific TCM terminology) Responsiveness: Diagnosis and treatment change in response to patient reported changes 	<p>Theory (Treatment)</p>	<p>Root and Branch</p> <ul style="list-style-type: none"> Surface and underlying issues <p>Individualised Treatment</p> <ul style="list-style-type: none"> Diagnosis and treatment change with any new information or insights Continuous process
<p>5.</p> <ul style="list-style-type: none"> Mechanism of change is dependent on affecting the balance of Qi, Yin and Yang and other defined substances of the person as decided by the differential diagnosis Acupuncture works by affecting change in the balance of Qi, Yin and Yang and other imbalances as defined by the differential diagnosis 	<p>Rationale</p>	<p>How does it bring about change?</p> <ul style="list-style-type: none"> Balance the <i>Qi</i> Treat according to the <i>zang fu</i> Continuous process of reflection and new understanding of the patient
<p>6.</p> <p>An iterative, individualistic and interactive approach: At each session the practitioner uses the principles of looking, listening, asking, touching (tongue and pulse) to make a differential diagnosis and to formulate a new treatment.</p>	<p>Practice</p>	<p>Therapeutic Relationship</p> <p>Diagnostic Process</p> <p>Individualised Treatment</p>

<p>7. Non-linear, with degrees of uncertainty at each stage of treatment</p>	<p>Possible Causal Pathway</p>	<p>Non-linear and Multiple – a continuous process of reflection, change, new information and new understanding</p>
<p>8. Desired changes in the balance of Qi, Yin and Yang and other imbalances as defined by the differential diagnosis which will manifest in various aspects of the person in mind and body, in addition to any specific symptom changes</p>	<p>Outcome</p>	<p>What am I trying to achieve?</p> <ul style="list-style-type: none"> ▪ Enable wellness ▪ Enable coping ▪ Increase vitality ▪ Pre-empt side-effects ▪ Strengthen and fortify ▪ Help the whole person ▪ Facilitate the relationship ▪ Facilitate changes in perspective

Applying the ToC framework to the themes from the practitioner data demonstrates a strong match. The practitioners followed a model of good practice (which was successfully captured in the original framework) laid out by their professional body, the BAAC. For instance, how the practitioners described individualised and person-centred treatment related also to the idea of *responsiveness* in the theory; responding to changes within the person was a key to successful treatment. Using the complex exemplar of EBC provided a platform with which to observe how practice relied on disclosure, and therefore the therapeutic relationship, and exposed the *continuous process* of new information, new insight and understanding and changed treatment. The outcomes column in Table 11.1 reveals substantial detail which relates how the two practitioners interpreted the valued outcomes for these women. If this section were completed from, for example, the findings from the MacPherson et al (2006) chronic back pain study, the long term goals would likely have reported enabling increased self-care and lifestyle changes that contribute to maintaining the improvements in back pain.

Chapter Six reported on research relating to patient and practitioner perceptions of TA. The findings revealed that these studies suggested that TA encompassed more than was displayed in the ToC framework but with less detail on the processes of treatment. Regarding this existing literature, one outstanding observation already discussed is that several papers discussed increased agency of self-care as a significant part of TA. There is very little evidence of this in this EBC study. Long term goals for the practitioners and participants were about coping with the diagnosis and treatment rather than improving a

chronic condition. Diet was discussed according to the treatment logs only in relation to patients experiencing prolonged nausea. In the published literature, one major focus of the therapeutic relationship was to engage with patients to empower change in how they saw their illness and in using the explanatory model of TA to inspire change. This is a second difference in this EBC study, where the focus of the therapeutic relationship was very much about enabling trust to increase disclosure.

The one aspect of practice that is explicitly missing from the ToC framework in Box 1 (page 49) is the therapeutic relationship. The therapeutic relationship was extrapolated further in Chapter Nine as practitioners explained how and why they approached treatment. Practitioners worked hard at building trust and rapport to maximise disclosure, so that they could really get to know the individual and understand their needs and orientate the treatment appropriately. The ToC for TA involved a dynamic process involving information gathering, individualised treatment and the therapeutic relationship together which formed a whole person approach. Change as far as the practitioners' were concerned was brought about through addressing imbalances in the *Qi* and *Zang Fu* and interpreting the signs and symptoms according to the *root and branch* theory in Chinese medicine. Data from both the TA literature explored in Chapter Six and the EBC longitudinal qualitative study suggests there are multiple causal pathways of change.

Drawing on the PhD study's empirical findings, an addition to the ToC framework would concern the therapeutic relationship as a flexible tool with five aspects:

- 1) to aid disclosure for a differential diagnosis
- 2) to help orientate the goals of treatment towards the patient by exploring their needs and concerns in the context of their daily lives
- 3) to engage the patient in the theory of TA in order to increase agency in self-care and improve achievement of long term goals
- 4) to provide an opportunity for reflection on the individual's past and their potential future health
- 5) to provide comfort and support.

This leads to the presentation in Box 2 of a revised theory of change for TA, drawing together material from all the three different sources (professional curricula, TA practitioner and patient literature, PhD's longitudinal qualitative study).

Box 2. Revised Theory of Change for TA

TA – Theory	Component
<p>Approach is Orientated to the Whole Person</p> <ul style="list-style-type: none"> Based on an understanding that mind, body and spirit are integral Treatment is holistic, according to the <i>zang fu</i> 	<p>Theory</p>
<p>Aetiology of the Main Complaint:</p> <ul style="list-style-type: none"> A detailed history of the main complaint is integral to the diagnosis 	<p>Theory (Aetiology)</p>
<p>Differential Diagnosis:</p> <ul style="list-style-type: none"> Summary of the core curriculum theory of TCM encompassed by Bian Zheng or pattern differentiation <p>Diagnostic Methods:</p> <ul style="list-style-type: none"> Principles of looking, listening, asking, touching (tongue and pulse) are part of a differential diagnosis <p>Diagnostic Process:</p> <ul style="list-style-type: none"> The process is continuous, as new information comes to light, and change occurs from the beginning 	<p>Theory (Diagnosis)</p>
<p>Treatment Principles:</p> <ul style="list-style-type: none"> Understanding of main complaint in terms of context, nature and location including concepts of <i>xu</i> and <i>shi</i>, and <i>ben</i> and <i>biao</i> (specific TCM terminology) <p>Responsiveness:</p> <ul style="list-style-type: none"> Diagnosis and treatment change in response to patient reported changes and in relation to the continuous process of diagnosis and treatment 	<p>Theory (Treatment)</p>
<p>Agency of Change</p> <ul style="list-style-type: none"> Change is dependent on affecting the balance of <i>Qi</i>, <i>Yin</i> and <i>Yang</i> and other defined substances of the person as decided by the differential diagnosis Acupuncture works as a continuous process of reflection, new understanding and treatment 	<p>Rationale</p>
<p>An Iterative, Individualistic and Interactive Approach:</p> <ul style="list-style-type: none"> At each session the practitioner uses the principles of looking, listening, asking, touching (tongue and pulse) to make a differential diagnosis and to formulate a new treatment. 	<p>Practice</p>

<p>Therapeutic Relationship:</p> <ul style="list-style-type: none"> • Building rapport, trust and offering empathy are essential to maximise disclosure both for outcome setting and the differential diagnosis • Engaging the patient with new ways of understanding illness in relation to lifestyle and other contextual factors, guided by the explanatory model of TA, enables change and further reflection 	<p>Practice</p>
<p>Multiple and Non-linear:</p> <ul style="list-style-type: none"> • A continuous process of reflection, change, new information and new understanding 	<p>Possible Causal Pathway</p>
<p>Whole Person Changes:</p> <ul style="list-style-type: none"> • Desired changes in the balance of Qi, Yin and Yang and other imbalances as defined by the differential diagnosis which will manifest in various aspects of the person in mind and body as outcome patterns • Enable coping and wellness • Pre-empt further problems through strengthening and fortifying and increasing vitality • Facilitate changes in perspective and increase agency in self-care 	<p>Outcomes and Long Term Goals</p>

4. Strengths and Limitations of the Study

This study has a number of demonstrable strengths and important methodological dimensions. The research design was flexible and enquiring with openness about what might emerge. This led to the use of novel methods, in particular, using the theory of change to explore what TA is. The success of the ToC framework (Box 1, page 49), developed and then applied to both the literature reviews and the data from the longitudinal study, suggests that this approach was useful in answering the key research objectives relating to explicating the ToC for TA in research and practice. The research design and its undertaking also enabled the refinement of the ToC.

An additional strength relates to the factor of time. Time is an explanatory factor in the need for women to *'normalise'* their experience due to the speed of the treatment trajectory. Change over time was explored through using serial interviews and was an important analytical category in that focus was on processes of continuity and change as women progressed through the breast cancer trajectory. This highlighted a change process that would not be possible to capture in a single interview. Reflection, both from the perspective of the individual interviewee/woman and the researcher, is different when conducting multiple interviews with the same people; they provide different vantage points for looking

forward and looking back. Through this it was possible to understand the different ways that women had of managing their illness experience over time; a process of change was occurring but was articulated in different ways by participants at different time points. The methods in this study enabled insight into the diverse ways women had of adapting and coping at this time. While several of the studies in the literature review in Chapter Two collected data at multiple time points (Richer and Ezer 2006, Frith and Harcourt (2007), McCann et al 2010); their mode of analysis and reporting meant that valuable insights into this dimension were not sufficiently drawn out and demonstrated.

The methods adopted in this PhD study also enabled a particular view on the process of acupuncture. They facilitated an exploration of the degree to which as an intervention TA is person-centred and responsive to change in the person over time. The methods allowed new insight into the therapeutic relationship leading to the emerging concept of therapeutic befriending, from the women's accounts.

Setting up a longitudinal study to observe change over time offered rich participant data providing contributions concerning both what acupuncture is and the EBC experience. The in-depth interview data of a small sample of women, using serial interviews, provided many nuances and contradictions. The analysis ensured that a range of experience was explored. Analysis was carefully approached to ensure that change over time was not lost sight of. By offering women a choice of where they received their acupuncture insight into feelings about the setting and how different settings can influence what happens in the therapeutic encounter was tentatively explored.

Although direct observation of acupuncture treatment was considered, it was felt that this would be problematic because of privacy issues and how it might affect how the therapeutic relationship developed. Offsetting the limitations of the data collection against the privacy of the treatment room was a compromise. An ethnographic study could focus on either acupuncturists in how they deliver acupuncture or women with EBC. The methods could involve direct and prolonged observation and the output would be a detailed description of the cultural behaviour. Aside from considerations regarding possible threats to the establishment of the therapeutic relationship there were also not the resources to sustain a research presence through all of the acupuncture treatments. Moreover, direct observation may not necessarily have contributed in a better way to understanding the meaning of the illness and of the intervention. Not everything is open to observation, for instance, the decision making process of the practitioners which can only be accessed by talking with them. Importantly, as qualitative research aims to understand and examine phenomena in a real-world setting (Patton 1990) the presence of a researcher during acupuncture treatment

is likely to lead to a different experience for participants and substantially alter the output. For example, direct observation might affect how the practitioners practised, the conversations of the participants with the practitioners and disclosure, and thus compromised *inter alia* therapeutic befriending. Creswell (1998) suggests that ethnographic work is suited where change over time moves more slowly and where there is time for the researcher in the field to become less visible. Ethnographers working on change processes might argue differently; that this conflates both change and length of time in the field.

It is possible that diaries kept by women participants would have provided more immediate and detailed material regarding the experience of acupuncture. Diaries can be rich sources of data (Clayton and Thorne 2000), provide insight into change over time and can act an important source of triangulation. Although there is evidence of poor compliance with diary keeping (Stone et al 2002) these problems can be overcome by staying in regular contact with participants (Furness and Garrud 2010). It was unknown how burdensome the provision of acupuncture care would be for women during chemotherapy as there is no literature on offering women a supportive intervention during chemotherapy. It thus did not seem appropriate to make extra demands of the women. Future studies could perhaps explore the option of audio diary keeping by participants.

Although the study is limited to treatment by one of two practitioners, they were carefully selected for their long experience in teaching, making it most likely that their practice reflected the theory-based practice espoused in the BAAC. Future studies may increase rigour by using a larger pool of practitioners. The rigour of the study was increased, however, by gathering the practitioner data in two ways: firstly, their interviews focussed on gaining a general understanding of what the practitioners did; and secondly, the practitioners kept both treatment logs and diaries, each providing more specific data regarding what they did with individuals and why.

The researcher's role as practitioner-researcher created possible limitations that have been illustrated in Chapter Ten. There were, however, advantages to this role. For instance, comparing my own practitioner experience of treating women with breast cancer and the participants in this study enabled me to judge differences in how women present themselves and what information they share. This was both bewildering and helpful during participant interviews but provided unique insights into ways in which the interview-participant relationship is different to that of practitioner-patient. In interviewing my colleagues, our shared knowledge of TCM theory resulted in a much richer exploration of what practitioners try to achieve than if they had to explain the major concepts at the outset to a researcher without a detailed knowledge and practice experience of TA. This may however have

resulted in my making assumptions about what practitioners mean. This was guarded against by accessing other sources of data on TA such as Wiseman and Feng's Classical Dictionary of Chinese Terms (1998), the ToC framework (Box 1, page 49) itself developed from textbooks and returning to one of the practitioners for clarification; all helped to provide data verification. Similar studies in the future on theory and practice could request that the practitioners read the analysis of their interviews to further increase rigour.

Another consideration is sampling. It is possible that the oncologists were more likely to refer people as they saw fit, notwithstanding the inclusion criteria. But such clinical decision making is in keeping with a pragmatic approach. In addition, it was unknown whether women were invited into the study but decided against it as these data were not collected. It was also unknown how many potential participants were not invited due to how busy the clinics were on particular days.

Sample size is also relevant here. The final number of participants was fourteen, as there were limited funds to treat more women; in addition, the study had only one person under the age of forty although four were pre-menopausal. Having a greater balance between younger women or women with younger children would have offered a richer insight into the range of women who are diagnosed with breast cancer. From the analysis it became apparent that life stage was of more relevance than age per se when considering the impact of diagnosis and treatment; although half the women suffered from the effects of treatment on their physical appearance and as a result suffered a loss of confidence, this was not age related.

What This Study Adds

The work detailed within this thesis has attempted to add further definition to what acupuncture is, specifically traditional acupuncture, by extrapolating the change process into a theory of change. The Theory of Change approach has been developed and mainly used in the arena of policy interventions research to understand change pathways with many different contextual factors that may influence whether an intervention is successful or not.

A simple, theoretically based ToC framework (Box 1, page 49) that enables a clear differentiation between two models of acupuncture was initially developed. From its application it is easier to see the ways in which TA is a complex intervention and MA a simple one. This should aid clarity for researchers in deploying or evaluating acupuncture research. The application of the acupuncture framework from this study was published (Price et al 2011) and this paper included additional work specifically a model validity guide

(Table 3 in Price et al 2011: 8) for complex outcomes. Aiding model validity in the field of acupuncture research will enable more definitive results than have so far been seen.

Building on this initial ToC framework for TA, other TA practitioner and patient literature and most importantly findings from PhD's EBC longitudinal qualitative study (drawing on both practitioner and women participants' data) led to a revised theory of change for TA. Such explicit and clear expression of the multiple components of TA drawn together into a ToC is as far as is known unique within the TA and wider CAM literature. The revised ToC for TA provides a new contribution to the literature and a fruitful foundation for further refinement within TA research and for the application of the ToC approach to other CAM modalities.

In gathering together different kinds of evidence and data including the two literature reviews and the triangulated data from the longitudinal study, it is clear that there are a range of perceived benefits reported by patients relating to the whole person and specific symptom changes. Importantly, this study developed understanding of the therapeutic relationship both in terms of it being a flexible tool that is an integral part of the practice of TA, but also the nature of it as reported by the women participants. The therapeutic relationship has a direct impact on the health-related outcome (Price et al 2006) possibly due to the ability of practitioners to engage their patients with new insights into health and behaviour. In the acute stage of EBC, the comfort women found in being able to talk and the empathy and understanding and real concern that they could detect was highly valued.

The concept of suffering was developed whereby the analysis illuminated different dimensions of loss and physical and emotional suffering. New insight into the meaning and significance of the early breast cancer experience will provide understanding as to why some supportive interventions may be more acceptable than others. The study illustrated the ways in which TA offers supportive care for women with EBC, and added definition to what is meant by a whole person approach. Outcomes are not focussed on a change in the disease process but a change in the whole person.

Recommendations for Future Research

The findings of this thesis are suggestive of several areas for future research. The ToC approach has applicability to other complex complementary health care interventions such as homeopathy or CAM's in general. Applying the TA model in other complex outcomes especially where the biomedical mechanism is unknown such as fatigue or for co-morbidity may prove useful in terms of both understanding the phenomena of interest and the ways in which TA might prove helpful. Regarding TA, establishing how much the concepts and language of the theory of TA acts as a barrier to credibility may go some way to explaining

its low use in clinical research trials. The concept of therapeutic befriending is also ripe for further exploration in other CAM modalities.

Future research could focus on how TA enables coping in the face of uncertainty, for instance, whether it is related to vitality, as suggested in this study. Lastly the findings reinforce the need to develop tools that measure change over time for whole person approaches, and whole person effects, in particular exploring outcome patterns as discussed in this thesis, something others have so called for (Verhoef et al 2006). Further work on outcome patterns in TA would also illuminate the inter-relationships involved. From these findings, it was possible to see that women may give mixed messages about what kind of support would be useful or acceptable due to the overwhelming nature of the diagnosis and treatment; in this longitudinal study, acupuncture had a low attrition rate.

Conclusion

This thesis has successfully used a novel approach, the Theory of Change, within a CAM modality. Drawing on a range of sources, a ToC for TA has been developed and refined; the framework makes explicit the pathways of change necessary to achieve the long term goals of TA. EBC was used as a complex exemplar. This helped to demonstrate the multiple causal pathways to change, both in general given the complexity of EBC and in relation to use of TA, given the continuous process of new information, insights and treatment changes. Important new insight was gained into the purpose and use of the therapeutic relationship and the way in which it is valued by women with EBC, and extended into the emerging concept of therapeutic befriending. The whole person approach and the range of outcomes add further weight to the need to find ways of capturing change reflecting the outcome patterns emerging in this study. Women with EBC experience suffering, a concept illuminated and expanded in this study.

A key message for research into acupuncture is that where the outcome is complex it may be difficult to conduct an explanatory model of research without considerable compromise to model validity, especially where the mechanisms of the outcomes are unknown. One likely contribution of the acupuncture care is that, through a variety of ways, it helped women maintain their approach to keeping everything normal; it aided coping and reduced suffering. Future research could investigate how TA enables coping in the face of uncertainty for women with breast cancer, in addition to interventions that help relax and relieve the tension induced by mental anguish.

Bibliography

- Aglietti L, Roila F, Tonato M, Basurto C, Bracarda S, Picciafuoco M, Ballatori E, Del Favero A. (1990). A pilot study of metoclopramide, dexamethasone, diphenhydramine and acupuncture in women treated. *Cancer Chemotherapy & Pharmacology*. 26(3):239-240
- Ahles TA, Saykin AJ, Furstenburg CT, Cole B, Mott LA, Skalla K, Whedon MB, Bivens S, Mitchell T, Greenberg ER, Silberfarb PM. (2002). Neuropsychologic impact of standard-dose systemic chemotherapy in long-term survivors of breast cancer and lymphoma. *Journal of Clinical Oncology*. 20(2): 485-493.
- Akechi T, Nakano T, Akizuki N, Okamura M, Sakuma K, Nakanishi T, Yoshikawa E, Uchitomi Y. (2003). Somatic symptoms for diagnosing major depression in cancer patients. *Psychosomatics*. 44(3):144-8
- Allen JB, Schnyer RN, Hitt SK. (1998). The efficacy of acupuncture in the treatment of major depression in women. *Psychological Science*. 9(5):397-401
- Alreak T, Baerheim A (2001). 'An empty and happy feeling in the bladder...' health changes experienced by women after acupuncture for recurrent cystitis. *Complementary Therapies in Medicine*. 9 (1): 219-233
- Alraek T, Malterud K. (2009). Acupuncture for menopausal hot flashes: a qualitative study about patient experiences. *Journal of Alternative Complementary Medicine*. 15(2):153-8.
- Ancoli-Israel S, Moore PJ, Jones V. (2001). The relationship between fatigue and sleep in cancer patients: a review. *European Journal of Cancer Care*. 10(4):245-55
- Ancoli-Israel S, Liu L, Marler MR, Parker BA, Jones V, Sadler GR, Dimsdale J, Cohen-Zion M, Fiorentino L. (2006). Fatigue, sleep, and circadian rhythms prior to chemotherapy for breast cancer. *Supportive Care Cancer*. 14(3):201-9
- Anderson A. An introduction to theory of change. (2005). *The Evaluation Exchange*. 11(2): 12
- Andrykowski MA, Schmidt JE, Salsman JM, Beacham AO, Jacobsen PB. (2005). Use of a case definition approach to identify cancer-related fatigue in women undergoing adjuvant therapy for breast cancer. *Journal of Clinical Oncology*. 23(27): 6613-22
- Arman M, Rehnsfeldt A. (2003). The hidden suffering among breast cancer patients: a qualitative metasynthesis. *Qualitative Health Research*. 13(4):510-527
- Barlow F, Scott C, Coghlan B, Lee P, White P, Lewith GT, Bishop FT. (2011). How the psychosocial context of clinical trials differs from usual care: A qualitative study of acupuncture patients. *Biomedical Central Medical Research Methodology*. 11:79
- Beisecker A, Cook MR, Ashworth J, Hayes J, Brecheisen M, Helmig L, Hyland S, Selenke D. (1997). Side effects of adjuvant chemotherapy: perceptions of node-negative breast cancer patients. *Psycho-oncology*. 6:85-93
- Bell IR, Caspi O, Schwartz GER, Grant KL, Gaudet TW, Rychener D, Maizes V, Weil A: Integrative medicine and systemic outcomes research. *Archives of Internal Medicine* 2002, 162:133-140.

Bender CM, Ergyn FS, Rosenzweig MQ, Cohen SM, Sereika SM. (2005). Symptom clusters in breast cancer across 3 phases of the disease. *Cancer Nursing*. 28(3):219-25

Bennet B, Goldstein D, Lloyd A, Davenport T, Hickie I. (2004). Fatigue and Psychological distress – exploring the relationship in women treated for breast cancer. *European Journal of Cancer*. 40(11): 1689-95

Berger AM, Farr L. (1999). The influence of daytime inactivity and night time restlessness on cancer-related fatigue. *Oncology Nursing Forum*. 26(10):1663-71.

Berger AM, Farr LA, Kuhn BR, Fischer P. (2007). Values of sleep/wake, activity/rest, circadian rhythms, and fatigue prior to adjuvant breast cancer chemotherapy. *Journal of Pain Symptom Management*. 33(4): 398-409

Bikker AP, Mercer SW, Reilly D. (2005). A Pilot Prospective Study on the Consultation and Relational Empathy, Patient Enablement, and Health Changes over 12 Months in Patients Going to the Glasgow Homoeopathic Hospital. *Journal of Alternative and Complementary Medicine*. 11(4): 591-600

Birch S. (2004). Problems with systematic reviews of acupuncture. What should we do about these? *Clinical Acupuncture and Oriental Medicine*. 4:105-108

Bishop FL, Barlow F, Coghlan B, Lee P, Lewith GT. (2011). Patients as healthcare consumers in the public and private sectors: a qualitative study of acupuncture in the UK. *BMC Health Services Research*. 11:129

Blow AJ, Sprenkle DH and D SD (2007). 'Is who delivers the treatment more important than the treatment itself? The role of the therapist in common factors'. *Journal of Marital and Family Therapy*, vol 33, no 3, pp 298–317.

Blumer, H (1969), *Symbolic interactionism: Perspective and method*. Prentice-Hall, Inc: Englewood Cliffs, New Jersey

Boehmke MM, Dickerson SS. (2006). The diagnosis of breast cancer: transition from health to illness. *Oncology Nursing Forum*. 33 (6): 1121-1127

Bordin ES. (. 1979). The generalizability of the psychoanalytic concept of the working alliance. *Psychotherapy: Theory, Research and Practice*;16:252-260.

Bower JE. (2005). Prevalence and causes of fatigue after cancer treatment: the next generation of research. *Journal of Clinical Oncology*. 23(33):8280-2

BowerJE, Ganz PE, Desmond KA, Bernards C, Rowland JH, Meyerowitz BE, Belin T. (2006). Fatigue in Long-Term Breast Carcinoma Survivors. *Cancer* 106 (4): 752-758

Bradley C. The 12-item Well-being Questionnaire. Origins, current stage of development, and availability. *Diabetes Care*. 2000, 23:875..

Brezden CB, Phillips KA, Abdoell M, Bunston T, Tannock IF. (2000). Cognitive function in breast cancer patients receiving adjuvant chemotherapy. *Journal of Clinical Oncology*. 18(14):2695-701

- Browall M, Gaston-Johansson F, Danielson E. (2006). Postmenopausal women with breast cancer: their experiences of the chemotherapy treatment period. *Cancer Nursing*. 29(1):34-42
- Bury M. (1982). Chronic illness as biographical disruption. *Sociology of Health and Illness*. 4:165-182
- Bury, M. (1988) Meanings at risk: the experience of arthritis, in Anderson, R. & Bury, M. (eds) *Living With Chronic Illness: The Experience of Patients and their Families*, London: Unwin Hyman.
- Bury M. (1991). The sociology of chronic illness: a review of research and prospects. *Sociology of Health and Illness*. 13(4):451-468
- Bury M. (2001). Illness narrative, fact or fiction? *Sociology of Health and Illness*. 23(3):263–285
- Campbell A. (2001). *Acupuncture in Practice: Beyond Points and Meridians*. Butterworth-Heinemann. Oxford (Reed Elsevier)
- Carpenter JS, Gautam S, Freedman RR, Andrykowski M. (2001). Circadian rhythm of objectively recorded hot flashes in postmenopausal breast cancer survivors. *Menopause*. 8(3):181-8
- Carter SM, Little M. (2007). Justifying Knowledge, Justifying Method, Taking Action: Epistemologies, Methodologies, and Methods in Qualitative Research. *Qualitative Health Research*. 17:1316
- Cassell EJ. (1982). The nature of suffering and the goals of medicine. *New England Journal of Medicine*. 306:639-645
- Cassidy C. (1998). Chinese Medicine Users in the United States Part II: Preferred Aspects of Care. *The Journal of Alternative and Complementary Medicine*. 4(2): 189-202
- Cassidy C. (2009a). Moffet: on the similarity of response to “active” and “sham” acupuncture (editorial) *Journal of Alternative and Complementary Medicine*. 15(3): 209-210
- Cassidy C. (2009b). Model fit validity: seeking a balanced equation. (letter) *Journal of Alternative and Complementary Medicine*. 15(3): 1265-1266
- Cayless S, Forbat L, Illingworth N. (2010). Men with prostate cancer over the first year of illness: their experiences as biographical disruption. *Supportive Care in Cancer*. 18(1): 11-19
- Charles C, Redko C, Whelan T, Gafni A, Reyno L. (1998). Doing nothing is no choice: lay constructions of treatment decision-making among women with early-stage breast cancer. *Sociology of health and Illness*. 20(1):71-95
- Charmaz K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*. 5(2):169-195
- Charmaz K. (1999). Stories of suffering: subjective tales and research narratives. *Qualitative Health Research*. 9(3): 362-382

- Charmaz K. (2006). *Constructing Grounded Theory: A practical guide through qualitative analysis*. London Thousand Oaks Sage publications
- Chen HT, Rossi PH. (1980). The Multi-Goal, Theory-Driven Approach to Evaluation: A Model Linking Basic and Applied Social Science. *Social Forces*. 59(1): 106-122
- Ching SY, Martinson IM, Thomas KSW. (2009). Reframing: Psychological Adjustment of Chinese Women at the Beginning of the Breast Cancer Experience. *Qualitative Health Research* .19: 339
- Cimprich B. (1999). Pre-treatment symptom distress in women newly diagnosed with breast cancer. *Cancer Nursing*. 22(3):185-94
- Clayton, A., Thorne, T. (2000). Diary data enhancing rigour. *Journal of Advanced Nursing*. 32:1514-1521.
- Cohen SM, Rousseau ME, Carey BL. (2003). Can acupuncture ease the symptoms of the menopause? *Holistic Nursing Practice*. 17(6): 295-9
- Connell JP, Kubisch AC. (1998). Applying a theory of change approach in K. Fulbright Anderson, A.C Kubisch and J.P. Connell (Eds) *New Approaches to Evaluating Community Initiatives Volume 2: Theory, Measurement, and Analysis*. Washington DC.: The Aspen Institute.
- Corbin JM. (2003). The body in health and illness. *Qualitative Health Research*. 13: 256-267
- Corbin JM, Strauss AL. (1992). A nursing model for chronic illness management based upon the trajectory framework. In *The Chronic Illness Trajectory Framework: the Corbin and Strauss Nursing Model*. P9-28. New York: Springer.
- Corbin JM, Strauss AL. (2008). *Basics of Qualitative Research* (3rd Edition). Los Angeles, CA: Sage
- Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., & Andrykowski, M. A. (2001). Posttraumatic growth following breast cancer: A controlled comparison study. *Health Psychology*. 20, 176-185.
- Craig P, Dieppe P, MacIntyre S, Mitchie S, Nazareth I, Petticrew M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *British Medical Journal*. 337: 979-983
- Creswell JW. (1998). *Qualitative Inquiry and Research Design. Choosing among five traditions*. Sage Publications. Thousand Oaks, California.
- Dale, R.A. (1997). Demythologizing acupuncture, part I: the scientific mechanisms and clinical uses. *Alternative and Complementary Therapies* 3, 125–131.
- Davis K, Drey N, Gould D. (2009). What are scoping studies? A review of the nursing literature. *International Journal of Nursing Studies* 46:1386-1400.
- Deadman P, Al-Khafaji M, Baker K, (1998) *A Manual of Acupuncture*. JCM publications
- Deng G, Vickers AJ, Yeung KS, D'Andrea GM, Xiao H, Heerdt AS, Sugarman S, Troso-Sandoval T, Seidman AD, Hudis CA, Cassileth BR. (2007). Randomised Controlled Trial

of Acupuncture for treatment of hot flashes in breast cancer patients *Journal of Clinical Oncology*. 25(35):5584-5590

Department of Health (2008): report to ministers from the department of health steering group on the statutory regulation of practitioners of acupuncture, herbal medicine, traditional Chinese medicine, and other traditional medicine systems practised in the UK. (p.30) (online). Available from:

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086359

Dickson A, Allan D, O'Carroll R. (2008). Biographical disruption and the experience of loss following a spinal cord injury: An interpretative phenomenological analysis. *Psychology & Health*. 23(4): 407-425

Dong H, Ludicke F, Comte I, Campana A, Graff P, Bischof P. (2001). An exploratory pilot study of acupuncture on the quality of life and reproductive hormone secretion in menopausal women. *Journal of Alternative and Complementary Medicine*. 7(6): 651-8

Donovan KA, Jacobsen PB, Andrykowski MA, Winters EM, Balducci L, Malik U, Kenady D, McGrath P. (2004). Course of fatigue in women receiving chemotherapy and/or radiotherapy for early stage breast cancer. *Journal of Pain & Symptom Management*. 28(4):373-80

Dorsett DS. (1992). The trajectory of cancer recovery. In P Wood (ed). *The Chronic Illness Trajectory Framework: The Corbin and Strauss Nursing Model*. New York: Springer. (p29-38)

Downie FP, Mar Fan HG, Houede-Tchen N, Yi Q, Tannock IF. (2006). Cognitive function, fatigue, and menopausal symptoms in breast cancer patients receiving adjuvant chemotherapy: evaluation with patient interview after formal assessment. *Psycho-Oncology*. 15(10):921-30

Dundee JW, Ghaly RG, Fitzpatrick KT, Lynch GA, Abram WP. (1987). Acupuncture to prevent cisplatin-associated vomiting. *Lancet*.1:1083

Dundee JW, Ghaly RG, Fitzpatrick, KT. (1988). Randomised comparison of the antiemetic effects of metoclopramide and electro-acupuncture in cancer chemotherapy. *British Journal of Clinical Pharmacology*. 25(5): 678P-679

Epping-Jordan JE, Compas BE, Osowiecki DM, Oppedisano G, Gerhardt C, Primo K, Krag DN. (1999). Psychological adjustment to breast cancer: Processes of emotional distress. *Health Psychology* 18: 315–326.

Evans M, Paterson C, Wye L, Chapman R, Robinson J, Norton R, Bertschinger R. (2011). Lifestyle and Self-Care Advice Within Traditional Acupuncture Consultations: A Qualitative Observational Study Nested in a Co-Operative Inquiry. *Journal of Alternative and Complementary Medicine*. 17(6): 519-529

Eyles C, Leydon GM, Brien SB. (2012). Forming connections in the homeopathic consultation. *Patient Education and Counselling*. 10 (article in press)

Faircloth CA, Boylstein C, Rittman M, Young ME, Gubrium J. (2004). Sudden illness and biographical flow in narratives of stroke recovery. *Sociology of Health and Illness*. 26 (2): 242-261

- Fan HGM, Houede-Tchen N, Yi QL, Chemerynsky I, Downie FP, Sabate K, Tannock IF. (2005). Fatigue, menopausal symptoms, and cognitive function in women after adjuvant chemotherapy for breast cancer: 1- and 2-year follow-up of a prospective controlled study. *Journal of Clinical Oncology*. 23(31):8025-32
- Fernandes P., Papaikononou M. & Nieuwoudt J.M. (2006) Women suffering through their bodies. *South African Journal of Psychology* 36, 851–879.
- Ferrell BR, Grant M, Funk B, Garcia N, Otis-Green S, Schaffner ML. (1996). Quality of life in breast cancer. *Cancer Practice*. 4(6):331-40
- Fleishman SB. (2004). Treatment of symptom clusters: pain, depression, and fatigue. *Journal of the National Cancer Institute*. 32: 119-23
- Fønnebo V. (2006). Developing a theoretical framework for complementary and alternative medicine research in Whole systems research in cancer care – report of meeting in Tromsø. *Complementary Therapies in Medicine*. 14:157-164
- Frank AW. (1995). *The wounded storyteller: body, illness and ethics*. The University of Chicago Press.
- Frank AW. (2000). The standpoint of the storyteller. *Qualitative Health Research*. 10:354
- Frank AW. (2001). Can we research suffering? *Qualitative Health Research*. 11(3):353-362
- Frisk J, Carlhall S, Kallstrom A-C, Lindh-Anstrand L, Malstrom A, Hammer M. (2008). Long-term follow-up of acupuncture and hormone therapy on hot flushes in women with breast cancer: a prospective, randomised, controlled multi-centre trial. *Climacteric*. 11:166-174
- Frith H, Harcourt D. (2007). Using photographs to capture women's experiences of chemotherapy: reflecting on the method. 17:1340-1350
- Furness PJ, Garrud P. (2010). Adaptation after facial surgery: Using the diary as a research tool. *Qualitative Health Research*. 20(2) 262–272
- Gelso CJ, Hayes JA. (1998). *The Psychotherapy Relationship: Theory, Research, and Practice*. New York, John Wiley & Sons
- Glaser B, Holton J. (2004). Remodelling Grounded Theory. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 5(2)
- Glaser B, Strauss A. (1967). *The Discovery of Grounded Theory*. Chicago. Aldine
- Glaser B, Strauss A. (1965). *Awareness of Dying*. Chicago. Aldine
- Glaus A, Crow R, Hammond S. (1996). A qualitative study to explore the concept of fatigue/tiredness in cancer patients and in healthy individuals. *Supportive Care in Cancer*. 4(2): 82-96
- Gould A, MacPherson H. (2001). Patient perspectives on outcomes after treatment with acupuncture. *Journal of Alternative Complementary Medicine*. 7(3):261-8.
- Griffiths V, Taylor B. (2005). Informing nurses of the lived experience of acupuncture treatment: a phenomenological account. *Complementary Therapies in Clinical Practice*. 11: 111–120

- Guber EG, Lincoln YS. (1982). *Effective Evaluation*. Jossey-Bass Publishers London
- Haghighat S, Akbari ME, Holakouei K, Rahimi A, Montazeri A. (2003). Factors predicting fatigue in breast cancer patients. *Supportive Care in Cancer*. 11(8):533-8
- Hall WA, Callery P. (2001). Enhancing the Rigor of Grounded Theory: Incorporating Reflexivity and Relationality. *Qualitative Health Research*. 11:257-27
- Han JS, Terenius L. (1982). Neurochemical basis of acupuncture analgesia *Annu Rev Pharmacology and Toxicology*. 22:193-220
- Hammar M, Frisk J, Grimås O, Hook M, Spetz AC, Wyon Y. (1999). Acupuncture treatment of vasomotor symptoms in men with prostatic carcinoma; a pilot study. *The Journal of Urology*. 161(3): 853-6
- Hamersley M. (2008). Questioning Qualitative Inquiry. *Critical Essays*. Chapter Eight p.147. Sage. Thousand Oaks
- Hemenover SH. (2003) The Good, the Bad, and the Healthy: Impacts of Emotional Disclosure of Trauma on Resilient Self-Concept and Psychological Distress. *Personality and Social Psychology Bulletin*. 29 (10): 1236-1244
- Hervik J, Mjøland O. (2009). Acupuncture for the treatment of hot flashes in breast cancer patients, a randomized, controlled trial. *Breast Cancer Research and Treatment*. 116:311–316
- Hewitt J. (2007). Ethical Components of Researcher-Researched Relationships in Qualitative Interviewing. *Qualitative Health Research*. 17:1149
- Hilton AB. (1996). Getting back to normal: the family experience during early stage breast cancer. *Oncology Nursing Forum*. 23(4): 605-614
- Hoskins CN. (1997). Breast cancer treatment related patterns in side effects, psychological distress and perceived health status. *Oncology Nursing Forum*. 24(9): 1575-83
- Howe D 1993, *On being a client*. Sage. London
- Howie JGR, Heaney DJ, Maxwell M, Walker JJ: A comparison of the Patient Enablement Instrument (PEI) against two established satisfaction scales as an outcome measure of primary care consultations. *Fam Pract* 1998, 15:165-171.
- Horvath AO. (2010). The Therapeutic Relationship: From Transference to Alliance. *Psychotherapy in Practice*. 56(2), 163–173
- Huang MI, Nir Y, Chen B, Schnyer R, Manber R. (2006). A randomised controlled pilot study of acupuncture for postmenopausal hot flashes: effect on nocturnal hot flashes and sleep quality. *Fertility and Sterility*. 86(3)
- Huang W, Howie J, Taylor A, Robinson N. (2011). An investigation into the effectiveness of traditional Chinese acupuncture (TCA) for chronic stress in adults: A randomised controlled pilot study. *Complementary Therapies in Clinical Practice*. 17: 16-21
- Hubbard G, Kidd L, Kearney N. (2010). Disrupted lives and threats to identity: The experiences of people with colorectal cancer within the first year following diagnosis. *Health*. 14(2): 131-146

Hughes JG, Goldbard J, Fairhurst E, Knowles K. (2007). Exploring acupuncturists' perceptions of treating patients with rheumatoid arthritis. *Complementary Therapies in Medicine*. 15(2):101-8

Hughes JG. (2009). "When I first started going I was going in on my knees, but I came out and I was skipping": Exploring rheumatoid arthritis patients' perceptions of receiving treatment with acupuncture. *Complementary Therapies in Medicine*. 17:269—273

Jackson S, Scambler G. (2007). Perceptions of evidence-based medicine: traditional acupuncturists in the UK and resistance to biomedical modes of evaluation. *Sociology of Health and Illness*. 29 (3): 412–429

Jacobsen PB, Hann DM, Azzarello LM, Horton J, Balducci L, Lyman GH. (1999). Fatigue in women receiving adjuvant chemotherapy for breast cancer: Characteristics, course, and correlates. *Journal of Pain & Symptom Management*. 18(4):233-42

Jacobsen PB, Donovan KA, Weitzner MA. (2003). Distinguishing fatigue and depression in patients with cancer. *Seminars in Clinical Neuropsychiatry*. 8(4): 229-40

Janelins MC, Kohli S, Mohile SG, Usuki K, Ahles TA, Morrow GR. (2011). An update on cancer- and chemotherapy-related cognitive dysfunction: current status. *Seminars Oncology*. 38(3):431-8

Jonas WB: (2005). Building an evidence house: challenges and solutions to research in complementary and alternative medicine. *Forschende Komplementärmedizin / Research in Complementary Medicine*. 12(3): 155-159

Kelner M. (2000). The therapeutic relationship under fire. Chapter Four. In *Complementary and Alternative Medicine: Challenge and Change* edited by Ed: Merrijoy Kelner, Beverly Wellman).

Khorsan R, York A, Coulter ID, Wurzman R, Walter JAG, Coeytaux RR. (2010). Patient-Based Outcome Assessment Instruments in Acupuncture Research. *The Journal of Alternative and Complementary Medicine*. 27-35.

Kim YS, Lee SH, Jung WS, Park SU, Moon SK, Ko CN. (2004). Intradermal acupuncture on Shen-Men and Nei-Kuan Acupoints in patients with insomnia after stroke. *American Journal of Chinese Medicine*. 32(5): 771-778

Koithan M, Verhoef M, Bell IR, White M, Mulkins A, Ritenbaugh C. (2007). The Process of Whole Person Healing: "Unstuckness" and Beyond. *The Journal of Alternative and Complementary Medicine*. 659-668.

Kralik D (2002). The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*. 39 :146–154.

Kralik D, Visentin K, Van Loon A. (2006). Transition: a literature review. *Journal of Advanced Nursing*. 55(3), 320–329

Kralik D, van Loon A. (2007). Understanding transition in chronic illness. *Australian Nursing Journal* 15: 29-34

Kuhn TS. (1962). *The Structure of Scientific Revolutions*. University of Chicago Press, Chicago

- Kumar N, Allen KA, Riccardi D. (2004). Fatigue, weight gain, lethargy and amenorrhea in breast cancer patients on chemotherapy: is subclinical hypothyroidism the culprit? *Breast Cancer Research & Treatment*. 83(2):149-59
- Landmark BT, Strandmark M, Wahl A. (2002). Breast cancer and experiences of social support. *Scandinavian Journal of Caring Sciences*. 16:216-223
- Launsø L, Skovgaard L. (2008). The IMCO scheme as a tool in developing team-based treatment for people with multiple sclerosis *Journal of Alternative and Complementary Medicine*. 14(1):69-77.
- Liddle J, Carlson G, McKenna K. (2004). Using a Matrix in Life Transition Research. *Qualitative Health Research*. 14(10): 1396-1417
- Lincoln YS, Guba, EG. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications
- Lofland J, Lofland LH (1995) *Analysing social settings*. 3rd edition. Belmont, California., London: Wadsworth
- Long AF. (2002). Outcome measurement in complementary and alternative medicine: unpicking the effects. *Journal of Alternative and Complementary Medicine*. 8(6): 777-786.
- Long AF, Godfrey M. (2004). An evaluation tool to assess the quality of qualitative research studies. *International Journal of Social Research Methodology*. 7(2):181-196
- Long AF, Mercer G, Hughes K. (2000). Developing a tool to measure holistic practice: A missing dimension in outcomes measurement within complementary therapies. *Complementary Therapies in Medicine*. 8(1):26-31
- Longman AJ, Braden CJ, Mishel MH. (1996). Side effects burden in women with breast cancer. *Cancer Practice*. 4(5):274-80
- Macciocia G. (2005). *The Foundations of Chinese Medicine*. (2nd Ed). Churchill Livingstone, London.
- Macciocia G. (2008). *The Practice of Chinese Medicine*. (2nd Ed). Churchill Livingstone, London.
- MacPherson H, Thorpe L, Thomas KJ. (2006). Beyond needling—therapeutic processes in acupuncture care: a qualitative study nested within low back pain trial. *Journal of Alternative and Complementary Medicine*. 12(9):873—80.
- MacPherson H, Altman DG, Hammerschlag R, Youping L, Taixiang W, White A, Moher D. (2010). Revised Standards for Reporting Interventions in Clinical Trials of Acupuncture (STRICTA): Extending the CONSORT statement. *PLoS Med* 7(6):e1000261.doi:10.1371/journal.pmed. 1000261
- Malassiotis A, Sylt P, Diggins H. (2007). The management of cancer-related fatigue after chemotherapy with acupuncture and acupressure: An RCT. *Complementary Therapies in Medicine*. 15(4):228-237
- Martin DP, Sletten CD, Williams BA, Berger IH. 2006. Improvement in fibromyalgia symptoms with acupuncture: results of a RCT. *Mayo Clinic Proceedings*. 81(6):749-57

Mason S, Tovey P and Long AF. (2002). Evaluating complementary medicine: methodological challenges of randomised controlled trials. *British Medical Journal*. 325: 832-834

Matthews DA, Suchman AL, Branch WT. (1993). Making "Connexions": Enhancing the therapeutic potential of patient-clinician relationships. *Annals of Internal Medicine*.118: 973-977

McCann L, Illingworth N, Wengstrom Y, Hubbard G, Kearney N. (2010). Transitional experiences of women with breast cancer within the first year following diagnosis. *Journal of Clinical Nursing*. 19:1969–1976

Mead N, Lester H, Chew-Graham C, Gask L, Bower P. (2010). Effects of befriending on depressive symptoms and distress: systematic review and meta-analysis. *British Journal of Psychiatry*. 196:96-101

Mehnert A, Koch U. (2008). Psychological comorbidity and health-related quality of life and its association with awareness, utilization, and need for psychosocial support in a cancer register-based sample of long-term breast cancer survivors. *Journal of Psychosomatic Research*. 64(4):383-91

Miles MB and Huberman AH. (1994). *Qualitative data analysis*. Thousand Oaks, CA: Sage Publications.

Moch SD. (1990). Health within the experience breast cancer. *Journal of Advanced Nursing*. 15:1426-1435

Mock V, Atkinson A, Barsevick A, Cella D, Cimprich B, Cleeland C, Donnelly D, Eisenberger MA, Escalante C, Hind J, Jacobsen PB, Kaldor P, Knight SJ, Peterman A, Piper BF, Rugo H, Sabbatini P, Stahl C. (2000). NCCN Practice Guidelines for Cancer-Related Fatigue. *National Comprehensive Cancer Network Oncology*. 14(11A): 151–161

Morrow GR, Andrews PL, Hickok JT, Roscoe JA, Matteson S. (2002). Fatigue associated with cancer and its treatment. *Support Care Cancer*. 10(5):389-98.

Morrow GR, Hickok JT, Roscoe JA, Raubertas RF, Andrews PL, Flynn PJ, Hynes HE, Banerjee TK, Kirshner JJ, King D. (2003). Differential effects of paroxetine on fatigue and depression: a randomized, double-blind trial from the University of Rochester Cancer Center Community Clinical Oncology Program. *Journal of Clinical Oncology*. 21(24):4635-41

Mruck K, Breuer, F (2003). Subjectivity and Reflexivity in Qualitative Research—The FQS Issues [17 paragraphs]. *Forum: Qualitative Social Research*, 4(2), Art. 23, Available from <http://nbn-resolving.de/urn:nbn:de:0114-fqs0302233>

Nedstrand E, Wikma K, Wyon Y, Hammar M. (2005). Vasomotor symptoms decrease in women with breast cancer randomised to treatment with applied relaxation or electro-acupuncture: a preliminary study. *Climacteric*. 8(3):243-250

Oakley A, Strange V, Bonell C, Allen E, Stephenson J. (2006). Process evaluation in randomised controlled trials of complex interventions. *British Medical Journal*. 332:413-332

Okuyama T, Akechi T. (2000). Factors correlated with fatigue in disease-free breast cancer patients: application of the Cancer Fatigue Scale. *Supportive Care in Cancer*. 8(3):215-22

Ortiz Aragón A, Giles Macedo JC. (2010). A 'Systemic Theories of Change' Approach for Purposeful Capacity Development. *IDS Bulletin*. 41 (3): 87-99

Otto LM, Howerter A, Bell IR, Jackson N. (2010). Exploring Measures of Whole Person Wellness: Integrative Well-Being and Psychological Flourishing. *Explore*: 6(6): 364–370

Paraskeva, A. Melemini, A. Petropoulos, G. Siafaka, I. Fassoulaki, A. (2004). Needling of the extra 1 point decreases BIS values and preoperative anxiety. *American Journal of Chinese Medicine*. 32(5):789-94

Paterson C. Measuring outcome in primary care: a patient-generated measure, MYMOP, compared to the SF-36 health survey. *British Medical Journal* 1996;312:1016-20.

Paterson C. (2006). Measuring changes in self-concept: a qualitative evaluation of outcome questionnaires in people having acupuncture for their chronic health problems. *BMC Complementary and Alternative Medicine*. 6:7

Paterson C, Baarts C, Launsø L, Verhoef MJ. (2009). Evaluating complex health interventions: a critical analysis of the 'outcome' concept. *BMC Complementary and Alternative Medicine*. 9:18

Paterson C, Britten N. (2003). Acupuncture for people with chronic illness: Combining qualitative and quantitative outcome assessment. *The Journal of Alternative and Complementary Medicine*. 9(5): 671-681

Paterson C, Britten N. (2004). Acupuncture as a complex intervention: a holistic model. *Journal of Alternative and Complementary Medicine*. 10(5): 791-801

Paterson C, Britten N. (2008). The patient's experience of holistic care: insights from acupuncture research. *Chronic Illness*. 4:264

Paterson C, Dieppe P (2005). Characteristic and incidental (placebo) effects in complex interventions such as acupuncture. *BMJ*. 330:1202-05

Patton MQ. (1990). *Qualitative Evaluation and research methods*. Newbury Park, CA. Sage

Pawson R, Tilley N. (1997). *Realistic Evaluation*. London. Sage publications.

Pinnock H, Kendall M, Murray, Scott A, Worth A, Levack P, Porter M, MacNee W, Sheikh, A. (2011). Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. *British Medical Journal*. vol./is. 342/(0-0)

Price S, Mercer SW, MacPherson H. The impact of empathy, enablement and health outcome: a prospective study of acupuncture patients. *Patient Education and Counselling*. 2006 63(1-2): 239-245

Price S, Long AF, Godfrey M, Thomas KJ. (2011). Getting Inside Acupuncture Trials: exploring intervention theory and rationale. *BMC Complementary and Alternative Medicine*. 11:22

Reeler D. (2007). A Three-fold Theory of Social Change and Implications for Practice, Planning, Monitoring and Evaluation *Community Development Resource Association*

Reilly D, Fischer M, Singh B, Haidvogel M, Heger M. (2001). Homeopathy and Conventional Medicine: An Outcomes Study Comparing Effectiveness in a Primary Care Setting. *The Journal of Alternative and Complementary Medicine*. p.149-159.

Richardson A, Ream E. (1996). The experience of fatigue and other symptoms in patients receiving chemotherapy. *European Journal of Cancer Care*. 5(2 Suppl): 24-30

Richer MC, Ezer H. (2002). Living in it, living with it and moving on: dimensions of meaning during chemotherapy. *Oncology Nursing Forum*. 29(1): 113-119

Ritchie J, Lewis J. (2003). *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. Thousand Oaks, C.A: Sage Publications

Rogers, C. (1951). Client-centered therapy: Its current practice, implications and theory. London: Constable

Rogers PJ. (2008). Using programme theory to evaluate complicated and complex aspects of interventions. *Evaluation*. 14:29

Rorsman I, Johansson B. (2006). Can electroacupuncture or transcutaneous nerve stimulation influence cognitive and emotional outcome after stroke? *Journal of Rehabilitation Medicine*. 2006;38:13-19

Roschke J, Wolf C, Muller MJ, Wagner P, Mann K, Grozinger M, Bech S. (2000). The benefit of whole body acupuncture in major depression. *Journal of Affective Disorders*. 57:73-81

Roscoe JA, Morrow GA, Hickok JT, Bushunow P, Matteson S, Rakita D, Andrews PL. (2002). Temporal interrelationships among fatigue, circadian rhythm and depression in breast cancer patients undergoing chemotherapy treatment. *Supportive Care in Cancer*. 10(4): 329-336

Roscoe JA, Morrow GR, Hickok JT, Mustian KM, Griggs JJ, Matteson SE, Bushunow P, Qazi R, Smith B. (2005). Effect of paroxetine hydrochloride (Paxil) on fatigue and depression in breast cancer patients receiving chemotherapy. *Breast Cancer Research & Treatment*. 89(3):243-9

Roscoe JA, Kaufman ME, Matteson-Rusby SE, Palesh OG, Ryan JL, Kohli S, Perlis ML, Morrow GR. (2007). Cancer-related fatigue and sleep disorders. *Oncologist*. 12:35-42

Rugg S, Paterson C, Britten N, Bridges J, Griffiths P. (2011). Traditional acupuncture for people with medically unexplained symptoms: a longitudinal qualitative study of patients' experiences. *British Journal of General Practice*. 61 (587):e306-e315

Ryan JL, Carroll JK, Ryan EP, Mustian KM, Fiscella K, Morrow GR. (2007). Mechanisms of cancer-related fatigue. *Oncologist*. 12:22-34

Sandaunet AG. (2008). A Space for Suffering? Communicating Breast Cancer in an Online Self-Help Context. *Qualitative Health Research*. 18: 1631-1641

Sandberg M, Wijma K, Wyon Y, Nedstrand E, Hammer M. (2002). Effects of electroacupuncture on psychological distress in postmenopausal women. *Complementary Therapies in Medicine*. 10:161-169

Sanders C, Donovan J, Dieppe P. (2002). The significance and consequences of having painful and disabled joints in older age: co-existing accounts of normal and disrupted biographies. *Sociology of Health & Illness*. 24(2):227-253

Schagen SB, Van Dam FSAM, Muller MJ, Boogerd W, Bruning PF. (1999). Cognitive deficits after postoperative adjuvant chemotherapy for breast carcinoma. *Cancer*. 85 (3): 640-650

Schultz PN, Klein MJ, Beck ML, Stava C, Sellin R. (2005). Breast cancer: relationship between menopausal symptoms, physiologic health effects of cancer treatment and physical constraints on quality of life in long-term survivors. *Journal of Clinical Nursing*. 14(2):204-11

Schroer S, MacPherson H, Adamson J. (2009). Designing an RCT of acupuncture for depression—identifying appropriate patient groups: a qualitative study. *Family Practice*. 26: 188–195.

Shekelle PG, Morton SC, Suttrop MJ, Buscemi N, Friesen C. (2005). Challenges in systematic reviews of complementary and alternative medicine topics. *Annals of Internal Medicine*. 142(12-2): 1042-1047

Shen J, Wenger n, Glaspay J, Hays RD, Albert PS, Choi C, Shekelle PG. (2000) Electroacupuncture for control of myeloablative chemotherapy induced emesis: A randomized controlled trial. *Journal of the American Medical Association*. 284(21): 2755-61

Shilling V. Jenkins R. Morris G. Deutsch and D. Bloomfield. (2005). The effects of adjuvant chemotherapy on cognition in women with breast cancer--preliminary results of an observational longitudinal study. *Breast*. 14:142

Smith LA, Oldman AD, McQuay HJ, Moor RA. (2000). Teasing apart quality and validity in systematic reviews: an example from acupuncture trials in chronic neck and back pain. *Pain* 86:119-132

Smithson J, Britten N, Paterson C, Lewith G, Evans M. (2010). The experience of using complementary therapies after a diagnosis of cancer: A qualitative synthesis. *Health*. 16(1) 19–39

Smithson J, Britten N, Paterson C, Evans M, Lewith G. (2010b). Cancer patients' experiences of using complementary therapies: polarization and integration. *Journal of Health Services Research and Policy*. 15 S2: 54–61

Spence, D. W, Kayumov, L, Chen, A, Lowe, Jain U, Katzman MA, Shen J, Perelman B, Shapiro CM. (2004). Acupuncture increases nocturnal melatonin secretion and reduces insomnia and anxiety: a preliminary report. *Journal of Neuropsychiatry & Clinical Neurosciences*. 16(1):19-28

Stame N. (2004). Theory-based Evaluation and Types of Complexity. *Evaluation*. 10(1): 58–76

Stein KD, Jacobsen PB, Hann DM, Greenberg H, Lyman G. (2000). Impact of Hot Flashes on Quality of Life Among Postmenopausal Women Being Treated for Breast Cancer. *Journal of Pain and Symptom Management*. 19(6): 436

Stone AA, Shiffman S, Schwartz JE, Broderick JE, Hufford MR. (2002). Patient non-compliance with paper diaries. *British Medical Journal*. 324:1193

Strauss AL. (1987). *Qualitative Analysis for Social Scientists*. Cambridge University Press. US

Strauss, A. and Corbin, J. 1998. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. 2nd ed. Newbury Park, CA: Sage.

Streitberger K, Friedrich-Rusi M, Bardenheuer H, Unnebrink K, Windeler J, Goldschmidt H, Egerer G. (2003). Effect of acupuncture compared with placebo-acupuncture at P6 as additional antiemetic prophylaxis in high dose chemotherapy and autologous peripheral blood stem cell transplantation: a randomized controlled single-blind trial. *Clinical Cancer Research*. 9:2538-44

Stux G, Pomeranz B, Berman B. (2003). *The Basics of Acupuncture* (5th Edition). Springer-Verlag

Sutherland EG, Ritenbaugh C, Kiley SJ, Vuckovic N, Elder C. (2009). An HMO-Based Prospective Pilot Study of Energy Medicine for Chronic Headaches: Whole-Person Outcomes Point to the Need for New Instrumentation. *The Journal of Alternative and Complementary Medicine*. 15, (8): 819-826

Theory of Change Community 2012 Theory of Change [Online] Accessed June 2011. Available from: <https://www.theoryofchange.org/>

Thomas-MacLean R. (2004). Memories of Treatment: the immediacy of breast cancer. *Qualitative Health Research*. 14(5):628-43

Thompson TDB, Weiss M. (2006). Homeopathy – what are the active ingredients? An exploratory study using the UK Medical Research Council's framework for the evaluation of complex interventions. *BMC Complementary and Alternative Medicine*. 6:37

Thorpe KE, Zwarenstein M, Oxman AD, Treweek S, Furberg CD, Altman DG, Tunis S, Burgel E, Harvey I, Magid DJ, Chalkidou K. (2009). A pragmatic explanatory continuum indicator summary (PRECIS): a tool to help trial designers. *Journal of Clinical Epidemiology* 62: 464-475

Thomas, K., Thorpe, L., MacPherson, H. (2003). Preliminary findings from a pragmatic randomised controlled trial demonstrate acceptability of acupuncture as a treatment for low back pain. *Clinical Acupuncture Oriental Medicine*. 4 (1):56-56

Tritter JQ, Calnan M. (2002). Cancer as a chronic illness? Reconsidering categorization and exploring experience. *European Journal of Cancer Care*. 11:161-165

Verhoef MF, Lewith G, Ritenbaugh C, Boon H, Fleishman S, Leis A. (2005). Complementary and alternative medicine whole systems research: beyond identification of inadequacies of the RCT. *Complementary Therapies in Medicine*. 13: 206-212

Verhoef MF, Mulkins A, Boon H. (2005b). Integrative health care: how can we determine whether patients benefit? *Journal of Alternative and Complementary Medicine*. 11(S1) :S-57–S-65

Verhoef MF, Vanderheyden LC, Dryden T, Mallory D, Ware MA.(2006). Evaluating complementary and alternative medicine interventions: in search of appropriate patient-centred outcome measures. *BMC Complementary and Alternative Medicine*. 6:38

- Verhoef MJ, Mulkins A, Carlson LE, Hilsden RJ, Kania A. (2007). Assessing the Role of Evidence in Patients' Evaluation of Complementary Therapies: A Quality Study. *Integrative Cancer Therapies*. 6(4):345-53
- Vickers AJ, Strauss DJ, Fearon B, Cassileth BR. (2004). Acupuncture for post-chemotherapy fatigue: a phase II study. *Journal of Clinical Oncology*. 22(9):1731-5
- Walker G, de Valois B, Young T, Davies R, Maher EJ. (2004). The experience of receiving traditional Chinese acupuncture. *European Journal of Oriental Medicine*. 4(5):59–65.
- Wayne PM, David EK, Macklin EA, Schnyer RN, Kaptchuk TJ, Parker SW, Scarborough DM, McGibbon CA, Schaechter JD, Stein J, Stason W. (2005). Acupuncture for upper-extremity rehabilitation in chronic stroke: a randomised sham-controlled study. *Archives of Physical Medicine and Rehabilitation*. 86:2248-55
- Wayne PM, Hammerschlag R, Langevin HM, Napadow V, Park JJ, Schnyer RN. (2009). Resolving paradoxes in acupuncture research: a round table discussion. *Journal of Alternative and Complementary Medicine*. 15 (9): 1039-44
- Wefel JS, Lenzi R, Theriault RL, Davis RN, Meyers CA. (2004). The cognitive sequelae of standard-dose adjuvant chemotherapy in women with breast carcinoma: results of a prospective, randomized, longitudinal trial. *Cancer*. 100(11):2292-9
- Wieneke MH, Dienst ER. (1995) Neuropsychological assessment of cognitive functioning following chemotherapy for breast cancer. *Psycho-Oncology*. 4 (1): 61–66
- Weiss CH. (1995). Nothing as practical as a good theory: exploring theory-based evaluation for Comprehensive Community Initiatives for children and families. In: *New Approaches to Evaluating Community Initiatives: Concepts, Methods, and Contexts*. Connell JP, Kubisch AC, Schlorr LB and Weiss CG (eds). Washington, DC: Aspen Institute.
- White A. (2009). Western medical acupuncture: a definition. *Acupuncture in Medicine* 27:33-35
- Williams SJ. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness*. 22(1):40-67
- Wilson S. (2007). 'When you have children, you're obliged to live': motherhood, chronic illness and biographical disruption. *Sociology of Health and Illness*. 29(4): 610-626
- Wiseman N, Feng Y. (1998). *A Practical Dictionary of Chinese Medicine* (2nd Ed). Paradigm Publications, Brookline, Massachusetts.
- Wolcot H (1994). *Transforming qualitative data: description, analysis and interpretation*. Thousand Oaks, C.A: Sage Publications
- Wyon Y, Lindgren R, Lundeberg T, Hammer M. (1995). Effects of acupuncture on climacteric vasomotor symptoms, quality of life and urinary excretion of neuropeptides among postmenopausal women. *Menopause*. 2(1): 3-12
- Wyon Y, Wigma K, Nedstrand E, Hammar M. (2004). A comparison of acupuncture and oral estradiol treatment of vasomotor symptoms in postmenopausal women. *Climacteric*. 7(2): 153-64

APPENDIX I

Search terms for the literature reviews in Chapter Two

Epidemiological Literature – Scoping Review

Initially a scoping search was conducted to find the common symptoms and side-effects being measured using 'breast cancer' AND 'chemotherapy'. The abstracts were sifted through to explore only those collecting data in the first year of diagnosis. Five key outcomes were consistently measured.

i) The databases searched were:

EMBASE, OVID and PsychINFO.

ii) Search Terms were:

'breast cancer' AND 'fatigue'

'breast cancer' AND 'vasomotor' or 'hot flushes'

'breast cancer' AND 'anxiety'

'breast cancer' AND 'depression'

'breast cancer' AND 'insomnia'

Two additional outcomes were searched for:

'breast cancer' AND 'nausea' or 'vomiting'

'breast cancer' AND 'cognitive function'

Results: 75 reviewed papers of which 36 had cancer-related fatigue as the main outcome.

Qualitative Literature

Selected papers were examined using an evaluation tool for qualitative studies (Long and Godfrey 2004). Data was extracted and described according to categories such as 'phenomena under study' or 'data collection' and evaluated according to the appropriateness or validity or other quality markers. As the focus of this thesis is women with early breast cancer at the start of the treatment experience that is before, during and after chemotherapy studies that recruited women up to one year from the point of diagnosis were included and all studies located after adjuvant treatment were excluded.

Sample: A systematic electronic search of five databases (Amed, British Nursing Index, MEDLINE, PsychoINFO, ASSIA), was conducted in order to locate articles exploring breast cancer patient experiences.

Search terms: 'breast AND cancer AND experiences AND/OR qualitative' taken from 1988 to 2009.

Excluded studies: those using only quantitative methods, literature reviews, studies excluding chemotherapy experiences, and studies relating to the impact of particular interventions.

Citation search: of the included studies and of literature reviews

Hand search: Psycho-oncology and Oncology Nursing Forum

This search was repeated in its entirety to ensure no papers had been missed and the date increased to 2010 which brought the total number of included papers to eleven.

APPENDIX II

TREATMENT AUDIT TOOL/LOG

Tx No.:..... Date:.....

Participant code:.....

1. PATIENT REPORTED PROBLEMS OR CONCERNS

Main Complaint:

Secondary:

-
-
-
-

Primary syndrome:

Secondary syndromes:

Acupuncture interventions

List acupuncture points used (indicate unilateral or bilateral)

Other Interventions:

- Massage
- Cupping
- Electro-acupuncture
- Other (specify)

Home-based self-treatments prescribed:

- Specific physical exercise
- Tai-chi
- Yoga
- Self-massage
- Relaxation classes
- Other (specify)

Facilitating and supporting lifestyle changes

Dietary Advice:

- Low dairy
- Low wheat
- Ensure food is warm and cooked
- Avoid wines and spirits
- Stop coffee/tea/caffeine
- Other dietary advice (specify)

Non dietary change

- Stop smoking
- Take more exercise
- Take more rest
- Protect from cold and damp
- Other (specify)

General support and empowerment (describe):

.....

.....

.....

.....

.....

.....

Medication Change Report. (record any changes or additional medication taken by the patient for instance additional painkillers, anti-depressants, laxatives, anti-emetic use in the last week):

.....

.....

.....

.....

2. PATIENT REPORTED REACTIONS or INCIDENCES to ACUPUNCTURIST

Type 1. Reactions to normal treatment, which could be positive indicators (but could be experienced as adverse by newer patients) and are communicated spontaneously by the patient during, or after treatment or at the next visit:

- Light- headed
- Energised
- Tired
- Relaxed
- Drowsy
- Hungry
- Other.....

.....

Type 2: Reactions to normal treatment, which result in an aggravation of symptoms followed by a significant improvement (better than before treatment) as a result of asking if the patient had any reactions to the previous treatment:

List symptoms that worsened:

When starting after treatment?:

For how long did the symptoms last?:

Any other details:

Type 3: Adverse Events

- Fainting
- Fit (convulsions)
- Vomiting
- Skin reactions
- Unacceptable bruising
- Unacceptable bleeding
- Unacceptable pain at point of needling
- Unacceptable worsening of symptoms
- Forgotten needle
- Broken needle
- Moxa burn
- Pneumothorax
- Cross infection
- Other (specify)

Please write about the incident in some detail:

.....

.....

APPENDIX III

Patient Study Pack

School of Healthcare

Baines Wing
The University of Leeds
PO Box 214
Leeds LS2 9UT

Sarah Price contact details:
Mobile: 07984202041
Email: s.price05@leeds.ac.uk



Acupuncture Care for Breast Cancer Patients

I would like more information on the above study and I would like the researcher, Sarah Price, to get in touch with me about it.

Name:

Address:.....
.....

Tel no: (daytime) (evening)

..... (mobile)

I am under no obligation to take my interest any further.

If you are interested in the above study and you would like to know more, you need to return this slip sooner rather than later as the start of the study takes place just before your first chemotherapy session.

Please give this slip back to the oncology nurse

School of Healthcare

Baines Wing
The University of Leeds
PO Box 214
Leeds LS2 9UT



Protocol Number 2 Version April 08

PATIENT INFORMATION SHEET

Acupuncture Care for Breast Cancer Patients

We would like to invite you to take part in a research study. Before you decide, you need to understand why this research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

This trial is designed to help us find out what it would be like for patients to have acupuncture whilst undergoing chemotherapy for breast cancer. The information gathered from the participants in this trial will allow a better understanding of any benefits that might be gained for individuals seeking acupuncture care during their chemotherapy. In turn, it may help in the planning of further research into the benefits of acupuncture care for cancer patients.

Some of the information collected will also be used towards a doctoral thesis for the chief investigator.

Why have I been invited?

You have been invited into this study because you are about to commence a course of chemotherapy. The purpose of this trial is specifically to understand what your needs might be during the first three months of chemotherapy and whether acupuncture meets any of those needs. The acupuncture treatment is designed to help with the symptoms and side effects of chemotherapy. Approximately 19 other participants will be invited too.

Do I have to take part?

No - it is up to you to decide whether or not you wish to take part. We will describe the study and go through this information sheet, which we will then give you. We will then ask you to sign a consent form if you have agreed to take part. You are free to withdraw at any time, without giving a reason. Most importantly, the treatment you receive for your breast cancer will not be affected by your decision about taking part in this study or not.

What will happen to me if I take part?

It is expected that you will be involved in this project for not more than 16 weeks. Your involvement will consist of two meetings with the researcher, Sarah Price, at the beginning and at the end of the project, and up to ten acupuncture treatments in between these two meetings. The meetings with Sarah will last about an hour; and the acupuncture appointments will last about 45 minutes.

How do I get involved?

If you are interested in being involved in the study please indicate to the oncology nurse who gave you this form, and she will inform Sarah, the researcher, of your interest. Sarah will then contact you. Sarah will ensure you have read this information sheet and ask you to sign the consent form attached.

Once you decide to take part, Sarah will arrange to meet with you at your convenience but before you start your chemotherapy. At this meeting, Sarah will ask you a series of open questions about your health and your feelings about your treatment. Sarah will also help you complete three questionnaires that are commonly used to gather information about the health and well-being of cancer patients. This interview will be audio-recorded, but your personal details such as your name will not be known to anyone except Sarah, and she will ensure that the information you give will be kept confidential and secure at all times. Sarah will give you her contact details so that you may discuss any further questions or concerns with her.

Sarah will then arrange your first acupuncture appointment with the trained acupuncturist. This appointment will take place in a private acupuncture clinic, which is registered with the local authority and only yourself and the acupuncturist will be present. This will happen during the week after your first chemotherapy treatment.

Acupuncture Treatment

Acupuncture as practiced by members of the British Acupuncture Council (BAcC) is an holistic approach to health based on over 2,000 years of development and refinement in the Far East. Although sometimes described as a means of pain relief, traditional acupuncture is actually used to treat people with a wide range of illnesses. Its focus is on improving the overall wellbeing of the patient, rather than the isolated treatment of specific symptoms. The skill of an acupuncturist lies in their ability to make a traditional diagnosis from what is often a complex pattern of disharmony. The exact pattern and degree of disharmony is unique to each individual and so following diagnosis, the acupuncturist puts together a personalised treatment plan. According to traditional Chinese philosophy, our health is dependent on the body's motivating energy - known as qi - moving in a smooth and balanced way through a series of meridians (channels) beneath the skin. The flow of qi can be disturbed by many factors, physical, mental and emotional. By inserting fine needles into the channels of energy, an acupuncturist can stimulate the body's own healing response and help to restore its natural balance.

All of the information that you give to the acupuncturist will be treated in the strictest confidence and the notes relating to the treatment will not identify you in anyway. The acupuncturist will keep a log of the specific acupuncture treatment. The acupuncturist in this study is very experienced, is a member of the British Acupuncture Council. She will ask you specific questions about your symptoms and your general health so that she is able to give you a personalised individual acupuncture treatment. Acupuncture treatment involves the insertion of very fine sterilised needles. Patients sometimes report a mild prick and a transient tingling sensation during this process, and the needles are retained for up to 20 minutes. After the first acupuncture treatment, the acupuncturist will arrange your next appointment with you at your convenience.

The acupuncture treatments and the interviews with the researcher, Sarah, are additional to your usual care and are what constitutes this trial.

At the end of your ten acupuncture treatments, Sarah will arrange to meet with you again. In this final interview, which will be audio-recorded, as before, Sarah will ask you to talk about your experiences of acupuncture care and chemotherapy. You will be asked to complete a second set of questionnaires as you did in the first meeting with Sarah.

What are the possible risks and disadvantages to taking part?

Negative reactions to treatment are expected to be mild and transient and seldom put patients off continuing with their acupuncture treatment. The acupuncturist to ensure that safety guidelines are established will use a monitoring schedule, that is a record of any minor event or adverse effect will be logged on a form that will be analysed at the end of the study.

What are the possible side effects of acupuncture treatment?

Acupuncture has relatively few side effects. Recipients of acupuncture sometimes report a tingling sensation with treatment or occasionally a transient mild dull ache. Sometimes a slight bleed or small bruise can occur at the site of insertion after the needle is removed.

What are the possible benefits of taking part?

It is possible that you may experience some easing of your symptoms and side effects caused by chemotherapy. We can't promise that acupuncture care will help you but information we get from this study will enable us to test further how helpful acupuncture care may be.

What happens when the research study stops?

When the research study stops, you will continue with your chemotherapy treatment as usual, under the direction of your oncologist, as well as normal follow-up.

Will my taking part in the study be confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you that leaves the hospital or acupuncture clinic will have your name and address removed so that you cannot be recognised. Each participant will be given a code so that his or her identity is protected. Questionnaires and transcribed data will only carry the code and be stored in a locked cabinet. The information collected for the study will be securely destroyed once the study is completed and the results published; and any information from the study used in the doctoral thesis will be anonymised.

What will happen if I don't want to carry on with the acupuncture treatment?

If you decide to withdraw from the acupuncture treatment, it will still be very helpful to have the final interview with Sarah as described above. Understanding why you have stopped will help us evaluate the acceptability of acupuncture care for individuals. Information that has already been collected from you may still be used.

What if there is a problem?

If you have a concern about any aspect of this study, please contact the researcher, Sarah Price, and she will do her best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained from the hospital. You can also contact the British Acupuncture Council; the phone number is given at the end of this document.

In the event that something goes wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against either the University of Leeds or the British Acupuncture Council but you may have to pay your legal costs. The normal National Health Services complaints mechanisms will still be available to you (if appropriate).

Informing your General Practitioner

It would be routine to inform your GP that you are involved in the study, but we will only do this if you give consent for us to do this.

What will happen to the results of the study?

Participants who have expressed a wish to know the findings of the study will be sent a copy of the report once the data has been analysed and written up.

Who is organising and funding the research?

The sponsor of the research is the University of Leeds, and the British Acupuncture Council is funding the costs of the acupuncture treatment.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well-being and dignity. This study has been reviewed and given favourable opinion by the Leeds Research Ethics Committee.

APPENDIX IV

Topic Guides

Topic Guide – Breast Cancer Participants First Interview

How have BC sufferers experienced the impact of diagnosis and treatment and in what way has it changed them: their whole self.

Opening Question: *Tell me about how you first discovered you had breast cancer?*

Prompts:

- What did you feel when you were told it was cancer?
- How has this experience changed you
- How have your loved ones/those close to you reacted?
- Do you feel altered since the diagnosis?
- Have those close to you changed how they treat you?
- How was the surgery for you and how did you feel afterwards?
- How do you feel about the chemotherapy?
- What made you decide to try acupuncture?
- What concerns or worries do you have?
- Are there other sources of support that you might pursue?

Added after fifth interview:

- Could you say there has been anything positive about this experience?

Topic Guide Breast Cancer Participants follow-up Interview

Opening Question: *How are you and how have things been in the last 3 months?*

Prompts:

- When we last spoke – *notes from first interview*
- need to be independent – *notes from first interview*
- concerns... - *notes from first interview*
- What has been the most challenging thing in the last three months?
- Differentiate between the experience and the management of it
- How has this experience changed you?
- How have you found the chemotherapy?
- What do you think about your decision to have chemotherapy? Would you take the same decision again?
- You've had some acupuncture treatment – can you take me through what happened – how was it for you having acupuncture?
- How has it affected you? In what ways has it affected you? How has this happened?
- Some people may experience difficulties with acupuncture – were there any for you?
- Would you consider having acupuncture again?
- Would you consider continuing your acupuncture treatment at this stage if you could?
- What things have you found supportive?
- What is important to you now? Is this different from before?

Topic Guide Breast Cancer Participants Third Interviews

To explore whether they felt the acupuncture care helped them maintain a sense of self or 'get them back on track'.

Opening Question: *How are you feeling about things just now?*

- How long is it since your last chemo?
- Looking back, how do you feel about the acupuncture and what do you think it did for you, if anything?
- Was it offered at the right time?
- Given what you know now, are you glad you said yes to the acupuncture?
- In what ways do you think this experience has changed you as a person?

Include notes from previous two interviews with particular individual to follow-up certain points

Topic Guide Acupuncturists – First Interview

Initiate conversation with background to the PhD, that it is about an exploration of what acupuncture care means in practice for individual practitioners, and in relation to the treatment of breast cancer patients. The overall objective is how we can understand not just does it work, but how and in what way - the how and in what way in relation to particular outcomes.

- Outcomes *What are we trying to achieve for this patient?*
- Treatment *How is this outcome going to be achieved?*
- Theory *Why is this treatment going to work?*

Opening Question: *When someone comes to your practice for the first time – can you describe to me how you go about finding the information you need in order to treat them?*

Prompts:

- What kind of information do you seek?
- Why is this information needed?
- What does holism mean to you?
- What has to change in the patient for you to change your treatment strategy?
- Why do you believe the acupuncture is going to work?
- What kind of things are you expecting to happen after each treatment?
- In what way does knowing the biomedical disease background affect your treatment?
- What do you believe the catalyst for change is in patients?
- In what way does knowing the history of the main complaint affect your approach?
- What do you hope to achieve overall with your patients?
- What kind of advice do you give your patients?

- Allow participant to read the vignette, and ask them again:

- How would you go about helping this particular patient?
- With this kind of patient – what would you be hoping to achieve?

Breast Cancer Vignette

A 45 year old woman has recently been diagnosed with BC. She arrives at your practice a month after having had surgery to remove the tumour and has some pain and discomfort resulting from that. She has just had her first cycle of chemotherapy, which takes place every 3 weeks and will continue for another 4 months or so. This is what she reports to you:

“I was feeling fine until I felt the lump – it was such a shock to be told I had breast cancer – I was really scared. The surgeon was great and I feel better now, but I still can’t sleep well, and I feel so drained a lot of the time. The chemotherapy has started and I am so worried that I am not going to be able to cope with everything. I felt dreadful after the first chemo, really sick, and anxious and out of sorts. I am so tired. I’m told it might get easier with chemo or it might get worse – it is a long time to have this treatment – a bit of a sentence. I really want to cope, but I don’t know what I can do to help myself, I feel I have lost my confidence.”

Topic Guide Acupuncturists: Follow-up Interview

- Outcomes *What are you trying to achieve for this patient?*
- Treatment *How is this outcome going to be achieved?*
- Theory *Why is this treatment going to work?*

Opening Question: *How did you find treating this group of patients?*

- What kind of things do you think the acupuncture helps with?
- What do you think you are trying to achieve
- Therapeutic relationship – differentiate from acupuncture treatment
- Relationship versus counselling – comments?
- Would you talk to them about how their feelings or their lifestyle was impacting on their health?
- Acupuncture – how does it bring about change?

APPENDIX V

Reactions to treatment – please complete any of the following that apply to you										
Response	Did you experience this?	<i>If yes,</i> How would you describe the strength of your response? <i>(circle one)</i>			<i>If yes,</i> How much did this response bother you at the time? <i>(circle one)</i>				<i>If yes,</i> Would you be prepared to experience it again?	
		Mild	Moderate	Severe	Not at all	A bit	Quite a lot	A great deal	Yes	No
1. Temporary worsening of symptoms	Yes No	Mild	Moderate	Severe	Not at all	A bit	Quite a lot	A great deal	Yes	No
2. Dizziness/light-headedness	Yes No	Mild	Moderate	Severe	Not at all	A bit	Quite a lot	A great deal	Yes	No
3. Tiredness/ drowsiness	Yes No	Mild	Moderate	Severe	Not at all	A bit	Quite a lot	A great deal	Yes	No
4. Energised	Yes No	Mild	Moderate	Severe	Not at all	A bit	Quite a lot	A great deal	Yes	No
5. Relaxed	Yes No	Mild	Moderate	Severe	Not at all	A bit	Quite a lot	A great deal	Yes	No
6. Hungry	Yes No	Mild	Moderate	Severe	Not at all	A bit	Quite a lot	A great deal	Yes	No
7. Other <i>please specify:</i>	Yes No	Mild	Moderate	Severe	Not at all	A bit	Quite a lot	A great deal	Yes	No

Patient satisfaction with acupuncture care

YOUR TREATMENT FROM THE ACUPUNCTURIST

Thinking about your own health care, how would you rate the following?

(please circle one number on each line)

a. Explanations of acupuncture treatment procedures?	Poor	Fair	Good	Very Good	Excellent
	1	2	3	4	5
b. Attention given to what you have to say?	Poor	Fair	Good	Very Good	Excellent
	1	2	3	4	5
c. Advice you were given about ways of avoiding illness and staying healthy?	Poor	Fair	Good	Very Good	Excellent
	1	2	3	4	5
d. Friendliness and courtesy shown to you by the acupuncturist?	Poor	Fair	Good	Very Good	Excellent
	1	2	3	4	5
e. Personal interest in you and your problems?	Poor	Fair	Good	Very Good	Excellent
	1	2	3	4	5
f. Respect shown to you, attention to your privacy?	Poor	Fair	Good	Very Good	Excellent
	1	2	3	4	5
g. Reassurance and support offered to you by the acupuncturist?	Poor	Fair	Good	Very Good	Excellent
	1	2	3	4	5
h. Amount of time you had with the acupuncturist during each visit?	Poor	Fair	Good	Very Good	Excellent
	1	2	3	4	5

APPENDIX VI

Author (Year) Title	Aim	Findings
Vasomotor		
Wyon Y, Lindgren R, Lundeberg T, Hammer M Effects of acupuncture on climacteric vasomotor symptoms, quality of life and urinary excretion of neuropeptides among postmenopausal women (1995)	To study if, and to what extent, two different kinds of acupuncture affected postmenopausal hot flushes, urinary excretion of neuropeptides and Quality of Life (QoL)	Acupuncture significantly affects vasomotor symptoms with effects persisting at least 3 months after the end of treatment; CGRP was also significantly decreased with treatment.
Hammar M, Frisk J, Grimas O, Hook M, Spetz AC, Wyon Y. Acupuncture treatment of vasomotor symptoms in men with prostatic carcinoma; a pilot study. (1999)	To establish 'if acupuncture therapy could be used to treat vasomotor symptoms in men who underwent castration therapy for prostatic carcinoma'	Participants reported at 3 months after the last treatment a 50% reduction in number of flushes
Dong H, Ludicke F, Comte I, Campana A, Graff P, Bischof P. An exploratory pilot study of acupuncture on the quality of life and reproductive hormone secretion in menopausal women. (2001)	To assess the effects of acupuncture on the QoL and reproductive hormones secretion in menopausal women.'	Acupuncture effective in relieving vasomotor and physical symptoms in menopausal women for at least 3 months after end of treatment
Sandberg M, Wijma K, Wyon Y, Nedstrand E, Hammar M Effects of electro-acupuncture on psychological distress in postmenopausal women (2002)	To evaluate effects of EA on general psychological distress and relate to experience of climacteric symptoms in 30 postmenopausal women	This study does not show that EA is better than superficial needle insertion for the amelioration of general psychological distress and experience of climacteric symptoms in women with vasomotor symptoms post-menopausal
Cohen SM, Rousseau ME, Carey BL. Can acupuncture ease the symptoms of menopause? (2003)	To explore the efficacy of acupuncture for menopausal symptom management	Acupuncture holds promise for non-hormonal relief of hot flushes and sleep disturbance.

<p>Wyon, YWijma, K.Nedstrand, E.Hammar, M.A</p> <p>Comparison of acupuncture and oral estradiol treatment of vasomotor symptoms in postmenopausal women. (2004)</p>	<p>To compare the effects of electro-acupuncture with oral estradiol and superficial needle insertion on hot flushes in postmenopausal women'</p>	<p>EA decreased the number of hot flushes significantly over time, but not as much as oestrogen treatment, and not significantly more than SNI.</p>
<p>Nedstrand, E. Wijma, K. Wyon, Y. Hammar, M</p> <p>Vasomotor symptoms decrease in women with breast cancer randomized to treatment with applied relaxation or electro-acupuncture: a preliminary study (2005)</p>	<p>To evaluate the effect of applied relaxation and electro-acupuncture on vasomotor symptoms in women treated for breast cancer.'</p>	<p>Flushes were reduced in both groups including at 6 month follow-up.</p>
<p>Huang MI, Nir Y, Chen B, Schyner R, Manber R.</p> <p>A randomised controlled pilot study of acupuncture for postmenopausal hot flushes: effect on nocturnal hot flashes and sleep quality. (2006)</p>	<p>To assess the effectiveness of acupuncture on postmenopausal nocturnal hot flashes and sleep.</p>	<p>Acupuncture significantly reduced the severity of nocturnal hot flashes compared with placebo (Streitberger needle).</p>
<p>Frisk J, Carlhall S, Kallstrom A-C, Lindh-Anstrand L, Malstrom A, Hammer M.</p> <p>Long-term follow-up of acupuncture and hormone therapy on hot flushes in women with breast cancer: a prospective, randomised, controlled multi-centre trial. (2008)</p>	<p>To evaluate the effects of electro-acupuncture (EA) and hormone therapy (HT) on vasomotor symptoms in women with a history of breast cancer</p>	<p>Electro-acupuncture is a possible treatment of vasomotor symptoms for women with breast cancer and should be further studied for this group of women</p>
<p>Deng G, Vickers AJ, Yeung KS, D'Andrea GM, Xiao H, Heerdt AS, Sugarman S,Troso-Sandoval T, Seidman AD, Hudis CA, Cassileth BR.</p> <p>Randomised Controlled Trial of Acupuncture for treatment of hot flashes in breast cancer patients. (2007)</p>	<p>To determine the immediate and long-term effects of true acupuncture versus sham acupuncture on hot flush frequency in women with breast cancer</p>	<p>A cross-over design with a 6 month follow-up found no significant difference in the two groups but acupuncture treatment for longer could have produced a larger reduction</p>

Fatigue

<p>Kho HG. Eijk RJ. Kapteijns WM. van Egmond J. Acupuncture and transcutaneous stimulation analgesia in comparison with moderate-dose fentanyl anaesthesia in major surgery. (1991)</p>	<p>29 patients underwent retro-peritoneal lymph node dissection, this compared a small dose of anaesthetic and acupuncture and TENS with a larger dose of the same anaesthetic.</p>	<p>Various parameters surrounding post-operative medication and recovery time found no disadvantages of acupuncture in this small patient group</p>
<p>Vickers AJ. Straus DJ. Fearon B. Cassileth BR. Acupuncture for post-chemotherapy fatigue: a phase II study (2004)</p>	<p>To determine whether improvement in post-chemotherapy fatigue following acupuncture treatment is substantial enough to warrant a controlled trial.</p>	<p>Acupuncture is worthy of further study in the treatment of post-chemotherapy fatigue</p>
<p>Harris RE, Tian X, Williams DA. TianTX, Cupps TR, Petzke F, Groner KH, Biswas P, Gracely RH Treatment of fibromyalgia with formula acupuncture: investigation of needle placement, needle stimulation, and treatment frequency. (2005)</p>	<p>'To investigate whether typical acupuncture methods, such as needle placement, needle stimulation and treatment frequency were important factors in fibromyalgia syndrome improvement.' 4 groups: traditional site with traditional needle stimulation, traditional site with no stimulation, non-traditional site with no stimulation, non-traditional site with traditional stimulation.</p>	<p>114 randomised participants although needle insertion led to analgesia and improvement in other somatic symptoms, correct needle location and stimulation were not crucial</p>
<p>Molassiotis A, Sylt P, Diggins H The management of cancer-related fatigue after chemotherapy with acupuncture and acupressure: a randomised controlled trial. (2006)</p>	<p>To assess the effects of acupuncture and acupressure in managing cancer-related fatigue and also to assess feasibility for large RCT</p>	<p>Acupuncture was more effective than acupressure or sham acupressure and the trial methodology is feasible. A longer treatment period is needed to have more sustained results and the author suggests teaching patients to self-needle. 15 in acupuncture group and 32 in other groups.</p>
<p>Martin DP. Sletten CD. Williams BA. Berger IH. Improvement in fibromyalgia symptoms with acupuncture: results of a randomized controlled trial. (2006).</p>	<p>To test the hypothesis that acupuncture improves symptoms of fibromyalgia</p>	<p>50 participants with the acupuncture group significantly improving mostly for fatigue and anxiety.</p>
<p>Insomnia</p>		
<p>Kim Ys, Lee S. H. Jung W. S. Park S. U. Moon S. K. Ko C. N. Cho K. H. Bae H. S.</p>	<p>To explore effects of intradermal acupuncture on insomnia after stroke in 30</p>	<p>Intradermal acupuncture on <i>Shen-Men</i> and <i>Nei-Kuan</i> is a useful treatment for post stroke-onset insomnia.</p>

<p>Intradermal acupuncture on shen-men and nei-kuan acupoints in patients with insomnia after stroke. (2004)</p>	<p>subjects randomised to 2 groups (real or sham acupuncture)</p>	
<p>Spence, D. W, Kayumov, L, Chen, A, Lowe, Jain U, Katzman MA, Shen J, Perelman B, Shapiro CM Acupuncture increases nocturnal melatonin secretion and reduces insomnia and anxiety: a preliminary report. (2004)</p>	<p>To evaluate acupuncture's effects on insomnia and anxiety using objective measures (polysomnographic markers of sleep quality, anxiety scores and melatonin production) on 18 volunteers who suffered insomnia for > 2 years previously and score >50 on anxiety scale.</p>	<p>Found objective changes in a pre-post clinical trial for objective outcome measures reported above.</p>
<p>Depression and Anxiety</p>		
<p>Allen JB, Schnyer RN, Hitt SK. The efficacy of acupuncture in the treatment of major depression in women (1998)</p>	<p>To examine the effectiveness of acupuncture as a treatment for major depression in women</p>	<p>Patients receiving specific acupuncture treatments improved significantly more than those receiving placebo-like non-specific acupuncture treatments. Acupuncture can provide significant symptom relief in depression at rates comparable to those of psychotherapy or pharmacotherapy. The placebo-like non-specific acupuncture treatment was active acupuncture treatment tailored for that individual for a pattern of disharmony other than that related to the individual's depression.</p>
<p>Roschke J, Wolf C, Muller MJ, Wagner P, Mann K, Grozinger M, , Bech S The benefit of whole body acupuncture in major depression. (2000)</p>	<p>To investigate the efficacy of acupuncture in addition to drug treatment in major depression comparing verum acupuncture, placebo acupuncture and control group.</p>	<p>Additional acupuncture improved the course of depression, but no differences between placebo acupuncture and verum acupuncture were detected. (placebo acupuncture was described as acupuncture at non-specific locations). The authors conclude that 'there is no specific effect of needling defined acupuncture points in the treatment of major depression'; but in the discussion section also consider that needling individually according to each patient might produce different results</p>
<p>Paraskeva A, Melemeni G, Petropoulos G, Sifaka</p>	<p>To investigate the effect of acupuncture on</p>	<p>Needling the extra 1 point (Yintang) preoperatively</p>

I, Fassoulaki A. Needling of the extra 1 point decreases BIS values and preoperative anxiety. (2004)	the Bispectral Index (BIS) values and anxiety in 50 patients randomised to 2 groups.	significantly decreases the BIS values compared to the control point, but no difference was found between the two groups for the verbal score scale (for anxiety).
Wayne PM, David EK, Macklin EA, Schnyer RN, Kaptchuk TJ, Parker SW Acupuncture for upper-extremity rehabilitation in chronic stroke: a randomised sham-controlled study. (2005)	To compare the effects of traditional Chinese acupuncture with sham acupuncture on upper-extremity function and QoL in patients with chronic hemiparesis from stroke.	No statistical difference between sham and active treatments, therefore the authors conclude that acupuncture does not improve UE function or QoL in patients with chronic stroke symptoms but acupuncture may help patients with chronic stroke symptoms.
Rorsman I, Johansson B. Can electroacupuncture or transcutaneous nerve stimulation influence cognitive and emotional outcome after stroke? (2006)	To assess the effects of acupuncture combined with electro-acupuncture and transcutaneous electrical nerve stimulation on emotional and cognitive functioning	Although all patients demonstrated cognitive and emotional improvements, the study does not suggest any treatment effects on emotional status or cognitive functioning.
Nausea and Vomiting		
Dundee JW, Ghaly RG, Fitzpatrick KT, Lynch GA, Abram WP Acupuncture to prevent cisplatin-associated vomiting. (1987)	To explore the anti-emetic effect of electro-acupuncture in patients with Cisplatin-associated sickness.	10 inpatients receiving an infusion of chemotherapy had a history of severe sickness found significantly less sickness after each acupuncture treatment
Dundee, J. W., Ghaly, R. G., Fitzpatrick, K. T. J. Randomised comparison of the antiemetic effects of metoclopramide and electro-acupuncture in cancer chemotherapy. (1988)	To compare the effects of an anti-emetic drug and EA on P6 for 20 consecutive patients.	Anti-emetic group twice as sick as acupuncture group but symptoms delayed but thinks anti-emetic is easier to administer
Aglietti L, Roila F, Tonato M, Basurto C, Bracarda S, Picciafuoco M, Ballatori E, Del Favero A. A pilot study of metoclopramide, dexamethasone, diphenhydramine and acupuncture in women treated. (1990)	Usual care compared to usual care plus acupuncture for 22 women plus 22 control	Acupuncture increased protection from nausea and decrease intensity and duration of nausea and vomiting but tricky to use in this setting. Anti-emetic drugs alone produced side-effects such as diarrhoea, and sedation

Shen J, Wenger n, Glaspy J, Albert PS, Choi C, Shekelle PG

Electro-acupuncture for control of myeloablative chemotherapy induced emesis: A randomized controlled trial. (2000)

To compare the effectiveness of EA versus minimal needling and mock electrical stimulation or antiemetic medications alone in controlling emesis among patients undergoing a highly emetogenic chemotherapy regime.

EA more effective than controls or antiemetic therapy alone, (delivered over 5 day period)

Streitberger K, Friedrich-Rusi M, Bardenheuer H, Unnebrink K, Windeler J, Goldschmidt H, Egerer G.

Effect of acupuncture compared with placebo-acupuncture at P6 as additional antiemetic prophylaxis in high dose chemotherapy and autologous peripheral blood stem cell transplantation: a randomized controlled single-blind trial. (2003)

Compare P6 acupuncture with (new non-skin penetrating) placebo acupuncture (this could also have been about validating the new device)

No difference was found between groups. (80 patients randomised to usual care or usual care plus P6 acupuncture).

APPENDIX VII

Vignettes

Acupuncturists

The acupuncturists were local to their area. Both acupuncturists were in their mid-fifties and coincidentally both had previous careers as nurses although this was not known when they were recruited into the study. I had known both acupuncturists for some years prior to the start of this study; I would describe my relationship with them as friendly work colleagues. No doubt if I lived nearer either of them we would socialise to some degree together. They were both my first choice as practitioners in this study and I completely trusted them to work professionally and offer the highest of standards of care.

Diane

Diane qualified as a professional acupuncturist in 1991 and became a member of the BAAC. She was a clinical supervisor between 1995 and 2006 at an esteemed college of acupuncture, and at another University course as an acupuncture clinical supervisor between 2001 and 2003. Diane left the NHS as a senior staff nurse in 1994 to concentrate on her acupuncture practice. She had previously been involved in another large trial of acupuncture and was familiar with the demands research entails. Diane is always well turned out and gives an impression of warmth and calm. She married for the second time having brought up her two children as a single parent, and she recently became a grandmother. During our meetings over the two years of this study she always expressed concern that I was doing too much. We talked about our children, and partners and holidays and what was the latest news from the College we were both associated with. During the course of the study her father had a stroke, she cared for him briefly before he died and this left her unavailable for work for three weeks. It was during these early weeks, along with bad weather that meant that Lindsay and Natasha were unable to get all ten sessions of treatment during the allocated time. During the time of the study Diane got a job at a large newly opened breast cancer support centre thereby rapidly increasing her experience of acupuncture care for women with breast cancer.

Helen

Helen qualified as an acupuncturist in 1996 and became a member of the BAAC. Helen has been a lecturer in Acupuncture from 2000 to 2005 at the same College that Diane and I have both worked at, and is still a clinical supervisor there. Helen has also been a clinical supervisor on the acupuncture courses of two other Universities. In her previous career Helen was a nurse and left the NHS as Area Health Promotions Manager in 1996 to focus on her acupuncture career. Helen comes across as a warm and sincere person, highly professional and keen to do the best job possible. She is approximately the same age as Diane in her mid-fifties with an energetic and healthy aura about her.

Participants (in order of recruitment)

The age range for the women participants was 29 to 75 years and the mean age was 54 years. Nearly all the epidemiological studies in Chapter Two had approximately the same mean age. A key factor in research breast cancer is menopausal status as it seems that chemotherapy and other adjuvant treatment such as Tamoxifen can exacerbate menopausal symptoms such as hot flushes. There were only four women in the study who had not had the menopause; it took a long time to recruit the last participant as it was hoped she would also be pre-menopausal but even though she was 48 years she had become menopausal unusually early. Only one participant was educated to degree level, and two had professional nursing qualifications, all the other participants had no further education and all but one had worked or were working in order to support themselves and their families. For all the women participants which acupuncturist they saw and whether they had a third follow-up interview after the chemotherapy had finished is mentioned at the beginning.

Jane

(acupuncturist: Diane; 3 interviews)

Jane was a mother of three, in her early forties she lived with her partner who is the father of her youngest, a 12 year old boy. Jane has always worked full-time in a demanding job as a senior nurse in the NHS. Jane had a very straight forward way of talking, she let her thoughts and feelings roam freely during the interview. She was one of two participants who has co-morbidity: hypo-thyroid and some chronic joint pain and although she talked of suffering fatigue, her determined nature meant it had not stopped her being active or working. Her middle daughter had been problematic and recently aged 18 had become pregnant with Jane's first grandchild. Jane's fatigue during chemotherapy prevented her from being at the birth which she was very sad about. Jane talked of her family a lot. Her partner was a source of support to her and her mother came to live with her during chemotherapy to help. Jane was nervous of this at first but the experience changed their

relationship for the good. She spent some time in the first interview discussing her family, especially her relationship with her parents and their reaction to her breast cancer. Jane had every intention of returning to work after her diagnosis but was astonished to find she became too emotional. Despite many incidents in her life of stress or poor health – nothing had ever stopped her working before. She relished the time away from work, and was reluctant to go back. She cited this time away as being formative in a shift in lifestyle, namely getting a new kitchen and a puppy and just generally being more relaxed. This emerged during our third interview.

Jane has found the acupuncture very beneficial and she continued to have it after chemotherapy had finished. Here is an extract from Jane's vignette of the first interview, written using her own words:

"I'm fairly well I think, I am quite tired from the surgery. I'm just getting back to doing some basically normal things, without, or trying not to tire myself out too much but I do get quite tired easily anyway. And it's a fight to make myself more active. The diagnosis was a shock. In my line of work it is difficult not to look at cancer and know all the ins and outs, so you have to take every day as it comes. Sometimes I'm weepy sometimes I'm ok. To be told that you have cancer changes the whole of the rest of your life; and to speak with your children about it, and the other people around you - they treat you differently. It changes everything, you have got something that is life threatening."

Lindsay

(Acupuncturist: Diane)

Lindsay, in her early sixties, had two grown-up children who live away and was currently going through an acrimonious divorce. It was for this reason she decided not to tell anyone about her diagnosis because as she said '*he'll dine out on this news*'. She attended the first interview with her new partner, but during the time of the study her relationship ended. She was the only participant who had not worked since having her children. Lindsay had a history of breast cancer and had had a mastectomy 15 years previously but no chemotherapy. She had recently only just grown back her hair having had alopecia and was very upset about the prospective loss of her hair, along with her breast.

Lindsay gave the impression of being tough and determined and did not want to be associated with cancer. She dressed very smartly on both occasions when I met her and had a slightly formal air and despite my efforts it was difficult to change our relating into

something more relaxed and intimate. She had to care for her elderly mother and decided not to tell her either of her diagnosis. Due to bad weather and Diane being away, she had only seven sessions of acupuncture. A new experience for her was to discover friendship in hospital with three other women when having a mastectomy, she continued to meet up with them and enjoyed being older and more experienced having had breast cancer before. She felt that she coped a lot better than they did with the chemotherapy and that gave her some strength and confidence.

During the second interview, I asked Lindsay if she felt the experience had changed her and she had great difficulty articulating anything:

“(sighs) it’s very hard to explain, I don’t know. You just, it just does make you feel different as a person and I can’t really explain this. Umm... (pause) I don’t know how to answer that one in a way. (pause)... it’s just an experience I suppose...”

Anne

(Acupuncturist: Diane)

Anne was 52 and lived alone. She had one grown up daughter who was very busy and although she made several appearances at the beginning, soon dropped off her support. Anne also had a partner who lived nearby who was very upset about the diagnosis. She remonstrated with him when she found him crying. Her mother and auntie were supportive and took her away on a surprise caravan weekend during the chemotherapy. Anne complained that everyone was making too much fuss and was not able to understand why everyone was so upset. She had trauma from her past, her brother had been murdered and she herself had been the victim of domestic violence. When her brother died she had become severely depressed and suicidal, she had a great fear of her depression returning and was very grateful for the acupuncture because she believed it helped stave off her depression. She really believed the acupuncture helped her a lot, and loved talking with Diane. She had severe night-sweats, being unable to sleep most of the night, and she felt the acupuncture had helped keep them under control.

She became isolated during the treatment because of her fear of infection and also to avoid talking about or hearing about cancer. She really disliked waiting in the waiting room for this reason. Anne loved her home and talked of how having the acupuncture always gave her the energy to have a big clean and tidy. She was the only participant who had a positive view of counselling, but she chose not to have any other support aside from the acupuncture during the study. She was determined to have more holidays once her treatment was over, and become more focused on herself and her needs.

Anne verbally grappled in the first interview with the idea that she had cancer and here is an extract from her vignette written in her own words:

“Both my partner and my daughter get upset and worry, but I like to do these things on my own, I like my space, I’m independent and I do things myself. Because the way I feel in myself, I feel fine. You know, I feel ok. I’m telling you the truth about this. Do I really need treatment, do I really need to have tablets, but obviously the doctors know better than me don’t they?”

Natasha

(Acupuncturist: Diane)

Natasha was the youngest participant at 29 years. She lived with her parents and taught music in schools but was on low income. During the chemotherapy she was diagnosed with diabetes and briefly was hospitalised while her blood sugar was stabilised and there she got a chest infection. She had been using the cold-cap to keep her hair but while hospitalised to stabilise her glucose level was administered chemotherapy without it and consequently lost some of her hair. She bravely raised money for charity by having her head shaved in her local pub. She talked of the diagnosis as being like a train crash and was aware that her mother was probably much more upset than she was letting on. She found her younger brother crying and that upset her too. She just wanted everyone to behave as if nothing has happened. She felt very ill at times during the chemotherapy but had difficulty articulating what it all meant to her. She really enjoyed the contact with Diane and felt benefit from the acupuncture but was not able to attend all the appointments due to Diane being away. Her father had a severe stroke during her treatment which gave her an extra resonance with Diane. Here is Natasha talking about the acupuncture and Diane

“It was just what it helped me with, I suppose the sleep and the anxiety and stuff like that, that was a big plus for me. Also you build a relationship up, umm... and you just feel at home if you like.... Because it were just like talking to a friend. It was just.... It wasn’t like you were going to the doctors or you were going to see a consultant if you like, to see whatever. It was just... like going to see a friend, but at the same time she’s helping you.”

Lena

(Acupuncturist: Helen; 3 interviews)

Lena was in her mid-fifties and lived with her husband and three grown-up children. She had worked full-time night-shifts in the NHS as an acute psychiatric nurse for 25 years and

had been planning to apply for early retirement when she was diagnosed. She had had very little time off work even when she had her children, so she has worked very hard all her life. She was a practising Christian and her faith helped her keep positive at the beginning. She found the loss of her breast and hair difficult to come to terms with and it affected the intimacy in her relationship as well as her confidence.

Lena was able to articulate at each stage a change in her outlook, at the beginning she was very positive about her diagnosis, which led to an additional question in the topic guide but by the second session she was really suffering and was very glad of the acupuncture. At the third interview she knew she was not returning to work and was relaxing into a new lifestyle. She had a great resistance to dependence and, the fatigue, because at times it kept her in bed for several days, was very difficult for her.

Lena had similar experiences to Jane in that she relished the time away from work and was granted retirement while away which meant she never returned. She felt intense happiness at having time for herself and her family including her dependent elderly father. Lena found the acupuncture care very beneficial, and wished she could have had it all the way through chemotherapy. Unlike Jane, Lynne and Julie, she was not able to access free acupuncture care once she had had ten sessions. Like Anne she had a fear of becoming depressed and of not coping. She felt much more ill when the acupuncture stopped. Here is an extract from the third interview, she has just got upset about remembering the diagnosis which had happened one year previously

“...well I feel well before the diagnosis, I was feeling ok, I looked ok, feeling ok, and I thought well it’s deceiving you know? How somebody looks and how they feel do don’t know what is going on deep on the inside sort of thing yeah, so that made me, with the diagnosis that made me sort of more – try to be more in tune and be more aware of my body I would say and not take it for granted. I’m always thinking now you know I wonder what is going – at the back of my brain, I wonder what is going on inside my body you know where I can’t see or feel. Because as I said before I didn’t realise it you know?”

Mary

(Acupuncturist: Helen; 3 interviews)

Mary had just celebrated her sixtieth birthday when she was diagnosed. She lived with her husband whom she described as very supportive and had two grown-up sons. Her close friends live far away. She disliked any association with cancer and avoided talking with anyone in the waiting room. At home no one discussed the cancer either and as a family they did not talk about feelings. She very much enjoyed wearing a wig because she said it

was better than her normal hair. She never returned to work and consequently never experienced closure regarding her working life and retirement; she reported this as like living 'in limbo'. While she had chemotherapy her father's dementia increased and he had to be put in a home which upset her as she felt she had failed to take proper care of him. Mary had a very close friend die from ovarian cancer three years before.

Mary was the only participant who did not become emotional during the interviews and she reported that she had not cried once about it which she found very strange. Mary greatly enjoyed her sessions with Helen, but she found it hard to relate to how acupuncture could work. She did report that she was glad to have received the acupuncture and would say yes to it again. During her third interview she said she would only take on board properly that she had had cancer if she had a recurrence. She adapted to the diagnosis by not changing anything. Despite this she did find herself thinking about it, especially because her sleep was poor or she would find herself reading the obituaries in papers but she was unable to talk to anyone about her fears. She very much enjoyed talking with Helen.

Mary describes the moment of diagnosis and only when she came out of the room did she get close to weeping:

"But I thought I'm not going to stand in a public corridor weeping and so I sort of took control of myself and didn't cry and then haven't really since then."

Kathy

(Acupuncturist: Diane)

Kathy was in her mid-forties and lived with her partner and 20 year-old daughter. She worked full-time and although she did not have too many physical symptoms she did suffer anxiety initially and some fatigue towards the end of her treatment. She was very glad to be away from work and was negotiating with her office being able to work more from home. Kathy was the only participant to describe her confusion as to why she had got cancer and like Lindsay felt angry that she had. She was one of the more reflective of the participants. Her partner came with her to every hospital appointment, by co-incidence he was signed off work for several months with a knee injury. Kathy was glad to have his company.

Kathy really enjoyed seeing Diane, and found the whole experience very supportive. She was articulate and had a good sense of humour. Her anxiety disappeared after the first session of acupuncture which she found astonishing. During chemotherapy she talked of becoming depressed but came out of it after a while. She did have one session with a counsellor but did not seek any more as she said it was not for her. She played down her

symptoms by for instance suggesting that her fatigue was *'being lazy'*. Kathy described at the second interview one of the major experiences for her

"But then when you are away from work, and all your routine is hospital visits it changes completely and that is all you have got to focus on is treatment, hospital visits you know, and then there is no structure to your day. And I think that is probably the low point and, and because what I realised was I mean I'm 47 now and I have never actually been out of control, never been out of control in my life...so I'd always had control over everything, and then it had been taken away. And I didn't have the answers, and there was nothing that I could do on my own to make this any better."

Lynne

(Acupuncturist: Diane; 3 interviews)

Lynne was 42 and lived with her husband and three children aged 11 to 16 years. She worked full-time and was the only participant to have been educated to degree level. Just before diagnosis she had been promoted over the head of a colleague and felt enormous pressure to carry on working during chemotherapy. She eventually stopped when her employer and GP advised her to because she was so emotional. She was the only participant to receive anti-depressants at the point of diagnosis due to her emotionality. She never talked about her husband apart from mentioning that he did a bit of housework. She received a lot of support from her friends and it was to them that she expressed her emotions rather than at home. She reflected a lot on her situation and was determined to let it not affect her children too much. Unlike all the other participants, she openly talked about her diagnosis and told all and sundry about it. She said it helped her to make it real. Lynne knew of three other women with breast cancer, one of whom died while she was receiving treatment. Like all the other women in the study so far, she gave the impression of being strong and independent.

Lynne did not suffer very much physically from the treatment, and kept her hair because she was able to use the cold-cap treatment. She found the acupuncture tremendously supportive and continued to have it until after chemotherapy had finished. She had been able to return to work, and unlike the other participants was really glad to. She was a contrasting case for several reasons – her physical reaction to the chemotherapy was milder; she was clearly happy to talk about cancer and that helped her to process it; she was very happy to be returning to work. She is a great advocate of the acupuncture and really believed it had to keep her well and to keep her calm and relaxed. She was an interesting case because she was very positive and vocal about her diagnosis but also had underlying

anxiety. An extract from her third interview is provided: having spent time describing her life now having returned to normal she expresses her hidden anxiety and rationalises this by saying her vigilance makes her a survivor.

“I mean for example, when I went to see my oncologist, out of the blue she said have you got a thyroid problem and I said not that I know of and she said well I want you to go and see your GP I think you’ve got a goitre and she must have seen my face, and she said don’t worry about it. And I thought you can’t say something like that to somebody who has got cancer, because they do worry about it. So I have been to my GP, he agreed it was enlarged, so I have had blood tests and I have an ultra sound today actually, so ... of course.. I’m thinking that it is enlarged because I have got thyroid cancer. Whereas if I haven’t had cancer before I would have just thought oh it’s my – that’s why I’m overweight it’s my gland I’ve got a thyroid problem.... But err... I mean I have got – every kind of ache and thing I do know I’m aware that I’m thinking it is probably cancer but then another voice in my head says ah but you know.”

Vera

(Acupuncturist: Helen)

Vera was 67 years old and she lived alone; her daughter lived in a nearby town and her son lived several hours drive away. She had worked hard all her life, and nursed her husband through a long illness until his death. Vera had given her beloved dogs to her son to look after when she was diagnosed because she feared not coping. Vera had other health problems including diabetes, heart disease and chronic neck pain from an injury and took a range of medication. She really enjoyed her treatments with Helen, and felt the acupuncture helped enormously. While she was receiving treatment she stopped her pain medication and had a better appetite and ate healthily and felt much better. Once her acupuncture treatment was finished, she had a change of chemotherapy and reacted very badly to one of the new drugs. This made her very ill and about two weeks later she suffered a stroke. She did not finish the course of chemotherapy and was the only participant whose health was seriously affected by treatment. Her daughter had to move in with her to care for her and Vera found this loss of independence very difficult even though she got on very well with her daughter. Her second interview with me took place two days after she had had her stroke but she was wrongly diagnosed at that point as having Bell’s palsy, after our interview she was admitted to hospital where she received a different diagnosis.

Vera was a large woman, appearing to me strong and independent like the others and she called a spade a spade. It was a real joy to interview her the first time and very sad to see

her so transformed later. She had had her share of life's adversity and despite her co-morbidity before the diagnosis went on lots of holidays and was close to her family. She was a strong advocate of the acupuncture treatment, and although she '*had a laugh*' with Helen, as far as she was concerned the benefit she got was purely from the acupuncture. This extract has Vera talking in the first interview about her diagnosis and her children's reaction to it.

"I fight back. I was talking to my sister the other day and she said you're the only one. And I said I know. I said I make up for everybody else. I'm not frightened about it – or anything like that no. And my daughter and son, they are batting jokes at me, I know they worried, but err... they are making jokes of it.... Well, I'm glad in a way, that they can be like that, not sitting about and moping and as they said and I said what will be will be. There is nothing you can do about it. Well there's certain treatments you can do about it but it's no good sitting down and moping and saying oh I'm not going to be here for a long while, you know. Just get on with it."

Julie

(Acupuncturist: Diane)

Julie was 62 and had been retired a year at diagnosis. She lived with her husband whom she described as enormously supportive. She had two grown-up sons and a mother with whom she had a difficult relationship. Julie was tall, attractive and softly spoken. She dressed well and talked about her appearance being very important to her. Like most other participants, she vocalised several times her desire to be independent. Of all the participants she talked more about her husband's support and how invaluable it was to her. Once she was diagnosed she suffered from anxiety as well as fatigue and muscle stiffness. She had had a mastectomy and reconstruction and was told she did not need chemotherapy. Within weeks though she discovered a second lump and this destroyed her confidence in her body and in the diagnosis as she could not understand how it could grow so quickly.

Julie seemed quite a self-contained and private person but she really enjoyed talking with Diane and appreciated both Diane's professionalism but also the friendly nature of the conversation. She described herself as someone who did not have close friendships; but unlike Lindsay she was very happy to talk and reflected on her experiences quite openly. She felt the acupuncture really helped with her anxiety and with her fatigue and wished it had lasted for the duration of the chemotherapy. Her fatigue seemed similar to Lena's, Mary's and Jane's, it was associated with feeling unwell and came on suddenly enough to

disconcert her. She gave a vivid description of being taken ill on a shopping trip and had not been out on her own since. Like several other participants she had not told her husband that she had an aggressive form of cancer because she did not want to worry him. She did not like to complain and felt embarrassed about describing her long list of symptoms, of which fatigue and anxiety were the main ones. This extract is from the second interview; she is missing the acupuncture.

“But it has got harder, the chemotherapy I’ve got to say, as much as you can fight, you feel yourself every little thing. I mean this arm is all sore now, with the umm... chemotherapy and all my veins and everything. I’m stiffening up here because I’m not doing my exercises properly; I could do them this morning before coming out. My toenails are all horrible... Little things like your sore mouth, which I have controlled with mouthwash from the hospital but I have had it, quite bad, my gullet and you think.... but the soreness was really bad once but I’ve controlled that but if I swallow too quickly it hurts, you know what I mean, I know that will all get better, tiny little things – eyesight, dry eyes, obviously your hair loss, which is – that is the least of my worries, but silly little niggly things that sound like your complaining they all build up, especially when you are so healthy to start with. Am I ever going to be normal again?”

Lilly

(Acupuncturist: Diane)

Lilly was 75 at diagnosis and lived alone - her husband died many years before. She had two grown up daughters who were supportive and loving. No-one in the family had much money. Lilly had met her husband during the war and moved to England with him; she seemed to have friends and a good social life. Her grandson had told her she was going to live until she was 109 years and this response to her diagnosis delighted her. Lilly took a lot of pride in her appearance and found the effects of chemotherapy making her ‘tired and ugly’ difficult to bear. She found much benefit in seeing Diane and felt the acupuncture really helped her. Like several other participants she was upset when the acupuncture stopped but could not afford to pay for more. As with nearly all other participants seeing a therapist for supportive care involving a therapeutic relationship was a completely new experience. Lilly reported that for many years she had suffered from anxiety and worry, but with the diagnosis she felt extraordinarily calm; after a while her anxiety started to return but she found the acupuncture both energising and calming. Lilly was very sprightly in the first interview and wondered at her calmness but she suffered with the chemotherapy

“My confidence – yeah the chemo has brought me down a lot, not just by strength, I don’t like to see myself in the mirror I think I look horrible. Just, I try to do my best, you know, like sometimes I just prepare little things in the kitchen, and then I am tired, I’ve got to go and lie down. I try to motivate myself, because if I am not, I just lay down on the bed or the settee and then I don’t fall asleep really, or I do a little bit and then I lie down.”

Brenda

(Acupuncturist: Helen)

Brenda was 51 and lived with her partner. She had grown-up children and looked after her grandchildren regularly as well as working part-time. Brenda had an extensive family network, all of whom lived within a few streets of each other. She appeared more comfortable than many of the other participants with her diagnosis and her family regularly popped in to see her and do errands and jobs for her and tell her directly they loved her. Her part-time work was for her son’s firm, and she reported being able to continue to do bits of this while receiving treatment although she was not able to look after her grandchildren. Even though we seemed to establish a good rapport it felt as if Brenda had less of a need to talk or was unused to talking and reflecting compared to the other women. Helen also reported this about Brenda.

Brenda had a needle phobia, and found receiving the acupuncture more of an ordeal than the other participants although she found it helpful and relaxing. This may explain why she did not complete her course of treatment, she had seven sessions altogether. She also reported not needing to chat much with Helen, because she has so much support from her sisters and other family members, one of whom had survived breast cancer years previously. During her chemotherapy she went away with her girlfriends as she always did every year; it was during this holiday that she realised how affected she was because she struggled to keep up with them in terms of energy and found she was not able to drink much alcohol. She did have her down moments but said she always pulled herself back up.

“but like I mentioned before, my best friend Sheila died two years ago of cancer, she was the strongest person I ever knew, she was a wonderful, wonderful woman and she was a really strong person and she is up there looking down on me, saying Brenda, don’t be silly, get on with it and all this, I really do... She has helped me through it I know she has.”

Liz

(Acupuncturist: Helen; 3 interviews)

Liz aged 61 lived with her partner of ten years having been widowed when her two children were small. Liz's partner had just recovered from prostate cancer when she was diagnosed. Always having been 'in charge' it was difficult for Liz to adjust to being the one who needed support. Liz worked part-time and loved her job which was head of reception for a large company, a sociable job. It was a difficult decision for her to not return to work but she felt that too much had changed and too much time had gone by for her to resume her old working life. She adored her grandchildren and was stoic when she told me during the third interview that her son had emigrated to Australia along with his two sons. Her daughter, a nurse had children too and Liz shared with me a beautiful card her daughter had written to her expressing her love and desire to support her. Liz found her hair loss very difficult to bear, and did not feel confident with her wig which meant she limited her social life. She took great pride in her appearance and found it very disconcerting seeing herself in the mirror without hair. She was unable to recognise herself. Like several other participants she was very careful not to let her partner see her without her wig on or a head scarf even at night. In thinking of this, Liz's hair had not returned by the third interview which was eight months after the start of chemotherapy, which is a long time to make efforts to keep hidden. She was one of only two participants (Jane is the other) receiving Herceptin so she continued to return to hospital every three weeks; and plans for visiting Australia had to wait.

Liz found seeing Helen very supportive; she appreciated being able to talk openly and provided numerous examples of feeling better after acupuncture treatment. She was also glad to find she could cope on her own when the acupuncture finished, and felt this was due to the previous acupuncture treatment helping her feel stronger and giving her confidence. Here Liz is describing the diagnosis within the first few minutes of the first interview

"Everything seemed to take a long time, you know 'two weeks' 'two weeks'; and I'm thinking umm... and then I went, my daughter came with me for the results and they said yes its cancer and I am gob smacked because I work, I'm fit, I'm well I've no symptoms I've no lumps and to be told that you have got this sort of life threatening thing inside you it was awful. Yeah, I was devastated. Yeah.... So... that is how I found out that I had got it (weeping). And then obviously, they all take - it just takes over your life and yeah...."

Sue

(Acupuncturist: Helen; 3 interviews)

Sue was 48 at diagnosis. Sue had a terrible time during the period of the study with a combination of factors outside of her control. She was in the middle of a bitter divorce having discovered her husband had been having an affair for several years. She described

coming under pressure from her two sons aged 18 and 21 to give up any financial claims. Hearing of her diagnosis did not appear to make her husband behave in any way supportively. She was supported by her sister and her mum. Her sister took over the running of her business, a local shop and delicatessen while she had chemotherapy. Her business was very sociable with lots of local customers. She vividly described standing in the corner where she made sandwiches as she got a phone call confirming her diagnosis. She was unable to return until after her chemotherapy had finished. During chemotherapy she had to pack up the family home of 20 years and sell it moving into much smaller accommodation near her sister. At this time her older son also attempted suicide due to the emotional turmoil of his parents' divorce. She had a new partner she met before diagnosis, whose sister had died from breast cancer. Sue knew two other women with breast cancer when she was diagnosed, one of whom died while she was having chemotherapy. In the space between the second and third interview, Sue's sister was diagnosed with lung cancer and died. Sue had to return to her business to keep it going while she sold it which not only had strong associations for her with her own shock at diagnosis, but meant that regular customers were always asking her how she was, or asking her where her sister was, and Sue would have to explain. It is hard to describe how much suffering emanated from Sue as she described this. She had no choice though because she had to sell her business or be riddled with debt.

Sue found the acupuncture very supportive. She felt it helped her with physical symptoms but also kept her emotionally stable. She described to me that she had a strong urge to die in the first weeks after her diagnosis. She was so fearful of the acupuncture ending after ten sessions that MacMillan paid for her to continue until after the end of her radiotherapy. Her life at this point became chaotic with the diagnosis and death of her sister. Sue really suffered with the loss of her breast and struggled to accept her new appearance. She had to find enormous strength to cope for her niece at the death of her sister. She herself was convinced she was going to die, and her partner appeared to be desperately trying to support her and convince her that she was beautiful and that she would live. Sue told me about the death of her sister within the first two minutes of the third interview

"She just went downhill so quick, she had no fight in her whatsoever Sarah, and she – she gave up, and she's got a daughter and a son, he has just gone to Afghanistan, and two of his men have gone down, and my niece well she is like the daughter that I never had. So my sister said to me that I can go knowing that you will look after our Kirsty, so I said I always will look after. So she is in the process of being rehomed; but she can't stay on her own, she is right – you know because Kirsty found her. Well she rang me, I had finished at the shop and then she rang me – well obviously Jill wasn't too well and I

went down every night, and then we went one night on my own, and she was saying oh stay a bit longer auntie Sue, you know, and I said no I've got to go because I had to work in the morning and anyway and she never says that. Anyway Saturday morning I got back home and the phone rang and she was screaming poor kid, and saying Sue she's died, she's died, well I couldn't get there quick enough – anyway, bless her, she was just laid on bed but she had died. And I can't believe this – 51, 51 year old."