

SELF-MANAGEMENT  
STRATEGIES OF CANCER  
SURVIVORS: WHO DOES WHAT  
AND WHY? A MIXED METHODS  
STUDY

by

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## **Abstract**

This thesis examined self-management (SM) strategies of cancer survivors from pre-diagnosis, through treatment and into survivorship. A healthcare definition of SM as a lifestyle modifying behaviour potentially impacting on cancer survivors' health, wellbeing and quality of life (QoL) was given. Due to a lack of existing literature, a systematic review and meta-analyses investigating whether complementary and alternative medicine (CAM) improves cancer survivors' QoL was undertaken, finding moderate to poor quality evidence of this.

A mixed methods study explored SM patterns over time. The questionnaire study examined the prevalence and distribution of SM patterns, finding SM uptake was highest in survivorship. Subgroup analyses found SM uptake was highest in breast cancer and chemotherapy respondents, whilst correlation analysis revealed significant associations between SM uptake and both QoL and internal health locus of control (HLC), but none between SM uptake and work ability.

The interview study explored how and why cancer survivors made decisions about incorporating SM practices into their daily lives. The concept of normality in survivorship emerged, with cancer survivors assembling a new health-related normality to adapt to their new lives post-cancer. A theoretical framework proposed that cancer survivors use SM as a supportive mechanism to attain their new health-related normality.

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## **Contributorship Statement**

All the Chapters in this thesis are entirely the product of my own work, with help and guidance from my supervisors Dr Nicola Gale, Prof. Sheila Greenfield, Dr Taina Taskila, Dr Inigo Tolosa and Mr Roger Holder.

The systematic review undertaken in Chapter 3 was undertaken primarily by myself, with contributions to the conduct of the review and manuscript being undertaken by Dr Yen-Fu Chen, Research Fellow in Systematic Review and Quality Improvement (Primary Care Clinical Sciences, University of Birmingham), as well as from three of my supervisors, Dr Taina Taskila, Dr Nicola Gale and Prof. Sheila Greenfield. The mixed methods study was designed primarily by myself with advice from two of my supervisors, Dr Nicola Gale and Dr Taina Taskila. The questionnaire data reported on in Chapters 4 and 5 were data checked by Anu Krishna.

# **Table of Contents**

<b>CHAPTER 1. INTRODUCTION.....</b>	<b>p1</b>
1.1 Introduction to Chapter.....	p2
1.2 Thesis Aims and Objectives.....	p3
1.3 Rationale for Using Mixed Methods.....	p4
1.4 Practice and Stakeholder Engagement and User Involvement Throughout the Research Process.....	p13
1.5 Thesis Structure.....	p16
1.6 Conclusion.....	p19
1.7 Chapter Summary.....	p20
<b>CHAPTER 2. BACKGROUND TO THE STUDY.....</b>	<b>p21</b>
2.1 Introduction to Chapter.....	p22
2.2 SM and Cancer Survivorship.....	p22
2.3 Integrating SM Practices with Biomedicine.....	p27
2.4 Defining SM.....	p34
2.5 The Social Context of SM and Chronic Illness.....	p40
2.6 SM in a Policy Context.....	p42
2.7 Categories of SM.....	p44
2.8 Conclusion.....	p44
2.9 Chapter Summary.....	p45
<b>CHAPTER 3. THE EFFECT OF COMPLEMENTARY AND ALTERNATIVE MEDICINE ON THE QUALITY OF LIFE OF CANCER SURVIVORS: A SYSTEMATIC REVIEW AND META-ANALYSES.....</b>	<b>p47</b>

3.1	Introduction to Chapter.....	p48
3.2	Background.....	p49
3.3	Methods.....	p51
3.3.1	Criteria for Considering Studies for this Review.....	p51
3.3.2	Search Methods for Identification of Studies.....	p53
3.3.3	Selection of Studies.....	p54
3.3.4	Data Extraction and Assessment of Risk of Bias.....	p56
3.3.5	Missing Data.....	p56
3.3.6	Data Synthesis.....	p56
3.4	Results.....	p57
3.4.1	Characteristics of Included Studies.....	p57
3.4.2	Risk of Bias in Included Studies.....	p58
3.4.3	Description of Interventions and Controls.....	p58
3.4.4	Effectiveness of CAM Interventions of QoL.....	p64
3.5	Discussion.....	p67
3.5.1	Summary of Main Findings.....	p67
3.5.2	Evidence for Individual CAM.....	p74
3.5.3	Limitations of this Review.....	p75
3.6	Conclusion.....	p76

3.7 Chapter Summary.....p77

**CHAPTER 4. THE PREVALENCE AND DISTRIBUTION OF SELF-MANAGEMENT PRACTICES IN CANCER SURVIVORS FROM PRE-DIAGNOSIS, THROUGH TREATMENT AND INTO SURVIVORSHIP.....p78**

4.1 Introduction to Chapter.....p79

4.2 Background.....p79

4.3 Methods.....p82

4.3.1 Cross-Sectional Studies.....p82

4.3.2 Ethics.....p83

4.3.3 Setting, Access and Data Collection.....p85

4.3.4 Questionnaire Design.....p89

4.3.5 Sample Size.....p97

4.3.6 Statistical Analysis.....p99

4.4 Results.....p105

4.4.1 Demographics.....p105

4.4.2 Prevalence and Distribution of SM Scores.....p107

4.4.3 Demographic Differences between SM Categories.....108

4.4.4 Variations Within CAM.....p109

4.5 Discussion.....p110

4.5.1	Strengths and Limitations.....	p114
4.5.2	Practice and Policy Implications.....	p115
4.6	Conclusion.....	p115
4.7	Chapter Summary.....	p116

**CHAPTER 5. ASSOCIATIONS BETWEEN SELF-MANAGEMENT UPTAKE AND QUALITY OF LIFE, INTERNAL HEALTH LOCUS OF CONTROL AND ABILITY TO WORK.....p117**

5.1	Introduction to Chapter.....	p118
5.2	Background.....	p119
5.2.1	Quality of Life.....	p119
5.2.2	Health Locus of Control.....	p121
5.2.3	Ability to Work.....	p123
5.3	Aims and Objectives.....	p124
5.4	Methods.....	p125
5.5	Results.....	p126
5.5.1	EQ-VAS and EQ-5D and Their Relation to SM Uptake.....	p126
5.5.2	Internal HLC and its Relation to SM Uptake.....	p127
5.5.3	Work Ability Scores and SM Uptake.....	p128
5.6	Discussion.....	p128

5.6.1	Strengths and Limitations.....	p132
5.6.2	Practice and Policy Implications.....	p133
5.7	Conclusion.....	p134
5.8	Chapter Summary.....	p134

**CHAPTER 6. INTERVIEW STUDY METHODOLOGY AND AN OVERVIEW OF THE MAIN THEMES RELATING TO SELF-MANAGEMENT UPTAKE IN CANCER SURVIVORS OVER TIME.....p136**

6.1	Introduction to Chapter.....	p137
6.2	Methods.....	p138
6.2.1	Thematic Analysis.....	p138
6.2.2	Sampling, Access and Data Collection.....	p143
6.2.3	Data Analysis.....	p146
6.3	Findings.....	p150
6.3.1	Themes emerging from the Interviews around SM Use.....	p150
6.3.2	SM Use Pre-Diagnosis.....	p150
6.3.3	SM Use during Treatment.....	p155
6.3.4	SM Use Post-Cancer.....	p170
6.4	Discussion.....	p180
6.4.1	Strengths and Limitations.....	p183

6.5	Conclusion.....	p185
6.6	Chapter Summary.....	p185

**CHAPTER 7. THE ROLE OF SELF-MANAGEMENT IN CREATING A NEW,  
POST-CANCER.....p187**

7.1	Introduction to Chapter.....	p188
7.2	Background: Normality in Chronic Illness.....	p189
7.3	Findings.....	p193
7.3.1	Overview of Findings.....	p193
7.3.2	Changes in Normality Pre-Diagnosis and Treatment.....	p194
7.3.3	SM and the Emergence of a ‘New’ Health-Related Normality in Survivorship.....	p199
7.3.3.1	The Reassessment of Normality.....	p199
7.3.3.2	The Fight to Maintain Normality.....	p203
7.3.3.3	Maintaining the Appearance of Normality.....	p205
7.3.4	Comparing Old and New Normalities.....	p210
7.3.5	A Model of SM and Health-Related Normality in Cancer Survivorship.....	p214
7.3.6	Strengths and Limitations.....	p222
7.3.7	Practice and Policy Implications.....	p224
7.3.8	Areas for Future Research.....	p225

7.4	Conclusion.....	p227
7.5	Chapter Summary.....	p227
<b>CHAPTER 8. DISCUSSION AND CONCLUSION.....</b>		<b>p229</b>
8.1	Introduction to Chapter.....	p230
8.2	Overview of Findings.....	p231
8.2.1	Patterns of SM Over Time.....	p231
8.2.2	Associations between SM and QoL, Internal HLC and Ability to Work.....	p232
8.2.3	Motivations and Constraints for SM Use over Time.....	p234
8.2.4	The Role of SM and the Concept of Normality.....	p235
8.3	Contribution to the Literature.....	p236
8.4	Contribution to Methodology, Theory and Practice.....	p240
8.5	Strengths and Limitations.....	p247
8.6	Future Research Opportunities.....	p252
8.7	Conclusion.....	p260
8.8	Chapter Summary.....	p262
<b>LIST OF REFERENCES.....</b>		<b>p263</b>
<b>APPENDICES.....</b>		<b>p281</b>

Appendix 1	Reflections on Specialist Role as Research Support Nurse in a Breast Oncology Clinic.....	p281
Appendix 2	Complementary Therapies and Their Effect on Quality of Life - Data Extraction Form.....	p289
Appendix 3	Questionnaire Survey Used in Phase 1 Study.....	p293
Appendix 4	Letter to Consultants to Enable Access to Study Participants.....	p306
Appendix 5	Invitation Letter to Participate in Study.....	p308
Appendix 6	Information Sheet for Phase 1 Study.....	p309
Appendix 7	ICD-10 Codes for Inclusion in Study.....	p312
Appendix 8	Reminder Letter.....	p331
Appendix 9	Study Feedback Letter.....	p333
Appendix 10	Information Sheet for Phase 2 Study.....	p335
Appendix 11	Interview Topic Guide.....	p339
Appendix 12	Consent form for Phase 2 Study.....	p349
Appendix 13	Snapshot of Framework Analysis Matrix Spreadsheet.....	p340

## **LIST OF ILLUSTRATIONS**

Figure 2.1 Risk Stratified Model of Care.....	p26
Figure 3.1 Flow of Information through the Different Stages of the Systematic Review.....	p55
Figure 3.2 Changes from Baseline in Overall QoL at Three Months between Cancer Survivors Receiving CAM Intervention and Control.....	p70
Figure 3.3 Changes from Baseline in Overall QoL at Six Months between Cancer Survivors Receiving CAM Intervention and Control.....	p71
Figure 3.4 Changes from Baseline in Physical QoL at Three Months between Cancer Survivors Receiving CAM Intervention and Control.....	p72
Figure 3.5 Changes from Baseline in Mental QoL at Three Months between Cancer Survivors Receiving CAM Intervention and Control.....	p73
Figure 4.1 Bar Chart Showing Respondents Mean Uptake across the Six Categories of SM.....	p108
Figure 5.1 Internal and External HLC.....	p122
Figure 7.1 SM Practices Used by Participants to Achieve Health-Related Normality.....	p221

## **LIST OF TABLES**

Table 1.1	To Show How Qualitative Methods Can Be Used Before and After Cross-Sectional Studies.....	p9
Table 3.1	Characteristics of RCTs Included in the Review.....	p60
Table 3.2	Risk of Bias for Studies Included in the Systematic Review.....	p62
Table 3.3	Observed Effects of the Different CAM Interventions on QoL.....	p68
Table 4.1:	One Year Survival Estimates for the Most Commonly Diagnosed UK Cancers From 2004-08.....	p88
Table 4.2:	Listed SM Practices in the SM Questionnaire Categories.....	p91
Table 4.3:	Scores of the Independent Variable Measurement Tools When Split into Quintiles.....	p104
Table 4.4:	Demographic Characteristics of Respondents.....	p106
Table 4.5:	Demographic Differences between SM Categories.....	p110
Table 6.1	Categories and Codes Included in the Qualitative Analytical Framework.....	p153

**LIST OF ABBREVIATIONS**

CAM - Complementary and Alternative Medicine

CBT – Cognitive Behavioural Therapy

EORTC - European Organisation for Research and Treatment of Cancer

EQ-5D – EuroQoL 5D Descriptive System

EQ-5D-3L – EuroQoL 5D-3L

EQ-VAS –EuroQoL Visual Analogue Scale

FACT B - Functional Assessment of General Health - Breast

FACT G - Functional Assessment of General - General

GSE – General Self-Efficacy

HLC – Health Locus of Control

KS – Kolmogorov-Smirnov

LGFB – Look Good Feel Better

MBSR - Mindfulness Based Stress Reduction

MHLC - Multidimensional Health Locus of Control

NCSI - National Cancer Survivorship Initiative

NCCAM – National Centre for Complementary and Alternative Medicine

NHS – National Health Service

## SM Strategies for Cancer Survivors: Who Does What and Why?

QoL - Quality of Life

RCT(s) – Randomised Controlled Trial(s)

SC – Self-Care

SD - Standard Deviation

SF-36 – Short Form 36

SM – Self-Management

UHB – University Hospitals Birmingham

UK – United Kingdom

WAI – Work Ability Index

WBRT – Whole Brain Radiation Therapy

WMCIU - West Midlands Cancer Intelligence Unit

# CHAPTER 1.

## INTRODUCTION

## **1.1 Introduction to Chapter**

This thesis reports on the findings from a study examining the use of self-management (SM) practices of cancer survivors. It examines the prevalence and distribution of SM practices over time as well as exploring how and why cancer survivors make decisions around whether or not to incorporate certain SM practices into their everyday lives. A mixed methods study design has been used to undertake the research, comprising two phases. Phase 1 consists of a quantitative survey study gathering data on patterns of SM uptake in cancer survivors from pre-diagnosis, through treatment and into survivorship. It also collects information relating to cancer survivors' quality of life (QoL), health locus of control (HLC) and ability to work. This informs the phase 2 study as any SM patterns and associations identified in phase 1 can be used as a basis for exploring reasons for how and why cancer survivors make sense of their decision-making around the use of SM in their daily lives.

This chapter begins by outlining the aims of the thesis. Following this the methodological and philosophical principles underpinning the mixed methods study will be discussed. A description of how practice, stakeholder engagement and user involvement have been incorporated throughout the research process will then be given, before the chapter concludes by presenting an outline of the structure of the chapters making up the remainder of this thesis.

## **1.2 Thesis Aims and Objectives**

The use of SM practices in supporting the health and wellbeing of cancer survivors is increasingly being recognised as an important area for exploration (1-3) , yet it is an area that has so far been under-researched, thus providing the overall rationale for this study. The study's rationale will be described in more depth in Chapter 2, but first the thesis aims and objectives will be outlined below.

This mixed methods study incorporates both quantitative and qualitative research methods in order to investigate patterns of SM uptake amongst cancer survivors and to answer the question 'who does what and why?'

The aims of the quantitative phase 1 study were to:

- a. Map patterns of SM over time from pre-diagnosis, through treatment and into survivorship.
- b. Explore the relationship between SM uptake and specific outcome measures to answer the following questions:
  - Does the uptake of SM practices have an impact on the QoL of cancer survivors?
  - Does the uptake of SM practices have an impact on the internal HLC of cancer survivors?
  - Does the uptake of SM practices have an impact on the perceived ability to work of cancer survivors?

Findings from the phase 1 study provided the basis for the phase 2 qualitative study by informing the development of an interview topic guide, based on the patterns of SM identified and any associations between SM and QoL, HLC and work ability. By identifying which SM practices cancer patients are using and when, the phase 1 study enables the phase 2 study to unravel the reasons behind the following research questions:

- How and why do cancer survivors make decisions about their use of SM practices in their daily lives?
- How and why do cancer survivors alter their health behaviours throughout diagnosis, treatment and into survivorship, with regard to their QoL, health beliefs and ability to work?
- How do cancer survivors interpret changes in their SM practices over time?
- How do cancer survivors' health beliefs and health experiences inform their decision-making in relation to SM?

To be able to adequately answer these research questions a suitable study design was employed. A rationale for using mixed methods as a basis for this research study will now be given.

### **1.3 Rationale for Using Mixed Methods**

Two different research questions, one relating to the 'what?' and the other to the 'why?' of SM in cancer survivors, have been developed for the purpose of this study, requiring the incorporation of two different research methods to answer both questions sufficiently. To explain the rationale for the use of mixed methods, attention to different epistemological

perspectives is required to generate the appropriate philosophical standpoint for discovering truth and reality within research.

The way truth and reality are encountered is fundamental in the quest for knowledge (4). Different research paradigms consist of different sets of beliefs and practices which influence how researchers select their research questions and methods (5). Different epistemological stances have distinct belief systems that influence the way research is carried out due to their philosophical standpoint around the nature of knowledge and knowing. Three prominent epistemological perspectives - objectivism, constructivism and subjectivism - can be used to inform different methodologies and their resulting methods, enabling conclusions to research questions to be answered from different theoretical perspectives (6).

In an objectivist view, meaning and a meaningful reality exist apart from the operation of any consciousness (6). Positivism, a theoretical perspective stemming from the objectivist epistemology, stipulates the truth of a statement is determined by its correspondence with observed facts, an objective reality (7). Positivism suggests only knowledge gained through the senses is acceptable, testable by observation or experience (8). Recurring experiences form the basis for scientific laws, allowing prediction of future occurrences of the same phenomena (9). Positivism offers the assurance of unambiguous and accurate knowledge of the world, discovering meaning that is already inherent in the object it considers (6). This alleged objectivity of scientific knowledge contrasts with the opinions, beliefs, feelings and assumptions gained in non-scientific ways (6).

The positivistic idea that quantifiable knowledge can be proven through repetition of the same occurrence was challenged by Karl Popper, whose 'Falsification' theory proposed that scientists should be called upon to try to disprove rather than prove a theory and that it was only when scientific theories have survived every attempt to try to disprove them that they can be 'provisionally' accepted as true (6). This paved the way for post-positivism, with post-positivists claiming a higher level of objectivity and certainty for scientific findings than for other opinions and beliefs, but without the absoluteness found in positivism, with claims to the validity of findings being approached more tentatively and in a more qualified manner (6).

In contrast to objectivism, subjectivism is aligned with the idea that meaning is imposed on the object by the subject and that the object makes no contribution to the generation of meaning (6). The meaning that is formed may evolve from our dreams, or our belief systems and values, but is not derived from any interaction between subject and object (6).

Finally, the constructivist epistemology is positioned between objectivism and subjectivism, deriving meaning from the interaction between both subject and object (6).

Constructivism holds the view that all knowledge and meaningful reality is contingent upon human practices, being constructed in and out of interaction between human beings and their world and developed and transmitted within an essentially social context.

Constructivism views meaning as being 'constructed' rather than 'discovered', as meaning can only emerge when human consciousness engages with the object and the world it is interpreting (6). Constructivism brings together the object and the subject, highlighting the

interdependence between humans and the human world in the formation of meaning. It recognises that, within and between cultures, people make sense of the same phenomenon in different ways, resulting in no true or valid interpretations of reality, but rather multiple useful interpretations. Thus meaningful reality is socially constructed with different interpretations of truth and reality being equally valid (6).

Interpretivism, a theoretical perspective arising from constructivism, has emerged in contradistinction to positivism. It attempts to understand and explain social reality by looking for culturally derived and historically situated interpretations of the social-life world (6). It acknowledges the place and impact of consciousness on human behaviour (10) and sees time, space, our relationships and bodies as lived, not abstract phenomena observable to the objective, detached observer (11).

When looking at objectivism, constructivism and subjectivism, one can see how differing epistemological outlooks can influence the choice of research methodology used i.e. the strategy for determining how research is subsequently conducted, interpreted and presented. The issue of incommensurability between different epistemological paradigms has long been upheld by some purists, who claim that it is difficult to create a one to one correspondence between ideas in two different paradigms, as this would make it impossible to translate or reinterpret research between them (5). Rather than upholding this view that different epistemological stances are impenetrable and incompatible with one another, an alternative approach is to view different epistemological approaches as being on an epistemological continuum (12). This enables a blending of the existing

paradigms, which proponents argue draws out the strengths and minimises the weaknesses by using multiple approaches.

Epistemological beliefs do not restrict researchers to using only certain methodologies (12). A mixed methods approach allows shared assumptions, including that what we notice and observe is affected by our background and that multiple theories can fit a single set of empirical data (12). However, the epistemological link between qualitative and quantitative research methodologies must be clear (13). When methods are mixed without considering certain assumptions, rules and expectations regarding their conduct, results become questionable. A balance needs striking between total adherence to techniques, perspectives and values of traditional methods and drawing useful strategies from these traditions, recognising modifications and their implications (14). Good mixed methods require sound knowledge of the multiple methods used, their assumptions, analysis procedures and an ability to interpret results derived from the different methods. Validity of mixed methods stems from the appropriateness, thoroughness and effectiveness of their application and thoughtful weighing of the evidence, rather than from the application of certain rules or adherence to established traditions (14).

In this study the use of mixed methods allows aspects of human behaviour to be both measured and understood, recognizing similarities and differences between quantitative and qualitative methodologies to maximise the strength of both. Whilst an objective testable reality is apparent, as humans we possess subjective multiple realities which in turn affect our actions. The use of multiple integrated approaches can be useful in

exploring social and behavioural processes that are difficult to capture using quantitative or qualitative methods in isolation (15). It allows the impact of demographic variations between respondents to be examined, with the influence of factors such as age, culture and gender being explored in detail. Mixed methods can generate comprehensive research findings through extrication of different data elements. It can be used to answer differently conceived or separate questions, demanding the co-presence of multiple methods, or for asking questions about connecting parts of a social whole, using an integrative approach (16). The following table has been developed from a similar table outlining how qualitative methods can be used alongside randomised controlled trials (RCTs) (15) and can be used here to demonstrate the various ways qualitative methods can be used alongside cross-sectional quantitative studies (table 1.1).

Table 1.1: To Show How Qualitative Methods Can Be Used Before and After Cross-Sectional Studies

<b>Usefulness of Qualitative Methods Alongside Cross-sectional Quantitative Studies in Healthcare Research</b>
Before a Cross-sectional Study
<ul style="list-style-type: none"> <li>• To explore issues related to the healthcare question or research context</li> <li>• To generate hypotheses for future examination in the cross-sectional study</li> <li>• To develop appropriate outcome measures</li> </ul>
After a Cross-sectional Study
<ul style="list-style-type: none"> <li>• To explore the reasons for associations between demographic variations within the study population and outcome measures</li> <li>• To generate further questions or hypotheses</li> <li>• To examine the appropriateness of the underlying theory</li> <li>• To inform the qualitative sample size, based on the variation in findings from the cross-sectional study</li> </ul>

When examining the three epistemological perspectives described in relation to the mixed methods research study, the constructivist approach appears the most suitable paradigm from which to generate the methodology due to its emphasis on the interaction between subject and object in the generation of meaning. Within the mixed methods approach certain methods used in the study sit further towards one end of the continuum than the other. For example, the questionnaire study has roots in positivism, collecting data which can be counted and is quantifiable, easily analysable through standardised statistical techniques (17). However, other aspects of the questionnaire study are left open much more to interpretation, by both the researcher - in designing the questionnaire and drawing conclusions from the data analysed - and by the respondents - in how they interpret the questions listed in the questionnaire and respond to them accordingly. The questionnaire has been sent to cancer survivors living in a real-world setting with existing operations, structures and relations in place, being complex to evaluate and likely to affect individual responses to the questionnaire. Responses may be influenced by social and cultural factors, meaning that the findings from the questionnaire cannot be objectified, but must be interpreted with these socially constructed factors in mind.

Similarly, the narrative interview study is largely interpretive in nature, involving multiple representations of reality, due to the cultural influences shaping people's recollections and experiences. However, it contains facets that move more towards the objectivism end of the continuum. The interview guide used in the interview study contains structured prompts to guide respondents towards talking about pre-specified topics around cancer survivorship and SM, shaping the nature of the narrative in a certain direction.

Additionally, the qualitative data analysis techniques involve using a structured, repeatable

method, coding and recoding the data to make it more manageable and succinct. Thus, it is apparent that this mixed methods approach applies both quantitative and qualitative research methods to help answer both parts of the research question. Constructivism underpins this mixed methods approach by recognising the benefits of integrating subjective and objective approaches to find a useful interpretation of truth and reality inherent in the research context (6).

The recognised importance of aligning certain epistemological stances with appropriate methodologies and subsequent methods, allows us to consider pragmatism as the chosen methodology to answer the research question from a constructivist perspective.

Pragmatism is a well-developed philosophy for integrating perspectives and approaches and a useful philosophy for supporting mixed methods research (18). A pragmatic approach to conducting research reminds us that our values are always a part of who we are and how we act (5). It acknowledges that we make our own choices about what is important and that these choices involve aspects of our personal history, social background and cultural assumptions (5). The emphasis on ‘what difference it makes’ to believe one thing versus another in research (5) sits alongside the constructivist view that the interface between subject and object formulates the construction of meaning and reality (6). The pragmatic emphasis on an inter-subjective approach to research is appropriate to answer the research question, searching for useful points of connection between qualitative and quantitative research methods, rather than dismissing them as wholly incompatible (5, 18). The recognition that there is a single ‘real world’ but that individuals all have their own unique interpretation of that world, is central to pragmatism, treating inter-subjectivity as a key element of social life (5), supporting paradigm integration and helping mixed methods

research to peacefully coexist with the philosophies of quantitative and qualitative research (18).

There is a debate in the academic literature around the use of the first or third person with regard to writing style and the conventions of publication in this field (19). However, in keeping with the reflective, subjective and person-related epistemology inherent in qualitative research it was thought appropriate, where relevant, to write in the first person throughout Chapters 6 and 7 (where qualitative findings are reported), so as not to obliterate the social production of the research process and as a way of encouraging reflexivity (20). However, the third person will be used throughout the rest of this thesis to maintain a more objective and impersonal writing style that sits more easily within the quantitative research paradigm (21).

In health services research there is a growing understanding that the enlargement of our theoretical understanding of phenomena depends on the collection and interpretation of richer and deeper forms of data, which cannot always be answered by quantitative research alone (22). In order to move beyond answering research questions using RCTs and other quantitative methods, which are based around issues of efficacy and effectiveness, qualitative data can be incorporated to illuminate lay knowledge, highlighting the meanings people attach to their behaviours and experiences in relation to their context and cultural environment, to help us understand why something is the way it is (22). In this research study the use of mixed methods provides a breadth and depth of findings, with the questionnaire study providing a large survey population which can

provide a context for the study and form a basis for empirical generalisations, whilst the narrative interview study can provide insights as to why people behave the way they do, something that is essential to understanding the variation in health behaviours amongst different population groups (22). Mixed methods provides an approach to knowledge that attempts to consider multiple viewpoints (18), something that is compatible with a constructivist approach to knowledge generation and a pragmatic approach to conducting research.

#### **1.4 Practice and Stakeholder Engagement and User Involvement Throughout the Research Process**

Much academic literature has focused on the importance of stakeholder engagement and public and patient involvement throughout the research process in order to improve the relevance of the research being undertaken, as well as producing patient centred outcomes and high quality standards of care that can be readily adopted into clinical practice (23-25). With this in mind, throughout the process of this PhD study the research findings have been disseminated to as wide and diverse an audience as possible through a number of different methods in order to find ways of engaging with others in the field of SM and cancer survivorship. This has included publishing some of the study findings detailing the systematic review and meta-analyses reported on in Chapter 3, in a peer-reviewed academic journal.

I have also taken part in poster presentations, both at the Research Poster Conference at the University of Birmingham in 2012, for which I was awarded runner up prize and at the British Psychosocial Oncology Conference in 2013. I have orally presented some of my

research findings at a national level at the International Society for Complementary Medicine Research, at the Institute of Medicine, in London. In addition to this in February 2014 I travelled to Florida to present my findings to a global audience in an oral symposium at the American Psychosocial Oncology Society's annual conference.

I have also had the opportunity to spend time at two international research institutions, the Sylvester Comprehensive Cancer Centre at the University of Miami, Florida, in February 2014 and the University of Leipzig, in Leipzig, Germany, in April 2014. At these research centres I was able to share the findings from my research with new colleagues, as well as learning more about the work they undertake in the area of SM and cancer survivorship. These networking opportunities have paved the way for the potential for future collaboration with international colleagues in the field of cancer survivorship.

As well as disseminating my research findings to an academic audience, I have been keen to share the study findings with other clinicians in this field. As a result in January 2014 I presented the findings of my thesis to a number of practitioners, including medical doctors and complementary and alternative medicine (CAM) therapists, at Freshwinds (<http://freshwinds.org.uk/>), a charitable organisation in Birmingham which helps to support children and adults living with life limiting illnesses, including cancer. Here I was able to discuss with clinicians the impact of my research at a practical level and gain feedback from them as to the types of SM practices they thought were of particular use to their patient groups.

My background as an oncology nurse generated my interest in SM practices in cancer survivors, as I experienced in my own clinical practice the multitude of difficulties and

challenges – both physical and psychological – that cancer survivors live with post cancer. Finding ways to help ameliorate these problems is an area that is relevant to nursing care, as nurses are the principal care providers for cancer patients and survivors. As a result it is imperative that the use of SM interventions for cancer survivors are further researched so that nurses are well placed to help support patients make suitable health and lifestyle choices which will enable them to live well in survivorship. In order to engage with cancer patients on a clinical level, I spent three months in 2013 working as a specialist oncology nurse in a breast cancer clinic at University Hospitals Birmingham (UHB), providing extra support to patients who required information on a number of wide-ranging issues relating to their cancer treatment and its subsequent impact on their lives, including social, emotional, psychological, financial and physical issues. This clinical work drew on the findings from this study in relation to highlighting to patients the potential benefits of various SM practices in improving some of the obstacles they were facing. This was a valuable experience in witnessing first-hand the positive impacts on patient care that can come about through taking the time to discuss with patients the different strategies available to them for optimising their long-term care pathways. A reflective piece on my role in this clinic has been documented (appendix 1).

It has also been important to incorporate and consider the views of service users throughout the research process. Service user involvement in research aims to improve the way research is commissioned, prioritised, undertaken and used, leading to more relevant research being undertaken (26). Service users have generally had long-term experience of health services (27), so it seems logical that research reflecting their needs and views will bring about improvements to clinical practice. In this study service users were involved in designing the questionnaire, providing feedback as to its comprehensibility and usability,

which allowed alterations to be made as a result. In addition a topic guide was designed for the interview study. This topic guide was then tested in a practice interview with a patient representative from the West Midlands. Following the practice interview the patient's comments were sought in relation to the usefulness of the topic guide as well as the way the interview was conducted to enable any necessary alterations to be made before commencing the interviews. This input from patient representatives allowed the design of the quantitative and qualitative research tools to remain patient focused and orientated to help ensure that they would be interpreted in a way that is appropriate and relevant to the user population.

## **1.5 Thesis Structure**

The thesis is structured in the hybrid style format which is presented as a mixture between the traditional thesis format and the thesis by publication format where chapters are presented in the style of a series of published papers. The hybrid style is appropriate for a thesis where the research component is made up of several relatively discrete phases (28, 29) . It provides the opportunity for sections of the thesis to be peer-reviewed by external experts in the field, providing valuable feedback and enhancing the credibility of the work, as well as allowing academic skills in paper writing to be developed (28, 29). The hybrid style thesis provides the opportunity to make significant contributions to research at the earliest opportunity through publications, something that is highly regarded in academic fields and for a successful research career (28, 29). Chapter 3 contains a published paper. The citation for the publication will be given at the start of the chapter before the publication is inserted into the chapter. The remainder of the chapters will be presented in the traditional thesis style format.

The thesis reports on a sequential mixed methods study design comprising a quantitative survey study followed by a qualitative interview study. It can be argued that using sequential mixed methods may lead to a series of seemingly disconnected parts, rather than a conceptually integrated whole (30). However, within the context of this thesis, sequential mixed methods seemed appropriate for use, as the quantitative findings were used to inform the subsequent qualitative study, resulting in rich findings being produced. The decision to present the thesis in a hybrid style format reinforced this view, as presenting the quantitative and qualitative findings separately strengthened the likelihood of the chapters being published in esteemed journals (31).

In this research study it is important to carry out the quantitative study prior to the qualitative study to provide an overview of the patterns of SM cancer survivors are using over time and to identify any links between SM and QoL, HLC and work ability. This can enable the ‘*what?*’ of ‘who does what and why?’ to be answered. Building incrementally on these findings it is then possible to delve further into the reasons ‘*why?*’ in the qualitative study. Findings from the quantitative study have been used to develop a qualitative topic guide to explore reasons behind the patterns of SM identified. This relates to issues around cancer survivors’ health views, social support, views on SM, work ability, QoL and views about the future (appendix 11). The use of quantitative and qualitative methods in the same research study can make an important contribution to health research (32) and whilst qualitative methods are often used to generate ideas with which to inform the subsequent quantitative study (16) in this case it is important to carry out the quantitative phase first. In doing so, an ascertainment of what cancer survivors are doing in their daily lives with regard to SM can be facilitated so that these patterns can be further explored through the qualitative analysis. This incremental accumulation and integration

of data between the quantitative and qualitative findings can enable a full and complete picture to be developed around the ‘what?’ and ‘why?’ of SM in cancer survivorship.

The following chapter (Chapter 2) will provide a background to the research study, giving an overview of SM within the context of cancer survivorship. Chapter 3 will then report on a systematic review and meta-analyses examining whether CAM use improves overall QoL in cancer survivors. Although six categories of SM (diet, exercise, CAM, support groups, psychological therapies and spirituality/religion) were examined in the research study, it would not have been possible to include all six SM categories in the systematic review as the search criteria would be too wide, therefore it was decided to focus on one specific SM category. Following a preliminary literature search it became apparent that two SM categories - CAM and spirituality/religion - appeared to be the least researched in terms of their effectiveness in improving QoL outcomes in cancer survivors. As a result one of these categories, CAM, was selected for examination in the systematic review.

Previous research has found CAM to be more popular in cancer patients than the normal population (33-35), therefore an exploration of whether this increased use of CAM is beneficial to QoL warranted investigation. Although many systematic reviews have been carried out examining CAM and QoL in cancer patients and survivors undertaking *specific* CAM practices (36-40), none have examined *multiple types* of CAM interventions and their effect on the QoL of cancer *survivors*, identifying an important gap in the literature which linked in with the research question.

Following on from the systematic review and meta-analyses Chapters 4 and 5 will report on the quantitative survey study, detailing study design and methodological issues, before presenting the survey results and providing a discussion of the findings. Chapter 4 will

focus specifically on the prevalence and distribution of SM patterns over time in cancer survivors, whilst Chapter 5 will examine any associations that may exist between SM and QoL, HLC and work ability. Chapters 6 and 7 will then move on to report on the qualitative study. In Chapter 6, methodological details around study design will be discussed, before an overview of the main themes from the interview narratives are summarised in relation to the motivations and constraints of cancer survivors for using SM practices. Chapter 7 will move on to discuss in more depth the concept of SM and normality in cancer survivorship, a theme which consistently recurred throughout the interview narratives. When examining the different categories of data constructed from the interviews, normality became the unifying theme linking all of these categories together and creating connections between them. In Chapter 7, a new model relating to SM and normality in cancer survivors is presented. Finally, Chapter 8 will provide an overall discussion of the previous chapters' findings as well as identifying the study's contributions to the theoretical, empirical and methodological literature around SM and cancer survivorship and any implications for future policy and practice.

## **1.6 Conclusion**

This chapter has provided the overall aims and objectives of the PhD study in relation to SM and cancer survivors, asking the research question 'who does what and why?' The topic of SM in cancer survivorship is an important area to study. Therefore it has been important in this chapter to consider a range of different epistemological perspectives to ensure that the research undertaken was approached from the most appropriate philosophical standpoint. A pragmatic, constructivist approach was chosen in order to answer the research question sufficiently, using a mixed methods study design, so as to understand in greater depth 'who does what and why?' It is important that the research

findings from this PhD are disseminated to as wide an audience as possible so as to share insights and make connections with others in the field of SM and cancer survivorship. This may be through conference presentations, academic publications, clinical work and the sharing of ideas and findings with fellow clinicians, academic colleagues and patient groups. Finally, the use of the hybrid style thesis has been used as a means of enhancing academic writing skills, allowing new contributions to the research around SM and cancer survivorship to be made at the earliest opportunity.

## **1.7 Chapter Summary**

Chapter 1 has outlined the aims and objectives of the research study and the rationale for using mixed methods in the study design. Details of practice, stakeholder engagement and user involvement in the research process have been given. Finally justification for the hybrid style thesis, incorporating a mixed methods approach, has been presented and the remainder of the thesis structure has been outlined. Chapter 2 will now set the scene for the study by presenting a case for the research in the context of SM and cancer survivorship, establishing the rationale behind the need for SM interventions in cancer survivors' lives.

# CHAPTER 2. BACKGROUND TO THE STUDY

## **2.1 Introduction to Chapter**

This chapter aims to give an overview of SM within the context of cancer survivorship. It begins by exploring the need for SM interventions within modern healthcare systems in countries where ageing cancer populations are a prominent feature. It then goes on to critically examine some of the literature relating to SM in cancer survivorship, assessing arguments for and against incorporating and integrating SM interventions alongside the evidence-based biomedical model of healthcare. Many different definitions of SM exist due to its ambiguous parameters, with different people having their own interpretations of what they consider SM to be (3). The rationale for the SM definition chosen for use in this study will be explained further in section 2.4, before wider literature relating to SM and chronic illness is discussed, to help illustrate how the definition of SM relates to this existing body of work. SM within a policy context will also be discussed. The six categories of SM used in the study will then be specified, before the chapter concludes.

## **2.2 SM and Cancer Survivorship**

Breakthroughs in cancer treatments and technological advances in cancer care mean that cancer patients are living longer, with over 64% surviving for at least five years after their initial cancer diagnosis (41). On average a cancer patient in the United Kingdom (UK) has a 46.2% chance of being alive ten years after diagnosis compared with 23.6% thirty years ago (42). Although this figure varies depending on cancer type at diagnosis (43), it serves to illustrate the improvements that have been made in cancer diagnosis, treatment and management.

As a result of these improvements in cancer survival, a growing ageing cancer population has emerged (41). This has developed alongside increasing expectations of high quality healthcare and service delivery from the general public, increased financial pressures to streamline National Health Service (NHS) resources, growing consumer pressure for greater participation in decision-making in healthcare and an ageing population. As a result increasing clinical, financial and political pressure is being placed on UK health services (3, 44). Though these pressures are pertinent to the NHS they are also applicable to healthcare systems globally, in countries such as the USA, Germany and Australia, where an escalation in the number of people living with chronic illnesses into old age has led to increased financial burdens being placed on healthcare systems, medical care insurance, and long-term care, due to the increased healthcare costs in older age per capita (45-47).

Cancer survivors are more likely than the general population to suffer from secondary health problems such as fatigue, anxiety, depression, nausea and pain and are at increased risk of developing secondary tumours (48-50). These increased co-morbidities place financial pressure on healthcare systems due to the need to manage the health pathways of an increasing number of cancer survivors, leaving clinicians short of adequate time, skills and resources to adequately address these people's requirements (51). This can result in many cancer survivors lacking support and advice on how to deal with the after-effects of their cancer and treatment (52). Many patients also report feeling abandoned and isolated following cessation of active treatment (52), which could lead to exacerbation of symptoms such as depression and anxiety. Cancer is often perceived and treated from an acute illness framework and it is often only once this acute framework has been disbanded post-treatment that cancer survivors become aware of the chronicity of their symptoms and side-effects (53, 54). There has also been a tendency to focus on the importance of longevity in survivorship, usurping the

value of QoL in the process (55). This may impact on the QoL of many patients, which has been reported as being lower in cancer survivors than other population groups (56, 57). QoL can be defined as:

*'A personal sense of well-being encompassing a multidimensional perspective that usually includes physical, psychological, social, and spiritual dimensions or domains' (58).*

It is important therefore to look at ways of improving cancer survivors' QoL and long-term health outcomes. This may be facilitated by examining ways of easing the increasing strain being placed on UK cancer services to enable the provision of high quality care to those patients who are most in need. This is especially relevant as the current follow-up service provision within the NHS is unsustainable due to increased referral for new cancers, an increase in the number of cancer survivors and substantial resource limitations (59). One initiative that seeks to improve the QoL and health outcomes of cancer survivors encourages the use of SM strategies - such as diet, exercise, support groups, CAM therapies, spirituality and religion and psychological interventions, to empower patients to take control of their lifestyle choices to improve their health and wellbeing, while also easing pressure on healthcare resources and promoting patient choice (3). In 2006 the Department of Health's White Paper 'Our Health, Our Care, Our Say' identified the need to provide better support for people with long-term conditions (2). More recently the Macmillan Cancer Support SM work stream of the National Cancer Survivorship Initiative (NCSI) has advocated the use of cancer SM. The NCSI defines a cancer survivor as 'someone who is living with or beyond cancer' (1). It acknowledges that the awareness and active participation of individuals in their recovery, recuperation and rehabilitation can help to minimise the long-term side-effects of

their treatment, as well as aiding their survival, health and wellbeing and ability to work (1, 33, 60).

SM support represents a collaborative approach delineating how both health professionals and healthcare organisations can support patients to self-manage (53). It encourages health services to aid and promote strategies and interventions that will motivate people with cancer to improve or maintain their health and wellbeing (61). The overarching aim of many of these interventions is to educate patients to self-manage their condition and illness, thus improving their QoL and reducing pressure on health service utilities (53). This emphasis on SM strategies is important from a health service planning and policy perspective due to the escalating economic costs associated with an increasing number of cancer survivors living with long-term repercussions from cancer (62). Macmillan Cancer Support proposed key recommendations for designing self-supported SM interventions for cancer survivors (1, 63, 64). These included incorporating a needs assessment plan, a theoretical framework, intervention delivery, an implementation plan and evaluation of the service (65). The Risk Stratified Model of Care provides a theoretical framework for SM, enabling clinicians and cancer patients to make decisions about the best form of aftercare required, based on their knowledge of the disease, the treatment and the patients' perceived required levels of support (1). The following diagram (figure 2.1) illustrates the risk stratification process, with differing levels of professional care being provided depending on the individual patient's level of need.



Figure 2.1: Risk Stratified Model of Care. This shows the three levels of care-'self-managed care', 'shared care' and complex care' available to cancer patients dependent on their level of need. Movement between these options occurs due to fluctuations in disease and treatment progression and management (1).

An increasing number of SM programmes, such as the Expert Patients Programme and CHARGE (C-hoose a concern, H-ave the Information, A-ssess the situation, R-ecord the plan, G-ain confidence and insight, E-value your progress), have been piloted by health services to try to aid and encourage people with long-term conditions to make daily decisions that will improve their health-related behaviours and outcomes, by encouraging lay-led SM skills (63, 66, 67). A central tenet of SM is improving self-efficacy (68) and many programmes have found a marked impact on self-efficacy, empowerment, improvements in energy, increased QoL, decreased depressive symptoms, improved

coping mechanisms and changes in healthy behaviours (63, 66-70). However, it cannot be presumed that all patients who incorporate therapies such as CAM or exercise into their daily lifestyles are investing in the idea of SM as a way of taking control over their lifestyle and health outcomes. Some people utilising these types of behaviours may hold the belief that the solution to their health problems is 'out there' and may be led by external influences which serve to reassure them, rather than by a desire to take responsibility for their own health and wellbeing. The extent to which people believe their health is or is not determined by their own behaviour is known as their health locus of control (71).

### **2.3 Integrating SM Practices with Biomedicine**

Access to many SM groups and clinics is through clinician referral, providing an interface between lay provided and formal healthcare and promoting a shared care approach (63). Yet many clinicians often lack time and training to provide effective SM support and may lean towards proposing conservative risk-averse SM strategies such as compliance with medication, rather than recognising the wider health needs and priorities of patients (63). Oncologists may also be sceptical about some forms of SM approaches, such as CAM, with many reluctant to discuss CAM therapies with their patients due to a lack of accreditation or evidence-base of many treatments, lack of time and a mistrust of their efficacy or effectiveness (52, 72). This polarization of biomedicine and CAM visualised by some clinicians can restrict patients' ability to seek advice from their doctor about different treatment approaches for fear of negative and unhelpful reactions from them (52, 73). The nature of an oncologist's response towards SM programmes and interventions can be critical,

with negative attitudes resulting in patients failing to disclose, hiding, or discontinuing these practices, or diminishing their enthusiasm for non-biomedical alternatives. Pragmatic acceptance or positivity towards non-biomedical interventions however, can bolster patients' determination to pursue these practices, as well as enhancing the doctor/patient relationship in terms of satisfaction with decision-making (51).

However, the extent to which SM practices are advocated by healthcare professionals must be considered with regard to their evidence-base. Frequently certain SM practices, most notably CAM, are criticised for failing to provide substantial, high quality evidence in the form of RCTs, with regard to their efficacy in improving patient health outcomes (74, 75). As the principles of biomedicine are embedded in empirical research, where treatments are generally only recommended and prescribed following the generation of statistically and clinically significant findings regarding their efficacy (76), it is right to question whether health professionals should make an exception to this solid evidence-base when considering making recommendations about SM practices. There is a danger that, by advocating the use of certain SM practices that have not been thoroughly tested in terms of their benefits to health, patients' lives could be put at risk. Examples of unregulated products are rife with regard to diet and CAM, especially with the rise of the global media where unregulated 'natural' supplements are often freely advertised with the promise of enhancing weight loss, muscle mass and sexual function (77, 78). There is the risk that these products may be marketed as replacements for prescribed medication, or without proper information explaining their contraindications with other medication (79). Additionally there have been instances of herbal supplements being advertised through online retailers which have falsely and illegally claimed to treat, prevent or cure diseases such as cancer, diabetes and cardiovascular disease (80). Many of these

supplements have not undergone any form of rigorous testing and may contain undeclared, harmful, or deceptively labelled ingredients, such as synthetic steroids, mercury, lead and arsenic, which can contribute to negative health effects such as cancer and renal damage in high doses (77-80).

Dietary supplement usage has increased in recent years with around 53% of Americans and 33% of British people using them on a daily basis; the most popular ones include fish oil/omega 3/DHA, multivitamins, glucosamine, echinacea, flaxseed oil or pills, vitamin C and ginseng (78, 80). However systematic reviews investigating the health benefits of many of these dietary supplements, such as echinacea, ginseng, ginkgo, glucosamine and omega oils, have found limited or inconclusive evidence as to their benefit (81, 82). The apparent difficulties faced in both regulating the safety, and verifying the benefit of, these products helps explain the caution felt by some healthcare professionals in advocating certain SM interventions. The overarching tenet of the medical profession is to ‘first do no harm’ (83) and careful consideration and contemplation must be given as to the types of SM practices that are beneficial rather than detrimental to the patient.

The biomedical argument that more evidence of the efficacy and effectiveness of SM interventions is required before they can be safely recommended (74, 84), is an important one and can often create a barrier to verifying the legitimacy of SM practices. The RCT study design used in clinical trials compares the current ‘gold-standard’ treatment or a placebo against a new treatment, with research participants often blinded to which treatment they are receiving (8). However the RCT design is not always suitable for testing the effectiveness of

SM practices, as a blind control is not always feasible due to the nature of the intervention under study. For example, in a study investigating the efficacy of an exercise programme in reducing anxiety in cancer survivors compared with a control group which does not receive the exercise programme, it would be impossible to blind the study participants as to which group they had been randomised into, thereby increasing study bias and decreasing the validity of the findings.

Even when blinding is possible, a lack of funding into SM research makes it difficult to build up a robust evidence-base compared with biomedical treatments (84, 85). Pharmaceutical companies are under increasing pressure to show that their products are cost-effective, as economic analysis of pharmaceuticals and medical devices is playing an increasingly important role in healthcare decision-making because of the rising costs of healthcare (86-88). As a result, the lack of rigorous evidence regarding the safety, efficacy and cost-effectiveness of many SM practices (80) can act as a deterrent to pharmaceutical companies contemplating investing in SM research. This creates a 'catch 22' situation as the less SM research that is undertaken the less likely it is that future funding will be directed towards it and vice-versa (74).

Though more rigorous and robust research is required into the efficacy of certain SM practices, it is not the only area where there is a lack of evidence-based practice, with this issue being frequently overlooked in biomedicine (89-93). Examples of this in clinical practice are that approximately 50% of eligible patients do not receive beta blockers following a myocardial infarction, despite evidence of their benefit (89); incorrect guidelines are

followed for the use of the antibiotic, vancomycin, 68% of the time (91) and only 16% of patients' digoxin levels - a drug used to decrease heart rate - are appropriate in the inpatient setting when digoxin is given (90). Within oncology, there is inconclusive evidence as to whether whole brain radiotherapy treatment (WBRT) is more effective than WBRT as a combination treatment or compared to supportive care alone in terms of survival, cognitive function and QoL (92, 94). However WBRT is often given to cancer patients if the oncologist feels it might provide some benefit to the patient or if the patient is keen to pursue some form of active treatment. It could be argued that prescribing WBRT to a cancer patient in these circumstances is similar to recommending acupuncture to a cancer patient for pain relief. In both circumstances conclusive evidence as to the benefit of these practices is limited (92, 94, 95). However, if the patient believes that it is of some benefit to them, this may provide psychological benefits, aiding relaxation and positivity, as well as acting as a coping mechanism for helping them to live with their disease. The argument for evidence-based medicine becomes less clear here, as benefit cannot always be measured through biomedical parameters alone. Equally important are the emotional, psychological and social benefits induced through the treatment intervention. To ignore this is to revert to a polarised view of the body as a purely physical entity, rather than taking into account its psychological, emotional, social *and* physical components as a whole.

Sackett (1997) describes how the practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research (96). Clinical expertise can be acquired through clinical experience and clinical practice, increasing skills in judgement and proficiency and taking account of the individual patient's predicaments, rights and preferences to reach a conclusion about their care. Relying

on clinical evidence alone without using clinical expertise may lead to unsuitable clinical decisions being made which are inappropriate for the individual (96). A balance between clinical expertise and best evidence can help to ensure that the best available care is provided to patients at an individual level. If a patient has a particular treatment preference even though its benefit over another treatment is equivocal, it may still be the best treatment for that individual due to their confidence in its worth, potentially contributing to them experiencing improved health outcomes, greater QoL and increased satisfaction with their care pathway (97). SM practices may provide benefits to health and wellbeing that cannot be measured solely through the evidence-based medicine model, as the effects on the individual are likely to be more varied and diverse than by measuring efficacy alone.

The 'placebo effect' occurs when a patient is unaware they have been given a treatment which has no known physiological benefit, and so subsequently report side-effects they believe they are experiencing from the 'treatment' (98). These self-reported side-effects are thought to be a result of the patients' beliefs and expectations rather than as a result of the placebo itself (97). The 'placebo effect' is thought not to occur only from receiving the placebo, but also as a result of the individual characteristics of the patient, practitioner, the patient-practitioner interaction, the nature of the illness, treatment and setting in which the placebo is administered (97). Placebo effects have been reported in both biomedical settings and where SM practices, such as CAM, spirituality/religion and exercise are utilised, due to the psychosocial benefits resulting from them (97, 99, 100). For example performing a religious ritual such as prayer may provide benefits to patients in the form of relaxation, positivity and hope, enabling them to cope better with other aspects of their health and lifestyle. Similarly, the evidence-base for acupuncture may be ambiguous (95), but the benefits derived from the

interaction between patient and practitioner and the setting in which it is undertaken may produce enhanced psychological wellbeing.

Rather than producing the ‘fastidious efficacy’ commonly attributed to specific biological consequences (97), these treatments can produce a ‘performative efficacy’, relying on the power of belief, imagination, symbols, meaning, expectation, persuasion and self-relationship in relation to the healing process (97). Hence, the merits of SM practices in contributing to the health and wellbeing of cancer survivors can be considered, with the potential capacity to produce benefits which enable them to cope better with their disease and treatment sequelae, albeit through different mechanisms to those mandated in evidence-based medicine. The idea of using SM as a means of coping rather than curing should be asserted here due to the important improvements this can bring for cancer survivors in terms of improving QoL, regaining normal life post-cancer and alleviating treatment side-effects.

Despite the resistance voiced about many SM practices in mainstream healthcare, many NHS hospitals now offer SM interventions to patients which are based within primary and secondary care. These include CAM therapies such as acupuncture, aromatherapy, chiropractic, homeopathy, massage, osteopathy and hypnotherapy (101), chaplaincy services (102), food and physical activity courses (103), psychological therapies such as counselling (104) and access to support group services (105). Within many NHS cancer centres, such as the Royal Marsden in London and The Christie in Manchester, complementary therapies are offered to cancer patients as a means of providing symptomatic relief and relaxation, despite the acknowledgment that there is little evidence to verify their benefit (106, 107). This

presents an anomaly with regard to evidence-based practice in healthcare, creating confusion for cancer patients who are considering using these practices and who may assume they are evidence-based as they are available through the health service.

It could be argued that clinicians should not be offering non-evidence based practices to their patients on the basis of their empirically-based training as it undermines the value of their decision-making regarding other treatments. However, it has been reported that many cancer patients and survivors often fail to disclose their SM, and especially CAM, use to clinicians (51, 52). This is often for fear of receiving negative reactions or ambivalence from their doctor or nurse, or of not being taken seriously or wanting to waste their time (51, 52). This has implications in terms of the potential for being unaware of possible contraindications of certain SM practices with treatment (51). It also highlights an imbalance of power in the doctor/nurse and patient relationship, suggesting that these issues may create barriers in communication between the two parties. Perhaps clinicians need to be more open in discussing the pros and cons of certain SM practices with their patients to promote open communication pathways and information disclosure, to enable both patient and clinician to be fully informed in terms of planning and managing the care pathway.

## **2.4 Defining SM**

In health psychology SM has previously been defined as ‘patients’ involvement in the management of their care’ (108) and in relation to chronic illness, ‘the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition’ (109). Despite this, SM as a concept is difficult to define, encompassing many different practices such as support groups, diet, exercise, CAM, spirituality and religion and psychological interventions (108). However,

these practices are not always viewed as SM by individuals, who may see these practices from a non-healthcare orientated perspective (109). This nebulous concept of SM can make it difficult to categorise and quantify.

Self-care (SC) is a term often associated with SM, with the terms often being used interchangeably (53). SC can be viewed as a person's actions resulting from their sense of personal control over their health (110), encompassing all actions that individuals take to maintain health and wellbeing, whereas SM is more concerned with the ability to manage daily problems resulting from chronic health conditions (111). Barovsky (1978) proposed that SC can be threatened by the socialisation of patients into the healthcare environment whereby they are coerced into accepting standard medical practices, modifying their lifestyle behaviours and practices accordingly (110). The amount by which the individual is socialised into the medical system reflects the subsequent level of SC they are able to retain (110). SC ranges from the reactive (taking measures to restore health after diagnosis or once symptomatic), to the preventative (implementing healthcare behaviours to minimise risk factors contributing to disease onset), to the regulatory (the non-health related observation that each time people protect themselves from an environmental extreme, they are caring for themselves to avoid adverse effects) (110). Hence, SM can be viewed as a subset of SC, concerned with regulating, maintaining and improving health after the onset of disease. Thus SM, as opposed to SC, has been chosen as the focus of the research study.

Previous work around SM and SC in chronic illness has suggested that people with higher levels of self-efficacy are more likely to engage with SC and SM behaviours due to increased feelings of confidence in their personal ability to manage problems associated with their illness (112, 113). Bandura (1977) defined self-efficacy as 'the personal

judgements in one's ability to succeed in a particular situation', something which is determined by how people think, behave and feel (68, 112). Adding to this, Foster et al (2011) propose that although many people require help to manage the impact of cancer on their lives, they often lack the confidence to seek this help due to feelings of vulnerability and lowered self-esteem following their cancer diagnosis and treatment (53). This can have negative implications in terms of recovery from cancer, minimising the chances of engaging in effective and appropriate SM strategies. This can result in detrimental effects on the health and wellbeing of cancer survivors, reducing their capacity to 'live well' in survivorship (53).

Different forms of SM will be undertaken by cancer survivors depending on the stage of their cancer trajectory, as the intention, need and desire for SM will be dependent on whether the individual is viewing their health status from a reactive or regulatory perspective, time and place. This is influenced by the time-point in the cancer pathway that the SM practice is initiated and by any other co-morbidities or risk factors present. Having been cancer free, emotions such as fear, uncertainty and anxiety are often prominent in the period leading up to diagnosis due to the onset of symptoms and investigations being undertaken (114). During treatment cancer patients are often faced with severe and debilitating treatment side-effects resulting in changes to work and social life (33, 115, 116) and psychological implications are often incurred in the form of lowered self-esteem, as well as decreased confidence and body image (115, 117, 118). Post-treatment cancer survivors often report a fear of recurrence (119). They also have to adapt to their new life post-cancer taking into account the physical and mental changes cancer has left them with (115, 120), as well as frequently dealing with challenges in returning to work and regaining their social roles (121).

At all times throughout the cancer pathway a person's ability to cope will be underpinned by factors such as their level of social support, financial and work security, personal outlook and disease and treatment severity (50, 121-124). It is important to recognise the similarities and differences faced by cancer patients at different stages along their cancer pathway as this may directly influence the types of SM practices they choose to use or discard, depending on their emotional, psychological and physical needs at these times. Hence it is important to examine patterns of SM in cancer survivors over time to create a picture of how, why and when these SM practices vary.

Whether engaging in a health promoting activity or managing their disease, cancer patients and survivors are responsible for this day-to-day management (125). The idea that people cannot *not* manage their health is vital in this understanding as by choosing not to engage in a healthful activity or be active in managing a disease, they are still reflecting a personal management style (125). Taking this into consideration it is necessary to recognise that all people, to a greater or lesser extent, self-manage their lifestyles on a daily basis, whether consciously or subconsciously. As discussed, people's motivations for SM may not be generated from concerns or an awareness of the need to protect and ensure their own health. Instead SM practices may be initiated and maintained for a multitude of reasons, whether behavioural, social, religious or familial. Therefore what constitutes SM in a healthcare context for one person, such as participating in a team sport to increase physical health and fitness, may be construed by another person as a way of socialising with peers and will not be motivated, initiated, or maintained by health considerations. This example serves to illustrate the difficulty in defining SM as a concept within clearly defined parameters due to differing perspectives around what it constitutes and differing motivations surrounding its implementation. Countless practices could be categorised as

SM, such as brushing teeth in the morning, practicing yoga, putting on a raincoat, going mountain climbing, or socialising with friends.

Yet, despite the context in which it is perceived, SM can still provide significant, lasting health benefits (1) and for this reason the current study has chosen to view SM within the context of healthcare by exploring the impact it can have on cancer survivors' health and wellbeing. Within this healthcare context, SM can be split into three components: medical, role and emotional management (126). Medical management refers to such things as medication compliance, whilst role management refers to maintaining, changing and creating new meaningful behaviours and life roles. Emotional management relates to how people manage the emotional sequelae of living with a chronic condition (126).

Historically, health professionals have focused largely on the medical management component, but to truly engage with the concept of SM all three components need to be realised (125). The shift in focus in the twentieth century from healthcare provision being centred around families and communities to healthcare providers and institutions has led to a shift in expectation, with people distancing from SM due to increasing reliance on healthcare professionals (125). However the increasing financial, political and clinical pressures being placed on healthcare systems (3, 44), (as discussed in 2.1) may result in a shift back towards families and communities, as well as healthcare professionals, resulting in a shared care approach where SM is increasingly integrated into cancer survivors' daily lives (125).

Cancer survivors use certain SM practices more than other population groups (66, 127). However, it is not known which types of SM are being utilised nor at what stage in the patient journey. This is an important area for exploration as SM utilisation can improve

self-efficacy and feelings of control over illness, positively affecting both health status and health behaviours and outcomes (125). The questionnaire study was designed to enhance understanding about the types of SM practices cancer patients are using at various stages along their cancer pathway, allowing the reasons why certain SM practices provide particular benefits to these people at different time-points to be inspected further in the qualitative interview study. This can help establish which types of SM practices may be beneficial to different types of cancer patient, potentially improving their QoL, health and wellbeing, as well as reducing the load on encumbered healthcare resources. To make the concept of SM manageable within the study context, the following definition (previously outlined in section 2.1) of SM has been developed:

*'Any conscious decision by the individual living with the after-effects of cancer and its treatment, to adopt or abandon a lifestyle-modifying behaviour, whether it be a reactive, preventative or regulatory process, that may have the potential to impact on their future health and/or wellbeing.'*

This broad definition of SM can enable more to be discovered about the uptake of SM practices in cancer survivors. In this study, it is important to be as inclusive as possible when considering SM. Little is known about the SM patterns of cancer survivors over time, providing a rationale for the study. As such, the study's aim is to discover more about the patterns of SM practices over time to enable improvement in the long-term health outcomes of cancer survivors through the provision of appropriate SM interventions. In order to understand how the definition of SM provided relates to other literature in this area, SM will now be considered within the wider context of chronic illness in society.

## **2.5 The Social Context of SM and Chronic Illness**

In the past few decades cancer has emerged as a chronic, rather than an acute illness, due to improvements in survival rates (41). Yet, despite this biomedical reassessment of the nature of cancer and its treatment, there remains an expectation within society that people with cancer and other chronic illnesses will suffer only temporary disruption to their lives as a result of their illness, before returning to 'normal' (128, 129). These societal expectations can lead to increased suffering in people with chronic illnesses, as they struggle to live up to these expectations (129). Hence, maintaining a 'normal' life becomes a symbol of the valued self (129) and the pressure to appear normal to others in a taken for granted world, becomes a burden of conscious and deliberate action (130, 131). This can result in people with chronic illnesses withdrawing from society and living increasingly restricted lives, to protect themselves from situations where they might be open to embarrassment and public mortification as a result of their functional limitations being exposed (129, 130, 132). The low feelings of self-confidence and self-worth that this can induce, can be magnified further due to family strains, financial worries, stigma, increased dependence on others and decreased productive function, following the onset of illness (129, 130). This can result in changes in self-concept and an assault on the identity, as the lives of people with chronic illness become consumed by it and lose their sense of purpose and meaning (129, 133).

Bury (130) views chronic illness as a disruptive event, as the structures of everyday life are disrupted and the recognition of pain, suffering and even death, become real concerns, rather than being the plight of others. The commonly held view of chronic illness as a stable entity is instead replaced by a fluctuation in symptoms and the prospect of an uncertain outcome, adding to the uncertainty of illness (130, 134). This uncertainty can be

addressed to some extent through medicine, with medical conceptions of chronic illness being reified from a lay perspective (130, 133). However, ambiguity often persists, as questions around illness management and what will happen in terms of future health, remain (130, 133). As a result, people with chronic illness may look to supplement knowledge about their illness from their own personal biographies, to search for a sense of meaning and a cause for its onset (130, 133).

William's (133) 'narrative reconstruction of chronic illness,' theorises that people with chronic illness establish this sense of meaning through a narrative reconstruction of their changing relationships with the world they live in and the creation of illness within it. This is done to understand their illness in terms of their past social experiences and to reaffirm to them that life has a cause and the self a sense of purpose (133). To this end, moral, religious, familial and social factors become central in elucidating the illness experience and making the biographical disruption they have experienced intelligible (133). The ability of people to self-manage and make adjustments to the emotional, physical, social and psychological changes that have occurred, may determine how readily they are able to regain a sense of normality and order in their lives (130, 131, 133), demonstrating the need for effective SM strategies that may be of benefit to them.

A number of studies have identified the need for tailored self-support in people with chronic illness (108, 109, 135, 136). A systematic review examining the nature and effectiveness of different SM interventions for chronic illness, found that changes in SM behaviours did occur after the implementation of some of the interventions (108). The study characterised SM interventions as successful if they led to participants taking substantial responsibility for managing their illness (108). However, the objectives of the

SM interventions differed, making it difficult to draw direct comparisons across interventions (108). The review recognised the value of identifying who benefits most from which SM interventions, as a way of targeting more effective resources (108).

A literature review exploring SM approaches for people with chronic conditions, concluded that a tailored approach to SM may help people to effectively self-manage their illness (109). Another study, involving focus groups on cancer survivors who had been successfully treated for cancer, showed that individualised tailored support was integral in helping cancer patients to find a new normal in survivorship (135). Similarly, a systematic review and narrative synthesis examining lay and health professional understandings of SM, found that lay people understood SM as generating a collaborative partnership with health professionals through tailored self-support (136).

The definition of SM given in section 2.4 relates to the literature presented here around SM in chronic illness, recognising that the extent to which cancer survivors choose to adopt or abandon SM practices can impact on how well they make adaptations to living with their illness. The literature also highlights the need for research to examine the specific types of SM practices cancer survivors and other people with chronic illness are using and their reasons for doing so, to try to improve the provision of tailored SM support throughout health services. The policy developments that have evolved in light of this will now be considered.

## **2.6 SM in a Policy Context**

In 2008, a policy document from the Department of Health, 'Raising the Profile of Long Term Conditions Care,' emphasised the need for a policy drive focusing on long-term

conditions, due to their increasing prevalence, as a result of an ageing population (137). It highlighted the need for health and care services to be responsive to meet the needs of people living with long-term conditions to improve their health outcomes, provide better care management and cost-effective care, through improvements in clinical care and support for self-care (137). Following this, the Department of Health's Long Term Conditions Compendium (138) promoted supportive self-care and shared decision-making for people with long term-conditions, to enable them to become active participants in their care decisions. This was as part of an evidence based long-term conditions model, which encourages people to be more involved, informed, independent, confident and in control of their condition, in order to facilitate positive health and wellbeing outcomes (138).

A further report by the Department of Health, 'Living with Long Term Conditions: A Policy Framework,' (139) stipulated that SM should support people with long-term conditions with the knowledge and skills to manage their condition and enhance their health, wellbeing and clinical, emotional and social outcomes. It highlighted the importance of effective partnership between individuals, carers and care providers to support people to self-manage and provide value for money to the health service (139). The report recommended that commissioners should work to secure the provision of a range of evidence-based, formal and structured SM programmes and informal SM support systems, which are able to provide value for money and are effective in meeting the needs of individuals using them (139). It also recognised that different people require different methods and strategies for managing their condition and that a holistic needs assessment should inform what information, treatment, support and follow-up are required to allow people to self-manage. This would enable a tailored care plan to be constructed, which is specific to the needs and abilities of individuals (139).

These policy documents illustrate the increasing importance of tailored SM support for people with chronic illness, to respond appropriately to their needs and provide cost-effective care (137-139), strengthening the rationale for this study. Having examined the literature and policy documents pertaining to SM in chronic illness, the six categories of SM that were used in this study will be specified, and the source of this categorisation identified.

## **2.7 Categories of SM**

When defining SM for the purpose of this study it was important to be inclusive as possible, to allow respondents to include anything that they felt constituted SM. However, it was recognised that some overlying structure was required for this definition, due to difficulties in placing SM within any clearly defined boundaries. As a result, following the examination of relevant literature around SM (34, 35, 63, 66, 67, 69, 127, 140-143), six categories of SM were selected. These were diet, exercise, CAM, psychological therapies, support groups and spirituality/religion. It was felt that these categories were broad enough to incorporate all of the main areas considered to be SM, whilst at the same time maintaining some cohesiveness in their definition. To ensure inclusivity, respondents were also given the opportunity to add any additional practices that they considered to be SM when they completed the questionnaire (appendix 3). More details of how the SM categories were developed are detailed in section 4.3.4.

## **2.8 Conclusion**

This chapter has set the scene for answering the research question around exploring patterns of SM uptake in cancer survivors and asking ‘who does what and why?’ It is

important that ways of incorporating SM practices and interventions into cancer survivors' daily lives are examined to try to improve their health outcomes and to relieve the financial, political and clinical pressures which are being placed on healthcare organisations. However, many difficulties, opportunities and challenges are involved in trying to integrate SM alongside biomedicine, which is heavily embedded in the principles of evidence-based medicine (76). Nonetheless, it can be argued that the value of many SM practices can often be measured outside of these standardised biomedical parameters. Though a wide and broad-ranging concept, for the purpose of this study SM has been positioned in a healthcare context, being viewed as a lifestyle behaviour which has the potential to positively impact on cancer survivors' health, QoL and wellbeing. The positioning of SM and cancer survivorship alongside other chronic illnesses has been recognised and is important in placing the study findings within the context of this wider body of literature.

## **2.9 Chapter Summary**

Chapter 2 began by providing an overview of SM within the context of cancer survivorship, exploring the potential need for SM interventions within the modern healthcare system. It then presented arguments for and against integrating SM practices alongside biomedicine in relation to their evidence-base. A discussion of how SM has been framed and can be understood, within the wider context of policy and chronic illness, has been detailed. Finally the six categories of SM chosen for use in the study have been specified, before the chapter's conclusion.

Chapter 3 now builds on this background chapter by reporting on a systematic review and meta-analyses which was carried out to examine in more depth one of the six categories of SM (diet, exercise, CAM, psychological therapies, support groups, spirituality/religion) used in the study, CAM, and its impact on the QoL of cancer survivors. The reasons for focusing on CAM rather than another of the SM categories have been discussed in Chapter 1 (section 1.5), as the review explores the use of multiple types of CAM use in cancer survivors, something which previous systematic reviews have not reported on. As discussed in this chapter, SM practices have the potential to improve the QoL of cancer survivors and the following review attempts to assess whether, and what types of, CAM improve QoL in this population group.

CHAPTER 3. THE EFFECT OF  
COMPLEMENTARY AND  
ALTERNATIVE MEDICINE ON  
THE QUALITY OF LIFE OF  
CANCER SURVIVORS: A  
SYSTEMATIC REVIEW AND  
META-ANALYSES

*A paper based on the work presented in this chapter has been published as:*

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### **3.1 Introduction to Chapter**

This chapter will present the findings from a systematic review and meta-analyses which explored whether CAM improves the QoL of cancer survivors. After providing a brief explanation of why this research is needed, the chapter moves on to detail the study's methods including the search criteria, study selection methods and data extraction and synthesis methods. It then reports on the study findings, detailing the study characteristics, the risk of bias of the included studies, a description of the interventions and controls and the effectiveness of the CAM interventions on QoL. A discussion of the findings from the review is then presented and strengths and limitations are acknowledged, before the chapter concludes.

Of the six categories of SM – diet, exercise, CAM, psychological therapies, support groups and spirituality/religion - CAM was selected as the focus for this systematic review. This was because, CAM, alongside spirituality/religion, appeared to be the least researched SM practice in terms of its impact on the QoL of cancer survivors. In addition, most of the studies looking at the impact of CAM on QoL reviewed cancer patients' still undergoing active treatment or receiving terminal or palliative care (38, 40). The reviews also focused on the effectiveness of individual types of CAM (36, 40), rather than looking at multiple CAM practices. As CAM is known to be more popular in cancer patients than the normal population (33-35), it seemed

appropriate to examine its impact on cancer survivors' QoL, so as to provide an evidence-base for its effectiveness.

Although many of the benefits of CAM identified by cancer patients (49, 50, 127, 144) cannot be measured from a biomedical perspective, it is still important to provide some sort of empirical evidence for their potential benefits in improving QoL. As discussed in Chapter 1 (section 1.3), the epistemological perspective chosen to approach this thesis is embedded in constructivism, which recognises the value of the interaction between objective and subjective realities in the formation of meaning (6). However, it is important to recognise the value of alternative epistemological perspectives when carrying out research. Different research methods are weighted differently in terms of their impact on policy and practice, with systematic reviews widely considered to be the most valid in providing answers to research questions (8). The usefulness of a positivist approach when gathering research around the effectiveness of CAM in improving QoL demonstrates this, providing a credible evidence-base, on which justifications for the use of CAM can be argued for and against. This type of empirical evidence is of value within the context of this thesis, demonstrating the ability to engage critically with epistemological debates, as well as pragmatically recognising the value of using different research methods to engage with different research perspectives.

### **3.2 Background**

As noted in Chapter 2 a growing ageing UK cancer population has emerged in recent years (41) resulting in cancer survivors experiencing long-term sequelae from their cancer and treatment, which can manifest in the form of both physical and psychological symptoms and side-effects (48-50). Many cancer survivors experience decreased psychological

wellbeing as a result of feeling disconnected and alone once their cancer treatment has ceased, negatively impacting on their QoL (52, 56). The QoL of cancer survivors can be difficult to compare across different studies due to the multitude of scales that have been designed to evaluate it. However, in recent years more rigorous QoL tools have been developed, and the importance of recognising its value is reflected by the increasing number of studies specifying QoL as an outcome measure (145).

CAM has previously been defined as:

*'A variety of different medical systems and therapies based on the knowledge, skills and practices derived from theories, philosophies and experiences used to maintain and improve health, as well as to prevent, diagnose, relieve or treat physical and mental illnesses. CAM has been mainly used outside conventional health care, but in some countries certain treatments are being adopted or adapted by conventional health care'* (146).

CAM encompasses a wide range of therapies including acupuncture, homeopathy, meditation, chiropody, reflexology and massage therapy (50). It has often been utilised by cancer patients as a way of regaining control over their bodies, developing therapeutic relationships with care providers, alleviating side-effects from treatment and improving QoL (49, 50). Having a strong belief in CAM, seeing CAM as a last resort and finding hope from using CAM therapies have also been cited as reasons for uptake (49, 127, 144). Previous studies have suggested that cancer patients have a higher use of CAM than the

normal population (34, 35, 56). It is estimated that across Europe 36% of cancer patients use some form of CAM (147) and a recent systematic review examining the number of cancer patients using CAM across North America, Australasia and Europe found the combined prevalence across studies to be even higher at 40% (148).

Despite this, little work has focused on the effect of CAM on QoL in cancer *survivors*, with the majority of systematic reviews examining its effect on people still under curative treatment (36-38, 40, 149-154). The aim of this systematic review was therefore to assess whether and what type of CAM improves QoL in cancer survivors.

### **3.3 Methods**

The systematic review was registered with PROSPERO (registration number CRD42012002017) (155). The PRISMA statement was followed (156, 157).

#### **3.3.1 Criteria for Considering Studies for this Review**

Types of Studies:

All RCTs, quasi-RCTs and controlled before and after studies were considered for inclusion in this review. Observational cohort studies in which voluntary CAM users were compared with CAM non-users were excluded.

Types of Participants:

The population was limited to adults'  $\geq 18$  years of age, with a previous cancer diagnosis who had finished their cancer treatment when the intervention was initiated and were not undergoing palliative or terminal supportive care. The review aimed to include all types of cancer diagnosis. If  $\geq 50\%$  of study participants had completed their cancer treatment at the start of the intervention, the study was deemed eligible for inclusion.

Types of Interventions:

This review included studies where any type of CAM was used in the intervention group with QoL measured using a validated instrument and including a control group without any CAM interventions. For the purpose of this review an intervention was classified as being CAM if it met the category criteria outlined by the US National Centre for Alternative and Complementary Medicine (NCCAM). These categories are natural products, mind and body medicine, manipulative and body based practices, movement therapies, traditional healers, energy fields and whole medical systems (158).

Primary Outcome:

All studies were required to report QoL as a primary or secondary outcome measure to be eligible for inclusion.

The primary outcome for this review was changes in QoL in cancer survivors who had undertaken a CAM intervention, compared to those who had not. This review focused on overall QoL and two of its major domains - physical and mental QoL. Among the studies reviewed, overall QoL is measured by both the European Organisation for Research and Treatment of Cancer (EORTC) (159) and the Functional Assessment of General Health-Breast or General (FACT B and FACT G) (160). The physical and mental domains of QoL are covered by subscales of these questionnaires and additionally the Short Form 36 (SF-36).

Secondary Outcome:

The secondary outcome for this review was adverse events. An adverse event in this context referred to any harm caused to participants attributable to the CAM intervention.

### **3.3.2 Search Methods for Identification of Studies**

A search of the following databases was initially carried out on 23/01/2012:

MEDLINE, CENTRAL, CINAHL, PSYCHINFO and EMBASE.

Search terms were combined as in the following:

(‘Cancer patients’ OR ‘cancer survivors’ OR ‘oncology patients’)

AND (‘quality of life’ OR ‘wellbeing’)

AND (‘CAM’ OR ‘complementary medicine’ OR ‘complementary therapies’ OR ‘alternative medicine’ OR ‘alternative therapies’ OR ‘acupuncture’ OR ‘yoga’ OR

‘homeopathy’ OR ‘herbal medicine’ OR ‘phytotherapy’ OR ‘meditation’ OR ‘mindfulness’ OR ‘vitamin supplements’).

Both text words and indexed terms (such as MeSH) were used and they were modified as necessary in each database. The ClinicalTrials.gov database was also searched using the above terms to identify any finished but not yet published trials, as well as any trials that were still ongoing.

The search was updated and expanded on 20/02/2013 with the use of additional terms to cover herbal medicines commonly used by cancer patients (161):

(‘Medicinal plants’ OR ‘plant extracts’ OR ‘aloe’ OR ‘ayurvedic medicine’ or ‘traditional Chinese medicine’ or ‘black cohosh’ or ‘flower remedies’ OR ‘carctol’ OR ‘chaparral’ OR ‘echinacea’ OR essiac’ OR ‘green tea’ OR ‘St John’s wort’ OR ‘mistletoe’).

Searches were limited to papers published from 1990 onwards due to the relatively new focus of CAM on QoL of cancer survivors making it unlikely that relevant articles would be found prior to this time period. Articles of all languages were considered.

### **3.3.3 Selection of Studies**

All studies identified were screened for inclusion based on the study selection criteria. All titles and abstracts of articles which clearly did not fulfil the eligibility criteria were

excluded. Full text copies of the remaining articles were obtained and those not meeting the eligibility criteria were discarded. Those that remained were included in the systematic review. To ensure rigour in the study selection process two reviewers (CS, TT) independently checked through all the records identified to minimise bias. Any papers not unanimously excluded or included were re-examined by both reviewers until a consensus was reached. Figure 3.1 illustrates the study selection process.

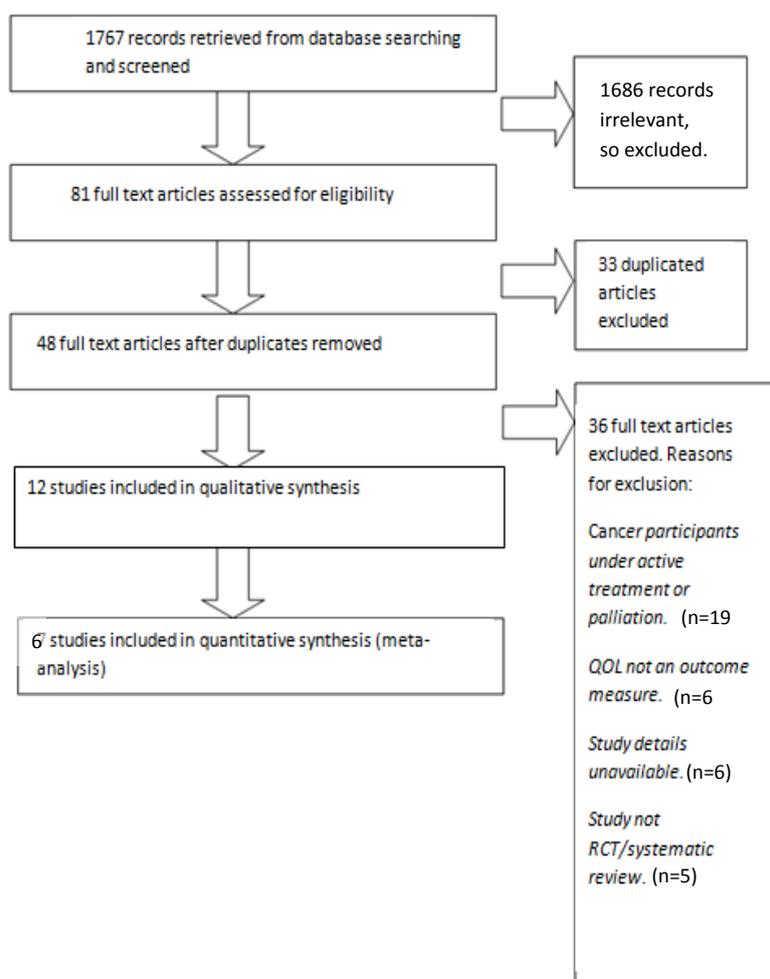


Fig 3.1: Flow of Information through the Different Stages of the Systematic Review. Any unreported information on the study's eligibility was sought by contacting the study author. If no response was given, the article was excluded from the review.

### **3.3.4 Data Extraction and Assessment of Risk of Bias**

Data from included studies was extracted independently, discussed and collated, by two reviewers (CS and TT, YFC, or NG) using a data extraction form (appendix 2). The quality of the studies was independently assessed by two reviewers (CS, TT) using the Cochrane Collaboration's Tool for Assessing Risk of Bias (162). Any disagreement between the reviewers about the criteria or level of bias was discussed until a mutual decision was reached. Where necessary the study authors were contacted to obtain more detailed information.

### **3.3.5 Missing Data**

Authors of six studies were contacted to obtain data to determine their eligibility for inclusion in the review and/or data required for meta-analyses. Four authors provided the information requested (163-167). Two studies where the authors were unable to provide sufficient data were excluded (168, 169). Missing statistics were calculated where possible from other available statistics and where standard deviations of change values were not reported they were calculated using a published method for imputing standard deviation (170).

### **3.3.6 Data Synthesis**

Studies with sufficient data which were judged to be sufficiently similar were pooled within each type of CAM according to the aforementioned categories defined by NCCAM (158), using RevMan 5.0 software. A standardised mean difference was calculated using a

random effects model given the different QoL scales used between studies and the diversity of patient population and interventions. Tests for homogeneity within CAM groups were carried out using Chi<sup>2</sup> tests and I<sup>2</sup> statistic was also computed.

Due to the large differences in follow-up time between studies, data was analysed to reflect short-term (3 months) and longer-term results ( $\geq 6$  months).

### **3.4 Results**

#### **3.4.1 Characteristics of Included Studies**

Thirteen studies met the inclusion criteria. Characteristics of these studies are shown in table 3.1. In total 1228 cancer patients were included: all were RCTs, including one unpublished study. Participants in all of the studies had previously received anti-cancer treatment with surgery, chemotherapy and/or radiotherapy. Ten of the thirteen studies involved cancer patients with a prior diagnosis of breast cancer. The average age of participants ranged from 49.8-63.9 years. Five studies evaluated the impact of yoga on QoL, three evaluated mindfulness/meditation, one meditation and yoga, one homeopathy, one energy healing, one medical qigong and one mistletoe therapy. Eleven studies were carried out in North America, one in Australia and one in Europe.

### **3.4.2 Risk of Bias in Included Studies**

Overall nine studies were deemed to have a high risk (163, 166, 171-177) and one a low risk of bias (167). Three studies had an unclear risk of bias due to insufficient information being provided (178-180). Table 3.2 provides a summary of the risk of bias assessment for the 13 studies. The proportion of information from studies at high or unclear risk of bias was deemed sufficient to affect interpretation of results.

### **3.4.3 Descriptions of Interventions and Controls**

*Yoga:* Of the five studies using yoga as their main intervention, three practised hatha style yoga (171, 174, 179), one restorative yoga (172) and one Iyengar yoga (175) and all were taught by experienced yoga instructors. All interventions were compared with waitlist control group and lasted  $\leq 12$  weeks, apart from one six month intervention (174). Yoga sessions were practiced at least weekly across studies, lasting 1-1.5 hours. Four held community yoga classes, whilst one used the hospital's cancer centre (179). Two studies encouraged additional yoga practice at home and supplied additional multimedia support (174, 179).

*Meditation/Mindfulness:* Two studies practised Mindfulness Based Stress Reduction (MBSR) in their intervention group versus a waitlist control group (166, 177), whilst a third used transcendental meditation versus a control group that received basic breast cancer literature (163). One study (166) incorporated a second intervention group consisting of a nutrition education programme. All meditation techniques were taught by

trained instructors and additional home practice monitored through participant self-report was encouraged in two studies (163, 177). The classes were either hospital based (166, 177) or occurred in a community transcendental meditation centre (163). Intervention length and timings varied, with one having seven sessions of 1-1.5 hours over two years(163), the second 8-12 sessions lasting 2-7.5 hours over five months (166) and the third having two hour weekly sessions over six weeks (177). A further study was also identified examining the efficacy of MBSR in treating sleep disturbance in women with breast cancer (181). QoL was measured using the FACT-B but results relating to QoL were not reported. Consequently this study was excluded from the review.

*Yoga and Meditation:* One study (173) evaluated an intervention which included meditation, yoga, mindful communication skills and mindful breast examination/awareness. The intervention was undertaken in a hospital by a physician formally trained in yoga and MBSR. Nine sessions spanned eight weeks and lasted 2-4 hours and daily meditation and/or yoga was encouraged and reported through self-completion logs.

*Homeopathy:* This study (167) consisted of two homeopathic intervention groups, one consisting of a placebo combination medicine and a verum single remedy and the other a verum combination medicine and a placebo single remedy, as well as a placebo control group. The medications were distributed over one year and participants were asked to self-medicate daily. Compliance was evaluated through asking participants to return any unwanted medication at study visits.

SM Strategies for Cancer Survivors: Who Does What and Why?

Table 3.1: Characteristics of RCTs Included in the Review

Study	Cancer Type	Study Country	Gender (% female)	Number of Patients - Intervention (I): Control (C)	Length of Intervention	Tool Used for QoL	Mean Age of Participants (years)
Yoga							
Banasik et al. (2011)	Breast	USA	100	9:9	Eight weeks	FACT-B: Overall QoL	62.9
Culos-Reed (2006)	85% breast, 15% Unknown	Canada	95	20:18	Seven weeks	EORTC QLQ-C30: Overall QoL not reported	50
Danhauer et al. (2009)	Breast	USA	100	22:22	Ten weeks	FACT-B: Overall QoL	55.8
Moadel et al. (2007)	Breast	USA	100	108:56	Twelve weeks	FACT-G: Overall QoL	54.8
Littman et al. (2012)	Breast	USA	100	32:31	Six months	FACT-G: overall QoL	60
Meditation/mindfulness							
Henderson et al. (2012)	Breast	USA	100	53 (I1):52 (I2):58 (C)*	Five months	FACT-B : Overall QoL	49.8
Lengacher et al. (2009)	Breast	USA	100	41:43	Six weeks	SF-36: MCS and PCS	57.5
Nidich et al. (2009)	Breast	USA	100	64:66	Two years	FACT-B: overall QoL	63.9

SM Strategies for Cancer Survivors: Who Does What and Why?

Study	Cancer Type	Study Country	Gender (% female)	Number of Patients - Intervention (I): Control (C)	Length of Intervention	Tool Used for QoL	Mean Age of Participants (years)
Meditation and yoga							
Lerman et al. (2012)	Breast 70.6%, other cancers 29.4%	USA	100	53:24	Eight weeks	EORTC QLQ-30: overall QoL	57.0
Homeopathy							
Jacobs et al. (2005)	Breast	USA	100	30 (I1):26 (I 2):27 (C)**	One year	SF-36, only subscale general health reported	55.6
Energy healing							
Jain (2009)	Breast	USA	100	17:14	Four weeks	FACT-B: overall QoL	52.5
Medical qigong							
Oh et al. (2010)	Breast 37.7%, other cancers 62.3%	Australia	57.5	79:83	Ten weeks	FACT-G: Overall QoL	60
Mistletoe Therapy							
Schwiersch (1999)	Breast 100%	Europe	100	171 Intervention and control not known.	Four weeks	SF-36	Not reported.

SM Strategies for Cancer Survivors: Who Does What and Why?

Table 3.2: Risk of Bias for Studies Included in the Systematic Review

Study	Random Sequence Generation	Allocation Concealment	Blinding of Participants and Personnel	Blinding of Outcome Assessment	Incomplete Outcome Data	Selective Reporting	Other Sources of Bias	Total Risk of Bias Within Study
<b>Yoga</b>								
Banasik et al. (2011)	Unclear	Unclear	High Risk	Unclear	Low Risk	Low Risk	Low Risk	<b>High Risk of Bias for One or More Key Domains High Risk of Bias for One or More Domains High Risk of Bias for One or More Key Domains Unclear Risk of Bias for One or More Key Domains High Risk of Bias for One or More Key Domains</b>
Culos-Reed et al. (2006)	High Risk	Unclear	High Risk	Unclear	Low risk	Low Risk	Unclear	
Danhauer et al. (2009)	Unclear	Unclear	High Risk	Unclear	Low Risk	Low Risk	Low Risk	
Moadel et al. (2007)	Unclear	Unclear	Unclear	Unclear	Unclear	Low Risk	Low Risk	
Littman et al. (2012)	Low Risk	Unclear	High Risk	Unclear	Low Risk	Low Risk	Low Risk	
<b>Meditation/Mindfulness</b>								
Henderson et al. (2012)	Unclear	Unclear	High Risk	Unclear	Unclear	Low	High Risk	<b>High Risk of Bias for One or More Domains High Risk of Bias for One or More Domains High Risk of Bias for One or More Key Domains</b>
Lengacher et al. (2009)	Unclear	Low Risk	High Risk	Unclear	Low Risk	Low Risk	Low Risk	
Nidich et al. (2009)	Low Risk	Low Risk	High Risk	Low Risk	Unclear	Low Risk	Low Risk	

SM Strategies for Cancer Survivors: Who Does What and Why?

Study	Random Sequence Generation	Allocation Concealment	Blinding of Participants and Personnel	Blinding of Outcome Assessment	Incomplete Outcome Data	Selective Reporting	Other Sources of Bias	Total Risk of Bias Within Study
Meditation and Yoga								
Lerman et al. (2012)	Low Risk	Unclear	High Risk	Unclear	Low Risk	High Risk	Low Risk	High Risk of Bias for One or More Key Domains
Homeopathy								
Jacobs et al. (2005)	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk	Low Risk of Bias for All Key Domains
Energy Healing								
Jain (2009)	Low Risk	Low Risk	Low Risk	Unclear	Low Risk	Low Risk	Low Risk	Unclear Risk of Bias for One Key Domain
Medical Qigong								
Oh et al. (2010)	Low Risk	Unclear	High risk	Unclear	Low Risk	Low Risk	Low Risk	High Risk of Bias for One or More Domains
Mistletoe Therapy								
Schwiersch (1999)	Low Risk	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear Risk of Bias for One or More Domains

*Energy Healing:* This hospital based study (180) compared an energy healing intervention with a mock-healing control group. Two hour long sessions over eight weeks were performed. Energy healing practitioners were used in the intervention group, whilst mock healing was undertaken by researchers who were taught specific hand placement techniques.

*Medical Qigong:* The study (176) using a medical qigong intervention versus usual care control group lasted ten weeks and consisted of 20 sessions lasting 90 minutes. Medical qigong was taught by an experienced instructor in a hospital setting. Participants were encouraged to undertake home practice daily. Compliance was monitored with a participant self-completion diary.

*Mistletoe Therapy:* This unpublished study (178), identified through a Cochrane review, was based in a rehabilitation clinic and compared subcutaneously administered mistletoe therapy versus placebo in breast cancer patients who had previously completed adjuvant treatment. Twice weekly treatments over four weeks, followed by a four week observation period, were undertaken.

#### **3.4.4 Effectiveness of CAM Interventions on QoL**

Table 3.3 provides a narrative summary of the effects of the interventions across the studies. Overall QoL was reported in eleven studies, physical QoL in seven studies and mental QoL in eight studies. Quantitative data, including results of meta-analyses, are

shown in figures 3.2 to 3.5. Data were available for meta-analyses from only six of the 13 studies, including four of the yoga studies (overall, physical and mental QoL at 3 months) and two of the meditation/mindfulness studies (overall QoL at 6 months).

*Yoga:* Of the five yoga studies four reported on overall QoL. The pooled estimate of three studies shows a statistically significant difference in favour of yoga interventions at 3 months and the results were consistent across studies (figure 3.2; standardised mean difference 0.51, 95% CI 0.18 to 0.84,  $I^2=0\%$ ). Only one study reported 6-month overall QoL and no significant difference was found. No significant differences in physical QoL were found between intervention and control in any of the four studies. Pooled estimate also showed no significant effect at 3 months (figure 3.4; standardised mean difference 0.20, 95% CI -0.15 to 0.55,  $I^2=0\%$ ). All five studies reported on mental QoL. The pooled result of four studies shows statistically significant differences in favour of the CAM intervention at 3 months (figure 3.5; standardised mean difference 0.46, 95% CI 0.14 to 0.77,  $I^2=0\%$ ).

*Meditation/Mindfulness:* Of the three studies two reported on overall QoL (163, 166). The pooled result shows a small but statistically significant improvement in overall QoL (figure 3.3; standardised mean difference 0.32, 95% CI 0.06 to 0.57,  $I^2=0\%$ ) for the intervention group compared with control at 5 to 24 months. One study reported significant improvements in physical QoL in the intervention group compared to control at six weeks and both studies reporting mental QoL found it to be significantly improved in the intervention group compared to the control (at 6 weeks and 2 years) (163, 177).

Yoga and Meditation: This study reported significant improvements in overall QoL in the intervention group between baseline and follow up. However no numerical data was reported on differences between the intervention and control groups (173).

Homeopathy: This study reported only on the general health subscale of the SF-36 finding a significant increase at one year in both homeopathy intervention groups versus control (167).

Energy Healing: A greater improvement in overall QoL in the intervention group versus control was found in this study, though this did not reach statistical significance (180).

Medical Qigong: This study found significant differences in the intervention group versus control when measuring overall QoL and both the physical and mental domains of QoL using the FACT-G scale.

Mistletoe Therapy: This study only reported details of the general health subscale of the SF-36 and found no significant differences between the intervention and control group. No numerical results were provided (177).

Adverse effects were mentioned in two studies, one in which there was a significant increase in headaches in the group receiving homeopathic combination ( $p=0.04$  at 6

months and  $p=0.03$  at 12 months) (167). The other study reported localised reactions around the injection site in the intervention group receiving subcutaneous mistletoe therapy. No numerical data from this study was available (178).

## **3.5 Discussion**

### **3.5.1 Summary of Main Findings**

This review has examined the effects of CAM on QoL in cancer survivors who have ceased active cancer treatment. Although the findings suggest that a number of CAM interventions may improve QoL in cancer survivors, the credibility of the results was weakened by the moderate to high risk of bias for most studies. In addition, the number of studies included for each type of CAM intervention was small, thus it was not possible to assess or rule out publication bias and chance findings.

This review differs from other published systematic reviews in this area as it has a broader scope in terms of the types of CAM. It also focuses purely on cancer survivors, whereas most other existing research has examined cancer patients still undergoing active cancer treatment or patients in the palliative or terminal phases of their disease (36-40). Despite this broader coverage of CAM, only a relatively small number of studies were found that focused on cancer survivors. The finding highlights a significant gap in the evidence-base for the effectiveness of CAM on QoL in cancer survivors.

## SM Strategies for Cancer Survivors: Who Does What and Why?

Table 3.3: Observed Effects of the Different CAM Interventions on QoL

	Overall Risk of Bias	Overall QoL	Physical QoL	Mental QoL
<b>Yoga</b>				
Banasik et al. 2011	High Risk	N/A	Physical wellbeing subscale of FACT-B at eight weeks, no significant difference vs. control, mean difference -0.05, CI 95% -0.76 to 0.66	Emotional wellbeing subscale of FACT-B at eight weeks, no significant difference vs. control, mean difference -0.19, CI 95% -31.30 to 30.92
Culos-Reed et al. 2006	High risk	EORTC, significantly better than control at 7 weeks, F=7.36, p<0.01	N/A	Emotional function domain of EORTC significantly better at 7 weeks than control, F=6.90, p<0.05).
Danhauer et al. 2009	High risk	FACT-B, at 10 weeks, no significant difference vs. control mean difference 12.60, 95% CI -1.77 to 26.07, p=0.052	Physical subscale of FACT-B, no significant difference vs. control, mean difference 2.40 95% CI -1.56 to 6.36, p=0.86	Emotional subscale of FACT-B, significantly better at three months than control, mean difference 3.0 95% CI 0.11 to 5.89,
Moadel et al. 2007	Unclear risk	(From post-hoc analysis). FACT-G, no significant difference vs. control at 3 months, mean difference 8.70, 95% CI -1.74 to 19.14	Physical subscale of FACT-G, no significant difference vs. control at 3 months, mean difference 0.98, 95% CI -2.07 to 4.03	Emotional subscale FACT-G, no significant difference vs. control at three months, mean difference 2.24, 95% CI -0.36 to 4.84
Littman et al. 2012	High risk	FACT-G, no significant difference vs. control at six months, mean difference 1.40, 95% CI -5.22 to 8.02, p>0.3	Physical subscale of FACT-G, no significant difference vs. control, mean difference 0.60, 95% CI -1.13 to 2.33, p>0.3	Emotional subscale of FACT-G, no significant difference vs. control, mean difference 0.00, 95% CI -1.64 to 1.64, p>0.3
<b>Meditation/mindfulness</b>				
Henderson et al. 2012	High risk	FACT-B at 5 months, no significant difference vs. control, mean difference 3.0 95% CI -2.56 to 8.56	N/A	N/A
Lengacher et al. 2009	High risk	N/A	SF-36 PCS at 6 weeks, intervention 50.3 vs. control 46.9, mean difference 3.40, 95% CI 1.41 to 5.39	SF-36 MCS, at 6 weeks, intervention 53.0 vs. 50.1, mean difference 2.90, 95% CI 0.15 to 5.65
Nidich et al. 2009	High risk	FACT-B, at two years, significantly better than control, mean difference 3.62, 95% CI 0.68 to 6.56, p=0.037).	Physical wellbeing subscale FACT-B, at 2 years, no difference between intervention and control, mean difference -0.69 95% CI -1.97 to 0.59.	Emotional wellbeing subscale FACT-B, at 2 years, significantly better vs. control, mean difference 1.05, 95% CI 0.05 to 2.05.

SM Strategies for Cancer Survivors: Who Does What and Why?

	Overall Risk of Bias	Overall QoL	Physical QoL	Mental QoL
<b>Yoga and Meditation</b>				
Lerman et al. 2012	High risk	EORTC at 8 weeks, intervention group significantly improved between baseline and follow up, p=0.005, unlike control group, p>0.14. No numerical results for intervention vs. control reported.	N/A	N/A
<b>Homeopathy</b>				
Jacobs et al. 2005	Low risk	General health subscale of SF-36 only reported. Significant increase at 1 year in both homeopathy groups vs. control, p=0.02 (single versus placebo) p=0.03 (combination vs. placebo).	N/A	N/A
<b>Energy Healing</b>				
Jain 2009	Unclear Risk	FACT-B at four weeks, no significant difference vs. control over time mean difference 4.8, CI - 9.27 to 18.87.	N/A	N/A
<b>Medical Qigong</b>				
Oh et al. 2010	High risk	FACT-G at 10 weeks, significantly better vs. control, mean difference 8.99, 95% CI 7.51 to 10.47, p<0.001.	Physical wellbeing subscale FACT-G significantly better vs. control, mean difference 2.08, 95% CI 0.65 to 3.51, p<0.001	Emotional wellbeing subscale FACT-G significantly better vs. control, mean difference 1.55 95% CI 0.46 to 2.64, p<0.001
<b>Mistletoe Therapy</b>				
Schwiersch (1999)	Unclear	SF-36 at 8 weeks, no difference vs. control in overall QoL. Numerical data were not reported.	N/A	N/A

SM Strategies for Cancer Survivors: Who Does What and Why?

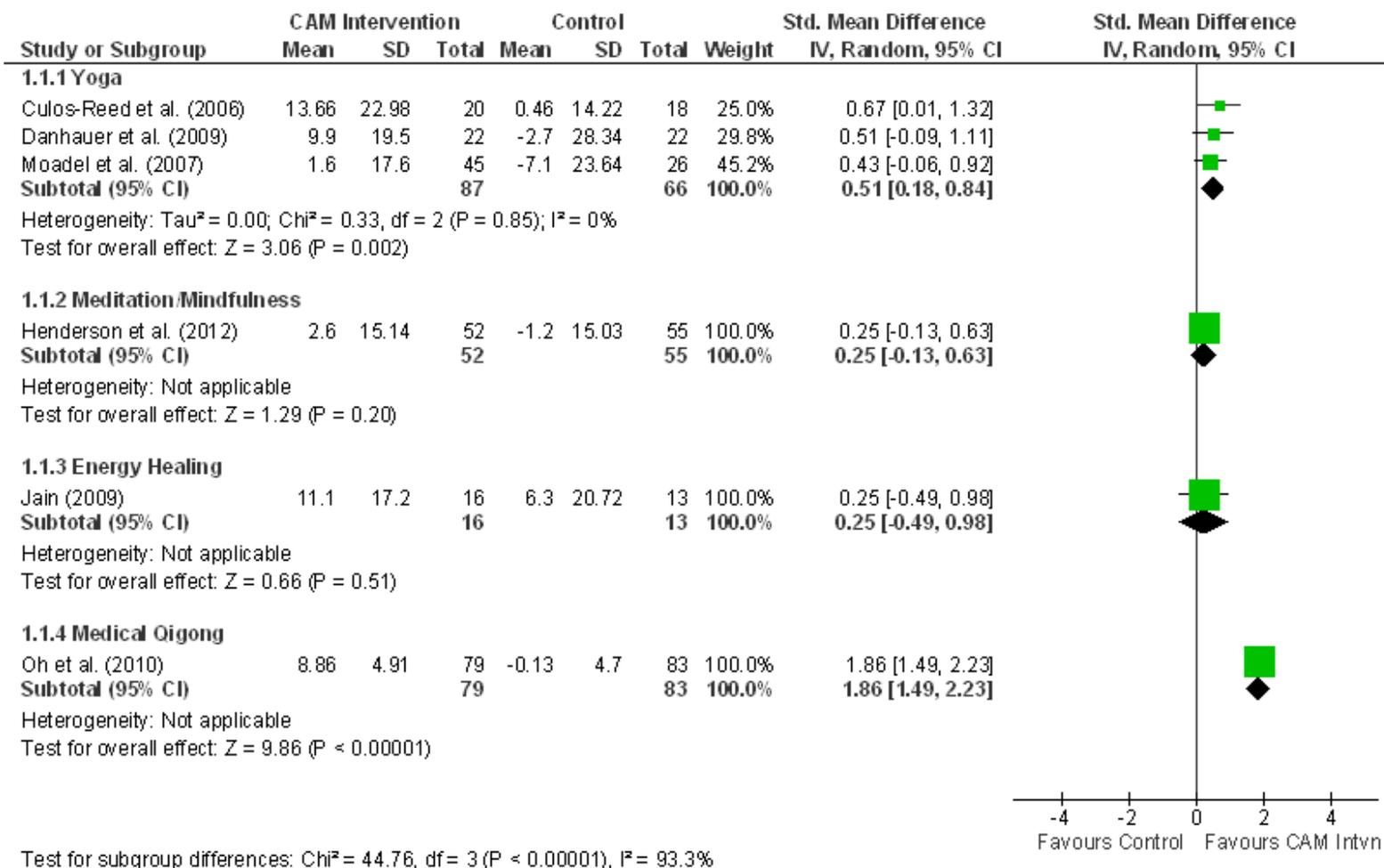


Figure 3.2: Changes from Baseline in Overall QoL at Three Months between Cancer Survivors Receiving CAM Intervention and Control

SM Strategies for Cancer Survivors: Who Does What and Why?

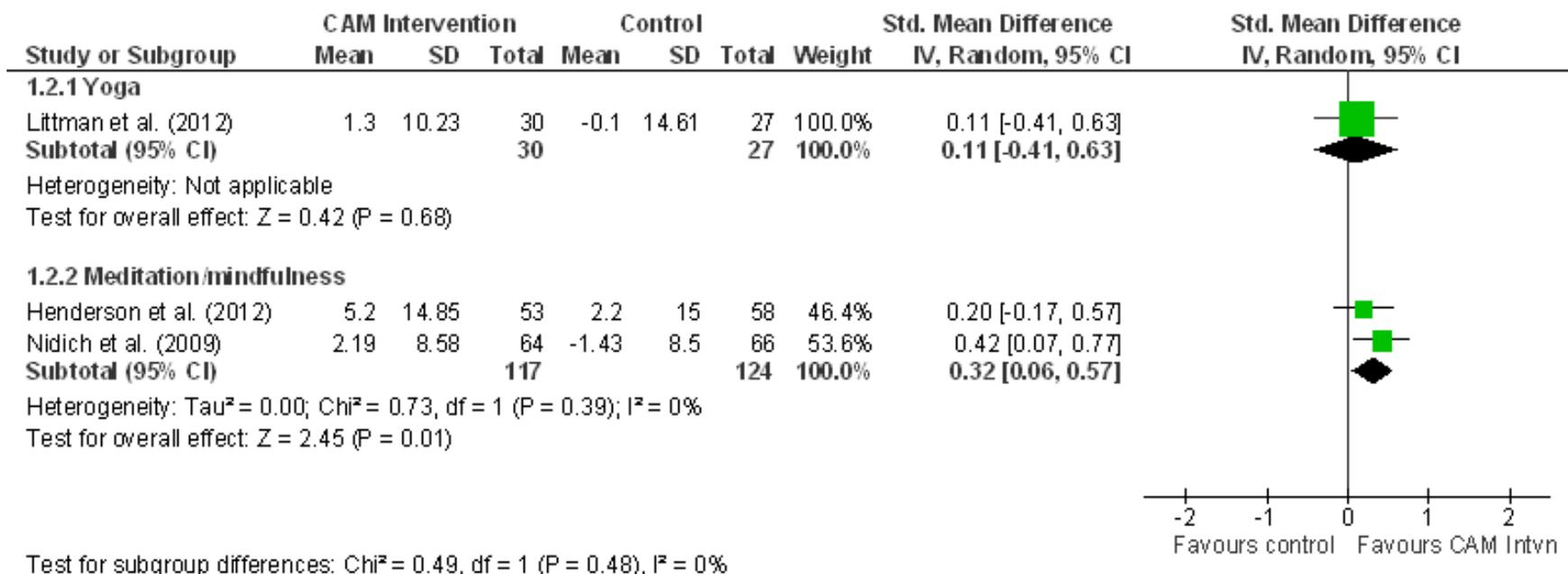


Figure 3.3: Changes from Baseline in Overall QoL at Six Months between Cancer Survivors Receiving CAM Intervention and Control

SM Strategies for Cancer Survivors: Who Does What and Why?

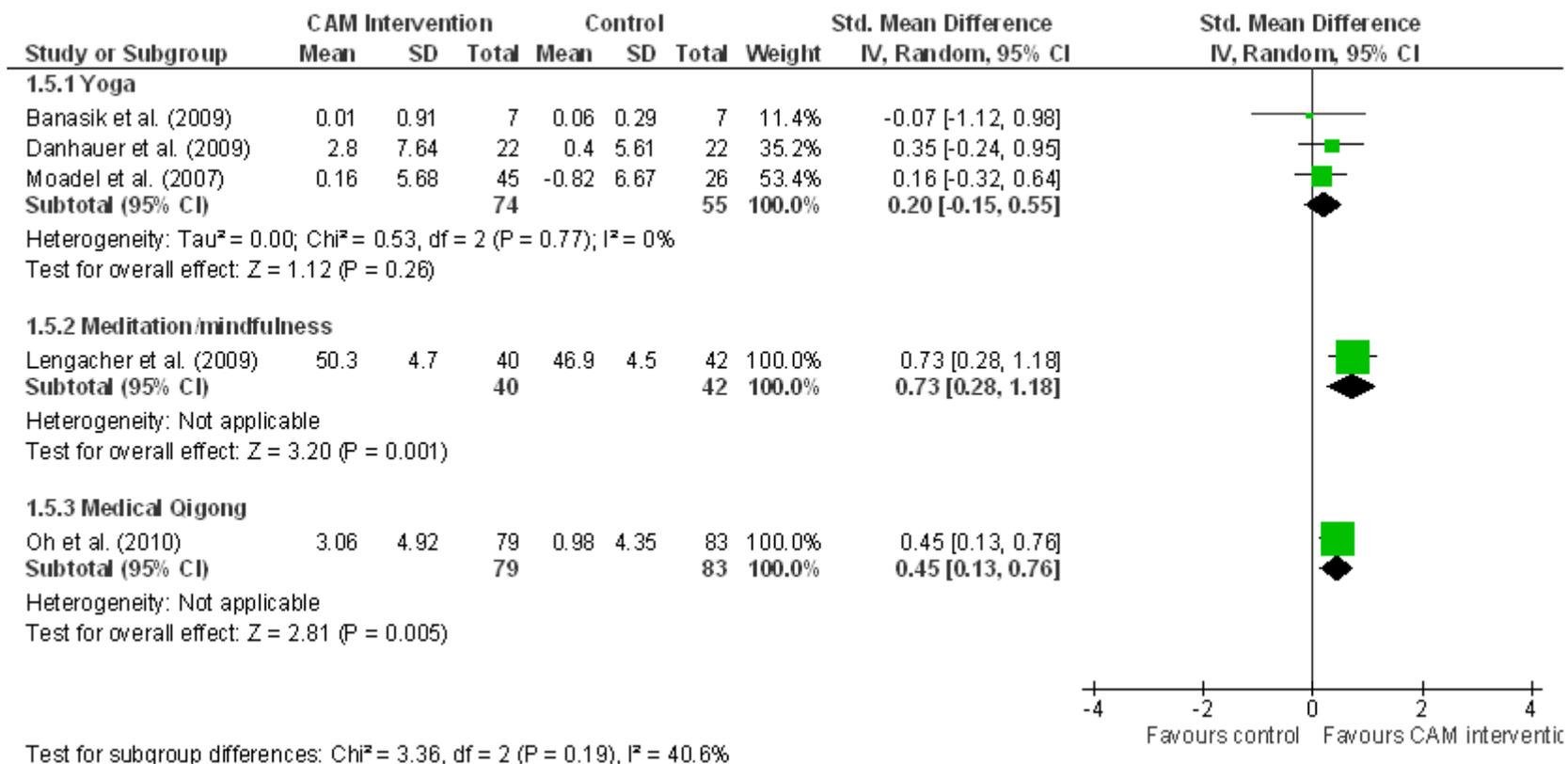


Figure 3.4: Changes from Baseline in Physical QoL at Three Months between Cancer Survivors Receiving CAM Intervention and Control

SM Strategies for Cancer Survivors: Who Does What and Why?

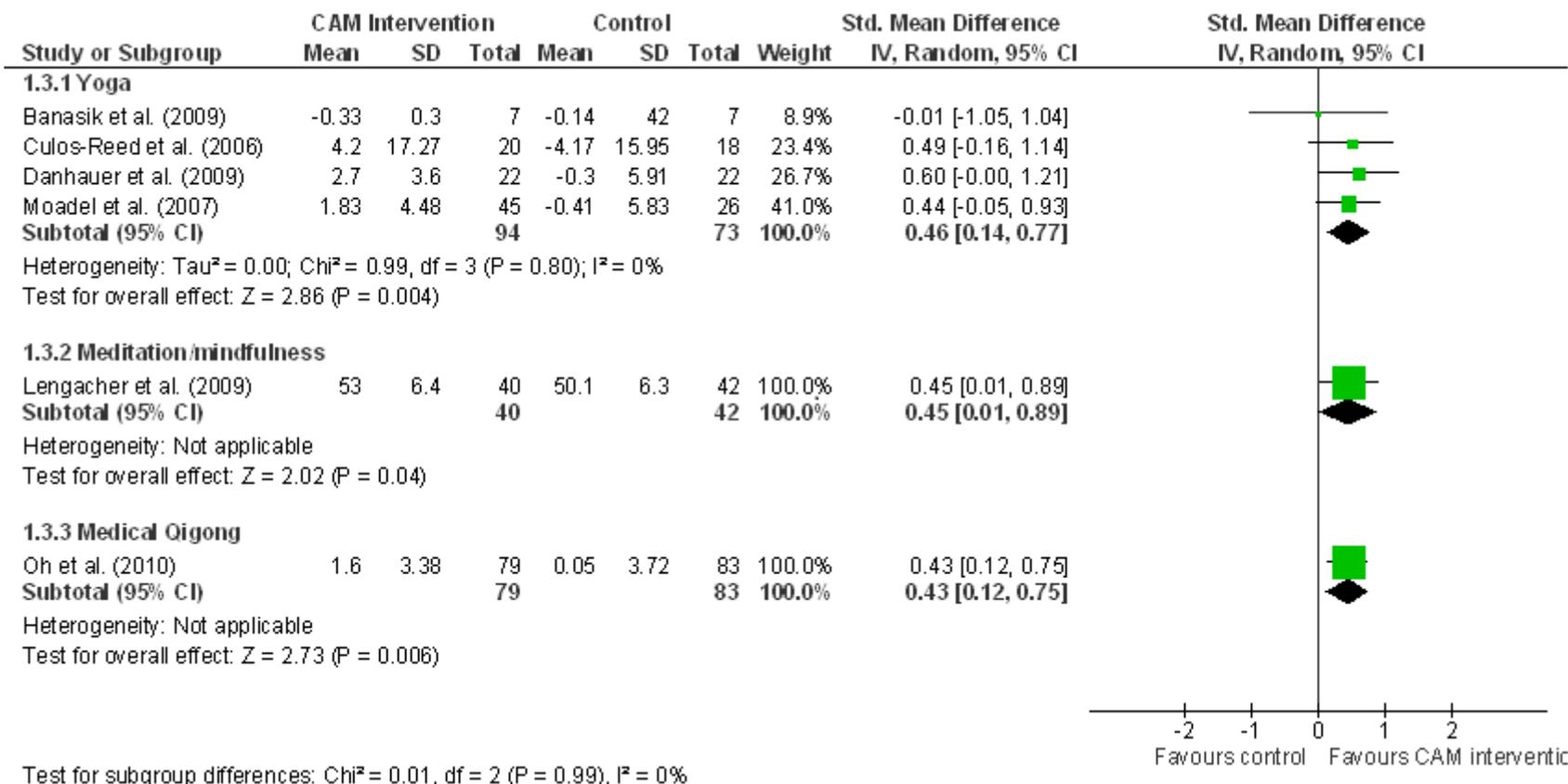


Figure 3.5: Changes from Baseline in Mental QoL at Three Months between Cancer Survivors Receiving CAM Intervention and Control

### **3.5.2 Evidence for Individual CAM**

Yoga appears to improve overall and mental QoL, but not physical QoL, according to the meta-analyses. Two recent reviews also covered the effects of yoga on QoL in cancer survivors (38, 150). Both included studies in which patients were still receiving active treatments. Culos-Reed et al. covered four of the five RCTs included in this review, but did not carry out meta-analyses (151). Based on various definitions of clinical significance, they concluded that yoga interventions hold promise for improving cancer survivors' well-being. By contrast, Cramer et al. stated there is evidence of efficacy for yoga only during active cancer treatment but not after completion of active treatments (36). However the finding was based on a subgroup analysis containing only two of the five studies identified in this review.

While the pooled estimate from this review's meta-analyses suggested a magnitude of effect that is clinically significant for yoga interventions (182), the results are based on studies of unclear or high risk of bias due to uncertainty in methods of randomisation, allocation concealment and blinding. The difficulty in blinding participants highlights a common challenge in separating out the true 'intervention effect' from a general 'trial effect' for many types of CAM. For example, the positive effect of yoga may come from the regular social interaction during the attendance of sessions rather than yoga itself. Future studies might benefit from incorporating a control group that features regular group sessions/social interactions to regulate the potential effects from these interactions.

Two published systematic reviews have examined mistletoe therapy (39, 148). Again both included studies in which patients were receiving active cancer treatments. Kienle et al. reviewed controlled clinical studies and found that the majority reported a QoL benefit for mistletoe therapy (39). They included 10 RCTs in which mistletoe therapy was independent (i.e. not concomitant) of conventional cancer treatment. However seven of these studies were conducted by a single centre and measured only 'self-regulation' rather than general QoL and none used a generic QoL tool. They were therefore not eligible for inclusion in this review. The majority of studies included in the Cochrane review on mistletoe therapy by Horneber et al. focused on patients who were receiving active cancer treatment or palliative care (38). Only one unpublished RCT, which found no significant differences between intervention and control groups, met this review's inclusion criteria. The quantity and quality of evidence is currently inadequate for an appropriate assessment of effectiveness for other types of CAM.

### **3.5.3 Limitations of this Review**

Every effort was made to provide a comprehensive and systematic review of the literature. However, it is possible that some studies may not have been captured in the search and screening process due the diversity of CAM and the difficulties in ascertaining whether cancer patients were still undergoing treatment. In addition, some of the information required for the review was not documented in the study papers, and contact with the study authors proved unfruitful.

The limited evidence identified in this review does not allow a comparison between different types of CAM. Nor is it possible to explore whether the effects of a CAM vary between survivors of different types of cancer, with different prior treatments or at different stages of survivorship. These questions need to be addressed with further research.

The majority of included studies only recruited breast cancer patients. Although breast cancer is the most prevalent UK cancer today (43), it cannot be assumed that the results directly apply to other cancer survivors. Breast cancer patients may hold more positive outlooks, demonstrate fewer treatment effects and have a higher QoL than patients with poorer prognoses (183, 184). Breast cancer survivors are almost all female and may hold different values towards CAM compared to males (34, 147).

### **3.6 Conclusion**

This review has identified significant gaps in the evidence base for the effectiveness of CAM on QoL in cancer survivors.

Further work in this field needs to adopt more rigorous methodology to help support cancer survivors to actively embrace SM and effective CAMs, without recommending inappropriate interventions which are of no proven benefit. There is a need to establish exactly what types of SM strategies cancer survivors are using throughout their cancer journey to enable research as to their individual benefit to be undertaken.

### **3.7 Chapter Summary**

Chapter 3 has presented the findings from a systematic review and meta-analyses exploring whether CAM improves the QoL of cancer survivors. It began by providing a rationale for the need to explore this issue, before outlining the methods used to undertake the systematic review and meta-analyses. The study findings have been presented in terms of the individual study characteristics, their risk of bias, a description of the interventions and controls used and the effectiveness of the CAM interventions on QoL in cancer survivors. A discussion of the findings from the review was then given and strengths and limitations considered, prior to the conclusion of the chapter.

Chapter 4 will now present the methods and the findings from the quantitative study, examining the prevalence and distribution of different types of SM practices in cancer survivors over time.

CHAPTER 4. THE PREVALENCE  
AND DISTRIBUTION OF SELF-  
MANAGEMENT PRACTICES IN  
CANCER SURVIVORS FROM PRE-  
DIAGNOSIS, THROUGH  
TREATMENT AND INTO  
SURVIVORSHIP

## **4.1 Introduction to Chapter**

This chapter presents the background, methods and findings from the questionnaire survey relating to the prevalence and distribution of SM practices in cancer survivors from pre-diagnosis, through treatment and into survivorship. The chapter begins by providing a rationale for exploring SM uptake and any associations with QoL, HLC and ability to work. It then details the questionnaire study design, outlining why a cross-sectional study design was chosen as well as discussing issues relating to population access and setting, sample size, data collection and analysis techniques, questionnaire design and ethical issues involved with the study. Results from the survey study are then presented. Demographic variations within the population group are identified and the prevalence and distribution of overall SM scores is reported. Any demographic differences between SM categories (diet, exercise, support groups, CAM, psychological therapies, spirituality/religion) are disclosed in relation to income, gender, age, ethnicity, treatment type and cancer type. Variations in SM uptake between the four subgroups of CAM (158) as classified by NCCAM are also detailed. A discussion of the study findings is then provided and study strengths and limitations are discussed, before the chapter concludes by highlighting the implications of the study findings for policy and practice.

## **4.2 Background**

UK cancer mortality rates have fallen from 213.8 per 100,000 in 1971 to 166.7 per 100,000 in 2012 and are predicted to fall to 141.5 per 100,000 by 2030 (185). People are now living six times longer after their cancer diagnosis than 40 years ago due to earlier detection rates and improved cancer treatments, with the median survival rate rising from one year in the 1970s to almost six years today (186). This emphasises the need to promote the integration of SM

strategies into cancer survivors' daily lives to help to alleviate the strain on trammelled NHS resources and healthcare professionals, who may face difficulties in meeting the demands of this ageing cancer population (3).

Despite increasing pressure to self-manage the consequences of their illness, many cancer survivors are not equipped with the appropriate resources to allow them to rehabilitate sufficiently (144). Accordingly, appropriate SM interventions designed to support cancer survivors in their transition through treatment into survivorship are required, to optimise their daily functioning, health outcomes and QoL. However before this occurs there is a need to examine exactly which SM practices cancer survivors are currently undertaking throughout this time-period. Once this has been established, mechanisms for incorporating SM practices into cancer survivors' lives can be considered based around a comprehensive understanding of the prevalence and distribution of the types of SM being undertaken by them, as well as the benefits and disadvantages associated with different types of SM practices.

As noted in section 2.2, the transition from cancer patient to cancer survivor can be a difficult one and is often marred by physical problems such as fatigue and pain and psychological problems such as anxiety and depression (48-50). Challenges can also arise in cancer survivors' social and working lives, as physical and mental changes experienced render them unable to participate fully in these areas of their lives (33, 187, 188). This can result in feelings of decreased confidence, self-worth and inadequacy as they are unable to fulfil work and social roles that they previously took for granted (116, 189). Fatigue is the most common side-effect for people who have undergone cancer treatment and is often severe enough to impact on their daily life by necessitating changes to their normal routine and their ability to carry out activities of daily living, as well as limiting their social activities (115, 120). As a

result there is a need to identify which SM strategies cancer survivors are using to try to help manage some of the side-effects from treatment and at what times throughout their cancer pathway.

Health professionals have a tendency to focus on the conventional medical approach to treating cancer due to limited time and resources given to addressing the more holistic aspects of cancer care (190, 191). However this lack of holistic care provision is often recognised by cancer patients, especially with regard to their unmet psychosocial needs which are frequently left unaddressed in medical consultations (190-192). Problems surrounding awareness of and access to psychological services throughout the UK are widespread and can often result in cancer patients missing out on crucial psychological support at a time when it is most required (190). This is apparent in UK and international cancer services where previous studies have shown that cancer patients with significant anxiety or depression were not accessing counselling or psychological treatment, largely due to a lack of identification of their psychological distress by clinicians, leading to decreased referral rates (190-193). A more balanced assessment of patient care requirements from health professionals and a consideration of other treatments that might complement conventional cancer care, might go some way to resolving this problem, rather than the sole focus being on the medical management of the problem (194, 195).

Cancer patients' SM practices have been examined previously, with studies largely focusing on lifestyle practices taken up after diagnosis (41, 196-198). Much literature has focused on the efficacy of various SM practices in relation to health outcomes of cancer survivors (199, 200), but there is a lack of research on descriptive studies around what types of SM practices cancer survivors use and when. Previous systematic reviews have

looked at SM practices such as support groups, exercise, psychological therapies, spirituality/religion and CAM in relation to health outcomes and QoL. These have shown mixed outcomes, with some evidence to suggest that these practices positively affect health outcomes and QoL (41, 196-198). Despite the breadth of evidence, no literature exists examining the use of *multiple* SM practices amongst cancer survivors. Additionally, the majority of existing literature has reviewed cancer patients' use of SM practices at stand-alone points in time. None have looked at the uptake of multiple SM practices spanning multiple time-points. This is necessary as it is important to understand more about the whole experience of managing a disease - incorporating the psycho-social aspects of care - rather than focusing purely on a one-dimensional, intervention focused, bio-medical approach. By exploring the use of multiple SM practices in cancer survivors a clearer picture can be drawn as to how their combined use contributes to their overall health and wellbeing. The aim of this chapter is therefore to describe SM patterns in cancer survivors over time, in order to examine how the prevalence of SM behaviours fluctuates throughout the cancer experience.

## **4.3 Methods**

### **4.3.1 Cross-Sectional Studies**

Cross-sectional studies are widely used to determine prevalence at a given point in time. They are relatively cheap and quick to undertake as data are only collected once, multiple outcomes can be studied and no follow up is required (201). Associations between different variables can be identified through the use of cross-sectional studies though it is not possible to make inferences about cause and effect of these associations using this method, or to provide explanations for their findings as data is being collected at a single

point in time (201). Although longitudinal studies would ideally be better suited to answering the aims of this study as they would be able to give a more accurate insight into the changing relationships of SM in relation to QoL, health beliefs and work ability over time, a retrospective cross-sectional study was more appropriate for use due to the limited time and financial resources allocated to the researcher undertaking the study.

Cross-sectional studies are most commonly undertaken using questionnaires (201). Questionnaires can collect data in standardised, repeatable, measured forms, making associations between variables and quantitative inferences which can be generalised to repeatable, wider populations, strengthening findings through provision of easily analysable results (202, 203). Questionnaires can measure attributes and behaviours, measuring patterns of uptake of SM, QoL, HLC and work ability in the proposed study.

#### **4.3.2 Ethics**

Ethical approval was sought from the West Midlands local research ethics committee, and was obtained following an ethics committee meeting in February 2012 (Study protocol number RG\_11-175, REC reference 12/WM/0030). Following this, research governance approval was obtained from the local research and development department at University Hospitals Birmingham (UHB). This was authorised in April 2012 under the project reference number RRK4412.

All personal data obtained throughout the study was treated confidentially and stored securely to uphold ethical principles of research protecting participants' rights to

confidentiality and anonymity (204). All data and survey responses were stored in locked filing cabinets in swipe-access protected areas of the university. All electronic records were kept in password protected databases and any transfer of identifiable data between the hospital and the university was undertaken using encrypted memory sticks.

Questionnaires (appendix 3) were individually coded with a four-digit number on the front page to enable patient questionnaire data to be anonymised. The four digit code was matched against a list of patient names which only the researcher who held an honorary contract with UHB had access to, to ensure patient confidentiality was maintained. Any contact details provided by respondents in section 7 of the questionnaire were labelled with the four-digit study number so they could be matched with the relevant questionnaire and were then detached from the rest of the questionnaire and stored securely in locked cabinets to maintain patient confidentiality.

Whilst every effort was made to ensure that only patients who met the eligibility criteria were contacted to participate in the study, distress could have occurred due to families of deceased patients being contacted. To minimise the likelihood of this occurring all patient records were cross-checked against data from the West Midlands Cancer Intelligence Unit (WMCIU) to ensure vital status (dead/alive) and to ensure they had a confirmed cancer diagnosis. This increased the likelihood that the data collected was accurate and up-to-date. However, despite this a small proportion of patients that were sent information were either deceased or had disease recurrence, due to records not being updated in the interim period. One questionnaire was returned by a family member reporting that the patient was deceased, whilst two respondents were unable to participate in the interview phase of the study due to disease recurrence in the period between questionnaire completion and

interview. Contact numbers of the clinical lead and details of support services were made available to all patients sent information to minimise the distress that may have been caused through this and to answer any questions that might have arisen. To maximise the safety and robustness of the participant identification and recruitment process, letters were also sent to oncology consultants at UHB informing them of the study outline and requesting their permission to include their patients in the study (appendix 4). Those that granted this permission were sent letters intermittently throughout the data collection process to keep them informed of the study's progress and to ask them to notify the researcher if they had had any complaints from participants regarding the study. No reports of complaints were fed back to the researcher.

#### **4.3.3 Setting, Access and Data Collection**

The study setting was the West Midlands, UK. Access to the sample population was sought by contacting the relevant oncology consultants based at UHB (appendix 4), who acted as gatekeepers to the study population. Following this, patients meeting the eligibility criteria specified below were identified, contacted and invited to participate in the study (appendix 5 and 6):

##### ***Inclusion Criteria:***

- Eighteen years or older.
- Histological diagnosis of one of the ten most common UK cancers (breast, lung, colorectal, prostate, non-hodgkin's lymphoma, melanoma, bladder, head and neck, stomach and oesophagus) (205).
- Willing to provide informed consent.
- Free from metastatic disease/local recurrence of disease at study start.

- Must have undergone active cancer treatment which ended less than 5 years and more than 12 months previously.

***Exclusion Criteria:***

- Multiple prior cancer histologies/cytologies.
- Evidence of metastatic spread/local recurrence of disease.
- Active oncology treatment received within the previous 12 months.
- Cancer treatment finished over five years ago.
- Participants being treated palliatively.

The researcher who collected the data from the hospital database has a professional clinical background in oncology nursing, is registered with the Nursing and Midwifery Council and held an honorary contract at UHB. No other members of the research team were granted access to any identifiable patient data. The researcher collected data from electronic medical records regarding patients' demographics, cancer diagnosis, date of diagnosis, treatment type (e.g. chemotherapy/radiotherapy/surgery etc.) and current disease status (present/absent). If the researcher felt uncertain as to whether a patient fulfilled all of the eligibility criteria, clarification was sought from the consultant responsible for the individual patients care. Patients' postal addresses were also obtained from these databases.

957 people were invited to participate in the study. To enable the study to obtain data on the ten most common UK cancers (and thus be representative of the general UK cancer population) participants were recruited, based on the WMCIU figures for the ten most

commonly diagnosed UK cancers from 2004-08 (table 4.1) (43). Histological cancer type was identified according to the ICD-10 classification for malignant neoplasms (205) (appendix 7). The WMCIU figures also provided an estimate of one-year relative survival for the ten commonest UK cancers (43) (table 4.1). This information was used to calculate the number of patients from each of the ten cancer types that were invited to participate in the study, stratifying it by cancer type. This was done by dividing the number of (for example) breast cancer survivors, at one year by the total number of survivors at one year, then multiplying it by the total number of people required in the study sample (table 4.1).

Initially, eligible patients were selected at random from lists on UHB's oncology patient databases using a random number generator. Their eligibility criteria were checked against the inclusion/exclusion checklist by the researcher. It was intended that all patients would be randomly selected from a large pool of patient data until the required number of eligible patients from each group had been identified. However, it became apparent that to enable sufficient participant numbers to be recruited, a more streamlined approach was needed as the number of patients that fulfilled the eligibility criteria was lower than expected and the recruitment method used was placing significant time constraints on the research process. As a result, consultants' clinic lists were accessed from the database and any new patient clinics were automatically discarded as they would have contained either newly diagnosed patients or patients still undergoing active treatment, making them ineligible. This meant that only the patient follow-up clinic lists were randomly searched for eligible participants, making the identification process faster. From this, electronic annotations from patients' medical notes could be checked to verify their eligibility.

Table 4.1: One Year Survival Estimates for the Most Commonly Diagnosed UK Cancers From 2004-08

Cancer Site	Number in survival cohort	Relative survival rate (%)	Lower confidence interval (%)	Higher confidence interval (%)	Number of survivors at one year	Number in sample (n=957)
Breast	206,875	95.8	95.7	95.9	198,186	269
Trachea, Bronchus and Lung	170,180	29.4	29.1	29.6	50,033	68
Colorectal	162,408	74.2	74	74.4	120,507	164
Prostate	169,675	95	94.8	95.1	161,191	219
Non-Hodgkin's Lymphoma	48,652	76.4	76	76.8	37,170	51
Melanoma of the Skin	46,829	97.1	96.9	97.3	45,471	62
Bladder	43,815	73.8	73.3	74.3	32,335	44
Head and Neck	38,990	79.5	79	79.9	30,997	42
Stomach	34,552	40.9	40.4	41.5	14,132	19
Oesophagus	34,850	40.6	40.1	41.2	14,149	19
<b>TOTAL</b>					<b>704171</b>	<b>957</b>

- 95% confidence intervals have been reported. Where confidence intervals overlap between cancer sites, no statistically significant difference exists in survival estimates. The numbers in the study sample per cancer type have been calculated from examining the proportion of survivors per cancer type at one year compared to the total survivors at one year.

The majority of participants were recruited to the study in this way, with the exception of some of the lung cancer patients. Many of these patients had had their initial surgery for lung cancer at another hospital trust in Birmingham and were subsequently followed up at UHB. Hence, it was necessary to acquire their surgical histology from data that had been made available between the two trusts to confirm a diagnosis of lung cancer and from this

match their individual histology with their NHS hospital number to enable access to their electronic records.

Eligible participants were sent a study pack by post, which included a letter of invitation to participate in the study, a participant information sheet and the questionnaire (appendices 3, 5, 6). If willing to participate, they were asked to return the questionnaire to the University of Birmingham in a pre-paid envelope. Questionnaire completion and return implied consent to participate. This was explained in the information sheet sent with the questionnaire (appendix 6). The researcher's contact details were provided in case participants had any queries about the study. Those that did not wish to participate were also asked to return the uncompleted questionnaire along with the invitation letter in the pre-paid envelope provided so that their non-participation could be logged. Those participants who had not returned the questionnaire after one month were sent a second questionnaire along with a reminder letter (appendix 8) asking them once again to participate. If no response was made to the second postal questionnaire, patients were not followed up any further.

All respondents included in the study were logged onto an electronic database and returned questionnaire data were recorded in SPSS 19.0 in preparation for data analysis, using a pre-prepared codebook. An independent research assistant randomly checked fifty questionnaires.

#### **4.3.4 Questionnaire Design**

The questionnaire was designed to inform the study aims stipulated and questions were developed to generate an understanding of cancer survivors' use of different SM

strategies, their health beliefs (internal HLC), QoL and their ability to work (appendix 3). The questionnaire was piloted on three patient representatives from the Pan Birmingham Cancer Network, and one other member of the public who had had a previous cancer diagnosis, to gain feedback as to its comprehensibility and usability and to increase face and content validity. Suggested changes were incorporated into questionnaire design.

Section 1 of the questionnaire collected demographic data from patients regarding age, sex, ethnicity, religion, smoking history, level of education and income. These details enabled subgroup analyses to be carried out on the sample during data analysis.

Section 2 asked participants to identify, retrospectively, from a list of SM practices (table 4.2) which (if any) they used pre-diagnosis, during treatment and during survivorship (1-5 years post treatment). To enable SM to be adequately measured in a questionnaire, an 'operational' definition was required to ensure that a comprehensive list of SM practices was included. This list was generated following discussions with oncology health professionals, cancer support workers and CAM researchers in the West Midlands, about the main types of SM practices thought to be predominantly used. Information from Macmillan Cancer Support booklets and other published research also identified relevant SM initiatives available to cancer survivors (34, 35, 63, 66, 67, 69, 127, 140-143).

Accessible SM support groups in the West Midlands area were also included in the list following a discussion with a facilitator at the Patrick Room in the Cancer Centre at UHB. Though the list was not all-encompassing it covered the main types of SM strategies thought to be predominantly used. The questionnaire also asked participants to specify details of any other SM strategies that did not appear on the list, to try to ensure that all

SM practices used by patients were identified. The SM practices were classified under six different categories of SM: support groups, diet, exercise, psychological therapies, CAM and spirituality/religion. Section 2 also asked participants how they found out about the various SM practices they chose to undertake (friends/family/internet/doctor etc.) to provide information about where cancer patients' access support and information.

Table 4.2: Listed SM Practices in the SM Questionnaire Categories

SM Category	SM Activity
Support Groups	<ul style="list-style-type: none"> <li>• Aquarius (alcohol support)</li> <li>• Expert Patient Programme</li> <li>• Look Good...Feel Better UK</li> <li>• Solihull Support Group or other support group</li> <li>• Stop Smoking</li> <li>• Other</li> </ul>
Diet	<ul style="list-style-type: none"> <li>• Essential fatty acids or fish oils</li> <li>• High protein diet</li> <li>• Non-dairy</li> <li>• Low fat diet</li> <li>• Raw</li> <li>• Reduced alcohol intake</li> <li>• Macrobiotic</li> <li>• Vegan/vegetarian</li> <li>• Vitamin or mineral supplements</li> <li>• Other diet e.g. Bristol/Budwig/Gerson</li> </ul>
Exercise	<ul style="list-style-type: none"> <li>• Individual sports e.g. tennis, swimming, skiing, jogging</li> <li>• Martial arts e.g. karate, kung-fu</li> <li>• Tai-chi/chi-gong/pilates/yoga</li> <li>• Team sports e.g. football, netball</li> <li>• Walking</li> <li>• Gym</li> <li>• Gardening</li> <li>• Other</li> </ul>
Psychological Therapies	<ul style="list-style-type: none"> <li>• Cognitive behavioural therapy</li> <li>• Counselling</li> <li>• Group therapy</li> <li>• Problem solving therapy</li> <li>• Psychoanalysis/psychotherapy</li> <li>• Other</li> </ul>

SM Strategies for Cancer Survivors: Who Does What and Why?

SM Category	SM Activity
CAM	<p><i>Natural Products:</i></p> <ul style="list-style-type: none"> <li>• Aromatherapy</li> <li>• Bach Flower Remedies</li> <li>• Herbal Medicine</li> </ul>
	<p><i>Mind and Body Medicine:</i></p> <ul style="list-style-type: none"> <li>• Art therapy</li> <li>• Drama/dance/music therapy</li> <li>• Guided imagery/visualisation</li> <li>• Hypnotherapy</li> <li>• Journaling</li> <li>• Meditation/mindfulness</li> </ul>
	<p><i>Manipulative and Body Based Practices:</i></p> <ul style="list-style-type: none"> <li>• Acupuncture/Acupressure</li> <li>• Chiroprody</li> <li>• Colonic irrigation/hydrotherapy</li> <li>• Massage</li> <li>• Metabolic therapy</li> <li>• Osteopathy</li> <li>• Shiatsu</li> <li>• Reflexology</li> </ul>
	<p><i>Other CAM:</i></p> <ul style="list-style-type: none"> <li>• Alexander technique</li> <li>• Crystals</li> <li>• Reiki</li> <li>• Theta healing</li> <li>• Therapeutic touch</li> <li>• Ayurveda/Chinese medicine</li> <li>• Homeopathy</li> <li>• Traditional healer/'medicine man'</li> <li>• Spiritual healer</li> <li>• Other</li> </ul>
Spiritual/Religious Practices	<ul style="list-style-type: none"> <li>• Attending religious services</li> <li>• Prayer or intention</li> <li>• Worship</li> <li>• Group healing</li> <li>• Spiritual music/singing</li> <li>• Other</li> </ul>

Section 3 measured participants' QoL using the generic measure of health-related QoL, the EuroQol 5D-3L (EQ-5D-3L) (206). When choosing a QoL tool to use in the questionnaire a number of scales were considered. The EORTC QLQ-C30 questionnaire is cancer specific, appropriate for self-administration and designed for use across a range of cultural settings (159), therefore it seemed appropriate for use. However it was felt important that a tool that measured general health-related QoL, as opposed to cancer-specific, was used, as although study participants had had a prior cancer diagnosis, at the time of questionnaire completion they should have been disease free. As a result although ongoing symptoms from their cancer and treatment may have been present, so might other non-cancer specific health problems. Thus it was felt more suitable to include a QoL measure that reflected people's general health status. Additionally, due to the already lengthy size of the questionnaire it was felt that the EORTC QLQ-C30 would be too long to include, potentially deterring participants from completing and returning it. Similarly, the FACT-G scale is a 33 item scale (160) and was felt too long to use in the questionnaire. Additionally, the FACT-G is used to specifically evaluate patients who are undergoing cancer treatment (160). As the questionnaire study was interested in exploring the QoL of cancer survivors who had finished their active cancer treatment, the FACT-G was felt to be inappropriate for use.

The SF-36 is a multi-purpose, short-form health survey consisting of 36 questions (207). It yields an 8-scale profile of functional health and well-being scores as well as psychometrically-based physical and mental health summary measures (207). The SF-36 is a generic measure of health (207), as opposed to one that targets a specific age, disease, or treatment group. However, once again it was felt that the large number of items in the survey was too many to use in the already lengthy questionnaire.

The EQ-5D-3L is a shorter 15-item questionnaire that has good reliability and has been validated for use with cancer patients and survivors (208). The EQ-5D-3L is designed for self-completion by respondents and is ideally suited for use in postal surveys (209). The EQ-5D-3L consists of the EuroQol 5D descriptive system (EQ-5D) - comprising of five dimensions; mobility, self-care, usual activities, pain/discomfort and anxiety/depression - and the EQ visual analogue scale (EQVAS) which records the respondent's self-rated health on a vertical, visual analogue scale and can be used as a quantitative measure of health outcome as judged by the individual respondents (209). This information would allow a comparison of QoL to be made between cancer survivors with high and low levels of uptake of SM practices and was therefore chosen for use.

When measuring respondents' health beliefs in section 4 both the General Self-Efficacy scale (GSE) and the MHLC scale were considered. The GSE scale has been designed to evaluate self-efficacy as a broad personality disposition (210). It is a 10-item psychometric scale designed to assess optimistic self-beliefs to cope with a variety of difficult demands in life (211). It captures differences among individuals in their tendency to view themselves as capable of meeting task demands in a broad array of contexts and has been used in more than 200 published studies (212). It also has a high internal consistency reliability, with Cronbach's Alpha values ranging from 0.79 to 0.89 (210, 212). However, in terms of validity, the GSE scale has previously failed to predict specific self-efficacy behaviours and has been criticised for its multidimensional structure, measuring self-efficacy using three distinct empirical factors - behaviour initiation, persistence and effort (212). This multidimensional structure contrasts with the concept of self-efficacy as an undifferentiated, one-dimensional belief in one's generalised ability

(212). In addition behaviour initiation, effort and persistence are all *outcomes* of self-efficacy, rather than measurements of self-efficacy itself; this questions the content validity of the GSE scale and makes it difficult to accurately interpret its findings (212).

The MHLC scale is an 18-item scale that has a well-established validity and reliability, (71) and has previously been used with cancer patients (213). The scale has three subscales - *Internal*, *Chance* and *Powerful Others*, measuring the extent to which individuals believe their health outcomes are affected by these factors (71). The MHLC was designed to be applicable to a variety of health-related behaviours and situations, but sensitive enough to adapt as a function of individual health-related experiences (214). Since its construction in the 1970s it has been used by hundreds of researchers, increasing the evidence for its face validity (214). It has also been shown to have high internal consistency reliability, with Cronbach's alpha values ranging from 0.60 to 0.75 (214). However, a number of studies that have attempted to correlate MHLC scores with measures of health behaviour have found little evidence for a strong association between the two (215). As it is hypothesised that someone scoring highly on the MHLC scale should be more likely to carry out healthy behaviours, this calls into question the validity of the measurement tool (214).

Moreover, a study by Christensen et al. (1991) found that when the MHLC was used in a transplant setting, those with high internal HLC scores were more depressed than those with low scores, again calling into question the tool's validity, as it would be expected that those with higher internal HLC scores would be more motivated and less depressed than those with low scores (216). However, it may be that those who have strong beliefs in the controllability of their health, experience detrimental effects when these beliefs are

challenged through the experience of illness (217). Additionally it is important to remember that the MHLC does not operate alone to determine behaviour potential in individuals. Other factors such as the value a person places on their own health and their level of self-efficacy will moderate the relationship between health behaviours and HLC (215). In this study the use of the MHLC was with cancer survivors in remission from their disease rather than those undergoing treatment, therefore it was anticipated that the findings from Christensen's study would not be applicable here.

Therefore due to its high reliability and face validity, its applicability to the healthcare environment and previous research verifying its validity (214), the MHLC scale was chosen as the most suitable tool for measuring health beliefs in the study. The MHLC consists of three parts A, B and C. Part C is designed for patients with a specific disease or long-term condition and was not felt suitable for use due to participants recruited to the study being cancer survivors who were currently cancer free. Part A and B of the MHLC can be used interchangeably. On examination it was felt that part B was slightly more appropriate for use in the questionnaire due to it using the term 'doctor' rather than 'physician' (used in part A), which is a more common term among the UK population. The information collected from the *Internal* subscale of the MHLC was used to identify whether participants with a higher internal HLC (who believe they have more control over their own health outcomes than those with a high external HLC) had a higher uptake of SM practices. It was also used to measure whether different categories of SM practices were apparent amongst respondents with a higher internal rather than external HLC.

Section 5 assessed respondents' ability to work using a question from the Work Ability Index (WAI), a validated tool for measuring self-assessed work ability (218). The WAI is

used in research to assess work ability during health examinations and workplace surveys and is determined on the basis of answers to questions which account for work demands and the health status and resources of workers (219). It has been used in a wide number of international research studies (220, 221) and its reliability and validity have been evidenced in previous research (219, 222, 223). The question selected from the WAI for use in the questionnaire asked: *'Assume that your work ability at its best has a value of 10 points. How many points would you give your current work ability? (0 means that you cannot currently work at all).'* Respondents were also asked to indicate their current employment status. Those who indicated they were retired or unable to work due to illness or disability were asked not to complete the WAI question. The information gathered was used to identify whether the type and number of SM practices undertaken differed in participants with higher and lower levels of work ability.

Finally, section 6 asked respondents whether they would be willing to discuss their health and lifestyle activities in person and to provide contact details if so. Those who indicated they would be happy to talk in more depth at a later date were considered for interview in the qualitative phase of the study. Additionally, respondents who indicated they would like to receive feedback on the study findings were sent a study feedback letter once the study had been completed (appendix 9). This letter was piloted on the patient representatives who piloted the questionnaire to ensure that it was comprehensible and readable.

#### **4.3.5 Sample Size**

Sufficient power and significance levels were selected to ensure a sample size large enough to be representative of the population of interest and to allow inferences to be

made about the underlying population that had acceptable margins of random variability (202).

The EQ-VAS score can be used as a quantitative measure of clinical outcome, using individual respondent's own judgment regarding their global health status (224). As the study is concerned with examining the QoL of cancer survivors in terms of their overall general health, sample size calculations were based on expected between-group differences on the EQ-VAS. This was deemed more appropriate than the EQ-5D which would have been of more benefit in calculating the sample size if the primary outcome measure was concerned with examining differences between groups on dimensions such as pain or mobility (209).

Previous literature (225) aiming to provide a guide to the calculation of sample sizes in comparative studies using the EQ-5D as an outcome variable showed that a small effect size (0.2) on the EQ-VAS is equivalent to a difference of 3.5 points on the EQ-VAS in the general population and 3.9 points in critically ill patients. Other literature has indicated that significant differences between EQ-VAS scores in individuals differing in health status were around 5% of their entire score ranges (equivalent to five points on the EQ-VAS scale) (226).

Assuming that the prevalence of cancer survivors using SM is 40% (147); sample size calculations indicated that data from 468 survivors would be required to show a four point difference in QoL measured by the EQ-VAS (SD 13.3) between high users and low/non-users with 90% power and 5% significance. The EQ-VAS scale ranges from 0-100 (227), therefore a difference of four points between the two groups seemed feasible. Once the

questionnaire data had been collected the SM scores were split at the median value of SM practices used to ensure the two groups were evenly balanced between high and low scoring groups.

Postal questionnaires usually generate low response rates (202, 228) with approximately 50% of studies having recruitment problems, leading to study abandonment or reduced statistical power (229). To minimise this risk questionnaires were sent to twice the required sample population to compensate for participants that might drop out of the study or were ineligible. Conservatively assuming 5% deaths and a response rate of 50%, 957 cancer survivors were identified and sent a questionnaire. It was deemed feasible to recruit this number of patients because at the time of recruitment to the study there were approximately 11,000 cancer outpatients at the collaborating hospital UHB, many of whom would have been treated for the ten commonest UK cancers.

#### **4.3.6 Statistical Analysis**

Software:

All data were recorded and analysed using SPSS version 19.0. Descriptive statistics were calculated with all variables to summarise the sample and a number of statistical tests were employed. Statistical significance was measured at the  $p \leq 0.05$  level. All means and standard deviations (sd) are presented in the following format: mean (sd).

Tests for Normality:

Parametric or non-parametric tests were employed based on the significance of the Kolmogorov-Smirnov (KS) test for normality which assesses whether or not data are normally distributed. A non-significant KS result ( $p > 0.05$ ) indicates that the data are

normally distributed and thus suitable for parametric testing. Therefore where the KS test was significant ( $p \leq 0.05$ ) violation of the assumption of normality of the data was assumed, indicating the need for non-parametric testing.

#### Descriptive Data-Patterns of SM:

Total SM scores of individual respondents were measured by adding together the total number of different SM practices they had used pre-diagnosis, during treatment and in survivorship. If a participant had scored that they went swimming pre-diagnosis, during treatment and in survivorship then this would count as three (rather than one) for that particular category. The parametric repeated measures ANOVA or the non-parametric Friedman test were conducted (dependent on the significance value of the KS) to compare total SM uptake scores pre-diagnosis, during treatment and into survivorship and to compare patterns of uptake across different types of SM (support groups, diet, exercise, CAM, psychological therapies, spirituality/religion). The individual SM practices attributed to the six SM categories were identified in accordance with the SM practices listed under these SM categories in the questionnaire (table 4.2). However, the data could have been cut in different ways due to the overlap between certain SM practices and their classification type. For example in the questionnaire yoga was listed under the exercise category of SM but could have alternatively been placed in the CAM category. Equally vitamin supplements were listed in the diet section but could instead have been listed under CAM. These reclassifications could have potentially altered the findings from the statistical analysis. Wilks' Lambda was used to assess whether there was a statistically significant effect for time across the three time periods. Where eta squared is mentioned, this is in relation to the size of the effect of a statistically significant finding, with 0.01 being a small effect and 0.14 a large effect (203).

Subgroup Analyses:

Subgroup comparisons, using the chi-square test for independence for categorical data and the independent t-test for continuous data, were carried out on the descriptive data to discover whether SM uptake was affected by the following demographic factors: income, gender, age, ethnicity, cancer type and treatment type.

For the purposes of the analysis of income the data were split into high and low income groups, with the low income group earning < £25,000 per annum, and the high income group earning  $\geq$  £25,000 per annum. This split reflects the national average wage in the UK in 2012 of £26,500 per annum (230). Additionally, due to the small proportion of respondents from non-white ethnic minorities in the sample making the groups for comparison unevenly balanced, it was decided to examine ethnicity by comparing white with all non-white respondents. The ten cancer types included in the study were grouped into four categories: (a) breast b) prostate c) lung or colorectal d) 'other' cancers.

Treatment types were divided into respondents who had undergone chemotherapy alone or in combination with other treatments and those who had received non-chemotherapy cancer treatments.

Further subgroup analyses were carried out between the four CAM subgroups identified in the questionnaire - 'natural products', 'mind and body medicine', 'manipulative and body-based practices' and 'other CAM' - to identify whether there were demographic differences between respondents undertaking these types of CAM. The chi-squared test was also used to identify any significant differences between responders and non-responders in relation to categorised age, cancer type and treatment type.

Relationships between SM and QoL, HLC and Work Ability:

Statistical analysis explored any associations between SM uptake scores in survivorship (SM survivorship scores) and the independent variables QoL (EQ-VAS and EQ-5D), internal HLC and work ability. As the QoL, HLC and work ability measurement scales are used to assess people's 'real-time' perspectives it was felt that it was appropriate to compare scores on these scales with respondents' SM uptake in the survivorship phase *only*, rather than looking at total SM uptake which incorporates past uptake levels as well. Subgroup analyses also explored any significant differences in HLC across the six SM categories (support groups, CAM, diet, exercise, psychological therapies, spirituality/religion).

Correlation Analysis:

Initially, scatter-plots were generated to visually demonstrate the strength and the direction of the relationship between the continuous variables SM and QoL, SM and HLC and SM and work ability. Preliminary analyses were also visually performed to ensure no violations of normality, linearity and homoscedasticity, to ensure they were suitable for correlation analysis. Any extreme outliers identified from the scatter plots generated in SPSS were removed from the data set to reduce their effect on the correlation co-efficient (r) value (203). Removal of extreme outliers is often recommended as a method for preventing the distortion of the data, to allow the statistical analysis to reflect the majority of the data rather than being highly influenced by one or two errant values (231).

Correlation analysis was carried out using either the parametric Pearson product-moment correlation coefficient (normally distributed data), or the non-parametric, Spearman Rank Order Correlation (abnormally distributed data), to describe the strength and direction of

the relationship between the variables. The size of the correlation co-efficient ( $r$ ) relates to the strength of the correlation with 0.10 being a weak correlation, and 1.0 a perfect correlation (232).

Differences between High and Low Scoring Groups:

A KS test for normality of the residual data distribution was carried out to determine whether a t-test between groups (parametric) or a Mann-Whitney U (non-parametric) test would be used to look for any extreme phenomena that existed between high and low independent variable scores and SM uptake. The independent variable scores were split at the median value following data collection to create the high and low scoring groups. As the median value of all these variables were held by more than one respondent the t-test/Mann-Whitney U test was run twice (Group A or B) for each variable (EQ-VAS, EQ-5D, HLC and work ability):

Group A) with the median score included in the high scoring group

Group B) with the median score included in the low scoring group.

The independent variable scores were then split into quintiles to assess any significant differences that existed across the quintiles between the independent variables and SM uptake scores (table 4.3). Depending on the normality of the residual data identified by the KS, either the between groups ANOVA (parametric) or the Kruskal-Wallis test (non-parametric) was undertaken to assess these differences between the groups. Outliers were retained in the dataset so long as the trimmed means were not too distant from the means.

Table 4.3: Scores of the Independent Variable Measurement Tools When Split into Quintiles

	Independent Variables			
	EQ-VAS	EQ-5D	Internal HLC	Work Ability
Group 1	0 – 20	-0.594 – 1.000	6 – 12	0 – 2
Group 2	21 – 40	-0.276 – 0.043	13 – 18	3 – 4
Group 3	41 – 60	0.044 – 0.362	19 – 24	5 – 6
Group 4	61 – 80	0.363 – 0.681	25 – 30	7 – 8
Group 5	81 – 100	0.682 – 1.000	31 – 36	9 – 10

Multilinear regression:

Multilinear regression can be used to explain the relationship between one continuous dependent variable from two or more independent variables (233). Therefore a multiple linear regression model was used to examine associations between primary and secondary outcome measures (SM survivorship, internal HLC, EQ-5D, EQ-VAS, work ability scores) and socio-demographic factors (age, gender, ethnicity, income, cancer type and treatment type). The KS was undertaken to ensure normality of the residuals. If residual data was not normally distributed the square root of the SM uptake variable was calculated and the KS was recalculated on the residual data. If this showed KS ( $p < 0.05$ ) but the Q-Q plot followed a relatively normal data distribution, the stepwise general linear regression was undertaken, as large data sets often show KS ( $p < 0.05$ ) but the degree of non-normality is not excessive. Stepwise general linear regression allows a statistical model to be built by removing variables one-by-one based on their co-efficient values, allowing any significant associations between variables to be recalculated at each stage of the regression (234). Stepwise general linear regression was appropriate for use in the data analysis, identifying

whether any covariates were significantly associated with the primary and secondary outcome measures at the  $p \leq 0.05$  level once other covariates had been controlled for.

## **4.4 Results**

### **4.4.1 Demographics**

Of the 957 questionnaires sent 445 (46%) were returned. Fifty-one per cent of respondents were male which is representative of the even gender split of cancer patients in the West Midlands (235) (table 4.4). Respondents' average age was 65.6 years and 56.3% were retired. No significant age difference was found between responders and non-responders ( $p=0.181$ ). However, respondents were significantly younger than the average age at diagnosis of a cancer patient in the West Midlands (3.1yrs,  $p<0.0001$ ). The most common cancer types amongst respondents were breast (28.3%) and prostate (25.2%), with statistically significantly higher response rates amongst breast, prostate and head and neck cancer patients compared to the proportion of these cancer patients in the West Midlands (breast:  $p<0.0001$ ; prostate:  $p<0.0001$ ; head and neck:  $p=0.017$ ). The proportion of lung and stomach cancer respondents was low compared to the West Midlands (lung:  $p<0.0001$ ; stomach:  $p=0.012$ ). Most respondents (79.8%) had an income of less than £25,000 per annum. Regarding ethnicity, the majority of respondents (89.2%) were White. The response rate amongst Asian (4.5%) and Black (4.9%) populations was significantly higher than expected, when comparing it with the proportion of Asian (2.3%) and Black (1.7%) people diagnosed with cancer in the West Midlands (Black:  $p<0.0001$ ; Asian:  $p=0.006$ ).

## SM Strategies for Cancer Survivors: Who Does What and Why?

Table 4.4: Demographic Characteristics of Respondents

Demographic	All Respondents N=445	%=100n/N n (%)
Gender n (%)	Male	229 (51)
	Female	216 (49)
Age n (%)	≤65years	210 (47.1)*
	≥66 years	233 (52.2)*
Ethnicity n (%)	White	397 (89.2)*
	Black	22 (4.9)*
	Asian	20 (4.5)*
	Other	3 (0.6)*
Income n (%)	<£25,000	356 (79.8)*
	≥£25,000	51 (11.4)*
Treatment Type n (%)	Chemotherapy or chemo combination treatment	173 (38.8)*
	Non-chemo treatment	270 (60.5)*
Cancer Type n (%)	Breast	126 (28.3)*
	Prostate	112 (25.2)*
	Colorectal	73 (16.4)*
	Lung	24 (5.4)*
	Melanoma	28 (6.3)*
	Non-hodgkin's lymphoma	27 (6.1)*
	Bladder	13 (2.9)*
	Head and Neck	23 (5.2)*
	Stomach	7 (1.6)*
Marital Status n (%)	Oesophageal	10 (2.2)*
	Married/civil partnership/co-habiting	307 (69)*
	Single/divorced/widowed	129 (29)*
Religion n (%)	Christian	331 (74)*
	Other	34 (7.6)*
	None	74 16.6)*

\* The numbers do not add up to 100% because of missing values.

#### **4.4.2 Prevalence and Distribution of SM Scores**

Ninety-five per cent of respondents who provided data on SM uptake had used some form of SM. The number of SM practices used by individual respondents ranged from 0-48, with a mean value of  $10.98 \pm 8.4$  (SD) and a median value of 9.0. The most common SM type at each time-point was exercise, undertaken by 88% of respondents. This was followed by diet (62%), CAM (32.1%), spirituality/religion (31%), support groups (24%) and psychological therapies (9%). SM mean uptake scores were highest in survivorship [ $4.32$  (mean)  $\pm 3.40$  (SD)] and lowest during treatment [ $3.01$  (mean)  $\pm 3.0$  (SD)]. Amongst all SM categories (table 4.2), uptake was highest in survivorship (support groups 15.9%, diet 55.7%, exercise 83.7%, psychological therapies 7.2%, CAM 30.3%, spirituality/religion 29.6%;  $p \leq 0.05$ ) (figure 4.1). For support groups, psychological therapies and diet, scores increased incrementally from pre-diagnosis to survivorship. For exercise and spirituality/religion, scores were lowest during treatment and highest in survivorship. CAM mean uptake scores were the same pre-diagnosis and treatment, but rose in survivorship.

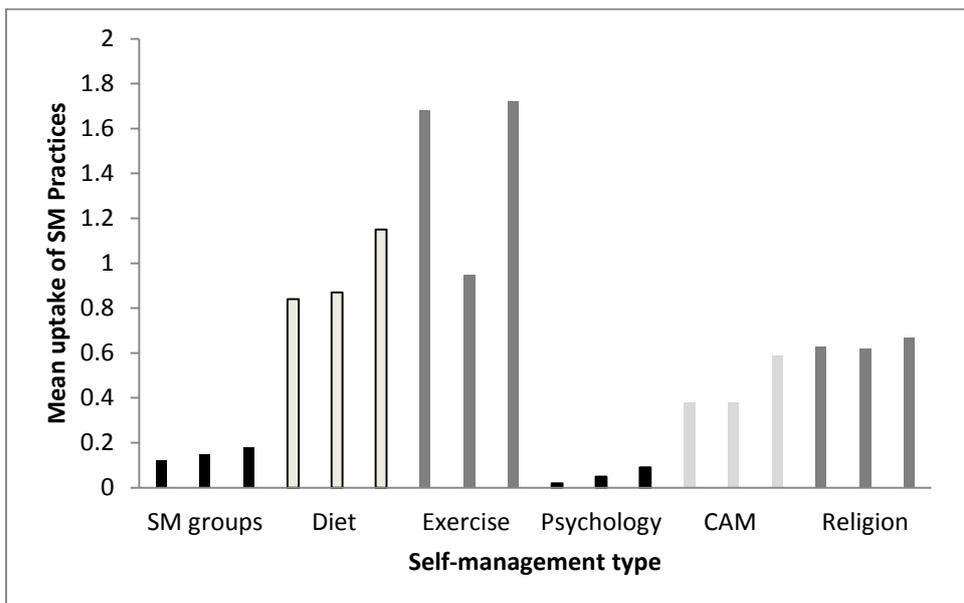


Figure 4.1: Bar Chart Showing Respondents Mean Uptake across the Six Categories of SM. (The first bar in each category represents uptake pre-diagnosis, the second uptake during treatment, and the third uptake during survivorship).

#### 4.4.3 Demographic Differences between SM Categories

No significant differences were found between respondents on high ( $\geq£25,000$ ) and low ( $<£25,000$ ) incomes across the six SM categories (table 4.5). No significant differences in diet, exercise, or psychological therapy uptake were found between genders. However, uptake of CAM ( $p<0.0001$ ), spiritual/religious practices ( $p<0.0001$ ) and support groups ( $p=0.038$ ) were significantly higher in women than men. No significant differences in exercise uptake or religion were found in relation to age. However, those using support groups ( $p=0.003$ ), diet ( $p<0.0001$ ), psychological therapies ( $p<0.0001$ ) and CAM ( $p=0.027$ ) were younger than those who did not use these SM practices. No significant changes in support groups, diet, exercise, psychological therapies and CAM were found between white and non-white respondents. However, significantly more non-white

(72.1%) than white respondents (26.2%) undertook spiritual/religious practices ( $p < 0.0001$ ).

No significant differences in diet, exercise, or psychological therapy uptake were found between respondents with different cancer types. However, uptake of support group ( $p = 0.029$ ), CAM ( $p = 0.028$ ) and spiritual/religious practices ( $p = 0.021$ ) were highest in breast cancer respondents. No significant differences in spiritual/religious practice uptake were found between those who had undergone chemotherapy and those who had not. However exercise ( $p = 0.032$ ), support group ( $p < 0.0001$ ), psychological therapy ( $p = 0.008$ ), diet ( $p = 0.001$ ) and CAM ( $p < 0.0001$ ) uptake were significantly higher in respondents who had undergone chemotherapy than those who had undergone other forms of treatment.

#### **4.4.4 Variations within CAM**

Within the four CAM subgroups (158) uptake was highest in survivorship, apart from in 'mind and body medicine' where scores were lowest pre-diagnosis [(0.09) mean  $\pm$  0.325 (SD)] and highest during treatment [0.12 (mean)  $\pm$  0.403 (SD)]. 'Natural product' scores pre-diagnosis [0.07 (mean)  $\pm$  0.265 (SD)] dropped to their lowest during treatment [0.06 (mean)  $\pm$  0.258 (SD)] and rose again in survivorship [0.07 (mean)  $\pm$  0.269 (SD)]. 'Manipulative and body-based practices' had the highest overall mean uptake in survivorship [0.25 (mean)  $\pm$  0.578 (SD)], but uptake dipped to its lowest during treatment [0.13 (mean)  $\pm$  0.444 (SD)]. The uptake of 'other CAMs' was lowest pre-diagnosis [0.06 (mean)  $\pm$  0.267 (SD)], rose during treatment [0.07 (mean)  $\pm$  0.348 (SD)] and peaked in survivorship [0.08 (mean)  $\pm$  0.353 (SD)].

## SM Strategies for Cancer Survivors: Who Does What and Why?

Table 4.5: Demographic Differences between SM Categories

Demographic Characteristics	SM Categories Showing Significant and Non-significant Differences					
	Increased Dietary Changes	Increased Exercise	Increased Use of Support Groups	Increased Use of Psychological Therapies	Increased CAM	Increased Spiritual/Religious Practices
Income (≥£25,000/annum)	0.378 X <sup>2</sup> =0.78	0.078 X <sup>2</sup> =3.11	1.000 X <sup>2</sup> =0.00	1.000 X <sup>2</sup> =0.00	0.560 X <sup>2</sup> =0.34	0.160 X <sup>2</sup> =1.99
Gender (women)	0.131 X <sup>2</sup> =2.28	0.695 X <sup>2</sup> =0.15	<b>0.038</b> X <sup>2</sup> =4.29	≥0.095 X <sup>2</sup> =2.80	<b>&lt;0.0001</b> X <sup>2</sup> =16.70	<b>&lt;0.0001</b> X <sup>2</sup> =14.20
Cancer Type (breast)	≥0.055 X <sup>2</sup> =7.59	0.405 X <sup>2</sup> =2.91	<b>0.029</b> X <sup>2</sup> =9.02	0.167 X <sup>2</sup> =5.07	<b>0.028</b> X <sup>2</sup> =9.08	<b>0.021</b> X <sup>2</sup> =9.68
Treatment Type (chemotherapy/chemotherapy combination)	<b>0.001</b> X <sup>2</sup> =12.00	<b>0.032</b> X <sup>2</sup> =4.61	<b>&lt;0.0001</b> X <sup>2</sup> =14.49	<b>0.008</b> X <sup>2</sup> =7.10	<b>&lt;0.0001</b> X <sup>2</sup> =12.29	0.249 X <sup>2</sup> =1.33
Ethnicity (non-white)	0.931 X <sup>2</sup> =0.01	0.683 X <sup>2</sup> =0.17	0.442 X <sup>2</sup> =0.59	1.000 X <sup>2</sup> =0.00	0.615 X <sup>2</sup> =0.25	<b>&lt;0.0001</b> X <sup>2</sup> =36.19
Age (younger people)	<b>&lt;0.0001</b>	0.313	<b>0.003</b>	<b>&lt;0.0001</b>	<b>0.027</b>	0.997

- Bold values show statistically significant results ( $p \leq 0.05$ ). Chi-square tests were used to examine any associations between SM uptake and the demographic variables income, gender, cancer type, treatment type and ethnicity. A t-test was used to examine any associations between SM uptake and the continuous variable, age.

### **4.5 Discussion**

These results provide insights into the patterns and use of different SM practices of cancer survivors over time. Ninety-five percent of respondents had used some type of SM

practice before, during or after treatment; the most common ones being exercise (88%) and diet (62%). SM utilisation was lowest during treatment and highest in survivorship. All six SM categories had the highest uptake in survivorship, implying that the appeal for SM practices increases throughout the cancer pathway. Income made no difference to SM uptake, whilst women and younger people were more likely to use certain SM practices than men and older people. Respondents diagnosed with breast cancer and those who had received chemotherapy were more likely to undertake certain types of SM. Within CAM, the 'manipulative and body-based practices' subgroup had the highest SM uptake.

On average, respondents had used eleven different SM practices, suggesting that cancer survivors may accommodate their lifestyle in multiple ways for the sake of their health. However, it is likely that some were not solely considered 'health' practices, but also had social or spiritual goals, or were simply hobbies. The lowest mean SM uptake was during treatment, possibly because cancer patients are focusing on their conventional treatment pathway, with less time, energy and inclination for SM. Certain SM types are also contraindicated due to a lowered immunity, specific treatment regimens and unpredictable treatment side-effects (236). Conversely, in survivorship, SM increase may reflect a desire to regain a sense of personal empowerment, as new therapeutic relationships form (35) and new health directions appeal.

The majority of studies concerned with SM and cancer survivorship have been conducted among breast cancer participants (36, 67, 69). This study however, was carried out with the ten most common cancers in the UK, allowing differences in SM uptake between these cancer types to be observed. The higher support group uptake amongst breast cancer

respondents compared to other cancer types corresponds with previous findings that more women than men attend support groups, utilising these networks by sharing experiences (237). Informational support, to guide and advise, is often perceived by cancer patients as helpful from health professionals, but unhelpful from family and friends (238). Thus, cancer patients can access support groups to facilitate alternative information sources and advice. The desire for sharing experiences could partly explain women and breast cancer respondents' increased utilisation of religious/spiritual practices which often revolve around social support networks (239). Breast cancer is the most high profile cancer in terms of public relations campaigns, media agendas and patient activism (183). This can positively impact on breast cancer patients, giving them more confidence to seek support than patients with less well publicised cancers (183).

Increased CAM uptake in younger people, women and breast cancer respondents, is supported by previous literature reporting that women and younger people are most likely to use CAM (34, 50, 240). Having experienced a regimented treatment pathway, female breast cancer survivors may embrace a holistic approach (34, 50) which provides access to supportive social networks. A common weakness within biomedical treatments can be the personal care aspect and hospital setting, which is often viewed as depersonalized, rejecting the idea of individualised care and patient decision-making (144). CAM can improve the QoL of cancer survivors (196), who often utilise it for personalised care post-treatment to reconnect their mind and body and promote wellbeing and empowerment (144).

The high levels of uptake across the CAM subgroups in survivorship has highlighted that cancer survivors are utilising a variety of CAMs post-cancer. The most popular subgroup,

‘manipulative and body-based practices’, provides new insights into the types of CAM that appeal to cancer survivors. Most practices within this subgroup require input from a CAM therapist, partially explaining the high uptake due to the benefits of these therapeutic relationships (144). They often also require a substantial amount of physical manipulation and may be selected by cancer survivors due to a heightened sense that the treatment is healthful. However, uptake dipped during the treatment phase, possibly because some therapies are contraindicated (241) and may require active participation from already severely fatigued cancer patients.

Those who underwent chemotherapy had a higher uptake in all SM categories apart from spirituality/religion than those who received non-chemotherapy treatments, suggesting SM practices are of particular benefit to chemotherapy patients and may be undertaken in response to chemotherapy’s gruelling treatment regimes. Common side-effects include fatigue, nausea and vomiting, night sweats, physical weakness, weight changes, sleep disturbances, depression, constipation, diarrhoea and a dry mouth (242, 243) and SM practices can be utilised to ameliorate these problems. However, more research is needed to understand why SM is of particular benefit to chemotherapy patients. It is also important to look at in more detail the most popular types of SM practices (e.g. exercise and diet) so healthcare professionals can make specific recommendations to their patients of useful SM practices. Finally, people’s varying perceptions of what constitutes SM may have an impact on their decision-making processes when choosing them. Issues around the efficacy of various SM practices may help cancer survivors to make informed choices in this area.

#### **4.5.1 Strengths and Limitations**

A study strength was its large sample size and 95% of the target response rate was achieved. Postal questionnaires can often receive response rates as low as 20% (228), so the substantial response rate of 46%, which provided 89% power at 5% significance, was large enough to provide credible findings. Another strength was that respondents were largely representative of the population in the West Midlands in terms of ethnicity and gender and there were no statistically significant age differences between responders and non-responders. This enhances the generalizability of the study findings, increasing their applicability to other settings. The significantly higher response rates in Asian and Black populations compared with the West Midlands population indicates that the questionnaire design was culturally sensitive, as black and minority ethnic communities are usually under-represented in survey studies (244). Additionally most previous studies examining SM in cancer survivors have focused on women with breast cancer (36, 67, 69). However this study looked at the ten commonest UK cancers, enhancing representativeness of the findings to the UK cancer population.

The questionnaire study is not without its limitations. Although every effort was made to send a second postal questionnaire to non-responders after one month, correspondence from a number of respondents revealed that they had received it within a couple of days of the first questionnaire, perhaps due to the postal system or a fault at the printing distribution centre. Receiving two questionnaires within a close proximity could have affected the response rate. The study may have been affected by responder bias, with cancer survivors interested in SM being more likely to respond. For non-responders SM uptake may have been lower than for responders. Recall bias may also have affected findings as respondents were asked retrospectively to identify SM practices used pre-

diagnosis and during treatment, resulting in possible discrepancies with what they actually undertook. In addition it is not possible to distinguish from the questionnaire survey which SM practices were undertaken as hobbies and which were undertaken specifically with the aim of improving or maintaining health. This is something that the qualitative study explored further.

#### **4.5.2 Practice and Policy Implications**

Cancer patients are increasingly expected to take more responsibility for decision-making around their health, illustrated by the recommended implementation of specialised care pathways for cancer survivors who might benefit from self-supported SM interventions (1, 63). The study findings provide policy-makers with pertinent insights into the types of SM interventions currently being used. This information can be used in practice, to help design tailor-made SM packages to help promote cancer survivors' long-term health, wellbeing and QoL and to help clinicians discuss SM with their patients in an open and supportive way. These tailor-made SM packages can take into consideration the nuances between people with different cancers and treatment types.

#### **4.6 Conclusion**

The findings have contributed to the SM and cancer survivorship literature, describing the prevalence and distribution of different types of SM practices being used by cancer survivors. Notably all SM categories had their highest uptake in survivorship. This indication that cancer survivors, especially those who have undergone chemotherapy, are

using SM increasingly in their daily lives demonstrates the potential for SM strategies to help support these people.

#### **4.7 Chapter Summary**

Chapter 4 began by providing a rationale for exploring the patterns of SM practices in cancer survivors over time, before detailing the methods used to undertake the questionnaire study. This included information on cross-sectional study designs, ethical issues, setting, access and data collection, questionnaire design, sample size and statistical analysis methods. The chapter then presented the results from the survey study, providing the demographic details of respondents, the prevalence and distribution of SM practices from pre-diagnosis, through treatment and into survivorship, as well as indicating any demographic differences that existed between different SM categories. These findings were then discussed, strengths and limitations of the study were outlined and implications for policy and practice were indicated, before the chapter's conclusion was reached.

The potential impact of SM uptake in improving the day-to-day lives of cancer survivors will now be explored in Chapter 5. The chapter will present the remainder of the results from the questionnaire study reporting on any associations that might exist between SM uptake and QoL, HLC and ability to work.

CHAPTER 5. ASSOCIATIONS  
BETWEEN SELF-MANAGEMENT  
UPTAKE AND QUALITY OF LIFE,  
INTERNAL HEALTH LOCUS OF  
CONTROL AND ABILITY TO  
WORK

## **5.1 Introduction to Chapter**

This chapter is concerned with examining any associations which might exist between cancer survivors' uptake of SM practices and their QoL, internal HLC and perceived ability to work, exploring any demographic variations that may exist. It will begin by giving some background as to the relevance of SM in relation to QoL, internal HLC and work ability, before outlining the study aims and objectives. The study findings will then be reported on and discussed. Study strengths and limitations, practice and policy implications and areas for future research will also be considered. Once the chapter has concluded, a brief summary of the findings from the overall questionnaire study will be given and their pertinence in informing the qualitative study will be explained.

The relevance of exploring the advantages of using SM to enable the provision of significant, long-lasting health benefits to cancer survivors has been recognised in Chapter 2, due to its potential benefits in promoting patient autonomy over lifestyle choices, easing pressure on NHS resources and improving health and wellbeing (1, 44, 84). The examination of any associations between the SM uptake of cancer survivors and their QoL, internal HLC and ability to work can allow the identification of any possible relationships between these variables, generating insights into mechanisms for improving cancer survivors' work and social lives and helping to understand any potential motivations for cancer survivors to undertake a variety of SM practices. The effects of demographic factors such as income, gender, cancer type, treatment type, ethnicity and age, may also be determinants of any existing relationships between these variables and their influencing role will also be reported on in this chapter.

## **5.2 Background**

The term ‘longevity’ increasingly features in the terminology surrounding cancer survivors (55) due to the changing profile of the disease, meaning that cancer is moving from an acute-illness model to one which sits more within the framework of chronic illness (53, 54). However, although increases in survival rates, due to advances in early detection and diagnosis and more sophisticated treatment regimens (186), forecast good news for cancer patients, longevity is not the solution to all aspects of cancer survivors lives.

For cancer survivors it is imperative that methods of improving their QoL and long-term health outcomes are also considered to facilitate support to those who need it, rather than solely focusing on the importance of survival rates as outcome measures. The incorporation of SM strategies into the daily lives of cancer survivors is a mechanism for doing this. Policy-makers have previously identified the need to provide better support for people with long-term conditions (2), with recent recommendations promoting the use of SM in helping people live with the after-effects of cancer (1).

### **5.2.1 Quality of Life**

QoL has multiple dimensions encompassing the physical, emotional, spiritual, social and financial aspects of life and can be altered in cancer survivors due to the long-term sequelae arising from their disease and its treatment (245). It has been established in previous chapters (sections 2.2, 3.2, 4.2) that cancer survivors are often left with debilitating physical and mental consequences from their cancer and treatment (242, 243) and that they often feel

eschewed by health professionals following the end of their cancer treatment (48-50, 144) exacerbating symptoms such as depression and anxiety, all of which can contribute to decreased QoL (56).

Previous systematic literature reviews have looked at various types of SM in relation to health outcomes and QoL. The effectiveness of peer support SM programmes for cancer patients in providing psychosocial adjustment found a high level of satisfaction for the programmes, yet evidence for their psychosocial benefit was mixed (197). Systematic reviews summarising the effect of exercise on physical function and QoL in cancer patients and survivors (200, 246-248), found moderate quality evidence to suggest that exercise does improve these outcomes. Other research on exercise in cancer survivors has reported positive effects on vigour and vitality, cardio-respiratory fitness, QoL, depression, anxiety and fatigue (57, 249). No systematic reviews were identified examining the effect of diet on the health outcomes of cancer survivors. However a literature review exploring lifestyle changes of cancer patients post-diagnosis found consumption of a 'healthier diet' to be reported by between 30-60%, suggesting that those undergoing treatment may be more careful to provide their bodies with the correct nutrients to promote healing (250).

A meta-analysis (41) investigating the effects of the psychological therapy, cognitive behavioural therapy (CBT), on depression, anxiety and QoL in cancer survivors found CBT to have a significant effect on improving depression and anxiety in the short-term and QoL in both the short and long-term. A systematic review examining whether religious/spiritual coping strategies affected illness adjustment in people with cancer, found some evidence for its beneficial effect. However, other studies found religious

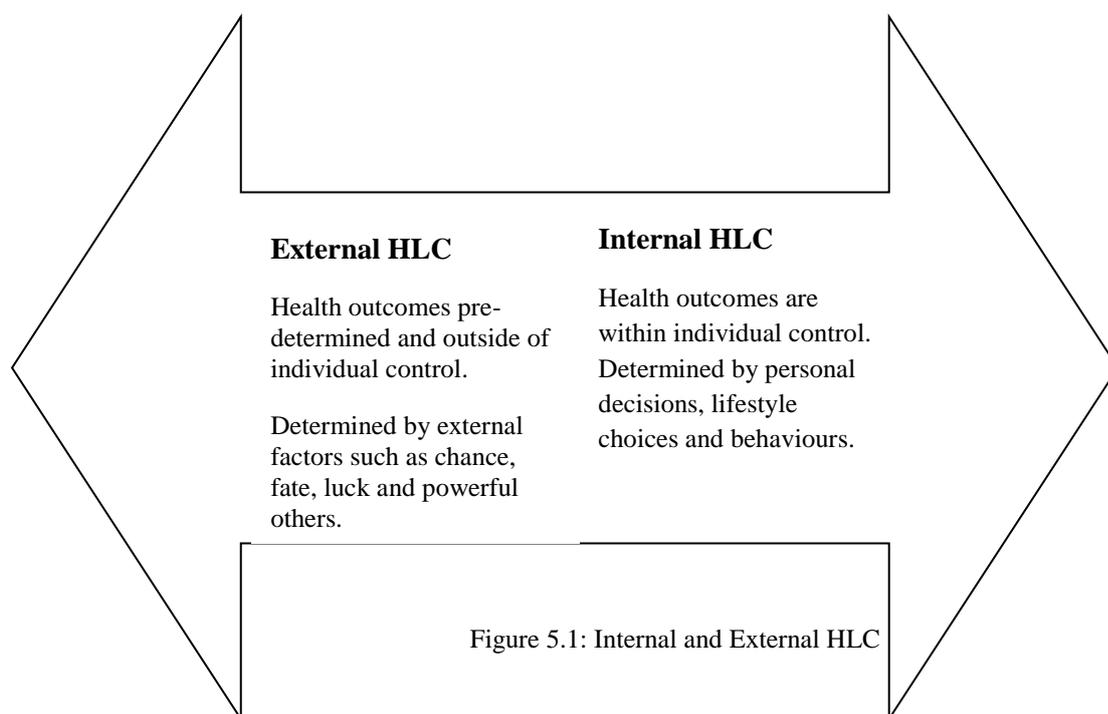
coping to be of no benefit or harmful, increasing psychological distress, anxiety and cancer related stress and decreasing psychological adjustment, life satisfaction and emotional and social wellbeing. Many of these studies suffered serious methodological problems, mainly due to how religious coping was conceptualised and measured (198). In terms of CAM and QoL, many systematic reviews have been published (36-40), but the majority have examined patients undergoing active cancer treatment, or those in the palliative or terminal phases of disease. In addition, the reviews tend to focus on individual types of CAM. However, a recent systematic review and meta-analyses examining the effect of different types of CAM in improving QoL in cancer survivors showed CAM to be significantly associated with increased QoL, although the authors pointed out that the quality of the evidence reviewed was poor, indicating more rigorous research needs to be undertaken (196).

### **5.2.2 Health Locus of Control**

HLC is the extent to which people believe their health is or is not determined by their own behaviour (figure 5.1). Those with a high external HLC are presumed to have generalised expectancies that factors such as fate, luck, chance and powerful others determine their health, whereas those with a high internal HLC believe that someone becomes healthy or unwell as a result of their own behaviours (71). Cancer patients with high internal loci of control may be more likely to access SM practices due to an increased sense of responsibility and self-governance towards their own health outcomes (240). A systematic review evaluating the evidence concerning the role of beliefs relating to control in attracting people to CAM found mixed results, with three of the thirteen studies included in the review finding significant associations between internal HLC and CAM use (251). A further cross-sectional survey

study exploring how HLC influenced peoples' attitudes towards CAM found that those with a higher internal HLC reported more CAM use (252).

These findings suggest that people with a high internal HLC are more motivated to incorporate certain SM practices into their daily lives than those with a low internal HLC. In addition, a systematic review examining the relationship between psychosocial factors and health behaviour change in cancer survivors found a high internal HLC was associated with positive behaviour changes depending on survivors' perceptions of the link between the health behaviours and cancer and its recurrence (253). This suggests that SM uptake in cancer survivors may increase if they perceive the SM practice to be beneficial in minimising the risk of a cancer recurrence. Changes in a cancer survivor's HLC over time may influence their motivation to commit to certain health behaviours, potentially affecting their health outcomes on an emotional, psychological and physical scale. It is useful therefore to examine the association between cancer survivors' HLC, their QoL and their SM practices.



### 5.2.3 Ability to Work

Previous studies examining working life after cancer have suggested that the sense of identity and purpose that can be provided through working life is often threatened by a diagnosis of cancer as the normality of working life is interrupted and threatened (33, 60). Successfully returning to work post-cancer is perceived by many cancer survivors to be a means of regaining a sense of normality and repossessing elements of their life prior to cancer (33, 60). However the ability to successfully return to work can be complicated by factors including level of employer support, with good relationships with employers and colleagues being cited as a major influence in returning to work (254, 255). Conversely, those who perceive that they have experienced employer discrimination as a result of their cancer are less likely to return to work (121). A systematic review examining cancer survivors' employment and work ability identified the importance of practical support in the workplace from employers to facilitate the return to work process (187). Cancer survivors who reported a strong commitment to the work organisation or who enjoyed a good social climate at work also identified less impairment regarding their work ability (187). The review also found that factors decreasing the likelihood of cancer survivors returning to work included lower levels of education, working in blue collar (often more physical) jobs and older age (187). Those with higher levels of fatigue also took longer to return to work, highlighting the impact of cancer related treatment in inhibiting the return to work process (187).

Difficulties in returning to work post-cancer can have negative impacts on self-esteem, QoL and social or family roles as cancer survivors feel they are no longer able to fulfil these roles sufficiently (116, 189). These negative emotions can be exacerbated for cancer survivors

experiencing financial hardship as a result of no longer working, leading to feelings of shame and embarrassment at no longer being able to provide for themselves or their families (116, 189). It is important therefore to examine, in this study, whether the use of SM practices alters cancer survivors' perceptions about their successful ability to work, as this may have positive implications in terms of their physical and psychological wellbeing. The uptake of certain SM practices, such as exercise regimes to rebuild muscle strength and stamina, or attending religious services to gain community support and spiritual strength, may facilitate the successful transition back in to work for cancer survivors, impacting on their QoL and having positive implications in terms of workplace productivity and longevity (121, 187).

### **5.3 Aims and Objectives**

This chapter adds a unique contribution to the SM literature as it reports on study findings relating to the use of multiple SM practices in cancer survivors and how their uptake is associated with their QoL, health beliefs and work ability. This chapter's remit is to identify any changes in cancer survivors' use of SM practices with regard to their QoL, HLC and ability to work. This is an important step in attempting to improve cancer survivors' health pathways and their experiences of living with cancer. The study aimed to answer the following questions:

- Does the uptake of SM practices have an impact on the QoL of cancer survivors?
- Does the uptake of SM practices have an impact on the internal HLC of cancer survivors?
- Does the uptake of SM practices have an impact on the perceived ability to work of cancer survivors?

- Are any associations between QoL, internal HLC, ability to work scores and SM uptake affected when controlling for the demographic variables, age, ethnicity, gender, income, cancer type and treatment type?

## **5.4 Methods**

A full explanation of the study methods has been detailed in Chapter 4. Respondents were asked to complete the study questionnaire which included the EQ-5D-3L scale, the MHLC scale, and the Work Ability scale to assess their QoL, internal HLC and ability to work, respectively. Any associations between SM survivorship scores and the independent variables QoL (EQ-5D and EQ-VAS), internal HLC and work ability, were explored with SPSS version 19.0, using correlation analysis. Due to the abnormal distribution of the data non-parametric testing was used. The Spearman Rank Order correlation co-efficient was used to describe the strength and direction of the relationship between the variables.

In addition, the non-parametric Mann-Whitney U test (203) was used to look for differences between high and low independent variable scores (EQ-5D, EQ-VAS, internal HLC and work ability) and SM survivorship scores. To ensure the high and low scoring groups were evenly balanced, the independent variable scores were split at the median value following data collection. For EQ-VAS scores, the median value was 80, very similar to the mean value of 82.8 attributed to the EQ-VAS literature from a UK general population survey (209, 256). The median score of 0.814 used in the study for the EQ-5D differed slightly from the score of 0.66 in the UK general population survey (209, 256). For internal HLC the median score used in the study was 23. This is only marginally

higher than the mid-score range of between 15-22 usually attributed to this subscale (257) and ensured that the dataset was evenly split. The median score of 9 in the study was also higher than the mean value of 7.1 for the work ability scale that is reported in the literature for people with chronic illness (258). The independent variable scores were then split into quintiles (table 4.3) to assess any significant differences that existed across the quintiles in relation to SM uptake scores, using the Kruskal-Wallis test (203).

Multi-linear regression explored whether associations between a number of independent variables (EQ-5D, EQ-VAS, internal HLC and work ability) and SM scores existed when controlling for age, gender, ethnicity, income, cancer type and treatment type.

## **5.5 Results**

### **5.5.1 EQ-VAS and EQ-5D and Their Relation to SM Uptake**

A significant positive association was found between SM survivorship scores and EQ-VAS scores ( $r=+0.138$ ,  $n=427$ ,  $p=0.004$ ), with respondents with higher SM survivorship scores having higher EQ-VAS scores. There was a positive correlation between age, ethnicity, EQ-VAS scores and SM survivorship scores, with younger people ( $p<0.0001$ ) and non-white respondents ( $p=0.024$ ) being more likely to use SM practices and score higher on the EQ-VAS scale than older people and white respondents. There was also a positive correlation between EQ-5D scores and age and ethnicity, with younger respondents ( $p<0.0001$ ) and non-white respondents ( $p=0.02$ ) also scoring higher on the EQ-5D scale than older people and men. This implies that the demographic variables age and ethnicity strengthen the association between both SM uptake and EQ-VAS scores and SM uptake and EQ-5D scores.

When the EQ-VAS was split above and below the median value of 80, a significant difference in SM survivorship scores ( $p \leq 0.015$ ) was found with the high scoring group having a higher median uptake of SM survivorship scores. The effect size was small in both cases (eta squared  $< 0.02$ ). When the EQ-VAS was further subdivided into quintiles (table 4.3) the highest median uptake of SM survivorship scores were in the lowest (Md=6.0) and highest (Md=5.0) scoring groups ( $p=0.005$ ).

When examining functional QoL and SM uptake scores, no significant associations were found between EQ-5D scores and SM survivorship uptake scores. When the EQ-5D scores were split above and below the median value of 0.814, no significant differences were found between groups. No differences between groups were found when the EQ-5D was further subdivided into quintiles.

### **5.5.2 Internal HLC and its Relation to SM Uptake**

The impact of SM uptake on internal HLC was also examined. High internal HLC scores were positively associated with high SM uptake with a significant, but small, positive correlation between the two variables ( $r=+0.100$ ,  $n=412$ ,  $p=0.043$ ), suggesting an association between high internal HLC scores and high SM survivorship scores exists. After controlling for cancer type, age became a significant factor in the relationship between HLC and SM scores ( $p=0.043$ ), with younger people more likely to have a higher HLC than older people ( $p<0.0001$ ). When internal HLC was split above and below the median value of 23, no statistically significant differences in SM uptake scores were found. Furthermore, no differences between groups were found when internal HLC was subdivided into quintiles.

A significant difference ( $p=0.006$ ) was revealed in internal HLC between respondents who undertook dietary changes (Md=24.0, n=264) and those who did not (Md=22.0, n=155), with those making dietary changes having higher median internal HLC scores. No other differences between internal HLC scores and other types of SM were observed.

### **5.5.3 Work Ability Scores and SM Uptake**

The analysis of work ability excluded the 283 (66%) respondents who were retired or unable to work due to illness and disability. No significant relationship was found between work ability and SM scores. Respondents with high work ability scores, where the median value was 9, were no more likely to have a high SM uptake than those with low work ability scores. Additionally, when the work ability scale was subdivided into quintiles no significant differences in SM scores were found between them. No significant association between work ability scores and SM survivorship scores was found when controlling for the six covariates.

## **5.6 Discussion**

These results have uncovered any associations between SM uptake and QoL, HLC and ability to work. Statistically significant associations were found between SM uptake and EQ-VAS scores. However, no association was found between SM uptake and EQ-5D scores. SM uptake was associated with increased internal HLC scores and those making dietary changes were found to have a significantly higher HLC than those who did not. No association was found between SM uptake scores and work ability scores.

The positive association between SM uptake and EQ-VAS scores could be for a number of reasons. It may be that cancer survivors with higher feelings of overall health choose to engage with SM practices to maintain their QoL and standard of living. Alternatively, it could be that cancer survivors with a higher uptake of SM practices experience greater feelings of overall health as a result of using SM. The finding that cancer survivors in the lowest scoring group on the EQ-VAS scale also had a high SM uptake suggests there may be a subset of people with a lower QoL who utilise SM as means of *improving*, rather than *maintaining*, their QoL, health and wellbeing. This idea of using SM to improve health outcomes links in with the concept that those with a high internal HLC may be more inclined to utilise SM practices to improve their long-term health outcomes and QoL. Cancer survivors will have different motivations for utilising SM interventions depending on factors such as their health status, treatment side-effects and level of social support (253, 259). The subsequent types of SM they choose to engage with may vary accordingly, but are likely to be influenced by their HLC and whether their desire is to maintain or improve their general health and QoL.

The findings indicate that younger, non-white respondents have a higher QoL and SM uptake, compared to older, white respondents. Previous research has shown age to significantly impact on the QoL of cancer survivors, with younger cancer survivors more likely to report ongoing emotional symptoms, whilst older age-groups report more physical problems, both of which can decrease QoL (48, 50). It may be that in survivorship, the presence of physical side-effects from cancer, alongside other co-morbidities related to ageing, markedly impact on the overall QoL of older people. The influence of ethnicity could reflect cultural differences in responses to disease and

treatment sequelae, with factors such as views of illness and disease, fatalism, belief systems and family influences and concerns impacting on the QoL of cancer survivors with different ethnic backgrounds (49).

The lack of association between SM uptake and EQ-5D scores suggests there is some disparity between the two QoL measures used in the study. The EQ-VAS is a subjective measurement of general health (209), revealing how individuals view their health-related QoL at a particular time-point (209). Cancer survivors using SM practices may in turn feel more in control of their lifestyle choices, improving their self-efficacy and leading to improvements to general health, wellbeing and QoL. The lack of any significant association between EQ-5D scores and SM scores may be because the EQ-5D has been designed to measure health-related QoL through more specific, practical parameters (209). When measuring QoL against these constructs cancer survivors may have different measurement standards when thinking about their general health as a subjective concept.

The term 'quality of life' has long been disputed, with some viewing it from a task analysis approach, whilst others emphasise its subjective aspects and the patient's perspective of health (260). One QoL definition, related to individual goals, states '*A good QoL can be said to be present when the hopes of the individual are matched and fulfilled by experience. The opposite is also true: a poor QoL occurs when the hopes do not meet with the experience.*' An alternative definition views QoL as '*being functionally orientated, addressing day-to-day living issues and focusing on distinguishing functional states within the population*' (261). These contrasting ideas about what constitutes QoL help explain the different findings between the EQ-VAS and the EQ-5D measures in

relation to SM uptake. The findings suggest that SM practices may generate improvements in cancer survivors' perceptions of their general health and wellbeing. Previous literature has cited positivity as an effective coping mechanism for dealing with the effects of cancer and its treatment (262), highlighting the potential contribution of SM in supporting this process, as improvements in QoL may induce positive emotions as a result.

Respondents who made dietary changes had a significantly higher HLC than those who did not, suggesting that dietary changes can be perceived by cancer survivors as an active process for promoting good health (250, 263, 264). Cancer survivors have been shown to spontaneously adopt lifestyle changes in the hope of achieving improved health (263-265). The study finding adds to the survivorship literature, suggesting that cancer survivors may be more motivated to make changes to their diet than other types of SM practices in the pursuit of good health. This idea of positive behaviour change as a way of promoting health in cancer survivors has been verified in a systematic review linking positive behaviour change to its perceived benefits in relation to a cancer recurrence (253). With this in mind, the link between internal HLC and dietary changes suggests cancer survivors may view dietary modifications as a means of protecting their bodies from future health threats (250).

The lack of correlation between SM scores and ability to work suggests SM uptake has no direct influence on the work ability of cancer survivors. However, the questionnaire excluded respondents who were retired or unable to work due to illness or disability from completing the work ability scale, providing a study limitation. Employment and impaired

ability to work has most commonly been found to be associated with cancer type, treatment type, health status, education and physical workload (187). The wide variety of cancer types and treatments in the study may have meant that some respondents were unable to work or had retired due to the more severe side-effects from their cancer and treatment. This may have affected the findings as respondents who were working may have been suffering less severe health problems than those who were not. Further research is required to assess the disease related, work-related and person-related factors that might have an effect on work life and return to work (187).

### **5.6.1 Strengths and Limitations**

The measurement tools used in the study provided design limitations. The EQ-VAS is a subjective measurement of QoL with participants stating from their own perspective how they rate their health from 0 (worst possible health) to 100 (best possible health) on a certain day (209). Changes in understanding or perceptions of health-related QoL constructs may occur between individuals if their internal perceptions of certain health states on the scale differ in relation to others, a term known as ‘response shift’ (266). The EQ-VAS has no fixed parameter indicating what zero represents, hence for some it may mean bedbound, for others paralysis and for others death, leading to respondents having different starting points from which to benchmark their health status. This could have affected the reliability of the EQ-VAS findings due to this lack of consistency between respondents (266).

Though the HLC scale is domain specific, in this case being applied to the health domain, it is not stable across time or domain (267). As such, a cancer patient may believe that good dietary practices will lead to a decreased risk of a cancer recurrence, scoring highly

on the internal HLC. Yet the same patient may also believe that their oncologist has the greatest influence over their health outcomes, thus scoring highly on the external HLC scale. Hence one can see how discrepancies can arise when scoring the HLC, affecting how it is subsequently interpreted.

Additionally, the questionnaire design omitted asking respondents who were retired or unable to work from rating their work ability. In retrospect, as discussed, it may have been beneficial to include all respondents to get a better overview of ability to work.

### **5.6.2 Practice and Policy Implications**

The multitude of physical and mental health problems commonly experienced by cancer survivors has been documented extensively in previous literature (48-50) and can have debilitating consequences in terms of QoL (115, 116, 120, 189). This study has illustrated the associations that exist between cancer survivors' uptake of SM practices, their QoL and their HLC. Any causative relationships between these variables need exploring further. However, the findings suggest that SM, QoL and HLC have a dynamic relationship, interacting with each other to a greater or lesser degree depending on factors such as levels of social support, income, general health and lifestyle practices (253, 259). This interactive relationship has implications for cancer survivors as the types of SM practices they choose to utilise may have positive impacts on their QoL. Likewise, cancer survivors with a high QoL may utilise more SM practices, which may engender positive benefits to their health outcomes and wellbeing. The influence of HLC in contributing to these decisions around SM is a valid one, as is the concept that by engaging in more SM

practices cancer survivors may experience changes in their internal HLC as they see the benefits to their health outcomes and QoL.

## **5.7 Conclusion**

These findings have added to the existing literature around QoL and internal HLC, suggesting that, in this study, SM can play an important role in influencing these components of cancer survivors' lives. The correlation between SM uptake and EQ-VAS scores and SM uptake and internal HLC scores in this study suggests that cancer survivors using SM may be more motivated to utilise SM practices to improve their health outcomes, generating a more positive health outlook in the process.

The links between SM, QoL and HLC are important when thinking about the most appropriate mechanisms for incorporating SM into the lives of cancer survivors. Future research would benefit from assessing the motivations and benefits of cancer survivors in terms of their decision-making about whether or not to use different SM practices on a daily basis and the subsequent impact this has on their QoL.

## **5.8 Chapter Summary**

Chapters 4 and 5 have provided some background as to why it is important to examine patterns of SM over time in cancer survivors in relation to the study aims and objectives. Chapter 4 has given a detailed account of the methods and methodological considerations used in carrying out this questionnaire study, before detailing when and what types of SM practices cancer survivors are using throughout their cancer pathway. The study findings

have shown that SM practices are utilised the most in survivorship. Exercise, followed by diet, were the two most commonly used SM practices and most SM practices have been shown to be used the most by breast cancer survivors and those who have undergone chemotherapy. Chapter 5 has added to these findings showing an association between SM uptake and QoL and SM uptake and HLC in cancer survivors, whilst no association was found between SM uptake and work ability. This suggests that the reasons for cancer survivors' differing levels of work ability are complex and multi-factorial (187).

These findings from the quantitative study have enabled an overview of when specific types of SM practices are being implemented to be obtained and have indicated that they may be valued the most in survivorship due to their increased use at this time. It is important now, however, to try to understand the reasons why and how cancer survivors use SM at different time-points along their cancer pathway and what influences their decision-making about whether or not to use certain practices on a day-to-day basis. By understanding motivations for and constraints on SM use, the importance and value placed on certain SM interventions and the reasons behind their perceived importance can be explored. Only then can thought be given as to how to implement appropriate SM interventions into both the clinical and the community setting to help improve the health, wellbeing and QoL of cancer survivors. The qualitative study detailed in Chapter 6 provides a method through which to explore these questions further to allow a deeper understanding of the complexities and mechanisms involved in utilising SM practices on a daily basis in survivorship. Chapter 7 will then provide a more detailed account of the most prominent theme to come out of interview data. This relates to the concept of SM and health-related normality in cancer survivorship and a new model relating to this concept will be proposed.

CHAPTER 6. INTERVIEW STUDY  
METHODOLOGY AND AN  
OVERVIEW OF THE MAIN  
THEMES RELATING TO SELF-  
MANAGEMENT UPTAKE IN  
CANCER SURVIVORS OVER  
TIME

## **6.1 Introduction to Chapter**

The past two chapters have focused on the ‘what?’ of SM, reporting on patterns of SM over time and exploring any associations that exist between SM, QoL, HLC and work ability. It is now necessary to shift focus away from the ‘what?’ and move on to explore the ‘why?’ in the context of SM. In doing so some of the decision-making processes cancer survivors are faced with when choosing whether or not to use certain SM practices can be scrutinised. Motivations and constraints within the daily lives of cancer survivors may facilitate or undermine their subsequent utilisation of SM, consequently affecting their long-term health outcomes and QoL. This chapter will begin to unravel some of the ideas, issues, concepts and processes relating to SM uptake in cancer survivors by presenting the findings from the interview study. It will explore the reasons why and how cancer survivors make decisions around whether or not to incorporate certain SM practices into their daily lives. The main themes to arise from the interviews will be summarised in relation to SM to give an overview of the different influences impacting on cancer survivors’ use of various SM practices.

This chapter reports the qualitative methods and methodology used to carry out the interview study. This includes a description of the purposive sampling methods used to recruit participants to the study. It also details the data collection methods employed to carry out the interviews and the thematic analysis techniques used to interpret the data. The chapter will then provide an overview of the main themes to arise from the narrative interviews in relation to decision-making around cancer survivors’ use of SM practices over time and any motivations and constraints to using them, before it concludes.

## **6.2 Methods**

### **6.2.1 Thematic Analysis**

The interpretative paradigm states that social reality is not simply a given but is a constructed, dynamic process, shaped by social meaning and tied to a certain point of view or perspective (268). Within this paradigm many different principles and methods of analysis exist. For the purpose of the qualitative research aims in this study a thematic analysis approach using interviews has been chosen. Thematic analysis focuses on what is said, rather than how it is said. It identifies units of meaning by attributing codes to blocks of text throughout the narrative. Patterns of codes and group characteristics develop into themes and the relationships between themes can then be assessed and interpreted (269).

To ensure credible and trustworthy research findings when carrying out the thematic analysis, bias must be minimised. Bias in qualitative research can be generated through my own biases as a researcher. It can occur if my interpretation of findings is influenced intentionally or unintentionally through my pre-existing views on a topic, my moral and cultural views, my limited experience in the area I am researching, or by the professional environment that I am working within. My own personal multiple biographies as a White British, able-bodied, heterosexual, cisgendered, middle-class woman, will inevitably shape my perception and outlook depending on the different environments in which I am placed. Furthermore, my professional background as a nurse, who comes from a medical family, is likely to influence my thought processes, feelings and views and my interpretations of the study findings may be skewed due to the healthcare focused environment from which I have evolved. This could lead to me interpreting the data to fit pre-existing theories and beliefs around the subject, flawing the study findings. To reduce this risk it is important to

maintain reflexivity and conduct rigorous analysis throughout the research process, being aware of how my personal beliefs and perspectives can influence data collection and analysis and guard against this happening (270). It is also imperative to check the data analysis methods and interpretations with others and this was done by sharing and comparing my findings with my supervisors throughout the analysis process. Maintaining transparency throughout is important in ensuring that the methods undertaken throughout the research process are as explicit as possible so it is clear how the study conclusions are reached.

Bias can also be incurred through the observer effect, whereby my presence in the interview setting can affect the behaviours and responses of participants, as they present themselves differently according to the social situation they are in so as to portray themselves in the best light possible (271). Observer bias is impossible to eradicate completely and it was exaggerated in the study due to the interviews taking place in an 'artificial' setting, with myself and individual participant's situated on a one-to-one basis in a room at the hospital, in their own homes, or in their workplace. However, it was possible to minimise this bias by developing a friendly, open rapport with the interview participants, and through implementing a non-judgemental approach, as well as interfering with their narrative as little as possible.

Procedural bias can also affect the trustworthiness and credibility of findings. This can be incurred by asking closed questions which force participants to respond to pre-set categories, rather than appealing to the exploratory nature of qualitative research (8).

Leading questions also incur procedural bias by suggesting to participants appropriate ways in which to respond to questions rather than by encouraging them to give an honest

account of their thoughts and feelings. Inconsistency in data collection by treating participants differently throughout the research process is also a threat to credibility and trustworthiness (8). To minimise the risk of procedural bias I developed a study protocol to ensure that the study design was detailed in a transparent and structured fashion. Additionally any deviations in data collection were reported and an interview topic guide was created to help shape the content of the interviews.

Sampling bias cannot be avoided completely in research as study volunteers may have different characteristics from those who decline to participate. However, it can be minimised by employing a protocol-directed emphasis on a particular group of people. Purposive sampling is a good way of achieving this due to its strategic nature, as it samples participants on the basis of wanting to interview people who are relevant to the research questions (8). In purposive sampling, relevance is more important than randomness and events, incidents and experiences, not people per se, are typically the objects of the sampling (272), with people being sampled because of the information they can yield about a particular phenomenon (273). Purposive sampling can provide a sample that produces the type of knowledge necessary to understand the structures and processes within which individuals or situations are located (22).

People enter qualitative studies primarily by virtue of having direct and personal knowledge of some event, such as cancer, that they are able and willing to communicate to others (273). It is better to have fewer individuals with a rich knowledge of the subject than many individuals with little knowledge to inform the research question (22).

Demographic variation is a frequently employed method of purposive sampling, seeking variation based on people related characteristics within the sample (273). Purposive

sample sizes vary, ranging from as few as five to as many as 60 or more (274). Forty participants were selected for the interview study, as this enabled enough demographic variation to be incorporated into the sample, with regard to SM uptake, ethnicity, gender, age and cancer type. The sample was large enough to be confident that most or all of the perceptions that might be important would be uncovered, without becoming so large that the data would become repetitive or superfluous (274).

Systematic bias can occur as a result of poor data analysis and was minimised throughout the research study through the use of a protocol driven analysis, consistent coding techniques, good record keeping and a transparency of findings, enabling me to justify the steps taken at all stages of the research process.

It is important to address issues of generalisation in a qualitative interview study, as increasingly it is recognised as an important source of evidence for healthcare research and practice (275). Generalisation originates in empirical research, being an act of reasoning which draws inferences from the unobserved based on the observed, and is crucial in healthcare research for applying findings to people and settings to provide evidence-based practice (275). In qualitative research the approach to generalisation is slightly different, with two models - 'analytic generalisation' and 'transferability' - used to draw broad conclusions from particular instances (275). Analytic generalisation involves qualitative researchers distinguishing between information that is relevant to most people in the sample and information that is unique to certain individuals, throughout the course of their analysis. Thus inductive generalisations are created and can be applied to other healthcare settings (275). This was done in the study through the construction of an analytical

framework, which allowed similarities and differences within and between participants and themes to be identified, collated and managed within a framework matrix (276).

Transferability refers to the extent that the study findings can be transferred to another setting or group (277). No study, irrespective of the method used, can produce universally transferable findings (278). However, transferability can be enhanced by giving a clear description of the study participants' characteristics, the sampling methods used and the culture and context of the study (277). In addition, a thorough presentation of the findings, illustrated with appropriate quotations, can enhance transferability. This detailed presentation of the study findings is often termed 'thick description' and allow readers to make inferences about 'transferring' findings to other settings. 'Thick description' involves paying attention to contextual detail in observing and interpreting social meaning when conducting qualitative research, taking into account not only the immediate behaviours in which people are engaged but also the contextual and experiential understandings of those behaviours that render the event or action meaningful (279). It conceptualises a gradient of similarity for times, people, settings and contexts, from one study environment to another, until a degree of congruence between different environments is reached (275). Writing analytic memos throughout the data analysis process allowed the themes identified in the framework matrix to be generalised through 'thick description', enhancing the transferability of the findings to other study environments as well as allowing deviant cases to be distinguished from the rest of the dataset (275, 276).

Though triangulation of data originally derives from quantitative methods to test measurement validity based on a set of empirical assumptions within a positivist framework (280), in qualitative research triangulation methods are used more to deepen

understanding of different aspects of an issue, as part of a fallibilistic approach to fieldwork (281). This fits in with constructivist epistemology by offering a way of revealing multiple perspectives or constructions of the accounts and actions of people in a particular setting, adding scope, depth and consistency to the data analysis (282, 283). Across the whole study, investigator triangulation was achieved by combining the use of both qualitative and quantitative methods in order to gain different insights and perspectives on the same topic. Further discussion of how the findings from both the quantitative and qualitative studies were used to inform each other will be given in section 6.4.

### **6.2.2 Sampling, Access and Data Collection**

Two hundred and fifty-four respondents who had returned the questionnaire indicated they would be happy to be interviewed. Forty participants were selected using purposive sampling to ensure variety, so that sample members differed in terms of their key characteristics (8). Participants were selected for interview based on the results of the quantitative data analysis which showed trends in SM uptake across the six types of SM. For example dietary uptake was lowest pre-diagnosis, increasing during treatment and peaking in survivorship. A number of participants whose own SM pattern followed this trend were invited for interview. Participants showing different trends across the support group, diet, exercise, CAM, psychological therapy and spirituality/religion groups were chosen to give an even spread of these different SM patterns.

Of the 40 participants, 20 men and 20 women were selected to give a balanced representation of both genders. Ten types of cancer were included in the study therefore four people from each cancer type were selected. The majority of the interview study

participants were White. However four Asian and seven Black participants were included to obtain an ethnically diverse sample. Participants were also selected on the basis of age, with approximately 13-14 participants chosen from each of the following groups: 20-40 years, 41-60 years and over 60 years.

Once the 40 participants had been chosen they were sent a letter or an email (depending on their preferred means of communication) inviting them to take part in the interview study (appendix 10). This was followed up one week later with a phone call asking them to confirm their participation. If willing, a date and time was then arranged for the interview. Of the 40 participants originally sampled, 33 agreed to be interviewed, with the remaining seven declining for reasons including a change of address and a cancer recurrence in the interim between having returned the questionnaire and being invited for interview. Seven more participants were subsequently invited for interview using the purposive sampling criteria described above, all of whom agreed to be interviewed.

Participants were given the option of undertaking the interview either in their homes or in a consulting room at the Cancer Centre at UHB. Although this produced some variability in terms of the data collection setting which could have contributed to procedural bias (8), I felt it was more important to carry out the interviews in a setting that was the most relaxing for the participant. Additionally, factors such as time, finances, working life and childcare may have affected the ability of the participants to be interviewed in either location, thus a choice was offered. If the participants came to the hospital for the

interview they were offered £5 as compensation for travel expenses. Twenty-six participants were interviewed at the Cancer Centre, 13 at home and one at her workplace.

Prior to commencing the interviews I undertook a pilot interview in December 2012 to test the topic guide I had designed for the study (appendix 11). The practice interview was conducted on a cancer survivor who was not involved in the study and none of the data from the practice interview was included in any subsequent data analysis. Good interviewing requires reflexive awareness of, and engagement with, the emotional, embodied and performed dimensions of the interview (284). My presence as interviewer could affect the methods, values and interpretations drawn from the research and it was important that I was as aware of this as possible so as not to cloud the research findings with my own social biases. To enhance rigour, one of my supervisors (NG) listened to the interview and reviewed the transcript to ensure she was satisfied with the interview style and techniques used. Following this, 40 interviews were conducted between January-April 2013.

All 40 interviews were guided by the interview topic guide (appendix 11). The content of the topic guide was informed directly from the findings from the questionnaire study (Chapters 4 and 5) and covered themes relating to health perspectives, social networks, attitudes to SM, work ability, QoL and the future. It asked participants about the different types of SM practices they used at different stages along their cancer pathway and any reasons they had for continuing or discontinuing these practices. Participants were asked to describe the different kinds of social support they had received at different time-points

to enable an understanding of how social support might influence the utilisation or maintenance of certain SM practices.

The association between high SM uptake and increased QoL identified in the questionnaire study initiated questions in the topic guide relating to the impact of cancer on the QoL of the interview participants. It asked whether cancer had changed their outlook on life or altered any aspects of their daily lives. It also asked them about the impact cancer had had on any physical and mental changes to their bodies. Questions relating to participants' future health outlooks were incorporated into the topic guide to see if those with a positive health outlook had a different attitude to using certain SM practices than those with a negative outlook. They were asked how much they felt in control of their health and what affected their decision-making around their health and lifestyle choices, linking in with the findings around HLC and SM uptake reported on in Chapter 5. The questions developed in the topic guide allowed an understanding of how and why SM practices are incorporated into the daily lives of cancer survivors. Interviews were recorded using a digital-voice recorder. Prior to commencing the interview all participants were asked to sign a written consent form indicating their willingness to participate (appendix 12).

### **6.2.3 Data Analysis**

All 40 interviews were transcribed verbatim, the first ten by myself and the remaining 30 by a professional transcriber. All identifying details of names and places were removed in the transcription process or after return from the transcription company to protect the

participants' rights to confidentiality and anonymity. Twenty-one transcripts were originally single coded and then two of these transcripts were double-coded by two of my supervisors (NG, SG), who have extensive experience in qualitative research. This was done to enhance rigour in the data analysis process (8) by cross-checking that the codes attributed to the transcripts by myself were similar to those identified by my supervisors. Following this a working analytical framework was established from the coded scripts (table 6.1) and all subsequent transcripts were indexed using the categories and codes contained within the framework. Occasionally a new code was inserted into the analytic framework as new data emerged that did not fit within pre-existing codes. Following this, data from the transcripts was inserted into a framework analysis matrix spreadsheet (appendix 13) to enable ordering and synthesis of the data, whilst retaining the meaning and feeling of the interviewees' words (276). The framework analysis matrix allows interview data to be compared across and within cases, providing an audit trail and reducing the volume of data produced from the original transcripts, to make the dataset more manageable. This allows the data to be managed effectively at the same time that data analysis is taking place, enhancing the rigour of the analytical process and the credibility of study findings (269).

Data collection and analysis was an iterative process during this time, with interviews being carried out whilst preliminary coding was underway to help shape the interview process as initial themes from the coding emerged. I also regularly engaged in team discussions with my supervisors (NG, SG) throughout the data collection and analysis process to allow multiple interpretations of the data to be expressed and projected, through engaging with alternative perspectives.

Once all the interviews had been undertaken and transcribed and the preliminary coding had been completed, analytic memos were written to summarise the data for each of the individual codes so that any ideas, impressions or early interpretations of the data could be noted down (276). The memos were illustrated by quotes extracted from relevant transcripts, as well as giving details of any deviant cases where participants' stories stood apart from the general themes emerging from the majority of the narratives. This allowed similarities and differences between various characteristics to be identified as well as illuminating links and connections between categories which allowed me to reflect on the relationships between them. For example participants' reasons for making dietary changes were often prompted by cancer reinforcing the importance of healthy eating for improved health. However others did not believe that making dietary changes would make any difference to their health outcomes and others lacked the desire to make dietary changes as they enjoyed their food too much or had limited knowledge of what constituted a healthy diet. These motivations and constraints to changing dietary practices were often linked to other categories and codes such as the provision of social support in helping people sustain dietary changes and participants' personal sense of control and responsibility for their health. To increase rigour, one of my supervisors (NG) read a selection of the memos to establish she was content with their quality. Once all of the memos were written, I reread them and any new thoughts, themes, or ideas were summarised and incorporated into the memos, alongside references to any existing literature on the emerging topics.

As the thematic analytic process continued I had the challenge of deciding which part of the dataset to focus on due to its enormity. In its entirety the dataset comprised of 88 codes within ten categories: personal attributes, provision of social support, types of self-

management, embodiment, the care pathway, working life, daily life, emotions, values and concepts and attitudes and the future (table 6.1). The dataset had a diverse and rich content, but the issue of normality seemed to be a constantly recurring theme running through participants' narratives and linking into many aspects of their lives. Participants spoke of normality in relation to their lives pre, during and post-cancer and related it to other categories and codes such as embodiment and body image, working and social lives, social support and changing relationships with other people, as well as the future and reassessing their priorities (table 6.1). They also spoke frequently of how they used certain SM practices to help them to get back to normal life again post-cancer.

Through studying the data from the transcripts and the existing literature around normality I was able to develop concepts of normality in cancer survivorship. I drew inspiration from some of the methodological work on grounded theory such as taking an iterative approach by moving back and forth between data and theory and using the constant comparison method (using the analytic memos) to draw similarities and differences between participants (8). Although this didn't lead to the development of a full substantive theory, it did allow me to focus on one theme around normality which had resonances with some of the existing literature on normality (131, 135). I was then able to explore how this concept of normality manifested itself in relation to the use of SM practices by cancer survivors to help them create a new, post-cancer normality. This concept was also relevant to the original basis of my research question exploring 'who does what and *why*?' as it is crucial in understanding how and why cancer survivors make decisions about their health and lifestyle practices, something which underpins the entire study. These findings relating to SM and normality will be covered in detail in Chapter 7. This chapter, however, will

now provide an overview of the other main themes arising from the interview study in relation to motivations and constraints influencing cancer survivors' use of SM practices.

## **6.3 Findings**

### **6.3.1 Themes Emerging from the Interviews around SM Use**

Many themes emerged from the interviews relating to cancer survivors' SM use at different stages along the cancer pathway (table 6.1). Many of these themes overlapped and were apparent in different areas of cancer survivors' lives, impacting on their decision-making around whether or not to employ certain SM practices. In order to summarise the main themes to emerge from the narratives in relation to SM use, the qualitative findings will now be presented within the context of the experiences of cancer survivors at different time-points. Social support was identified from the narratives as being a major factor in influencing participants' decision-making around SM throughout their cancer journey and the types of social support gathered at different time-points will also be described here.

### **6.3.2 SM Use Pre-Diagnosis**

Chapter 4 (section 4.4.2) reported that participants undertook a wide range of SM practices throughout their cancer pathway, though it was not clear whether these SM practices were undertaken for health reasons or were driven by other motivating factors such as social lives, spiritual beliefs or simply because they were enjoyable hobbies. The interviews revealed that participants often used SM practices, in particular diet, exercise and CAM,

pre-diagnosis as a way of maintaining their general health, fitness and wellbeing. With exercise this took the form of numerous sporting activities, as well as hobbies such as dancing and gardening, or being ‘on the move a lot’. A few participants described how their work had kept them very fit prior to cancer and that retirement had decreased their physical activity and in some cases led to weight gain. The majority, whether working or retired, described feeling very fit prior to cancer, though for some increasing age, or other co-morbidities, significantly inhibited their levels of physical activity.

*‘I’ve always been active, I’m not, I don’t sit down much. I mean I do my job, I’m up, down, sideways like, I’m not a sitting down person at all.’*

*(ID: 1174; female, 60yrs, Asian, breast cancer)*

Diet wise, many participants spoke of how prior to cancer they maintained a ‘normal’, healthy diet, consisting of lots of fish, chicken, fruit and vegetables. However, others spoke of their lack of motivation to eat healthily prior to cancer, with a diet high in sugar, salt, processed and ‘junk’ foods, fat, fizzy drinks and alcohol. CAM was not widely used pre-diagnosis, but where it was, reasons included to promote self-healing, improve mental and physical health and to provide healing therapy to others using Reiki, crystal healing and hypnosis. Where used, CAM was commonly incorporated into participants’ daily routines, viewed as a positive habit to embrace, with its comprehensive benefits widely acknowledged.

*'I was also doing lots of, and this is where I think helped me, I did lots of Reiki, I was sort of a Reiki, level 2 what they call it, before you get a Master so I was doing lots of self-healing.'*

*(ID: 1207; female, 51yrs, White, breast cancer)*

For some participants SM use was due to longstanding beliefs in its therapeutic benefits for the mind and body and the promotion of good health. Exercise, spiritual/religious rituals such as prayer and reading holy books, dietary practices such as vegetarianism or a low fat diet and CAM practices such as crystal healing and Reiki, were viewed by some as important features in contributing to their overall health and wellbeing.

*'It's always what I've thought, anyway, throughout my life. Say your prayers, you know, it helps...It makes me feel all right when I just say my prayers, like, wherever, you know.'*

*(ID: 1419; male, 73yrs, White, prostate cancer)*

These insights into the reasons why these cancer survivors chose to incorporate certain SM practices into their daily lives pre-cancer demonstrate that for many participants SM activities were already a regular part of their daily lifestyles, undertaken for reasons unrelated to cancer. Very few participants used or expressed a need for psychological therapies prior to their cancer diagnosis compared to after diagnosis. This indicates the psychological impact that a cancer diagnosis can bring to people who previously have not

Table 6.1: Categories and Codes Included in the Qualitative Analytical Framework

Categories	Attributes	Provision of Social Support	Types of Self-Management	Embodiment	Care Pathway
<b>Codes</b>	<ul style="list-style-type: none"> <li>• Age</li> <li>• Gender</li> <li>• Cancer type</li> <li>• Ethnicity</li> <li>• Religion</li> <li>• Income</li> <li>• Employment</li> <li>• Qualifications</li> <li>• Marital status/family</li> <li>• Smoker</li> <li>• Other health problems</li> <li>• Domestic/home situation</li> <li>• Other</li> </ul>	<ul style="list-style-type: none"> <li>• Health professional support</li> <li>• Family support</li> <li>• Support of partner/spouse</li> <li>• Support of friends</li> <li>• Support of colleagues</li> <li>• Support of employer</li> <li>• Support of therapist</li> <li>• Social care support</li> <li>• Other</li> </ul>	<ul style="list-style-type: none"> <li>• CAM pre-diagnosis</li> <li>• CAM during treatment</li> <li>• CAM post treatment</li> <li>• Psychological therapies (PT) pre-diagnosis</li> <li>• PT during treatment</li> <li>• PT post-treatment</li> <li>• Diet pre-diagnosis</li> <li>• Diet during treatment</li> <li>• Diet post-treatment</li> <li>• Exercise pre-diagnosis</li> <li>• Exercise during treatment</li> <li>• Exercise post-treatment</li> <li>• Spirituality/religion (SR)pre-diagnosis</li> <li>• SR during treatment</li> <li>• SR post-treatment</li> <li>• Support groups (SG) pre-diagnosis</li> <li>• SG during treatment</li> <li>• SG post-treatment</li> </ul>	<ul style="list-style-type: none"> <li>• Physical changes to body</li> <li>• Sexuality</li> <li>• Body image</li> <li>• Self-perception</li> <li>• Vulnerability of body</li> <li>• Other</li> </ul>	<ul style="list-style-type: none"> <li>• Initial symptoms</li> <li>• Mode of referral</li> <li>• Investigations</li> <li>• Diagnosis</li> <li>• Treatment</li> <li>• Follow-up care</li> <li>• Other</li> </ul>

SM Strategies for Cancer Survivors: Who Does What and Why?

<b>Categories</b>	<b>Working Life</b>	<b>Daily Life</b>	<b>Emotions</b>	<b>Values/Concepts/Attitudes</b>	<b>The Future</b>
<b>Codes</b>	<ul style="list-style-type: none"> <li>• Working life pre-diagnosis</li> <li>• Working life during treatment</li> <li>• Working life post-treatment</li> <li>• Desire to work</li> <li>• Work ethic</li> <li>• Finances</li> <li>• Other</li> </ul>	<ul style="list-style-type: none"> <li>• Social roles pre-diagnosis</li> <li>• Social roles during treatment</li> <li>• Social roles post-treatment</li> <li>• Other</li> </ul>	<ul style="list-style-type: none"> <li>• Anger</li> <li>• Fear</li> <li>• Disgust</li> <li>• Happiness</li> <li>• Disbelief</li> <li>• Sadness</li> <li>• Gratitude</li> <li>• Guilt</li> <li>• Other</li> </ul>	<ul style="list-style-type: none"> <li>• Normality</li> <li>• Confidence in organisation/ system</li> <li>• Belief in recovery</li> <li>• Outlook</li> <li>• Associations with cancer</li> <li>• Belief in causes of cancer</li> <li>• Regret</li> <li>• Responsibility for health/sense of control</li> <li>• Motivations for changes in SM</li> <li>• Changing relationships with other people</li> <li>• Other</li> </ul>	<ul style="list-style-type: none"> <li>• Reassessing priorities</li> <li>• Mortality</li> <li>• Helping others</li> <li>• Other</li> </ul>

experienced significant symptoms of anxiety, depression or distress, with studies showing that breast cancer patients undergoing treatment are twice as likely to suffer from depression as those without cancer (285, 286).

Participants also spoke of varying levels of social support prior to their cancer diagnosis. The majority spoke of how they had supportive family lives and friendship networks, which seemed to help them post-diagnosis. Conversely those who had difficult family relationships or who struggled to maintain friendships, often found their subsequent diagnosis harder to deal with and battled with feelings of isolation, indicating how a lack of social support can have negative implications in terms of coping with cancer.

*'The family's non-existent really; my sister went down the path of money and the house. I didn't go along that line, so it is difficult; I'm on my own a lot with it...It's when people say you can choose your friends, but you can't choose your family.'*

*(ID: 1892; male, 55yrs, White, melanoma)*

### **6.3.3 SM Use during Treatment**

As the cancer trajectory progressed, reasons for utilising SM altered, with increasing emphasis being placed on SM as a means of keeping the mind and body strong to withstand cancer treatment. This was linked to the concept of holistic care, with many participants feeling that to prepare their body for cancer treatment they had to prepare their mind and vice-versa. Here, SM took the form of CAM therapies such as transformational

breathing, meditation, emotional freedom therapy and Reiki. These were seen as methods for releasing negative energy, drawing on positive energy and aiding relaxation.

*'It [meditation] helps you rest. I was in so much discomfort it's very difficult to sleep. I couldn't breathe very well, I couldn't swallow and it seemed to help me get better quality rest and there's a certain sort of quality it also brings in, sort of nothing, I'd be just supported by the ground and a sort of sense of...Sort of surrendering a bit...So that seemed to help and I did get a better quality rest and, you know, took some of the stress out of it.'*

*(ID: 1035; male, 51yrs, White, head and neck cancer)*

This desire to keep the body strong was also identified through participants actively seeking out a healthier diet through measures such as decreasing alcohol intake, initiating a vegetarian/vegan diet and increasing supplement use.

*'I think it's [cancer] just changed my way of thinking...Avoiding processed food...I made a conscious effort to look into the ingredients of certain types of food, and if there's so many additives... I would avoid them....I always try and get the natural, the ingredients...And if I could get organic vegetables I would get them...Because for me the natural nourishment that the vegetables would get from the soil is the most natural way, that's probably the most wholesome way.'*

*(ID: 1593; female, 41yrs, Asian, colorectal cancer)*

However, others admitted that despite awareness post-diagnosis of the importance of eating healthily, they had continued with unhealthy food patterns, out of habit and because they wanted to still eat foods they enjoyed, instead of letting cancer impinge on this.

*'I eat what I feel, mostly potato and mostly solid food. You know because at my age you know I don't feel for anything but I like chicken, I like a lot of meat and I'm not a vegetable person. I eat what I feel for. You know. Sometimes spinach and we like spinach, but it's funny I like spinach, you know. Yeah, yeah. Green peas, broccoli, as I said vegetables wasn't my taste, but I eat it now and again.'*

*(ID: 1533; female, 81yrs, Black, colorectal cancer)*

SM practices were also undertaken during treatment to manage and minimise cancer side-effects and symptoms. Dietary modifications were seen particularly in head and neck, stomach and oesophageal patients, where changes to physical function meant participants could only eat certain foods, or were restricted to smaller portions. Taste changes during chemotherapy also altered eating habits, with participants reporting distaste for previously enjoyable foods and craving foods they would not usually consider.

*'I was having chemotherapy, it changed my tastes then, during the time I did have a glass of wine once and I told my husband there was something wrong with it, and there was nothing wrong with the wine...No, no. it was me...And I did eat differently...But yes, various things tasted odd. I had some chips from the chip shop and they were disgusting,*

*there was nothing wrong with them, and it was just - so that did affect me actually at the time.'*

*(ID: 1201; female, 56yrs, White, breast cancer)*

Some CAM practices and certain exercises were deemed too strenuous during treatment due to the onset of severe symptoms and side-effects such as fatigue, pain and shortness of breath. One man who regularly practiced meditation and yoga pre-diagnosis spoke of his intention to continue these throughout treatment, but soon realised this was impossible due to the severity of his chemotherapy.

*'I had this idea that I'd try and keep it going and it would help me through it but the chemotherapy is so intense. Now after the first session I was reeling a bit and I realised no, it is a question of just sort of hanging on in there.... It did tail off a bit...It was just a pretty basic level of just trying, you know, stay alive and stay as positive as I could.'*

*(ID: 1035; male, 51yrs, White, head and neck cancer)*

During treatment certain SM practices may be too gruelling to undertake due to cancer patients' limited physical capabilities (287). In addition, uncertainty over potential contraindications of CAM alongside conventional medicine may make it off-putting to some (51, 227). This highlights the importance of raising general awareness of different SM practices and of setting out transparent guidelines as to their specific benefits, side-effects and contraindications. Recommendations as to which SM practices may be useful

adjuncts to cancer treatment and which may be too invasive, would allow cancer survivors to make independent, well-informed choices about using them. Changes in the suitability of certain SM practices at various time-points along the cancer pathway highlight the need for more information as to their specific advantages and disadvantages.

A few participants reported undertaking counselling during treatment, as a coping mechanism, or for dealing with depression. These participants valued the psychologist's ability to enable them to confront difficult emotions and underlying issues. Other participants felt they may have benefited from counselling but were never offered it or were unaware that the service existed.

*'I thought afterwards, there isn't anywhere to go...Where you can...Say that this is how I felt and...I could've done with a complete stranger who could've listened and asked the right questions and I could've just said all this and got it out of my system and then got on with it...Nothing was offered and I wouldn't have known where to go...I think a one-off session would've been very helpful...I don't know that hospitals supply that kind of thing.'*

*(ID: 1645; female, 60yrs, White, oesophageal cancer)*

These issues and concerns around accessibility to and awareness of services corresponds with literature showing that cancer patients often have unmet psychological needs and psychiatric morbidity that go unrecognised and therefore untreated (190-192). A study examining major depression in outpatients attending a regional cancer centre found that of

those suffering with major depression only 7% had been referred to specialist mental health services (psychology or psychiatry) and only 5% had received any formal psychological treatment for depression (190), illuminating a huge gap in the service due to unmet treatment needs. This could partly be attributed to decreased provider referral as the focus is on the patient's medical management rather than their psychosocial needs and partly to limited psychological services being available due to long waiting lists (190). These issues need addressing to ensure that the psychological aspects of a cancer diagnosis are not neglected across UK cancer services.

Participants' social support networks included family, friends, health professionals, other patients, therapists, work colleagues and employers. Numerous SM practices were initiated during and post-treatment following participants listening to lifestyle advice from family and friends, health professionals and therapists to enable them to firstly, recover from cancer, and secondly, try to prevent the cancer recurring. The most common advice revolved around CAM and diet, with popular recommendations including specific dietary programmes, increased supplement or herbal remedy use and homeopathy. Family members were generally cited as the biggest support, acting as a constant presence in participants' experiences and significantly influencing their reasons for wanting to utilise or discard SM practices. Support was identified as practical, emotional, psychological, community and spiritual support. Participants valued the practical and emotional support they received throughout treatment from family and friends, including help with domestic chores, providing transport to hospital, sharing fears and worries, providing hope and positivity and helping them to maintain a sense of humour. This corresponds with previous research showing positive associations between perceived social support, open communication channels and psychological adjustment to cancer (124, 285, 288-290).

*'I think the main thing is...Keep a sense of humour. Laugh about it, because if you don't laugh you're gonna cry anyway. Like I said about the wig, we made a joke of it, we made fun of it and lots of things that...You find humour in it.'*

*(ID: 1790; female, 68yrs, White, non-hodgkin's lymphoma)*

This social support often catalysed participants to use SM practices, as they felt empowered to alter their lifestyle practices for their own and their families' benefit. Participants whose family members engaged in SM practices with them often identified this as a motivator and incentive for sustaining these practices. However, sometimes a cancer diagnosis highlighted the lack of emotional or practical support received, leading to feelings of anger, sadness and frustration.

*'Nobody really asked how you felt. Or if they did ask, they didn't really want to hear the answer, and you always went, "Oh, yeah, yeah, I'm fine. I'm doing well." So, I became quite angry, not necessarily at getting cancer, but just, I suppose, the lack of support.'*

*(ID: 1178; female, 36yrs, White, breast cancer)*

Those who did lack support from family and friends often sought support from elsewhere, with SM used as a mechanism for seeking emotional support through community or spiritual practices. These SM activities encompassed things such as accessing support groups, going to church, praying, practicing Reiki and crystal healing.

*'It's (cancer) strengthened my faith. It's always been there, I had a long time away from not going to church...And I went back to it but not when I had cancer....And went into the Methodist church...And I was just welcomed at the door straight away...But they didn't fuss you, it was a very gentle thing...And just from there it's just taken off and, well my faith has grown because of the practical help that I've had and my belief.'*

*(ID: 1205; female, 67yrs, White, breast cancer)*

In terms of health professional support, there was a general consensus among participants that the provision of a supportive relationship with their doctor was important in generating hope, security and a belief in survival. Though the majority felt well-supported, some spoke of feeling undervalued and commodified due to their doctor's offhand and disinterested manner, something which has been acknowledged in other literature with factors such as lack of warmth and friendliness, failure to take account of patient views or concerns, lack of clear explanation, the use of medical jargon and ignoring patient cues and questions, all contributing to this failure and causing considerable distress (291-293). A failure of health professionals to effectively elicit information from cancer patients about their health concerns and worries may lead to potentially negative ramifications occurring throughout their care pathways (294).

*'I just didn't like him at all...The very first time when he came to see me...He came in on Saturday morning to do a round and he was so unfeeling and so disconnected and so disinterested that, you know, I thought... "I really don't like you at all, actually, I don't want to see you again...." I felt right from the start I was just a number.'*

*(ID: 1859; male, 78yrs, White, bladder cancer)*

Participants often placed more trust in health professionals' words than those of family and friends, often clinging to the literal meaning of the spoken word as an assurance that they would survive cancer. Trust in health professionals was viewed as highly important and participants placed value on being individually listened to and treated with respect, as this reassured them that they would be okay. They also spoke of how positive attitudes from health professionals instilled a similar positivity in themselves.

*'I think consultant's attitudes have a lot to play...My oncologist was wonderful, my breast surgeon was wonderful...The amount of patients I know the oncologist sees I still felt I was that person in that room...They can install confidence in you or they can just really turn you into a worrier...Just to be treated as an individual...Is a big...Bonus...My breast [surgeon]...Said, we can treat this and that's all I kept saying to myself...And my oncologist [said]... 'This treatment we have is just to mop up anything that – that's left over really'; I kept thinking okay yeah it's mopping it all up and it will all be okay.'*

*(ID: 1207; female, 51yrs, White, breast cancer)*

This idea is supported in previous literature that suggests effective communication between cancer patients and healthcare providers is associated with greater satisfaction with care, increased psychological adjustment, reduced anxiety and depression and increased QoL. Good physician/patient relationships have also been associated with trust, respect and patient-centred care (285, 289, 290, 295-298). Additionally, a recent study examining whether a larger specialist nursing workforce in cancer care was associated with better patient experience found that patients in Trusts with higher specialist staffing

nurse levels felt they were given more emotional support during treatment than those with low specialist staffing levels (299). This suggests that a greater provision of nursing staff may improve cancer patients' experience due to more time being given to meet their individual needs.

Most participants talked about how they trusted their doctor to make the best treatment choices for them, sometimes speaking of how they 'handed themselves over' to them. This reinforces the traditional Parsonian doctor/patient role of co-operating fully with the doctor in the belief this is the best way to aid recovery, in return for the their specialist knowledge and skills, immediately placing the doctor in a position of authority in relation to the patient (300).

*'I felt when I was in the hospital, and particularly when I was having the treatment, the only way I could cope with it from a psychological point of view was...To accept that these people are the experts...I just did what they told me... I just went into hospital whenever I had to...I just did what I was told because I'm not a medical person, I have no idea...But it did knock my confidence because I thought, 'Here I am in a bed in pyjamas and I'm like a baby in a sense because I can't – even if I know what's going on what can I do about it?' So I just let them do their job.'*

*(ID: 1645; female, 60yrs, White, oesophageal cancer).*

This paternalistic style is based around the idea of the doctor as expert, with the patients' role being to cooperate. However, problems can arise with this if doctors work within their own bio-medical disease-centred model, focusing on the objective description of physical symptoms with the aim of reaching a diagnosis and prescribing treatment efficiently and effectively, which can inhibit patients from expressing their own beliefs and concerns and considering other modes of treatment which might provide more widespread health benefits (301).

In recent years growing attention and emphasis has been placed the idea of patient centred care and patient participation in decision-making, with an interactive relationship between doctor and patient thought to be the most effective in facilitating open lines of communication and addressing patient needs and concerns (302, 303). Though this was often expressed by participants who talked of having excellent relationships with their doctors, for a minority of participants scepticism was expressed at the level of expertise held by the medical profession and at their motives for prescribing treatment, with the idea that patients were often duped into accepting treatment without realising the potential harm they were doing to themselves.

*'What I found is a lot of doctors, they're sort of blinkered into...It's like they're working for drugs companies...I found that they were motivated by only drug companies, and only knew about stuff that drug companies made money out of...And any health foods or herbal remedies, it was all 'hoo haa, get back to your cauldron.'*

*(ID 1091: female, 58yrs, White, breast cancer)*

Though these views were in the minority, they are worthy of consideration, highlighting the need for patients to make well-informed treatment choices based around not only the advice of their doctor but also their personal preferences and needs.

The benefits of therapeutic relationships between CAM practitioner and client have been well documented (127, 144), as has the role of support groups in the provision of practical assistance, emotional support and a sense of belonging and community (304, 305).

Participation in religious practices has also been found to promote good support networks and community involvement (306-308). Thus the iterative relationship between the development of social support networks and SM use can be understood, as SM uptake can enhance social support and vice-versa. When considering which cancer survivors may benefit from which SM practices, the level of social support the SM practice is likely to generate is an important consideration.

Observing others with cancer was a powerful incentive for some participants to alter their lifestyle behaviours. This was particularly evident from participants who described having investigations, procedures and treatments in hospital and drawing comparisons with frail patients around them who had their cancer or were having similar treatments and procedures. The shock and realisation that they could experience similar or worse health states often prompted them to alter their lifestyle behaviours to improve their health.

*'There was three other guys in this ward...They'd got pipes in their throats....And this guy was talking to me with a blackboard, he couldn't talk so he was writing it down and he asked me what I was in there for and I said a biopsy on my throat. And he said, "That's what I came in for" and on that sort of note I thought that's it, I am never, ever going to smoke again and I didn't, did I?...It scared me quite a bit really.'*

*(ID: 1737; male, 59yrs, White, lung cancer)*

Peer support, through sharing experiences with others with cancer, may help alter attitudes about lifestyle behaviours, serving as a reminder of the fragility of life when observing other cancer patients' realities. Peer support can provide emotional and informational support through the perspective of shared personal experience (309), something that is often missing from relationships with friends and family (305). Hence, peer support can be an important motivator for initiating lifestyle changes to guard against any future threat from cancer.

Participants picked up information about their cancer through multiple sources including the Internet, education leaflets, books, newspapers and support groups. Support groups can provide practical assistance, emotional support, a sense of belonging and community, unconditional acceptance and realistic information about living with cancer (304, 305). However benefits vary depending on the individual needs and experiences of group members (259, 304, 310) and some participants were wary of them, viewing them as scaremongering through the transmission of inaccurate information and here-say.

*'If you belong to a group you pick these things [information] up all the time. But I think they can also be a bit dangerous and kind of you know people find out things that they don't necessarily need to know, that may not help them or may make them feel worse.'*

*(ID: 1201; female, 56yrs, White, breast cancer)*

Prior studies have shown that patient barriers to accessing support groups include decreased awareness of the service, lack of provider referral and already having sufficient support (259). It is important to recognise that varying sources of information and support will be suited to different people depending on their existing support networks and individual coping mechanisms. Some may cope better with less information and others may feel better supported by engaging with as much information as possible. By measuring the different information requirements of individuals with cancer, through the use of appropriate screening tools, health professionals can signpost cancer survivors towards supportive resources to meet their level of need (311).

Some participants chose to access information through the Internet, finding it helpful in decision-making around lifestyle choices and practices. Additionally, many people now use Internet forums as a way of sharing and gaining information from others (312). However, the reliability and accuracy of much Internet information is questionable and whilst informing some, alleviating feelings of isolation and loneliness, it can provide disheartening and depressing information for others (312). Generally, participants viewed the information on the Internet with scepticism, with many describing it as scary, inaccurate and misleading, making them paranoid and anxious.

*'You start reading things on the Web, and that terrifies you, because I've read about lymphoma and it said about night sweats. And I'd been having lots of sweating in the night since I'd had her [baby], but apparently that's a, sort of, side effect of breast-feeding, but I didn't know that, and so you just think, "Oh, no."'*

*(ID: 1687; female, 38yrs, White, melanoma)*

Finally, some participants spoke of feeling blessed in ways, as their cancer experience had opened up new support networks, strengthened their faith and made them appreciate the number of people offering support. In particular, participants from religious backgrounds often spoke of how the supportive actions of others, through prayer, pilgrimage, lighting of candles and attending religious services, fortified their religious and spiritual connections. This was due to the belief that these acts of kindness and generosity of spirit aided their recovery from cancer. Regarding prayer, some were unsure whether it was the power of prayer, the knowledge that people were praying for them, or the two combined, that aided their recovery and this had deepened their spiritual connection with God. The sense of community experienced through these spiritual connections was also greatly valued, with the social interactions forged through going to church or temple often becoming an equally important reason for maintaining these practices as their spiritual or religious attachment.

*'They pray for me all the time and if they don't see me come to church... [They're] wondering "What happened to [her]?"' Yes, this is all them, it's a Catholic church...When*

*I go to church and they pray for you and the pastor preach to you, you feel so happy, it's like you on a different, it's like you're into a different world. Yes, you are so happy.'*

*(ID: 1652; female, 51yrs, Black, stomach cancer)*

#### **6.3.4 SM Use Post Cancer**

Post-treatment, social support networks again played an important role in motivating participants to alter their lifestyle practices, with many expressing a desire to provide support to their families by engaging in healthier diets, or by increasing physical activity. They spoke of wanting to live to see their children or grandchildren grow up, wanting to protect and support them in the future and of feeling needed and valued by them.

*I'm the main one that supports everybody in the family, so I had some goals to get back to me children, wanting to live and getting up out of bed every day...Just to not give in like, you know, I think I've got a lot of determination and resilience...Not to give into it...And say this is the end...I think that probably helped me, like my attitude.'*

*(ID: 1772; male, 55yrs, White, non-hodgkin's lymphoma)*

Post-treatment, when participants lacked support they generally rationalised that this was due to an inability of friends and family to know how to respond to their situation.

Nevertheless this often led to feelings of isolation and a distance from central figures in

participants' lives, decreasing self-confidence and self-worth. This subsequently detracted from the incentive to utilise SM or take part in social activities.

*'I don't go out...What can I do if I go out? I've got to have a bottle of water with me, eh...I can't drink, I can't eat, to be quite frank with you a lot of people won't eat or drink in front of me because they know that I can't eat or drink.'*

*(ID: 1004; male, 61yrs, White, head and neck cancer)*

However for some people, the lack of support shown to them by their friends had led to them making reassessments of these friendships and often casting them aside.

*'When I had cancer there was a few people I'd known for years, that I thought would ring me to see how I was, and didn't. That's upsetting...I think it also gives you a realistic view of how people really are. I have really nothing to do with certain people who were like that. It has made me a bit stronger...You see that other people wouldn't be bothered whether you were dead and you think, "Well, sod them."'*

*(ID: 1892; male, 55yrs, White, melanoma)*

Motivations for using SM practices in relation to physical wellbeing altered post-treatment. Whilst the salubrious benefits to the mind and body in providing relaxation, gaining positive energy, keeping the body strong, managing side-effects and promoting

overall health and fitness, were still acknowledged, additional reasons for utilising SM emerged. Exercise was frequently described as a way of regaining physical fitness following its decline during treatment. Walking was the most popular form of exercise and other exercise such as swimming, hiking and gardening were also commonly undertaken.

*'I've started swimming as well and going swimming a couple of times a week. That's nice cos there's water around you and stuff...And walking the dog. And I've been for a few long walks with him; it's been like two hours solid walking.'*

*(ID: 1091; female, 58ys, White, breast cancer)*

Cancer generally served as a motivator for participants to get their bodies as fit and strong as possible, with some acknowledging that they were fitter post-cancer than prior to diagnosis. Chapter 4 (section 4.4.3) stated that respondents who had received chemotherapy were more likely to use SM practices than those who had not. The reasons for this finding were explained by some participants who described how post-chemotherapy they had felt more motivated to take up certain SM practices, such as diet and exercise, to rebuild their health, following the chemotherapy-induced attacks their bodies had had to withstand.

*'When I did finish my chemotherapy, we did get a juicer, so we would get fresh vegetables and I would get...I know beetroot was one of the main things that we juiced and I had that*

*soon after my chemotherapy finished, just to build up on the immune system. Um, and carrots and all this other organic stuff...And juice them.'*

*(ID: 1593; female, 41yrs, Asian, colorectal cancer)*

The types of exercise undertaken were often initiated to ameliorate specific side-effects of treatment, such as lymphedema and muscle weakness, rather than because of its overall benefits to health. Other participants avoided specific exercise regimes due to fear of doing damage to parts of their bodies already weakened by cancer.

*'Because of the lymphedema they say don't scratch it because it might swell so I was very worried about getting bumped or scratched so I just stopped netball altogether.'*

*(ID: 1207; female, 51yrs, White, breast cancer)*

For a few participants, secondary health problems from cancer such as pain, breathlessness, muscle weakness and fatigue, had rendered them unable to undertake any formal exercise, making even basic activities of daily living challenging.

*'I'm not so active as what I was, I'm taking steroids without doing anything physical really. It's made me put a lot of weight on...I'm out of breath doing stuff now and my left hand is no good and I've had these blackouts. So I'm worried about pushing myself too much sometime.'*

*(ID: 1772; male, 55yrs, White, non-hodgkin's lymphoma)*

In some cases participants spoke of experimenting with SM practices they would not have considered prior to cancer, which had made them more aware of their body's vulnerability and increased their willingness to consider previously dismissed SM practices. Certain dietary practices, exercise and CAMs provide the commonest examples of this, with many participants reporting herbal remedy and supplement use since their cancer treatment, or undertaking practices such as acupuncture, yoga and meditation. For some, this corresponded with the belief that these practices would provide holistic benefits; others believed the practices would promote physical healing, whilst others believed the practices would do no harm even if they were uncertain of their benefit.

*'So I did investigate more...I did go and see a local homeopathic doctor, who was very good, and treated you, again, as a whole person, and said, "What you're doing is fine with exercise, diet, doing yoga..." So, yes...It's maybe when you get a diagnosis you're prompted to do more.'*

*(ID: 1674; female, 61yrs, White, melanoma)*

The consideration of therapies and practices which would not have been contemplated prior to cancer is apparent here. CAM is often ridiculed or discredited as being unworthy of being taken seriously as a therapeutic practice (51). However, post-treatment cancer survivors may be more inclined to consider these types of SM practices as the detrimental side-effects of conventional treatment lead them to seek alternatives to help their bodies heal. A systematic review exploring beliefs involved in the uptake of CAM found CAM users were more likely to have active coping styles and value non-toxic, holistic

approaches to their health, as well as believing lifestyle factors were important in the development of illness (251). It may be that post-treatment cancer survivors turn to these practices, viewing their holistic benefits as a method of helping them cope with the side-effects from treatment and keeping the mind and body strong in the process.

Changes to participants' diet post-cancer was sometimes fuelled by guilt, as they attributed the cause of their cancer to previous unhealthy dietary patterns and did not want to experience the same sense of guilt if their cancer recurred and they had not altered their lifestyle.

*'I'm doing all that I can to support myself in preventing the return of cancer...Nobody knows what triggers a recurrence, or, or anything, so...I can't say a 100% that they'll stop it recurring. What I would say is that I feel better in myself for doing them a) because I'm doing them, and b) because I've made that decision, I think, to try and help myself. So that's how I would, how I would view it. I'm aware that it is a very difficult disease to, to control and to, you know but I think I'm, yes, doing everything that I can.'*

*(ID: 1674; female, 61yrs, White, melanoma)*

Barriers to maintaining a healthy diet included holidays, socialising, family priorities, finances and working life, all of which provided challenges in complying with healthier eating one hundred per cent of the time. The recognition that it was 'okay' to have deviations from healthy eating was acknowledged, as was striking the balance between

healthy living and enjoying life. Gaps in health education around diet were also conveyed. One man in particular provided an illustration of how though he perceived himself to have improved his diet post-cancer he was still consuming largely unhealthy foods.

*'We don't eat junk food...I'll have a couple of pints of cheap Aldi bitter...Just to have a drink. But, despite the size of myself...We eat fantastically healthy...I'm a bugger for sugar and salt, but apart from that it's, it's healthy food....Our food intake has got slightly smaller, but I haven't altered an awful lot. Food wise, I'm still enjoying a curry...I nip out and get some Kentucky Fried Chicken, or what have you. And we've got Thursday, Friday, Saturday, Sunday, drinking beer, eating pasties and just doing nice things.'*

*(ID: 1788, male, 48yrs, White, non-hodgkin's lymphoma)*

Whilst some may blame their cancer on external, uncontrollable factors (313), others may be incentivised to change through guilt at past unhealthy lifestyle behaviours. It is important to recognise these influences on health behaviours in order to implement supportive mechanisms for change through health promotion and education and practical and emotional support, to encourage people to make informed decisions about their lifestyle behaviours.

SM was often incorporated into participants' lifestyles as a way of guarding specifically against the threat of recurrent cancer, as cancer had reminded them of their lack of invincibility, sense of mortality and fear of death. This was often reflected in the types of

SM practices undertaken. Some participants described taking herbal remedies in the belief that they might keep the cancer 'down', whilst others made dietary changes such as cutting out wheat and dairy, or following specific regimes such as the 'juicing' or 'rainbow' diets.

*'The rainbow diet...I have blueberry, I have strawberry, I have orange yeah. In my salad I have red pepper, yellow pepper....I used to have very less salad, I hate salad...I was not a salad person, but now...We just buy baby spinach, red pepper, yellow pepper, green pepper, baby tomatoes... So all that makes it rainbow, isn't it? You have the salad every day, have the fruit every day. And then have a normal vegetarian food. And I'm not controlling on milk or anything. I have a glass of milk every day. And I have yoghurt. And that's how, that's how I'm here today.'*

*(ID:1229; female, 66yrs, Asian, breast cancer)*

Often, changes in SM practices came about post-treatment as a result of participants reflecting on what they believed had triggered their cancer. Beliefs were wide ranging and included psychological factors such as stress, depression, negative thoughts and emotional trauma. These traumas included marriage breakups, relationship problems and other life events, with the belief that they negatively affected their mental and physical wellbeing, lowered their levels of immunity and caused their cancer cells to mutate. Behavioural factors such as smoking, poor diet, heavy drinking, excessive sun exposure, vitamin deficiencies, anaemia and being overweight were also cited as likely causes of cancer. Additionally environmental factors such as asbestos exposure and the use of chemicals in daily life from foodstuffs, washing powders and detergents were associated with cancer.

Hormonal changes and family history were also attributed to causing cancer. This fits with other literature attributing common beliefs for the causes of cancer as due to fate, karma, God's will, family history, mental stress or physical weakness, relationship problems, lifestyle behaviours, or the suppression of negative thoughts (314).

*'You have to take a step back and look at what's possibly causing the changes in cells to grow out of control, and if you can get to whatever...Triggers that do that, then you could stop it...So you do need to look behind what may have caused it . And I was convinced that stress can, obviously, for melanoma, exposure to sun; poor diet, which I had for two or three years.'*

*(ID: 1674; female, 61yrs, White, melanoma)*

Depending on the participant's belief system, certain SM changes were initiated or modified accordingly. These included ceasing to smoke, reducing alcohol intake, making dietary modifications, increasing exercise uptake, having counselling, undertaking CAM practices and engaging in spiritual and religious practices to find inner strength.

*'Before I used to think that if it's written in your fate it's gonna happen to you...But now I think that no, nothing is written. You have to do things. The food is there, it's not gonna come in your mouth. You have to pick it up and eat it. So whatever you want to do you have to work for it and then your destiny is created.'*

*(ID: 1229; female, 66yrs, Asian, breast cancer).*

Engaging in these practices often led to increased psychological wellbeing as participants felt they were actively managing their disease to minimise the chances of it recurring.

However, a few participants said they had made minimal lifestyle changes, feeling that the healthy lives they had led pre-diagnosis had not prevented their cancer. They felt their health was down to fate and if cancer was going to recur they were powerless to stop it.

*'I don't abuse myself with the wrong things and, you know - and then they're a lot of people who do that, and they don't become ill. So you can't really say, "Oh, it's because I didn't do this..." So you think, "What else could I have done right?" you know. I'm not a heavy smoker as such or a drinker. So it's got to be something else.'*

*(ID: 1621; female, 58yrs, Black, colorectal cancer)*

It is apparent from these narratives that individual belief systems can influence motivations for SM uptake. Many common beliefs in the causes of cancer relate to factors outside of individual control, such as fate, whilst others are preventable, such as smoking. The sense of personal responsibility held for contributing to the onset of cancer is related to peoples' internal HLC and is likely to influence their subsequent level of SM uptake. This is verified by the findings from Chapter 5 which found a positive association between a high internal HLC and SM uptake. Discussions with health professionals about the possible and probable causes of cancer and the preventative measures that can be taken to minimise a recurrence, may help to shift perspectives around personal responsibility for health, incentivising cancer survivors to consider the value of SM in this.

## **6.4**      **Discussion**

The qualitative findings presented in this chapter have helped to make sense of the findings from the quantitative study. The purpose of choosing a mixed methods study design to answer the research question was to enable the findings from the quantitative and qualitative studies to inform one another. In doing so a more thorough understanding of what SM practices are being used by cancer survivors over time and why can be gathered, with the qualitative findings offering explanations for some of the questions raised in the quantitative study.

One of the questions raised from the quantitative findings (section 4.5) was whether the higher SM uptake in cancer survivors who had undergone chemotherapy compared to those who had not, was as a result of the severity of the chemotherapy induced side-effects. This was explored in the interviews (section 6.3.4) with the acknowledgement from some participants that certain SM practices such as diet, exercise and CAM had been introduced in survivorship specifically to strengthen the body following the chemotherapy related side-effects it had endured. This reinforces the need for further research to be carried out to investigate in more depth how and why specific types of SM practices bring benefits to chemotherapy patients post-treatment.

In Chapter 4 (section 4.5), the importance of finding out more about why the most popular forms of SM, exercise and diet, were used by cancer survivors was recognised, so that health professionals could make specific recommendations to their patients about why these practices might be beneficial to them. In terms of exercise, the interviews revealed

that there were many motivations for undertaking exercise in survivorship. These included exercising to regain physical fitness which had declined during treatment and to guard against specific cancer and treatment related side-effects. However the interviews also revealed that for some participants exercise was not deemed suitable for them, either because participants felt that exercise might cause further harm to their already vulnerable bodies, or because they were simply too incapacitated to carry out any strenuous physical activity.

For diet, the interviews found that reasons for making dietary changes in survivorship were often due to an increased willingness of participants to experiment with new SM practices post-cancer. Diet was also chosen for its holistic benefits, to promote physical healing, to guard against a cancer recurrence and due to the belief that making dietary changes would do no harm even if it did no good. Belief systems also played a part, with participants speaking about how they had to '*do things*' if they wanted to remain in good health. This corresponds with the findings in Chapter 5 (section 5.6) which showed respondents with a higher HLC had a higher uptake of dietary practices. However, participants also spoke about using SM practices other than diet as a means of actively promoting better health, suggesting that all SM practices can be influenced, to some extent, by an increased internal HLC. These findings can be used to help enhance health professionals' understanding of the sorts of SM practices that may or may not be useful to their patients in survivorship, emphasising the need for individualised, holistic assessments to be made when considering making recommendations about SM interventions to cancer survivors.

Participants revealed in the interviews that SM practices were often used as a means of regaining or promoting good health, providing a major motivation for their uptake in survivorship. This helps to explain the question in Chapter 5 (section 5.6) regarding the direction of the relationship between the two variables, SM uptake and QoL. The interview findings suggest that for the majority, SM uptake is used as a method for improving QoL, by, for example, improving physical fitness, promoting healing, or aiding relaxation. However, interview participants described how the subsequent maintenance of these SM practices in survivorship was often due to them experiencing improvements in their QoL as a result. This suggests that though the initial uptake of SM practices may, generally, be driven by a desire to improve QoL, in the longer term these practices are only maintained if the tangible benefits from using them are recognised.

Some older participants described how their levels of physical activity had decreased since they retired, due to the more sedentary lifestyles they had adopted. Other participants spoke of how increased co-morbidities or simply age itself, had led to their levels of physical activity being restricted. This helps to explain the finding in Chapter 5 that older age was associated with decreased QoL (section 5.5.1). The disparity between the non-significant association between SM uptake and the EQ-5D and the positive association between SM uptake and the EQ-VAS was discussed in section 5.6, with a possible explanation for the difference being that the use of SM practices might generate improved perceptions of cancer survivors' health and wellbeing, something that is reflected in the EQ-VAS scores. This idea is reinforced by the qualitative findings (section 6.3.4) with many people speaking of how SM practices allowed them to feel they were helping themselves and were more in control of their health. As such, SM strategies can be seen as

a useful coping mechanism for helping cancer survivors to restructure their lives post-cancer and regain confidence in their bodies.

#### **6.4.1 Strengths and Limitations**

A study strength was that interview participants were selected using purposive sampling, stratifying participants according to different SM patterns of uptake, ethnicity, age, gender and cancer type. This allowed a balanced representation of these variables. I was also able to achieve diversity among participants in relation to income and employment, working, social and family lives, educational status, marital status, smoking history and other co-morbidities. This enabled a diverse and comprehensive collection of narratives to be gathered and analysed, enhancing the trustworthiness of the findings.

The importance of transparency in assessing the quality of the research findings is increasingly recognised as an important part of the research process (8) and has been addressed here in terms of detailing study design, sampling methods and data collection and analysis techniques.

Interview participants were given the choice of being interviewed in a private clinic room at the participating hospital, or in their own homes. This was considered a study strength as it allowed participants to be interviewed in the environment which they found the most natural and comfortable, putting them at ease and increasing the likelihood of an open and relaxed dialogue between the interviewees and myself.

Ten of the 40 interviews were personally transcribed, allowing a closer relationship with the data, as well as allowing the identification of key themes early on in the data collection and analysis and an awareness of key differences and similarities between participants' accounts. This time to reflect on the individual and collective narratives allowed the formation of new ideas, thoughts and questions which could be explored in later interviews. Ideally, it would have been beneficial to personally transcribe all forty interviews, but this was not possible due to limited time and resources.

Throughout the study I attempted to be reflexive in considering my role in interpreting the study findings, due to my own social, academic, economic, healthcare and personal backgrounds having the potential to infringe on the way in which the narratives were perceived. In particular, my healthcare background as an oncology nurse may have influenced the analysis of the findings due a greater emphasis being placed on the healthcare aspect of the dialogue due to a predefined interest in this subject. It may also have altered participants' attitudes as to what they could or could not disclose in the interviews. For this reason I chose not to reveal to participants my nursing background unless specifically questioned by them. Additionally, I considered that the transcripts may have been coded in accordance with my own beliefs and value systems. To minimise this risk of bias, a process of triangulation was employed, with a selection of transcripts being triple coded with the help of two of my supervisors (NG, SG), both of whom are experienced qualitative researchers, to ensure consistency in the coding process.

## **6.5 Conclusion**

This chapter has presented an overview of some of the main themes arising from the interviews in relation to cancer survivors' use of SM practices at different time-points and the motivations and constraints affecting their decision-making around whether or not to use them. It is important to be aware of the overall landscape relating to SM use and decision-making in cancer survivorship, recognising that cancer survivors' reasons for utilising certain SM practices may change throughout their cancer pathway. This is an important finding, helping us to understand more about the different considerations that cancer survivors are faced with when trying to make appropriate choices around their use of SM and suggesting that these choices are multi-factorial and fluctuate throughout the cancer journey, depending on individual experiences, circumstances and support networks.

## **6.6 Chapter Summary**

The qualitative study described in this chapter has outlined the methodological considerations and techniques used in the interview study, providing a rationale for the methods used. It has gone on to explore some of the reasons for cancer survivors' use of SM to be unpicked and described in detail, by describing cancer survivors' motivations and constraints for using different types of SM practices pre-diagnosis, during treatment and into survivorship. It has then discussed how the findings from the qualitative study have been used to inform some of the findings from the quantitative study, providing explanations for some of the questions raised and reaffirming the value of using a mixed methods study design. Following this, the strengths and limitations of the qualitative study have been outlined, prior to the chapter concluding. Whilst Chapter 6 has focused on

describing the interview data to provide an overall picture of cancer survivors' experiences in relation to SM, Chapter 7 is more concerned with viewing normality as a central concept linking together all of these different themes and holding a model for SM in place.

Chapter 7 will now go on to report in more depth on the concept of normality, which was a continuous and persisting theme running through participants' narratives, connecting up many different facets of their lives both pre, during and after cancer, with SM often described as a method for helping cancer survivors achieve their post-cancer normality. Concepts based around normality in survivorship emerged through data collection and analysis, by drawing similarities and differences between participants. This allowed me to formulate a model relating to the role of SM in creating a new post-cancer health-related normality, something which will be detailed in the following chapter.

**CHAPTER 7. THE ROLE OF SELF-  
MANAGEMENT IN CREATING A  
NEW, POST-CANCER  
NORMALITY**

## **7.1 Introduction to Chapter**

Chapter 6 has detailed the qualitative study design and provided an overview of the main themes to emerge from the interview study. This chapter will now explore in more detail the concept of ‘normality’ which is the core theme to emerge from the interviews with cancer survivors and plays a central role in influencing their decision-making around their use of SM practices. Normality, or normal, in this context can be defined as ‘the internalisation of images of a self that can fulfil regular social roles without experiencing impairment or discrimination because of one’s health status’ (315). Although the topics covered in the interviews with the 40 cancer survivors were far more wide-ranging than the theme of normality alone (table 6.1), it was the theme that recurred throughout the majority of the participants’ narratives, providing a link between and within other concepts and themes and linking into the ‘why?’ of SM.

Therefore, in relation to answering the research question of why cancer survivors are using SM practices in their daily lives, this chapter will argue that the pursuit of normality is central to SM uptake. The chapter will examine participants’ perceptions of normality before and during treatment, before exploring their perceptions of normality post-treatment in relation to their uptake of SM practices in survivorship. A new model will then be proposed to explain the role of SM in facilitating the creation of a new post-cancer normality in survivorship.

The chapter will begin by giving an overview of some of the existing literature relating to normality and cancer survivorship, to provide a contextual backdrop for the research question to be framed within. Following this a discussion of the study findings will occur, in relation to the key concept of SM and how it can help to inform a new post-cancer normality in survivorship. Study strengths and limitations will then be discussed, alongside practice and policy implications and areas for future research before the chapter concludes.

## **7.2 Background: Normality in Chronic Illness**

Normality can be viewed as a product of society, a context dependent social construct which is value based and culture specific (316). Norms radically alter over time and can be exemplified by peoples' changing attitudes as to what constitutes, for example, normal sexuality or normal child rearing. Thus it could be argued that there is no normality outside of a particular social context (316). Within society, it is the presumed majority which defines what is normal through their actions and behaviours, marking out those who deviate from their conventions as deviants, or eccentrics (316). This marked departure from normality can lead to feelings of stigma invoking emotions such as guilt, shame and spoiled identity on the grounds of being labelled inferior or socially unacceptable compared to the rest of society, thus increasing social and psychological morbidity (317-319).

As well as the acute illness that cancer can bring, individuals also experience chronic changes to their bodies stemming from their cancer and treatment (53). However within

Western societies there is an expectation that people should return to normal life as quickly as possible post-cancer as a symbol of their valued self (53). When people are unable to do this as a result of debilitating side-effects, this valued self is lost, causing a crisis of identity. This can manifest in social isolation, restrictions to daily life, financial problems and altered relationships with family and friends (53, 129). On entering survivorship therefore, cancer survivors often need to work to rebuild their fragmented identity and reshape it according to their newly found circumstances (130).

Perceptions of normality are fluid, with its boundaries influenced by time and circumstance (320). Tiefer (2004) suggests that normality can be defined subjectively, statistically, idealistically, culturally, or clinically, resulting in a wide range of ideas of what is normal depending on the viewpoint from which it is perceived (321). Subjective normality describes individuals who perceive themselves as normal when making social comparisons with others. Subjective normality could also result in individuals perceiving themselves as abnormal when making this comparison (322). Statistical normality refers to the statistical norm or average; ideal norms refer to perfection; whilst cultural norms refer to the norms within a particular culture. Clinical normality refers to the parameters that health professionals would refer to as healthy, with anything outside of this seen as unhealthy (322). When judged within this clinical environment one can see that normal parameters of health pre-diagnosis may be very different to normal parameters of health once diagnosed. This is because symptoms such as fatigue and pain may be seen as explainable and manageable once diagnosed whereas they may symbolise uncertainty and a significant threat to health prior to diagnosis. Therefore healthcare professionals can be viewed as a

contributory influence on perceptions of normality, classifying through diagnosis and treatment who is sick and who is not (320).

The example above illustrates how definitions of normality can overlap and clash, with someone's cultural or subjective normality being perceived as abnormal when viewed from a health perspective. Cancer patients may rely on health professionals for reassurance as to whether or not the symptoms they are experiencing are normal within their specific model of disease, affecting their subsequent confidence levels and self-efficacy (323). These reclassifications of normality can result in people with cancer altering their boundaries of normality as they reassess the new norms and expectations determined by their disease. This desire to achieve normality, albeit a changing one, may reflect a need to construct order and control amidst the uncertainty and ambiguity of cancer (320). Once this increased confidence and control is achieved cancer survivors are able to redefine for themselves their new normality based around the mechanisms they have incorporated to help them to adapt to their new realities (323). This new normality can be redefined through changes in appearance, adjustments to daily and social life, or by a reassessment of the way they are perceived by others (322).

Qualitative research exploring female breast cancer patients' perceptions of normality following breast cancer and reconstructive surgery found that one of the parameters for normality revolved around having normal health, something that was judged by the removal of any reminders of cancer and ill health, by feeling healthy both emotionally and physically and by regaining a sense of 'wholeness' (322, 324). For cancer patients,

achieving normality can be seen as an endpoint in their journey, by having a normal life again or by being cancer free (322). Strategies for achieving this normality include returning to normal lifestyle patterns, minimising the changes incurred from cancer and treatment and leaving cancer behind (320). In particular, returning to work is often cited as a way of returning to normality, being viewed as a positive sign of moving on from cancer and regaining control over life, as well as a way of showing others that they are no longer unwell (33, 325). This idea of normality is true amongst other people with chronic illness, with normal health being perceived as having the freedom to undertake activities of daily living without having to make compromises or sacrifices in doing so. Here returning to normal can be viewed as a departure from cancer and the often gruelling side-effects entailed whilst undergoing treatment (323).

Cancer survivors can seek to achieve normality, whether by reconstructing a new normality for themselves, or through discarding any tangible elements of cancer from their daily lives. Both of these versions of normality indicate that being normal means different things to different people and that being healthy and being normal are intertwined, linking in with each other and influencing the way that normality is perceived (131, 322). This concept of health-related normality involves three inter-related processes: the continued reassessment of normality, the fight to maintain normality and maintaining the appearance of normality (131). This chapter will ask what role SM plays in supporting this concept of a new health-related normality in survivorship? It will argue that the use of SM can play an important role in helping cancer survivors to achieve a new normality, by providing

supportive mechanisms for undertaking the processes of reassessing and maintaining normality. This argument will be detailed more thoroughly in the chapter's findings.

## **7.3 Findings**

### **7.3.1 Overview of Findings**

The theme of normality was consistently threaded through the interview dataset, weaving in and out of many aspects of participants' lives. Issues around normality featured prominently and reinforced findings already in the literature around the concept of finding a new normality post-cancer. Reassessing normality, maintaining normality and maintaining the appearance of normality have previously been identified as inter-related processes for achieving health-related normality and this was further verified in the interview data. The interview findings make a new contribution to the literature around normality in cancer survivors by providing a model whereby SM practices can act as supportive mechanisms for facilitating these inter-related processes, as well as providing direct routes towards a new health-related normality. Thus normality can be viewed as a key driver in the uptake of SM practices.

The concept of normality only has meaning within someone's whole biography as the construction of a new normality can only take place based around previous parameters of normality. Therefore the findings will begin by exploring how cancer patients' expressions of normality change between pre-diagnosis and during treatment, before the survivorship phase has been entered.

### 7.3.2 **Changes in Normality Pre-Diagnosis and During Treatment**

Personal narratives are able to highlight how major events have a causative sequence and how meaning is created from this sequence of events. Thus it is important to understand cancer survivors' interpretations of normality both prior to being diagnosed with cancer and during treatment. This can enable a better understanding of the reasons behind their subsequent reassessments of normality in survivorship. Peoples' life courses are made up of a series of stages and transitions in life which are culturally and institutionally framed from birth and which help define what is considered normal within society. The health, social, cultural, familial and working behaviours employed by a person informs to a large degree how much they are considered a normal part of society (326). Being 'healthy' can be measured against this social construct of normality (320, 327), illustrated in the literature by the stigmatization often felt by people who are labelled as disabled or diseased (317, 318). This concept was apparent when participants spoke of their lifestyle behaviours prior to diagnosis. To these people their lifestyles prior to cancer represented a time before they had to consider making any adaptations to their normal lives. Participants spoke of their normal health, work and social behaviours prior to their cancer diagnosis and often used them as reference points when discussing how their lives had since changed. Often participants described how they had been fitter and in better health prior to being diagnosed with cancer.

*'At that point, I was – I was very fit because I was playing badminton...I felt as though I could knock a building over.'*

*(ID: 1646; female, 71yrs, White, oesophageal cancer)*

*'I think I've always played football, like before I had this like although I've put a lot of weight on now due to the steroids, I think being unemployed and being active before...I was quite fit before, and quite active like.'*

*(ID: 1772; male, 55yrs, White, non-hodgkin's lymphoma).*

Participants' normal social roles generally revolved around social life, work and levels of physical activity. Generally participants had busy lives of a high quality. Participants spoke, often with remorse, at how prior to cancer their QoL had been much greater as they had been able to do much more both physically and socially.

*'Before I probably would have went dancing with you, I'm telling you, I was...I'm a single guy, I had a great life, I was a foreman electrician...I was running that, earned plenty of money, loved a drink, joke, round the clubs doing this...I have grandkids and this and that but I live by myself and I used to have a great time.'*

*(ID: 1004; male, 61yrs, White, head and neck cancer)*

Participants also spoke of their normal working lives prior to diagnosis, often describing how they were very busy and always on the go. This ability to push themselves to the extreme in working life contrasts sharply with the experiences of many cancer survivors who are at greater risk of being unable to work due to poor health or who will experience considerable mental and physical limitations in the workplace (328).

*'After working eighteen hours I work seven hours somewhere else... I work nights somewhere....Then I come home, sleep. I work two till five with Birmingham City Council. That's how I work before I started the treatment. So when I was about to start the treatment I let them know that I resign. I have to resign there.'*

*(ID: 1497; male, 53yrs, Black, prostate cancer)*

Perceptions of normal life pre-cancer usually altered once cancer treatment began due to the mental and physical impact of treatment. Unlike the majority of chronic illnesses, such as heart disease, diabetes or multiple sclerosis, most people diagnosed with cancer face the added burden of adapting to and surviving a gruelling treatment regime, necessitating further reassessments and reconstructions of normal life to be made. Previous literature in this area suggests fatigue affects the majority of patients undergoing chemotherapy and radiotherapy and is usually significant enough to have an impact on daily life by necessitating alterations to patients' normal routines and their ability to carry out activities of daily living, as well as decreasing their social activities (115, 120). Studies have also shown that cancer related fatigue can increase levels of depression, anxiety and mood disturbance as well as exacerbating feelings of isolation, dejection and a loss of emotional control (120). This was exemplified in the interviews with treatment side-effects inhibiting many participants from carrying out their usual SM practices due to experiencing both physical and mental fatigue.

*'I think...Confidence went; I remember feeling very tired and so energy wise you know it's daft really isn't it I mean if you exercise more you get more energy but it was trying to break that vicious cycle.'*

*(ID: 1207; female, 51yrs, White, breast cancer)*

The debilitating effects of fatigue reduced some participants' social lives dramatically due to their physical weakness, which severely limited their ability to interact with others, work, or go out as normal.

*'I was physically exhausted...It was all I could do to get out of bed and go to the toilet...And that was hard to cope with for me because I've always been very...Active.'*

*(ID: 1025; male, 64yrs, White, head and neck cancer)*

*'With the chemo and everything - that's when I did start crying a lot, when I was at home on my own...You spend a lot of time on your own during the day, because most people are at work, but you don't have the energy to go anywhere.'*

*(ID: 1178; female, 36yrs, White, breast cancer)*

With regard to working life, previous qualitative research has found that many cancer patients choose to continue to work throughout their treatment if possible, using it as a

means of distracting themselves from dwelling on their cancer experience and helping them to retain a semblance of control in their otherwise fast-changing lives (33, 255).

*'All that time...I was working. I remember sitting at the appointment...Doing work in the waiting room. And the day after I...had my diagnosis in October...I went into work the next day...Looking back, I think...I felt I needed to, because, to me, that was the only way of making...A sense of normality and I think if I had, sort of, stopped and given up everything, just because I had had the diagnosis, I would have felt even worse.'*

*(ID: 1687; female, 38yrs, White, melanoma)*

Work can help to provide a continued sense of identity, purpose and self-worth throughout treatment, helping to maintain a sense of normality which might otherwise be threatened (33, 60, 255). Many participants who were unable to work experienced a subsequent loss of control and order as their working identity was abandoned. This loss of control was also apparent in people who had retired but had previously had busy, active, structured lives.

*'When I decided to retire...I had lots of plans...All the things we were going to do and all the rest of it and started off fine and very confident. We went off on a cruise and we went off to Venice and we did all sorts of things...Then, wham, this happened and I wasn't in control. I wasn't in control of my own life, my own body, and that was a terrible shock.'*

*(ID: 1645; female, 60yrs, White, oesophageal cancer)*

### **7.3.3 SM and the Emergence of a ‘New’ Health-Related Normality in**

#### **Survivorship**

Examining concepts of normality in cancer patients pre-diagnosis and throughout treatment enables increased understanding about how cancer survivors make further reassessments of normality post-treatment to establish a new normality. Previous qualitative studies have suggested that cancer survivors emerge as a more authentic self in survivorship, having been transformed and enlightened by the psychological and social stages of their recovery (329, 330). As discussed in the background section to this chapter, this new health-related normality involves three processes: the reassessment of normality, the fight to maintain normality and maintaining the appearance of normality (131). The interview data has identified that the implementation of certain SM practices are useful mechanisms for supporting cancer survivors undertaking these processes to achieve their new normality.

#### **7.3.3.1 The Reassessment of Normality**

In making reassessments of normality those with chronic illness often compare themselves to how they were before they became ill, to others with their illness, or to healthy others (131). This reconstruction of normality is a combination of what is remembered from the past and what is imagined for the future and is a constantly shifting process (331). Social comparison theory suggests people often engage with downward social comparisons with others experiencing chronic illness as a strategy to maintain their sense of normality, improving wellbeing through the assertion that there are others worse off than themselves (332). This was evident from the narratives with participants speaking of how they felt they had not suffered as much as many other people with cancer.

*'I feel very compassionate towards other sufferers, and most people have suffered considerably more than I have.'*

*(ID: 1790; female, 68yrs, White, non-hodgkin's lymphoma)*

This social comparison with others with cancer links into SM usage as cancer survivors may utilise SM strategies, such as diet, as a means of retaining some control over their illness in order to conquer it and maintain this new level of normality (131). Participants described doing this through numerous approaches including by maintaining a positive attitude to beating cancer which often involved utilising various SM practices. Many had the idea that by taking good care of the mind and body, the production of a positive outlook would be expedited and vice versa, with SM seen as an important tool in this.

*'You just have to get on with it don't you?...You've just got to go forward and think positive...Don't keep feeling like you're - because you've had cancer, or you have cancer, that you're sick, in the mind, like if you keep saying you're sick well you will be sick. You've just got to get on with it. Be a normal person, because you are normal.'*

*(ID: 1667; male, 71yrs, White, bladder cancer)*

By having a positive outlook, cancer patients may purposefully try to initiate more SM practices into their lives to strengthen the mind and body physically, therapeutically and holistically. This in turn could bolster feelings of positivity as they feel more in control and

experience the benefits to their overall wellbeing, leading to the maintenance of these SM practices. Associations between SM use and QoL have been shown previously in Chapter 5, adding credibility to this idea.

*'I thought, "Look; I'll just have good diet. Do what I can do best..." Many people survive from breast cancer so I kept on very positive.'*

*(ID: 1229; female, 66yrs, Asian, breast cancer)*

Much literature suggests that having a positive psychological coping style helps increase cancer survival rates, whilst negative coping styles, incorporating feelings of helplessness and hopelessness, lead to poorer outcomes (123, 333, 334). However a systematic review investigating the association between psychological coping styles and cancer survival and recurrence found no significant association between psychological coping styles and survival or recurrence (335). Nevertheless, being positive could enable cancer patients to continue with their daily lives, helping them cope with the effects of cancer and its treatment by putting appropriate strategies into place (262).

*'There's a down side and there's positive sides, but you've got to try and think of the positives all the while...I've been able to see my grandchildren...I get a lot of pleasure out of them now, my grandchildren, my family, I'm quite family orientated. I love my family.'*

*(ID: 1772; male, 55yrs, White, non-hodgkin's lymphoma)*

In the study participants employed a whole range of SM practices to generate positive energy, promote good health and actively take control of cancer in an attempt to vanquish it. The Look Good Feel Better (LGFB) support groups provide an example of this (336), with women describing their involvement in the groups in terms of opening communication channels with others, bolstering self-esteem, sharing experiences, forgetting their problems and having fun through shared humour.

*'It was nice to discuss because then you know what type of thinking other ladies were going through...And you learn a bit from each other...And it was good talking to them. But they were all very friendly, we had a lovely time...And it was fun. And you forget your worries because you are in that environment and you then know that you are not the only one...So it makes a difference.'*

*(ID: 1229; female, 66yrs, Asian, breast cancer)*

However, the LGFB groups provide an example of how cultural standards are often used to define normality. The LGFB groups have been shown to improve self-image and social interactions and decrease anxiety amongst women with cancer and are aimed at trying to improve the image related effects of cancer, thus boosting self-image and body confidence in these women (337). However, it has been argued that in doing so they are attempting to normalise female cancer patients by hiding the physical signs of cancer and returning to the dominant concept of women as healthy, heterosexual and able-bodied (338). The idea that by disguising their cancer and looking outwardly attractive, women can increase their self-

esteem and lead an outwardly 'normal' life, serves to legitimise in some ways the stigma that is attached to people with cancer (338). This 'normalisation' of femininity does nothing to support those women with cancer who choose not to wear make-up, who show any physical disfigurements, or who do not fit the 'normal' perception of womanhood.

### **7.3.3.2 The Fight to Maintain Normality**

Motivations for using SM practices in relation to physical wellbeing and normality altered in survivorship. Ameliorating effects on the mind and body in providing relaxation, gaining positive energy, keeping the body strong, managing side-effects and promoting general health and fitness during treatment were still acknowledged.

*'I find Reiki helps, particularly last thing of a night time when things start to look a bit bleak, I find that helps me to relax and forget about the problems.'*

*(ID: 1943; male, 68yrs, White, lung cancer)*

However, additional reasons for utilising SM also emerged. Exercise was frequently described as a way of regaining physical fitness following its decline as a result of harrowing treatment regimens, most notably chemotherapy. Walking was the most popular form of exercise, with dog walking an incentive for doing so; other types of exercise like swimming, gardening and yoga were also popular. Often these strategies were viewed as a

method for maintaining control over their health and their bodies, although it was recognised that this was not always fully within their grasp.

*'I do think it's possible to control through diet and thought process, and looking after your body as a functioning mechanism, that you can influence some things, hopefully for the good.'*

*(ID: 1674; female, 61yrs, White, melanoma)*

Participants spoke of how post-treatment they persevered gradually, building up their physical activity day-by-day until they had regained their normal pre-cancer levels of fitness.

*'After the surgery they said "You need to exercise." ...So I started walking round the block which was about two, three hundred metres. And I've gradually built that up over three and a half years. I can now go out for about an hour and a quarter, hour and a half. Just walking round.'*

*(ID: 1551; male, 59yrs, White, colorectal cancer)*

Yet many spoke of the frustration of this process, as they realised just how much cancer had taken out of them.

*'She [wife] said, "What's the matter?"...And I said, "I can't get up the stairs." I said, "I'll go up this way." And I said to her..."My darling, you're looking at a man who's climbed Everest and now I cannot even get up my own bloody staircase." You know. And we just sat and laughed about it. But that's very frustrating, you know.'*

*(ID: 1025; male, 64yrs, White, head and neck cancer)*

However, cancer generally served as a motivator for participants to get fit to get their bodies as strong as possible to retain the levels of physical function they had previously enjoyed, with some acknowledging that as a result of cancer they were now fitter than they had been prior to their diagnosis.

### **7.3.3.3 Maintaining the Appearance of Normality**

It was apparent that participants were aware of maintaining the appearance of normality at certain times, especially to peers and at times health professionals, partly due to a fear of being labelled as a cancer patient by others, partly due to not wishing to be a burden or cause distress and partly to try to forget about their illness for a while.

*'When I went out with friends it was brilliant. And you didn't want to be there as the person who'd got cancer, you wanted just to chat and banter, so you'd probably make more of an effort to be a bit more social, a bit more funny, a bit more cute...Than normally*

*you would do, because you're just thinking, "Gosh, you know, I don't want people to feel," not pitying, but, "To.....Treat you differently."*

*(ID: 1178; female, 36yrs, White, breast cancer)*

This desire to appear normal to others mirrors Goffman's conceptual framework relating to 'The Presentation of Self in Everyday Life' (271). Goffman (1959) suggested that within any social establishment when an individual appears before others they knowingly and unwittingly project a definition of the situation - of which a conception of the self is an important part - as well as monitoring the behaviours of the people they are encountering. Thus any face-to-face encounter can be interpreted as a theatrical performance, with the actors in the performance enacting lines and roles that are carefully constructed to maximise the potential for deception (271). This was apparent from the interview dataset where putting on a 'brave face' was often seen to be socially acceptable, allowing a 'normal' exterior to be presented to friends and family (131).

*'When you meet people...Who don't know anything about you [you have] to act as if you're just normal because you never think of yourself as normal when you have cancer, so...You act like you would actually before you had cancer...You're not normal in as much [as]...Well your body changes for a start, like the breast removed and stuff. And I think even when I have the reconstruction it will not be the same as having your own breast.'*

*(ID: 1191; female, 55yrs, White, breast cancer)*

Goffman (1959) went onto theorise that if an event occurs which is incompatible with this projected impression it can disrupt the social interaction which is taking place, leading to embarrassment, discreditation and disorganisation of the established social structure (271). Again this scenario was verified from the dataset as participants were not always able to present their 'normal' exterior to other people around them due to the physical and mental impairments experienced by them. This had subsequent repercussions on their social and working lives, often undermining their self-image and negatively impacting on their QoL.

*'Social life has changed. I mean after work you'd go for a drink or you've got football or something to discuss, like men things and laughing and joking at work and you miss that kind of thing...You're just there with your wife and then next she probably gets a bit bored and then we get a bit bored, but she's got her own friends as well.'*

*(ID: 1772; male, 55yrs, White, non-hodgkin's lymphoma)*

SM was frequently seen as a mechanism for improving these physical and mental impairments in an attempt to return to the person they were pre-diagnosis and regain an appearance of normality. This could be through the mental benefits of carrying out religious practices such as prayer, through the holistic benefits commonly attributed to CAM, through promoting health and fitness through diet and exercise regimes and through psychological input or gaining advice and sharing experiences at support groups.

*'The best thing that happened to me after, after I'd finished all my ops and [chemotherapy and radiotherapy], I started hot yoga...That was the best thing, because, actually, the [lymphedema] has...It's gone really...I couldn't move this arm very well...So I've been able to move...So that's what I do. You've gotta find something that works.'*

*(ID: 1289; female, 40yrs, Asian, breast cancer)*

However, though these practices served as coping mechanisms, non-disclosure of information about the nature and severity of cancer to close friends and family due to fear, distress, shame and worry, can cause alienation from crucial support networks due to a breakdown in communication channels. Lack of disclosure of diagnosis and prognosis has been verified in previous literature, with the worry that family members will seek reassurance about the illness serving as a deterrent for openly discussing feelings (339-342), leading to potential isolation due to the restriction of emotions.

*'To talk to members of your family is different because they get upset. My sons still get upset if I do mention anything about the cancer. If I'm saying I'm just going for my annual check-up they're on tenterhooks to know that everything's okay when I come out of it again. They're not comfortable with the fact that I had it.'*

*(ID: 1205; female, 67yrs, White, breast cancer)*

The benefits of disclosure have been debated, with some commentators arguing that disclosure allows people to reorganise their thoughts and feelings and make sense of their experience, lowering psychological distress (343, 344), whilst others have suggested cancer patients would rather talk about things going on in their 'normal lives' and that disclosure makes no difference to the psychological and social adaptations to having cancer (341, 342). These views can be debated, yet it is likely that non-disclosure of information to friends and family will reduce the forum for cancer patients to consider specific SM practices that might be suited to them, due to decreased opportunity to openly discuss their needs, worries and uncertainties. There is a need to promote good communication pathways and decrease the stigma and taboo attached to cancer. This often stems from a fear of cancer, due to its association with death, and a lack of understanding of the disease (345). Stigma can increase cancer patients' awareness of the vulnerability of their bodies, often heightening their embarrassment of it (317, 339, 346). By removing some of the fearful associations linked to cancer, positive, open and honest dialogues can be initiated and mechanisms for SM can be established. This may be particularly challenging for some black and minority ethnic groups, who often view discussion of serious illness and death as being disrespectful, of eliminating hope, causing unnecessary anxiety and depression and of tempting providence due to the power of the spoken word (347, 348). This is exemplified in the following quote from a South Asian woman who hid the news of her diagnosis from her mother to protect her from distress.

*'My mum's...We didn't tell her that [it was cancer] because it would have been devastating for her I think...When she sees me I think she thinks I'm healthy so she doesn't worry about*

*it and because I'm back to my normal, this is the way I was...It was hard not to tell her but it was all decided, I didn't want her to worry because, I mean the family thought maybe we should, but then in end I said no, I don't want her worrying about it more and so I think it would have been a shock for her because of how healthy I've been all my life; it was a shock to everybody.'*

*(ID: 1174; female, 60yrs, Asian, breast cancer)*

#### **7.3.4 Comparing Old and New Normalities**

Within the context of health-related normality in chronic illness, the interplay between cancer survivors' continual reassessment of normality, their fight to maintain normality and maintaining the appearance of normality (131) was apparent when participants compared their current lives with their lives pre-cancer. Physically, many participants expressed regret that they were no longer as fit or strong as they had been pre-diagnosis, or were impeded by symptoms or side-effects from their illness which restricted their physical function. Mentally, participants often reported feelings of anxiety, depression and lowered self-esteem, self-confidence and self-worth. Some also reported feeling that their brains were 'slower' than they had been pre-treatment and that they weren't as intelligent as they had been pre-cancer.

*'I wanted things to be normal again...I don't think they ever are to be honest, I don't think you're ever quite the same person you were, physically...Mentally I don't think I am. But I*

*don't know how much of that is the mental affects or whether it's actually an effect of the drugs.'*

*(ID: 1201; female, 56yrs, White, breast cancer)*

The negative assessment of mental and physical changes to the body commonly stemmed from a reluctance to accept changes to their post-cancer selves and accept a newer version of normality, often eliciting feelings of anger, sadness and frustration. Cancer patients in previous qualitative interviews have described cancer as being an inconvenience or a nuisance, getting in the way of daily life and inhibiting them from doing what they wanted to do (349). Hence measures of returning to 'normality' can be gauged by regaining physical fitness, improving in mood and confidence, returning to work, looking after friends and family and regaining social function (33, 328, 350, 351). Achieving these targets can be seen as indicators of returning to a pre-cancer state, beating cancer in the process.

*'I could have retired after 60. But I stuck at it to try and get back. It was a mental thing for me to think okay I've gone, you know, through this dark tunnel. And it was very dark. And then eventually there was a little light at the end of the tunnel. And it got brighter and brighter. And I wanted to get back in my own mind to where I was before I had the cancer.'*

*(ID: 1654; male, 66yrs, White, stomach cancer)*

However, when these physical and mental parameters of normality were not met this had repercussions on participants' social and working lives, often undermining their self-image and negatively impacting on their QoL.

*'I started crying, because I thought, "Yeah, I had all this plan and I, it doesn't look like it's going to be the same anymore."...You can't do what you used to do.'*

*(ID: 1608; female, 56yrs, Black, colorectal cancer)*

However, not all participants had a desire to return to their old 'normality' with some expressing the view that cancer had served as a 'wake-up call' and had prompted them to view things from a larger life perspective rather than get caught up in the minutiae of everyday life.

*'Once you're sort of back in normal life...It can just seem like a distant memory, "Oh yes, I went through cancer and now life's back to normal." Well I don't want life to be back to normal really, I want, I think it can be quite a, you know, a boost to living life...Living out your own values and gaining what you want to out of life. So I'm trying to, you know, see in that sense and so far...It has been my experience.'*

*(ID: 1035; male, 51yrs, White, head and neck cancer)*

For these participants there was no desire to return to their old lives. Instead they placed added emphasis on living for the moment and appreciating what was important to them, like family, friends, holidays and travel. SM also played a motivating role in their lives as they were aware of the need to take good care of themselves so that they could continue to enjoy their life to its maximum potential for as long as possible.

*'Cancer can be a bit of a wakeup call...You can appreciate more...The fragility of life and, you know, your mortality and things you took for granted before...Like good health and so on...I think I appreciate more what a good life I've got and what good opportunities I've got...I think like a lot of people I got a bit lazy and sort of took things for granted and maybe didn't make the most of my opportunities but now I've got that sort of awareness which I hope I don't lose.'*

*(ID: 1035; male, 51yrs, White, head and neck cancer)*

This sense of cancer producing a reassessment of priorities in terms of appreciating life and its opportunities raises the question as to what being 'normal' really means in this context and how it can be defined. Frank's (1995) classification of the three main types of illness narrative suggest that the restitution narrative, which is commonly upheld in Western societies and revolves around a belief in restorable health, does not fit in with people experiencing chronic illness (128). Similarly, the chaos narrative, based around all life events being contingent with no-one being in control, does not correspond with participants' explanations for their illness onset or their subsequent SM use. Rather, the

quest narrative is seen as more suitable here, where the person undergoing illness maintains the belief that something is to be gained from the illness experience, using it as an impetus for change and searching for alternative ways of 'being well' (128). Perhaps 'normal' for cancer survivors is viewed less in terms of how they carry out their daily lives and more in terms of ensuring that cancer and any associations with it, are eradicated from their lives. In describing measures of returning to normality such as regaining physical fitness, or returning to work, it could be that cancer survivors are emulating the quest narrative, strengthening their resolve against cancer by implementing appropriate lifestyle changes, rather than 'returning' to their previous life as the restitution narrative would suggest. This is an important distinction, leading to considerations as to the types of SM that cancer survivors would utilise to achieve this and suggesting that they would be interested in exploring new SM practices rather than simply replicating past lifestyle patterns and behaviours.

### **7.3.5 A Model of SM and Health-Related Normality in Cancer Survivorship**

A social constructivist approach to illness experience is based on the concept of reality as a social construction. It views all illnesses as being socially constructed at the experiential level, based on how individuals come to understand and live with their illness (352). Individuals will control the manner in which they reveal their disease to others and make different lifestyle adaptations to cope with their illness, depending on the social and cultural systems around them which shape their illness experience (353). Different illnesses have different social or cultural meanings which can impact on the way people deal with their health and illness. The often negative connotations associated with cancer,

mean that it is often used as a metaphor for evil, with people finding the word ‘cancer’ uncomfortable and often choosing not to speak of it for fear it will make it a tangible entity (314, 354, 355). This can lead to people with cancer feeling stigmatised and excluded from ‘normal’ society, due to the negative social response shown towards their illness (352). As a result, cancer survivors often struggle to make sense of their illness and reclaim their sense of self, as they attempt to understand and come to terms with living with their disease (352). It is important, therefore, that strategies are put in place to enable cancer survivors to successfully adapt to living with the after-effects of cancer, so they can feel valued and integrated in society, rather than ostracised and alone. SM strategies can be viewed as one method for helping cancer survivors make these adaptations to their new lives post-cancer, providing them with the appropriate resources to re-establish themselves in society and create a new identity in survivorship.

With this in mind it is important to consider the role of self care (SC) in relation to SM and lifestyle choices. SC has already been discussed in Chapter 2 (section 2.4) and can be viewed as a person’s sense of personal control over their own health. The narratives have illustrated that different levels of SC will emerge depending on the stage of the participant’s individual cancer trajectory, from pre-diagnosis through to survivorship. However, the incentives for initiating SC and subsequent SM practices may differ markedly from the outcomes of using them. For example, diet and exercise regimes may be initially utilised in an attempt to minimise some of the side-effects from cancer treatment, but in the process new social relationships may be formed, new benefits to health acknowledged and a reassessment of priorities established. In survivorship, some aspects of cancer patients’ lifestyles will revert to how they were pre-cancer, whilst other aspects

will have been significantly altered. The level of SC and SM practices that a person chooses to engage with will subsequently influence how their lives are shaped in the future. Thus survivorship can be seen as an active process whereby cancer patients choose the extent by which they will self-manage and control their health and lifestyles, shaping their new versions of normality using the inter-related processes of reassessing normality, fighting to maintain normality and maintaining the appearance of normality.

*'I think with cancer...It's easier for some people to just hand themselves over so it's not their problem... And they want somebody else to say "Well it's alright, we're gonna do this, this, this, and this."...But I can't be like that...I'm not totally reliant on myself, but I like to believe I am...And I think the hardest thing about having cancer for me was making those decisions to say "Well, I'm not gonna have that," or "Should I have that?"'*

*(ID: 1091; female, 58yrs, White, breast cancer)*

As already noted (section 6.2.2), the theme of normality was a constant part of the interview narratives, continuously linking in with different aspects of participants' daily lives, whether in respect to their work, social lives, or the future, or their bodies. When I began to think about whether any links existed between the theme of normality and SM in survivorship, I began to build a theoretical model, by moving back and forth through the interview dataset and identifying similarities and differences in instances and patterns, within and across cases (356). In doing so, I was able to identify numerous examples of when cancer survivors used different types of SM practices to achieve specific health outcomes. These included wanting to improve fitness, aid relaxation, or to improve self-esteem. In addition to using SM to achieve these health outcomes, I became aware that

participants' reasons for using SM practices showed commonalities with the existing literature about the interrelated processes of normality (131), with SM practices often being used either as a way of reassessing, fighting to maintain, or maintaining the appearance of normality. The SM practices used by participants were often identified as useful mechanisms for supporting these inter-related processes in survivorship. Examples of this included strengthening the mind and body, promoting relaxation, increasing self-esteem and confidence, generating support networks, promoting good health and fitness, instilling positivity and regaining control over the body post-cancer. This often resulted in a reworking of social, practical, emotional and psychological boundaries until cancer survivors reached a new equilibrium they were satisfied with.

*'I reached a point where I felt I could pick up on, on life again...Or normal life again.'*

*(ID: 1025; male, 64yrs, White, head and neck cancer)*

In survivorship, a new health-related normality happens to some extent by the very essence of surviving cancer and engaging in the processes underpinning this concept. However, I became mindful that the dataset gave examples of how SM practices could be used as a catalyst for these processes, providing cancer survivors with the motivation and support to undertake them. From this, I was able to begin to form a model for understanding the role of SM in creating a new normality in survivorship. This model revolved around the notion that the ease with which cancer survivors' accomplish their new normality and the resulting satisfaction that this evokes, is shaped by the SM practices that they incorporate into their daily lives to support the transition from cancer patient to cancer survivor. Cancer survivors can be viewed as active agents in their own lives and the extent to which

they are motivated to make decisions regarding their use of SM on a day-to-day basis will inform the subsequent creation of their new post-cancer normality.

*'I like to think that I'm responsible for myself rather than hand myself over to someone...I think, doctors...They mean well because they obviously...They know no other way...And they don't know what it's like to be the patient really you know. They can only advise...So really you have to, I think, take responsibility for your own life, you know, cos that's what it's all down to in the end. I mean it's...Taking responsibility.'*

*(ID: 1091; female, 58yrs, White, breast cancer)*

In the model, 'SM and health-related normality in cancer survivorship', SM practices exist as mechanisms for supporting cancer survivors in making reassessments of normality, maintaining normality and fighting to maintain the appearance of normality. In doing so, SM practices can act as facilitative and supportive structures on which cancer survivors can lean and gain strength from (both physically and mentally), to enable them to work through these inter-related processes in a way that is appropriate and compatible with their health needs and requirements. Thus, SM practices can enhance the ease with which cancer survivors make the transition towards their new health-related normality.

However, the proposed model recognises that not all reasons for undertaking SM practices underpin these three processes for achieving a new health-related normality. It became clear from the interview dataset that although the majority of participants used SM practices as a facilitative mechanism for undertaking the three processes of normality, sometimes SM practices were used for other reasons. Though these reasons, such as having

faith in God, or taking advice from others, were still used to help participants reach their new health-related normalities, they were not directly intertwined with any of the three processes for achieving normality. Instead, here, the SM practices used provided a direct pathway towards reaching a new health-related normality. Therefore, the model acknowledges that SM can itself be a direct route to helping cancer survivors achieve their new normality, rather than always acting in conjunction with the three inter-related processes of normality.

Figure 7.1 outlines the specific SM practices identified by interview participants who were constructing their new health-related normalities and the variety of reasons for choosing to use them. These reasons might include for improving self-esteem, to maintain general health and fitness, to access social support, or to minimise and manage the side-effects from cancer (246, 259, 265, 306). In undertaking these SM practices, cancer survivors can begin to undergo the processes of reassessing normality, fighting to maintain normality and maintaining the appearance of normality, using SM practices as a mechanism for working through these processes, until a new health-related normality is attained. In addition, some SM practices will be used by cancer survivors to help them directly accomplish a new health-related normality in survivorship. It is likely that a combination of SM strategies will be used by cancer survivors and that this combined use of SM practices will contribute to their new health-related normality in survivorship.

The list of SM practices at the bottom of the diagram have all been identified by participants as interventions that have been beneficial to them in achieving one or more of the health benefits detailed in the rectangular boxes. Of these boxes, those which sit

underneath one of the three processes for achieving health-related normality have been identified as useful mechanisms for supporting each of these processes. For example, gardening, might be used by a cancer survivor because of the therapeutic benefits and relaxation it brings to them whilst they are undertaking a reassessment of what is normal for them in survivorship and whilst they are fighting to maintain this normality. Thus gardening can be seen as a mechanism for supporting these processes, in turn contributing to the subsequent production of a new health-related normality. In conjunction with this, prayer, for example, may provide some cancer survivors with strength and comfort, due to their belief in God. As such the ritual of praying itself may provide a cancer survivor with adequate support to help them achieve their new health-related version of normality. Here, it is possible to see how SM practices can be used as supportive, or independent, mechanisms for achieving a new health-related normality. In figure 7.1 the health benefits in boxes with arrows leading straight to health-related normality have been identified by participants as mechanisms for helping them to directly achieve health-related normality, rather than supporting one of the three underlying processes.

In terms of SM and cancer survivorship, the new model can be used as an educational tool for healthcare providers and healthcare students, designed to help them understand the role of SM in helping cancer survivors return to normality once they reach the end of their cancer treatment pathway. The model can help illuminate the importance of considering supportive strategies in survivorship that are not embedded purely in bio-medicine, but which seek to encompass a more holistic model of health and wellbeing that takes into account the physical, psychological, social and emotional needs of cancer survivors. These factors can play a large role in determining the ease with which cancer survivors are able to

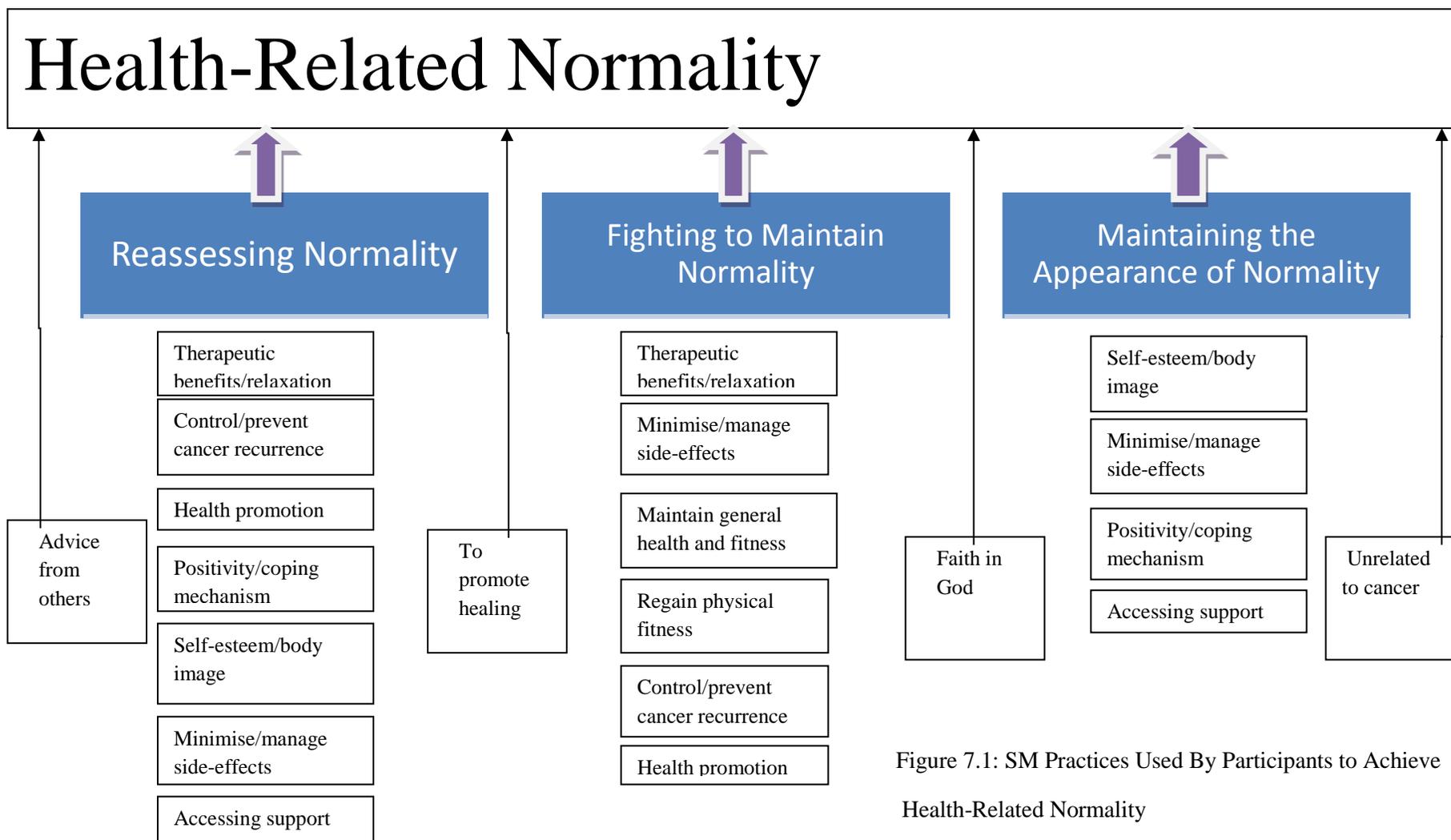


Figure 7.1: SM Practices Used By Participants to Achieve Health-Related Normality

**Spirituality/religion:** prayer, reading holy books **CAM:** angel therapy, reiki, crystal therapy, hypnotherapy, transformational breathing, emotional freedom technique, visualisation, homeopathy, acupuncture, meditation, herbal remedies, trauma therapy **Support groups:** Look Good Feel Better, other support groups **Exercise:** walking, yoga, swimming, individual sports, climbing, gardening **Diet:** low fat diet, vegetarian/vegan diet, supplement use, smaller portion sizes **Psychological therapies:** Counselling

optimise their QoL post-cancer. In understanding more about how different SM strategies can have wide-ranging uses and consequences in survivorship, healthcare professionals can use the model as a reference point when considering strategies that identify and consider these issues relating to cancer care in survivorship.

### **7.3.6 Strengths and Limitations**

In addition to the strengths and limitations detailed in section 6.2.5 the narrative interview study was open to recall bias as the study participants had recalled their personal accounts after a prolonged period of time, increasing the likelihood of inaccuracy between what they remembered happening and what actually happened.

Narrative accounts of illness situate the occurrence of illness within the context of a person's life, relating how the past is remembered in accounting for a present condition (357). In remembering the past, people search for meaning and explanation, drawing on their experiences and knowledge to link the past with present concerns and future possibilities (357). Thus, a person's cultural knowledge will serve to guide how they remember the past, so that remembering becomes a reconstructive rather than a reproductive act, as what is recalled depends on what is believed now as well as what was once stored (357).

Narrative accounts convey the efforts to make sense of the past from the perspective of the present, pointing to meaningful connections amongst events and drawing connections

between the illness in the past and how it is being dealt with in the present and the future (357, 358), adding meaning to people's lives and preparing them for coping with the onset of future illness (359, 360). This is important to acknowledge in the study context, as what participants remembered doing, prior to the onset of their cancer or during treatment, is likely to have been influenced by the subsequent cultural environment they were immersed in, altering their recollections. For example, participants may have recalled eating a high sugar, high fat diet prior to their cancer diagnosis and may have associated this with their subsequent cancer diagnosis due to their beliefs that a diet high in fat and sugar is a risk factor for cancer. Therefore, it is impossible to separate present knowledge, beliefs, time and contexts from recollections of the past, as individual experiences are related to pre-existing explanatory frameworks available within a cultural setting (361, 362).

However, despite the likelihood that reconstructed memory will recall a past event differently to how it actually occurred, this is not of huge importance in this research study, where interest lies more in how memory reconstructions can serve as a resource in everyday life (363). Rather than using memory to act as a stringent, accurate record of the past, instead, through remembering, culturally available knowledge becomes situated knowledge, connected to a particular person, context and illness history (357). This was important in the research study which was concerned with understanding reasons for decision-making around the use of SM practices, something which is dependent on the meanings participants attribute to their past experiences, rather than focusing on the specific details of past events. How and why recalling past experiences informed the present and future life plans of cancer survivors were all issues which merited exploration

in the research study, strengthening the case for the use of narrative interviews in this context.

### **7.3.7 Practice and Policy Implications**

SM strategies are increasingly recognised as important in helping cancer survivors engage in health and lifestyle practices to manage the after effects of their cancer and positively improve their health and wellbeing (66, 364). However, to encourage engagement in SM practices it is imperative that policy makers have an understanding of the reasons how and why cancer survivors make decisions about whether to incorporate SM practices into their daily lives and the constraints and motivations for doing so. Following this, practical solutions to address these constraints can be implemented into the clinical setting, by addressing issues such as increasing levels of social support, removing barriers around returning to work, increasing accessibility and awareness of SM services and driving health promotion and education efforts. Implications for policy, practice and future research opportunities will be discussed further in Chapter 8 (section 8.2 and 8.6).

The study has identified new ideas about the concept of normality in survivorship, suggesting that for many cancer survivors the term ‘normality’ refers to a resolve to eradicate cancer from their daily lives and create a new normality, rather than a desire to replicate their pre-cancer lifestyle. This has important implications for policy and practice, suggesting that cancer survivors will be open to experimenting with new SM practices rather than reverting to their old habits and behaviours. Policy makers can use this

opportunity to promote healthy lifestyle behaviours to cancer patients entering the early stages of survivorship through information and guidance around different SM practices. An assessment of individual need requires consideration of the cancer patient's level of social support, desire for information, severity of symptoms and stage along the cancer trajectory. SM practices already being utilised may also need reviewing to assess their suitability in light of the repercussions from cancer.

The findings have identified the role of SM in helping cancer survivors to find their place along the survivorship spectrum and achieve a balance between initiating SC and SM practices and seeking support from healthcare professionals and institutions. SM practices can be used as a medium for cancer survivors to experiment with different healthcare processes, gauging the outcomes of different practices and the impact that they have on their daily lives, QoL and wellbeing. The model that has been developed can provide an educational tool for health professionals and healthcare students, helping them to understand the role of SM practices in helping cancer patients make the transition from cancer patient to cancer survivor.

### **7.3.8 Areas for Future Research**

Many of the findings from the interview analysis relating to normality may also apply to people with other types of chronic illness. Future research could focus on whether the SM strategies identified in this study for achieving a new normality could be directed towards other areas of chronic illness. HIV has similarities with cancer in the respect that people

are now living with the illness, often symptom free, for many more years due to improvements in research and treatments (315). Therefore future research could explore whether HIV patients using the same model proposed in this study achieve the same outcomes regarding the formation of a new health-related normality. This research could also be undertaken with people suffering from other chronic illnesses such as multiple sclerosis, diabetes and heart disease. The levels and types of SM required and desired by individuals with chronic illness is likely to vary according to levels of need, autonomy and disease progression (365).

The model of SM and health-related normality in cancer survivorship that has been presented in this chapter was developed through studying the data from the transcripts (section 6.2.3) and drawing on previous work around the concept of normality (128-131). This enabled me to conceptualise the ‘nature’ of normality in survivorship in relation to cancer survivors’ use of SM practices. The model is worthy of further development and critique and the interview data could be analysed further to explore how the model sits alongside the existing literature on chronic illness (128-131), which has been explored in section 2.5. In doing this, the model could be developed to help identify whether cancer survivors with different illness narratives use SM practices in different ways, to help them to achieve their new normality in survivorship. This highlights the contribution of the model to the literature around concepts of normality in cancer survivorship and other chronic illnesses.

## **7.4 Conclusion**

The findings from this interview study have reinforced what is already known in the qualitative literature about the concept of the creation of a new post-cancer health-related normality in survivorship. The processes employed by individuals to achieve this new normality involve making reassessments of normality, fighting to maintain normality and maintaining the appearance of normality (131), something which has been exemplified through the experiences of the interview participants. This study has identified the role of SM practices in helping cancer survivors to achieve their new health-related normalities in survivorship, viewing them as mechanisms through which cancer survivors can make reassessments and adaptations to their lifestyles until they reach a new normality that they are satisfied with. This idea has been conceptualised with the development of a theoretical model ‘SM and health-related normality in cancer survivorship’, which delineates SM practices as instrumental in helping cancer survivors to shape their daily lives in the direction of their desired optimum new normality, either through supporting the three inter-related processes of normality, or by acting independently of them. This model can be used by healthcare providers, equipping them with an educational tool with which they can learn more about the supportive role that SM practices can play to help cancer survivors adapt to their new ‘normal’ lives post cancer.

## **7.5 Chapter Summary**

This chapter has provided some background to the concept of normality in chronic illness, before going onto describe and critically analyse the findings from the narrative interviews in relation to the concept of normality and how it is viewed by cancer survivors pre-

diagnosis and during treatment. The idea of normality was then revisited in survivorship where the processes for achieving a new-health related normality were discussed and a new model to explain the role of SM in helping cancer survivors to achieve a new health-related normality was proposed.

The findings from the quantitative study (Chapters 4 and 5) relating to patterns of SM uptake provided some insight into when and what types of SM were being used throughout the cancer pathway as well as showing significant associations between SM uptake and QoL and SM uptake and internal HLC. These findings gave a broad profile of what was occurring in cancer survivors' lives with regard to the use of SM. The subsequent qualitative study has enabled some of the reasons for cancer survivors' use of SM to be scrutinized, revealing motivations and constraints influencing their decision-making in this area. It has focused in particular on the role of SM in facilitating the construction of a new health-related normality in survivorship, by supporting the processes of reassessing normality, fighting to maintain normality and maintaining the appearance of normality. Chapter 8 will now provide an overall discussion of the findings from both the quantitative and qualitative studies and delineate the importance of the findings in contributing something new to the literature around SM and cancer survivorship.

# CHAPTER 8. DISCUSSION AND CONCLUSION

## **8.1 Introduction to Chapter**

This chapter synthesizes the findings presented throughout this thesis. The main aim of the research, as stated in section 1.2, was to investigate patterns of SM in cancer survivors over time to explore ‘who does what and why?’. Chapter 2 set the scene for the research question by providing a background and a rationale for the study within the setting of cancer care and survivorship. The use of CAM as a SM strategy was then investigated in Chapter 3, which provided details of a systematic review and meta-analyses examining whether CAM interventions improved QoL in cancer survivors. Following this, Chapters 4 and 5 presented an overview of the findings of the quantitative study examining patterns of SM in cancer survivors from pre-diagnosis, through treatment and into survivorship, as well as exploring any associations between SM uptake and QoL, internal HLC and ability to work. Chapter 6 moved on to detail the methods and methodology used in the qualitative study, using interviews to explore the reasons how and why cancer survivors made decisions about whether or not to incorporate SM strategies into their daily lives. An overview of the motivations and constraints affecting cancer survivors’ use of SM strategies was given, before Chapter 7 provided a more detailed discussion relating to the role of SM in helping cancer survivors achieve a new health-related normality post-cancer. This was the concept that emerged most prominently from the interview dataset, linking in with the other themes that were covered by participants (table 6.1). A summary of the main findings from the overall study will now be given.

## **8.2 Overview of Findings**

### **8.2.1 Patterns of SM over Time**

One of the overarching aims of the thesis was to identify what types of SM practices cancer survivors were using and at which points in time. Previous literature has examined the lifestyle practices of cancer patients and survivors after diagnosis (41, 196-198) and the efficacy of these practices in relation to health outcomes (199, 200), but none have looked at multiple patterns of SM in cancer survivors over a prolonged period of time. A retrospective, cross-sectional questionnaire study was employed for this remit. The study design and findings were presented in Chapter 4, finding that total SM uptake was highest in survivorship, compared to pre-diagnosis and during treatment. This suggests that there is an increased perceived need for SM strategies in survivorship. Across the six individual categories of SM, uptake was highest in survivorship, with exercise being the most popular practice, followed by diet.

CAM uptake was highest in survivorship across all of its subgroups (158) apart from ‘mind and body medicine’, with the ‘manipulative and body-based practices’ subgroup having the highest uptake, though this dipped notably during treatment, perhaps due to many of these practices being contraindicated at this time.

Breast cancer respondents had a higher uptake across the CAM, spirituality/religion and support group categories compared with other cancer types. This is likely to be due to these breast cancer respondents being women and more likely than men to access support

networks to share their experiences with others (237). Those treated with chemotherapy had a higher uptake of SM practices across all categories apart from spirituality and religion, than those who had received other treatments. This suggests chemotherapy patients may be engaging with more SM practices to manage their treatment side-effects, which are often more debilitating than for those undergoing other cancer treatments (242, 243).

### **8.2.2 Associations between SM and QoL, Internal HLC and Ability to Work**

The thesis also aimed to examine any associations between SM uptake in survivorship and QoL, internal HLC and ability to work. Chapter 5 detailed these findings showing that increased SM uptake in survivorship was associated with increased general health-related QoL, which was measured by the EQ-VAS. This suggests that cancer survivors who use SM practices may do so to promote and maintain good health and wellbeing, engendering feelings of positivity and self-efficacy. However, cancer survivors with low EQ-VAS scores also had increased use of SM practices, suggesting that for a subset of cancer survivors SM practices may be employed as a way of improving rather than maintaining their general health and QoL. The lack of association between SM uptake in survivorship and functional parameters of QoL, measured by the EQ-5D, suggests that when cancer survivors are asked to measure their QoL against task-orientated, practical parameters they have different measurement standards than when they are rating their general health and wellbeing, due to the different concepts of QoL that are being conveyed.

Total SM uptake in survivorship was positively associated with internal HLC suggesting that cancer survivors with a high internal HLC are more motivated to pursue SM practices to achieve better health outcomes. Dietary changes were associated with an increased internal HLC, whereas no significant association existed between the other SM categories (exercise, support groups, CAM, psychological therapies, spirituality/religion) and internal HLC. This indicates that for cancer survivors who assume increased responsibility for their health behaviours and outcomes, diet may be viewed as the most useful mechanism for achieving this aim, compared to the other categories of SM. This is an interesting idea as exercise had the highest overall uptake of the SM categories, suggesting that some cancer survivors may choose to undertake exercise regimes for reasons other than to promote better health outcomes, such as to socialise, or because it is a hobby they enjoy. Dietary modifications however, may be more specifically linked to the idea of healthy living, suggesting that diet is viewed by cancer survivors as an important mechanism for improving health outcomes.

No associations were found between SM uptake and work-ability, suggesting SM has little impact on this aspect of cancer survivors' lives. However, cancer survivors who had retired or were unable to work due to illness and disability did not complete the work ability scale, which could have altered the strength of any association, providing a study limitation.

### **8.2.3 Motivations and Constraints for SM Use over Time**

Another main objective of the thesis was to explore cancer survivors' reasons for making decisions around whether to incorporate SM into their daily lives. Chapter 6 detailed the interview approach used to explore these issues, identifying motivations and constraints for using SM practices throughout the cancer pathway. The interviews uncovered many themes relating to cancer survivors' use of SM, with reasons for their uptake altering depending on their stage in their cancer journey. Pre-diagnosis SM practices were commonly used either to maintain health, fitness and wellbeing, or due to beliefs in their salutary gains on the mind and body, or because they were already a regular feature in participants' daily lives. During treatment common reasons for SM use were to minimise the side-effects from treatment and to keep the mind and body strong in preparation for treatment. The interviews revealed that certain SM practices, including some exercises and CAM practices, were discontinued during treatment due to the severity of treatment side-effects meaning that cancer patients were unable to participate in them. Additionally, problems around accessibility and awareness of services were raised, with some participants missing out on psychological support services due to a lack of provider referral or a lack of knowledge that the service existed.

Post-treatment, reasons for SM use varied, with cancer survivors using them to regain physical fitness, guard against a cancer recurrence and improve the long-term side-effects of treatment. Post-treatment cancer survivors were more open to experimenting with new SM practices to see what benefits they might bring to the mind and body. Beliefs in the causes of their cancer often prompted changes in SM behaviours, whilst others spoke of

barriers to SM uptake and maintenance, such as family, work and social pressures. Social support was a big influence throughout the cancer pathway and generally those with more social support were more motivated to make healthy changes to their lifestyles. However, for some, SM use was curtailed due to the debilitating symptoms and side-effects from cancer and treatment, which rendered them unable to carry out many of the SM practices they had previously enjoyed.

#### **8.2.4 The Role of SM and the Concept of Normality**

Chapter 7 provided a detailed discussion and critique of the theme of normality, this being the theme which emerged most prominently from the interview dataset, as it was constantly spoken about throughout participants' narratives. Participants spoke of normality in relation to their lives pre, during and post-cancer, relating it to other categories and codes which had been developed (table 6.1). They also spoke frequently of how certain SM practices were used to help them to get back to normal life again post-cancer. Therefore it seemed appropriate to focus on this concept in relation to SM, as the search for a health-related normality seemed to be a major driver in participants' use of SM practices.

The findings reinforced what is already known in the qualitative literature about the creation of a new post-cancer health-related normality in survivorship. It identified that for many cancer survivors achieving normality is not achieved by trying to replicate their lives prior to cancer. Rather a 'new' normality is desired where cancer and its associations are

left behind and new goals and parameters are set through which to measure their new version of normality. The formation of this new health-related normality is brought about through the interwoven processes of reassessing normality, fighting to maintain normality and maintaining the appearance of normality (131). The evidence presented in this thesis suggests that SM can play an important role in supporting these processes by providing mechanisms for cancer survivors to work through to reach their new normalities. For example, certain exercise regimes may be employed by cancer survivors to help them regain their pre-cancer physical health and fitness levels in an attempt to maintain the appearance of normality to others and to prove to themselves that these prior levels of fitness can be maintained. Equally, CAM practices, such as Reiki, may be used by cancer survivors who are undergoing a reassessment of their normality, to help them to cope with and adapt to the changes they are faced with on a daily basis. Hence, SM can help cancer survivors to manage these processes, resulting in the formation of a new health-related normality that has been shaped according to individual needs so as to optimise the long-term health outcomes of cancer survivors and increase independence and autonomy in their daily lives.

### **8.3 Contribution to the Literature**

The study findings have added to the literature around SM and cancer survivorship, reinforcing what is already known as well as contributing new findings, ideas and concepts. The study has been able to look at *multiple* types of SM uptake spanning from pre-diagnosis, through to survivorship, whereas previous literature has focused on the effect of specific types of SM practices on cancer patients and survivors at stand-alone

points in time (41, 196-200). The finding that across all categories of SM, uptake was highest in the survivorship phase suggests that cancer survivors may be using SM practices in survivorship as a means of regaining control over their health and lifestyles, using SM as a supportive mechanism with which to achieve optimum health outcomes.

The study has also revealed that cancer survivors are using a wide variety of CAM practices post-cancer, suggesting that CAMs' diverse nature has widespread appeal, with different CAM therapies providing varying levels of support and relief to cancer survivors. The finding that the highest uptake of CAM practices was in the 'manipulative and body based practices' subgroup reinforces previous literature suggesting that many people using CAM do so because of the therapeutic relationships formed (144), as the majority of CAM practices in this subgroup require interaction with a CAM therapist. However, the notable drop in uptake during treatment suggests that many of the practices are not viable during treatment, requiring too much active participation from already fatigued patients.

As noted in section 4.2, fatigue is the most commonly reported side-effect of cancer patients and can be attributed to factors such as anaemia, cancer therapy, cachexia and tumour burden (366, 367). Whereas in healthy individuals fatigue can act as a pleasant or protective response to physical or psychological stress, for cancer patients it can become a major distressing symptom (367). Qualitative studies with cancer patients have found that fatigue encompasses the mind and body and is experienced by the whole person in terms of physical and cognitive fatigue (367, 368). Fatigue is often described as incorporating psychological stress, emotional affection, lack of motivation, abnormal weakness, loss of

concentration, malaise and passivity (368). This can have a negative impact on the physical, social, psychosocial and spiritual dimensions of cancer patients QoL (369), as well as creating social limitations and decreased self-esteem, with feelings of hopelessness, frustration and insecurity commonly being experienced (368). Self-help activities such as walking, swimming, planning daily activities and socialising have all been described by cancer patients as methods for helping them to cope with fatigue (367, 368). This suggests that whilst certain SM practices may be too strenuous for cancer patients and survivors experiencing extreme fatigue, gentler SM regimes, such as walking, may help to counteract its negative effects, providing both psychological and physical relief from fatigue.

The findings contribute to the literature by detailing which types of cancer survivors are using SM practices, indicating that they are used most by breast cancer survivors and those who have undergone chemotherapy. Breast cancer respondents higher support group, CAM and religious/spirituality uptake than other cancer types corresponds with previous literature that more women than men are likely to use these types of SM practices due to the increased social networks they provide (34, 50, 237, 239, 240). The higher uptake of SM practices in chemotherapy patients compared to patients who have received other cancer treatments is likely to be due to the especially harrowing side-effects induced by chemotherapy compared to other types of cancer treatment (242, 243) leading to these cancer survivors accessing more SM practices to try to minimise their treatment-related problems.

The study findings have also reinforced findings from previous literature associating high SM uptake with increased QoL (36-41, 196, 200, 246-249), strengthening what is already known about SM practices in relation to this outcome measure. The finding that dietary modifications are associated with a high internal HLC in cancer survivors suggests that diet may be viewed by them as a more effective way of protecting their health than the other SM practices in the study. This sheds new light on the types of SM practices that may be seen as effective health promotion strategies by cancer survivors. This is useful when thinking about the types of SM practices that can be used as mechanisms for facilitating behaviour change in cancer survivors who are motivated to alter their lifestyle practices to potentially improve their health outcomes. They suggest that changes to diet may be easier to instil in cancer survivors who are engaged with the concept of health promotion, than other types of SM such as exercise and CAM.

The qualitative study has contributed to the SM literature by identifying the different influences on cancer survivors' decision-making around whether or not to use SM practices in their daily lives. It has illustrated that motivations for using SM change throughout the cancer pathway and supports existing literature which suggests that social support is a major influence on how cancer survivors cope with, adjust to and manage their disease in everyday life (124, 285, 288-290). A further contribution to the literature has been generated from the study in the form of a new model outlining the role of SM in helping cancer survivors create their new health-related normality in survivorship. The important role of SM in helping cancer survivors to manage aspects of their daily lives in order to achieve their newly formed normality is an essential part of the process of recovering from cancer and can help cancer survivors make necessary and desired

modifications to their lives in order to maximise their health status. The model, which views SM as a supporting role in achieving this aim can be used as a reference point for healthcare professionals and healthcare students who are trying to understand more about the role of SM in survivorship and how it can be used to facilitate the effective resumption of normal life for many cancer survivors.

The study findings relate to existing literature around SM and chronic illness (128-131, 133) and reinforce Bury's (130) work on the biographical disruption of illness. This views the onset of chronic illness as a disruptive event, whereby the structures of everyday life and the cause of meaning attributed to them are thrown into disarray (130). The qualitative findings revealed that for many cancer survivors, maintaining the appearance of normality to the outside world was a struggle, often leading to feelings of isolation and lowered self-esteem. However, the findings also revealed that the use of SM practices reaped benefits for many cancer survivors, in terms of increasing their levels of social interaction and leading to them regaining a sense of control and order over their lives. These findings align with other literature on the use of SM strategies in chronic illness (108, 109, 135, 136), suggesting that many of the adjustments that cancer survivors have to process following the onset of their illness overlap, and are applicable to, people experiencing other types of chronic illness.

#### **8.4 Contribution to Methodology, Theory and Practice**

This study has used a mixed methods design and is an example of how both quantitative and qualitative methods can be used to complement and enhance each other's findings. Mixed methods allow multiple, integrated approaches to be used to explore social and

behavioural processes that can be hard to capture using quantitative methods alone (15). This research study provides a good example of how sequential mixed methods can make use of quantitative methods to understand the objective factors and structures that contextualise SM use, whilst the qualitative methods can explore the subjective processes underlying their uptake. Through mixed methods it is possible to better understand the relationship between objective social factors such as income, gender and ethnicity which can place constraints on behaviour and the possibility for intentional, subjective action (370). The social structures, such as class and ethnicity, that pattern human behaviour can be discerned through objective, quantitative inquiry. However, understanding the subjective dimension to these behaviours requires the use of qualitative methods. This interplay between objective and subjective social factors enables a richer understanding of the different dimensions and determinants of human behaviour (370).

This study has made a contribution to the methodological processes surrounding mixed methods (section 1.2), by proposing how qualitative methods can be used before and after a cross-sectional study to enhance the research design, strengthening the link between qualitative and quantitative methods (table 1.1). In this study, qualitative methods have been used *after* the cross-sectional study to explore the quantitative findings in more depth. Interview questions in the qualitative study were generated through the creation of an interview topic guide, which was developed from the survey study findings and which aimed to expand on these findings. The empirical data collected from the quantitative study relating to SM uptake, QoL, internal HLC and work ability, allowed a schema to be constructed in relation to how these variables featured in cancer survivors' lives. Through thick description (section 6.1.1), the qualitative interviews then enabled a commentary and

interpretation of the quantitative findings to be built around this schema, adding depth, detail and meaning to the findings and taking into account the subjective and complex nature of human interactions and relationships in order to explain the culture under study (371). In doing so, new concepts and theories emerged from the data, most notably around the role of SM in helping to achieve a new health-related normality in survivorship.

The large sample size of the quantitative study also helped to inform the qualitative sample size, as participants with different patterns of SM uptake over time were selected for interview to explore any reasons for these variations. This was achieved through a purposive sampling strategy which sought to achieve demographic variation based on people related characteristics within the sample (273) (section 6.1.1). Using qualitative methods after quantitative methods also allowed any demographic differences impacting on outcome measures which were identified in the quantitative study to be explored further through the interview study. Hence, when considering study design, table 1.1 can be used as a helpful methodological reference tool for establishing the potential usefulness of qualitative research methods in conjunction with cross-sectional studies.

The study findings have added to the theoretical knowledge around SM in cancer survivorship by identifying in Chapter 4 that multiple types of SM are used by cancer survivors and by theorising in Chapter 7 that SM plays an important role in recovery from cancer. This has provided new insights into the ways that SM practices can be used to help cancer survivors reconstruct their disrupted identities post-cancer. The findings can help advance theorising in chronic illness, as the model developed in Chapter 7 can be used to

help understand more about how the use of SM practices in cancer survivors fits alongside the wider literature around normality and chronic illness (128-131, 133).

These findings provide another example of how quantitative and qualitative methods can complement each other. The pattern of increased SM uptake in survivorship identified in the questionnaire study was explored further through the interviews, helping to develop an understanding of the reasons how and why cancer survivors use SM in their daily lives. This was an overall aim of the research study. Further analysis of the interview data led to the importance of SM in survivorship - in relation to the concept of normality - being unpicked. The connections that have been formed between quantitative and qualitative methods to enrich the study findings, by linking structure and agency in human actions have led to new contributions to health research being made in the field of SM, cancer survivorship and chronic illness.

In practice the study findings have implications for clinicians working with cancer patients, particularly those who have undergone chemotherapy treatment. For these cancer patients, certain SM practices may be of particular benefit in helping them manage and minimise some of their long-term treatment side-effects. Clinicians can also use the findings to make specific recommendations to cancer survivors based on the most popular form of SM, exercise, identified through the questionnaire study. There is already a significant evidence-base supporting exercise interventions for improving the physical and psychological health outcomes of cancer patients and survivors (200, 246-249). The study findings add to this, indicating that exercise is a popular SM activity amongst cancer survivors. The popularity of exercise interventions coupled with their apparent health

gains, strengthens the case for exercise to be recommended by clinicians as a useful SM intervention for cancer survivors who might benefit from it. Clinicians also need to be vigilant in ensuring that men are receiving appropriate psychological support, as they may be less likely to actively seek out and engage with these support mechanisms than women (237, 372, 373), increasing their risk of isolation and decreasing their feelings of wellbeing and self-esteem. The study has illustrated the lack of clinician referral to psychological services (190), despite many participants acknowledging that they may have benefited from the service in order to work through any emotional difficulties and challenges they were facing.

The study revealed that dietary changes were linked to a high HLC and dietary modifications were widely acknowledged by participants as being a positive step in improving health. It may be that dietary changes are easier for many cancer survivors to undertake than other forms of SM which require active physical involvement. For example taking exercise or attending a support group may be difficult for somebody with physical limitations, whereas lowering their fat sugar and salt intake may be something they are realistically more able to achieve. As a result clinicians are well positioned to support cancer survivors to make healthy changes to their diets by offering practical advice and support about how to implement pragmatic and sustainable dietary changes into their daily lives.

The study has also highlighted the role of religious and spiritual practices in engendering community and social support. CAM practices and support groups were also noted to facilitate and promote positive interactions with others, resulting in the formation of

supportive social networks and relationships through the sharing of information, emotional support and a sense of belonging (304, 305). This is an important consideration for clinicians when they are thinking about methods for improving the QoL, health and wellbeing of cancer survivors, as the benefits of social support in helping to achieve this are well documented, with social support being linked to beneficial adaptive health behaviour changes in cancer survivors (124, 253, 288).

Clinicians can also engage with the concept of SM as a mechanism for helping cancer survivors to achieve their new health-related normalities, by working alongside patients to explore which SM practices will be useful in achieving this aim. This will be dependent on many factors including their level of social support, level of need, severity of symptoms, side-effects and psychological stressors (365). By recognising the place of SM in improving individualised care pathways for cancer survivors, clinicians can help to ensure that their patients are well-supported entering survivorship and are given appropriate tools with which to self-manage to the best of their ability, alongside sufficient and appropriate collaboration and support from healthcare professionals. This is in line with policy recommendations which advocate the use of holistic needs assessments, to help ensure that supported, tailored care plans are constructed (in partnership with individuals, carers and care providers) which are specific to the needs and abilities of individuals (139).

However, clinicians alone cannot be held responsible for establishing appropriate SM interventions into cancer survivors' daily lives. As established in section 2.1 and 2.3, the increasing financial, political and clinical pressures being placed on healthcare systems (3, 44), may create a shift in the onus for healthcare provision being placed largely on

healthcare professionals (125). For SM practices to be successfully accepted and incorporated into the lives of cancer patients there is a need to promote a more shared view of care, where patients' health needs are supported not only by health professionals and institutions, but by families and communities to encourage SM integration and help individuals learn the principles for changing and maintaining their lifestyle behaviours (125). In doing so, cancer survivors will have the potential to self-manage effectively, through the provision of supportive and informative communication channels.

As touched on in section 1.4, the study findings are relevant to nursing practice, as research into what types of SM practices cancer survivors are using at different points along their care pathway can enable nurses to be better equipped to support their patients when dealing with all aspects of their care. Oncology nurses are often responsible with coordinating the care pathway of cancer patients from diagnosis, through treatment and into survivorship and are recognised as integral members of every multi-disciplinary cancer team, whether in a hospital ward, in outpatient clinics, or in the community (374). They are often placed in the position of having to problem-solve for cancer patients by trying to alleviate the physical, psychological, emotional, social and financial burdens left over from their cancer, paying attention to both the technical and person-centred aspects of their care (375). Information and knowledge about the types of SM practices that might help to resolve some of these problems, can equip nurses with the skills and expertise to make informed recommendations and suggestions to patients about SM practices that might bring benefit. Health promotion and education are an important component of the nurse's role (376) and by introducing SM practices into the dialogue, nurses can positively engage with cancer

patients on an personal level, recognising and evaluating the value that specific SM practices might bring to the individual.

## **8.5 Strengths and Limitations**

This thesis endeavoured to produce high quality research findings through the synthesis of a systematic and transparent research process. The systematic review and meta-analyses reported on in Chapter 3 entailed a structured, methodical process, resulting in a comprehensive review of the literature being constructed.

The sampling techniques employed in the quantitative study (Chapters 4 and 5) were appropriate for a questionnaire study design, with the large sample size increasing the generalizability of the findings to the wider UK population of cancer survivors. The quantitative sample size was determined on the basis of a power calculation, to provide 90% power and 5% significance (377). In order to compensate for the low response rate of postal questionnaires (228), the sample size was doubled, as it was anticipated that a response rate of approximately 50% would be reached. This was almost achieved with a response rate of 46%, which was able to provide 89% power and 5% significance, so was large enough to provide credible findings (377).

There were no statistically significant differences in age between respondents and non-respondents and the sample population was representative of the West Midlands, UK, in terms of ethnicity and gender. The increased response rate of Asian and Black populations compared with the West Midlands suggests that the questionnaire was culturally sensitive to the usually underrepresented Black and minority ethnic groups who are usually under-

represented in survey studies (244). The sampling strategy also selected, proportionally, cancer survivors who had been diagnosed with the ten commonest UK cancers, enhancing representativeness of findings to the general cancer population rather than focusing on one or two specific cancers. The study findings can be applied to cancer survivors within the NHS, as well as in other, partially publicly, funded healthcare systems in countries such as Sweden, Germany, France, Belgium and Australia (378, 379), where there is a need to examine ways of improving the QoL and wellbeing of cancer survivors, whilst minimising the impact on healthcare resources.

The study recruited cancer survivors who had been treated at UHB, a large teaching hospital in the West Midlands. Although, sometimes cancer patients are treated at smaller hospitals, it is more common for cancer patients to be referred to tertiary care centres such as UHB, where cancer centres of excellence offer specialist knowledge and expertise (380). Therefore the tertiary care setting for the study increases the generalizability of findings to other cancer survivors treated within this healthcare framework.

Within UHB's cancer centre patients are routinely offered information and advice about a wide range of SM practices including diet, CAM, exercise, local support groups, psychological therapies and spirituality/religion and are encouraged to use these interventions where appropriate and with guidance from cancer support workers. The promotion and recommendation of a comprehensive range of SM practices within this cancer centre may have made respondents more aware of the SM interventions and services available to them and provided verification as to their usefulness and worth, making them more likely to use these practices than if they were recommended in a non-

medical institution or setting. In hospitals and cancer centres that do not offer this SM support, the uptake of SM practices may have been lower amongst cancer survivors due to a decreased awareness of their availability and potential benefits.

Despite efforts being taken to minimise bias in the quantitative study (Chapters 4 and 5), it was impossible to eradicate completely due to the nature of the study design. The study was open to responder bias due to questionnaire responders possibly being more likely to return the questionnaire due to a pre-determined interest in SM compared to non-responders. It is also possible that socio-demographic differences between the two groups may have influenced their likelihood to respond to the questionnaire. Although some socio-demographic data was collected for non-responders, the study was unable to collect the same amount of data on non-respondents as respondents, making a full comparison between these groups unfeasible and providing a study limitation. Additionally, some of the reminder questionnaires were sent out at the wrong time-interval, being posted only a few days after the initial questionnaire rather than the pre-specified one month, which could also have influenced the response rate.

Recall bias is also likely to have provided a study limitation as respondents were asked to recall which SM practices they used both pre-diagnosis and during treatment. What they recalled and what they actually used may not have been entirely compatible, increasing the likelihood of bias. Recall bias was also present in the qualitative study (Chapters 6 and 7) due to the narrative interviews meaning that participants were likely to recall past events differently to how they actually happened, due to the cultural context that they were situated in influencing their recollection of past events (357). However, this was not

viewed as a significant study bias as rather than being overly concerned with the exact details of participants' cancer experiences, the qualitative study was more concerned with the agency of individuals and how the meaning participants placed on past events affected their actions going forward.

Bias could also have been introduced when using the EQ-VAS QoL measure as it has no fixed parameter indicating what zero represents on its scale. This could have affected the reliability of the general health-related QoL findings, due to creating ambiguity between the respondents using the measurement tool (266). Problems occurred with the use of the work-ability scale too, as respondents who were retired or unable to work due to illness or disability were excluded from completing the work-ability scale, which may have significantly affected the findings as many of those retired or unable to work may have been experiencing substantial side-effects from cancer and treatment, hindering their ability to continue working.

The qualitative study (Chapters 6 and 7) used a purposive sampling technique, which was appropriate for the interviews as it allowed participants to be stratified according to the different SM categories patterns of uptake identified in the quantitative study, as well as by age, ethnicity, gender and cancer type. This allowed a balanced representation of these variables to be selected, increasing the diversity of the participants' socio-demographic backgrounds. Throughout the qualitative study, rigour in the data collection and analysis process was demonstrated through detailed transparency to ensure the quality of the research could be adequately assessed. Reflexivity was also employed throughout to ensure that social, cultural, personal and professional biases were acknowledged and reflected on.

It is important that the biographies and behaviours of researchers in relation to their topic under study are recognised, through a critical awareness of their social location in relation to the research object and process. This can ensure insightful and trustworthy research outcomes are generated (381). To verify that the interpretations, concepts and ideas emerging from the interview process were convergent with the views and interpretations of others triangulation methods were employed. This involved techniques such as the evaluation of a selection of the interview transcripts by other qualitative researchers in addition to myself, as well as regular team discussions with supervisors to debate new ideas and themes that were emerging from the dataset.

Situational bias during the qualitative study was minimised by allowing participants to choose the setting they preferred to be interviewed in, whether at the hospital, at home, or at work, to allow them to feel as relaxed as possible when being interviewed. In addition, ten of the forty interviews were personally transcribed. This allowed a close relationship to be formed with the data, allowing the identification of key themes early on in the data collection and analysis, as well as an awareness of key differences and similarities between participants' accounts. This time to reflect on the individual and collective narratives allowed the formation of new ideas, thoughts and questions which could be explored in later interviews.

Finally, the thesis was presented in a hybrid style format (section 1.5) which provided the opportunity for sections of the thesis to be peer-reviewed by external experts in the field, providing valuable feedback, enhancing the credibility of the work and granting the opportunity to make significant contributions to research at the earliest opportunity through

publications (28, 29). However, choosing to present the thesis in this hybrid style format meant that the quantitative and qualitative studies were presented sequentially. This was to increase the likelihood of publishing the chapters in established journals, as difficulties are often experienced when trying to publish integrated quantitative and qualitative research (31). This provided a study limitation, as in seeking to use sequential mixed methods the work may appear to be a series of seemingly disconnected parts, rather than a conceptually integrated whole (30). However, a more integrated mixed methods approach was not possible, due to being limited in terms of what could be presented within the confines of this thesis. Instead a sequential mixed methods approach was felt to be appropriate, allowing the findings from the quantitative phase of the research to inform the subsequent qualitative phase, producing rich findings. However, different approaches to analysing and presenting the data could have been used, by taking a more integrated mixed methods approach to data analysis.

## **8.6 Future Research Opportunities**

Cancer patients are increasingly expected to take more responsibility for decision-making about their health due to increasing policy drives promoting individual rather than state led responsibility for health (1, 63), something which is potentially in conflict with the founding NHS values pertaining to a collectivist society responsible for individual misfortune (382). The vast technological innovations and medical breakthroughs that have come about since the creation of the NHS have transformed the nation's health needs (383). The focus of UK healthcare is no longer based around acute medicine, but is instead being shaped around parameters of increased life expectancy and chronic illness, increasing service demand (383).

Increasingly, patients are being viewed as consumers in healthcare, something which is deemed important as a means of empowering them to make suitable health choices (382).

This is exemplified by policies such as the 2007 Cancer Reform Strategy (384) which aims to improve choice by giving cancer patients access to information about cancer services, facilitating the idea of the centrality of the consumer in healthcare (385).

Increasingly the consumer is viewed as an autonomous, rational decision-maker who calculates, assesses and, if necessary, counters expert medical knowledge in order to maximise the value of their healthcare (386). However this fails to account for the experience of healthcare as being an inter-subjective and dynamic process, affected by cultural and psychosocial factors which impact on individuals' everyday life choices, decisions and actions (386). It ignores that the experience of illness is disempowering, placing people in vulnerable positions of uncertainty and negotiation, whereby they are dependent on others for help (385). In a culture where increasing emphasis is placed on autonomy and rationality, this need for dependency may be viewed as weak and irrational (386). Thus, a tension is created between wanting to behave as a consumer in healthcare, avoiding dependency on doctors and wanting to take on the 'passive patient' role by emotionally investing in doctors, placing trust and faith in their ability to make the correct treatment choices on the patient's behalf (386).

The ability of cancer survivors, who have finished treatment, to make optimal decisions about the best ways to manage their health, may be undermined if choice is prioritised and they feel pressurised to make stressful and difficult decisions, without appropriate recommendations from health professionals, or without relevant interventions being implemented to support them (385). On the other hand, if the patient takes on the role of

the 'passive patient' there is a danger that they may miss out on the opportunity to test out certain SM practices, due to paternalism in healthcare and a scepticism of some healthcare professionals about the usefulness of some types of SM (52, 72, 387). As discussed in Chapter 2 (section 2.2) the ambivalence or disregard of some healthcare professionals towards certain SM practices (51, 52) may leave the 'passive patient' unaware of their availability and their potential lifestyle benefits. Therefore, an equilibrium must be reached whereby cancer survivors are well supported by health professionals and are provided with sufficient information to make appropriate SM choices, whilst the benefits of the doctor-patient relationship, in terms of its ability to provide reassurance, comfort, hope and security, are maintained (386).

This equilibrium can be facilitated through further research to match specific SM practices to cancer survivors who have undergone different care pathways, by exploring how they are of benefit to them. This can help ensure cancer survivors receive adequate support, advice and resources for making decisions about how to self-manage and achieve better health and lifestyle outcomes. These health and lifestyle outcomes may include the attainment of a new health-related normality, improved QoL, a reduction in physical and mental side-effects from treatment, increased self-confidence and improvements to work and social life. Thus, SM interventions can be used to help cancer survivors improve aspects of their lifestyles which are not necessarily solved through medical management. It is important to acknowledge that post-cancer these non-medical outcomes may be of more relevance to cancer survivors than medical outcomes, as they try to adapt to their new life post-cancer and treatment. If used correctly, SM can be a valuable mechanism for cancer

survivors adjusting to their new lifestyle changes, helping them to achieve their newly reassessed health outcomes.

It has already been established in Chapter 2 that the lack of an evidence-base for many SM practices is not necessarily a reason to discredit their value in improving the lives of cancer survivors. However, it is imperative that further research into the efficacy and effectiveness of SM practices in relation to the health outcomes of cancer survivors is carried out.

Indeed, if SM practices are to be incorporated and accepted into mainstream healthcare it is important to accumulate as much evidence as to their benefit as possible to secure their position as a valuable therapeutic option. This is also necessary to avoid ambiguity and confusion for patients over the evidence-base of many SM practices, as their gradual integration into healthcare services (104, 106) may lead some patients to assume that this implementation goes hand-in-hand with their solid evidence-base.

The ‘catch 22’ situation described in section 2.2, whereby pharmaceutical companies refuse to fund research into SM interventions, such as CAM or spiritual/religious practices, due to their lack of an evidence base and vice-versa (74, 80), needs to be addressed if progress in this area is to be made. White et al. (2001) suggest that alternatives to the traditional RCT based approach to research need adapting for CAM research, due to problems with funding and methodological weaknesses in relation to blinding (74). This could take the form of uncontrolled trials, which can serve several purposes including establishing that there is a clinical effect worth investigating, identifying the most suitable patients and treatments and providing information on effect size (74). Perhaps, if

preliminary evidence in this form is collected, pharmaceutical companies may be more willing to invest in SM related research in the future.

Future research could focus on examining in more detail the context in which SM is perceived by cancer survivors, whether from a religious, social or family perspective and whether cancer survivors view different types of SM practices as active or passive mechanisms or behaviours. The extent to which cancer survivors engage in each of the three components making up SM in a healthcare context - medical, role and emotional management (126) (section 2.3) – may be influenced by the way in which they relate certain SM practices to this area of their lives. By understanding more about how different SM practices are perceived by cancer survivors, work can be undertaken to create the formation of individualised, tailor-made SM packages, which can be distinguished according to level of need, social support, severity of side-effects and personal characteristics of the individual (365).

These individualised SM packages could include a ‘Guide for Survivors’ which could be used to help signpost cancer survivors towards the most suitable types of SM to meet their individual requirements. Rather than being a protocol stipulating what cancer survivors should or shouldn’t be doing – something which may in itself be unappealing following on from often months of prescribed, regimented treatment – the ‘Guide’ could be used to help identify a range of different SM practices which may be of benefit to the individual cancer survivor, leaving them free to make independent SM choices but through well supported information channels and with appropriate guidance from health professionals. In

particular, suggested dietary interventions may be of benefit due to cancer survivors appearing to value this type of SM for the promotion of better health (section 5.6). The design of the 'Guide for Survivors' could account for cancer type and treatment type, reflecting the study findings which suggest those with different cancer and treatment types have varying levels of need for different SM practices (section 4.5). More work could be done to examine specifically what sorts of SM practices are used by chemotherapy patients and what sorts of benefits these SM practices bring, to enhance the relevance of the findings to this population group.

In addition, a separate SM 'Tool for Clinicians' could be developed, aimed at equipping clinicians with adequate information about the accessibility and appropriateness of different SM practices for cancer survivors, to enable them to make informed judgements when making recommendations to patients. This requires careful consideration by clinicians however, in deciding whether or not to encourage the use of certain SM practices, when their benefits to health may often be anecdotal rather than evidence-based (74, 75) (section 2.2). Medical rhetoric has long established the importance of evidence-based medicine alongside clinical expertise in making the correct treatment decisions (76), so it is understandable that clinicians may feel uncomfortable in recommending interventions without any substantiated empirical evidence with which to verify their worth.

Conversely, however, the use of SM practices is on the rise, with cancer patients often using them despite their lack of an evidence base and extolling their benefits in terms of

their soothing, relaxing and invigorating therapeutic qualities and the psychological and physical benefits they bring (34, 56, 78, 80). Cancer survivors' desire for SM practices may often be based around these non-medical benefits, with emphasis being placed on QoL and holistic wellbeing, rather than medically based parameters of health. This non-medical rationale for using SM may be helpful for clinicians who are debating whether or not to advocate the use of certain SM interventions. The relatively recent evolution of cancer as a chronic disease (53, 54), requires clinicians to reassess the ways in which they think about providing care to their patients. If cancer survivors QoL, health and wellbeing can be enhanced through the use of SM practices, enabling holistic benefits to the mind and body to be experienced, then surely the use of these practices is something that should be taken seriously by healthcare professionals. By providing detailed knowledge of the pros and cons of different SM practices, the SM 'Tool for Clinicians' could be used to ensure that firstly, the medical tenet 'first do no harm' is upheld, and secondly, that the benefits to cancer survivors' wider health and wellbeing are actively assessed, encouraged and explored.

Following on from the design of these SM tools, a pilot study could be designed to address the feasibility, acceptability and effectiveness of implementing a SM 'Guide for Survivors' and separate 'Tool for Clinicians' into the oncology clinical setting, to assess whether they are instrumental in increasing awareness and uptake of SM, as well as examining their effect on patient satisfaction with their care pathway, self-referred follow-up patterns, functional health outcomes, QoL and healthcare resource use.

Research should be undertaken to explore whether the role of SM in supporting cancer survivors who are undergoing the process of creating their new post-cancer normalities can be applied to other types of chronic illness, such as diabetes, HIV and heart failure. Cancer differs from other chronic illnesses in that the harrowing treatment regimens often faced by cancer patients often result in the production of more long-term side-effects than the cancer itself (243, 388). As a result the mechanisms for supporting cancer survivors may differ from other chronic illnesses where treatment is usually associated with improvements in health (389). However, as discussed (section 2.5), similarities between cancer and other chronic illnesses exist, with many of the challenges of living with a chronic illness resulting in a reworking of normal life to cope with the illness and its subsequent management (129, 130, 133). Further research is needed to explore ways in which to help people with chronic illness to adapt to their newly reconstructed lifestyles. This could be through evaluating the effectiveness and uptake of tailored self-support programmes, as well as exploring what motivates people with a range of chronic illnesses to use specific types of SM interventions. Research into whether SM practices have the same transferable qualities when applied to other types of chronic illness will add new insights to the growing literature surrounding this topic.

Finally, the presentation of the thesis in a hybrid style format (section 1.5) reinforced the decision to present the quantitative and qualitative studies sequentially, increasing the likelihood of the findings being published in high quality academic journals (31).

However, a number of different strategies could have been employed for mixing methods, to answer questions relating to health research and to provide a more integrated approach

to data analysis (16). In future, the dataset could be interrogated using some of these different strategies, to enable research questions to be answered that require the concurrent use of quantitative and qualitative data.

## **8.7 Conclusion**

This thesis has examined the use of SM practices in cancer survivors over time. It has provided a rationale for answering the research question ‘who does what and why?’ in relation to SM and cancer survivorship, through the use of a mixed methods study design. It has included a systematic review and meta-analyses which showed some evidence to suggest that one type of SM, CAM, does improve the QoL of cancer survivors, although the quality of the evidence was moderate to poor. The quantitative phase of the mixed methods study examined the prevalence and distribution of SM patterns from pre-diagnosis, through treatment and into survivorship, finding SM uptake to be highest in survivorship. Subgroup analyses revealed that chemotherapy respondents utilised SM more than those who had received other treatments, suggesting that this subgroup of cancer survivors may have a greater need for SM practices.

The positive association found between SM uptake and QoL reinforces previous findings linking increased SM uptake to improvements in QoL (36-41, 196, 200, 246-249). The positive association between SM uptake and internal HLC implies that cancer survivors who assume greater responsibility for their health behaviours and outcomes are more likely to use SM, potentially viewing these practices as mechanisms for taking control of their

health and lifestyles. In particular, dietary practices may be viewed by cancer survivors as providing the greatest benefits to health, as illustrated by the positive association between diet and internal HLC. The lack of association between SM uptake and ability to work could be due to cancer survivors having a diverse array of reasons for using SM depending on their level of health and subsequent work ability. In addition the exclusion of cancer survivors who were retired or unable to work from completing the work ability scale provided a significant study limitation.

Findings from the qualitative study explored the reasons for how and why cancer survivors used SM in their daily lives, revealing that motivations and constraints for using SM practices altered according to the stage of the cancer pathway. The qualitative study also revealed a new model for the role of SM in survivorship. The interviews uncovered that SM can play a supporting role in facilitating the processes of reassessing normality, fighting to maintain normality and maintaining the appearance of normality, in order to create a new health-related normality in survivorship. This new contribution to the literature around SM in cancer survivorship can be used to help health professionals understand more about how SM practices can help cancer patients make the successful transition forwards into survivorship, as well as providing support to cancer survivors trying to achieve this target.

## **8.8 Chapter Summary**

The final chapter of this thesis has presented an overview of the main findings from the research study. It has outlined how the findings have reinforced and added to the existing literature around SM and cancer survivorship, as well as detailing how it has contributed to methodology, theory and practice in this area. An overview of the study strengths and limitations were also given. Finally, the chapter has proposed future research opportunities that have been generated from the study findings, prior to the chapter and this thesis concluding.

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# APPENDICES

## Appendix 1. Reflections on Specialist Role as Research Support Nurse in a Breast Oncology Clinic

### Background to the Service

For three months between May to August 2013, I took on the role of research support nurse in an oncology breast cancer clinic that was being held once a week on a Wednesday morning at a large teaching hospital in the West Midlands. The idea behind this role developed following discussions with one of the oncology breast consultants, the lead nurse for cancer services, and a clinical psychologist at the hospital who were concerned with a potential gap in the service. It was felt that due to staff constraints, time management and organisational issues many patients were not being given enough time by either the oncology doctors or specialist breast nurses to identify and talk through any wider issues, needs or concerns relating to their cancer or treatment. As a result it was felt that these patients could be experiencing dissatisfaction with their care pathway as a result of not being supported fully enough in this area.

As a result it was proposed that a pilot scheme be undertaken in the oncology breast clinic, involving a nurse-led clinic which ran alongside the consultants clinic where patients could come in addition to seeing the consultant, allowing them more time to discuss any concerns or issues that there wasn't time for in the consultant led clinic. I was approached and asked if I would be willing to take on the nurse led role for the duration of the scheme,

and I agreed to do so as I felt it was extremely relevant to my research in terms of identifying, through a clinical setting, any unmet needs of cancer patients, and helping to provide support and advice around various aspects of their health and lifestyle to improve their health and wellbeing.

To facilitate the nurse led clinic a Macmillan Assessment and Care Plan tool was incorporated into the clinic structure. This Macmillan tool asked patients to identify from a list of fifty-seven physical, practical, family/relationship, emotional, spiritual/religious, and lifestyle or information concerns, which (if any) had caused them concern in the last week. Of those identified as concerns, they were then asked to score these concerns between 1-10, with one being the lowest level of concern and ten the highest. The three highest scoring concerns were then entered into the Macmillan care plan by myself and were discussed in the clinic. My role in the clinic was to administer the Macmillan assessment tool, complete the care plan, and discuss with the patients the three concerns identified. This could include providing advice on symptom control, providing emotional and practical support, and offering patients access to information relating to topics such as financial concerns, housing issues, and self-management practices such as diet, exercise and complementary therapies. It also involved making appropriate referrals where necessary, for example to psychological services when it was felt counselling for the patient may be beneficial.

Appropriate patients were identified at the start of each clinic following a discussion between myself and the oncology consultant regarding who would benefit from attending

the nurse-led clinic. These could be newly diagnosed patients', patients undergoing treatment (chemotherapy and/or radiotherapy, neo-adjuvant and adjuvant treatments), palliative patients, or those in follow up. The identified patients were then informed that they would see a nurse prior to seeing their doctor in the clinic. This was decided as it was felt that by seeing a nurse first patients could talk through any concerns troubling them so that when they did see the oncologist they could focus on the more bio-medical aspects of their care, rather than having to reiterate these problems. Additionally, if any concerns about their physical symptoms or treatment side effects were identified in the nurse-led clinic which warranted the attention of the oncologist these could be flagged up to the medical staff or highlighted to the patient as a reminder to discuss it with the doctor themselves. Additionally, it allowed the consultant the opportunity to review any issues we had discussed in clinic as the patient was asked to show their copy of the assessment sheet to the consultant if it was felt there was anything they ought to be aware of. Generally this system worked well, although due to the busy nature of the clinic sometimes the order at which patients saw the doctor or nurse was switched round.

In total the clinic ran for eleven weeks, and 46 patients were seen. Of these, 21 patients returned to the clinic more than once. Twenty-four of the 46 patients were undergoing cancer treatment, 13 were palliative and nine were in follow up. Fourteen of those undergoing treatment returned to the clinic more than once as did five of the 13 palliative patients, and two of the follow ups. This suggests that the clinic was more valuable for chemotherapy and palliative patients perhaps due to them experiencing more problems in terms of symptom control and management, as well as them facing more emotional and practical uncertainties around the future than those in follow up. No new patients were

referred to the service. This was due to the oncologist feeling that she needed to see these patients for a long initial consultation at the offset to talk through treatment options and the care pathway, where many of these issues covered in the nurse-led clinic would hopefully be raised. Additionally, it is not often until a patient has started on their treatment pathway that many problems, concerns and worries can arise. At the initial consultation the patient is likely to be shocked and may not benefit from the additional input of another clinical service at that point in time.

#### Patients' Reaction to the Service

Reactions to the clinic and assessment over the three month period varied. The majority of patients seemed to view it quite positively and expressed the view that they thought it was a useful resource and was helpful to have more time to discuss their concerns. Some found the symptom control advice valuable, as talking through things with them seemed to provide them with reassurance about side-effects and symptoms and how to manage them. Similarly, providing links in to support around practical concerns such as finance, parking etc...and talking through emotional concerns such as depression, worry, and loneliness, was generally received really well. For some having the space to break down and admit how much they were struggling was an outlet in itself. In addition some patients were unaware that a counselling/psychology service was available to them if it was required. I felt that the clinic provided the most benefit for those patients who returned a number of times over the three month period as it enabled us to build up a trusting relationship, review any prior concerns to see if they had resolved, and to continue to work on any ongoing problems. I think it was these patients who benefited most from the service, something which they often vocalised themselves.

However, a few people, although in the minority, did not place much value on the clinics. A couple of people refused to be seen again after the first visit and a few people identified no concerns or were reluctant to talk through any issues with me. I think the two main reasons for this were a) that they had no genuine additional concerns they needed to discuss and b) they were on the defensive and didn't want to open up about anything. Ironically it may be these people that could have benefitted from some additional input from, for example, psychology services. I found this frustrating but on reflection I realised that the service existed as an opportunity to provide extra support and signpost people in the direction of other services that might provide them benefit. However, if a minority of patients are unwilling to engage in this service provision it is beyond the remit of the nurse to force them to do so.

The diversity of reactions to the service highlighted to me that a better way of streamlining/triaging the patient's could be implemented in future to ensure that the clinic is used for cancer patients who are going to find it beneficial, rather than using it for people who don't have a need for the service or are reluctant to use it.

#### Other Observations from the Clinic

Over the three months running the clinic I reflected on a number of other issues that I had observed or experienced, which could be useful in the future when thinking about ways of improving the running and development of this service.

Sometimes patients attended the nurse-led clinic alone, but more often it was with a friend or family member. This raised the question of whether patients should be seen on their own or not. A positive outcome of assessing the patient with their friend/family member was that it allowed the family member/friend to raise any concerns that they knew the patient had been experiencing but would not have identified. However, the disadvantage of somebody else being present is that it may have sometimes hindered the patient from identifying and talking through certain concerns relating to family relationships, or emotional problems. However, patients returning to the clinic over time will hopefully be aware of the opportunity to discuss family/relationship/emotional concerns with the nurse in private, and can make the decision at this point to attend the consultation on their own if they feel it may be of benefit to them.

It was frustrating at times when some patients seemed reluctant to talk even though it seemed clear they had some unresolved issues to work through and could possibly benefit from some input (e.g. from psychology). However, although it felt unsatisfactory to not be able to help them, the assessment tool provided them with the opportunity to discuss any problems and the knowledge that the service was available at a later date if they changed their mind.

Completing the assessment tool in clinic was a waste of clinic time as it was a struggle to get the assessment completed and discuss three concerns in depth in a ten minute time slot, especially as some of the topics covered were quite complex or emotive. It would make more sense if the patients' completed the form once they had checked into the clinic at the

reception desk. This would also give them more time to think through any concerns they might like to raise before they saw the nurse.

Finally, the screening approach used by myself and the consultant worked to a large extent but could be improved on as some of the patients' I saw did not have a need for the service, whilst others who may have might have been missed. It might be better to initiate a system whereby all patients attending the clinic complete the assessment form when they check in at the reception desk, and depending on how highly certain concerns are scored, different people are offered different levels of input from healthcare professionals. For example patients scoring 5 or below could be seen by a band 5 oncology nurse, and those scoring above 5 could be seen by a specialist oncology nurse of a higher band. This would enable us to streamline staffing resources and the service more effectively, increasing efficiency, whilst making sure the needs of cancer patients are being met and managed appropriately.

#### Feedback and Relevance to My Research

Following cessation of the pilot scheme I met with the oncology consultant, lead cancer nurse, and clinical service to debrief and discuss any issues that had emerged. I was informed from the oncologist that she had received largely positive comments from patients over the pilot period, as they had fed back to her how much they valued the time to be able to discuss various concerns with a nurse in more depth. She also said how it had resulted in her saving time in her clinic as patients hadn't needed to reiterate their concerns to her as they were satisfied with the outcomes from the nurse-led consultation.

Observations from the clinic raised above were also documented and sent to the lead nurse for Cancer Services alongside a breakdown of patient numbers accessing the service over the three months. This information was fed back into the breast cancer services team at a strategic level and infiltrated through to managers, medics, breast nurses, and MDTs as a way of identifying current gaps in the breast cancer service, and to make recommendations for service improvement.

I feel the role I played in setting up and running this service was extremely valuable in terms of helping to develop patient and service needs, improving patient care and outcomes, as well as providing an example of where the findings from my research study are highly relevant in terms of supporting patients to make individualised decisions around managing their long term health outcomes from cancer. This model has shown how a generic assessment tool can be implemented at the patient level to provide individualised outcomes of care that are tailored towards prioritising patient needs whether that be on a psychological, physical, emotional, practical, social, spiritual, or financial level, through clinical support and raising awareness of support mechanisms available to patients. A similar tool for both patients and clinicians would be of value, based on my study findings, to identify areas where cancer survivors could benefit from different forms of SM.

**Appendix 2: Complementary Therapies and Their Effect on Quality of Life - Data Extraction Form**

Article author, year:	Reference ID:
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**Methods**

Setting where study was conducted:			
Hospital/Secondary Care Not reported	Community/Primary Care	Home	Other
Country:	Not reported		

Type of Study:		
RCT	Quasi RCT	Controlled before and after study

Study Objectives:
-------------------

Method of Participant Recruitment:
------------------------------------

Randomization, Allocation Concealment and Blinding:			
Method of randomisation:			
Who performed randomisation?	Not reported:	N/A:	
Was study: Single-Blinded Reported	Double-Blinded	Not Blinded	Not
If blinded, who was blinded?	Participants	Person performing intervention	

Study Funding:
Was any conflict of interest observed?

Other Comments:
-----------------

**Population**

Inclusion Criteria:
Exclusion Criteria:

Participant Demographics:	Intervention	Control	Overall
NR			
Mean Age at diagnosis (SD)			
Gender (% male/%female)			
Education Level:			
Ethnicity:			
Cancer Type:			
Cancer Stage:			
Previous treatment received:			
% on active treatment at start of study:			
% not on treatment at start of study:			

**Interventions:**

Number of participants:	Intervention	Control	Overall	NR
Identified:				
Contacted:				
Recruited:				
Met eligibility criteria:				
Consented:				
Randomised/allocated:				
Followed up:				

Lost to follow up:	Intervention	Control	Overall	NR
Details if more than one intervention group:				
Other comments:				

**Control Group:**

Intervention in control group:	
Control intervention assured: Y/N	Not reported:
Details if >1 control group:	
Opinion Of control group:	

Other comments/details (e.g. crossover study):
--

**Outcomes:**

Primary outcome measure (QOL outcomes):
What was the QOL measurement tool used?
At what time-points were these measured (weeks/mnth from baseline)?

Secondary outcome measure (adverse events):	Not reported:
Does study specify monitoring of adverse events as an outcome measure?	
Is any harm (ae) reported in the paper as a result of the CAM intervention?	

**Data Analysis**

Statistical Tests Used:
Intention to Treat Analysis:            Yes:            No:            N/A:
Baseline similarities between groups:
Baseline differences between groups:
Prognostic factors not measured/not reported at baseline:
Are participants not receiving active tx analysed separately from those receiving tx:
Yes:            No:            Not reported:
Additional comments:

Authors Conclusions:
----------------------

**Results: only include analysis of participants not on active treatment: exclude patients on active treatment from analysis.**

Primary Outcome QOL:	Intervention	Control	Intervention 2 (if applicable)
Baseline QOL scores (mean) :			
Number (n=):			
Follow Up 1:			
Number (n=)			
SD			
Follow Up 2:			
Number (n=1)			
SD			
Follow Up 3:			
Number (n=)			
SD			
Confidence Intervals			Not reported:
P Value			Not reported:

Need to contact author?

Other Comments:

### Appendix 3. Questionnaire Survey Used in Phase 1 Study

ID:	1			
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UNIVERSITY OF  
BIRMINGHAM

#### Self-Management Patterns of Cancer Survivors-A Questionnaire Survey

**Thank you for agreeing to take part in this study about health and lifestyle activities.**

We know we are asking you to provide a lot of information about yourself and your experiences, but the information you provide is very important for us to understand what types of activities people engage in during their cancer experience, and how this influences their health and well-being. We therefore ask you to try and answer all the questions.

Be assured that any personal details disclosed will remain confidential and all answers will be anonymised.

#### Section 1: General Information

1) What is your gender? (please circle).      Male    Female

2) What is your date of birth (date/month/year)? .....

3) Which ethnic group do you belong to? Please tick the box.

- White: British, Irish, or any other
- Mixed: White and black Caribbean, White and black African, or any other
- Asian or Asian British: Indian, Pakistani, Bangladeshi, or any other
- Black or Black British: Caribbean, African, or any other
- Chinese
- Other (please specify) .....

4) What is your religion? Please tick the box.

<input type="checkbox"/> Christian	<input type="checkbox"/> Muslim
<input type="checkbox"/> Buddhist	<input type="checkbox"/> Hindu
<input type="checkbox"/> Sikh	<input type="checkbox"/> Jewish
<input type="checkbox"/> None	<input type="checkbox"/> Other (please specify)

5) What is your current marital status? Please tick the box.

<input type="checkbox"/> Married/Civil Partnership	<input type="checkbox"/> Single
<input type="checkbox"/> Living with partner	<input type="checkbox"/> Divorced/Dissolved Civil Partnership
<input type="checkbox"/> Widowed	

6) Which of these qualifications do you hold? Please tick the boxes of all options that apply to you.

<input type="checkbox"/> O levels or CSE's or GCSE's or School Certificate	<input type="checkbox"/> NVQ level 3 or Advanced GNVQ
<input type="checkbox"/> A levels or AS levels or Higher School Certificate	<input type="checkbox"/> NVQ level 4 or NVQ level 5 or HNC or HND
<input type="checkbox"/> First Degree (e.g. BA or BSc)	<input type="checkbox"/> Qualified Professional (e.g. Doctor, Nurse, Teacher)
<input type="checkbox"/> Higher degree (e.g. MA or PhD or PGCE or postgraduate certificates Or diplomas)	<input type="checkbox"/> No qualifications
<input type="checkbox"/> NVQ level 1 or Foundation GNVQ	<input type="checkbox"/> Other qualifications (please specify).....
	<input type="checkbox"/> NVQ level 2 or Intermediate GNVQ

7) What is your annual household income?

- Less than £25,000
- £25-49,999
- £50-74,999

Over £75,000

8a) Do you smoke tobacco? (please circle)

Yes                      No

8b) If yes, how many times do you smoke per day (please circle).

1-10 times      11-19 times      20 or more times

8c) If you are currently not smoking, but have previously smoked, please tell us

approximately how many years ago you stopped smoking:.....years

## Section 2: Health and Lifestyle Activities

9) We are interested in the types of health and lifestyle activities you have been carrying out throughout your cancer experience. **Specifically, we would like to know, which of the activities listed below you tried in the year leading up to your diagnosis, during the time you were undergoing curative treatment at the hospital, and after you completed your treatment.**

We would like you to place a cross (X) in the boxes of activities you have tried and at what time you specifically used them, such as before diagnosis, during treatment or after treatment. It does not matter if you used them regularly or only once.

If you have never tried or not heard of any of the activities or therapies, then just leave the boxes blank.

**For example:** if you engaged in yoga before your diagnosis and after your treatment, but not during it, you would provide the following response:

Activity	Year before diagnosis	During treatment	After treatment
Yoga	X		X

**Please do now provide answers regarding the following activities as they apply to you.**

Self-Management Programmes	Year before diagnosis	During treatment	After treatment
Aquarius			
Expert Patient Programme			
Look Good...Feel Better UK			
Solihull Support Group or other Support Group			
Stop Smoking			
Other (please specify)			
Diet	Year	During	After treatment

SM Strategies for Cancer Survivors: Who Does What and Why?

	<b>before diagnosis</b>	<b>treatment</b>	
Essential fatty acids or fish oils			
High protein diet			
Non-dairy			
Low fat diet			
Raw			
Reduced alcohol intake			
Macrobiotic			
Vegan/vegetarian			
Vitamin or mineral supplements			
Other diet (please specify) e.g. bristol/budwig/gerston			
<b>Exercise</b>	<b>Year before diagnosis</b>	<b>During treatment</b>	<b>After treatment</b>
Individual sports (e.g. tennis, skiing, swimming, jogging)			
Martial arts (e.g. karate, kung fu)			
Tai chi/chi gong/pilates/yoga			
Team sports (e.g. football/netball)			
Walking			
Gym			
Gardening			
Other (please specify)			
<b>Psychological Therapies</b>	<b>Year before diagnosis</b>	<b>During treatment</b>	<b>After treatment</b>
Cognitive behavioural therapy			

SM Strategies for Cancer Survivors: Who Does What and Why?

Counselling			
Group therapy			
Problem solving therapy			
Psychoanalysis/Psychotherapy Other (please specify)			
<b>Complementary and Alternative therapies</b>	<b>Year before diagnosis</b>	<b>During treatment</b>	<b>After treatment</b>
<i>Natural Products</i>			
Aromatherapy			
Bach flower remedies			
Herbal medicine			
<i>Mind and Body Medicine</i>			
Art therapy			
Drama/dance/music therapy			
Guided imagery/visualisation			
Hypnotherapy			
Journaling			
Meditation/Mindfulness			
<i>Manipulative and Body Based Practices</i>			
Acupuncture/Acupressure			
Chiropody			
Colonic irrigation/Hydrotherapy			
Massage			
Metabolic therapy			
Osteopathy			
Shiatsu			

SM Strategies for Cancer Survivors: Who Does What and Why?

Reflexology			
<i><u>Movement Therapies</u></i>			
Alexander technique			
<i><u>Energy Fields</u></i>			
Crystals			
Reiki			
Theta healing			
Therapeutic touch			
<i><u>Whole Medical Systems</u></i>			
Ayurveda/Chinese medicine			
Homeopathy			
<i><u>Traditional Healers</u></i>			
Traditional healer/"medicine man"			
Spiritual healer  Other complementary or alternative therapies (please specify)			
<b><u>Spiritual/Religious Practices</u></b>	<b>Year before diagnosis</b>	<b>During treatment</b>	<b>After Treatment</b>
Attending religious services			
Prayer or intention			
Worship			
Group healing			
Spiritual music/singing			
Other (please specify)			

SM Strategies for Cancer Survivors: Who Does What and Why?

**10a)** How did you find out about the different self-management behaviours which you undertook (If any)? Please tick all that apply.

- Internet
- Family and friends
- Support Groups
- Doctor
- Specialist Nurse
- Booklets
- The Patrick Room (at the Queen Elizabeth Hospital)
- Other (please state).....

**10b)** From the list below, which source did you find *the most* useful for accessing support about different self-management options? Tick one box only.

- Internet
- Family and friends
- Support Groups
- Doctor
- Specialist Nurse
- Booklets
- The Patrick Room (at the Queen Elizabeth Hospital)
- Other (please state).....

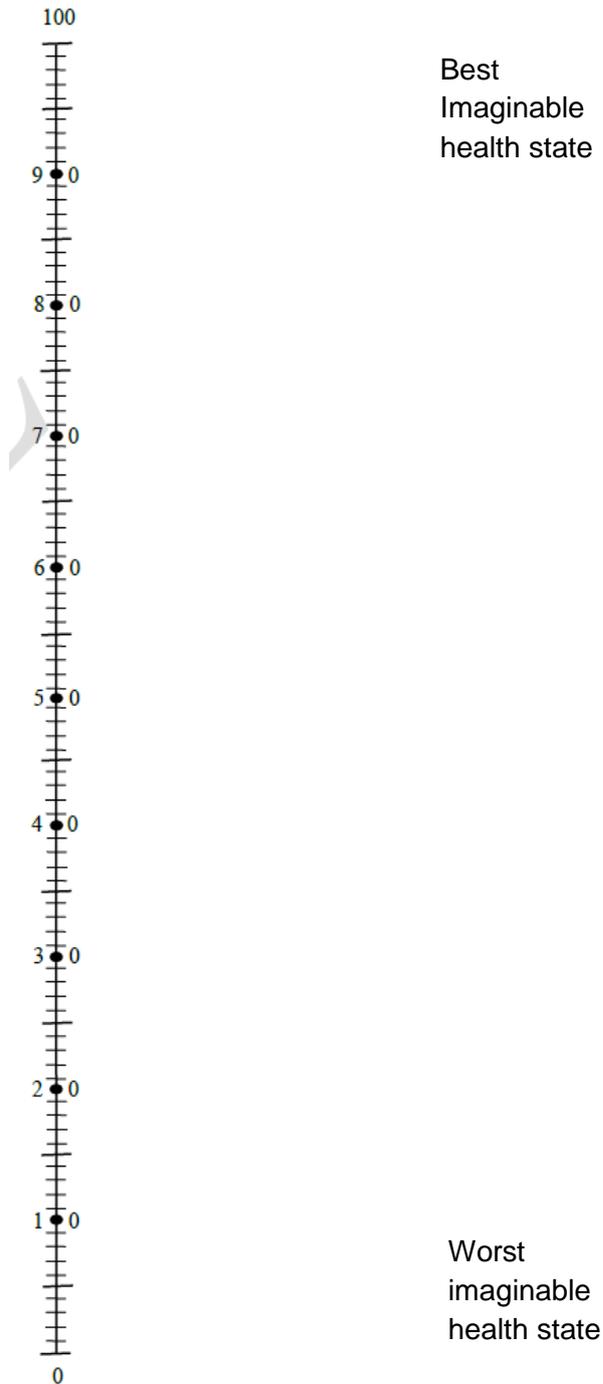
**Section 3: Your Wellbeing**

11) By ticking **one box in each group** below, please indicate which statements best describe your feelings **today**.

<b>Mobility</b>	
I have <b>no</b> problems in walking about	<input type="checkbox"/>
I have <b>some</b> problems in walking about	<input type="checkbox"/>
I am confined to bed	<input type="checkbox"/>
<b>Self-Care</b>	
I have <b>no</b> problems with washing and dressing myself	<input type="checkbox"/>
I have <b>some</b> problems washing or dressing myself	<input type="checkbox"/>
I am <b>unable</b> to wash or dress myself	<input type="checkbox"/>
<b>Usual Activities</b> (e.g. work, study, housework, family or leisure activities)	
I have <b>no</b> problems with performing my usual activities	<input type="checkbox"/>
I have <b>some</b> problems with performing my usual activities	<input type="checkbox"/>
I am <b>unable</b> to perform my usual activities	<input type="checkbox"/>
<b>Pain/Discomfort</b>	
I have <b>no</b> pain or discomfort	<input type="checkbox"/>
I have <b>moderate</b> pain or discomfort	<input type="checkbox"/>
I have <b>extreme</b> pain or discomfort	<input type="checkbox"/>
<b>Anxiety/Depression</b>	
I am <b>not</b> anxious or depressed	<input type="checkbox"/>
I am <b>moderately</b> anxious or depressed	<input type="checkbox"/>
I am <b>extremely</b> anxious or depressed	<input type="checkbox"/>

**12)** To help people say how good or bad their health state is, we have drawn a scale below, on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0. We would like you to indicate on this scale how good or bad your own health is today, in your opinion.

Please indicate how good or bad your health is by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.



**Section 4: Sense of Control**

**13)** Each item below is a belief statement about your medical condition with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, the lower will be the number you circle. Please make sure that you answer **EVERY ITEM** and that you circle **ONLY ONE** number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

		<b>SD</b>	<b>MD</b>	<b>D</b>	<b>A</b>	<b>MA</b>	<b>SA</b>
		1=STRONGLY DISAGREE ( <b>SD</b> ) 2=MODERATELY DISAGREE ( <b>MD</b> ) 3=SLIGHTLY DISAGREE ( <b>D</b> )			4=SLIGHTLY AGREE ( <b>A</b> ) 5=MODERATELY AGREE ( <b>MA</b> ) 6=STRONGLY AGREE ( <b>SA</b> )		
1	If I become sick, I have the power to make myself well again.	1	2	3	4	5	6
2	Often I feel that no matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6
3	If I see an excellent doctor regularly, I am less likely to have health problems.	1	2	3	4	5	6
4	It seems that my health is greatly influenced by accidental happenings.	1	2	3	4	5	6
5	I can only maintain my health by consulting health professionals.	1	2	3	4	5	6
6	I am directly responsible for my health.	1	2	3	4	5	6
7	Other people play a big part in whether I stay healthy or become sick.	1	2	3	4	5	6
8	Whatever goes wrong with my health is my own fault.	1	2	3	4	5	6
9	When I am sick, I just have to let nature run its course.	1	2	3	4	5	6

SM Strategies for Cancer Survivors: Who Does What and Why?

10	Health professionals keep me healthy.	1	2	3	4	5	6
11	When I stay healthy, I'm just plain lucky.	1	2	3	4	5	6
12	My physical well-being depends on how well I take care of myself.	1	2	3	4	5	6
13	When I feel ill, I know it is because I have not been taking care of myself properly.	1	2	3	4	5	6
14	The type of care I receive from other people is what is responsible for how well I recover from an illness.	1	2	3	4	5	6
15	Even when I take care of myself, it's easy to get sick.	1	2	3	4	5	6
16	When I become ill, it's a matter of fate.	1	2	3	4	5	6
17	I can pretty much stay healthy by taking good care of myself.	1	2	3	4	5	6
18	Following doctor's orders to the letter is the best way for me to stay healthy.	1	2	3	4	5	6

**Section 5: Employment**

14) What is your current employment status? Please tick one box.

<input type="checkbox"/> Working full-time (30 hours or more per week)	<input type="checkbox"/> Caring for home or family	<input type="checkbox"/> Unemployed
<input type="checkbox"/> Working part-time (less than 30 hours per week)	<input type="checkbox"/> Student	<input type="checkbox"/> Unable to work due to illness or disability ( <b>Please go to section 6</b> ).
<input type="checkbox"/> Retired. ( <b>Please go to section 6</b> ).		

15) What is your present occupation? (Job title).....

16) Assume that your ability to work at its best has a value of 10 points. **How many points would you give your current work ability?** (0 means that you cannot currently work at all). Please circle one.

0   1   2   3   4   5   6   7   8   9   10

Worst imaginable work ability		Best possible work ability
-------------------------------	--	----------------------------

17a) How do you rate your current work ability with respect to the physical demands of your work? Please tick one box.

<input type="checkbox"/> Very good	<input type="checkbox"/> Rather good	<input type="checkbox"/> Moderate	<input type="checkbox"/> Rather poor	<input type="checkbox"/> Very poor
------------------------------------	--------------------------------------	-----------------------------------	--------------------------------------	------------------------------------

17b) How do you rate your current work ability with respect to the mental demands of your work? Please tick one box.

<input type="checkbox"/> Very good	<input type="checkbox"/> Rather good	<input type="checkbox"/> Moderate	<input type="checkbox"/> Rather poor	<input type="checkbox"/> Very poor
------------------------------------	--------------------------------------	-----------------------------------	--------------------------------------	------------------------------------

**Section 6: Further Information**

SM Strategies for Cancer Survivors: Who Does What and Why?

We would like to invite some participants to discuss their participation in health and lifestyle activities in person. Would you be happy to be contacted by one of our researchers to discuss your experiences of health and lifestyle activities? Even if you have not carried out any health or lifestyle activities throughout your cancer experience we would be very interested in speaking to you (please tick the box).

<input type="checkbox"/> Yes	<input type="checkbox"/> No
------------------------------	-----------------------------

If you are happy for us to contact you please provide your contact details below. Please note that any contact details you supply will be kept separate from the completed questionnaire and will not be used to identify you with the answers that you have provided.

Name:.....

Telephone number:.....

E-mail address (optional):.....

We may also wish to access your medical records to gain more information about your diagnosis and treatment for cancer. All information accessed will be treated confidentially and anonymised. If you do not wish for us to access this information please place a tick in the box provided below. **If you do not wish for your medical notes to be accessed you can still complete and return the questionnaire in the pre-paid envelope provided.**

I **do not** want my medical notes accessed to gain information about my cancer diagnosis and treatment.

*Finally if you would like us to send you feedback on the study findings at the end of the study please tick this box.*

**Thank you for taking the time to complete this questionnaire.**

## **Appendix 4. Letter to Consultants to Enable Access to Study Participants**

### **Self-Management Patterns of Cancer Survivors-A Questionnaire and Interview Study**

Dear Dr (personalised),

I am a PhD student at the University of Birmingham and have recently gained ethical approval to undertake a study exploring patterns of self-management in cancer survivors in an attempt to explore who does what and why. The project will aim to examine self-management strategies of cancer survivors in relation to their quality of life, health beliefs and ability to work. Self-management strategies include mechanisms such as diet, exercise, complementary therapies, support groups, psychotherapy, and spirituality, and Macmillan Cancer Support has advocated the use of self-management in facilitating the recovery, recuperation and rehabilitation of cancer survivors and helping to minimise the consequences of their treatment.

In order to collect information on the use and types of self-management strategies employed, the study plans to send postal questionnaires to cancer survivors. Approximately 960 patients from the Queen Elizabeth hospital who have received active treatment for a cancer diagnosis in the past 5 years, and are currently free from local recurrence or metastatic disease will be considered for inclusion in the study. Eligible patients will be identified using the hospitals electronic databases, and patient information will be cross checked against the West Midlands Cancer Intelligence Unit database to ensure that all patient data is as accurate as possible to minimise the risk of questionnaires being sent out inappropriately.

Following recruitment to the questionnaire part of the study, forty patients will be interviewed in more depth to explore the influence of health beliefs and health experiences on decision-making with regard to self-management.

This research project has been approved by the Local research Ethics Committee and has R&D approval pending. The Principal Investigator is your colleague Dr Iñigo Tolosa, who

has asked me to get in touch with you. We tried to book a brief slot to present this at Oncology Executive but this meeting is too busy so I am writing to ask your permission to allow me to identify and recruit eligible patients to the study using the methods stated above. The study is important as it will enable us to understand what is important to cancer survivors in terms of self-management and what influences their health behaviours and decision-making with regards to their care. These findings will be used to develop a tool for screening/profiling cancer survivor patient preferences, and a “guide for survivors”, which will be developed in collaboration with the Pan Birmingham Cancer Network.

I have recently obtained an honorary contract at UHB, and am a registered nurse with a background in oncology so have experience of working in this field. If you have any questions or require further information about the study please contact myself Cathy Shneerson

If you are happy for information on your patients to be included in the study please sign and date the form overleaf and return in the envelope provided. Alternatively, email myself on \_\_\_\_\_ confirm your response.

Many Thanks,

Cathy Shneerson

I give permission for oncology patients that have been treated under my care in the past 5 years to be identified for inclusion in the study outlined above, and if deemed eligible, to be invited to participate in the study.

Name:

(sign and print)

Date:

If you would like to receive a summary of the study findings at the study conclusion please indicate by ticking this box

## Appendix 5. Invitation Letter to Participate in Study



University Hospital   
Birmingham  
NHS Foundation Trust

University Hospitals   
Coventry and Warwickshire  
NHS Trust

Title First Name Last name

Address line 1

Address line 2

Address line 3

Address line 4

Postcode

Date

Dear (personalised)

### **Self-Management Strategies in Cancer Survivors**

I am writing to ask if you can help us find out more about how and why people who have had cancer take up different lifestyle behaviours (such as diet, exercise, and complementary therapies) to help them to self-manage certain aspects of their health and wellbeing.

This hospital is working with the University of Birmingham on a research study which involves talking to people who have had cancer in the past but are currently cancer free, to find out more about the self-management strategies people who have had cancer use (if any).

We would very much like to hear your views on the subject of self-management. **I would be grateful if you would complete the enclosed questionnaire, whether you have used any self-management strategies or not**, and return the questionnaire in the FREEPOST envelope provided.

As well as the questionnaire, we also need to speak in greater depth to some people about their views on self-management and their beliefs about making lifestyle changes. Enclosed with this letter you will find an information sheet alongside a short questionnaire which includes a tick-box section indicating your acceptance to take part in a discussion with an independent researcher at a later date. Even if you do not want to take part in a one-to-one discussion, we would very much appreciate it if you would return the questionnaire in the FREEPOST envelope.

Our findings will eventually be used to help provide the information that cancer patients need about self management strategies.

## **Appendix 6. Information Sheet for Phase 1 Study**



UNIVERSITY OF  
BIRMINGHAM

University Hospital   
Birmingham  
NHS Foundation Trust

### **Self-Management Patterns of Cancer Survivors**

Protocol version 2	PIL Version: 2.0	Date: 22/02/2012
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#### **Information about the research**

We would like to invite you to take part in a research study. Before you decide, you need to understand why the 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.

The study is about exploring the types of self-management strategies (such as diet, exercise, complementary therapies) that people who have had cancer use before, during and after their treatment, if any. It aims to find out why people employ these health behaviours, and their impact on quality of life, health and wellbeing.

Ask us if there is anything that's not clear, or if you would like more information before deciding. Take time to decide whether or not you wish to take part.

#### **What is the purpose of the study?**

There are many self-management strategies such as diet, exercise, complementary medicine, religious practices, counselling and other support programmes. Though previous research has shown some of these things to be beneficial to patient's quality of life, little is known about how these lifestyle practices alter throughout the cancer experience.

We hope that this study will help us produce useful information for people in future so that we can help to support them to choose lifestyle practices that may benefit them.

#### **Why have I been invited?**

You're being asked to take part in this study because you have had a diagnosis of cancer in the past, but according to our records you are currently disease free. We are sending a questionnaire to people to find out what self-management practices they used in the past, during treatment, and at present. We would also like to arrange to talk to some of you about the reasons for making any changes to your lifestyle and the things that may have affected this.

### **What happens if I take part?**

If you decide to take part we would like you to complete the questionnaire provided. Additionally, if you would be happy to talk to us about your lifestyle activities since your cancer diagnosis we will ask you to tick a box at the end of the questionnaire indicating your consent to do so. Forty people will be contacted and invited to attend a short interview to discuss these issues further. The discussion, which is audio-taped, will be held locally and will last not more than two hours. We will pay back any reasonable out-of-pocket expenses you incur by taking part, such as travel costs. If you do not wish to be interviewed we would still like you to complete and return the questionnaire. The information provided by you in the questionnaire will be used in the study findings even if you do not wish to be interviewed.

If you decide to complete the questionnaire we may wish to access your medical records to gain further information regarding your diagnosis and treatment for cancer. All information accessed will be treated confidentially and anonymised. At the end of the questionnaire you will be asked to indicate whether or not you are happy for us to access this information. If you do not wish for this information to be accessed you can still complete the questionnaire.

### **Do I have to take part?**

It's entirely up to you whether to take part or not. You are free to withdraw or change your mind at any time without giving a reason. Even if you don't want to talk to us, we should be grateful if you would complete the questionnaire and return it in the FREEPOST envelope provided. If you do not want to complete the questionnaire at all please return it uncompleted in the freepost envelope provided. A researcher will contact you after two weeks if the questionnaire has not been returned in case there are any questions you would like to ask before completing the questionnaire.

### **What are the possible disadvantages and risks of taking part?**

This study doesn't involve any treatment or tests, so there is no physical risk involved. Some people may find it distressing to talk about their cancer experience with other people.

### **What are the possible benefits of taking part?**

You'll have the satisfaction of knowing that others may be helped by this research in the future, but there are no direct benefits to you personally.

### **What happens when the research study stops?**

When all the questionnaires have been returned and the interviews been held, a report will be prepared and the findings will be published in medical journals and at conferences. It will be several months before this happens. Once published, a summary of the report will

be available to all participants who would like one, and will be published on the University of Birmingham's website. All reports and publications will use the information collected in a way that makes sure that you cannot be identified.

#### **What if there's a problem?**

If you have any complaint about the way you are dealt with during the study, please contact [\[redacted\]](#). If you remain unhappy and wish to complain formally, you can do this by contacting the West Midlands Local Research Network, Solihull (tel 01527 582534) or the University Hospitals Birmingham NHS Foundation Trust, Research & Development Department (tel 0121 414 9087).

#### **What will happen if I don't want to carry on with the study?**

You can decide to leave the study at any time. This will have no effect on your care.

#### **Will my taking part in this study be kept confidential?**

Yes. We will follow ethical and legal practice and all the information about you will be handled in confidence. Any discussion you take part in will be audio-taped so that the researchers can listen to it and analyse it later, but no-one except the researchers will be able to identify you.

#### **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 a favourable opinion by West Midlands REC-Solihull Research Ethics Committee.

#### **How can I find out more?**

If you'd like more information about the study before you make up your mind, you can contact [\[redacted\]](#) or [\[redacted\]](#) or post (Primary Care Clinical Sciences Building, University of Birmingham, Edgbaston B15 2TT). You may also wish to contact the Patient Advice and Liaison Services by telephone (0121 371 3280) or email ([pals@uhb.nhs.uk](mailto:pals@uhb.nhs.uk)) for independent research advice.

#### **Who is organising and funding the research?**

The research is being carried out by a team from University Hospital Birmingham, and the Department of Health and Population Sciences at the University of Birmingham. It is funded by the National Centre for Primary Care Research/Research Support Facility.

## **Appendix 7. ICD-10 Codes for Inclusion in Study (181).**

### Breast Cancer

---

**C50** Malignant neoplasm of breast

*Incl.:*

connective tissue of breast

*Excl.:*

skin of breast ([C43.5](#), [C44.5](#))

C50.0 Nipple and areola

C50.1 Central portion of breast

C50.2 Upper-inner quadrant of breast

C50.3 Lower-inner quadrant of breast

C50.4 Upper-outer quadrant of breast

C50.5 Lower-outer quadrant of breast

C50.6 Axillary tail of breast

C50.8 Overlapping lesion of breast

[See note 5 at the beginning of this chapter]

C50.9 Breast, unspecified

### Trachea, Bronchus and Lung Cancer

---

**C33** Malignant neoplasm of trachea

**C34** Malignant neoplasm of bronchus and lung

C34.0 Main bronchus

*Incl.:*

Carina

Hilus (of lung)

C34.1 Upper lobe, bronchus or lung

C34.2 Middle lobe, bronchus or lung

C34.3 Lower lobe, bronchus or lung

C34.8 Overlapping lesion of bronchus and lung

[See note 5 at the beginning of this chapter]

C34.9 Bronchus or lung, unspecified

---

**C39** Malignant neoplasm of other and ill-defined sites in the respiratory system and intrathoracic organs

*Excl.:*

intrathoracic NOS ([C76.1](#))

thoracic NOS ([C76.1](#))

C39.0 Upper respiratory tract, part unspecified

C39.8 Overlapping lesion of respiratory and intrathoracic organs

[See note 5 at the beginning of this chapter]

*Incl.:*

Malignant neoplasm of respiratory and intrathoracic organs whose point of origin cannot be classified to any one of the categories C30-C39.0

C39.9 Ill-defined sites within the respiratory system

*Incl.:*

Respiratory tract NOS

### Colorectal Cancers

---

Malignant neoplasm of colon

C18.0 Caecum

*Incl.:*

Ileocaecal valve

C18.1 Appendix

C18.2 Ascending colon

C18.3 Hepatic flexure

C18.4 Transverse colon

C18.5 Splenic flexure

C18.6 Descending colon

C18.7 Sigmoid colon

Incl.:

Sigmoid (flexure)

Excl.:

rectosigmoid junction ([C19](#))

C18.8 Overlapping lesion of colon

[See note 5 at the beginning of this chapter]

C18.9 Colon, unspecified

Incl.:

Large intestine NOS

---

**C19** Malignant neoplasm of rectosigmoid junction

Incl.:

Colon with rectum

### Prostate Cancer

**C61** Malignant neoplasm of prostate

### Non-Hodgkin's Lymphoma

---

**C82** Follicular lymphoma

Incl.:

follicular lymphoma with or without diffuse areas

Excl.:

T-cell non-Hodgkin lymphoma ([C84.-](#))

C82.0 Follicular lymphoma grade I

C82.1 Follicular lymphoma grade II

C82.2 Follicular lymphoma grade III, unspecified

C82.3 Follicular lymphoma grade IIIa

C82.4 Follicular lymphoma grade IIIb

C82.5 Diffuse follicle centre lymphoma

C82.6 Cutaneous follicle centre lymphoma

C82.7 Other types of follicular lymphoma

C82.9 Follicular lymphoma, unspecified

Incl.:

Nodular lymphoma NOS

---

**C83** Non-follicular lymphoma

C83.0 Small cell B-cell lymphoma

Incl.:

Lymphoplasmacytic lymphoma

Nodal marginal zone lymphoma

Non-leukaemic variant of B-CLL

Splenic marginal zone lymphoma

*Excl.:*

Chronic lymphocytic leukaemia ([C91.1](#))

Waldenström macroglobulinaemia ([C88.0](#))

T-cell lymphoma ([C84.-](#))

C83.1 Mantle cell lymphoma

Incl.:

Centrocytic lymphoma

Malignant lymphomatous polyposis

C83.3 Diffuse large B-cell lymphoma

Incl.:

- Anaplastic
- CD30-positive
- Centroblastic
- Plasmablastic
- Immunoblastic
- Subtype not specified
- T-cell rich
- diffuse large B-cell lymphoma

*Excl.:*

mediastinal (thymic) large B-cell lymphoma ([C85.2](#))

T-cell lymphoma ([C84.-](#))

C83.5 Lymphoblastic (diffuse) lymphoma

**Incl.:**

B-precursor lymphoma  
Lymphoblastic B-cell lymphoma  
Lymphoblastic lymphoma NOS  
Lymphoblastic T-cell lymphoma  
T-precursor lymphoma

**C83.7 Burkitt lymphoma**

**Incl.:**

Atypical Burkitt lymphoma  
“Burkitt-like” lymphoma

**Excl.:**

mature B-cell leukaemia Burkitt-type ([C91.8](#))

**C83.8 Other non-follicular lymphoma**

**Incl.:**

Primary effusion B-cell lymphoma  
Intravascular large B-cell lymphoma  
Lymphoid granulomatosis

**Excl.:**

mediastinal (thymic) large B-cell lymphoma ([C85.2](#))  
T-cell rich B-cell lymphoma ([C83.3](#))

**C83.9 Non-follicular (diffuse non-Hodgkin lymphoma, unspecified)**

---

**C84 Mature T/NK-cell lymphomas**

**C84.0 Mycosis fungoides**

**C84.1 Sézary disease**

**C84.4 Peripheral T-cell lymphoma, not classified**

**Incl.:**

Lennert’s lymphoma  
Lymphoepithelioid lymphoma

**C84.5 Other mature T/NK-cell lymphomas**

**Note:**

If T-cell lineage or involvement is mentioned in conjunction with a specific lymphoma, code to the more specific description.

**Excl.:**

angioimmunoblastic T-cell lymphoma ([C86.5](#))  
blastic NK-cell lymphoma ([C86.4](#))

enteropathy-type T-cell lymphoma ([C86.2](#))  
extranodal NK-cell lymphoma, nasal type ([C86.0](#))  
hepatosplenic T-cell lymphoma ([C86.1](#))  
primary cutaneous CD30-positive T-cell proliferations ([C86.6](#))  
subcutaneous panniculitis-like T-cell lymphoma ([C86.3](#))  
T-cell leukaemia ([C91.-](#))

C84.6 Anaplastic large cell lymphoma, ALK-positive

*Incl.:*

Anaplastic large cell lymphoma, CD30-positive

C84.7 Anaplastic large cell lymphoma, ALK-negative

*Excl.:*

primary cutaneous CD30-positive T-cell proliferations ([C86.6](#))

C84.8 Cutaneous T-cell lymphoma, unspecified

C84.9 Mature T/NK-cell lymphoma, unspecified

*Incl.:*

NK/T cell lymphoma NOS

*Excl.:*

mature T-cell lymphoma, not elsewhere classified ([C84.4](#))

---

**C85** Other and unspecified types of non-Hodgkin lymphoma

C85.1 B-cell lymphoma, unspecified

*Note:*

If B-cell lineage or involvement is mentioned in conjunction with a specific lymphoma, code to the more specific description.

C85.2 Mediastinal (thymic) large B-cell lymphoma

C85.7 Other specified types of non-Hodgkin lymphoma

C85.9 Non-Hodgkin lymphoma, unspecified

*Incl.:*

Lymphoma NOS

Malignant lymphoma NOS

Non-Hodgkin lymphoma NOS

---

**C86** Other specified types of T/NK-cell Lymphoma

*Excl.:*

anaplastic large cell lymphoma, ALK negative ([C84.7](#))

anaplastic large cell lymphoma, ALK positive ([C84.6](#))

C86.0 Extranodal NK/T-cell lymphoma, nasal type

C86.1 Hepatosplenic T-cell lymphoma

*Excl.:*

Alpha-beta and gamma-delta types ([C86.6](#))

C86.2 Enteropathy-type (intestinal) T-cell lymphoma

*Incl.:*

Enteropathy associated T-cell lymphoma

C86.3 Subcutaneous panniculitis-like T-cell lymphoma

C86.4 Blastic NK-cell lymphoma

C86.5 Angioimmunoblastic T-cell lymphoma

*Incl.:*

Angioimmunoblastic lymphadenopathy with dysproteinaemia (AILD)

C86.6 Primary cutaneous CD30-positive T-cell proliferations

*Incl.:*

Lymphomatoid papulosis

Primary cutaneous anaplastic large-cell lymphoma

Primary cutaneous CD30+large T-cell lymphoma

---

**C88** Other B-cell lymphoma[malignant immunoproliferative diseases]

C88.0 Waldenström macroglobulinaemia

*Incl.:*

Lymphoplasmacytic lymphoma with IgM-production

Macroglobulinaemia (primary)(idiopathic)

*Excl.:*

small cell B-cell lymphoma ([C83.0](#))

C88.2 Other heavy chain disease

*Incl.:*

Franklin disease

Gamma heavy chain disease

Mu ( $\mu$ ) heavy chain disease

C88.3 Immunoproliferative small intestinal disease

*Incl.:*

Alpha heavy chain disease

Mediterranean lymphoma

C88.4 Extranodal marginal zone B-cell lymphoma of mucosa-associated lymphoid tissue [MALT-lyphoma]

*Note:*

Use additional code ([C83.3](#)) if desired, to specify transition to high malignant (diffuse large cell) lymphoma

*Incl.:*

Lymphoma of skin-associated lymphoid tissue (SALT-lymphoma)

Lymphoma of bronchial-associated lymphoid tissue (BALT-lymphoma)

C88.7 Other malignant immunoproliferative diseases

C88.9 Malignant immunoproliferative disease, unspecified

*Incl.:*

Immunoproliferative disease NOS

### Melanoma of the Skin

---

**C43** Malignant melanoma of skin

*Incl.:*

morphology codes M872-M879 with behaviour code /3

*Excl.:*

malignant melanoma of skin of genital organs ([C51-C52](#), [C60.-](#), [C63.-](#))

C43.0 Malignant melanoma of lip

*Excl.:*

vermilion border of lip ([C00.0-C00.2](#))

C43.1 Malignant melanoma of eyelid, including canthus

C43.2 Malignant melanoma of ear and external auricular canal

C43.3 Malignant melanoma of other and unspecified parts of face

C43.4 Malignant melanoma of scalp and neck

C43.5 Malignant melanoma of trunk

*Incl.:*

*Anal:*

- margin
- skin

Perianal skin

Skin of breast

*Excl.:*

anus NOS ([C21.0](#))

C43.6 Malignant melanoma of upper limb, including shoulder

C43.7 Malignant melanoma of lower limb, including hip

C43.8 Overlapping malignant melanoma of skin

[See note 5 at the beginning of this chapter]

C43.9 Malignant melanoma of skin, unspecified

*Incl.:*

Melanoma

### Bladder Cancer

---

**C67** Malignant neoplasm of bladder

C67.0 Trigone of bladder

C67.1 Dome of bladder

C67.2 Lateral wall of bladder

C67.3 Anterior wall of bladder

C67.4 Posterior wall of bladder

C67.5 Bladder neck

*Incl.:*

Internal urethral orifice

C67.6 Ureteric orifice

C67.7 Urachus

C67.8 Overlapping lesion of bladder

[See note 5 at the beginning of this chapter]

C67.9 Bladder, unspecified

### Head and Neck Cancers

**C00** Malignant neoplasm of lip

*Excl.:*

skin of lip ([C43.0](#), [C44.0](#))

C00.0 External upper lip

*Incl.:*

Upper lip:

- NOS
- lipstick area
- vermilion border

C00.1 External lower lip

*Incl.:*

Lower lip:

- NOS
- lipstick area
- vermilion border

C00.2 External lip, unspecified

*Incl.:*

Vermilion border NOS

C00.3 Upper lip, inner aspect

*Incl.:*

Upper lip:

- buccal aspect
- frenulum
- mucosa
- oral aspect

C00.4 Lower lip, inner aspect

*Incl.:*

Lower lip:

- buccal aspect
- frenulum
- mucosa
- oral aspect

C00.5 Lip, unspecified, inner aspect

Incl.:

Lip, not specified whether upper or lower:

- buccal aspect
- frenulum
- mucosa
- oral aspect

C00.6 Commissure of lip

C00.8 Overlapping lesion of lip

[See note 5 at the beginning of this chapter]

C00.9 Lip, unspecified

---

**C01** Malignant neoplasm of base of tongue

*Incl.:*

Dorsal surface of base of tongue

Fixed part of tongue NOS

Posterior third of tongue

---

**C02** Malignant neoplasm of other and unspecified parts of tongue

C02.0 Dorsal surface of tongue

*Incl.:*

Anterior two-thirds of tongue, dorsal surface

*Excl.:*

dorsal surface of base of tongue ([C01](#))

C02.1 Border of tongue

*Incl.:*

Tip of tongue

C02.2 Ventral surface of tongue

*Incl.:*

Anterior two-thirds of tongue, ventral surface

Frenulum linguae

C02.3 Anterior two-thirds of tongue, part unspecified

*Incl.:*

Middle third of tongue NOS

Mobile part of tongue NOS

C02.4 Lingual tonsil

*Excl.:*

tonsil NOS ([C09.9](#))

C02.8 Overlapping lesion of tongue

[See note 5 at the beginning of this chapter]

*Incl.:*

Malignant neoplasm of tongue whose point of origin cannot be classified to any one of the categories C01-C02.4

C02.9 Tongue, unspecified

---

**C03** Malignant neoplasm of gum

*Incl.:*

alveolar (ridge) mucosa

gingiva

*Excl.:*

malignant odontogenic neoplasms ([C41.0-C41.1](#))

C03.0 Upper gum

C03.1 Lower gum

C03.9 Gum, unspecified

---

**C04** Malignant neoplasm of floor of mouth

C04.0 Anterior floor of mouth

*Incl.:*

Anterior to the premolar-canine junction

C04.1 Lateral floor of mouth

C04.8 Overlapping lesion of floor of mouth

[See note 5 at the beginning of this chapter]

C04.9 Floor of mouth, unspecified

---

**C05** Malignant neoplasm of palate

C05.0 Hard palate

C05.1 Soft palate

*Excl.:*

nasopharyngeal surface of soft palate ([C11.3](#))

C05.2 Uvula

C05.8 Overlapping lesion of palate

[See note 5 at the beginning of this chapter]

C05.9 Palate, unspecified

Incl.:

Roof of mouth

---

**C06** Malignant neoplasm of other and unspecified parts of mouth

C06.0 Cheek mucosa

Incl.:

Buccal mucosa NOS

Internal cheek

C06.1 Vestibule of mouth

Incl.:

Buccal sulcus (upper)(lower)

Labial sulcus (upper)(lower)

C06.2 Retromolar area

C06.8 Overlapping lesion of other and unspecified parts of mouth

[See note 5 at the beginning of this chapter]

C06.9 Mouth, unspecified

Incl.:

Minor salivary gland, unspecified site

Oral cavity NOS

---

**C07** Malignant neoplasm of parotid gland

**C08** Malignant neoplasm of other and unspecified major salivary glands

*Excl.:*

malignant neoplasms of specified minor salivary glands which are classified according to their anatomical location

malignant neoplasms of minor salivary glands NOS ([C06.9](#))

parotid gland ([C07](#))

C08.0 Submandibular gland

Incl.:

Submaxillary gland

C08.1 Sublingual gland

C08.8 Overlapping lesion of major salivary glands

[See note 5 at the beginning of this chapter]

Incl.:

Malignant neoplasm of major salivary glands whose point of origin cannot be classified to any one of the categories C07-C08.1

C08.9 Major salivary gland, unspecified

Incl.:

Salivary gland (major) NOS

---

**C09** Malignant neoplasm of tonsil

*Excl.:*

lingual tonsil ([C02.4](#))

pharyngeal tonsil ([C11.1](#))

C09.0 Tonsillar fossa

C09.1 Tonsillar pillar (anterior)(posterior)

C09.8 Overlapping lesion of tonsil

[See note 5 at the beginning of this chapter]

C09.9 Tonsil, unspecified

Incl.:

Tonsil:

- NOS
- faucial
- palatine

---

**C10** Malignant neoplasm of oropharynx

*Excl.:*

tonsil ([C09.-](#))

C10.0 Vallecula

C10.1 Anterior surface of epiglottis

Incl.:

Epiglottis, free border [margin]

Glossoepiglottic fold(s)

*Excl.:*

epiglottis (suprahyoid portion) NOS ([C32.1](#))

C10.2 Lateral wall of oropharynx

C10.3 Posterior wall of oropharynx

C10.4 Branchial cleft

Incl.:

Branchial cyst [site of neoplasm]

C10.8 Overlapping lesion of oropharynx

[See note 5 at the beginning of this chapter]

Incl.:

Junctional region of oropharynx

C10.9 Oropharynx, unspecified

---

**C11** Malignant neoplasm of nasopharynx

C11.0 Superior wall of nasopharynx

Incl.:

Roof of nasopharynx

C11.1 Posterior wall of nasopharynx

Incl.:

Adenoid

Pharyngeal tonsil

C11.2 Lateral wall of nasopharynx

Incl.:

Fossa of Rosenmüller

Opening of auditory tube

Pharyngeal recess

C11.3 Anterior wall of nasopharynx

Incl.:

Floor of nasopharynx

Nasopharyngeal (anterior)(posterior) surface of soft palate

Posterior margin of nasal:

- choana
- septum

C11.8 Overlapping lesion of nasopharynx

[See note 5 at the beginning of this chapter]

C11.9 Nasopharynx, unspecified

Incl.:

Nasopharyngeal wall NOS

---

**C12** Malignant neoplasm of piriform sinus

*Incl.:*

Piriform fossa

---

**C13** Malignant neoplasm of hypopharynx

*Excl.:*

piriform sinus ([C12](#))

C13.0 Postcricoid region

C13.1 Aryepiglottic fold, hypopharyngeal aspect

Incl.:

Aryepiglottic fold:

- NOS
- marginal zone

*Excl.:*

aryepiglottic fold, laryngeal aspect ([C32.1](#))

C13.2 Posterior wall of hypopharynx

C13.8 Overlapping lesion of hypopharynx

[See note 5 at the beginning of this chapter]

C13.9 Hypopharynx, unspecified

Incl.:

Hypopharyngeal wall NOS

---

**C14** Malignant neoplasm of other and ill-defined sites in the lip, oral cavity and pharynx

*Excl.:*

oral cavity NOS ([C06.9](#))

C14.0 Pharynx, unspecified

C14.2 Waldeyer's ring

C14.8 Overlapping lesion of lip, oral cavity and pharynx

[See note 5 at the beginning of this chapter]

Incl.:

Malignant neoplasm of lip, oral cavity and pharynx whose point of origin cannot be classified to any one of the categories C00-C14.2

### Stomach Cancer

---

#### **C16** Malignant neoplasm of stomach

C16.0 Cardia

Incl.:

Cardiac orifice

Cardio-oesophageal junction

Gastro-oesophageal junction

Oesophagus and stomach

C16.1 Fundus of stomach

C16.2 Body of stomach

C16.3 Pyloric antrum

Incl.:

Gastric antrum

C16.4 Pylorus

Incl.:

Prepylorus

Pyloric canal

C16.5 Lesser curvature of stomach, unspecified

Incl.:

Lesser curvature of stomach, not classifiable to C16.1-C16.4

C16.6 Greater curvature of stomach, unspecified

Incl.:

Greater curvature of stomach, not classifiable to C16.0-C16.4

C16.8 Overlapping lesion of stomach

[See note 5 at the beginning of this chapter]

C16.9 Stomach, unspecified

Incl.:

Gastric cancer NOS

### Oesophageal Cancer

---

**C15** Malignant neoplasm of oesophagus

*Note:*

Two alternative subclassifications are given:

- .0-.2 by anatomical description
- .3-.5 by thirds

This departure from the principle that categories should be mutually exclusive is deliberate, since both forms of terminology are in use but the resulting anatomical divisions are not analogous.

C15.0 Cervical part of oesophagus

C15.1 Thoracic part of oesophagus

C15.2 Abdominal part of oesophagus

C15.3 Upper third of oesophagus

C15.4 Middle third of oesophagus

C15.5 Lower third of oesophagus

C15.8 Overlapping lesion of oesophagus

[See note 5 at the beginning of this chapter]

C15.9 Oesophagus, unspecified.

## **Appendix 8. Reminder Letter**



Title First Name Last name

Address line 1

Address line 2

Address line 3

Address line 4

Postcode

Date

Dear (personalised)

### **REMINDER LETTER: Self-Management Strategies in Cancer Survivors**

I am writing to remind you about a questionnaire that was sent to your home address two weeks ago, asking you to complete a questionnaire exploring self-management strategies in cancer survivors. If you have already returned this questionnaire please ignore this reminder letter.

We would like you to help us find out more about how and why people who have had cancer take up different lifestyle behaviours (such as diet, exercise, and complementary therapies) to help them to self-manage their health and wellbeing.

This hospital is working with the University of Birmingham on a research study which involves talking to people who have had cancer in the past but are currently cancer free, to find out more about the self-management strategies people who have had cancer use (if any).

We would very much like to hear your views on the subject of self-management. **I would be grateful if you would complete the enclosed questionnaire, whether you have used any self-management strategies or not**, and return the questionnaire in the FREEPOST envelope provided.

As well as the questionnaire, we also need to speak in greater depth to some people about their views on self-management and their beliefs about making lifestyle changes. Enclosed with this letter you will find an information sheet alongside a short questionnaire which includes a tick-box section indicating your acceptance to take part in a discussion with an independent researcher at a later date. Even if you do not want to take part in a one-to-one discussion, we would very much appreciate it if you would return the questionnaire in the FREEPOST envelope.

Our findings will eventually be used to help provide the information that cancer patients need about self-management strategies.

As is usual with research studies, your response will be treated entirely confidentially. Your care will not be affected in any way.

Yours sincerely

*(name of consultant)*

Although every effort has been made to ensure that this questionnaire has been sent to the appropriate patient population through thorough checking of patient databases, if you have recently experienced a recurrence of cancer please accept our apologies for potentially causing distress. If you would like to discuss any issues relating to this further please contact . Alternatively you can contact Macmillan Cancer Support on 0207 8407840 for general support and information, or Cancer Voices by phone on 020 70912006 or via their website [macmillan.org.uk/cancer-voices](http://macmillan.org.uk/cancer-voices).

## Appendix 9. Study Feedback Letter

### Self-Management Strategies of Cancer Survivors: Who Does What and Why? Findings from a questionnaire and interview study.

We are writing to update you on the findings from a research study you took part in for us in 2012-13. The study sent questionnaires to 957 cancer survivors living in and around the West Midlands and collected information about which types of self-management practices, such as diet, exercise, complementary therapies, psychological therapies, support groups and spirituality/religion you were using before, during and after your cancer treatment. It also collected information on your quality of life, health beliefs and ability to work. 445 questionnaires were completed and returned to us. After this, 40 of you who had completed the questionnaire were interviewed to find out more about the reasons why you chose or chose not to use these self-management practices. A summary of what we found out from you is given below.

#### Self-management practices were used:

- to maintain health and fitness
- to relax the mind and body
- to aid healing
- for their therapeutic benefits
- to manage treatment side-effects
- to access support from other people
- as a result of taking advice from friends and family members
- as a way to help people cope with having cancer
- for reasons not related to cancer
- to regain 'normality' post-cancer

Increased use of self-management practices was linked to perceived increases in quality of life. People who believed their health outcomes were affected by their lifestyle choices were more likely to use self-management practices than those who felt their health was down to fate, luck or chance.

## Self-Management Strategies of Cancer Survivors: Who Does What and Why? Findings from a questionnaire and interview study.

- Self-management uptake was highest in people post-cancer and lowest in people when they were undergoing their cancer treatment. Exercise was the most popular self-management practice used, followed by diet, complementary therapies, spiritual or religious practices, support groups and lastly, psychological therapies.
- Women, people diagnosed with breast cancer and younger people were more likely than men to use complementary therapies and access support groups than older people, men and people diagnosed with other types of cancer.
- The amount of self-management practices used by people in the study was not linked to how well they felt they were able to function at work.
- The interviews revealed that self-management practices were often used by people post-cancer to help them get their lives back to 'normal'. Self-management practices were often used to help shape people's new lives by providing a coping mechanism, aiding relaxation, promoting health and fitness, promoting healing, providing access to social support networks and to help them manage the long-term side effects from treatment.

*People who had had chemotherapy were more likely to use the self-management practices exercise, diet, psychological therapies, complementary therapies and support groups than people who hadn't had chemotherapy.*



**What's next?** The study findings are currently being written up for publication and it is hoped that doctors and nurses can use them to provide their patients with appropriate recommendations about the types of self-management practices that might help them.

We would like to thank you for taking the time to help us with this research study.

## **Appendix 10. Information Sheet for Phase 2 Study**



### **Self-Management Patterns of Cancer Survivors: Interview Study**

Protocol version 2	PIL Version: 2.0	Date: 22/02/2012
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#### **Information about the research**

We would like to invite you to take part in a research study. Before you decide, you need to understand why the 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.

The study is about exploring the types of self-management strategies (such as diet, exercise, complementary therapies) that people who have had cancer in the past use before, during and after their treatment, if any. It aims to find out why people employ these health behaviours, and their impact on quality of life, health and wellbeing.

Ask us if there is anything that's not clear, or if you would like more information before deciding. Take time to decide whether or not you wish to take part.

#### **What is the purpose of the study?**

There are very many self-management strategies ranging from diet and exercise to complementary medicine, religious practices, counselling and other support programmes. Though previous research has shown some of these things to be beneficial to patient's quality of life, little is known about how these lifestyle practices alter throughout the cancer experience.

We hope that this study will help us produce useful information for people in future so that we can help to support them to choose lifestyle practices that may benefit them.

#### **Why have I been invited?**

You're being asked to take part in this study because you have had a diagnosis of cancer in the past, but according to our records you are currently disease free. We previously sent you a questionnaire which you completed, and in which you indicated you would be willing to talk to a researcher in more detail about your lifestyle and health behaviours. We would like to arrange to talk to you on a one-to-one basis so that we can find out more about the reasons for making any changes to your lifestyle and the things that may have affected this.

### **Do I have to take part?**

It's entirely up to you whether to take part or not. You are free to withdraw or change your mind at any time without giving a reason

### **What happens if I take part?**

If you would be happy to talk to us about your lifestyle activities since your cancer diagnosis we will arrange a suitable time and place to meet to take part in a short interview to discuss these issues further with an independent researcher from the University of Birmingham. The discussion, which is audio-taped, will be held locally and will last not more than two hours. We will pay back any reasonable out-of-pocket expenses you incur by taking part, such as travel costs.

### **What are the possible disadvantages and risks of taking part?**

This study doesn't involve any treatment or tests, so there is no physical risk involved. Some people may find it distressing to talk about their cancer experience with other people.

### **What are the possible benefits of taking part?**

You'll have the satisfaction of knowing that others may be helped by this research in the future, but there are no benefits to you personally.

### **What happens when the research study stops?**

When all the interviews been held, a report will be prepared and the findings will be published in medical journals and at conferences. It will be several months before this happens. Once published, a summary of the report will be available to all participants who would like one, and will be published on the University of Birmingham's website. All reports and publications will use the information collected in a way that makes sure that you cannot be identified.

### **What if there's a problem?**

If you have any complaint about the way you are dealt with during the study, please contact [\[redacted\]](#). If you remain

unhappy and wish to complain formally, you can do this by contacting the West Midlands Local Research Network, Solihull (tel 01527 582534) or the University Hospitals Birmingham NHS Foundation Trust, Research & Development Department (tel 0121 414 9087).

#### **What will happen if I don't want to carry on with the study?**

You can decide to leave the study at any time. This will have no effect on your care.

#### **Will my taking part in this study be kept confidential?**

Yes. We will follow ethical and legal practice and all the information about you will be handled in confidence. Any discussion you take part in will be audio-taped so that the researchers can listen to it and analyse it later, but no-one except the researchers will be able to identify you. If you do decide to take part details from your medical records regarding diagnosis and treatment for cancer may be examined and included in the study findings and data analysis, but any data used will be handled confidentially, and will be non-identifiable if presented in the study findings.

#### **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 a favourable opinion by West Midlands REC-Solihull Research Ethics Committee.

#### **How can I find out more?**

You will receive a phone call in about one week in case you have any questions to ask about the interview before deciding whether or not to take part. Alternatively, if you'd like more information about the study before you make up your mind, you can contact

Primary

Care Clinical Sciences Building, University of Birmingham, Edgbaston B15 2TT. You may also wish to contact the Patient Advice and Liaison Services by telephone (0121 371 3280) or email ([pals@uhb.nhs.uk](mailto:pals@uhb.nhs.uk)) for independent research advice.

#### **Who is organising and funding the research?**

The research is being carried out by a team from University Hospital Birmingham, and the Department of Health and Population Sciences at the University of Birmingham. It is funded by National Centre for Primary Care Research/Research Support Facility.

## **Appendix 11. Interview Topic Guide**

### Cancer and its Effects on Individuals Views of Health.

*Sense of control of health and illness*

*Coping with cancer*

*Vulnerability of body*

*Decision-making-influences on health and lifestyle choices.*

### Social Networks.

*Biggest source of support?*

*Reactions of friends and family?*

*Relationships with health professionals.*

*Other sources of support-internet etc..*

### Views on Self-Management

*Types of SM uptake*

*Reasons for taking up and continuing/stopping SM*

*Importance of SM to daily life*

*Influences*

### Work Ability

*How has cancer diagnosis affected work*

*Working relationships*

*Desire to work*

### Quality of Life

*How has cancer changed outlook on life?*

*Day to day problems resulting from after affects of cancer.*

*Effects of mind and body (physical and mental changes).*

### Views About the Future

*Does cancer feature? Future health?*

## Appendix 12. Consent Form for Phase 2 Study



Patient Identification Number :

### CONSENT FORM

Research Study: Self-Management Patterns of Cancer Survivors: Interview Study

Name of Researcher: \_\_\_\_\_

Patient's Initials

1. I confirm that I have read and understand the patient information sheet dated.....22/02/2012....(version.....2.....) for the above study.

I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4. I agree to take part in the above study. I understand that I will undertake one discussion with a researcher that will be audio recorded and that my details and opinions will not be identified in any publication nor to anyone but the researchers.

\_\_\_\_\_  
Name of Patient

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

taking consent

*When completed, top copy for patient; 1 copy for researcher site file*

**Appendix 13: Snapshot of Framework Analysis Matrix Spreadsheet**

<b>Patient ID</b>	<b>1652</b>	<b>1191</b>
<b>Initial Impressions</b>	Positive lady with strong faith in God.	Talkative lady who seemed to want to confide in me, as felt unable to speak to family and friends a lot of the time about how she was feeling. Struggling with depression.
<b>Categories and Codes</b>		
<b>Attributes</b>		
Age	51	55
Gender	Female	Female
Cancer Type	Stomach	Breast
Ethnicity	Black	White
Religion	Christian	None
Income	<£25,000	<£25,000
Employment	Cleaner	Unable to work. Was a lawyer.
Qualifications	None.	Higher degree. Qualified lawyer.
Marital Status/Family	Divorced	Married
Smoker	Never smoker	Ex-smoker. Stopped 5 years ago.
Other health problems	Family history of cancer Q9.	Heart attack a year before cancer diagnosis Q44.  Heart attack combination of high blood pressure and stress. Recovered and returned to work, and had support from people around her Q529.