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The Sport of Dragon Boat Racing as experienced by Breast Cancer Survivors.

BY

Mary Milne

Thesis for the degree of Doctor of Clinical Practice

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ABSTRACT

FACULTY OF HEALTH SCIENCES

Thesis for the degree of Doctor of Clinical Practice

THE SPORT OF DRAGON BOAT RACING AS EXPERIENCED BY BREAST CANCER SURVIVORS

Mary Teresa Milne

For the increasing population of breast cancer survivors (BCS) in the United Kingdom, research evidence suggests that physical activity can address aspects of their unmet health and social care needs. In this exploratory study, members of one United Kingdom, Breast Cancer Survivor Dragon Boat Racing Team, were invited to tell the story of their participation in the sport, either in writing or in one-to-one, face-to-face, interviews, to gain an understanding of its impact on their breast cancer survivorship experiences. Eleven members were interviewed in their own homes and two in a location of their choosing. The interview process was guided by the Biographic-Narrative-Interpretive-Method (BNIM), and specifically the Single Question (aimed at Inducing Narrative) (SQUIN) (Wengraf 2001, p. 113). The stories were analysed using Frank's three narrative types (Restitution, Chaos, Quest), and the 'three facets' framework (Frank 1995) for the analysis of quest narratives. The combination of the latter and storytelling as a methodology, in relation to DBR, appears to be unique to this study. The study was underpinned by the principles of practitioner research.

Unmet needs, of varying quantity and level of intensity, were the strongest motivators for joining the team. The results revealed that dragon boat racing positively impacted on the breast cancer survivors' lives through; membership of an extended unique social support network, a new more positive identity as a breast cancer survivor and sportsperson, improved self-esteem and greater self-confidence, experiencing fun, joy, hope, as well as improved control over, and the amelioration of some upper body morbidities. The desire and opportunity to help others and to contribute to the legacy of DBR for future breast cancer survivors was also reported. The breast cancer survivors' stories included chaos, restitution and quest narrative types (Frank 1995) – the most common of these being quest. The study illustrates, using the metaphor of the weave (Frank 1995), the breast cancer survivors' constant movement between the three narrative types; this movement was often prompted by, what were interpreted as, five influential inspirations; Dragon Boat Racing ('In the Boat'), Social Support/Social Support Networks, Competition Events, Team/Group Membership, Physical and Psychological changes. The use of a storytelling methodology reveals the way in which the experience of DBR is woven into the lives of breast cancer survivors and illuminates the ways in which multiple narratives shape the breast cancer survivorship experience as well as how these women coped with the negative consequences of the DBR experience. These results have implications for charities supporting DBR, including; ensuring members feel integrated within the team, maintaining safety and fitness routines, ensuring DBR remains affordable, facilitating participation in competition events and the education of the public.

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DECLARATION OF AUTHORSHIP

I, Mary Milne
Declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

The Sport of Dragon Boat Racing as experienced by Breast Cancer Survivors.
I confirm that:
This work was done wholly or mainly while in candidature for a research degree at this university;
Where any part of this thesis has previously been submitted for a degree or any other qualification at this university or any other institution, this has been clearly stated;
Where I have consulted the published work of others, this is always clearly attributed;
Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
I have acknowledged all main sources of help;
Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I contributed myself;
None of this work has been published before submission.
Signed:
………………………………………………………………………………………………
Date:
………………………………………………………………………………………………

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Definitions and Abbreviations

BCS – Breast Cancer Survivor(s)/Breast Cancer Survivorship

BCSDBR – Breast Cancer Survivor Dragon Boat Racing

BNIM - Biographic Narrative Interpretive Methodology

Cellulitis – an infection of the deeper layers of the skin and the underlying tissues

Destination and Map – ‘Serious illness is a loss of the “destination map” that had previously guided the ill person’s life: ill people have to learn “to think differently” (Frank 1995, p.1).

DBR – Dragon Boat Racing

DOH - Department of Health

Dyadic Body –‘…the ill person is immersed in a suffering that is both wholly individual – my pain is mine alone - but also shared’ (Frank 1995, p.36)

Reflexivity – the tendency to examine and analytically to reflect upon the nature of research and the role of the researcher in carrying out and writing up empirical work. (Elliott 2005, p.153)

Remission society – ‘… all those people who, like me, were effectively well but could never be considered cured’ (Frank 1995, p.8).

SQUIN - Single Question Aimed at Inductive Narrative (Wengraf 2001)

Preface:
Historical Background to the Study

The Breast Cancer Survivor Dragon Boat Team referred to in this study was initiated by a group of breast cancer survivors after they participated in a joint collaborative project, between an NHS trust, and a local leisure service provider. The project was a Physical Activity Intervention Project, for which the researcher was project manager. The project aimed to assess the impact of a physical activity intervention on the health and wellbeing of the breast cancer survivors who participated in it.

In focus group sessions with the participants during the initiative, strategies to sustain physical activity levels beyond the life of the project were explored. To facilitate this, a half day of 'taster sessions' was held at the leisure centre where participants were given the opportunity to experience activities such as; Tai Chi, Yoga, Nordic Walking, and were introduced, by way of DVD, to the idea of Dragon Boat Racing for Breast Cancer Survivors (DBRBCS) (the DVD featured the accounts of members of a Dragon Boat Team for BCS in Canada).

Although there was an enthusiastic response to the idea of a DBR team, the nearest DBR team was approximately 100miles away and the nearest established DBR team for BCS approximately 300 miles away (only two others in the UK at that time, but approximately 130 worldwide). The BCS formed a working group and with support from the researcher, and leisure centre staff, they secured access to a dragon boat which was being used locally by an adventure holiday company.

The local media were engaged to help recruit more members and after three months the team decided they wanted to purchase their own boat. A committee was formed and charitable status applied for, and secured. The researcher (although not a BCS) was appointed as chairperson and all other roles, except for coach and helm (no one had the necessary skills, to fulfil these roles) were filled by BCS. In line with the agreement made at the outset of the team's formation the researcher stood down as chairperson and trustee when the team was established – this was prior to the commencement of this research study.

The team is now in its fifth year, and continues to recruit new members from a range of sources, including recommendations from the multidisciplinary breast team, the local media, and by word of mouth. Survivors of other cancers have expressed an interest in taking up the sport. The researcher continues to paddle with the team.

Chapter 1: Introduction

This thesis presents the results of an exploratory study, using storytelling, to describe the experiences of Breast Cancer Survivors (BCS[1]) who participate in the sport of Dragon Boat Racing (DBR). The thesis sets out the rationale for the study, gives details of the background literature, the research methods, presents the findings, discusses the findings in relation to the narrative, BCS, and BCSDBR, literature, as well as its contribution to the BCSDBR knowledge base, its limitations, recommendations and conclusion.

It was the combination of; the researchers own experience in practice, the call for interventions to address unmet needs in cancer survivors (DOH 2007, 2010, Harrison et al 2009), the emerging strong evidence relating to the positive effects of physical activity for BCS - and specifically DBR as a potential activity -that informed the researcher's decision to undertake this study, and gain a better understanding of the experience of DBR, as an activity for BCS. The researcher, in her professional career as a Clinical Nurse Specialist and Nurse Consultant in breast cancer care, had been aware of what appeared to be, increasing unmet needs in this patient population, and had attempted to address them in her own practice. However, it was after relocating, and while employed as a project manager (see Preface p. 1) on a one year BCS project that she initiated the Physical Activity Intervention Project. The latter aimed to go beyond identifying need, and instead take positive steps to attempt to address them. It was from this project that this DBR team originated. It is of significance to this study that as the project manager the researcher had no involvement in the care or treatment of any of the study participants while in that position. Her role was to interview BCS referred to the project by clinicians.

The Physical Activity Intervention Project, as well as originating from a need identified in practice, also coincided with a growing concern amongst many cancer survivors, and some voluntary and health care bodies, that cancer survivors have many unmet needs, and that, services frequently do

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[1] BCS refers to Breast Cancer Survivor/s, Breast Cancer Survivorship

not meet those needs (Department of Health 2007, 2010). For cancer survivors – and many of the research studies involved breast cancer survivors - research evidence supported the view that physical activity had the potential to address some of this unmet need in this patient population (Warburton et al 2006, 2011, McNeeely et al 2006, Mutrie et al 2007, Daley et al 2007, Irwin et al 2009, Department of Health 2010). The American College of Sports Medicine’s (ACSM) Roundtable on Exercise Guidelines for Cancer Survivors, stated that “some of the psychological and physiological challenges faced by cancer survivors can be prevented, attenuated, treated or rehabilitated through exercise” (Schmitz et al., 2010, p.1410).

Recent meta-analysis and systematic reviews of randomised controlled trials on physical activity for cancer survivors have concluded that for breast cancer survivors physical activity has a positive effects on mortality, physiology, body composition, physical functions, psychological outcomes and quality of life, (Ballard-Barbash et al 2012, Fong et al 2012, Mishra et al 2012). However, these authors have highlighted the need to interpret the positive results cautiously, due to the heterogeneity of exercise programs and assessment tools used, and the risk of bias in many of the studies.

The investigation of the relationship between DBR and BCS originated from a case study in Canada (McKenzie 1998) that examined whether the vigorous, repetitive upper-body sport of DBR was safe for women at risk from lymphoedema - a chronic and irreversible swelling of the arm. The study challenged the long held presumption that this type of strenuous exercise would lead to lymphoedema. The study concluded that the strenuous upper body exercise did not lead to the development of lymphoedema, or the exacerbation of pre-existing lymphoedema. Additionally, it found that the impact of the experience on the women was overwhelming with ‘the physical changes barely keeping pace with the changes in psyche’ (Mc Kenzie 1998, p. 377). At the end of the study the women refused to disband leading to the situation we know today where there are approximately 150 BCSDBR teams worldwide with five in the United Kingdom (UK).

Studies specifically addressing the impact of DBR, as a physical activity for BCS have demonstrated physical (McKenzie 1998, Mitchell and Nielsen 2002, Culos-Reed et al 2005, Lane et al 2005, McDonough et al 2008, McNeely et al 2009), psychological, social, and spiritual benefits (Unruh and Elvin 2004, Parry 2007, Morris et al 2010, Sabiston et al 2007, Mitchell et al 2007). The consistency of positive evidence supporting the potential benefits of physical activity for BCS, and specifically DBR, led the researcher, together with the physical activity intervention project participants, to set up a DBR team.

The present study aimed to gain an insight into the experience of Dragon Boat Racing (DBR), from the perspective of these Breast Cancer Survivors (BCS), who are all members of this United Kingdom (UK) DBR team, through storytelling - either verbally or in writing (Box 1.1). The stories were told over the time period May/June 2012.

Box 1.1 Study Aim

To explore and describe the experiences of BCS who volunteer to participate in the sport of DBR in one UK DBR team in an attempt to answer, broadly, but not exclusively, the following questions:

1. How do BCS taking part in DBR describe the impact that this activity has on their lives?
2. How can the registered charity hosting this Dragon Boat Team improve the quality and sustainability of the dragon boating experience for the team?

Chapter 2 presents the literature that was reviewed at the start of the study and after the analyses of the stories had been completed, both sets of literature are presented to support the reader's appreciation of the study's findings. Chapter 3 describes the methodology. Chapters 4 and 5 present the results from the analysis of the stories told by research participants using Franks (1995) three narrative types (Restitution, Chaos, Quest), Frank's framework (plot, action problems of embodiment (control, body-relatedness, other-relatedness, desire), self-story, power and limitations, plus the three facets of quest (memoir, manifesto, automythology) – as all the stories were of the quest narrative type. Chapter 5 adopts the metaphor of the weave to visually capture the constant movement between the three narrative types (Restitution, Chaos, and Quest) (Frank 1995), from foreground to background, where the weaver (BCS) is prompted by her remission society membership experiences (pre-DBR) and/or by five influential inspirations, which represent the impact of DBR on the participant's remission society experiences, to adjust the weave. These divisions are strictly for convenience only as they naturally overlap and iterate with each other throughout the stories. Chapter 6 discusses the study's results incorporating research findings from the BCS research literature generally, and specifically the field of narrative literature pertaining to BCS and BCSDBR studies. Chapter 7 concludes this thesis: it outlines the new knowledge gained in this study and how the findings from this research study add to the international body of knowledge relevant to the experience of BCS who participate in the sport of DBR in the UK, and discusses the study's recommendations and limitations.

Chapter 2: Literature Review

2.1 Introduction

This chapter and chapter 6 will present the results of the literature which was reviewed at the start of the study and after the analyses of the stories had been completed, both sets of literature are presented to support the reader's appreciation of the study's findings. The purpose of the review at the start of the study was to; situate the research, establish what was already known, and identify gaps. This aspect of the review focused on breast cancer survivorship literature (with particular reference to upper-body-morbidity, and the issue of safety in relation to physical activity), and how physical activity, and BCSDBR specifically, impacted on the cancer survivorship experience. The second set of literature related to illness, BCS, and BCSDBR narrative research, and was extended to include qualitative literature findings (Appendix A) - because of the paucity of available narrative literature - where the emphasis was on the experience of DBR for BCS. This element of the review was intentionally not undertaken in detail until after the analyses of the stories were completed, rather a brief reading to establish what was known was carried out. The researcher was concerned that reading this literature before the analyses could adversely influence her interpretation of the stories.

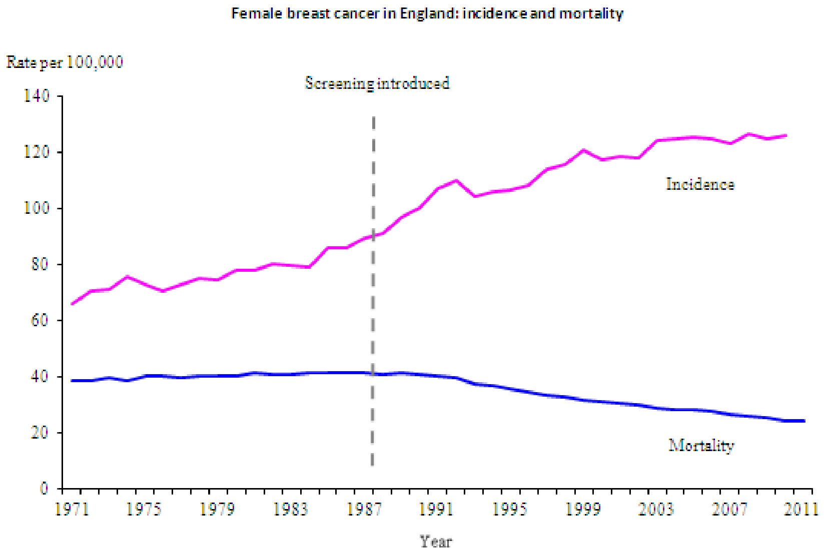
The review is presented under the following topic headings: breast cancer/breast cancer survivorship, physical activity, upper-body-morbidity, lymphoedema, DBR, storytelling, illness narratives and suggested areas for further research. The initial search strategy was guided by the researcher's interest - developed in practice as a Breast Cancer Specialist Nurse and Nurse Consultant - in the unmet needs of breast cancer survivors, and identifying safe interventions to help address those needs. Through clinical practice and the research literature she had become aware of DBR as a possible safe physical activity for BCS.

Relevant studies were identified by systematically searching databases which included: PubMed, AMED, CINAHL, Cochrane Reviews, Embase, Medline, IBSS, PsychINFO, Sociological Abstracts, Google Scholar, Websites (e.g. Department of Health, National Institute for Clinical Excellence, Delphis) Web of Knowledge, ZETOC, Dissertations and Theses, SportDiscus. Additionally, reference lists of all studies were also searched to identify potentially relevant articles. The search terms used related to breast cancer, breast cancer survivorship, breast cancer narrative(s)/stories, breast cancer experience, physical activity, dragon boat racing/ breast cancer survivors/experience, upper-body-morbidity, lymphoedema, storytelling, illness narratives, practitioner research. The identified studies were critically appraised using the following three stages: appraisal of the research design, appraisal of the conduct of the study, appraisal of the outcomes of the research (NHS Executive 1998) and the questions laid out in Appendix B (Murray 2011).

2.2 Breast Cancer/Breast Cancer Survivorship

Breast cancer has been the most common cancer in the UK since 1997, despite the fact that it is rare in men. It is by far the most common cancer among women in the UK, accounting for 31% of all new cases of cancer in females. The lifetime risk of developing breast cancer in the UK is estimated to be 1 in 8 for women (Cancer Research UK 2012). Figure 2.1 below show an increasing incidence of; although this has been levelling off, and decreasing mortality from, breast cancer, with a correspondingly increasing population of breast cancer survivors in the UK. It is predicted that the population of cancer survivors will continue to grow at a rate of over 3% per year (Department of Health 2013).

Figure 2.1 Female Breast Cancer in England. Incidence and Mortality, 1971-2011



Source: Office for National Statistics

Available at Office for National Statistics: http://www.ons.gov.uk/ons/rel/cancer-unit/breast-cancer-in-england/2010/sum-1.html (Accessed: 31 October 2012)

For this increasing population of cancer survivors there is recognition that they have a range of physical, psychological, social, spiritual, financial, and information needs and that at present services frequently do not meet these needs or are poorly integrated (Department of Health 2007, 2010, 2013, Harrison 2009, Carey et al 2012,). The following section will consider the concept of cancer survivorship with particular reference to breast cancer survivors.

There are a number of definitions for the term ‘cancer survivor’ with disagreement as to whether ‘survivorship’ begins at diagnosis or at the end of primary treatment. Working with cancer survivors and their carers Macmillan Cancer Support put forward the following definitions:

> ‘… someone who:

- Has completed initial cancer management and has no apparent evidence of active disease, or
- Is living with progressive disease and may be receiving cancer treatment but is not in the terminal phase of illness (last six months of life) or
- Has had cancer in the past' (Macmillan Cancer Support 2008, p. 6).

The breast cancer survivors who feature in this study fall within the first and last of these definitions.

A concept for cancer survivorship (Table 2.1) has only recently been put forward by Doyle (2008).

Table 2.1 The Concept of Cancer Survivorship.

Five Attributes:

- a process beginning at diagnosis
- involving uncertainty
- a life-changing experience
- a duality of positive and negative aspects
- unique to the individual but has some universality.

(Doyle 2008)

It is suggested that implicit within the principle of successful treatment of cancer is an acceptance that there is a real potential for some degree of damage to normal tissues. The resultant consequences of cancer or its treatment can be defined as symptoms and/or changes in function – whether physical or psychological – which develop following treatment for cancer. These problems might be persistent or develop months or years later, after a period of normal health, and when neither the patient, or the health professional, link them to the previous cancer treatment (Department of Health 2010, p. 53). In some cases the consequences of cancer or its treatment will take the form of a new long-term, or chronic condition, or an exacerbation of an established co-morbidity (Department of Health 2010, p. 53), [*and*] 'that cancer survivors are more likely than the general population to develop second cancers and have a significantly higher chance of developing heart disease or bone fractures' (Department of Health 2010, p. 41). Over recent years there has been a shift towards multi-agent (chemotherapies and hormone therapies) and multi-modality (surgery, radiotherapy, chemotherapy, hormone therapy biological therapy) treatments for breast cancer with a corresponding increase in consequences for survivors.

Breast cancer survivors' experience of breast cancer can be complex, affecting all aspects of their lives during and after treatment. Although each woman's experience is unique, they share common perspectives related to the physical and functional side effects of treatment (Binkley et al 2012). Each of the breast cancer treatments: surgery, chemotherapy, radiotherapy, hormone therapy and other targeted therapies, are associated with both short term and long term impairments. Common impairments include weight gain/obesity (Irwin et al 2005, Nissen et al 2011, Demark-Wahnerfried et al 2012), fatigue (Meeske et al 2007, Luctka-Flude 2007, Kangas et al 2008), impaired bone health (Saad et al 2008, Gralow et al 2009, Edwards et al 2011), and upper body functioning/lymphoedema (Hayes et al 2010, 2010a), NcNeely et al 2010, Fu et al 2009, 2009a, Campbell et al 2012), cardiac toxicity (Carver et al 2007, Curigaliano et al 2010, Smith et al 2010). The respective prevalence of the most common impairments include: pain, fatigue (94%), upper-extremity dysfunction (20% to 44%), lymphoedema (6% to 70%), weakness, joint arthralgia (36% of BCS taking aromatase inhibitors), neuropathy (in up to 83% of patients who are treated with taxanes), weight gain (10%), cardiovascular effects, and osteoporosis (5 fold more likely than age matched controls to have vertebral fractures) (Schmitz et al 2012). Additionally, breast cancer survivors can suffer one or a combination of other short and/or longterm consequences including: 'psychological distress, sexual dysfunction, infertility, impaired organ function, cosmetic changes, and limitations in mobility, communication, and cognition...' (Hewitt et al 2005, p.2) and impaired quality of life (Bicego et al 2009, Duijts et al 2011). Over a 6 year follow-up period it was found that more than 60% of women experienced 1 or more side effects amenable to rehabilitative intervention. The proportion of women experiencing 3 or more side effects decreased throughout follow-up, whereas the proportion experiencing no side effects remained stable, around 40%, from 12 months to 6 years (Schmitz et al 2012). Stout el al (2012) suggests that there is evidence to support the introduction of a Prospective Surveillance Model for Rehabilitation for Women with Breast Cancer to prevent or mitigate many of these concerns. The goals of the model would include the promotion and support of ‘physical activity and exercise behaviors through the trajectory of disease treatment and survivorship (Stout 2012, p. 2191). DBR would not be appropriate as a physical activity through the trajectory of the disease treatment but could be appropriate during survivorship.

In recognition of these many significant consequences of cancer survivorship for the individual and health and social care services, the decision to set up the National Cancer Survivorship Initiative (NCSI) was announced in the Cancer Reform Strategy (Department of Health 2007) and was formally launched in September 2008. The aim of the NCSI was that by 2012, to have taken the necessary steps to ensure that survivors get the care and support they need to lead as healthy and active a life as possible, for as long as possible (Department of Health 2007, p. 2).

To realise its vision the NCSI (Department of Health 2010) has identified the five shifts which are needed in the approach to care and support offered to cancer survivors (Table 2.2).

Table 2.2 Five Shifts in Care and Support for People Living with and Beyond Cancer

(Department of Health 2010, p. 26)

1. A cultural shift in the care and support for people affected by cancer – to a greater focus on recovery, health and well-being after cancer treatment.
2. A shift toward holistic assessment, information provision and personalised care planning. This is a shift from a one size fits all approach to follow up to personalised care planning based on assessment of individual risks, needs and preferences.
3. A shift toward support for self-management. This is a shift from a clinically led approach to follow up care to supported self-management, based on individual needs and preferences. This approach empowers individuals to take on responsibility for their condition supported by the appropriate clinical assessment, support and treatment.
4. A shift from a single model of clinical follow up to tailored support that enables early recognition of the consequences of treatment and the signs and symptoms of further disease, as well as tailored support for those with advanced disease.
5. A shift from an emphasis on measuring clinical activity to a new emphasis on measuring experience and outcomes for cancer survivors through routine use of Patient Reported Outcome measures in aftercare services.

The first of these shifts ‘a greater focus on recovery, health and well-being after cancer treatment’ is particularly relevant to this study.

There is also recognition of the need to acknowledge that the cancer experience is unique to each individual (Bredin1999, Thomas-MacLean 2005), and that a range of strategies will be needed to meet survivors’ health needs (Binkley and Harris 2012), and that survivors must play an active role in determining those strategies (Department of Health 2013). It is anticipated that the cumulative effect of all the changes will be an improved quality of life and experience of care for cancer survivors as well as securing the sustainability and efficiency of healthcare services. To realise these changes it is estimated that approximately 30% -50% of the cancer survivor population will require some form of intervention to enable them to effectively manage the consequences of the disease, or treatment, on their health and well-being (NHS Improvement 2008). Supporting the role of physical activity as one such intervention, there is emerging evidence to show that lifestyle factors including physical activity and diet, can influence the rate of cancer progression, improve quality of life, reduce side effects during treatment, reduce the incidence of relapse, and improve overall survival (Department of Health 2010, Binkley and Harris 2012, Ballard-Barbash et al 2012).

Therefore DBR, as a form of physical activity, has a potentially legitimate role to play in addressing some of the unmet health needs of breast cancer survivors.

2.3 Physical Activity

The benefits of physical activity and the negative health consequences of inactivity have been the subject of extensive research and government publications over recent years (US Department of Health and Human Sciences 2008, Wharburton et al 2010, Department of Health 2012).

It is suggested that for adults, 30 minutes of at least moderate intensity physical activity on at least five days a week helps prevent and manage over 20 chronic conditions including; coronary heart disease, stroke, type 2 diabetes, cancer, obesity, mental health problems and musculoskeletal conditions (Department of Health 2011, p. 10).

'Physical activity comprises a range of behaviours involving movement, expenditure of calories and raised heart rate. Physical activity can take the form of sport, recreational and occupational activity, active travel (e.g. walking and cycling as means of transport), and heavy domestic activity (e.g. gardening and housework)' (Department of Health 2009, p. 20). Table

2.3 below describes recommended types and levels of physical activity necessary to achieve health benefits. It is suggested that because of the dose-response relationship between physical activity and health, individuals who wish to: further improve their personal fitness, reduce their risk for chronic diseases and disabilities, or prevent unhealthy weight gain will likely benefit by exceeding the minimum recommended amount (C3 Collaborating for Health 2011). The relationship between physical activity and health outcomes is outlined in Table 2.4.

Table 2.3 At least five a week: evidence on the impact of physical activity and its relationship to health

(Department of Health 2004, p. 2)

Level of Physical Activity	**Descriptor**	**Typical Activity Pattern**	**Health Benefits**
1	**Inactive**	Always drives to work, Predominantly sedentary job, Minimal household and garden activities, No active recreation.	
2	**Lightly Active**	Will do one or more of: • Some active commuting on foot or by bicycle • Some walking, lifting, and carrying as part of work • Some undemanding household and garden activities • Some active recreation at light intensity.	Some protection against chronic disease. Can be considered a ‘stepping stone’ to the recommended level (level 3).
3	**Recommended Level Moderately Active**	Will do one or more of: • Regular active commuting on foot or by bicycle • Regular work-related physical tasks – for example delivering post, household decorator. • Regular household and garden activities • Regular active recreation or social sport at moderate intensity	High level of protection against chronic disease. Minimal risk of injury or other adverse health effects.
4	**Very Active**	Will do most of: • Regular active commuting on foot or by bicycle • Very active job – for example, labourer, farm worker, landscape gardener • Regular household or garden activities • Regular active recreation or sport at vigorous intensity	Maximal protection against chronic disease. Slight increase in risk of injury and possibly some other adverse health effects.
5	**Highly Active**	Performs high volumes of vigorous or very vigorous fitness training, often in order to play vigorous sports.	Minimal protection against chronic disease. Increased risk of injury and possibly some other adverse health effects.

Table 2.4 The relationship between physical activity and health outcomes. 'Let's Get Moving. A physical Activity Care Pathway. Commissioning Guidance' (Department of Health 2012, p. 12)

Health outcome	nature of association with physical activity	effect size	Strength of evidence
all-cause mortality	Clear inverse relationship between physical activity and all-cause mortality.	There is an approximately 30% risk reduction across all studies, when comparing the most active with the least active.	Strong
Cardiorespiratory health	Clear inverse relationship between physical activity and cardiorespiratory risk.	There is a 20% to 35% lower risk of cardiovascular disease, coronary heart disease and stroke.	Strong
metabolic health	Clear inverse relationship between physical activity and risk of type 2 diabetes and metabolic syndrome.	There is a 30% to 40% lower risk of metabolic syndrome and type 2 diabetes ; in at least moderately active people compared with those who are sedentary.	Strong
energy balance	There is a favourable and consistent effect of aerobic physical activity on achieving weight maintenance.	Aerobic physical activity has a consistent effect on achieving weight maintenance (less than 3% change in weight). Physical activity alone has no effect on achieving 5% weight loss, except for exceptionally large volumes of physical activity, or when an isocalorific diet is maintained throughout the physical activity intervention. Following weight loss, aerobic physical activity has a reasonably consistent effect on weight maintenance.	Strong Strong Moderate
musculoskeletal health	**Bone:** There is an inverse association of physical activity with relative risk of hip fracture and vertebral fracture. Increases in exercise and training can increase spine and hip bone marrow density (and can also minimise reduction in spine and hip bone density).	**Bone:** Risk reduction of hip fracture is 36% to 68% at the highest level of physical activity. The magnitude of the effect of physical activity on bone mineral density is 1% to 2%.	Moderate (weak for vertebral fracture)

However, despite the multiple health gains associated with a physically active lifestyle, worldwide, 31.1% of adults are physically inactive (Hallal et al 2012) while only 40% of adult men and 28% of adult women meet the CMO's (Chief Medical Officer) recommendations (outlined above). Additionally, there are significant health inequalities in relation to the prevalence of physical inactivity according to income, gender, age, ethnicity and disability (Department of Health 2012). This has significance for the population of women for whom this study, and the knowledge gained from it, has, or may have relevance, in that 8 out of 10 breast cancers are diagnosed in women aged 50 and over (Cancer Research UK 2012) and the evidence suggests that physical activity levels are lower in women than in men, and that they decline significantly with age (Department of Health 2012).

For cancer survivors – and many of the research studies involved breast cancer survivors - research evidence supports the view that physical activity has the potential to enhance psychosocial and physical outcomes such as: cardiopulmonary function, overall quality of life, global health, strength, sleep, self-esteem, reduced weight gain, depression, anxiety and tiredness, bone health (Courneya et al 2003, Warburton et al 2006, Daley et al 2007, Courneya 2009, Fong et al 2012, Binkley and Harris et al 2012) and recurrence and survival (Holick et al 2008, Irwin et al 2008, Ibrahim and Al-Homaidh 2010, Mishra et al 2012, Ballard-Barbash et al 2012). Despite these benefits it is recognised that the majority of cancer survivors are not meeting physical activity recommendations in the UK (Macmillan Cancer Support 2011) and this is in keeping with other published findings from other countries (Irwin et al 2008). Two recent qualitative studies have revealed factors, some of which were both barriers and motivators to BCS participating in physical activity post treatment and included; physical (e.g. cancer-related physical symptoms), environmental/organisational (e.g. lack of facilities/equipment, desiring an instructor that was knowledgeable about cancer), psychosocial (e.g. low social support, low confidence) (Brunet et al 2013, Whitehead and Lavelle (2009). Miedema et al (2008) also reported that arm morbidity was related to difficulties with recreational activities and the issue of what BCS perceive as safe exercise has also been highlighted (Sander et al 2012, Whitehead and Lavelle, (2009).

The potential, but currently unmet role of health professionals in addressing this issue has been highlighted (Kirshbaum 2006, Stevinson and Fox 2005, Irwin et al 2009, Department of Health 2010, Department of Health 2013). A recent qualitative study identified four strategic reasons why health professionals are reluctant to discuss health behaviours - including physical activity - with patients, in relation to their cancer diagnosis: the need to know the patient, lack of clinic time, minimizing guilt, avoiding blame, lack of appropriate support to make lifestyle changes (Miles, Simon and Wardle, 2010).

For health professionals and breast cancer survivors, concerns about issues related to upper-body-morbidity, especially lymphoedema risk, may offer one explanation for inactivity, and a failure to return to pre diagnosis levels of physical activity (Bicego et al 2006, Ahmed et al 2006, Schmitz and Speck 2010,).

2.4 Upper-Body-Morbidity

Upper body morbidity is typically characterized by 'the presence of sensory or motor symptoms and impairments such as pain, weakness, tightness, poor range of motion, nerve palsies, altered movement patterns or muscle recruitment, numbness, or swelling in the shoulder, arm, and/or breast [*lymphoedema*] of the affected side and is associated with alterations in the use and function of the upper body and adverse physical, psychosocial, and social ramifications that profoundly influence all aspects of daily life and hence quality of life' (Hayes et al, 2012, p. 2237).

2.5 Lymphoedema

Fu and Rosedale (2009) suggest that the wider research literature on lymphoedema reports significant prevalence of on-going multiple symptoms, but that little is known about how survivors with lymphoedema perceive and respond to lymphoedema in their daily lives. A few qualitative studies have focused on the experience of upper body morbidity in BCS, including lymphoedema, (Williams et al 2004, Thomas-MacLean et al 2005, 2009, Fu and Rosedale 2009, Ridner et al 2012). One study identified four themes within and across the cases: living with perpetual discomfort, confronting the unexpected, losing pre-lymphoedema well-being, and feeling handicapped (Fu and Rosedale 2009).

The role of physical activity in both the initiation and treatment of breast cancer related lymphoedema (BCRL) - a distressing incurable condition which can develop immediately or many years following treatment for breast cancer - has been controversial (McKenzie 1998, McKenzie and Kalda 2003, Lane et al 2007). Lymphoedema has been defined 'as an abnormal accumulation of protein rich fluid [*in the extravascular interstitial spaces],* edema, and chronic inflammation and can elicit pain, tightness, and heaviness in the upper extremity (UE), as well as lead to recurrent skin infections' (Bicego et al 2006) and a negative effect on Health Related Quality of Life (Morgan et al 2005, Thomas-MacLean et al 2005).

The oedema which can affect the arm, shoulder, neck, or torso, results from physical disruption or compression of the axillary lymphatic channels from surgery, radiotherapy or both (Ahmed at al 2006). '…it remains a poorly understood complication of the disease' (Lane et al 2007, p. 917).

The incidence and prevalence rates of BCRL are difficult to quantify because a variety of criteria are used to define and measure it. In 11 prospectively designed studies the median reported incidence was 20% (range, 0-94%) with 45% to 60% of patients presenting by 6 months postsurgery and 70% to 80% by 12 months post-surgery (Hayes et al 2012).

Concerns about physical activity as a potential risk factor for lymphoedema are frequently expressed by survivors and health professionals (Mc Kenzie and Kalda 2003, Schmitz and Speck 2010). 'Occupational and leisure time physical activity are feared as possible risk factors; however, no form of physical activity has been associated with lymphoedema in prospective research' (Ahmed at al 2006, p. 2765). In a systematic review of the literature a non-significant difference was found in the occurrence of lymphoedema between exercise and control interventions in the individual studies and when data was pooled (McNeely et al 2006).

More recently at a roundtable meeting of the American Sports Medicine Society to discuss the issue of safety and exercise for cancer survivors it was concluded that 'exercise training is safe during and after cancer treatments and results in improvements in physical functioning, quality of life, and cancer-related fatigue in several cancer survivor groups (Schmitz et al 2010, p. 1409).

McKenzie (1998) was one of the first researchers to challenge the recommendation that women should avoid strenuous activity by training a group of 24 women to take part in the sport of dragon boat racing. His findings, that DBR did not cause lymphoedema, have been replicated in all subsequent studies, including those referred to above, and have concluded that the benefits of physical activity extended beyond improved physical function to include psychosocial wellbeing (Harris 2012).

2.6 Dragon Boat Racing

For BCS, 'Dragon boat racing is a person-centred community based leisure pursuit focused on life after medical treatment for breast cancer' (Parry 2007, p.53). It originated from the McKenzie (1998) study referred to previously, when 24 breast cancer survivors (age range 31 – 62 years), participated in a three month fitness and DBR programme.

Dragon boat racing is a team watersport, involving the 'strenuous, repetitive upper body activity of 18-20 paddlers propelling a 40-60 foot craft, along a race course of 250-1000metres. The bow of the boat will always feature a dragon's head which is sometimes dressed with colourful garlands. The drummer, sitting at the bow, sets and maintains the rhythm for the paddlers, while the helm or steer stands at the rear. A well trained and experienced team will paddle at a rate of 70 – 80 strokes per minute, which is a considerable accomplishment as boats can weigh up to 2,250 kilograms when fully loaded with participants (Unruh & Elvin, 2004). Paddling can take place in lakes, rivers or sheltered bays.

The original study (McKenzie 1998) aimed to test the hypothesis that vigorous repetitive upper-body exercise was safe for women who had been treated for breast cancer. Study findings revealed no new cases of lymphoedema and no change in those who already had the condition. At the end of the study the women refused to disband leading to the situation we know today where there are approximately 150 BCSDBR teams worldwide. Further more rigorous quantitative studies and systematic reviews followed (all involving breast cancer survivors who were either participating in dragon boat racing, or other forms of progressive resistance training) which have supported that initial hypothesis (Harris and Niesen-Vertommen 2000, Lane at al 2005, Cheema et al 2008, McNeely et al 2009, Kwan et al 2011, Harris 2012). For dragon boat racing specifically, it has been suggested that the upper body exercise regime taught as part of the dragon boat racing programme 'can improve range of motion and reverse muscle atrophy, activate skeletal muscle (which may pump lymph), stimulate the immune system and reset the sympathetic tone of the lymphatic vessels' (McKenzie 1998, p. 159, Lane et al 2005).

While the initial hypothesis generated interest in further quantitative studies focused on safety, the unexpected finding that the experience had been overwhelming for the women and that 'the physical changes barely [kept] pace with the changes in psyche' (Mc Kenzie 1998, p.377) led to a number of qualitative studies aiming to understand what the sport meant to the paddlers themselves (Mitchell and Nielsen 2002, Unruh and Elvin 2004, Sabiston, McDonough and Crocker 2007, Mitchell et al 2007, Parry 2008, McDonough, Sabiston and Ullrich-French 2011). Studies of dragon boat teams have reported that ' dragon boat racing can decrease stress and shift the meaning of having breast cancer to a more positive view of the experience' (Unruh and Elvin 2004, p. 138), and that '[DBR] contributes to breast cancer survivors' social, emotional, physical, spiritual and mental health' (Parry 2008, p. 222) and gives a sense of cohesion (a potential correlate of social support) 'where survivors felt they belonged, had friends, had opportunities to participate, and had a common bond with other survivors' (Culos-Reed at al 2005, p. 602), an 'awakening of self, common bond, regaining control, being uplifted, and transcending the fear of death' (Mitchell et al 2007, p. 122), positive psychological growth (Sabiston et al 2007) and post-traumatic growth (Morris et al 2010).

A narrative review of the quantitative and qualitative literature relating to DBR concluded that in addition to improved fitness and challenging the long held myth about the dangers of vigorous sport, the studies revealed a number of themes, several of which were remarkably similar, including: 'feelings of camaraderie, a sense of renewed fitness and health, opportunities to promote awareness of a full and enjoyable life after breast cancer, and enhanced self-confidence and control of one's life' (Harris 2012, p. 3).

While the literature suggests that BCS report the experience of DBR as overwhelmingly positive, some have also reported negative consequences, such as; coping with disease recurrence, or death, in fellow team members, (Unruh and Elvin 2004, Parry 2007, McCausland 2010), relationship difficulties between team members (Mitchell and Nielsen 2002), tensions regarding the level of competition in which the team should engage (Mitchell and Nielsen 2002, Unruh and Elvin 2004, Parry 2007).

2.7 Breast Cancer/Illness Narratives

There is a growing body of mainly autobiographical, illness stories literature, based on cancer survivorship experiences, mainly breast cancer (Kaiser 2008). Two of the early contributors Davis Springer (1982), and Mullan (1983) identified a need to describe the cancer survivorship experience from a personal perspective. Davis Springer was a breast cancer survivor and based on her professional (health writer)and personal experience suggested that though people hunger for authoritative health information, they respond most strongly to stories about individual beings (Davis Spingarn 1999). In her book she suggests that she wove her own experiences of cancer and that of others with the psychosocial and medical issues confronting survivors and her book became one of the early self-help guides empowering survivors in ways such as, communicating with health professionals in a more assertive, constructive way, or dealing with the psychological impact of survivorship. Similarly Mullan (1985) a doctor, described his very personal experience of being diagnosed with and treated for testicular cancer and wrote what could be described as a seminal work (Mullan 1985) in which he described the four seasons of survivorship[2]. He suggested that the challenge in overcoming cancer was not only to find therapies that would prevent or arrest the disease quickly, but also to map the middle ground of survivorship and minimize its medical and social hazards. His story was to play a significant role in helping to establish survivorship as a unique phase in the cancer experience. He went on to become the Founding President of the National Coalition for Cancer Survivorship in the United States of America. He believed that the first-person narrative was an important art form in health care and a potential player in the making of policy. In sharing his own cancer survivorship experience he reported that he wanted to say to the world that he wasn't dead and that he had perspectives on cancer, and cancer care, learned from his own painful journey that might be of use to other people. His belief in the power of storytelling, lead him to become editor of Narrative Matters, a section of a health policy journal. It was to bring a perspective to the quantitative material traditionally published in the journal that would promote understanding and help focus policy deliberations (Mullan et al 2006). The need to promote this understanding and to acknowledge the complex and devastating impact, including the social and medical hazards of cancer survivorship was also powerfully reported by Frank (1991) in his analytic memoir of his cancer survivorship experience. The book, he reports, became the basis of continuing personal encounters, letters, phone calls, conferences, lectures, that kept him in contact with individual people and support groups, as well as nursing, chaplain, administrative and medical groups (Frank 1995). His experiences in the world of illness were complemented by reading many published and unpublished illness stories. He also held the position of editor of the "Case Book" series in the professional journal 'Second Opinion, Faith, Ethics'. His

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[2] Four seasons of survivorship: acute survivorship, which involves diagnosis and initial treatment; extended survivorship, a time of watchful waiting with celebration, uncertainty, and transition; and permanent survivorship, the season of gradual confidence that there would be a future free of cancer (Mullan 1985)

commitment in the series was to publish first person accounts of illness experience. He found that the professional literature failed to describe the experience he had gone through. In his book The Wounded Storyteller (Frank 1995) – which he describes as a survival kit put together out of his need to make sense of his own survival and to watch others seeking to make sense of theirs, in a world that did not immediately make sense. He described cancer survivors as being members of the remission society who, like him, were effectively well but could never be considered cured. This is similar to Susan Sontag's metaphor of illness as travel, in which she suggests that everyone who is born holds dual citizenship, the kingdom of the well, and the kingdom of the sick (Sontag 1978). Frank (1995) suggests that members of the remission society do not fit in either kingdom and are left in a 'demilitarized zone in between them, or else it is a secret society within the realm of the healthy'[3] (Frank 1995, p.9). Breast cancer survivors who have contributed very powerfully to this view of movement to another place include Raz (1999, p. x) who suggests that the BCS who contributed to her book had 'traveled beyond the margins of the known world' and another BCS described her experience 'on the far side of breast cancer' as the loss of control, ruptures in the self, disruption in the life story, and questions of meaning in the face of personal annihilation (Conway 2007)

The narrative survivorship literature also included stories of survivors; many of them breast cancer survivors, who described experiencing transformation, and positive growth after cancer (Armstrong 2001, Jose 2004, Girard 2008). However, Armstrong (2001), despite saying that cancer was the best thing that happened to him, also stressed that some of his story was not easy to tell, or comfortable to read, and that he was no hero. This literature generally tended to 'serve as a matter-of-fact, upbeat gift for the new or seasoned survivor' (Davis Spingarn 1999, p. ix) or as 'uplifting stories' (Delinsky 2001, p. ix). It was interesting that one author wanted her book 'to be written by women of every walk of life...to give women a voice, … I wanted to hear what they had to say myself – but only if it was positive (Delinsky 2001, p. ix). A study by Jensen et al (2000) on

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[3] Restitution Narrative: 'The plot of the restitution has the basic storyline: Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again' (Frank 1995, p. 77).

the lived experiences among women with breast cancer and the meaning of ‘Not Giving In’ suggested that the participants actively adopted strategies to cope with their breast cancer experiences which were somewhere between the narratives described above and those that follow.

One breast cancer survivor challenged the authenticity of what she described as these ‘triumph narratives’ in which she suggests the authors shrink from the complexity of their experience and focus on one slice of it – the final resolution which they portray as a triumph that results from determination and a positive attitude (Conway 2007). She suggests, and her views are in keeping with those of Sontag (1978), Mullan (1984, 1985), Frank (1991,1995) that by adhering to the culturally preferred narrative of triumph, authors typically downplay, or deny, other dimensions of their experiences, particularly, the more painful and unmanageable ones. She suggests that she uses the term ‘triumph narrative’ in the same way that Frank (1995) uses the term restitution narrative, described by him as the culturally preferred narrative. She proposes that the alternative to triumph narratives - ones that offer subjective experience of what it is like to suffer serious damage to one's body - can be articulated, reflected upon, and shared, providing a much needed conversation, that is often not possible within the family, and the wider society, about the ways in which the desolation of serious illness and disability cannot be managed as the self-help literature would have it. An example of this serious damage to the body was powerfully described by Gough (2005, p. 262) when she described how her practice as an environmental educator had been changed through ‘being an embodied subject in my own mine site story, stripped of my ore body’.

Similarly, Kaiser (2008) in her study of the lived experience of BCS found that the narrative of survivorship constructs a positive, cure-oriented definition of survivorship, and that this breast cancer culture has left many women searching for representations which acknowledge their fears, and the continued presence of cancer in their lives. Like Sontag (1978), Mullan (1983, 1985, 2006), Frank (1991, 1995), and Conway (2007), mentioned previously, she believes this dominant representation of disease poses challenges for individuals attempting to make sense of illness. Her findings suggested that BCS desire truthful, or what Frank (1995) refers to as “good” stories, rather than positive, cheerful stories. For breast cancer, a good story would acknowledge the long-term role of cancer in breast cancer survivors’ lives and their fears of recurrence. Such a framework would reduce the separation of the private and public experiences of cancer. Kaiser (2008) suggests that at an individual level BCS have the opportunity to join in the dominant culture of consumerism, pink ribbons and symbols but that fewer opportunities exist to act in alternative ways. Could DBR be one such alternative way?

2.7.1 BCS and DBR Experiences

The BCSDBR literature reviewed for this study (Appendix A) focused on narrative and largely qualitative studies where the emphasis was on the impact of the experience of DBR on BCS. Twelve studies were identified at first, two further studies were added. The additional studies were not qualitative but yielded information about experiences and were therefore included – one was a quantitative pilot study (McKenzie 1998) which described the initiation of DBR for BCS as we know it today and prompted subsequent quantitative and qualitative studies aimed at testing DBR’s physical impact and the unexpected impact it was found to have on the psychological well-being of the participants; the other was an article (Bodner 2010) which, whilst powerfully describing the author’s own experience of DBR also gave the perspective of the DBR team she founded. There was broad consistency across the literature that DBR was safe and had the potential to have a positive impact on the lives of the BCS who choose to participate.

One drawback in the DBR literature is that the predominant method of participant recruitment was through self-selection which has the potential to produce one-sidedness in results. The review revealed three noteworthy gaps in the literature: the first was the absence of studies of British BCS participating in the sport of DBR, secondly, where all team members were invited to participate in the research at the start of the project, and then randomly selected for inclusion by an intermediary, thereby working towards minimizing selection bias. The third related to the way the stories were analysed with none retaining the temporality of the story, rather researchers more commonly used thematic coding which dissociates time and content. There was therefore a need for an in-depth qualitative study of British participants that used narrative methods to understand the experience of DBR from each participant's unique perspective.

A number of researchers working in the field have identified areas for future research some of which are relevant to this study (Box 2.1).

Box 2.1 Suggested areas for future research

Author	Suggested areas for future research
Parry 2008, p.232.	1. Research is needed on teams within countries (located in different counties, states, provinces and between countries (there are approximately 140 teams worldwide). The purpose of such cross-cultural research would be to 'provide a broader understanding of 'the dimensions of breast cancer survivors' health that might be positively affected through dragon boat racing' 2. More research was needed 'not only on the broad health benefits of dragon boat racing for breast cancer survivors, but from a woman's private and personal perspective.' *The study described in this report seeks to do this.*
Mitchell and Nielsen 2002)	Research was needed to better understand the impact of the sport on other components of health - other than physical - including social and spiritual well-being, the communal context, as well as the physical and emotional health.
Unruh and Elvin 2004, p. 148	• Research was needed to explore 'occupation' (e.g. dragon boat racing) as a coping strategy and as a vehicle for social support.
Mitchell et al 2007, p.124	• Research was needed to understand and respond to '… the individual challenges of post-treatment survivorship. '… and the potential for dragon boating to improve breast cancer survivors' post –treatment quality of life'

McCausland 2010, p.53.	• Research was needed to conduct methodologically rigorous studies to develop additional interventions that address survivors' needs'

Chapter 3: Study Design/Methods

3.1 Introduction

The purpose of this exploratory study was to gain an understanding through storytelling of the impact of the experience of dragon boat racing on members of one UK BCSDBR team. Women, who were at various stages post treatment, and were active, registered members of the team, were invited to tell the story of their experience - in writing or in one to one face-to-face-interviews. The interview process was guided by the Biographic-Narrative- Interpretive- Method (BNIM), and specifically the Single Question (aimed at Inducing Narrative) (SQUIN) (Wengraf 2001, p.113). This choice of design was influenced by a number of factors including:

1. A need to capture the uniqueness of the experience of DBR (a new sport for BCS in the UK), from their own individual and unique perspectives, for a diverse group of participants, where a diagnosis of breast cancer was the only tentative thread linking each of them.
2. The need to minimize the potential risk of one-sidedness in the results due to the researcher's role as an insider (previous health professional, her early involvement in setting up the team and currently as a paddler with the team).
3. The knowledge that cancer survivors' needs are currently poorly understood, as confirmed by a recent consultation to identify future research priorities, where understanding cancer survivors' needs, and the need to test interventions focused on the consequences of cancer, and cancer treatments (in particular psychological distress), were the top priorities identified (Armes et al 2010).

In addition to contributing to this new body of knowledge, the study is underpinned by the principles of practitioner research to capture messages relevant to the charity's responsibilities for the practice of DBR, and the running of the charity. The knowledge gained will contribute to the body of knowledge relevant to the sustainability and development of the team for present and future BCS, and possibly other cancer survivors. It will also inform health and social care providers working in the field of cancer survivorship on the potential role of DBR as an activity in meeting cancer survivorship needs.

3.2 Aim

To explore and describe the experiences of BCS who volunteer to participate in the sport of DBR in one UK DBR team in an attempt to answer, broadly, but not exclusively, the following questions:

1. How do BCS taking part in DBR describe the impact that this activity has on their lives?
2. How can the registered charity hosting this Dragon Boat Team improve the quality and sustainability of the dragon boating experience for the team?

3.2.1 Ethics

Ethical approval for the study was sought and gained from the University Faculty's Ethics Committee (Appendix C). The two main ethical considerations for this study relate firstly, to the researcher as insider, and secondly, to any possible distress the participants might have experienced during the storytelling process - even though the intended focus of the study relates to the sport of DBR. The steps taken to reduce any potential negative consequences of the researcher being an insider will be outlined later in this chapter while those relating to potential distress, included; using the single question interview method enabling the storyteller to choose what issues they discussed, allowing them to choose where they wanted the interview to take place, and also arrangements were made with the breast care nurses at the relevant breast cancer treatment centres to offer immediate support to any of the participants who experienced distress as a result of taking part in the study.

The remainder of this chapter will be made up of the following sections: Participants, Recruitment, Interview Process, Storytelling, Practitioner Research, Frank's Narrative Types (Frank 1995).

3.2.2 Participants

The participants were 13 randomly selected breast cancer survivors who had completed primary treatment for breast cancer (some were on on-going hormonal treatment regimens), and were actively involved in paddling with the ‘study’ team, at the time of recruitment to the study. The age range was 39 to 72. Time since completion of primary breast cancer treatment ranged from three months to nine years. With the exception of one member, who had to withdraw from the study, no participant had experienced metastatic disease.

3.3 Recruitment

Preparation for gaining access to this study began when the outline research proposal was included as an agenda item at a team business meeting in February 2010, to which all members were invited. Members were invited to ask questions and give or withhold their support for the concept of this study. All present (n= 23) were fully supportive of the research. The full team membership was approximately 28 at that time.

To enable members to make an informed, and autonomous decision, as to whether they wished to participate in the study or not, they received written information on the study (Appendix D) by post, with an introductory letter, together with two envelopes, one addressed to the deputy chairperson, and the other free of all markings except for the recipient’s name and telephone number, (which was written on the inside of the sealed envelope). Those members who chose not to participate did nothing, while those who did, returned the sealed unmarked envelope, in the preaddressed envelope, to the deputy chairperson at the charity’s postal address.

Twenty four members were eligible to participate, twenty accepted the invitation. Seventy per cent of all eligible members (n=14) were randomly selected by the deputy chairperson to participate in the study. One member had to withdraw because of a sudden deterioration in health. 13 participants told their stories over the time period May/June 2012.

All remaining envelopes were shredded in their unopened state by the deputy chairperson. Therefore, neither the researcher, nor anyone else, knew which team members did not agree to participate.

There were no exclusion criteria.

3.4 Storytelling

It is suggested that 'Stories … gain a particular relevance at times of life transition or change, seemingly as a way of 'sense-making' or attempting to reshape and manage the shifting ground of our lives' (Bingley et al 2008, p. 654).

In this study the participants could also be perceived to be at a transition point between life before and after breast cancer. In addition to capturing the unique experience, storytelling had the potential to empower the storyteller, particularly as it was combined with the SQUIN (Wengraf 2001), to tell only the story that was important to them, as opposed to telling a story shaped by the interviewer's questions. This empowerment was also important to counter the potential power imbalance and potential for one sidedness in the results where the researcher was an insider due to her membership of the team as a paddler.

The terms stories and narrative are ambiguous and often used interchangeably in the literature (Riessman 2008). Frank (2010, p. 200) suggests that 'Narratives make no mention of individual person's; stories depend on characters. *Stories* are about particular people living lives animated by some principle of causality: class conflict…' In this context it is BCS experience of DBR. Frank (2010) does, however, acknowledge that the words narrative and story overlap so frequently that sustaining this distinction in consistent usage proves impossible. For the purposes of this study, stories can be defined as 'research participants' personal accounts of experiences' (East et al 2010, p. 19). It is suggested that narrative [s*torytelling*] is a methodology which begins with no preconceived questions in mind, and where the only focus is on the respondent's story (Carson and Fairbairn 2002). The past two decades have seen a growing interest, especially amongst nurse researchers, in exploring alternatives to quantitative research methods where the legitimate end product of the inquiry is ‘meaning’ rather than ‘truth’ (Kleinmann 1988, Bailey and Tilley, 2002, Bleakley 2005). Qualitative methods, (which includes storytelling), are primarily concerned with ‘in depth study of human phenomena in order to understand their nature and the meanings they have for individuals involved’ (Hunt 1994, p. 117). In narrative research the researcher ‘explores the lives of individuals and the story of their lives’ (Fox et al 2007, p. 16). It is suggested … ‘that storytelling should be centrally placed in any consideration of research that has as its focus human lives and human wellbeing’ (Carson & Fairbairn 2002, p. 16). Frank (2000, p.361) suggests that:

> ‘… storytellers tell stories to remind those who share their form of life what it is they share; peoples’ sense of being together is enriched within the storytelling relation. Storytellers also offer those who do not share their form of life a glimpse of what it means to live informed by such values, meanings, relationships, and commitments.’

All of these attributes of storytelling were relevant and important in enabling this study to capture the unique experience of each storyteller and achieving the study’s aims. The importance of capturing the uniqueness of the survivorship experience for each cancer survivor is emphasized in the Cancer Reform Strategy and Cancer Survivorship Initiative documents (DOH 2007, 2008, 2010) and should therefore extend to their experience of DBR if it is to add to the body of professional knowledge aimed at ‘improving practice’ (Reed & Procter 1995) for cancer survivors. A founding principle of the DBR team was to be its accessibility to all BCS - irrespective of their social or financial backgrounds. It was the team’s diverse membership, in terms of age, social background, previous participation or non-participation in: routine physical activity, water sports, or sports in general that informed the decision to use storytelling as a methodology.

Storytelling is common to all cultures, and was therefore perceived to be a less threatening methodology, facilitating the involvement of participants who may be uncomfortable, or refuse to participate, with other research methods. This methodology was also chosen to reveal the diversity/conformity, in the individual, unique experiences of DBR for the participants. 'Through stories, participants in research come to understand their experience, legitimize their behavior and share their emotional experience with others in holistic form which is not 'fractured' or disrupted by researchers' (Holloway and Freshwater 2007, p. 703).

This is new research in the UK, therefore, an inductive approach was the most appropriate to 'bring knowledge into view' (Clifford 1997, p. 10). Narrative (stories) is becoming increasingly commonly used across healthcare: research, education, audit, evaluation, and intervention (Frid et al 2000, Greenhalgh 2005, Stickley et al 2007, Crogan et al 2008, Bronwynne et al 2008, Evans et al 2008, Kirkpatrick and Byrne 2009, East et al 2010, Lai 2010). However, narrative theorists argue that 'the study of narrative/storytelling is by default less about accessing factual account and more about understanding the meanings that individuals' create and live by' (Bingley et al 2008, p. 657). The challenge in doing this research will be to create 'an acceptable and accessible research product' (Koch 1998, p.1182) not just for those who will utilize it but for those who have participated in it. Koch defines the research product as 'interpreted work communicated through writing' … where, through careful signposting of the research process, the reader can determine whether it is a 'legitimate research endeavour' (Koch 1998, p. 1182). At the design stage of this study the proposal was evaluated (favourably) against the guiding principles for evaluating what counts as 'good narrative research' (Greenhalgh & Wengraf 2008,) (Appendix E).

3.5 Goodness Criteria for a Study of this Type

The relevance of the notions of generalizability, reliability, validity and objectivity (commonly used criteria for the judgement of quality in quantitative research) has long been contested and debated by qualitative researchers with various groups and traditions within qualitative research adopting different positions towards them (Denzin and Lincoln 2011, Sparkes and Smith 2014,).

Qualitative methods facilitate the study of issues in depth and detail while quantitative methods require the use of standardized measures ‘so that the varying perspectives and experiences of people can fit into a limited number of ‘predetermined response categories to which numbers are assigned (Quinn Patton 2002, p. 14).

Acknowledging that qualitative and quantitative research is based on a different ontology and epistemology Guba and Lincoln (1989) proposed the notions of *credibility, transferability, dependability*, and *confirmability* for judging goodness in qualitative work and these ideas led others to specify key components of goodness that may be applied to qualitative research in general, and narrative research in particular.

Included amongst the debates and positions being put forward for qualitative research are: ‘parallel’, ‘diversification’ and ‘letting go’ perspectives (Sparkes 1998, 2002). For this study the researcher has chosen to take the position of the ‘letting go’ perspective where the notion of validity is abandoned and attention is focused instead on criteria that are appropriate for that particular work to be assessed (Barone and Eisner 2012).

‘What matters is the capacity for enabling members of an audience to re-experience the world from a previously unavailable vantage point, and the use of criteria is a way for an assessor to be reminded of what to pay attention to in judging that capacity’ (Barone and Eisner 2012, p. 147)

In keeping with the ‘letting go’ perspective, a number of scholars have suggested various lists of criteria for judging qualitative work in general, and certain traditions in particular. These include Tracy (2010), Holman Jones (2005) and Barone and Eisner (2012). Sparkes and Smith (2014, p. 202) suggest ‘that lists can be mixed and matched as required as long as the choices made are discussed in detail as part of a coherent rationale for the study’

Selecting the criteria for judging the quality of this study was influenced by the study aims - which in turn guided the collection of the stories - and the diversity of potential audiences who may wish to access its findings.

Potential audiences include the study's participants, BCS from other DBR teams, BCS who may be interested in participating in the sport of DBR, health, social care and leisure service providers, and future researchers. In addition to the narrative assessment criteria used (Greenhalgh and Wengraf 2008) at the initiation of this study to critique the proposal the following goodness criteria, adapted from Tracy (2010, p. 840), were identified as being useful for the assessment of this particular study: worthy topic (the topic of interest is relevant, timely, significant, interesting); sincerity (the study is characterized by self-reflexivity about subjective values, biases, and inclinations of the researcher and transparency about the methods and challenges) and, resonance (the research influences, affects, or moves particular readers or a variety of audiences through aesthetic evocative representations, naturalistic generalizations and transferable findings). These criteria are revisited in Chapter 6 in my reflective review of the study.

As the practice of DBR for BCS is new in the UK, the research study also aimed to capture messages to inform the charity responsible for the practice of DBR, and the running of the charity. This will contribute to the body of knowledge relevant to the sustainability and development of the team for these, and other survivors in the future. Other cancer charities, e.g. prostate cancer charities, are already expressing an interest in setting up their own DBR teams in other parts of the country.

3.6 Practitioner Research

This study is underpinned by the principles of practitioner research (Box 3.1), because it is a form of insider research[4], where one of its aims, is to improve the practice of DBR for the team, and the registered charity responsible for hosting it. In this study the participants are aware that the researcher has a background as a health professional but from the outset of the teams' formation she has purposefully separated the two aspects of

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[4] Insider – In traditional social science research the researcher was 'a visitor to the world of the practitioner' but with practitioner research the researcher undertakes research 'in their workplace, into their own practice and the practice of their colleagues (Reed and Procter 1995, p.10). In this context the researcher is an 'honorary' team member and researcher.

her life, her former professional life and DBR. The latter was seen by both parties as a move away from the health care environment so therefore to have an individual functioning as a health professional in their midst would have been undesirable and unwelcome from the perspective of both parties. The researcher was invited to be the chair of the charity when it was first set up on the understanding that this role would move to a BCS as soon as the team was established and a team member would accept the role. This was achieved before the researcher began her research.

Box 3.1 Key principles of practitioner research that make it relevant to this study (Reed and Procter, 1995).

- Practitioner researchers are part of the world and culture they are researching, and have a history and a future in that culture.
- The notion of practice improvement is critical to an understanding of practitioner research and from a methodological perspective, possibly the most important distinguishing characteristic.
- Improvement of practice and the expansion of the researcher's knowledge - base, is an intrinsic motivator, determiner, and aim, of most forms of practitioner research.
- It draws heavily on the role of 'insider' knowledge and experience in contributing to practice, and in developing the knowledge base of practice.
- One of the strengths of practitioner research lies in the integration of research with practice. It bridges the gap between theory and practice.

In practice 'the challenge … is to find ways of generating, disseminating and using knowledge that informs and is informed by practice itself' (McCormack 2003, p. 86). In this instance the practice is DBR – understanding this better will enhance the further practice of the team of

Dragon Boat Racers and the workings of the charity that supports them. I am a part of that experience, both because of my relationship with the team and with the charity – therefore I am a part of the “doing” of the DBR and part of the “enabling” of it.

As a methodology it had the potential to produce rich data to reach a new or better understanding of what it is like to participate in DBR for BCS in one UK DBR team and to contribute to the body of professional knowledge relevant to breast cancer survivors.

There are two central elements in relation to the development of practitioner research. The first is the relationship between the researcher and the research subjects, as detailed above, and the second is the relationship between the researcher and the data (Reed and Procter, 1995). The sensitivities and safeguards pertaining to both of these elements, relevant to this study are outlined in Appendix F. The insider/outsider issue (Box 3.2) is particularly relevant to this study because the researcher is an insider as she paddles with the team.

Box 3.2 Main Differences between Methodological Positions

(Reed and Procter 1998, p. 30).

‘Outsider’	**‘Insider’**
Aims ‘The primary aim of social science research is to explore a social phenomenon (nursing) in order to contribute to the body of social science knowledge.	Aims ‘The primary aim of nursing research is usually to solve a critical problem, thereby contributing to the body of nursing knowledge.
Access The choice of a research setting is wide, but their contact is superficial.	Access Their choice of a research setting is limited but their contact is deep.
Negotiation of Role	Negotiation of Role

‘Outsider’	**‘Insider’**
The social science researcher is a guest in the world of nursing. They have a single role which is temporary.	The nurse researcher is a member of the world being researched. They may have multiple roles, some of which are permanent.
Design and Planning Informed by knowledge of research methods	Design and Planning Informed by insider knowledge and frequently governed by therapeutic imperatives.
Analysis Does not share taken-for-granted assumptions and is therefore able to adopt a naïve stance towards the data.	Analysis Shares taken-for-granted assumptions the significance of which may not be recognized.
Dissemination and Commitment To academic community to further academic knowledge…’	Dissemination and Commitment To colleagues, professional and academic communities. Concerned about the way in which the research is used both locally and professionally’.

Although the researcher is not here as a nurse she found that methodologically practitioner research was useful to her thinking and planning of the project.

Having the researcher as an insider has the potential to impact both positively and negatively on the credibility, transferability, and trustworthiness, of this research study. This was given particular consideration at all stages of the study design.

3.7 Generalisation

Qualitative researchers often adopt a view of generalizability whereby the reader is left to decide if the evidence collected is generalizable to other settings or not (Elliott 2005). Referring specifically to generalizability and narrative research Elliott (2005, p. 28) suggests that the ‘generalizability of … [the] evidence will … depend on a demonstration of how widely … [the] intersubjective meanings are shared’.

The present study aspires to naturalistic generalisation, ‘which readers of the report themselves make’ (Stake 1995, p. 20). Stake and Trumbull (1982) distinguished between explicated generalizations[5], and naturalistic generalizations, formed from individual’s experiences. The latter ‘are conclusions arrived at through personal engagement in life’s affairs or by vicarious experience so well constructed that the person feels as if it happened to themselves’ (Stake and Turnbull 1982, p. 85). They suggest that naturalistic generalization is most important because of its embeddedness in the experience of the reader. In this study the three most significant sets of readers with be the study participants, other BCS who are, or may be, interested in participating in the sport of DBR, and professionals, involved in the care of BCS who may wish to share any new knowledge originating from the study with BCS in their care. All share an understanding of BCS supporting the concept of ‘embeddedness’, two through ‘vicarious experience’ and the other through ‘personal engagement’ (Stake and Turnbull 1982).

Stake (1995, p. 39) suggests that ‘Qualitative research tries to establish an empathetic[6] understanding for the reader, through description, sometimes *thick description*[7], conveying to the reader what experience itself would convey.’ (Stake 1995, p. 39)

It is anticipated that the combination of the SQUIN interview method (Wengraf 2001), Franks (1995) three narrative types to interpret and analyse the data and rich quotes from the stories will facilitate the ‘embeddedness’ and ‘empathetic understanding’ described by Stake (1995). The detail provided in the subsequent chapters are designed to

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[5] Explicated generalizations are generalizations received from others such as authors, teachers, authorities (Stake 1995, p. 85).

[6] ‘…the knowledge of the plight of another by experiencing it yourself’ (Stake 1995, p. 39)

[7] ‘Thick description is not complexities objectively described; it is the particular perceptions of the actors’ (Stake 1995, p. 42)

fulfil the following suggestions made by Stake (1995, p. 63). The researcher should:

'… develop *vicarious experiences* for the reader, to give them a sense of "being there", the physical situation should be well described. The physical space is fundamental to meanings for most researchers and most readers' and this will be adhered to. Researchers need to provide an opportunity for vicarious experience. Our accounts need to be personal, describing the things of our sensory experiences, not failing to attend to matters that personal curiosity dictates. A narrative account, a story, a chronological presentation, personalistic description, emphasis on time and place provide rich ingredients for vicarious experience. Emphasizing time, place, and person are the first three major steps.' (Stake, 1995: 86)

3.8 Interview Process

The interview process was guided by the Biographic-Narrative- Interpretive-Method (BNIM), and specifically the Single Question (aimed at Inducing Narrative) (SQUIN) (Wengraf 2001, p.113), where the interviewee's primary response is determined by a single question (asking for a narrative). In this study the question asked was:

'Please tell me the story of your experience of participating in the sport of Dragon Boat Racing, starting with your decision to join the team, and continuing to the present day'.

In accordance with the guidance (Wengraf 2001) after posing the initial question, interventions by the interviewer were effectively limited to facilitative noises and non-verbal support. The key features of SQUIN are:

- Interviewer self-restraint
- Non directional prompts but never probes
- Active Listening
- Note-taking

The aim of the interview was to enable the participant to 'provide a narration responding to the carefully designed SQUIN, the role of the interviewer is not to ask questions about the story, but just to enable the story to be told in the way the informant feels comfortable telling it' (Wengraf 2001, p.122).

The single question was used with the aim of, firstly, hearing the story from the perspective of each participant, secondly, that they were able to tell the story that was most relevant to them, and thirdly, that the researcher had the least possible influence on the participant. BNIM interviews have 3 subsessions:

Subsession one – the main interview

Subsession two – follows on immediately from subsession one and aimed to expand further on any particular incident narratives (PINs) generated in subsession one. Wengraf (2004) acknowledges that after some (long and full) answers to subsession 1's SQUIN, subsession 2 may not be needed and this was the case with some of the stories told in this study.

At the end of subsession two I wrote self-debriefing fieldnotes. The latter captured the interview as experienced by the researcher.

Subsession three – optional follow – up interview (much BNIM research does not use the third-subsession option) in which further narrative questions can be posed but also in which non-narrative questions and activities can be designed.

For this study it was not appropriate to do the optional follow-up interview (subsession three) - in subsession three 'the questioning is primarily 'determined by the system of relevance of the researcher' (Wengraf and Chamberlayne 2006, p.16).

In subsession one the researcher opted not to write notes during the interview for two reasons:

1. It felt to the researcher that writing, even a cue word, risked interrupting the flow of the story for the storyteller.
2. The issues raised in the stories were covered in sufficient detail that further questioning was not required, with one or two exceptions, and then the questions were easily memorised and raised in Subsession 2.

As soon as possible after the interview (usually within 24 hours) the researcher listened to the recording of each story to confirm that it was complete. Post interview field notes were a useful aid when undertaking this exercise.

The researcher also opted not to use the BNIM method of story interpretation and analysis. Wengraf and Chamberlayne suggest that this is acceptable - ‘It is perfectly possible for you to generate material by way of the BNIM interview, but then decide to use a non-BNIM way of interpreting some or all of the material’ (Wengraf and Chamberlayne 2006, p.5). BNIM requires that the transcript is processed into segments and requires panels made up of three or four people to analyse the analysis. This would not be appropriate given the potentially sensitive and very personal nature of the content of some of the stories. Wengraf (2004) reported that an increasing proportion of the studies using BNIM deal with “applied” issues in relation to policy and practice. After listening to the stories it became clear that Frank’s Narrative Types (Frank 1995) was a more appropriate method of analysis for these stories.

3.9 Transcription

Elliott (2005) suggests that the decision process on how transcription should be carried out is intimately connected with the type of analysis that is intended and that in most cases, the aim when transcribing is to find a method of preserving some of the additional meaning that was conveyed by the speaker’s use of intonation, pause, rhythm, hesitation, and body language, with the researcher’s particular analytic interests likely to determine which speech practices are preserved and attended to in the transcription process. In this study all of the above were important in conveying meaning and were therefore recorded (Appendix G).

1. All stories were listened to, to check that all recordings were complete, and to gain an initial understanding of the experiences of DBR as described by the BCS.
2. Each story was then transcribed verbatim in longhand.

3. The transcribed stories were then typed onto the computer using Microsoft word.
4. While listening to the tape recording, the transcribed stories were checked for accuracy, and further details, such as pauses, intonations, were added where appropriate. Mishler (1986) stresses the importance of returning repeatedly to the original recordings to assess the adequacy of the interpretation.
5. The recorded versions of the stories were transferred to a password protected computer and the version on the recording machine deleted.
6. Copies of each story were printed off, bound and used as working documents.

3.10 Analysis

The analysis began after all the stories had been told. It was broken down into two stages. Stage one (summarized in Appendix H) focused on the content of the stories (Shaw 1966, Bertaux and Bertaux-Wiame1981) (Appendix I), the metaphors and the language used. Stage two (see p. 53) focused on identifying the messages for the charity by again reading the content of the stories and the language directed towards the running of team and the charity.

In stage one, each story and corresponding reflective notes, written after each interview, were read intensely in their entirety, to gain a sense of the storyteller's experience as a whole. Although the researcher had read and was aware of Frank's (1991, 1995) work it was only at this stage that she noticed similarities that resonated with Frank's Narrative Types (Frank 1995). The stories, though different, in that they contained information specific to the individual, revealed that the experiences of BCS and the impact DBR had on their lives shared many commonalities. The movement between narrative types within each story was also evident at this early stage. Frank (1995) was then used as a structuring framework rather than being forced onto the data.

The narrative types were identified using the four sections of Frank's Narrative Types (Appendix J) (Plot, Action Problems of Embodiment, Self-Story, Power/Limitations) from the content of the stories, the metaphors and language used.

Prior to the second reading a grid was drafted with the vertical axis showing the pseudonym for each participant and the horizontal axis showing each narrative type denoted by a coloured dot (one for each narrative type) as they were identified during the reading. At the same time the corresponding text in the story was highlighted with the same colour using the same highlighter pen. The final table showed a series of coloured dots corresponding to the level of movement between narrative types in each story. This process was then repeated twice more until the story of the stories began to crystallize in the researcher's mind (Frank 2010). Frank (2010) distinguishes between social science research, which emphasizes sampling, or coding, to support claims about generalizable cases and his own work, where:

'Analysis often seems to emerge from recollection. As analysts think about and with the stories they have heard, the significance of those stories crystallizes, and how to tell the metastory of the stories becomes sufficiently apparent to begin writing and revising' (Frank 2010, p. 113).

Thinking with and about the stories was an important aspect of the analysis of the stories in this study. Thinking about stories is to reduce it to content and then analyze that content while thinking with stories takes them as already complete; there is no going beyond it (Frank 1995). Thinking with stories means joining with them such that the goal is empathy, not for the storyteller's self-story to become that of the researchers but that she developed sufficient resonance with it to 'feel its nuances and anticipate changes in plot' (Frank 1995, p. 158). For example, thinking with stories should ask 'how the present illness fits into the pattern of these people's lives' (Frank 1995, p.160). In the context of this study that question becomes:

'How does the experience of DBR fit into the lives of these BCS'?

To better understand this, the analysis incorporated elements of the pre-DBR phase to support a better understanding of the impact of the DBR experience on the lives of the BCS. Elements of each story, which concerned the pre-DBR phase, were given a separate colour code using a highlighter pen e.g.

'I went through a depression prior to joining…' (DB 11)

This process was repeated using a different colour to capture the elements of the stories that described the impact of DBR on their lives. From the latter, mindmaps were used to help tease out the experiences which eventually became the five inspirations.

Frank (2010) suggests that to skip over thinking with a story risks failing to understand how that story does its work of engaging; allowing oneself to be engaged is a significant first step in interpretation, but that once engaged, to refuse to think about the story risks missing what the story excludes; the other perspective it silences or marginalizes. Thinking with and about the stories during their numerous readings enabled the metaphor of weaving to appear to illuminate how participants were living with multiple narratives and the realisation that the inspirations were the triggers for the weaver changing the weave pattern.

Quotes from the stories were selected because of their ability to illuminate the women's experiences.

3.11 Arthur Frank

Frank began academic life as a medical sociologist but gave it up because he had trouble gaining access to what interested him most, the direct experiences of ill people. After a decade of pursuing other topics he was returned to illness experience by way of having a heart attack himself as a result of a virus (in 1985). Just over a year later when he was feeling fully recovered he was diagnosed with testicular cancer. A year after he had ended his treatment his mother-in-law who also had cancer was diagnosed as terminally ill and died.

After he had cancer he attempted to read some of the professional literature describing the experience he had gone through. He found the language ‘too distant from the immediacy of embodied suffering he had recently experienced’ (Frank 1995, p. 20).

In his book, ’The Wounded Storyteller’ - which he described as a work of theory and a ‘survival kit, put together out of my need to make sense of my own survival, as I watch others seeking to make sense of theirs’ (Frank 1995, p. xiii) - he presents ill people as wounded storytellers and through the book ‘hoped to shift the dominant cultural conception of illness away from passivity - the ill person as “victim of” disease and then recipient of care - toward activity’ and that ‘the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability’ (Frank 1995, p. xi). Many years later these same aspirations formed part of the National Cancer Survivorship Initiative (DOH 2008), an initiative which was driven by cancer survivors and cancer charities and which aimed to encourage cancer survivors to take a more active part in improving their health and wellbeing and more significantly, were the aspirations that motivated this research study.

From the researchers own experience, Frank’s work - and particularly his reference to: the ‘remission society[8]’, the loss of the ‘destination map[9]’ - is in line with recent health service thinking (Richards et al 2011, and a number of Department of Health publications, beginning with the Cancer Reform Strategy (DOH 2007) document, where the impact of the ‘cancer journey’ on the individual was first acknowledged, than it was, when his work was first published 18 years ago. This made his work very relevant to this study on cancer survivorship.

Analysis of the stories using Frank’s three narrative types compliment the SQUIN interview method where the aim is to ‘enable the story to be told in the way the informant feels comfortable telling it’ (Wengraf 2001, p. 122). This combination of the SQUIN interview method and Franks (1995) three

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[8] Remission Society – People who have experienced illness, are now well, but could never be considered cured (Frank 1995).

[9] Destination Map – ‘Serious illness is a loss of the “destination map” that had previously guided the ill person’s life: ill people have to learn “to think differently” (Frank 1995, p.1)

narrative types has been used by other researchers describing the experiences of women living with faecal incontinence (Collings 2010) and living with motor neuron disease (Brown and Addington-Hall 2008). Other examples of the successful use of Frank's (1995) narrative types in the analysis and interpretation of data include the experience of: anorexia (Shohet 2007), breast cancer (Thomas-MacLean 2004) chronic fatigue syndrome/myalgic encephalomyelitis (Whitehead 2006), men recovering from sport related spinal cord injury (Smith and Sparkes 2005). It is suggested that 'Rather than providing an analytical prescription, Frank's work suggests ways in which stories might be reflected upon, in order to be better understood by those who have experienced illness …' (Thomas-MacLean 2004, p. 1647). This is important in this research study as it is for, as well as about, breast cancer survivors, and potentially other cancer survivors.

3.12 Frank's Three Narrative Types

Frank (1995, p.75) suggests that 'a narrative type is the most general story-line that can be recognized underlying the plot and tensions of particular stories.' He acknowledges the risk that by proposing narrative types the particularity of the individual story may be subsumed, but suggests that, listening to illness stories can be difficult, because they mix and weave different narrative threads, and that the rationale for proposing some general narrative types was to 'sort out those threads (Frank 1995, p.76).

> '…any unique story is fabricated through a weave of at least three core narratives, which I call the restitution narrative, the chaos narrative, and the quest narrative' (Frank 2010, p.118).

He proposes frameworks, which he suggests helps to disentangle types of narratives and to recognize what 'basic life concerns are being addressed and how the story proclaims a certain relation of the body to the world' (Frank 1995, p. 24). He defends their use by suggesting that they are only a means of heightening attention to stories that are their own truths' (Frank 1995, p, 24) and suggests that although all three narrative types are told, alternatively and repeatedly, each narrative type reflects strong cultural and personal preferences. Each story was therefore analysed using Frank's (1995) framework; plot, action problems of embodiment (control, body-relatedness, other-relatedness, desire), self- story, power and limitations of each type to determine if the participants showed a preference for any particular narrative type.

3.12.1 Restitution Narrative

This is the dominant narrative, especially for people who are recently ill, but least often for the chronically ill. Again, this was evident in the stories, where the storytellers who had recently completed treatment focused more on restitution narratives than those who were further away although many recalled strong negative memories of their treatment at some point during the interview. The plot of the restitution narrative is that the person was healthy, now they are ill but tomorrow they will be well again.

The chaos narrative lies at the opposite end of the spectrum to the restitution narrative.

3.12.2 Chaos Narrative

In the chaos narrative 'the plot imagines life never getting better' (Frank 1995, p. 97). Stories are chaotic in their absence of narrative order. Events are told as the storyteller experiences life: without sequence or discernible causality, and the lack of any coherent sequence is an initial reason why chaos stories are hard to hear; the teller is not understood as telling a "proper" story' (Frank 1995, p. 97).

The cause or perpetrator of this loss is twofold: the suffering is so great that 'the voice of the teller is lost' (Frank 1995, p. 115). Chaos stories remain the sufferer's own story, but the suffering is too great for the self to be told. The voice of the teller has been lost as a result of the chaos, and this loss then perpetuates that chaos' Additionally, a feature of the chaotic body is that it is disabled with respect to entering relationships of care, as it cannot tell enough of its own story to formulate its needs, and ask for help; often it cannot even accept help when it is offered (Frank 1995).

In the chaos narrative, ‘troubles go down to bottomless depths. What can be told only begins to suggest all that is wrong’ (Frank 1995, p. 99).

Frank (1995) suggests that for the chaos narrative to be told there must be some distance from the chaos and that some part of the teller has emerged. All of the storytellers in this study had reached this stage where the chaos was being reflected upon retrospectively.

Although there were elements of chaos in all 13 stories, five of the stories, as they related to the pre DBR phase, could be described as being predominantly, of the chaotic narrative type, particularly, where they recounted elements of their diagnosis and treatment. As a listener one could appreciate Frank’s suggestion that ‘Chaos stories are as anxiety provoking as restitution stories are preferred’ (Frank 1995, p. 97).

3.12.3 Quest Narratives

‘Illness is the occasion of a journey that becomes a quest. What is quested for may never be wholly clear, but the quest is defined by the ill person’s belief that something is to be gained through the experience’ (Frank 1995, p. 113). In this section we will consider whether dragon boat racing is, or could be considered to be, this quest.

The Quest narrative was found to be the most significant[10] and powerful in regard to the DBR experience and therefore accounts for the largest part of the results chapter. Frank (1995) suggests that the range of quest stories is broad enough to make further specification useful and suggested that quest stories have at least three facets (memoir, manifesto, and automythology) (Box 3.3).

Box 3.3 Three Facets of Quest

Quest stories have at least three facets: memoir, manifesto, and automythology (Frank 1995).

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[10] One storyteller had many of the characteristics of the restitution narrative but on balance she was more closely aligned to the quest narrative.

Memoir	The memoir combines telling the illness story with telling other events in the writer's life. Life events are not told chronologically or in detail. Present circumstances become occasions for the recollection of certain past events.
Manifesto	'The least gentle quest stories are ***manifestos***. In these stories the truth that has been learned is prophetic, often carrying demands for social action. Writers of manifestos underscore the responsibility that attends even provisional return from illness. Society is suppressing a truth about suffering, and that truth must be told. These writers do not want to go back to a former state of health, which is often viewed as a naïve illusion. They want to use suffering to move others forward with them' (p.120/121)
Automythology	Automythology presents the author as one who not only has survived but has been reborn. Individual change, not social reform, is emphasized, with the author as an exemplar of this change. The focus is on enhancing 'the natural drive of the human mind and body toward perfectibility and regeneration. Protecting and cherishing that natural drive may well represent the finest exercise of human freedom' (Cousins 1981, p. 48).

The stories were re-read with the specific intention of identifying each facet within the stories. This analysis revealed that while there was evidence of all three, automythology was the most prevalent.

Frank (1995) suggests that the three illness narratives exemplify most actual stories and that narratives are not presented as linguistic structures, but as objectifications of the bodies that tell them. Furthermore, in any illness, all three types are told alternately and repeatedly and this was evidenced in each of the thirteen stories.

Frank (1995) described four continua of responses to the four action problems of embodiment[11] and from within the matrix of these four

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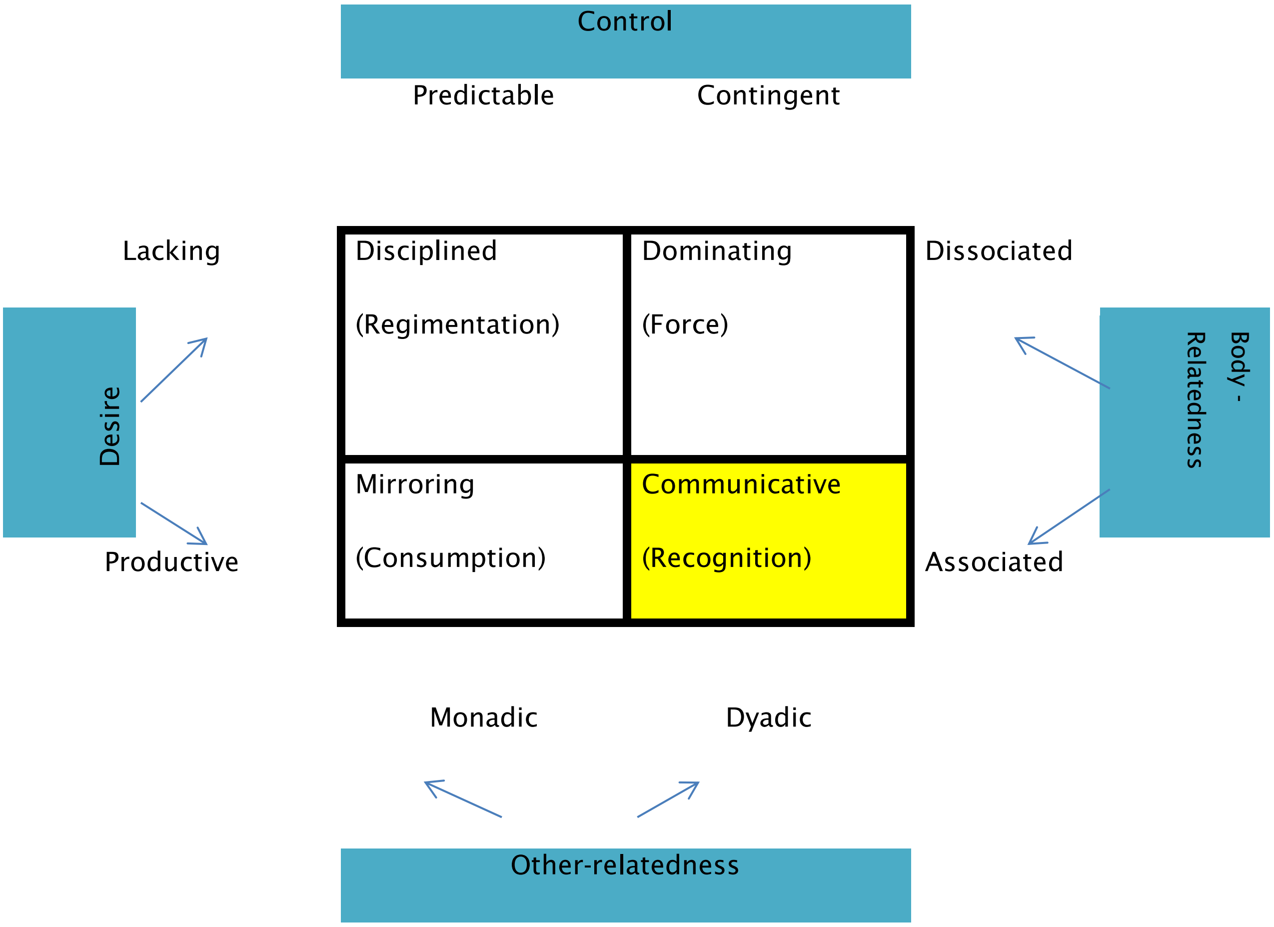
[11] Frank (1995) suggests that the body's problems during illness are not new; being a body always involves certain problems. Illness requires new and more self-conscious

continua he generated four ideal typical bodies: the disciplined body, the mirroring body, the dominating body, and the communicative body (Figure 3.1). He cautions that each range of possible actions, while it looks on paper like a dichotomy, is in reality a continuum of responses and also that actual 'bodyselves represent distinctive mixtures of ideal types' (Frank 1995, p. 29).

Figure 3.1 Four General Problems of Embodiment (Control, Body-Relatedness, Other-Relatedness, Desire) and the Four Ideal Typical Bodies (Disciplined, Mirroring, Dominating, Communicative)

(Frank 1995, p. 30).



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Each story was again reanalyzed to identify which was the most dominant body type for that particular story. All were of the communicative body

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solutions to these general problems. He proposes four general problems of embodiment: control, body-relatedness, other-relatedness, desire, and that 'each body problem is a problem of *action*: to act, a body-self must achieve some working resolution to each problem' (Frank 1995, p. 29).

type (Figure 3.1). Although the storyteller whose story had features of the restitution type had some features of the disciplined body, again the communicative body was more strongly represented. It must be stressed that according to Frank (1995, p.51) ‘Each of us is not one type or another, but a shifting foreground and background of types. The value of the types is to describe the extreme moments of these shifts, thus providing some parameters for hearing the body in the story’

The analysis, which involved re-reading and re-listening to the tape recordings, could therefore be described as having four distinct phases; identifying the narrative types (restitution, chaos, quest) within the stories, identifying if each story had a preferred narrative type, the facets in relation to quest narratives (memoir, manifesto, automythology) and the ideal body types (disciplined, mirroring, dominating, communicative). The emergence of quest as the most prevalent narrative type and the communicative body as the most prevalent body type were revelations.

Thinking with and about the interpretation and analysis of the stories using the three narrative types revealed a number of threads common to this diverse group of BCS and when sorted captured the impact of the experience of DBR on them, and will be reported in Chapters 4 and 5 as the five influential inspirations.

3.13 Messages for the Charity

A separate reading of the stories was undertaken to identify and highlight words and phrases from within the stories which carried a message to the charity e.g.

‘… without the travelling and the competitions I don’t think I would keep it up because I have kind of mastered it now, you need a new challenge and that is one that comes regularly uhm’ (DB 12)

The messages were identified by using a highlighting pen to highlight language within the stories which carried a message that could inform the charity. The quotes were then cut and pasted into a separate document and a mindmap was used to cluster the quotes together. Four broad themes emerged: the recruitment and integration of new members into the team, the importance of participating in competition events, safety and fitness, education of the public and ensuring membership of the team remains affordable for all BCS regardless of their financial status.

The themes were then translated into key messages for the charity. The messages emerged from within the quest narrative stories, and the communicative body type. The core messages are dominated by a desire to enable and support present and future members to enjoy the positive experience of DBR, and to support any initiative that would promote the availability of DBR for other BCS, in other parts of the country.

3.13.1 Relationship between the researcher and the research participants

To overcome some of the potential problems of being an insider the researcher recorded her views and feelings about DBR before collecting the stories (Kelly and Howie 2007) (they formed part of the process of interpretation) and developed an audit trail (Morse and Field 1998, Holloway and Freshwater 2007). In a reflective journal she critically examined and reflected on her assumptions and actions in relation to data collection, analysis and writing up (Bonner and Tolhurst 2002, Elliott 2005). The maintenance of a reflective journal to support reflexivity is about 'being aware of one's values and motivations, and the social, cultural and political context in which one makes decisions about what is valid about the research and the way the research is carried out' (Fox et al 2007, p. 189). '...keeping a daily journal to incorporate reflections and observations has been considered as a pivotal research activity in the making of a research product' (Koch 1998, p.1185). This reflexive approach to research, in which the role of the interviewer, relevant aspects of his or her identity, and the details of the interaction between researched and researcher are understood, constitutes an important part of the research evidence (Mishler 1986, Holstein and Gubrium 1995, Elliott 2005). Similarly, McCormack (2009, p.50) suggests that: in relation to practitioner research the important issues are 'firstly, ensuring that the methods answer the questions asked ... and secondly, applying both person and epistemological reflexivity to the operationalisation of the methods in order to ensure rigour'

In addition to the emphasis on reflexivity, the participants checked their stories for accuracy, and the data was independently reviewed by the researcher's supervisors, to mitigate against the potential negative effects the researcher, as insider, may have on the data. While being aware of and taking the steps described above to mitigate the potential negative impact of 'the self' in this research study it is also important to consider the potential benefits of having an existing relationship, and some knowledge of the participants. Shakespeare et al (1993, p.5) suggests that '[An] awareness of one's self is important in research; but equally important, is an awareness of the 'subjects of one's research. 'Other-awareness' is regarded as a first step towards sensitive interviewing and an empathetic approach, ... and a second step in the development of good research practices' (Shakespeare et al 1993).

It is also suggested that to use 'narrative as methodology and explore narrative as the phenomenon of interest, they [the researcher] must come to embrace a relational understanding of the roles and interactions of the researcher and the researched' (Clandinin 2007, p.15). Frank (2000) asserts that '... any good story analyst has both an ethical and intellectual responsibility to enter relations of storytelling; I have trouble conceiving listening outside of a relationship' (Frank 2000, p. 355). Similarly, Mishler (1986, p.118) refers to 'his intent to shift attention away from investigators 'problems' such as technical issues of reliability and validity, to respondents' problems, specifically, their efforts to construct coherent and reasonable worlds of meaning and to make sense of their experiences'. One such problem is the asymmetry of power between the interviewer and the respondent in traditional social science research. A key task is to empower respondents so that they have 'control of the processes through which their words are given meaning' (Mishler 1986, p.118). So rather than having a negative impact, the researcher as team member, has 'other-awareness', can reduce the asymmetry of power – as the researcher and the researched are equal in terms of team membership - and has a relationship with the participants. Interviewees were aware that their stories needed to be a true reflection of their experience, if the charity, team, and potential other teams, are to learn from the experiences described in their stories. This could be referred to as ‘Honoring individual agency and intention…’ (Riessman 2008, p.12). The notion of the ethical responsibility of the storyteller is summarized as ‘… Storytelling is *for* an other just as much as it is for oneself’ (Frank 1995, p.17). The researcher was therefore constantly aware of the significance of the role of self, as well as that of the storyteller, and combined, as the researcher-participant relationship in shaping not only ‘the field text but also the research text’ (Chan 2005, p. 55). An important element of this related to seeking feedback from participants on the audio and transcribed record of their story, to verify its accuracy and authenticity, as well as the opportunity to offer feedback, if appropriate.

3.13.2 Participant Feedback

As per the research proposal the stories, in written format and on disc, were hand delivered to each storyteller with a covering letter (Appendix K) advising them that they did not have to read or listen to the story if they did not wish to, and specifying the deadline for receipt of their comments, suggestions or requests should they wish to make any. The story and the disc were put into a separate envelope and marked ‘private and confidential’. The researcher also initialled the seal and put clear tape across it. This envelope was then placed inside another envelope with the covering letter.

The decision to hand deliver, and to package the stories in this way, was to respect the privacy and confidentiality of the storytellers and the stories they told. From an ethical perspective giving them the option to read/listen to their story was to avoid causing them possible distress. It was of considerable interest that the two people the researcher was most concerned about with regard to this potential for distress, were the two who contacted her immediately after receiving them. Both participants had read them, and were keen to share their perception that as people they had continued to grow in confidence even since the interview. None of the storytellers requested changes or offered any further comment on the returned stories.

Chapter 4: Results: the stories

4.1 Introduction

The results are presented in this and the following chapter. In this chapter the results of the analyses of the stories are presented using Frank's (1995) three narrative types (Restitution, Chaos and Quest), Frank's framework (plot, action problems of embodiment (control, body-relatedness, other-relatedness, desire) and self- story. Chapter 5 uses the visual metaphor of a woven pattern (Frank 1995) to capture the movement between narrative types during the period prior to joining the DBR team (pre DBR weave), and when remission society membership experiences have been modified by the impact of DBR (DBR weave).

As can be seen in the present chapter Quest was the dominant narrative type for all the storytellers, so each story is further analysed to identify the three facets of quest (memoir, manifesto, automythology). The power and limitations of the quest stories are reported with extracts from these stories at the end of this chapter.

In relation to the four action problems of embodiment[12] Frank (1995) describes four continua of responses to them and from within the matrix of these four continua he generated four ideal typical bodies: the disciplined body, the mirroring body, the dominating body, and the communicative body (Figure 3.1). In this study, and specifically in relation to the experience of DBR for BCS, the stories universally show evidence of the four qualities of the communicative body[13]: associated, dyadic, contingent, productive desire, making the communicative body the most prevalent body type.

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[12] Frank (1995) suggests that the body's problems during illness are not new; being a body always involves certain problems. Illness requires new and more self-conscious solutions to these general problems. He proposes four general problems of embodiment: control, body-relatedness, other-relatedness, desire, and that 'each body problem is a problem of *action*: to act, a body-self must achieve some working resolution to each problem' (Frank 1995, p. 29).

[13] The communicative body; is associated with itself, is open to contingency, is dyadic towards others and is desiring for itself in relation to others (Frank 1995)

Therefore, as the communicative body is only told in quest stories (Frank 1995), and as all participants were of the communicative body type, and DBR became their quest, this makes the quest narrative type the most powerful and relevant in this study. As restitution and chaos narrative types were the most dominant types prior to the DBR experience; Chaos (Phase 1 and 2) and Restitution (Phase 1 and 2) they form the foundation story to the BCS decision to take part in DBR (pre DBR experiences) (Table 4.1) and are included to create a more holistic story of the experience of DBR for BCS in this study. Additionally, and importantly, ‘restitution and chaos remain background voices when the quest is foreground’ (Frank 1995, p. 115). For the storytellers, changes in their own health, the health of other team members or in other aspects of their lives, not related to breast cancer, brought restitution or chaos back into the foreground.

To make the reporting of the results of the analysis of the stories more meaningful the present chapter is divided into four sections: Pre-DBR (Diagnosis and Treatment, Becoming Members of the Remission Society, Joining the DBR Team), Chaos (Phase 1 and 2), then Restitution (Phase 1 and 2) followed by Quest.

4.2 Pre DBR

Some participants chose to begin their story at the point of diagnosis, and twelve out of the thirteen participants made reference to the impact of the diagnosis, and/or treatment, at some point during the storytelling encounter (Table 4.1).

Table 4.1 A Summary of the Storytellers’ Journey

Pre-DBR and after DBR using Frank’s Three Narrative Types (Chaos, Restitution, Quest) (Frank 1995).

Pre-DBR	**Phase 1** **Chaos**	Point of Diagnosis Shock, disbelief
	Phase 1 **Restitution**	During Primary Treatment Surgery, Chemotherapy, Radiotherapy

	Phase 2 **Chaos**	End of Primary Treatment Depression, social isolation, disrupted social support networks, decreased physical fitness, side effects of diagnosis and treatment, Upper Body Morbidities, including Lymphoedema, loss of self-esteem, loss of confidence, weight gain, body image concerns, as well as the risk of recurrence of the disease, or premature death
	Phase 2 **Restitution Effort**	End of Primary Treatment for the participants who tried to move from Chaos to Restitution Exercise Programme, Reflexology, Emotional Freedom Technique, Support Groups. Adjuvant treatments
After DBR	**Quest**	Introduction of DBR Positive experiences of DBR: Fun, Social Support, Camaraderie, Inspiration, Hope, Joy, increased self-esteem, increased confidence, increased fitness, adaptation to the contingencies of membership of the remission society, greater appreciation of nature. Negative experiences in relation to DBR: Experiencing recurrent disease and death in fellow team members, relationship difficulties with fellow team members and tension regarding the level of competition to which the team should commit.

4.2.1 Diagnosis and Treatment

In all the stories there was evidence that, for the storytellers, the diagnosis of breast cancer had interrupted their lives, and that they had come to realise that this meant ‘living with perpetual interruption’ (Frank 1995, p. 56). Reflecting on the participant’s stories collectively, this was most acutely evident in Chaos (Phase 1 and 2) and Restitution (Phase 1 and 2)

(Table 4.1), while the Quest narratives attempted to restore order to the interruption.

Temporary escape from the chaos was achieved initially by all participants when they embarked on a '*horrific*' (as described by them) primary treatment programme, suggesting evidence of restitution (Phase 1 Restitution, Table 4.1), and the hope of a return to health, but for some the negative impact of treatment brought the chaos narrative back to the foreground during this phase.

However, in their stories, almost all participants vividly described the end of the treatment phase as one suggestive of a definite return to chaos (Phase 2, Table 4.1). This was caused by them losing regular contact with their health care professionals while at the same time suffering from a number of side effects of their diagnosis and treatment, including; lymphoedema, or the risk of developing it, fear of recurrence of the breast cancer, and possible premature death. Additionally, there was considerable consistency in the stories concerning the sense of social isolation, caused by a belief that friends and family did not understand, and could not understand, what it was like to go through what they had, and were, going through. Whether influenced by cultural, personal, or institutional expectations, some participants made efforts to escape chaos and return to restitution (Phase 2 Restitution Effort Table 4.1) by engaging in exercise programmes, reflexology, Emotional Freedom Technique (EFT) sessions, or, attending Breast Cancer Support Groups, while others reported that psychological and social issues perpetuated their sense of chaos. However, all participants, whether in chaos or in restitution, had acknowledged that a return to health could not be guaranteed, and that they needed to find a way to cope, not just with the risk of a recurrence of their disease, and possible premature death, but also the on-going side effects of their diagnosis and treatment, and, that this was a situation over which they had no control. One storyteller stated:

'… *I held myself together during it* [the treatment] *but when it was over …uhm I got very worried, very anxious, every twinge, every little pain, you wondered* [was it the cancer coming back], *I felt adrift*' (DB 1)

The latter statement capturing what was reported by many of the storytellers, and in keeping with what Frank (1995) calls, the ‘loss of the “destination and map’’ that had previously guided the ill person’s life’ (Frank 1995, p. 1)

4.2.2 Becoming Members of the Remission Society

While membership of what Frank (1995) calls the ‘remission society’[14] - where ‘they are living in the world of the healthy even if always subject to expulsion’ (Frank 1995, p. 9) - can begin at diagnosis, in the stories, it was more evident, that it began at the end of primary treatment. In this study all the storytellers are assumed to be members of the ‘remission society’ by virtue of having completed their primary treatment for breast cancer and without a known recurrence of their disease. A number of storytellers described how they realised at this point that they needed to get help to cope with what they were experiencing ‘*…I’ve got to find something that will get me out of this state that I’m in…*’ (DB1). An unexpected finding from listening to the stories, and reading the transcripts, was the realisation that for the storytellers the experience of DBR appeared to transform their stories from a combination of chaos and restitution narratives, to ‘another kind’ of narrative which was a quest narrative. Frank (2010, p.118) suggests that in ‘the *quest* narrative there is movement. The ill person is an active character who does find some kind of meaning in illness, and that may take different forms. Illness is not a good thing by any means but, protagonists of quest narratives find ways to work with illness, keeping their lives moving in a direction they experience as forward’. This was evident in the stories told in this study.

4.2.3 Joining the DBR Team

For some joining the team was self-initiated, either in response to a team poster (2) or media images (2) while the remaining nine had responded positively to either a direct invitation from a member of the health or social care team, or from having received the information from an acquaintance

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[14] ‘…people who [*are*] effectively well but could never be considered cured…’ (Frank 1995, p. 8)

who had read about the team, or had seen them on the river. Reflecting on their motivations for taking part in DBR, rather than any other activity, there was an overwhelming sense that the; physical nature of the activity, the positive image of the women in the boat – portraying; energy, vitality, and hope -, the expectation that they would meet like-minded people who wanted to get on with their lives and do something positive, and the opportunity to help others, were powerful motivators. For all, there was a desire to enhance some aspect of their health affected by the impact of their BCS experience. Specifically, for some participants, there was a desire to prevent, or manage (where it was already diagnosed), upper-body-morbidities e.g. lymphedema.

It is important to consider that membership of the remission society involves more than the cancer survivorship experience (diagnosis, treatment, side effects) and includes what Kleinman (1988) called, 'the interweaving of bodies, cultures and lives' (cited by Frank 1995, p.28). This was evident in the stories, where, for example, one storyteller, describing the impact her breast surgery had on her sexual relationship with her husband, suggested, it was '*a big problem uhm, problem, more of an adjustment, and a bereavement as well*' (DB 12) Additionally, the impact of DBR as captured in the stories, includes, not just the physical act of paddling but also the dry land fitness training, competition events, social events, fundraising events, and events to promote the importance of physical activity for cancer survivors.

4.2.4 Chaos Narrative

Frank (1995) suggests that for the chaos narrative to be told there must be some distance from the chaos and that some part of the teller has emerged. All of the storytellers in this study had reached a stage where DBR had been reported as the experience that had created this distance and enabled the storyteller to emerge; and the chaos was being reflected upon retrospectively (Frank 1995).

Although there were elements of chaos in all 13 stories, five of the stories (when describing the pre DBR phase) could be described, as being predominantly, of the chaotic narrative type. As a listener one could appreciate Frank's suggestion that 'Chaos stories are as anxiety provoking [for the listener] as restitution stories are preferred' (Frank 1995, p. 97) and their 'limitation is that chaos is no way to live' (Frank 1995, p. 114).

In the chaos narrative, 'troubles go down to bottomless depths. What can be told only begins to suggest all that is wrong' (Frank 1995, p. 99). In the element of the stories where the diagnosis of breast cancer was recounted there was a strong sense of, what Frank (1995, p. 102) describes as, '… being swept along, without control, by life's fundamental *contingency.*' Relationships are difficult, so in terms of other-relatedness, the body is monadic[15]. Association with one's own body is dangerous, because 'the body is so degraded by an over determination of disease and social mistreatment that survival depends on the self's dissociation from the body' (Frank 1995, p. 103). The chaotic body is also incapable of receiving comfort which both reflects and reinforces its *lack* of desire[16]. The chaos narrative is therefore, contingent, monadic, lacking desire, and dissociated – such is the configuration of traits that typify the chaotic body' (Frank 1995, p. 104).

As referred to previously the examples of chaos will be considered as Phase 1 (point of diagnosis) and Phase 2 (end of treatment).

4.2.5 Phase 1 Chaos

In this phase the shock of the diagnosis is told as chaos stories where the story is disjointed, and holds many of the features of the chaotic narrative described previously and in chapter 3.

The following is an extract from a story where the storyteller is describing the time leading up to her diagnosis of breast cancer following a routine mammogram.

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[15] Monadic – 'understanding…[oneself] as existentially separate and alone' (Frank 1995, p.36)

[16] Desire – 'Whatever desires it once had have been too frequently frustrated. In a world so permeated by contingencies that turn out badly, desire is not only pointless but dangerous, just as relationships with others have become dangerous' (Frank 1995, p.103)

'It was snowing … I thought, should I go, or shouldn't I, thought yeah, I'll go. It was difficult to get out on the road, it was icy on the roads, and I thought should I go or shouldn't I, but I thought I'll go, and it was difficult to get out of the road, it was very icy, but I got out, drove the car down and turned up, and when I got down, she said you're probably the only one today nobody else seems to be coming. So looking back I'm really glad I went to that mammogram. Anyway I got the recall on the bus and it was a Wednesday and I remember that very well. It was in January and then she said can you come on Friday? The reason I'm phoning you is because you won't get the letter on time because it's all very quick. So I sat on the top of the bus and suddenly went into a great big panic ((laughs)) like you've never known.' (DR 1).

For this storyteller the emotional distress she experienced and the chaos story she told relating to her diagnosis, may have partly originated (which was discovered later in the story) from her previous experience, where everyone she knew who had cancer died. This was compounded by her decision not to tell anyone about her diagnosis ('monadic' in terms of other-relatedness), and therefore did not know until she joined the DBR team that '…*you could get degrees of it* [breast cancer], *severities of it, I didn't know they could almost cure it really'*. (DB 1)

Most storytellers appeared to move quickly into restitution when they became focused on their primary treatment regime. Those who found their treatment traumatic appeared to carry the chaos forward through the treatment phase and into Phase 2 (Chaos).

4.2.6 Phase 2 (Chaos)

In this phase, when the storytellers had completed their treatments, and realised that the restitution story's desire for the body to get its former predictability back – '…not simply the mechanical functioning[17] that comes with a symptom-free life … but the deeper contingency represented by illness itself: the contingency of mortality' (Frank 1995, p.85) - was not the

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[17] Mechanical functioning – Frank (1995) suggests that in the restitution story, the implicit genesis of the illness is an unlucky breakdown in a body that is conceived on mechanical lines, and to be fixable, the body has to be a kind of machine.

reality of what they were experiencing, they returned to chaos. Reflecting on the stories, it appeared that the chaos in this phase was 'more intense' than in Phase 1, as demonstrated by, for example, the number of storytellers who volunteered to include it in their story, and in their choice of descriptive words e.g. the cancer '*lurking*' (DB 8) .

Frank (1995) suggests that this phase is marked by the survivors coming face to face with their own dissolution and their fear of entering a world that cannot imagine, and does not want to imagine, that dissolution. This often manifests itself 'as a kind of terror when the treatments they have hated finally ends' (Frank 1995, p. 107). From his own experience Frank (1995) suggests that:

'When liberation from the hospital comes, as welcome as it is, one's real trouble begins: the trouble of remaking a sense of purpose as the world demands' (Frank 1995, p. 107). This was similarly, and vividly, described by a number of participants.

'… they [family, friends, health professionals] *are all interested and supportive throughout the treatment, how it's going, treatment ends, and it kind of, switches off, and actually, that's really <u>low</u>:: it can also almost be a bereavement…'* (DB 12)

'… feel like you've almost been abandoned because you've been so intense in the hospital for such a long time, and now, it's almost like, 'off you go now', you know, with all the fears of what happens now, will it come back …?' (DB 9)

In the telling of all the chaos stories the storyteller's body language, tone of voice, and pauses - even for the storyteller who completed her treatment up to nine years earlier - suggested a level of chaos that could not easily be described. Frank (1995, p. 101) suggests that '… chaos is told in the silences that speech cannot penetrate or illuminate [and that the phrase] emotional battering is fundamental to chaos' (Frank 1995, p. 101) seemed highly appropriate, as the following story extract suggests:

'… I just, ((silent pause)), *I just,* ((silent pause)), *I went to a place that's all I can say, ((silent pause)) I don't know where I went or how long I was there, but I came back slowly,…((silent pause)) and chemo was just so horrific, absolutely horrific…'* (DB 9)

For the storytellers, the chaos appeared to originate, not only from the social isolation they experienced through altered relationships with their family and social network, but also from the loss of contact with the health professionals, the fear of recurrence and premature death, and the realisation that the diagnosis and its treatment may have a potentially long-term negative impact on their physical and psychological health. The following story extract captures, how the stories suggested, BCS were experiencing membership of the remission society, and leads to a sense that this is the point in the story of the stories where the '…illness story is wrecked because its present is not what the past was supposed to lead up to and the future is scarcely thinkable' (Frank 1995, p. 55).

'…I only ever heard of people dying with breast cancer I didn't know anybody, and I hadn't heard of anybody, who'd lived for 20, 30, 40 years, having had breast cancer, didn't come into my mind, because I'd never heard of it, so the worry is always there'. (DB 10)

The stories revealed two particular paradoxes in relation to the storyteller's membership of the remission society. The first, relates to the issue of social isolation, which the stories, either directly, or indirectly, referred to - although none of the storytellers were socially isolated in the conventional sense. The second concerns the issue of the impact of the loss of contact with health professionals at the end of primary treatment. While a number of the storytellers suggested it was significant, the same storytellers reported that they would not call the health professionals if they had a problem.

This ambivalent relationship with the treating hospital team was also revealed in a reference made by one of the storytellers referring to the fact she found it 'off putting' that the health professionals attended a support group she visited, and another who felt the health professionals knowledge was limited to the acute phase of treatment, and another who said she would want them to spend their time looking after people going through treatment. For the significant number who reported that they would not contact the health professionals it could be interpreted as extending their social isolation to include their health professionals.

A core element of this phase is ‘The Problem of Control’ as discussed by Frank (1995, p. 30) where he suggests that ‘the body is lived along a continuum from … predictability [at one end] …to contingency at the other end, and that contingency is ‘the body’s condition of being subject to forces that cannot be controlled’. Additionally, if ‘adult bodies lose control, they are expected to attempt to regain it, if possible, and if not, then at least to conceal the loss as effectively as possible’ (Frank 1995, p. 31).

Chaos feeds ‘on the sense that *no one* is in control’ (Frank 1995, p. 100).

For the storytellers this was strongly evident.

‘I just hated that feeling that this thing was there, is it going to come back again? I was constantly worrying about recurrence and, this, that and the other … I was always in control, always in charge, and suddenly this cancer was in charge of me …’(DB 1)

Although they complied with all treatment recommendations, it may be significant that, as referred to previously, in the five stories where ‘chaos’ was dominant, three out of the five had, up to the stage where they joined the dragon boat team, believed that cancer meant death.

An element of the loss of control illustrated in the extracts from the stories that follow, is the sense of a loss, or potential loss of desire, or purpose, which is a component of the ‘loss of the “destination map” (Frank 1995, p.1) Frank (1995) suggests that the latter is the map that previously guided the ill person’s life and that illness brings about a need to learn to think differently. He suggests that ‘they learn by hearing themselves tell their stories, absorbing others’ reactions, and experiencing their stories being shared’ (Frank 1995, p.1). In the first extract that follows, the storyteller captures this ‘loss of the destination and map’ and suggests that this is something experienced by other cancer survivors. The second is looking back retrospectively to what might have happened to her if she had not joined the DBR team.

'… I felt adrift. I have heard many ladies say that 'we feel adrift'. (DB 1)

'… otherwise I might be sitting within four walls feeling rather sorry for myself which quite a few people do, who I've come across …' (DB 3)

This chaos phase is particularly important in this study as it provides the background, or indeed the reason, why the BCS, as members of the remission society, decided to join the DBR team. This background consisted of reports of depression, social isolation, disrupted social networks, decreased physical fitness, upper-body-morbidities (including lymphoedema) loss of self-esteem, loss of confidence, weight gain, side effects of diagnosis and treatment, body image concerns, as well as the risk of recurrence of the disease, or premature death. Reflecting on the stories both individually and collectively one could interpret that the BCS who chose to take part in the sport of DBR were searching for a new 'destination and map' and that this was one aspect of their 'learning to think differently' (Frank 1995, p.1). The stories suggest they did this in two ways. Firstly, In relation to thinking differently, a number of them referred to having a different approach to life after diagnosis e.g. they worried less about what people thought about them and about other issues in life that previously seemed important. Secondly, they learnt to 'meet suffering head on … and to accept illness and seek to *use* it' (Frank 1995, p.115), as in Quest stories. This will be considered in the next section but before going on to this, the element of Restitution, which was much less significant than Chaos or Quest in these stories, will be considered, as Phase 1 (post diagnosis) and Phase 2 (post end of treatment).

4.2.7 Restitution Narrative

Frank (1995) suggests that this is the dominant narrative, especially for people who are recently ill, but least often for the chronically ill. This may explain why it is least important in this study, apart from the brief period while they were undergoing primary treatment (surgery, chemotherapy, radiotherapy) and later adjuvant therapy, and that the storytellers had come to realise a diagnosis of breast cancer has many of the features of a chronic disease, in that there is no guaranteed cure, and they may have to live with a number of longterm side effects, such as fatigue, lymphoedema, which some had already experienced.

Restitution stories can be told prospectively, retrospectively and institutionally (Frank 1995). The storyline is filled with talk of tests and their interpretation, treatments and their possible outcomes, the competence of physicians, and alternative treatments (Frank 1995). This was evident in the stories, where the women desired a move to Restitution, after a period of Chaos at the time of diagnosis.

4.2.8 Phase 1 Restitution

This phase, despite the challenges of surgery, chemotherapy and radiotherapy, provided hope that the treatments prescribed by the medical team, would treat the cancer, and that life would return to normal. The following story extract, referring to one storyteller's experience of surgery, captures this desire to return to normal;

'… I wanted it [the cancer] *out, it was out, and I got on, just moved on,'* (DB 4)

Their efforts at restitution post primary treatment, especially chemotherapy and radiotherapy are less successful as was reported in Phase 2 Restitution Efforts.

4.2.9 Phase 2 Restitution Efforts (efforts here highlights the distinction between this phase where the storyteller initiates the action and phase 1 where she follows the doctor's recommendations)

In this phase the women had just completed treatment and they were no longer adhering to the demands of their treatment regime - except for some, who are taking adjuvant treatments, such as hormonal therapies. Additionally, the restitution story is about 'remaking the body in an image derived either from its own history before illness or from elsewhere' (Frank

1995, p. 87) and they realise that their bodies no longer fit that image as the following storytellers reveals:

*'…I have found that because I think, after cancer, I don't know whether its general, but my health is not what it used to be, I suffer with my back, my legs ache, you know, the aches and pains in your arms …' (*DB 6).

'…*because of the disfigurement, uhm, which I felt slightly ((hesitant)) less feminine, and that was hard to take for a while'* (DB 3).

Maintaining restitution is either difficult or impossible when they are faced with; on-going side effects of primary and adjuvant treatments, the fear of recurrence, premature death, a diminished social network, and for some a health care environment, that no longer fully understands them. Frank (1995, p. 83) suggests that 'The restitution story, whether told by television commercials, sociology, or medicine, is the culturally preferred narrative' (Frank 1995, p. 83). Significantly, the ill person's own desire for restitution is compounded by the expectation that other people want to hear restitution stories as the following storytellers reveals:

Social expectations *'… at that point everybody was expecting me to be ((pause)) uhm OK, you know, the radiotherapy was over …' '… uhm and anyway from that point I was not OK…People were celebrating, but actually I think, that was the point, sort of fell to bits, really' …'* (DB 1)

Expectations of medicine *'… Dr Z was telling me to go into the exercise class at the [*name of the venue*] … I couldn't get out of bed ((indignant))!* (DR 9)

Some efforts to either meet this expectation or to achieve restitution were made by some of the storytellers. These included; reflexology, emotional-freedom-technique (EFT) and an exercise class for one storyteller, exercise classes for cancer survivors for a further four storytellers, two storytellers attended breast cancer support groups and for the other seven no specific interventions were reported in the stories.

'So I thought I've got to find something that will help get me out of this state that I'm in… I went for the 3 reflexology sessions … but just cried throughout ((laughs)) …it was quite helpful, it didn't sort anything, but it

was nice, but what did help was the EFT …just sorted me out physically…I was still way off being well but I felt it was something, it was a start uhm' (DB 1)

The two storytellers who reported attending breast cancer support groups found they did not meet their needs. The following extract captures their impression of the groups as reported by one storyteller and perhaps hints to why they chose DBR:

'I wanted to belong to a group or to be with other people that were in the same situation as myself …I went along …but after a couple of meetings I thought I don't really think this is for me … there were lots of people that wanted to talk about their cancer, wanted to talk about how they felt afterwards, and the problems that they were having, and I felt that I wanted to get on, and forget about it, that I wanted to do something positive, uhm forget about the cancer, but be with people like myself, that wanted to just 'go for it' (DB 6)

Following completion of their treatment these partly successful, partly unsuccessful efforts by the storytellers to move from chaos and regain restitution, takes this research study's story back to where it all began. It was while working on the Physical Activity Intervention Project - a study to identify potential interventions that could meet BCS needs - that the DBR team was initiated. As mentioned previously the Quest was the most prevalent story told in this research study, after the DBR experience.

4.3 Quest Narratives

> 'Quest stories tell of searching for alternative ways of being ill. As the ill person gradually realizes a sense of purpose, the idea that illness has been a journey emerges. The meaning of the journey emerges recursively: the journey is taken in order to find out what sort of journey one has been taking' (Frank 1005. p. 117)

Frank (1995, p.118) suggests that the quest narrative tells self-consciously 'of being transformed; undergoing transformation is a significant dimension of the storyteller's responsibility'. He also suggests that enactment of quest stories include involvement in patient advocacy and making significant vocational and personal changes in one's life. The following extract from a storyteller who referred to how '*…after …* [you've] *had cancer and you feel pretty low and miserable about yourself…'* she later described herself and her experience of taking part in the International Dragon Boat Festival in Peterborough;

'Well the highlight has to be me going to Canada, …it was really overwhelming to think that all the ladies there, and there were thousands of people there, that had all had BC, it's quite, it brings it home, how prevalent the disease is, and how, how, awful, it is, but on the other hand, you look at it on the optimistic side, and you think, ah yeah, but all those ladies there paddling have overcome the disease, to a certain degree, it might come back again, but we're out there, we're proving to the world that we are survivors, and I hate that, but we are, and that, you can't run away from it…' (DB 8)

Frank suggests that illness can be the occasion of a journey that becomes a quest. The genesis of the quest is some occasion requiring the person to be more than she has been, and the purpose is becoming one who has risen to that occasion. The genesis here is the consequences of the diagnosis and treatment of breast cancer for the storytellers. The stories suggest that the experience of DBR facilitated that movement from the impact of breast cancer and remission society membership, as an interruption, to DBR as 'an opening' that enabled the BCS to rise to the occasion (Frank 1995,). Their decision to seek out or respond positively to an opportunity to take up DBR, is in keeping with the plot of 'the quest stories [where they] meet suffering head on; they accept illness and seek to use it' (Frank 1995, p. 115).

Meeting suffering head on implies taking up a challenge and this could be seen to be evident in their choice of DBR- an activity the majority of them had never heard of, for which many had to overcome their fear of water to participate - to join a team of people they did not know, despite some members reporting feeling vulnerable – is in keeping with Frank's suggestion that what is quested for may never be wholly clear, but the quest is defined by the ill person's belief that something is to be gained through the experience.

All of the stories suggest that the experience of DBR may have enabled the BCS to move to a new place - '… *just when I thought one door had closed …a new door was opening up'.* (DB 3) and there was also a sense that DBR enabled them to rise to the occasion of coping with their remission society membership experiences, and that this began at their first sighting of the team - whether as a poster in the hospital, or down on the river. This first encounter with the DBR team was recounted in all the stories in a joyful, positive way - for some, almost cathartic - the body language and the words used to describe it, suggested it had a powerful impact on them, and was one of the key stages in their transformation (Frank 1995). The following extracts capture this element of their experience.

'…a few more ladies arrived [for a paddling session on the river] *and they were all so friendly and so happy and I thought all these ladies have all been through breast cancer and they all look pretty positive...' (*DB 13)

'*So I went ((*talking through tears*)) to the boat and there were women there all had breast cancer, all alive … I saw people laughing, being jolly, and having a good time on the boat… I saw people with cancer actually having a nice time ((*gentle sob*)) so I thought right this is it, this is what will help me and it did help me…* (DB 1)

Thinking with and about the stories these accounts of their first encounter with dragon boat racing appear to have a significance which corresponds to what Frank (1995) refers to as the metaphor of initiation used by tellers of quest stories. He suggests that they use it implicitly, and explicitly, and that '… in illness narratives only at the end of the initiation does the teller conceptualize what has been going on *as* an initiation, thus organizing the experience as coherent and meaningful' (Frank 1995, p. 118). In the stories the welcome they received appeared to form a significant part of this implicit initiation as the high number of storytellers who specifically referred to it so purposefully, would suggest.

‘*…so I went down* [to the boat] *…and it was fantastic, the girls were really, really, nice, very friendly, very welcoming…*’ (DB 7)

Beyond the impact for the storytellers of this first encounter with DBR Frank’s (1995) framework - developed under the four sections: Plot, Action Problems of Embodiment (control, body-relatedness, other-relatedness, desire), Self-Story, Power, Limitations, and the three facets (memoir, manifesto, automythology) (as all were of the quest narrative type) - will be used to illuminate how the experience of DBR contributed to the changes in the BCS as described in their stories.

4.3.1 Plot

In relation to narratives, the plot means that the topic develops in a particular way as the story unfolds (Gubrium and Holstein 2009)

The plot of the quest narrative means that it meets suffering head on it accepts illness and seek to use it (Frank 1995).

This storyteller captures the essence of the quest narrative plot by now being able to accept her own illness supported by her experience of DBR, but also wanting to use that experience to help others:

‘I’ve really, really, really, loved it [DBR] *uhm ((hesitant)). I think:: its* [DBR] *helped me, uhm … my husband says he’s noticed a big difference in my confidence since I’ve been going to [TEAM NAME], uhm I do things that I would sort of never, never, never have done before, uhm, and it’s just fun it’s great fun to meet up with everybody, uhm, and all the other bits that are tagged onto it, it’s all about when we do the fundraising, and we have our meeting, It’s just like everyone is coming together to do good …’* (DB 9)

4.3.2 Action Problems of Embodiment

Frank (1995) suggests that the stories that ill people tell come out of their bodies and that the body sets in motion the need for new stories when disease disrupts the old stories. Additionally, these embodied stories have two sides, one personal and the other social.

In the stories, the BCS talk about the impact breast cancer had, not just on them as individuals, but on their wider social network, and additionally how the DBR experience had impacted on members of this wider social network also.

'I think my family got *__really__* *fed up with hearing about my woes and worries ((laughs)), cause I'm one of five children, so there's always a crisis in somebody's life and uhm breast cancer is just one of the episodes in our family ((laughs))... so it's nice to have a group of people that I can talk to about how I'm feeling and that, but, there are no terms and conditions ... just accepted and loved, its good, Yeah'* (DB 12).

In quest narratives the responses to the four action problems of embodiment; control, body-relatedness, other-relatedness and desire are; contingent, associated, dyadic and productive desire (Figure 3.1) - these four responses make up what Frank (1995) calls the communicative body (Figure 3.1). Extracts from the stories illustrate how the experience of DBR may have influenced the participant's responses to these action problems of embodiment through the communicative body (Contingent, Associated, Dyadic, Productive desire) (Figure 3.1).

4.3.3 Contingent

Frank suggests that '...quest teaches that contingency is the only real certainty... and that the paradox learned on the quest is that surrendering their superficial control of health yields control of a higher order' (Frank 1995, p.126). In terms of health, membership of the remission society may include loss of control in relation to the body's appearance and function on a number of levels as the following extract suggests;

'...the treatment as you know is quite *__brutal__* *and affects people in very, very, different ways, psychologically uhm it affected me a little bit psychologically because of the disfigurement uhm which I felt slightly ((hesitant)), less feminine, and that was hard to take for a while'* (DB 3)

Important in relation to this study is Frank's suggestion that; 'A body's place on the continuum of control depends not only on the physiological possibility of predictability or contingency, but also on how the person chooses to interpret this physiology. As body-selves, people interpret their bodies and make choices; the person can either seek perfected levels of predictability, at whatever cost, or can accept varying degrees of contingency. Most people do both, and strategies vary as to what is sought to be controlled, where and how' (Frank 1995, p.32) In the following extract the storyteller featured above describes the choice she made in dealing with the body image changes she experienced;

'*But talking to the other* _*ladies*_ [DBR team members] *some of them actually worse off than me made me realise that really I shouldn't complain too much and that I should be grateful…*' (DB 3)

Throughout the stories, reference to changes in body image and function are contained almost exclusively within the pre DBR component of the stories (as above), while after DBR the stories talk of increased fitness, strength, self -confidence etc.

Frank (1995) also suggests that only the communicative body can reclaim interruption because only it associates with its own contingent vulnerability (Frank 195, p.165). The communicative body makes this contingency the condition of its desire, reaching towards others who share this vulnerability. In the stories there was evidence of reaching towards others who shared their vulnerability but not at this entry point, except for one team member who began her story by revealing that she had joined to help others who were in the same situation as herself, and to be part of a team. At the stage of deciding to join, all others appeared to be expecting to have one or more of their own needs met (social isolation, fear, lack of fitness, depression etc.). This is in keeping with Frank's suggestion that 'Most heroes are called to the quest not by their recognition of the suffering of others … but by their own suffering'.

The stories revealed that the storytellers shared a number of contingencies as members of the remission society, but also reveal how the experience of DBR helped them to adapt to those contingencies. The main contingencies were: membership of the remission society which included dealing with the side effects of their diagnosis and treatment, the risk of recurrence and premature death for themselves and their fellow paddlers, dealing with relationship difficulties within the team, and some tension concerning the level of competition to which the team should commit. One of the key ways in which the DBR experience helped them to deal with these contingencies was through social support and the social support network membership of the DBR team provided. Many described the social isolation they experienced when friends and family did not understand what it was like to experience cancer. For some storytellers, and as referred to previously, this isolation appeared to extend to include the health professionals involved in their care such that a number of them made reference to preferring to get help with remission society membership experiences from outside the hospital (no reference was made to a general practitioner in any story). The two choices referred to were, fellow cancer survivors, and the internet, as the following extract captures:

*'…I don't, don't phone them, it's much easier to either Google it or ((laughs)) speak to other ladies who understand…understands **exactly** what you're feeling like… …'* (DB 1)

'…*if I had something I was worrying about I would ask one of the girls, definitely wouldn't bother anyone at the hospital…'* (DB 9)

However, while the stories suggested that all the storytellers coped and adapted to these contingencies one storyteller referred to a team member who had left because she wanted to put cancer behind her and could not cope with disease recurrence and death in team members and another storyteller told how '…*it had crossed my mind,* [to leave the team] *but not for long*…' (DB 11) when a team member she was particularly close to died, but in keeping with the dyadic relatedness of the communicative body she wanted to honour the memory of the lost colleague by continuing with the team for the benefit of others as well as herself.

'…*we miss her very much and it's sad but yeah they would want us to go on* …' (DB 11)

As well as revealing that they coped, the stories revealed, how they coped with these contingencies. It was particularly interesting to note that there was considerable consistency between the storytellers, in the strategies they reported. The latter included; team support - using words such as ‘connectedness, ‘camaraderie’, being inspired by the way other team members had coped with situations - such as recurrence of their disease or imminent death, anticipating the team’s support - importantly it would be from ‘*people who understood’* - should it happen to them, and tolerance and respect for other people’s views, and perspectives. All of this is in keeping with the dyadic nature of their quest narratives, and extended to how they coped with relationship conflicts, and tensions as to how competitive the team should be. They also gained inspiration from participating in competition events e.g. being inspired by, and being in the company of large numbers of survivors at the international dragon boat festival (the stories seemed to imply that the large numbers was significant to them). The following extracts help to illuminate how they coped with these contingencies:

‘…I know some ladies haven’t been able to cope with …[the death of team members] …*It* [DBR] *reminds you that you’ve got cancer every day but I think you’ve just got to try and think there’s so many more people that are surviving who are benefiting from it* [DBR] *uhm* (DB 13)

‘I love the way that in dragon boating we say good bye to the ladies who have passed on. I think it’s a really healthy happy thing, uhm, I think it’s good to do the flower ceremony, as we do, and carry on as a club, and those who have passed away would really want us to carry on, so yeah, its I think it’s a healthy adjustment that happens every so often. Yeah it’s kind of taking stock of where we have come from, and not everybody does come through…’ (DB12)

The following extracts capture the essence of the dyadic way in which dealing with conflicts was reported in the stories:

‘I think it would be helpful for the team to make that distinction [between those team members who want to compete to a high standard and those who don’t] *and not to make a judgement of people who either choose one*

way or the other but just accept that we have different goals in life and different purposes and actually it will be OK to switch between the two streams…' (DB 12)

'…a whole bunch of ladies all together: you get your disagreements:: and not everybody gets on with everybody else but you've got to accept people for who they are and sometimes when they do things that annoy you, you just have to think well that's their way but it's not mine…' (DB 13)

4.3.4 Associated

Frank (1995, p. 127) suggests that Quest storytellers talk of their own bodies, including pains and disfigurements in sensuous detail and that their association with their bodies allows them to feel their own pain and to see the pain in others.

'…*when you walk in* [to the club house before a paddling session] *somebody could pop up to you and say 'are you alright? And uhm you think – how do they know I'm not feeling top notch today?* (DB 6)

Importantly, he suggests, that body association is 'the ground of dyadic relatedness, just as dyadic relatedness and desire are inseparable' (Frank 1995, p. 127). This desire to reach out to others and to make a difference in their lives was strongly evident in the stories and could be interpreted as one of the important positive impacts of the DBR experience for the storytellers. However, and this was stressed by a number of storytellers, the experience of DBR offered the opportunity to give, and receive, knowledge and support, but it was not the main focus of the experience (as they perceived applied to some breast cancer support groups), giving the impression that this was an important consideration.

'I think although you are aware you don't want to be reminded about it all the time, but that's one thing with [Team Name] *girls we don't dwell on anything, you know, if somebody has a real need they can talk about it but it's not something that we concentrate on, it's the benefits rather than the disadvantages'* (DB 6)

Perhaps the most powerful way in which body association was told in the stories was in relation to the fear of recurrence of their disease. While the latter was reported as a negative experience of DBR, a number of storytellers reported feeling inspired by the way other team members had coped in these situations and that they would now cope better, if faced with that situation, than they would before the experience of DBR.

'…I'm glad I met those lovely people and how they coped with it all and hopefully if it happened to me - you never know - do you?...I <u>*would*</u> *feel differently about it if I had it back in the other breast now and I had to lose my breast…at the time you sort of want to put your head in the sand and ignore what could happen…'* (DB 4)

In relation to body association one objective of this study was to gain some understanding of the BCS perception of the proposed expansion of the team to include other cancer survivors (e.g. prostate) - on them as individuals, and on the sustainability of the charity in general. It is of interest that none of the storytellers referred to this in their stories and one possible explanation being put forward by the researcher is that there may be a concern amongst team members, that this association with their bodies, which they shared in common, and which they highly valued, may be threatened with the introduction of other cancer survivors, who may have different experiences and perspectives.

4.3.5 Dyadic Body

Frank (1995) suggests that for the communicative body ' Seeking to be for the other, reaching out as a way of being does not mean rescuing this other from his own contingency …[but instead] to affect how the other understands her embodied contingency' (Frank 1995, p. 127) as the following extracts suggest:

'…and I think in some ways by talking about it we can help each other and everybody is there for everybody and we can push each other physically, and uhm, we're there for anybody mentally who needs help, or has any further problem, uhm …' (DB 4)

'I quite fancy meeting groups of people who were in a sort of terrified state like me that I could actually say, [I] *know what it's like, being through* [it], *I know what you're feeling, because nobody knows absolutely nobody knows unless you've been through it. '…so I'm doing the community activator*[18] *another positive thing. I feel it's putting something back into it, uhm.* (DB 1)

The sense of the importance of this unique shared understanding was expressed by almost every storyteller and was something that was highly valued as the following storyteller captures:

'… *I suppose it's just that you've shared that same experiences because you can say 'I know how you feel' but I don't think they* [non-BCS] *really do unless they have been through an experience and it's just like an unsaid like 'a little sisterhood'*…' (DB 9)

A related aspect of the dyadic body, as part of the communicative body, is what Frank (1995, p. 49) calls the 'communication of recognition that transcends the verbal [where] bodies commune in touch, in tone, in facial expression and gestural attitude, and in breath … [and suggests that] when bodies sense themselves in alignment with others, words make sense in the context of that alignment.' This was particularly evident in the stories and is captured as follows:

'…you just know they're on the same wavelength with you, one or two of them in particular you've only to look at them and sometimes it's just a hug or a peck on the cheek or something like that and you're connected again…' (DB 10)

A further interesting element of the dyadic body revealed in the stories related to the storyteller's anticipation and hope that through their membership of the DBR team - should they or other team members develop recurrent disease and die, or should their daughters develop breast cancer - membership of the dragon boat team would give them the

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[18] Community Activator – a local community project where cancer survivors volunteer to encourage other cancer survivors to become more physically active.

legacy of the support that they themselves had experienced. They also suggested that this could extend to partners and significant others.

'… it's really important to me as a woman that if the worst were to happen and I did die of breast cancer my husband and my boy can look to the group for support, and to me that's really encouraging, they don't need it, but it's really important that it's there, yeah ….' (DB 12)

4.3.6 Desire

'The desire in quest narrative is *productive* and importantly it is conditioned by its *dyadic* relationship to others'. (Frank 1995, p. 126) The latter was strongly expressed by all the storytellers.

Frank (1995) suggests that just as illness almost invariably plunges the body into lacking desire it can also instigate new reflections on how to be a body producing desire. 'Part of what becomes permitted is the exploration of desires' (Frank 1995, p. 39).

For the participants the stories produced as a result of their experience of DBR appeared to reveal a number of desires: to be 'normal', to share knowledge and concerns regarding their breast cancer remission society experiences – (although, conversely, they valued team membership because cancer and its related health issues were rarely discussed - but the opportunity existed to do so), to improve their physical health and fitness, including, to prevent or manage upper body morbidities (especially lymphoedema), to have fun, to appreciate beauty in the world around them, to receive and give social support, to increase their own team membership, work on, and support initiatives aimed at the maintenance and sustainability of their own team (e.g. affordability), developing more DBR teams, so that more BCS could experience what they were experiencing (camaraderie, hope etc) to have goals to aim for (e.g. through competition events), to experience the challenge of competition events. Additionally, one storyteller described how much she appreciated the relationships she had with team members, as it enabled her to satisfy her desire to have a 'normal' relationship with one, non-breast-cancer friend, in particular:

'...it's nice to go back to having in a normal relationship where breast cancer doesn't feature anymore, where you're just friends, like we were before breast cancer. She wants to be supportive, she's fantastic, but I really appreciate, especially that one friend going back to being normal again so that's good UHM...' (DB 12)

The desire to contribute in a positive way to the lives of their fellow BCS was universally expressed across the stories told in this study. This storyteller makes specific reference to helping younger BCS:

'... but the younger girls are sometimes bewildered, frightened, upset and all that's on their mind is cancer that's what it is for all of us, when we are diagnosed with cancer and to actually get in a big pink boat, with a load of ladies, and paddle, and laugh and get out and then compete, and also do this paddling, which is also very, very, good for your physical being, but mentally, it's such a great lift, and a positive lift, and uhm I hope uhm, everybody should have a go at it that possibly can, because it is so good, and I I'd like to support the younger people in particular, uhm to come through it....' (DB 11)

In the exploration of their desires, the stories suggest that the experience of DBR enabled them to ameliorate some of the negative consequences of remission society membership – *'part of their rehabilitation'* (DB 8) - and at the same time satisfy their desire to help others in the same situation as themselves. Competition events were reported positively and joyously and had a unique impact on every aspect of their lives. They appeared to provide a positive view, not just of the present, but of the future, through goal setting, through special memories and for some, it influenced their adherence to DBR. For the storytellers, competition events appeared to restore their 'sense of temporality' (Frank 1995, p.55), which was lost through their membership of the remission society.

'If we haven't got a competition that we are aiming for I lose the momentum to keep going, having the competitions is really important, because you've got to have a goal, we've got a time to beat ...' (DR 12)

'…*with breast cancer people it* [competition] *gives you something to aim for, it focuses you…'* (DB 10)

'…*obviously it is building up strength* [in relation to competition]… *just coming back from Venice that was* *__just__* *amazing, the support we all gave each other, it's just, I can't describe it, it's in my top five best* *__ever__*, *__ever__*, *experiences, because the bonding and the closeness of everybody that was there, it's just great* …'(DB 5).

The physical impact of competition events begins with improving fitness levels before the competition, and the physical challenge, joy and exhilaration of racing in 200 or 500 metre races, during it.

'…one really positive thing for me in the racing as a team, is the buzz when we first start racing, the buzz in the boat when all the girls, everyone's so happy and we're, we're overwhelmed by how well we've done…' (DB 7)

'…I think that it's all part of our rehabilitation, its uhm ((hesitates))…it does our wellbeing good, I think it uplifts your spirits, it does you good to be away all together, to get to know each other better, and uhm, overall it's a tremendous experience…it's a bonding thing…it's that network of support…'(DB 6).

The dyadic nature of desire was evident in the above extracts relating to the positive impact of competition events, but this also extended to the tension that was referred to by four members, in relation to the extent to which the team should be competitive. All expressed the desire to accommodate the needs of team members who were reluctant to increase the level of competition as the following extract captures:

'…we can do a bit of practising for competition, it doesn't mean to say that the others that don't want to be so competitive can't enjoy it too, because they only have to put in a few more minutes of extra exercise, and it's good for everybody, and they can pull their paddles out if they don't feel that they can, or that they really want to…' (DB 4)

The following storyteller has not yet taken part in a competition event, but hearing the stories, and seeing the pictures from fellow team members who have, has inspired her.

'I'm really looking forward to being able to do one of the events and uhm be part of, represent the team, represent what it stands for,' (DB 9).

Many storytellers made reference to having a greater appreciation of nature, especially the significance of the water, and the environment in which they paddle - a kind of spiritual awakening;

'You know you look at daffodils differently don't you ((chuckles)) you look at bluebells and marvel at that, you don't moan about things that are not important anymore'. (DB 1)

'Oh goodness me, and then the sunsets are so different, different times of the year, when it's the evenings are drawing in, it was <u>just uhm just</u> beautiful …' (DB 9).

'…you can't beat being out on the water with either the sunshine or even on a wet day it's still really enjoyable especially with like last night with the swans and other times there's been uhm kingfishers, and fish jumping out of the water, it's just lovely …'(DB 4)

The action problems of embodiment and the storyteller's responses to them (contingent, associated, dyadic, productive desire) form part of the self-story that is unique to the quest narrative (Frank 1995).

4.3.7 Self-Story

'Because the communicative body is dyadic, the self-story is never just a *self*-story, but becomes a self/*other*-story, and in telling such a story, the three issues of voice, memory and responsibility merge' (Frank 1995, p. 131). The latter are referred to as the three ethics of self-story (recollection, solidarity and commitment, and inspiration) (Frank 1995). Each of these will be considered in relation to the stories.

In quest stories the interruption is reframed as a challenge and the self-story hinges on answering the question “How did I rise to the occasion?” (Frank 1995). In the self-story the changes that enable the person to be more than she has been must go beyond simply claiming changes in character, and demonstrate these changes. Frank (1995) also suggests that the success of the story – its impact both on others and on the self – depends on how convincing this display of changed character is. For the BCS who chose to take part in the sport of DBR- to enable them to cope with membership of the remission society – their self-story, clearly demonstrate these changes.

‘I think [TEAM NAME] *is best, it’s the most positive, and there are discussion groups you can go around, … but to do something really, really, positive and be accepted as somebody who can compete along with, you know, just everybody’s in the same boat, and really enjoy it, and be healthier for it’* (DB 11)

‘I’m not very confident person by nature I’m not confident at all and to me when I’m on the back of the boat and I’m in charge of the boat there’s a little bit of me that comes back and instead of saying I can’t, it says I can, and I will, and it’s all very positive, and I think over the last year or so, since I’ve been helming, I think my confidence has grown on the boat, and when I’m on the back of the boat I know, I’m responsible, for 20 odd ladies on that boat…’ (DB 8)

Frank (1995, p. 115) also suggests that ‘…only in quest stories does the *teller* have a story to tell’ and this was true for all the storytellers in this study. Although all their stories were unique to them, they all shared this common thread of having risen to the occasion. In addition to overcoming possible negative challenges, as referred to previously, all accomplished the new skill of dragon boating, becoming team members, representing their team in competition, and in the case of international events, their country. The self-stories told in this study also incorporated the three ethics of self-story (recollection, solidarity and commitment, inspiration)[19]

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[19] Ethic of recollection – ‘… is practised when one who recollects shares memories of past action. Displaying one’s past to others requires taking responsibility for what was done’ (Frank 1995, p. 132)

as described by Frank (1995). Their recollections were mainly in terms of negative remission society membership experiences, or messages, and for solidarity and commitment they appeared to speak with one voice in delivering the positive message that DBR had many positive benefits and that it had enabled them to take on a new, more positive identity as a BCS – the latter was aimed not just at BCS but also the wider community - and finally in terms of inspiration, they recounted that they had been inspired themselves by members of the DBR team, and wanted to inspire others, to 'not just rise to the occasion but be more than they had been before (Frank 1995). The following extracts capture these messages:

'...just the fact that to begin with there was this myth that exercise was to be taken with care ...but we're able to do, we're able to do, this exercise and it can be quite strenuous and it's just for other ladies to know that they're able to exercise...'(DB 13)

'I just look at all those girls who paddle and they're just so full of life and happy and appear to be confident I'm sure some of them have got other insecurities uhm and I just find uhm some of them just a real inspiration and I just think well wow crikey and I'm just, things like that...'(DB 9)

'... it's just thinking of what some of those ladies have been through and how they, ... I'm thinking of a couple of them, they've had operations, and they are young, and they just take it all in their stride, and they go on, and they do more, and more, and more, get stronger, truly amazing people. I really am glad I've met them all...' (DB 4)

4.4 The Three Facets of Quest

Frank (1995) suggests that the range of quest stories is broad enough to make further specification useful and that they have at least three facets: memoir, manifesto, automythology (Box 3.3). The stories told by the

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Ethic of solidarity and commitment – '... is expressed when the storyteller offers his voice to others not to speak for them but to speak with them as a fellow-sufferer who, for whatever reason of talent or opportunity, has a chance to speak while others do not' (Frank 1995, p. 132)
Ethic of Inspiration '...Humans need exemplars who inspire. The heroic stance of the automythologist inspires because it is rooted in woundedness, the agony is not concealed'. (Frank 1995, p.133)

participants in this research study were a combination of all three, but automythology, was the most common facet. The storytellers described their experience of DBR as life changing for them.

4.4.1 Memoir

The memoir combines telling the illness story with telling other events in the writer's life. Frank (1995) suggests that it is the gentlest style of quest story. Trials are not minimized, but they are told stoically, without flourish. No special insight is claimed at the end; the insight ... is rather the incorporation of illness into the writer's life' (Frank 1995, p. 120). The memoir facets of the stories told by the BCS mainly tell of their lives before breast cancer and how DBR came into their lives. The following storyteller described how she had to overcome her dread of going back to the leisure centre where her husband died while swimming, ten years earlier, in order to take part in DBR.

'…I told the girls [her daughters] *about it* [DBR] *and they decided with me that if we went on mass as a family with the grandchildren and went to the swimming pool and …they would come along and support me…we were all absolutely dreading going in there, uhm, but it wasn't as bad as we expected, you know, so, it sort of laid ghosts, if you like, it sort of got us over that hurdle and uhm…'* (DB 2)

4.4.2 Manifesto

Frank (1995) suggests that manifesto is the least gentle style of quest story. The tellers of these stories believe that society is suppressing a truth about suffering and that the truth must be told. They want to use suffering to move others forward with them. The stories revealed possibly, five such truths; society's perception that the cancer survivor may be responsible for causing their cancer diagnosis, dispelling the image of the cancer survivor as victim, a message to society that cancer treatments are 'brutal', that after cancer treatment you do not return to full health, and the myth that it is not safe for BCS to exercise after treatment needs to be more robustly dispelled.

'I get really cross when people say about cancer that 'well I'm surprised she's got it I thought she was, you know, a healthy person' and that winds me up. (DR 4)

'... all those ladies there paddling have overcome the disease to a certain degree, it might come back again, but we're out there we're proving to the world that we are survivors and I hate that, but we are, and that you can't run away from it ...' (DB 8)

'...the treatment as you know is quite brutal...' (DB 3)

Although these extracts from the stories represent the views of individuals they were also expressed by others.

4.4.3 Automythology

Frank (1995) suggests that the predominant metaphor of automythology, is of the Phoenix reinventing itself, from the ashes of the fire of its own body. 'Automythology fashions the author as one who not only has survived but has been reborn ...Individual change, not social reform, is emphasized, with the author as an exemplar of that change' (Frank 1995, p.123). For the BCS describing their experience of DBR this was the most prevalent facet as the following extract suggests;

'all the ladies in the team were of the type that wanted to get on and do something positive with their life, and get something positive out of the negative' (DB 6).

Frank (1995, p. 52) also suggests that '...different bodies have "elective affinities" to different illness narratives'.

In their stories they described the challenges they had to overcome to experience, to varying degrees, the positive impact DBR had on their lives, and this was combined with a sense of self pride in their achievement.

'I really didn't think that at my age ... that I was going to be doing anything like this [DBR] *at all, having never participated in anything of this kind of thing ...* [describing what happened at her first contact with the

DBR team] *within ten: minutes I had a life jacket on, was given a paddle, I was in the boat ((laughs)) and it was fantastic, and I've never looked back, I've just really, really, enjoyed the whole time I've spent with [TEAM NAME] very supportive, everybody is very helpful … it's just a supportive system, and a very healthy one, where I just got stronger and better …'*(DB 11).

'…I'm not really keen on water. The thought of getting in a boat made me really nervous …[but] *I thought I'd do it just for one week, but then the next week I went back and I got hooked ((laughs)) and it was brilliant…'* (DB 13)

'…with a little bit of fear and trepidation, because I am not a particularly strong swimmer, but I went there [to join the DBR team on the river] (DB 3)

These extracts capture their joy in having experienced, not just the physical act of paddling, but of team membership, and the positive impact it had on their remission society membership experiences, as well as having risen to the challenge of overcoming their fear of water.

4.4.4 Power/Limitations

Frank (1995, p. 134) suggests that 'The story is the means for perseverance, to become active, reaching out to others, asserting its own ethic'. Similarly in this study the power of the quest story, as it relates to the experience of DBR for BCS, demonstrates the storyteller's perseverance in dealing with their remission society experiences, to be themselves transformed (Frank 1995), and to reach out to others, and to asserting their own ethics of recollection, solidarity and commitment and inspiration to support the transformation (Frank 1995) of others.

The power of the quest stories, and in this context the experience of DBR, appears to originate from a number of sources:

- The power that comes from being part of a large group who share a common experience. For example, the powerful message that the international community of BCS who participate in the sport of DBR deliver, not just to fellow BCS but the wider community, that, contrary to current thinking, BCS can participate in a physically demanding sport that requires stamina and concentration, and lead full and active lives.

- The power that comes from gaining back some control through exercise and competition. One way in which this was revealed in the stories is through greater self- confidence and self-esteem.
- The power that comes from mastering a new challenge and taking on a new identity as a sportsperson and athlete and having the opportunity to represent their country in competition, for some this may be the first, and only time in their life when they may be able to experience this and it was greatly valued.
- The power that comes from being part of something ‘special’. Many of the storytellers expressed pride in being associated with something that was unique, positive, and valued.

While all of these examples of the power of quest stories in relation to the experience of the impact of DBR for BCS, have been positive, Frank (2010, p.150) warns that, for storytelling in general ‘Its danger lies in its power’. He suggests that ‘stories put listeners in the position of hearing only one perspective or one slice of reality. This selection is already an evaluation, because it excludes from consideration other slices seen from other perspectives’ (Frank 2010, p.150). This was a concern for the researcher in this study, as she was an insider, there was a possibility the storyteller might feel the need to tell only the positive aspects of their DBR story. To reduce this risk, storytellers were encouraging to tell what they perceived were the positive and the negative aspects of their experience of DBR, as having a true reflection was important, if the study was to benefit themselves and other cancer survivors. Reflecting with, and on, the stories they told, the researcher believes, that in this study the storytellers told their stories from more than one perspective. In addition to this limitation of storytelling in general, Frank (1995) also identified limitations of quest narratives.

4.4.4.1 Limitations

Frank (1995, p.135) identified four limitations to the quest story (listed below) and while It is possible that all four limitations could apply to quest stories told in relation to the experience of DBR for BCS, thinking with[20] the stories suggests this may not the case. Each will be considered in relation to this study.

1. **Falling into the hubris that one's voice can ever be entirely one's own, is one of the failures that quest stories risk.**

The storytellers were consistent in their acknowledgement of the significance of the team spirit, as well as the support of people outside of the team, in being able to achieve what they had achieved through their participation in the sport of DBR. They also acknowledged how much they gained from being inspired by other team members.

2. **They risk romanticizing illness**

In the stories the storytellers did not romanticize illness but acknowledged their on-going health issues and the contingencies associated with a breast cancer diagnosis, but opted to do something positive with their life, and taking part in DBR, was one aspect of this.

3. **They risk giving the impression that the transformation is too complete.**

The storytellers all expressed the negative impact the risk of recurrence of the disease had for themselves, or recurrence or death of a team member - constantly reminding them of their vulnerability and the impossibility of a complete transformation.

4. **They can implicitly deprecate those who fail to rise out of their own ashes.**

Storytellers acknowledged that DBR would not appeal to everyone but hoped that their participation in DBR would encourage other BCS to realise that they could lead full and active lives after breast cancer, either through DBR or through some other means. However, it has to be acknowledged that the sport of DBR may be implicitly deprecating

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[20] 'Thinking with the stories' – Thinking with the stories takes the story as already complete; there is no going beyond it. To think with a story is to experience it affecting one's own life and to find in that effect a certain truth of one's life' (Frank 1995, p. 23)

for some BCS who have not found a way to ‘rise to the occasion’ (Frank 1995).

In more general terms the main limitation of the quest story, describing the experience of DBR for BCS, is that the experience is limited to BCS who are confident and willing to go into a boat with up to 19 other people. Being able to swim at least 50 metres is a recommended condition of entry (although not everyone meets this recommendation). It was also alluded to by one storyteller that one member had left the team because she could not cope with being confronted by news of recurrence of the disease, and death, in other team members. This may also prevent some BCS from joining the team. It is also a physically demanding sport and deterioration in a participant’s health can mean they are no longer able to take part. Coping with relationship difficulties and tensions regarding the degree to which the team should be competitive may also be challenging for some people.

4.5 Moving between Narratives

Repeated reading of the stories and reflective diary, as well as listening to the tapes, and the use of Frank’s frameworks (Frank 1995) to analyse the stories has revealed, what the researcher believes, could be regarded as the five influential, and commonly shared inspirations of the impact of DBR on the storyteller’s remission society membership experiences, and which prompted the storytellers to move between narrative types. They are; Dragon Boat Racing[21] (‘In the Boat’ - to include a greater appreciation of nature), social support/social support networks, competition events, team/group membership, physical and psychological changes. These divisions are for convenience only, because they naturally overlap or iterate with each other throughout the stories. These five inspirations will be used in chapter 5 to support the execution of the weave metaphor (Frank 1995) to capture the movement created by their pre DBR

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[21] While it may seem strange to the reader that DBR has been identified as an inspiration, when the whole study is about the impact of dragon boat racing, it was evident in the stories that the visual image of the women in the boat as well as being physically seated in the boat, was experienced as an inspiration in its own right.

experiences, to reveal the pre DBR weave, and the remission society membership experiences modified by DBR, as the DBR weave .

4.5.1 Summary

In describing the overall positive experience of the impact of DBR on their remission society membership experiences, although there were some negative experiences, the storytellers in this study have revealed that the impact is interwoven, into almost every aspect of their lives, and that it has not just helped to ameliorate the impact of their remission society membership experiences, but goes beyond that, in that, they have experienced some degree of transformation (Frank 1995), to become more than they were before.

Chapter 5: The Narrative Weave

'…illness stories mix and weave different narrative threads. (Frank 1995, p.76)

'…any unique story is fabricated through a weave of at least three core narratives, which I call the restitution narrative, the chaos narrative, and the quest narrative' (Frank 2010, p.118)

5.1 Introduction

From thinking with and about the stories told in this study this chapter will adopt Frank's (1995) metaphor of weaving (as in the above extracts), to illuminate the experiences of BCS, as remission society members[22] (Frank 1995), pre, and as a result of their experience of DBR, and how, the experience has impacted on their lives. As outlined at the end of the previous chapter five influential inspirations; Dragon Boat Racing[23] ('In the Boat' - which includes greater appreciation of nature), social support/social support network, competition events, team/group membership, physical and psychological changes have been identified. These are not separate experiences but are inextricably interconnected and interwoven. They will be interpreted, as the stories suggested, as inspirations that prompted the weavers (BCS) to change the weave pattern, representing the constant movement of the three narrative types, from the foreground to the background. In the weave the inspirations are represented by a flecked thread comprising five colours each fleck representing an inspiration felt by the women.

This chapter is presented in four stages; firstly, an extract from one story will illuminate the notion of the five influential inspirations, this will be

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[22] After his own experience of having cancer Frank (1995, p. 8) used the term '"remission society" to describe all those people who like him, were effectively well, but could never be considered cured, and that the many contingencies associated with this membership meant that although they were living in the world of the healthy they were always subject to expulsion.

[23] While it may seem strange to the reader that DBR has been identified as an inspiration, when the whole study is about the impact of DBR, it was evident in the stories that the visual image, as well as being physically seated in the boat, was experienced as an inspiration in its own right.

followed by an explanation of the concept of the weave to include two illustrative scenarios, and finally the weave incorporating the five influential inspirations (but beginning with the pre-DBR weave) . Additionally, three weave scenarios are presented visually at the end of a later section 'The Concept of the Weave'

5.2 The notion of the five influential inspirations

Extracts from the following story (DB 11) will introduce the notion of the five influential inspirations (Dragon Boat Racing 'In the Boat' - which includes greater appreciation of nature), social support/social support network, competition events, team/group membership, physical and psychological changes, and how they are woven into, and become an integral part of the storyteller's life, beginning with her motivation to join the team.

Her story began when she saw a '*poster above …* [her] *bed when …* [she] *came out of theatre with a lovely picture of the* [TEAM NAME] *boat and girls in it …'* One evening after her treatment had finished she described how she …'*bravely went along* [to where the team was based] *thinking, well, I'll have a look, I'll have a chat, I'm on my own, I need to do other things and keep busy and I'll see how this goes…I really didn't think that at my age … that I was going to be doing anything like this* [DBR] *at all, having never participated in anything of this kind of thing …* [I] *was made very, very, welcome, everybody welcomed me… within ten: minutes I had a life jacket on, was given a paddle, I was in the boat ((laughs)) and it was fantastic, and I've never looked back, I've just really, really, enjoyed the whole time I've spent with* [TEAM NAME],…*to actually get in a big pink boat with a load of ladies and paddle and laugh and get out and then compete and also do this paddling, which is also very, very, good for you…*[it is] *very supportive, everybody is very helpful … it's just a supportive system, and a very healthy one, where I just got stronger and better …* uhm, *from the dragon boat paddling, and things that go with it, like the exercise classes, where we warm up ((*smiling excitedly*)) … but uhm, physically its good, but also mentally. I went through a depression prior to joining and this has just sailed me through just absolutely brilliant* *so it's been really, really, good and I want to continue for as long as I possibly can ... we have a competition coming up and we're going to Venice in a few weeks' time. I'm really looking forward to that, last year ((*smiles*)) we went to Florence, and we competed in Dublin, both of which I really, really enjoyed and in 2014 we are actually going to America, so we'll keep fit...it's been a really positive experience for me...and the lovely area that we uhm do our training in... and I'm really happy to be part of* [TEAM NAME]*...'*

5.3 The Concept of the Weave

In this exercise no attempt is being made to present an authentic weave merely that the metaphor captures the constant movement between the three narrative types (Restitution, Chaos and Quest) (Frank 1995), from the foreground to the background and that the weave created is never ending. The reader is invited to imagine that the weaver (BCS) is inspired to create a weave pattern prompted by her remission society membership experiences pre DBR, or her remission society membership experiences modified by the impact of her DBR experiences.

Weave in this context means fabric created by interlacing two distinct sets of yarns at right angles. The longitudinal threads are called the warp and are represented by three columns of four threads, each column represents one of the three narrative types, and each has its own thread colour (Chaos = dark grey, restitution = green, quest = yellow). The significance of each narrative type, at any particular moment in time, is represented by the number of its threads (0-4) which are foreground (no formula was used, the numbers were not drawn from the findings, simply illustrative). For example, if chaos is strongly evident in the story being told it will be represented by 4 threads and if least evident by 0 (when chaos will be background). The two optional lateral threads, that cross them, are the weft or filling threads; one, representing remission society membership experiences (red) and the second the red flecked thread representing remission society membership experiences that have been modified by the impact of DBR experiences. The flecks represent the five inspirations. An observer looking over the weaver’s shoulder and observing the weave being created will know which narrative type is foreground, and which is background, and also whether the weave pattern has been influenced by a remission society membership experience (red weft thread) or a modified remission society membership experience (red and flecked weft thread), at that particular moment.

Although the notion of a weave is simplistic it attempts to visually capture, what the stories revealed, as the constant movement created by the ever changing impact of membership of the remission society on BCS, where ‘… the foreground and background of sickness and health constantly shade into each other’ (Frank 1995, p. 9)’, and describe how the experience of DBR as an activity, impacts on the issues that lead to this ever changing pattern Figures 5.1, 5.2, 5.3).

Figure 5.1Pre-DBR Weave

Figure 5.1

Pre-DBR Weave

(1 Restitution and 3 Chaos threads in the foreground and 3 Restitution, 1 Chaos and 4 Quest threads in the background)

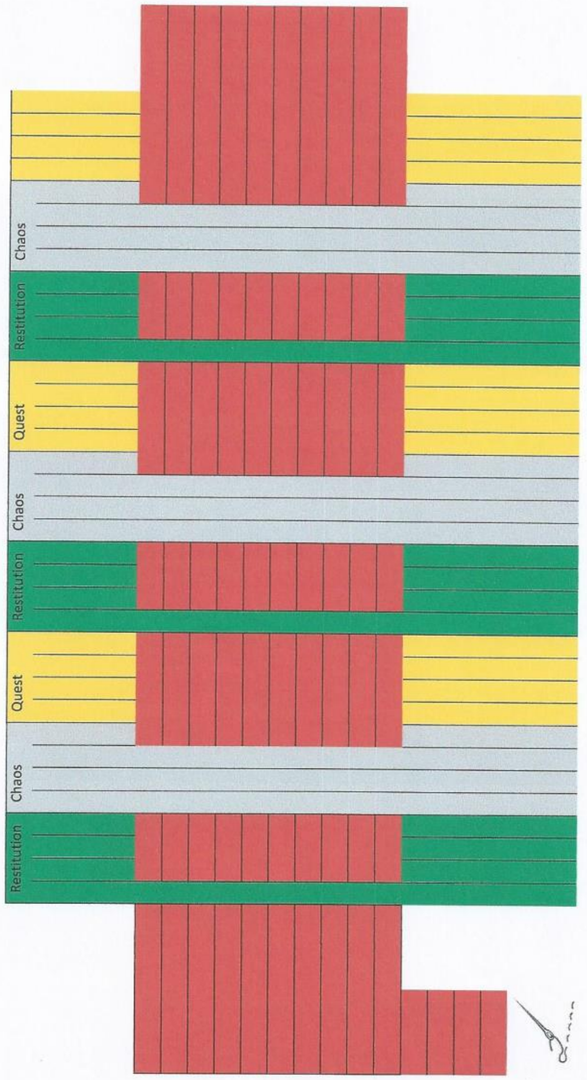

Figure 5.2DBR Weave

Figure 5.2

DBR Weave

(1 Restitution, 1 Chaos, 3 Quest threads in the foreground and 3 Restitution 3 Chaos and 1 Quest thread in the background)

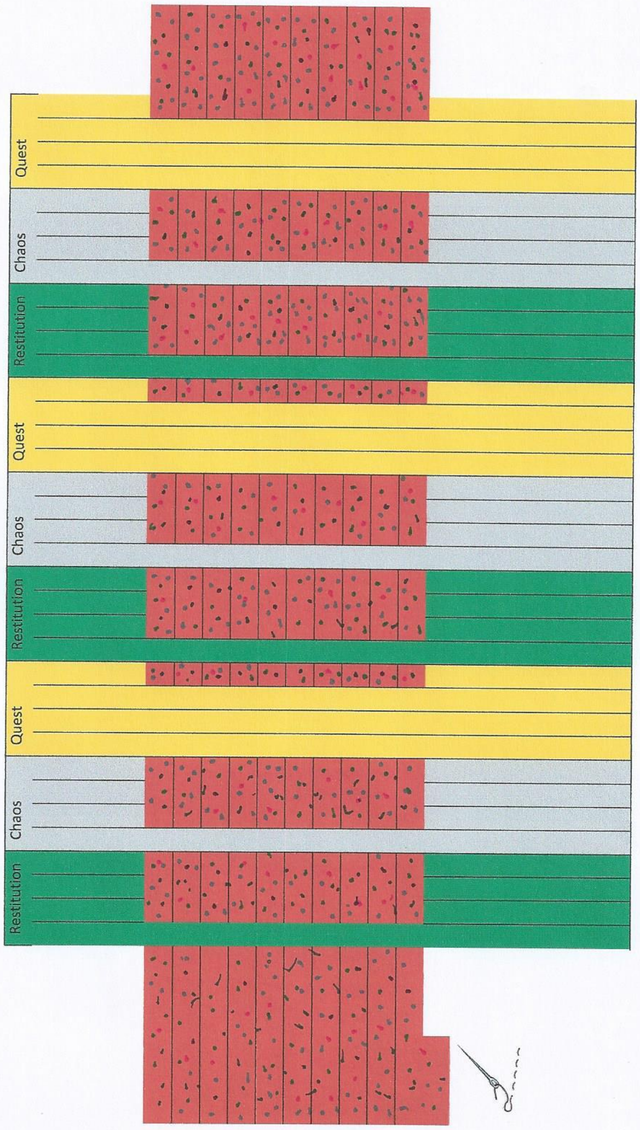

Figure 5.3Competition Event DBR Weave

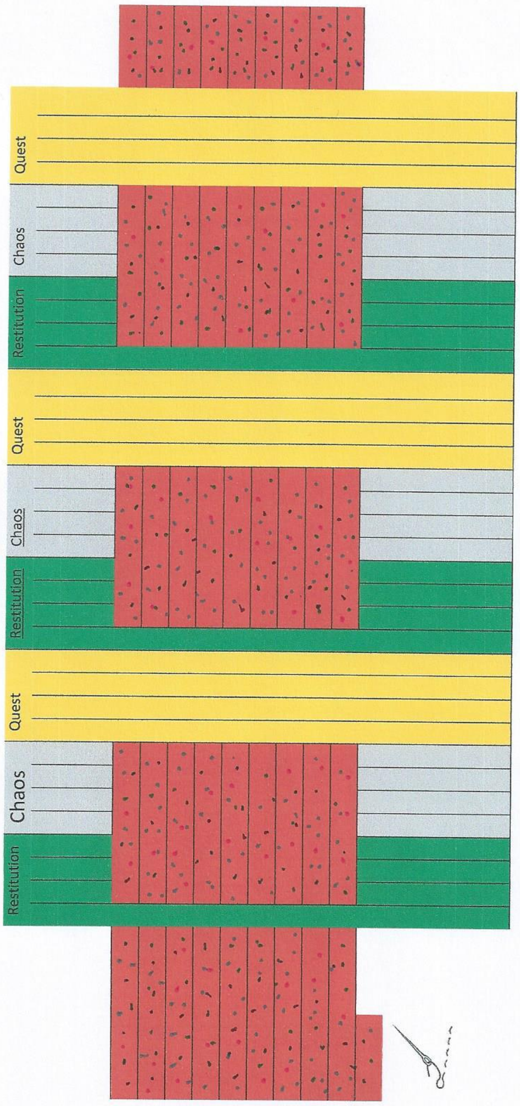

Figure 5.3

Competition Event DBR Weave

(1 Restitution and 4 Quest threads in the foreground, 3 Restitution and 4 Chaos threads in the background)

5.3.1 Creating the Weave

Depending on which of these two experiences (the remission society membership experience (pre-DBR), or the same experience modified by her DBR experience, are affecting the weaver at any particular moment in time she will be inspired to select the appropriate weft thread (red **or** red flecked thread) and using the needle attached to the end of it, goes under or over the threads in each of the four columns chaos (dark grey), restitution (green), quest (yellow) to have the effect of moving threads to the foreground or the background depending on the inspiration that is prompting the weaver at that particular moment in time.

The following two scenarios (based on the stories told in the study) aim to illustrate the concept:

Box 5.1 Scenario 1: 'Pre-DBR Weave' (Figure 5.1)

To create this weave the weaver, prompted by a remission society membership experience, for example, a persistent new ache or pain, may be thinking '*...Oh my God... is it* [the cancer] *coming back?...*' (DB 6), making her acutely aware of her remission society membership, and in relation to the control component of the action problems of embodiment, she is most likely to feel '...swept along without control...' (Frank 1995, p. 102), which will influence her weave pattern such that she will be inspired to select a red thread (weft)-remission society membership experience, and using the needle to which it is attached she goes under one and over three green threads – (restitution) – due to her adjuvant treatment, under three and over one dark grey threads (chaos) and over all four yellow threads (quest) repeating this all the way across the columns of longitudinal threads. The foreground narrative types are now 1restitution and 3 chaos threads with the red thread of the remission society experience woven horizontally through them. 3 restitution 1 chaos and 4 quest threads are in the background and visible on the under surface of the weave. This is the weave that will represent the narrative type guiding her story until she is inspired by either the next remission society membership experience, which may perpetuate her chaos narrative, or some investigation that discounts recurrent disease, when some or all of the chaos threads will move to the background.

Box 5.2 Scenario 2: 'DBR Weave' (Figure 5. 2)

Continuing with the BCS in scenario 1 who fears she has recurrence of her disease, and whose weave now has one green thread (restitution) and three dark grey threads (chaos) - in keeping with being at the contingent end of the predictable/contingent control continuum (Frank 1995) - because of the impact of this fear. She has recently joined the DBR team – we will assume that she became aware of her symptoms just before she joined the team - and decides to '*speak*[s] *to somebody who* … [she] *knows been through it and understands* <u>*exactly*</u> *what* … [she's] *feeling like*…' (DB 1). After speaking to a fellow team member she is reassured when she learns that other team members also experience this symptom from time to time and that it often disappears after paddling. This fusion of the remission society membership experience of fear of recurrence with the sharing of the knowledge and support of her fellow team members has modified her remission society membership experience such that she feels inspired to rise to the challenge of managing her remission society membership experiences, and is prompted to adjust her weave such that some quest threads are moved to the foreground, and chaos to the background. Hypothetically we can suggest a weave that now has one green thread (restitution), one dark grey (chaos) and three yellow (quest) in the foreground, with the flecked red thread (the experience created by the impact of DBR on her remission society membership experience) woven horizontally through it. This will remain her weave pattern until her next remission society membership experience.

Before going on to consider the pre-DBR and DBR weaves it is important to reiterate what the term remission society membership and DBR means in the context of this study. It will be supported by an extract from one of the stories. As discussed in Chapter 4 membership of the remission society may involve more than the cancer survivorship experience (diagnosis, treatment, side effects) to include cultural and social impacts. For example one storyteller alluded to the distress she felt because of her husbands' apparent failure to acknowledge her illness, as manifested by his suggestion that she should, just get on with life, and on his insistence, that she continue to prepare his evening meal, even when she felt fatigued by her treatment. Thinking with this and other stories, Frank (1995, p. 160) suggests, one should ask, 'how the present illness fits into the pattern of these people's lives…'? For this storyteller the answer could suggest that her remission society membership is affected negatively by; her fatigued body, a culture that treats health as the normal condition that people ought to have restored (Frank 1995, Mullan 1984, 1985, 2006, Sontag 1978, Conway 2007, 2013, Peltason 2008), and her relationship with her husband, leading to what she perceives as poor emotional, social, and practical support, while trying to cope with chemotherapy treatment, which she described as '*awful*'. There is a loss of control in terms of her health, but also in her personal life. Prior to DBR, her remission society weave is likely to have been 1 green thread (restitution) and 4 dark grey threads (chaos) in the foreground and 4 yellow threads (quest) and 3 restitution threads as background. In her story she reported that after a DBR session she always felt better, that dragon boating really boosted her confidence, it gave her something to look forward to each week and in particular her newly acquired skill of helming the boat. For her being in charge of, and responsible for, the twenty people on the boat, gave her back control – in her story she reported; '*…there's a little bit of me that comes back* [when she's on the boat] …'(DB 8). Here we see that the experience of DBR, by making her feel better and increasing her confidence has altered her weave to move chaos (dark grey) to the background and move quest (yellow) and the single green restitution to the foreground. The latter is now likely to include 1 green thread (restitution), 2 dark grey threads (chaos) and 2 yellow threads (quest)

The impact of DBR as described here and as captured in other stories includes not just the physical act of paddling but also includes the dry land fitness training, competition events, social elements such as fundraising, community activities, etc. While the stories suggest that the paddling was important to everyone, storytellers chose which of the other elements they got involved with. For example, one storyteller could not imagine life without the paddling and the competition events but chose not to get involved with any of the others elements. It was the impact of their chosen combination that gave the experience of DBR its richness from the perspective of each storyteller.

5.4 Pre-DBR Weave

The reader is invited to imagine that the weaver's (BCS), pre DBR weaves, were inspired by the shock of their diagnosis (Phase 1 Chaos) to move their 4 chaos narrative threads (dark grey) to the foreground of the weave, so that restitution and quest are background. When they began primary treatment (surgery, chemotherapy, radiotherapy) (Phase 1 Restitution) and, in keeping with the restitution narrative - when the possibly of cure is believed to exist, the four restitution threads (green) were moved to the foreground, and two of the four chaos threads were moved to the background. Moving 2 chaos threads to the background reflects the weaver's perception of regaining some control of the disease through her primary treatment regime but some chaos remained, principally because of the body image concerns reported post-surgery, and for the weavers who described chemotherapy as '*brutal*' and '*horrific*'.

However, at the end of primary treatment the chaos intensified (Phase 2 Chaos) as discussed in Chapter 4. The phase 2 Chaos brought back a weave pattern where; the foreground was made up of 4 Chaos and 1 Restitution threads and in the background the three restitution and four quest threads. As stated previously, the single restitution thread represents the adjuvant breast cancer treatment that is usually prescribed for at least 5 years from the end of primary treatment, plus self-care measures such as exercise classes, Reflexology, Emotional Freedom Technique, Support Groups, (Phase 2 Restitution Effort) which the storytellers hoped would play some part in restoring their health.

5.5 DBR Weave

In the DBR weave the weavers are inspired by their DBR experience (as an activity) to modify their remission society membership experience, such that the weavers (BCS) adjust the weave by moving some chaos threads to the background and/or bring yellow threads (quest)[24] to the foreground, and the weft thread now changes to the red flecked thread constantly adjusting the weave pattern to capture the impact, as the movement from the foreground to the background of the two narrative types (Chaos and Quest) - 'The particularity of any experiential moment can '… be described by the narrative type that predominates at that moment' (Frank 1995, p. 76). It will be called the 'DBR Weave'. The single green (restitution) thread remaining constant to represent adjuvant therapy.

All of the stories suggest a sense of movement to a new place at the point of joining the team, and that almost immediately, the dyadic component of the quest narrative comes into being, where, as Frank (1995) suggests, the teller of the story has been given something by the experience, usually some insight that must be passed on to others. To help the reader appreciate the significance of the five influential inspirations they will be illuminated through the stories told by three storytellers, in particular (DB 1, DB 3, DB 9) although there may be contributions from others.

'… *I held myself together during it* [the treatment] *but when it was over …uhm I got very worried, very anxious, every twinge, every little pain, you wondered* [was it the cancer coming back]*, I felt adrift*' (DB 1) (Pre-DBR)

'…the treatment as you know is quite brutal and affects people in very, very, different ways, psychologically uhm it affected me a little bit psychologically because of the disfigurement uhm which I felt slightly

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[24] The genesis of the quest narrative is some occasion requiring the person to be more than she has been, and the purpose is becoming one who has risen to the occasion. In the stories the occasion was the experience of membership of the remission society, while the experience of the impact of DBR enabled them to rise to the occasion and become more than they had been before. Their decision to seek out or respond positively to an opportunity to take up DBR is in keeping with the plot of the quest stories where they meet suffering head on; they accept illness and seek to use it (Frank 1995). Their route of entry to DBR could be interpreted as a way of illustrating how they attempted to meet suffering head on, the other two elements (accepting illness and seeking to use it becoming evident only after they experienced DBR.

((hesitant)), less feminine, and that was hard to take for a while' (DB 3) (Pre-DBR)

'…I think when you've just come out of chemo and everything and your body confidence and your confidence is really … very low…and because I was feeling vey unfit at the time uhm I didn't make contact with the team … Then it was on the BBC [that] *exercise … reduces the risk of cancer recurring and* [Team Name] *were actually on the news, so I emailed* [team secretary] (DB 9) (Pre-DBR)

5.5.1 DBR ('In the Boat' - to include greater appreciation of nature)

Their first sighting of the team, was recounted in almost all the stories in a joyful, positive way, suggesting it had a powerful impact on them and was one of the key points where the weaver (BCS) would have used the red flecked thread to adjust the weave such that 2 yellow threads (quest) were moved to the foreground and 2 dark grey (chaos) to the background. The single restitution thread remaining in the foreground and three in the background. It appeared to signal the beginning of their transformation through the inspiration of; the visual impact of seeing BCS as sportswomen, being happy, and having fun, being in the boat with fellow BCS, the physical act of paddling and their appreciation of the water and the beauty of the natural environment around them.

'*So I went ((*talking through tears*)) to the boat and there were women there all had breast cancer, all alive … I saw people laughing, being jolly, and having a good time on the boat… I saw people with cancer actually having a nice time ((*gentle sob*)) so I thought right this is it, this is what will help me and it did help me…* (DB 1)

'…with a little bit of fear and trepidation, because I am not a particularly strong swimmer, but I went there [to join the DBR team on the river] … *not knowing what I was getting involved in <u>at</u> <u>all</u>. I thought I was just being a spectator but to my amazement and surprise ((*laughs*)) I was asked to actually go into the boat…I think my first impression was, not so much, the exercise, it was the beauty of the river that took me. We were …*

paddling down the river… and it just, captured my imagination, and the beauty of it, and I thought I would come again the following week … that was the start of getting more actively involved in what the benefits could be to me as a person and the camaraderie I could see that seemed to exist with the … members…' (DB 3)

'…*it* '[her first experience at the boat] *was lovely absolutely lovely and I really wish I'd done it before UHM [I] was made …* [to] *feel really, really, welcome, everything was explained really, really, well uhm ... it's just the most amazing experience … The setting is just gorgeous <u>just</u>: <u>gorgeous</u>: I can't think of anywhere else that would be more perfect to be honest with you uhm' (*DB 9)

The stories revealed that in addition to the paddling, which was reported as the most important element – '*… it's the being together and actually doing the paddling* ...' (DB 6)

Thinking with and about the stories, every storyteller in this study referred to their joy and appreciation of the natural beauty of the water and the overall environment in which they paddle, and for some the appreciation extended beyond the water to include nature in general.

The following storytellers appear to capture this fusion of the feeling of connectedness between the storytellers, the physical act of paddling and the fun they enjoyed within an environment that in turn seems to connect them with nature in a way that is meaningful to them.

'…I've always been frightened of the water you know…but just the experience of actually sitting in a boat paddling down the river, it was just amazing, there is just something, I don't know, just something very calming about the water and being with all the girls…' (DB 6)

'…uhm you know just all having that <u>connection</u> and so much fun in that boat…it's just the freedom, the exhilaration of being out on the water…' (DB 2)

5.5.2 Social Support/Social Support Network

In the stories there was evidence that the experience of DBR was unique in that it offered the storytellers social support on a number of levels; at an individual level – as in the extract above, at the level of a team member, as members of the national and international community of BCSDBR paddlers, and through the support, and potential support it offered to significant others. It was also highly significant that DBR enabled them to offer support to others, an expression of the dyadic component of the communicative body and the quest narrative.

As previously suggested, membership of the remission society was reported as being associated with social isolation, and 'survivor loneliness'[25] (Rosedale 2009) - even for storytellers who reported that they were not socially isolated in the conventional sense. In the stories told in this study the social isolation began at diagnosis, and appeared to intensify at the end of primary treatment, when contact with the hospital team and the network of support it offered finished, and suddenly '…*you feel yourself thinking what now...you feel very much on your own*' (DB 6). The 'survivor loneliness' relates to the BCS perception that people who are not members of the remission society '*just can't, they can't realise* [what it's like to have a cancer diagnosis and treatment]' (DB 1), this includes their family as well as their current social network.

Some storytellers reported that they joined the team specifically to get this social support from people who '*were on the same wavelength*' (DB 10) while others reported that it was an unexpected additional positive experience.

'…although we did not talk about our experiences very much but we knew uhm that support was there if you did have a problem or if you wanted to talk about something it was done in a supportive matter of fact way uhm *which you don't get when you talk to friends about it who'd never been*

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[25] Survivor loneliness – '… alone in the awareness of mortality and … invalidated in the experience of ongoing symptom burden, a changed sense of identity and connection and an altered threshold for distress that pervaded their long-term experiences'. (Rosedale 2009)

through it, because they don't understand, truly understand what the process is – they'd heard about it but they don't really truly understand…' (DB 3)

'[DBR, as well as the fitness] … *it's also having people there, where if you have a daft question, and because that's exactly what I would do now, if I had something if I was worrying about, I would ask one of the girls, definitely, wouldn't bother anyone at the hospital, or it's a social thing, its shared experience thing, its I just think yeah the social side is also really important, I don't mean social as in going out drinking, but is actually having shared experiences, with the benefit of the fitness and the paddling uhm yeah* (DB 9).

The social support was also experienced through sharing of information and knowledge, e.g. about symptoms, treatments, self-care behaviours such as massage, clothes, and emotionally e.g. through friendships as the following extract reveals;

'…*I found the dragon boat team is good for that, uhm, other ladies have had the same sort of thing, and often you can hear snippets of conversation, somebody else felt like that, or somebody else has been there, or that sort of thing'* (DB 10).

The following story extract refers to a storyteller recounting how guidance on how to do massage as part of a lymphoedema self-care routine, which she had previously not adhered to, was more effective coming from a fellow BCS than a health professional.

'*I have no time to sit there and do that* [self-care massage for lymphoedema] *((laughs)) but when we were away in Venice …one of the girls in our flat regularly does the massage and so she was tutoring us others who don't do it and that was much more effective and more informal, and it felt more comfortable to learn about lymph massage that way than it did from the lymphoedema nurse who never really does it for real, so uhm, yeah, that's [a] much better way to learn …'*

Storytellers used a number of words and phrases to convey their experience of social support such as *'camaraderie'*, '*connectedness*', '*a* *little sisterhood'*, *'all in the same boat'* but regardless of the term used, the social support they experienced had a positive impact on their ability to cope, not just with the challenges that membership of the remission society presented but with enabling them to be more than they had been before, particularly through competition events.

As mentioned at the beginning of this section the social support was experienced at an individual and at a team member level. At an individual level it was in relation to personal issues, as well as the support offered to function within the team environment, e.g. learning paddling skills and meeting individual's specific needs. At the team level, team members reported feeling the support that comes from being identified as a member of the team whether during regular practise sessions on the water, '…*you get such a lovely response from everybody* … [we seem] *to get a lovely warm welcome everywhere …*' (DB 9), or representing '… *our country, our team, our ladies* …' (DB 10) in competition events away from home.

While all of the above refers to the positive impact social support, through DBR, had on the storytellers, additional benefit and further alteration of the weave to include more yellow threads (Quest), could be gained from providing social support to other BCS, and the wider community of women who have not yet been diagnosed with breast cancer, where it was perceived that the positive image of survivorship, as portrayed by participation in DBR might make a diagnosis of breast cancer less daunting for them.

'…I've now volunteered to become an activator[26] *uhm … we hope to have our first health walk ah next week or so and then eventually hopefully we shall be able to take out people who have also gone through cancer and hope that we can give support to them in the way that* [TEAM NAME] *and paddling has given to me and in that way its …opened yet another door…'* (DB 3)

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[26] Activator – community project promoting physical activity for cancer survivors

'… the chance to become an activator came up and I thought … I quite fancy meeting groups of people who were in the same sort of terrified state like me, that I could actually say…I know what you're feeling, because nobody knows unless you've been through it … I feel it's putting something back into it uhm' (DB 1)

This giving as well as receiving is a core element of the dyadic nature of the communicative body (Frank 1995). As referred to previously this desire to support others was not reported in the stories until the storytellers had experienced the transformation that originated, from the impact DBR had on their remission society experience. From this point a strong desire was expressed by all storytellers to support other BCS who were experiencing what they had experienced, and to show them that there is life, fun, joy, hope, after breast cancer through the camaraderie as well as the support, to take on new challenges such as competition events. This was a desire expressed by all storytellers but two storytellers made particular reference to wanting to support younger women, who, one storyteller perceived, are '… *bewildered, frightened, upset and all that's on their mind is cancer…*'(DB 11). Both of these ladies have daughters and did acknowledge that they worry in case they become affected by breast cancer. One expressed the view that realising there were organisations such as the DBR team, where they could meet other BCS, and belong to something positive, would be reassuring for her, should her daughter be diagnosed with breast cancer.

In terms of the weave in relation to social support, and the social support network the experience of DBR provided, it could be perceived that it permeates all aspects of the individual's life but its greatest impact would be in moving some chaos threads to the background, by for e.g.; reducing anxiety through sharing concerns with people who understood, the psychological benefits of gaining some control over e.g. lymphoedema, through information sharing around self-care practices, and the physical benefits of better management of e.g. lymphoedema, arm morbidities. Also the anticipation that should she or her daughter/significant other need support now or in the future it would be available. The desire to give support to others, which was referred to by almost every storyteller may be experienced as quest if the individual felt that they had not just risen to the challenge but become more than they were before.

5.5.3 Competition Events

The impact of DBR, by way of competition events, on the experience of membership of the remission society was reported as overwhelmingly positive, as in the above extract, and described by many as '*just amazing*'.

Eleven out of the thirteen storytellers had taken part in DBR competition events and the two who hadn't, expressed a strong desire to do so. Taking part in competition events, some in the UK, and some abroad, where they represented, not just their team, but their country, was something few, if any, of them had previously experienced. In thinking with and about the stories in relation to competition events a number of themes emerged which will be discussed to try to understand why, for example; a lady of 70 who has a fear of water, has never taken part in water sports before, would stretch herself financially to travel to a foreign country to paddle in a long narrow boat with 20 other people in a race situation. There was total consistency in the stories when they described the positive experience of taking part in competition events, regardless of age, time since diagnosis, or any other factors. Thinking about the weave in relation to competition events the positive impact as a quest experience would have begun as soon as the decision was made to take part in a particular event. This positive aspect of the pre-event stage was described as goal setting, having something to aim for, while also including team preparation in terms of paddling, improving fitness, and aiming to improve race times. Even the team spirit generated around planning the trip was part of this goal setting as well as providing some individuals with new experiences akin to event planning. Perhaps more than in any of the other inspirations, in competition events, the storytellers confirmed their entitlement to call their narratives, quest narratives, because, through these events their self-story not only claims the changes in character, but demonstrates them (Frank 1995), and in the midst of the celebration there is an acceptance of contingency. The following extracts capture some of these elements of the experience:

'…there was thousands of people there that had all had breast cancer…it brings home …how awful it is, but on the other hand you look at it on the optimistic side, and you think…all of those ladies there paddling, have overcome the disease, to a certain degree, it might come back again, but we're proving to the world that we are survivors…' (DB 8)

'…I think the competition side is really quite important because it focuses you … with breast cancer people it gives you something to aim for, it focuses you…' (DB 10)

'…it does our wellbeing good, I think it uplifts your spirits, it does you good to be away all together to get to know each other better, uhm, I think overall it's a tremendous feeling…' (DB 6)

'…it's been ascertained that we should perhaps do one international event each year which is wonderful because that really does bring the whole club together…I think we have to do a little bit more fundraising uhm to meet people's costs …particularly for people who can't afford to travel abroad so that the whole club is involved…' (DB 3)

'I would love to be able to come on the races, absolutely love to do that uhm…I just know that if ever I went [to a competition] *I'd just sit there and blubb because even just listening to them* [team members] *I'm feeling really, really, emotional about it …I'm really looking forward to being able to do one of the events and uhm … represent the team, represent what it stands for…'* (DB 9)

These extracts capture a number of the key elements also found in the other stories, including the sense that the sheer number of survivors present was important, interpreted as indicating the better survival from breast cancer, the positive image it portrayed of BCS - who were an inspiration, not only to other BCS, but to women in general, who may one day be diagnosed with the disease, and pride; in their individual identities as athletes and sportswomen, as members of their individual teams, and the international community of BCS. In relation to contingency the storytellers responded positively to the tradition of the ‘Flower Ceremony’ where each paddler lays a flower on the water to remember team members who have died, but the practice of survivors wearing labels on their person saying ‘10 years survivor’ ‘20 year survivor’ had a mixed response with some survivors reacting positively but one reported that she didn’t ‘*like that at all’* (DB 4)

The stories suggested that the strength of the social support network enabled individuals to take part in competition events, but that the competition events in turn, bonded the team, and further strengthened the support network.

One other benefit of competition events concerns the suggestion by some storytellers that not only did competition events impact on the other four inspirations but they were significant for some in encouraging their adherence to DBR.

‘If we haven’t got a competition that we are aiming for I lose the momentum to keep going, having the competitions is really important, because you got to have a goal, we’ve got a time to beat…’ (DB 12)

In terms of the weave therefore, competition events appear to have the capacity to both reduce chaos threads and/or increase the number of quest threads. Conversely, for team members not able to participate where they have no control over their non-participation e.g. they are a carer, it may increase their chaos threads or reduce their quest threads.

5.5.4 Team/Group Membership

The experience of DBR is unique in that it offers both team and group membership. The team element relates mainly to the paddling and water based aspects of the experience while non-paddling DBR related activities, such as organising fund raising events, an annual dragon boat festival, and promoting the team in the community, are more closely related to group membership.

A number of storytellers referred to the contrast between the social support they received from DBR and that offered by breast cancer support groups. The support group experience was reported as focusing on the cancer and the treatments, and was perceived as negative compared with DBR which was reported as '… *something much more positive and energetic* …' (DB 3) where the opportunity to discuss '*physical*', '*mental'* or other issues existed but '…*we don't dwell on anything … if somebody has a real need they can talk about it but it's not something that we concentrate on, it's the benefits rather than the disadvantages'* (DB 6). This was stressed by a number of storytellers suggesting it was an important aspect of the DBR experience for them.

Throughout the stories there was evidence that the storytellers identified themselves, and others identified them, in a positive way, as team and group members.

Whether thinking about, or actually being involved in some activity as a team, or group member, it is likely that the weaver (BCS) will have been inspired to move some chaos threads to the background and/or some yellow (quest) threads to the foreground depending on the experience. Conversely, a negative experience as a group/team member e.g. conflicts with team members may result in grey (chaos) threads being brought to the foreground.

The following storytellers capture this positive association with team membership: the opportunity to compete, feeling they belonged, and having fun, the health benefits of feeling fitter and a new image as a BCS.

'I think being out on the water and having that exercise, paddling together, and uhm, taking part in events, and actually organising events, and trying to organise things for the future, I think it's a very positive thing to do' (DB 6)

*'…dragon boat racing is just something special and when people hear that you do it they are quite amazed as well …' (*DB 4)

'…although there are lots of other charities, there are walking charities, running charities, that are connected with breast cancer, but this is just something a little bit different, … it's quite unique uhm' (DB 2).

'…I'd like to take my family more when we are competing away because they're really proud of their Mum and they're really proud of the team identity …' (DB 12)

'…I just find its lovely being part of a team, to be honest, ah they are a wonderful bunch of ladies. They have all got their various strengths and you gain so much from them, and listening to them and all about their lives and their families and hardships and things that they've gone through …' (DB 3)

5.5.5 Physical and psychological changes

The number and intensity of physical and psychological changes relating to their remission society membership experiences varied between each storyteller. The stories have also been very revealing in that the women, especially those whose stories were of a chaotic narrative type, gave no external indication of their level of psychological or social distress. As some storytellers reported that they would not go back to the breast care team, and none made any reference to their GP, it is of interest to reflect on what might have happened to them had they not joined the DBR team. One storyteller suggested the following possibility for herself;

'…I might be sitting within four walls feeling rather sorry for myself, which quite a few people do, who I've come across, who have not been actively involved in any form of exercise uhm I think it's just been a tremendous opportunity that was offered to me' (DB 3)

'I found [TEAM NAME] *a good thing you know it's been not all bad I found with* [TEAM NAME], *a good thing, a positive thing, I found some new friends, a new thing to go to. I love being out on the water, absolutely love it, and you know like doing the activator stuff and I've got into exercise and the spin off from that of course is that the children have started running and exercising because they've seen how I have improved and*

…they enjoy it as well so maybe there are some positive spin offs from all this …' (DB 1)

'*…it's* [paddling] *just the most amazing experience uhm as far as sort of fitness levels and helping you know with my shoulder…I used to get severe pain almost shooting pains and I've had it since surgery and I'm told it's something to do with the nerve endings uhm that has improved dramatically since I've been dragon boating uhm and I notice if I haven't been paddling I do tend to get the pain …'* (DB 9)

'I think it's a confidence thing I would never, and this may sound silly actually, I would never ((hesitates)) *go and have a tea or coffee in a café bar by myself…because I have put on so much weight since the cancer uhm I've* ((hesitates)) *I always used to think people were like staring at me uhm … I just look at all those girls who paddle and they're just so full of life…I just find some of them a real inspiration…I would never ride my bike, but I'm cycling everywhere now...I can go and have a coffee in a coffee bar I'm not worried that people are staring at me when I'm on my bike, not thinking, Oh my goodness look at her uhm and obviously that has a knock on effect because I'm losing weight because I'm cycling everywhere so yeah its really helped me, really helped me …'* (DB 9)

it's just a supportive system, and a very <u>*healthy*</u> *one, where I just got stronger and better, uhm, from the dragon boat paddling, and things that go with it, like the exercise classes, where we warm up* ((smiling excitedly)) *… but uhm physically its good but also mentally. I went through a depression prior to joining and this has just sailed me through just absolutely brilliant so it's been really, really, good and I want to continue for as long as I possibly can …'* (DB 11).

'…the fact that you are with other ladies uhm makes you <u>*really*</u> *aware that you are very, very, fortunate and having survived this process and that paddling gives you this tremendous feeling it gives you back your self-esteem, that's what it did for me … I like to help … with all the various events and hope that we can help other women in the process …'* (DB 3)

The impact of DBR could be interpreted as direct, through paddling and dry land fitness training, or indirect, through knowledge sharing and encouragement to participate in self-care behaviours. The latter aimed at preventing, or ameliorating, the impact of remission society membership experiences, such as lymphoedema, upper-body-morbidities, reduced fitness, depression.

The following extracts capture some of the experiences in relation to their physical or psychological health that may have prompted the weaver to move narrative threads from background to foreground, or foreground to background;

‘*This* [DBR] *was something much more positive and energetic and just the feeling of wellbeing afterwards, it was tremendous’* (DB 3)

‘… but to do something really, really positive and be accepted as somebody who can compete along with, you know, just everybody’s in the same boat, and really enjoy it, and be healthier for it’ (DB 11)

‘…*well after* [you’ve] *had cancer and you feel pretty low and miserable about yourself and when this idea came along to join a dragon boat team, and it was something that you could do which was really, really, good, it made you feel good, that you could actually participate, and become what is normal, you became part of the normal race …’* (DB 8)

Apart from feeling fitter, the most significant, and consistent, physical impact of DBR on their remission society experiences related to an improvement in their lymphoedema and shoulder function. As well as the physical effects of pain and discomfort, lymphoedema can also have a negative impact on their psychological health because it is a constant reminder of their cancer and affects all aspects of their lives.

‘*When I had my operation I had what was called … cording, so it’s like a tight cord literally going up the arm under the arm and then down to where the operation has been. Now if I don’t do anything with the dragon boat for a few weeks it tightens up. If I dragon boat without fail it’s great, I don’t know it’s there …’* (DB 10)

‘… if I don’t paddle the lymphoedema gradually builds up, it can become really unbearable and I’ve had cellulitis before when I haven’t paddled for

an extended time…that's why I stick with it really, uhm, because I've got to move that lymphoedema and it's the most enjoyable way that I have found to move it' (DB 12)

'… uhm I find it is, it's so much better, so much more comfortable, and whereas at one time I was always aware that I'd got the lymphoedema now sometimes I just forget I've got it' (DB 13)

Therefore a physical improvement may also impact on their psychological health, inspiring the weavers to move grey (chaos) threads to the background and/or quest threads to the foreground. The way in which the five inspirations are interrelated was referred to previously and inspired the notion of the flecked thread, the following extract captures this very well in relation to lymphoedema;

Referring to a recent dragon boat competition event in Venice she wrote:

'… when we were away in Venice [competition event] *it was interesting because one of the girls in our flat regularly does the massage and so she was tutoring us others who don't do it and that was much more effective and more informal and it felt more comfortable to learn about lymph massage that way than it did from the lymphoedema nurse who's never really doing it for real so uhm yeah that's much better way to learn I think and it's something I think we could expand though it's something that's really intimate to be stroking touching your body, as you have to, you have to have, that kind of trust which is only going to come from being a team sticking through stuff so uhm …'* (DB 12)

5.5.6 Summary

The metaphor of the weave captures the way in which remission society membership experiences are ever changing and how the impact of DBR on these experiences is interwoven into every aspect of the lives of the BCS, resulting in the constant movement between narrative types.

In chapter 6 these five influential inspirations that prompted the weaver, will be discussed and considered within the context of the breast cancer survivorship narrative and other relevant research literature.

Chapter 6: Discussion

'… [It] is my belief that any analysis ought to contribute something to human's understanding of how to live – not just how living is done, but how it *ought* to be done' (Frank 2010, p.19)

'… it's just a supportive system and a very healthy one where I just got stronger and better uhm from the dragon boat paddling and things that go with it like the exercise classes where we warm up ((smiling excitedly)) … have a bit of a giggle well, but uhm, physically it's good, but also mentally. I went through a depression prior to joining and this has just sailed me through just absolutely brilliant so it's been really, really, good, and I want to continue for as long as I possibly can'… (DB 11)

6.1 Introduction

The above extracts capture two important aspects in relation to this study. The first brings it back to the introduction and its aim to gain an understanding of the impact of the experience of DBR as an activity, on the remission society membership experiences of BCS, from their own individual and unique perspectives, through storytelling. The study findings reveal both 'how living is done' (Frank 2010) (as members of the remission society) and 'how it ought to be done' (Frank 2010) (remission society membership experiences modified by the impact of DBR). The second extract captures elements of the latter and the broadly positive impact of the experience of DBR, on the lives of the BCS who participated in this study.

The study findings will be discussed broadly around the five influential inspirations Dragon Boat Racing ('In the Boat'- to include greater appreciation of nature), Social Support/ Social Support Networks, Competition Events, Team/Group Membership, Physical and Psychological Changes, as reported in chapters 4 and 5. Although these divisions will be used to guide this discussion, it is important to remember that they were inextricably interconnected and interwoven for the participants. The metaphor of the weave (Frank 1995) was used to capture the movement between narrative types (Chaos, Restitution, Quest) (Frank 1995), based on the storyteller's perception of the experience of DBR and its interaction with their ever changing remission society membership experiences, to create the pre DBR and DBR weaves. Pre-DBR the inspiration was the remission society membership experiences, where cancer dominated the story, and Chaos and Restitution were the dominant narrative types. In the DBR phase the remission society membership experiences are modified by the impact of the DBR experience and the dominant narrative type moves to Quest. It is from these narratives and the five influential inspirations that ideas for what ought to be done to change understandings may be drawn.

The combination of storytelling as a methodology, the use of Frank's Narrative Types and the 'three facets' framework (Frank 1995) to analyse the stories of BCS participating in the sport of DBR, appears to be unique to this study. That its findings, in relation to BCS experience of DBR, incorporated those reported in other researchers' BCS and BCSDBR studies, but also provided a deeper, more holistic view of the experience of DBR on the lives of BCS, suggests it was an appropriate methodology to use.

The study uniquely captures the constant movement between the narrative types (chaos, restitution, quest) (Frank 1995) from the foreground to the background, and also reveals the way in which the impact of DBR is woven into the lives of BCS providing a more indepth appreciation of the experience than that reported using other research methodologies. For example, in this and other BCSDBR studies, the impact of the recurrence of breast cancer or death of fellow team members is reported as a negative aspect of the DBR experience, but in this study some of the ways in which the participants dealt with these difficulties are revealed e.g. being inspired by the way the individuals concerned dealt with their situation and also wanting to continue the legacy of DBR for future BCS.

6.2 Pre DBR

In their stories the participants reported physical, psychological and social BCS experiences consistent with those reported in the quantitative and qualitative research literature, including: weight gain/obesity (Irwin et al 2005,Demark-Wahnerfried et al 2012, Nissen et al 2011), fatigue (Meeske et al 2007, Luctkar-Flude et al 2007, Kangas et al 2008), upper body morbidities e.g. lymphoedema (Hayes et al 2010, 2010a, 2012), NcNeely et al 2010, Fu et al 2009), Campbell K.L. et al 2012, Williams et al 2004, Ridner et al 2012, Thomas-MacLean and Miedema 2005, Thomas-MacLean et al 2009, Kwan et al 2011, Ahmed et al 2008) Joint and muscle aches, pain, and stiffness (Winters-Stone et al 2010, Fenlon et al 2013), psychological experiences (including depression, decreased self-esteem/self-confidence, body image changes (Carpenter et al 1999, Kayser and Sormanti, 2002, Chantler et al 2005, Stein et al 2008 , Allen et al 2009, Tighe et al 2011, Silva et al, 2012, Brunet et al 2013), social isolation and disrupted social support networks (Rosedale 2009, Zucca et al 2010, Coreil et al 2012). The stories suggest that the sense of 'interruption' and 'loss of the destination map', referred to by Frank (1995) and other illness narrative writers (Mullan 1983, 1985, 2006, Frank 1995, Conway 1997, Raz 1999) is felt more acutely at this end of treatment phase (Phase 2 Chaos) than at the time of diagnosis (Phase 1 Chaos). Allen et al (2009, p.76) also found that 'the termination of treatment can shatter the tentative equilibrium that many cancer patients achieve during treatment'.

As discussed in chapter 2 this phenomenon is reported extensively in the illness narrative literature where Sontag (1978) suggests that there are two kingdoms, the kingdom of the well and the kingdom of the ill. Frank (1995) suggests that members of the remission society do not fit in either kingdom, and are left in a 'demilitarized zone in between them, or else it is a secret society within the realm of the healthy'[27] (Frank 1995, p.9). Also the illness narrative literature suggests there is a dichotomy in the way the

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[27] Restitution Narrative: 'The plot of the restitution has the basic storyline: Yesterday I was healthy, today I'm sick, but tomorrow I'll be healthy again' (Frank 1995, p. 77).

cancer survivorship experience is reported in the narrative literature. For some, the experience of cancer survivorship is experienced as the loss of control, ruptures in the self, disruption in the life story, and questions of meaning in the face of personal annihilation (Conway 2007), while for others it is experienced as one of transformation, and positive growth (Armstrong 2001, Jose 2004, Girard 2008). Reflecting on the stories told in this study, pre DBR, none of the participants reported their BCS experience as one of positive growth and/or transformative, instead they acknowledged the negative impact the cancer diagnosis had on their lives, to varying degrees, and their quest to find a way to live this new life while accepting the many contingencies associated with it. This finding is in keeping with that of Kaiser (2008) where in her study of the lived experience of breast cancer she found that the narrative of survivorship can construct a positive, cure-oriented definition of survivorship, and that this breast cancer culture has left many women searching for representations which acknowledge their fears, and the continued presence of cancer in their lives and that BCS desire truthful, or as Frank (1995) calls 'good' stories - a good story would acknowledge the long-term role of cancer in women's lives and their fears of recurrence, rather than positive cheerful stories. The latter were referred to as 'triumph narratives' by Conway (2007), a term which she suggests she uses in the same way that Frank (1995) uses the term restitution narrative, described by him as the culturally preferred narrative. She proposes that the alternative to triumph narratives - ones that offer subjective experience of what it is like to suffer serious damage to one's body - can be articulated, reflected upon, and shared, providing a much needed conversation, that is often not possible within the family, and the wider society, about the ways in which the desolation of serious illness and disability cannot be managed as the self-help literature would have it. Therefore the pre DBR element of the stories told in this study suggests that they were not told as triumph narratives but a combination of chaos and restitution narratives and that they all quested something to move them out of this state in much the same way that Conway (2007) describes above. For breast cancer, Kaiser (2008) suggests that at an individual level BCS have the opportunity to join in the dominant culture of consumerism, pink ribbons, and symbols, but that fewer opportunities exist to act in alternative ways. Could DBR be one such alternative way?

The impact of their physical, psychological, and social, remission society membership experiences, were compounded by simultaneously experiencing loss of support from health professionals. This was described as a feeling of abandonment and for one storyteller a kind of bereavement. This is in keeping with Thomas-MacLean (2004, p. 639) whose study suggests that this could be described as ‘a feeling of alienation’ as the women were leaving ‘the only socially sanctioned recourse to health and healing that currently exists in our culture’. This is interesting in relation to this study, as a number of the storytellers, despite reporting this sense of abandonment by the medical team as being significant, also reported that they would not contact that same team, if they had a problem, or a health concern, suggesting an ambivalence in the relationship, and a possible desire for an alternative source of support. Arman et al (2004) reporting on the health care experiences of breast cancer survivors suggested that there were differences in the paradigms of the patient and the caring staff, which seemed to increase the women’s suffering.

A number of possible reasons emerged from the stories, including a perception that the health care team’s expertise related to the acute phase and that they would want them to concentrate on BCS who were going through this phase, but more importantly, they were emphatic that they would want to access, and share knowledge, regarding any symptoms, treatment side effects, self-care practices, clothes etc. with other BCS, who really understood what they were experiencing. This was such a significant aspect of the stories that it will be explored further, as a remission society experience, and as a background to the impact of DBR in this regard.

Delinsky (2002, p. xi) a BCS survivor herself and editor of a book of stories written by BCS hoped that her book ‘… would be the support group that I had never joined but could have used, the one that offered all the practical little secrets to survival that have nothing to do with doctors, machines or drugs and everything to do with women helping women’. A number of autobiographical illness narratives (Mullan 1983, 1985, 2006, Frank 1995, Conway 1997, 2007, Raz 1999) have written passionately about this issue and concur with this sense of divide between those who are well and those who have experienced illness. Charon (2006, p. xii) one of the practising physicians who are acknowledging this divide, and the serious consequences it can have for the ill, suggests that '... it is as if doctor and patient were alien planets, aware of one another's trajectories only by traces of stray light and strange matter'. As a practitioner of narrative medicine[28] she puts forward four different types of divide that contribute to the divisions between doctors and patients: 1.The relation to mortality. 2. The contexts of illness. 3. Beliefs about disease causality. 4. The emotions of shame, blame, and fear. She suggests that to get better, the patient needs to feel included among those who are not ill and to continue to be, somehow, 'the self he or she was before illness struck' (Charon 2006, p. 21). DBR appeared to enable participants to at least experience the inclusiveness of team membership and being with people '*who understood'* and helped restore some elements of their lost identity. Some storytellers also used the internet or found relevant books to fulfil their information needs. General practitioners were never mentioned so what role they may, or may not play, is not known. This ambivalence towards the role of health professionals was further highlighted when one of the storytellers reported that she found it off putting that the specialist nurses attended the support group, which seemed to imply that health professionals were intruding into 'their world'. This ambivalence had the effect of potentially compounding their social isolation, and will be discussed later. Reflecting on the stories in regard to pre DBR (end of treatment phase) the weave appeared to show a dominance of the chaos narrative where restitution is less significant - as all primary treatment regimens have been completed - and the storytellers describe experiencing a loss of control on a number of levels, but principally in relation to altered relationships and their health and health related contingencies. This is also reported in the cancer survivorship literature including the following; (Arman and Rehnsfeldt 2003, Arman et al 2004, Thomas-Mac-Lean 2004, 2005, Coyne and Borbasi 2006, Allen et al 2009, Loerzel and Aroian

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[28] Narrative medicine – '...defined as medicine practiced with the narrative competence to recognize, absorb, interpret and be moved by the stories of illness' (Charon 206, p. vii)

2012), altered relationships with partners/spouses (Sprung et al 2011, Fergus and Gray 2009, family (Wiggs 2011), friends, acquaintances, health care professionals (Tighe et al 2010) which in turn leads to a crisis in their identity (Kaiser 2008). The impact of DBR on these remission society membership experiences will be discussed in the following sections under the five influential inspirations.

6.3 Five Influential Inspirations; Dragon Boat Racing ('In the Boat'), Social Support/Social Support Network, Competition Events, Team/Group Membership, Physical and Psychological Changes

6.3.1 Dragon Boat Racing ('In the Boat' – to include greater appreciation of nature)

'Survivor dragon boating enabled participants to shift cancer from the foreground to the background of their lives, to focus on life and living, joy and strength, rather than the fear of recurrence' (Mitchell et al 2007, p. 134)

'… and while we can compete and go abroad or even just go out on an evening and the weekend I think everybody although they like to go to meet up with everybody I think everybody is really drawn by the paddling they just love it so I think that's what makes the club it's the paddling and you forget at the end of the day that it's there to make you stronger because you just enjoy it so Its twofold really it's like a social club and its obviously beneficial health wise so the longer we all keep it up the better and long may it continue ((laughs))…' (DB 4)

In addition to addressing their negative remission society membership experiences, the overwhelming influence on their decision to join the DBR team, was the positive image of the BCS; as strong, engaging in a challenging physical activity, as part of a team, having fun, enjoying a sense of connectedness and camaraderie where the women were literally and figuratively in the same boat, and most importantly the activity was based on water bringing them close to nature. The image was sufficiently powerful to make them overcome a number of challenges (depression, lacking in confidence, feeling vulnerable, fear of water, poor swimmers, going alone to join a group of people they did not know) to participate in it. One storyteller referred to the sight of a poster of the team during treatment, as '*sowing a seed'* (DB 10), it could be interpreted as a seed of hope, and each time she saw it, it grew a bit more. One other storyteller had a similar experience, and they both recounted keeping the image in their minds, until the treatment was over and they could join. For all the storytellers in this study, their first experience of seeing the team and the boat was described in a way that suggested it had a powerful positive impact on them, and could be interpreted as the moment they realised DBR might be what they had quested to enable them to cope with their remission society membership experiences. This positive impact continued to grow as they became more involved with the team, culminating, for some, in them taking part in national and international competition events.

Harris (2012) in a review of the benefits of DBR for women with breast cancer reported a number of themes found in qualitative literature published between 2002 and 2011, which were remarkably similar; feelings of camaraderie, a sense of renewed fitness and health, opportunities to promote awareness of a full and enjoyable life after breast cancer and enhanced self-confidence and control of one's life.

A number of the storytellers, as in the extract from one story at the beginning of this chapter and in the following extract, used terms such as 'special' and 'unique' to describe the experience of DBR for BCS, and suggested there was nothing else like it that could address so many of their needs as members of the remission society:

'…I think [TEAM NAME] *is special … because everybody's so supportive, from the outside as well, and want to be involved in it, it's a unique group of ladies and … you know there isn't anybody else around…that would do something* [DBR] *like we do with such passion, and friendship and support … so that's why I think it is unique, special'* (DB 5)

Firstly, the exercise safely targets the upper body morbidities associated with remission society membership. These will be discussed in a later section on physical/psychological health.

It also captures the sense that as an activity it was different (being in a 40 foot boat with a dragon's head at the front and tail at the back and up to twenty people on board) and there was nothing else around like it. They were proud to be associated with it and appreciated the feeling that they belonged to an exclusive group. What made this even more special and unique compared to other BCS activities such as flyfishing, motor cycle challenge events, mountain climbing etc. was that they were participating in something created by, and for, themselves, and future BCS, and that they were, in addition to being beneficiaries, they were also custodians of this special experience. The team was set up by, and is entirely run by the team members where, in addition to the trustees, all team members are encouraged to take on tasks to support the running of the team, and the charity that supports it. This extends their sense of empowerment. For example, the participants in one organised motor cycle event, for BCS, experienced 'forced socialization' (Morris et al 2012), through the organisers determining that they had to have different room allocations each night, and while the benefit of facilitating connections between participants were appreciated, some reported it as challenging.

Many team members took on duties related to areas in which they are able to share their professional or other areas of expertise for the benefit of the team, which, as well as benefiting the team had a positive impact on restoring their sense of identity after breast cancer, in addition to achieving a more positive identity as a proactive survivor, through DBR. This new found positive cancer identity was also reported by the women who took part in the motor cycle challenge events (Morris et al 2012) - the closest BCS activity to DBR in terms of challenge and some requirement for the riders to function as a group, although the difference is that they are 'one off' events with pre and post event communications being conducted mainly, if at all, through email etc.

The legacy aspect in relation to DBR was raised by a number of storytellers, and the stories suggested that for current team members it relates to continuing the legacy left by those who are now deceased or who have recurrent disease, and are no longer able to paddle, and for those who are now deceased it leaves a support community for husbands or a resource for daughters or other women who may develop the disease in the future. This appears to be a unique contribution to DBR research.

Additionally, unlike many other sports it gave them the opportunity to experience the satisfaction of accomplishing a new skill regardless of their age (storytellers ranged in age from 39 to 72 years) level of fitness, co-ordination etc. Competence in the DBR paddling technique can be achieved quickly or slowly depending on the individual, as it is the team rather than the individual that propels the boat enabling those who are slower at mastering the technique to gain competence without being made to feel inadequate. While a number of storytellers referred to this feature of DBR one commented specifically on this and suggested that;

'… I have a co-ordination problem and it doesn't hinder me in the same way that swimming does, I don't feel such a twit. I've mastered the skills quicker than I ever did swimming and so that quick success is really important…there is more you can learn but you get a competence quite quickly which is probably key after having had your confidence knocked so much with breast cancer' (DB 12)

Its suitability for people of all levels of fitness relates to the fact that in DBR paddle technique is more important than strength, an individual can put as much, or as little effort into the stroke as they are capable of doing, the essential requirement is to keep time with other paddlers.

In addition to the satisfaction of becoming a competent paddler DBR also offered team members the opportunity to acquire additional skills such as helming and coaching. For the two storytellers who referred to this, the impact of this additional skill on their remission society membership experience extended beyond the personal satisfaction and pride in their achievement to the satisfaction that it enabled them to play a significant part in the life of the team.

DBR as a physical activity for BCS is also unique in that membership is open, enabling members to rejoin the team after periods of absence e.g. for health or social reasons, and rebuild their competence without interrupting other team members' enjoyment of team membership. They may also be able to continue to experience the support and camaraderie through participation in non-paddling aspects of team membership. Team members in this study pay an annual fee of £20 and £30 for their British Dragon Boat Association membership. There is a £1 per paddling session voluntary contribution to funds. Fundraising events and donations from organisations support the running of the team, and the facility to support team members, who might be excluded from participation in competition events for financial reasons. The affordability of DBR distinguishes it from other BCS peer support, challenge events e.g. motor cycle riding (Dunn et al 2009), mountain climbing (Burke and Sabiston 2010) where there is a requirement to raise an agreed sum of money prior to participation which may reduce accessibility to the experience. The issue of affordability appears not to have been raised in other studies but in this study was reported as being of considerable significance and determined the ability to participate for some storytellers. A recent UK study highlighted the negative impact cancer-related financial hardship/worries can have on family life including lifestyle and activities. In relation to breast cancer survivors Whitehead and Lavelle (2009) and Brunet et al (2013a) have also identified cost as a potential barrier to participation in physical activity interventions.

None of the women in this study had ever done DBR before they joined the team, and most did not know what it involved until they came to the boat for the first time. DBR presented the challenge, and the sense of achievement, that came from becoming a competent paddler, capable of paddling in unison with the rest of the team. It gave them a new identity as a sportsperson (Sabiston et al 2007). They expressed their own pride and that of family, friends, and the wider community in this new identity.

Another unique feature of DBR compared to any other physical activity a BCS might engage in is the opportunity to paddle at different levels.

Paddlers can choose to do, what is generally termed, social paddling, or they can train and compete at local, national and international events, enabling them to fulfil the essence of the quest challenge, by not just rising to the challenge of the remissions society experiences, but doing more than they had done before, and being able to demonstrate it, with pride, in a very public way. The opportunity to compete was itself a unique experience for the majority of the storytellers and to represent their country in a competition was a new experience for all of them. This was reported as a highly valued experience and other than in DBR it is difficult to think of any other sport where BCS could achieve this. Conversely this may also be experienced negatively where a tension arises between those in the team who want to move towards more competition events and those who do not (Mitchell and Nielsen 2002, Unruh and Elvin 2004, Parry 2007, McCausland 2010), or if, at an individual level, someone cannot take part in competition events for whatever reason e.g. financial (financial support is offered but not everyone will request it), being a main carer. DBR also facilitates the expression of the dyadic relationship that is part of the communicative body (Frank 1995) in a number of ways including e.g. support to other BCS, but most importantly to deliver a positive message to other breast cancer survivors, and the wider public, that BCS can live active lives beyond a breast cancer diagnosis and treatment.

While all of the aspects of DBR discussed so far in this section are likely to account for the movement in narrative types between chaos and quest experienced by the BCS, for some storytellers DBR also has a restitution role in that they appreciated the benefits of physical activity in the amelioration of remission society membership experiences and improved survival, and also in the prevention and management of upper body morbidities, especially lymphoedema.

The environment and the significance of the water (Mitchell and Nielsen 2002, Parry 2007, 2008) was referred to by almost every storyteller and suggested it played a major part in the overall positive impact of DBR on remission society membership experience. The following storyteller appears to capture the fusion of the feeling of connectedness between the storytellers, the physical act of paddling and the fun they enjoyed within an environment that in turn seems to connect them in nature in a way that is meaningful.

'…uhm you know just all having that connection and so much fun in that boat…it's just the freedom, the exhilaration of being out on the water…' (DB 2)

6.3.2 Social Support/Social Support Networks

'The dragon boat is a "*floating support group*". ' … they know that there is always someone right in the seat next to them with whom to confide…' (Bodner 2010, p.6)

The storytellers consistently referred to the powerful and positive impact the social support they experienced, as part of the DBR experience (as in the above extract) - and the new social network it created for them - had on their lives. A number of them chose to use words and phrases such as 'connected', 'camaraderie', 'all in the same boat' to convey the message that they were bound together in a very unique way through the shared understanding of what it is like to be a member of the remission society, and DBR created this connection in a way that they perceived could not be done in breast cancer supports groups or in any other environment. In relation to DBR the stories revealed that they felt connected not just, through their paddling in unison in the boat, but to their membership of the team, which they valued, and to the running of the charity to which they felt a responsibility, to contribute in some way, not just for their own benefit, but to increase the membership so that more BCS can benefit from the experience, now, and in the future.

None of them were socially isolated in the conventional sense, but for many their altered sense of self, connection, and identity, as BCS led them to experience what has been termed 'survivor loneliness' (Rosedale 2009). There is evidence of this experience of social isolation across the illness narrative and BCS narrative and qualitative literature (Allen et al 2009, Coyne and Borbasi 2006, Tighe et al 2011, Synder and Pearse 2010, Sadler-Gerhardt et al 2010), as well as in this study. Frank's (1991, 1995) work suggests that it was this aspect of his cancer survivorship experience that inspired him to devote almost his entire career, following his diagnosis, to promoting a greater understanding of cancer survivorship, through research, writing, teaching and editorial work, with the aim of minimizing its impact for cancer survivors. Perhaps this concept is more eloquently conveyed by the following breast cancer survivor describing the time after she had finished treatment:

‘I was left with a weakened body that I did not recognize or understand. I felt a sense of abandonment, isolation, and being forever different from my friends and family’ (Bodner 2010, p.6)

Additionally, even for those where social support was not one of the motivating factors for joining the team, they expressed how much they valued the unique support membership of the team offered. This finding was also reported by McDonough et al (2011). How women of very different ages (38 to 72), backgrounds, and levels of fitness, appear to experience this level of connection and support in ameliorating the remission society membership experience of social isolation, which was referred to by many of the storytellers in this study, is captured in the following story extract;

‘…it’s just having a support network of people who understands what you’ve gone through, what you’re going through, uhm, and everyone’s there to help each other, which is one of the, you know benefits of the DBR (DB 7)

Social support through DBR could be described as the inspiration that prompted much of the movement from chaos to quest, and appeared to begin on their first sighting of the team and with the welcome they received, which they so enthusiastically recounted in their stories. At the core is the one to one support team members gave to each other, through the shared common experience of breast cancer and the shared knowing and understanding that extended beyond the verbal to include non-verbal. While this could be achieved through any BCS remission society intervention, DBR uniqueness appeared to originate from it being able to offer an ongoing social support network, ownership and control of the experience, goal setting, positive relationships with most team members and a strong sense of ‘connection’,’ camaraderie’ little sisterhood’ within the team. While the DBR research literature includes reports of this range of social support (Mitchell and Nielsen 2002, Unruh and Elvin 2004, Parry 2007, 2008, Mitchell et al 2007, McDonough et al 2008, Sabiston et al 2007, Shermak 2008) through using storytelling as a methodology this study has expanded this knowledge to include a deeper understanding, not just of the existence of social isolation but how the experience of DBR impacts on it, through the availability of support on a number of levels, and through the unique way that this study reveals they gained support through the development of strong relationships over time, and a strong sense of connection, between team members.

Social support included the support the storytellers experienced; as a team member, as a team member within the local community, within the national community of BCSDBR paddlers, and finally as members of the international community of BCSDBR paddlers. The significance of this wider sense of social support was recounted by many of the storytellers as they enthusiastically described the impact the large number of survivors had on them at the international dragon boat festival in Canada, in particular. Many described the social impact in terms of feeling great pride and joy in being amongst hundreds of other BCS ‘*who’d all gone through the same thing, and everybody was so happy and cheery’* (DB 13), in representing their team and their country - a first in a lifetime experience for the majority of them. A number of storytellers also referred to its role in delivering the message that many women now survive breast cancer. Parry (2010) also made reference to the extended connections of participating in DBR but did not elaborate on its impact or what it meant to the women.

The research literature suggests that the size of the social network and how integrated the individual feels within it positively influences the level of social support available to them (Bloom 2001). An important recent finding in the social network literature suggests that relationship quality and not just network size influenced the survival benefit of breast cancer survivors who had good social support compared with those who did not (Kroenke et al 2013). The stories suggest that DBR in addressing remission society membership experiences offers both a large network, and quality relationships - with at least some team members. DBR uniquely supports the development of relationships in a number of ways; in most DBR teams all members are women[29], all are breast cancer survivors, they attract like-minded people (suggested by the storytellers and reported by Parry (2008), is a year round on-going activity, where relationships have time to develop, and these are strengthened by the bonding that was reported to develop when the team spent time away together competing in events, plus working together on non-paddling DBR related activities, and having shared goals for the paddling activities and the charity. The Emslie et al (2007) study highlighted that the BCS valued exercising with women in the 'same boat' because of the empathy and acceptance they received and the opportunities to exchange information and form friendships. There was evidence in the stories and in the DBR (McDonough et al 2011) and challenge event literature (Dunn et al 2009) of the importance of needing time, for at least for some BCS, to develop relationships ; '…[I've] *just been there a year now and just starting to form stronger friendships which is lovely…*'(DB 5). Unlike short BCS physical activity intervention projects DBR offers the opportunity for relationships to develop according to the individual, some quickly, some slowly. Additionally, this study revealed that the length of time team members spent together strengthened their relationships, for example, one storyteller compared the experience as '… *I guess it's like being in the services you know the men doing the services, it's just that camaraderie of being together all the time…*' (DB 6) Related to the quality of the relationships developed within DBR is the concept of '*connection*',' *camaraderie*,' reported in this and other DBR research studies (McDonough et al 2011, Parry 2010, McNicoll and Doyle 2010).

This study has provided an understanding of connections and camaraderie that goes beyond the knowledge that BCS participating in DBR feel uniquely connected; this study has also identified how, and why, this was

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[29] It is significant that in this study none of the storytellers made any reference to introducing men into the team, although this is something that has been raised from time to time.

an important aspect of the DBR experience in addressing remission society membership experiences. Firstly, all the elements that contributed to the development of strong on-going relationships, as discussed in the previous section, were essential pre requisites to feeling connected. For example, one storyteller described that having to miss so many sessions because of her business commitments meant she did not feel quite so connected as other people - although she stressed that it was how she felt, and nothing to do with how she was treated by other team members. Also, some participants in the McDonough et al (2011) study reported not feeling connected because of relationship conflicts and reminders of recurrence and death, as well as other barriers to participation.

Secondly, being literally in the same boat, paddling in unison, necessitates a true connection between paddlers to propel the dragon boat in the water. Paddlers on the boat are connected by a buddy system whereby each paddler is responsible for the paddler next to them in the event of a capsize, and the whole team has to trust their fellow paddlers to shares the responsibility of following the correct capsize procedure to ensure everyone is recovered safely from the water, in the event of such an incident occurring.

Thirdly, the team is uniquely connected in the maintenance and development of the team for current fellow team members and as a resource for future BCS who may wish to access it, as well as securing the legacy of DBR left by those members who were instrumental in setting up the team, but who are now deceased. As well as the trustees, all team members hold various positions of responsibility in relation to the water based aspect of DBR (e.g. safety etc.) the running of the charity, and organising competition, charity, or social, events.

Fourthly, some storytellers attempted to capture the sense of connectedness they experienced by describing team membership as like being part of a family, where they grew stronger through having to overcome difficulties together, and like being in the services where being connected, and group cohesion, are vital to not only achieve their goals but also protect each other.

Apart from DBR, the only other challenge event to report some level of connection and group cohesion was the repeat motor cycle riders in the Morris et al (2012) study. Price Herndl (2006, p. 225) commenting on the authors of breast cancer autobiographies suggests that they often incorporate the communal into this new sense of self. ‘In coming to terms with a changed body, they come to connect to a community that is defined by its relation to the body: the community of women with breast cancer’. Similarly McNicoll and Doyle (2010) and Parry (2007), referring to BCS participating in DBR reported that the most important factors contributing to well-being was the sense of connectedness and cohesion amongst members. This desire of BCS to connect with others was reported in the Rosedale (2009) study where it was reported that for BCS, loneliness emerged when they felt a crisis in their connection with others such that they silenced themselves, masked how they were feeling, or did not share aspects of their experience. These inauthentic acts aimed to preserve a sense of connection and create an impression of normalcy with those relationally connected to them (Rosedale 2009). These findings echo those of Sadler-Gerhardt et al (2010, p. 275) where the BCS reported ‘lacking an audience receptive to their stories’ and Carpenter et al (1999) where narrative analysis revealed three categories of transformation in BCS; positive, minimal and feeling stuck. The latter group reported not having social support through lack of information, or support from health care providers, friends and family and that they lacked the resources necessary for introspection.

The potential role of support groups in providing informational, emotional, and social support is well documented, but they are underutilised (Grande et al 2006, Owen et al 2007, Chantler et al 2005). The two storytellers who did attend support groups reported that there was too much emphasis or cancer, and this was also the perception articulated by other storytellers who made reference to support groups, although they had not attended any. There was also specific reference to feeling they did not identify with the people who attended cancer support groups. The significance of individual characteristics and group identity has been reported elsewhere in relation to participation (Harwood and Sparks 2003, Dunn et al 2009). While many of the storytellers could not describe what they wanted from

DBR- except they knew they wanted to get something '*to help me get out of this state that I'm in*' (DB 1) - many expressed a wish to meet people who had been through what they had been through, and who, like themselves, desired to do something positive after the negative of the breast cancer experience.

The storytellers all referred positively to the opportunity DBR gave to develop new friendships but uniquely in this study they expressed an acceptance and understanding, as part of their communicative body, that some would be close, like *'part of the family'* while others, were *'looser'* (DB 10), and indeed, that not everyone will get on with everyone else, demonstrating that the size of the DBR network enabled different levels of relationships. The importance of positive relationships to the social and psychological health of cancer survivors has been reported in other research studies (Kayser and Sormanti 2002, Loerzel and Aroian 2012). Regardless of the intensity of the individual relationships, the stories repeatedly referred to the storytellers experiencing feelings, of camaraderie, connectedness, '*a little sisterhood*' (DB 9). The following storyteller captures the essence of the DBR social support experience, as described in the stories:

'… I wanted to get on and forget about it… [and] *do something positive uhm forget about the cancer but be with people like myself that wanted to just 'go for it'…'* (DB 6)

Taking part in competition events became one significant component in 'going for it'.

6.3.3 Competition/ Challenge Events

The experience of DBR, and in particular performance in competition events, appeared to symbolise team member's transformation as part of their quest narrative, both literally and figuratively. They were transformed from BCS who were focused on cancer and a perception of illness, to BCS who were sportswomen, wearing a bright pink team kit and competing in an international competition event.

'… *Venice* [DBR BCS competition event] … *was just amazing, the support we all gave each other, it's just, can't describe it, it's in my top five best ever, ever, experiences, because the bonding and the closeness of everybody that was there, it's just great and I don't think you would get that, unfortunately, unless you had been through what we had all been through … it makes you feel good*' (DB 5)

The above extract captures the very powerful impact competition events had on the lives of the storyteller, as revealed in the stories. Uniquely, competition events were also reported as being important motivators to adhere to DBR, and this appears not to have been reported elsewhere in the literature. The goal setting and planning for these events seemed to restore some of the temporality lost with the diagnosis of breast cancer, where it gave BCS goals to aim for.

Seeing large numbers of BCS offered a message of hope that women do survive breast cancer, they felt inspired by the experience and hoped that in turn they would inspire others to view BCS in a more positive way, experiencing the camaraderie and the power they felt when they lined up to race, that individually, and collectively, they could win.

Reflecting on the language used to describe participation in one-off challenge events it is interesting to note that there may be differences between the participants in these other challenge events and those who take part in DBR, particularly in their motivations to taking part. DBR has a strong dyadic tendency where the emphasis is on the team effort while the others seem more consistent with a monadic[30] approach where participants are looking to achieve personal goals and a suggestion that they want to gain closure from the cancer experience (Gabbard 1998, Burke and Sabiston 2010, Parch 2008, Moore 2012). One may tentatively suggest that BCS who participate in these events, which have strong personal goals, and wanting to gain closure from cancer, may not choose to be exposed to disease recurrence, or death, in team members. In contrast, the stories suggest that DBR participants accept the contingency of mortality associated with remission society membership and are not trying to gain

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[30] Monadic – 'understanding…[oneself] as existentially separate and alone' (Frank 1995, p.36)

closure. A degree of caution in this proposition is necessary, based on the repeat riders in the motor cycle challenge, who reported, that unlike their first ride which was about self-exploration, subsequent rides were also to help the new riders and watch their transformation (Morris et al 2012), which is more in keeping with the dyadic relationship found in DBR.

In addition to the motivators for DBR and other peer support challenge events being different, in that one is perceived to be cancer driven, while the other is based on physical challenge with competitive goals, finance may also influence participation. Challenge events require a fee to take part, which is mostly donated to a pre-determined cancer charity, while the cost of participating in DBR is kept to a minimum to encourage the widest possible participation, and fundraising efforts are focused on maintaining the charity and offering financial support to team members, to support participation.

6.3.4 Team/Group Membership

‘Dragon Boat Racing makes me feel like part of a team, like a member of a group, and like part of secret sisterhood. Breast cancer has taught me that sisterhood is powerful and I am thankful I have it in my life’ (Parry 2007, p. 59)

‘*…I wouldn’t wish cancer on anybody ever, but, in a way you’re part of a privileged club who can make something positive out of something negative’* (DB 13)

DBR is a unique physical activity for BCS in that it functions as both a team and a group. On the water it is essential that BCS function as a team and paddle the boat in unison, while off the water, they have all the qualities of a group. The researcher is not aware of any other team based physical activity for BCS which offers both in such a unique way.

Frank (2010, p.130) suggests that ‘Groups are processes of people coming and going, pushing and pulling, weakening ties and strengthening them’ this is in contrast to the reference to ‘connectedness’ that was used by the storytellers to describe their experience of DBR and team membership. A meta-analysis looking at group versus individual exercise interventions for women with breast cancer (Floyd and Moyer 2010) has recommended that exercise intervention studies should investigate the effect of deliberately using group dynamic processes such as team-building experiences and group goal setting to foster group cohesion. These are naturally occurring components of the DBR experience.

Storytellers who attended, or made reference to breast cancer support groups, confirmed some previous findings that BCS have a preference for either the talk based or physical activity based cancer survivor groups (Emslie 2007, McDonough et al 2010). In a separate study (Carter et al 2010), cancer survivors were given the option to choose between a team based (DBR) and a group based (walkers) physical activity programme. DBR was seen as an opportunity to learn a new skill, that it was fun, and exciting, and that it was outside on the water while the three main reasons for choosing walking were that they enjoy walking, they needed an exercise routine, and the perceived health benefits/fitness. There is a sense that what the DBR group were looking for was similar to what the storytellers reported in this study about why they had chosen DBR and supports the need to offer different physical activity programmes to suit individual BCS preferences.

The stories suggest that a significant aspect of the experience of DBR was a strong sense of identity and pride in being associated with the team, but also a duty to support its progression, not just for themselves but for future BCS. This sense of commitment to the team was manifested in their motivation to adhere to the programme even on days when they did not feel like going. Carter et al (2012) reported a finding of greater adherence/attendance in the team based (DBR versus walking group) intervention as novel and felt it warranted further exploration to assess whether it was replicable, and to pinpoint whether it was due to team membership. He highlighted the importance of clarifying this question as intervention strategies that can effectively improve adherence/attendance to physical activity regimens hold considerable value. The stories told in this study contribute to this body of knowledge by suggesting some possible answers as to why there was greater adherence/attendance in the team based intervention, including; storytellers felt a sense of responsibility to fellow team members to attend regularly, and, to the team for its present and future survival. This also included respect for the BCS who were involved in setting up the team, but who are now deceased, such that they wanted to play their part in contributing to that legacy. Many also referred to the fact that they knew they would always feel better after taking part in a DBR session. Kirshbaum et al (2010) looking at group cohesion in a DBR team who were participating in a 20 week pre competition event reported similar findings, although slightly different to routine participation in that the latter had a defined timescale and goal. The similarities included commitment, group support, responsibility to the group and camaraderie.

The reasons for adherence/attendance are strongly linked to the communicative body and dyadic relatedness (Frank 1995). It would be interesting to know if owning and being responsible for the team as opposed to joining a team set up and run by someone else would influence adherence/attendance for BCS. The relationship between DBR and BCS is also quite unique in that almost all, if not all teams, have been set up and run by BCS themselves, whereas, other interventions such as the motor cycle challenge events, fly fishing etc. are usually organised and run, to a greater or lesser degree, by charities or other organisations.

While relationship difficulties within the team have been reported by others (McDonough et al 2011, Sabiston et al 2007,) and the importance of finding solutions highlighted as significant for team participation and individual personal growth (McDonough et al 2011), the way in which the BCS in this study dealt with these difficulties is new knowledge. Storytellers reported that recurrent disease and the death of team members - which was also reported by Mitchell and Nielsen (2002), Unruh and Elvin (2004) and McCausland (2010) - had a negative impact on them such that one team member reported that she considered leaving the team. However, their decision to stay with the team, despite this negative impact, was threefold, the first being the many benefits they gained from team membership, the second, a sense of responsibility to their fellow team members, and the thirdly a desire to continue the legacy created by those who were instrumental in setting up the team, but who are now deceased. Some also reported gaining strength and being inspired, by the way in which other team members had dealt with recurrence of their disease, or imminent death, and because of this experience they felt they would now cope better with these situations/experiences, than they would have done before they joined the team. They also felt reassured in anticipation that should they develop recurrence of their disease, they would be supported by team members '*who understood*'.

In a similar dyadic way the tension regarding the level of competition the team engaged in was seen as something which could be managed by compromise, where the needs of both sides were met. For example, one storyteller put forward the idea that during practice for competition, those who did not want to do the more intense paddling practice in the middle of a particular practice session, could pull in their paddles, thereby meeting their own needs, and enabling their fellow paddlers to meet theirs.

While these of the views of the storytellers in this project who raised the negative impact of the DBR experience, it may not be the views of those who did not take part in the project or those who may have left the team because of them.

6.3.5 Physical/Psychological Changes

In keeping with the findings of the qualitative, and where appropriate quantitative, DBR research literature (McKenzie 1998, Mitchell and Nielsen 2002, Unruh and Elvin 2004, Sabiston et al 2007, Mitchell et al 2007, McDonough et al 2008, 2011, Parry 2007, 2008, Bodner 2010, Shaw 2010, McCausland 2010, Harris 2012) the stories revealed that the sport of DBR positively impacted on the lives of breast cancer survivors in relation to their remission society membership experiences. The storytellers reported improved self-esteem, greater self-confidence, regaining some control and relief from their symptoms of depression as well as a renewed zest and purpose in life through the benefits they themselves experienced as part of their transformation, but also being able to help others. The DBR experience appeared to be interwoven into every aspect of their lives;

'I think [the lymphoedema] would probably be quite a deal worse if I didn't do paddling, that's another thing that it actually helps. It's the mental thing more than anything, uhm, because if you exercise and you do something positive, it does affect, it does affect, your attitude towards recovering from the illness and also dealing with your everyday life' (DB 6)

Physically, no negative effects of dragon boat racing were reported although it is recognised that failure to adhere to recommended training and fitness guidelines (McKenzie and Jespersen1998) has the potential to cause physical injury. That this was a sport that had been researched specifically in relation to BCS was referred to by some of the storytellers, and suggests that this was an important consideration in them deciding to take part in DBR. The main benefits reported, were improved sense of well-being, fitness, strength, and energy, but the most important impact of the experience of DBR in relation to physical remission society membership experiences related to the amelioration of upper-body-morbidity symptoms. This was experienced within the perceived safe environment of the team. The issue of safety concerned the storytellers perception that DBR was safe provided the team practiced within recommended guidelines/protocols (McKenzie and Jespersen 1998). There was a clear message for the charity that all aspects of the guidelines should be adhered to but especially around warm up and cool down practices. For BCS the fear of developing or exacerbating an existing upper body morbidity has been widely reported including by Whitehead and Lavelle (2009) and Sander et al (2012).

This section will focus on what may be perceived as new knowledge in relation to the experience of DBR on upper-body-morbidities, a remission society membership experience for BCS, and in particular lymphoedema. The stories reveal a diagnosis of lymphoedema; as a reason for joining the DBR team and for adherence to it.

The storytellers also felt their fellow BCS were being misinformed and that they themselves wanted to act as role models to deliver the message that vigorous repetitive exercise, such as DBR, was safe and it did not lead to the development of lymphoedema. The research literature confirms this message to be correct although some studies continue to address lymphoedema risk in breast cancer patients despite research studies elucidating the benefits of exercise for cancer survivors and that there is no adverse effects from slow progressive exercise (McNeely et al 2010, Kwan et al 2011). Exploration of the growing body of qualitative literature, relating to the experience of lymphoedma for BCS, is broadly consistent in highlighting the multiple distressing losses, and daily challenges, to all aspects of their lives, which can result in; frustration and resentment, failure to perform self-care, difficulties in their relationships, feelings of isolation and exclusion, (Ridner et al 2012, Williams et al 2004, Thomas-Mac Lean et al 2009). The experience of DBR positively impacted, in a number of ways on their lymphoedema, or their efforts to prevent it - for those BCS not yet diagnosed, including; helping to reduce or maintain their lymphoedema through the physical act of paddling, the knowledge they shared with each other relating to self-care - such as self-massage and skin care - and sharing suggestions, on how to manage the impact it has on their daily lives e.g. in relation to clothing, a sense of control over a condition for which they previously felt they had no control. This knowledge was seen as more relevant, than that provided by health professionals who had never experienced the condition.

6.4 Messages for the charity

One of this study's aims was to identify how the registered charity, hosting this Dragon Boat Team, can improve the quality and sustainability of the dragon boating experience for the team. As reported in the results chapter the stories revealed a number of important messages which appeared to originate from within the communicative body (Contingent, Associated, Dyadic, Productive desire) (Figure 3.1), (particularly dyadic and productive desire), where analysis revealed the core emphasis is focused on ensuring that the experience of DBR remains a positive one, not just for themselves, but for their current and future fellow team members. There was a strong emphasis on meeting the needs of others. As this study is underpinned by the principles of practitioner research and in keeping with the researcher's insider role - because of her relationship with the team and with the charity

- and that she is part of the doing of the DBR, and part of the enabling of it, she will now facilitate a focus group, outside of this research study, where the key messages (outlined below) will be shared with the storytellers to support the formulation of the final key messages that the storytellers will present to the trustees to inform decision making on the issues raised. This will have the effect of not only improving the researcher's knowledge base and improving practice, but will also support the integration of the research into the practice of DBR, which are key principles of practitioner research. The key messages are as follows:

- Ensuring that new members feel integrated into the team and also remaining constantly vigilant to ensure that all members feel integrated.
- Balancing the importance of participating in competition events with respecting the wishes of team members who desire less competition.
- Finding innovative ways to support members who would be excluded from participation in competition events through financial constraints, while being cautious not to give the impression that the charity's money was being spent on 'jollies'.
- Ensuring membership of the team remains affordable for all BCS regardless of their financial status.
- Maintaining safety and fitness routines to maximise the fitness benefits of DBR and reduce the risk of injury.
- Educating the public on the importance of physical activity for breast cancer survivors.

6.5 Reflection on Goodness Criteria

To reflect on goodness criteria I used the Greenhalgh and Wengraf (2008) list of criteria together with Tracy's (2010) three criteria; worthy topic, sincerity, and resonance. The study met the Greenhalgh and Wengraf (2008) criteria and the Tracy (2010) criteria will be discussed in the following section.

In terms of this research addressing a worthy topic I believed that the wide, and concurrent reporting, of the many unmet needs of the increasing population of BCS warranted research. Furthermore, DBR had been described as having the potential to ameliorate some or all of these unmet needs, but little was known about the experiences of women involved in DBR - the present study filled this gap. The study findings are relevant, timely, significant, interesting, and fill a gap in the literature.

In terms of sincerity, storytelling as a methodology combined with the single question appeared to enable each storyteller to tell the story of their own unique experience of DBR in the relaxed unhurried environment of their choosing. This supported multivocality and stories which focused only on the BCS/DBR topic. This ensured that the content of all the stories was incorporated into the thesis. As an insider the researcher was particularly concerned that participants might choose to recount a one-sided positive account of their DBR experience. However, this did not happen, instead, they all described both positive and negative aspects. Two factors in particular may have contributed to achieving this desired outcome, firstly, the researcher reminded each participant at the beginning of the interview that this was important, if the study was to be of relevance to their own team/charity, other BCS, and others who may wish to access its findings, and secondly, the participants themselves enthusiastically embraced the study and were motivated to share their experience of DBR with potential audiences.

In terms of resonance the sample of study participants represented a cross section of ages, social backgrounds, time since diagnosis, length of time since joining the team, previous sporting history, these when combined, with participant’s sharing of all aspects of their DBR experiences, led to a collection of stories which produced rich thick data. The latter having the potential to resonate with the wide diversity of potential audiences who may access the study thereby supporting its naturalistic generalization.

6.6 New Knowledge

1. All were Quest Narratives
2. The movement between narrative types
3. This study is the first to add the experiences - using a storytelling methodology - of one UK BCSDBR team to the international body of knowledge, relevant to BCS who participate in the sport of DBR. Parry (2008) had identified a need for research from the perspective of the women's lived experiences and also between and within different countries. This study adds to both.
4. The stories illuminated ways in which the storytellers coped with the negative consequences of DBR for BCS:
    - Reminders of their contingent vulnerability to disease recurrence and death:
        - ➢ Through gaining inspiration from fellow paddles, who were seen as role models - in particular those affected by recurrent disease - making the storyteller feel more empowered to deal with the situation if it happened to them, than they were before they joined the team.
        - ➢ As part of their dyadic relationship with others a desire to continue the legacy of DBR for BCS which was started by those who were now ill or deceased, out of respect for what they had achieved, and also their own desire to perpetuate that legacy.
    - In dealing with relationship difficulties within the team, to which a number of storytellers referred, they all adopted one or more of the following approaches:
        - ➢ They adopted a very philosophical approach, citing it as normal within any team that people will have differences of opinion about issues, and suggesting that you can respect that others are entitled to their views and you are entitled to yours.
        - ➢ As part of their greater appreciation of life and a re-evaluation of what's important and what isn't after a cancer diagnosis this was regarded as unimportant.

- An acceptance that you will form closer friendships with some people than with others and also that there are a number of people in the team making it possible to decide the level of friendship you want to have with any particular individual.

McDonough et al (2008, 2011) highlighted the need to explore how BCS deal with these challenges, as they may disrupt social relationships, and may contribute to declines in participation, and limited growth. This study has begun the process of contributing some knowledge to this important issue.

5. As well as illuminating the powerful benefits of challenge events such as DBR competition events for BCS, this study also identified possible differences between individuals who take part in team based challenge events such as DBR, and 'one-off' challenge events. The storytellers in this project who were taking part in a team event appear to have a more dyadic focus while some participants in 'one-off' challenge events seemed to describe a more monadic focus to the experience. For example, the storytellers in this project had found a way to accept contingency, and being able to support others was an important consideration, while in the one-off events people talked about 'getting closure' on cancer or putting it 'behind them' and their goals had a more personal focus (Burke and Sabiston 2010). In the Amazon Heart Thunder motorcycle challenge event where there is more of a team emphasis - riders have to train to ride in groups and look out for each other – participants talked about the importance of relationships and wanting to help each other. There are alternative explanations which are that the difference is real while the other may be that the lack of opportunity to take part in team based challenge events means they have little option but to go with what they can access. Additionally, considering the potentially powerful positive impact challenge events have for BCS it may be helpful to have these opportunities available where they are not directly linked to a particular cancer cause, and to a requirement to

raise a large amount of money. Currently many people may be excluded from the experience because of cost.

6. The storytellers revealed that they valued; and were proud to be associated with the team, the positive message and health benefits they gained from it as BCS, and that their sense of commitment to it was one reason why they sometimes attended, even when they didn’t feel like it. This is new knowledge to add to the novel finding of greater adherence/attendance in a team-based intervention and the suggestion that intervention strategies that can effectively improve adherence/attendance to physical activity regimens hold considerable value (Carter et al, 2012).
7. New knowledge linking the multifaceted potential role of the DBR experience in; physically improving and maintaining their lymphoedema, psychologically, by making them feel empowered to control the condition, and socially the knowledge sharing which was so emphatically reported as valued and important to them. One storyteller reported that she adhered to the programme to help control her lymphoedema. McCausland (2010) has suggested that future research should consider the potential cost savings and risk reductions of exercise programs that incorporate dragon boat racing, as compared with traditional lymphoedema management.
8. The importance of providing meaningful and acceptable ways in which BCS can exercise their desire to support others, as the giving of support appeared to be as important as receiving it.

6.7 Future research

A number of ideas for further research have been generated from this study and are detailed below.

1. Are same sex, same tumour site activities important to cancer survivors? Despite demonstrating strong dyadic relationships with each other, none of the storytellers referred to the issue of introducing men, or other cancer survivors, into the team.
2. Understanding the issues that contribute to BCS leaving the team.

3. Understanding the impact of DBR on the spouses/partners of BCS who participate in the sport of DBR.
4. Repeating the study with a researcher who is not known to the team and who is not familiar with dragon boat racing.

Chapter 7: Conclusion

'uhm, Dragon boating I think, the water is a special place, makes it special being out on the water…and the actual setting of where we do it is just fantastic, but dragon boating itself is [special]*…I don't think you could have got it with another sport because you can't have that many people, of so many different age groups, doing the same thing in unison, it would be impossible, you know, so dragon boating is special, because it brings together all different ages, backgrounds, uhm, it doesn't matter where you come from, it's, it's, not expensive, it's bringing together women who have got that one thing in common…'* (DB 5)

The use of a storytelling methodology has revealed how the impact of DBR appeared to be interwoven into many aspects of the breast cancer survivors' lives, beyond the paddling experience. In this study this was captured using the weave metaphor (Frank 1995) in Chapter 5. The five influential inspirations identified within the breast cancer survivors' stories, illuminated how DBR impacts on the lives of breast cancer survivors, and why, despite their diversity in terms of age, level of fitness and illness experiences they positively described their experience of DBR with such consistency. The inspirations prompted the weaver (each BCS) to adjust the ever changing weave pattern, to represent the narrative types that were in the foreground, or in the background, at any particular moment in time.

The experience of a breast cancer diagnosis and its treatment resulted in an interruption to the lives of the participants and the stories told relating to this time (pre-DBR) are in keeping with those of chaos and restitution narratives (Frank 1995), while the stories recounting their experience of DBR suggest a transformation to a quest narrative, where they began to view the impact of the diagnosis and treatment, and the many contingencies associated with membership of the remission society (recurrence of their disease, premature death, vulnerability to additional morbidities) as a challenge. DBR appeared to enable them to rise to the challenge in varying ways, to be more that they perceived they were before the diagnosis.

Consistent with current cancer survivorship research literature (Department of Health 2007, 2010, 2013) many of the participants reported significant unmet BCS needs and these were strong motivators for participants joining the team. In relation to unmet BCS needs during the pre-DBR phase, the stories suggested that the participants, as BCS, were uncertain about the role of the breast cancer team - in terms of its responsibility, or ability, to address their BCS needs, and as such, many had not, and suggested they would not contact the team with their concerns. They described vehemently, how much they valued DBR team membership - as a forum for sharing their concerns- where fellow team members understood, and where the information, support, and advice they received was valued more than that received from family, friends, or health professionals. The identification of unmet need contributes to the body of cancer survivorship knowledge and supports the recommendation to introduce 'Structured Holistic Needs Assessment and Care Planning (DOH 2013) at the end of primary treatment. This will enable health professionals to identify needs and suggest activities/interventions that can assist BCS - as well as providing clarity around the services that are available to them. Participants reported that they could not think of anything that was available locally to them that would address their needs in the way DBR did.

The visual impact of seeing the women in the dragon boat, as well as the experience of being 'in the boat' was described vividly by participants as an inspiration in its own right. '*…there I saw people* [with cancer] *laughing, being jolly, and having a good time, on the boat…'* (DB 1) The image was sufficiently powerful to tempt a number of participants, who were poor swimmers and afraid of water, to join the team. The calming effect of water, the beauty of the surroundings, and being in close proximity to wildlife, was reported as highly significant by all storytellers as is captured succinctly in the following extract ' … *once you're out on that water everything sort of melts away, you know. I find it quite exhilarating'* (DB 2).

Two words '*special*' and '*unique*' (as in the story extract at the beginning of this chapter) were used by a number of storytellers to describe both, DBR the activity, and their experience of it as members of the remission society. The latter can be summarized as the challenge and satisfaction of accomplishing a new skill, which enabled them to participate in a safe, challenging, affordable, fun, watersport; in a team they had created and over which they had control - not just of its present, but also its future activities. It gave them a new more positive identity as a pro-active BCS, and as a sportsperson - including the opportunity to develop new friendships, to travel and compete in national and international events - culminating in it having a positive impact on many aspects of their lives. They felt empowered to prove to themselves and to the world, that as a cancer survivor they could take part in a physically challenging sport - very visibly demonstrating that there was life after breast cancer - and that they could '*become normal*' (DB 8). The desire to have a dyadic relationship with others is an aspect of the communicative body (Frank 1995) and was strongly evident in all the stories, but only after the storytellers had experienced DBR.

Through the sport of DBR the breast cancer survivors reported experiencing fun, social support, camaraderie, connectedness, inspiration, hope, joy, increased self-esteem, greater self-confidence, increased fitness and strength, the amelioration of some upper body morbidities e.g. lymphoedema, some adaptation to the contingencies associated with remission society membership, and a greater appreciation of nature.

The unique social support they experienced through participation in DBR, was robustly reported by participants in this study, and was depicted as an inspiration. It countered the social isolation (Rosedale 2009) described in this study, as well as in the illness narrative (Sontag 1978, Mullan 1983, 1985, Frank 1995) and breast cancer narrative literature (Conway 1997, 2007, Peltason 2008, Allen et al 2009, Coyne and Borbasi 2006, Tighe et al 2011) by bringing them in contact with people who understood what they had been through, and were going through, in a way family, friends, or health professionals could not. It was described in terms such as ‘*connected*’, ‘*all in the same boat’ ‘little sisterhood’*. The uniqueness of the DBR social support inspiration included the opportunity for members to give as well as receive support and to be part of a wider supportive network within the team and the national and international community of BCSDBR members. Additionally, the breast cancer survivors anticipated, and valued, that it would be a support system for their daughters - should they develop the disease – and significant others, in the event that the participants themselves developed recurrent disease or died. For some, social support was a reason for joining and adhering to the sport, thereby facilitating improvement in their ‘*well-being’* (DB 6) and, additionally, for some team members, it gave them the confidence to travel and take part in competition events.

While the DBR research literature includes reports of social support (Unruh and Elvin 2004, Sabiston et al 2007, McDonough et al 2008, Parry 2008, Mitchell et al 2007), by using storytelling as a methodology, this study has expanded this knowledge to include a greater understanding of how**,** through being part of a team made up of a large number of personality types, BCS can have different relationships with different team members and the opportunity for these to develop and to be sustained over a long period of time. Additionally this study shows how they coped with relationship conflicts.

Negative aspects such as recurrent disease or death of team members and relationship conflicts were dealt with through; the support of other team members, an acceptance that they are a normal part of life, modelling how other people managed these situations, as well as a desire to continue the legacy of DBR for future BCS. McDonough et al (2008, 2011) highlighted the need to explore how BCS deal with these challenges, as they may disrupt social relationships, and may contribute to declines in participation, and limited growth. This study has begun the process of contributing knowledge to this important issue.

Reference was made to differences participants perceived existed between support offered by traditional support groups and that offered by DBR. They appeared to suggest that the former were too cancer focused while they wanted to accept cancer in their lives but do something positive - such as DBR - after the cancer and not dwell on it. This supports existing knowledge which suggests that some cancer survivors have a preference for physical activity based support groups over talk based groups (Emslie et al 2007, McDonough et al 2010).

The study has also identified breast cancer survivor's concerns, or fears, about the potential for exercise to cause, or exacerbate, upper-body-morbidity issues (especially lymphoedema), but also their perception that DBR was a safe physical activity - when DBR practice protocols were followed. The former was reported as being both a motivator for joining the team and for adherence to it, while the latter was an important message to the charity that maintaining safety in relation to all aspects of the practice of DBR was important to the team's present and future members. This appears to be a new contribution to the BCSDBR knowledge base. It is also an important message for health and leisure service providers, because, while participants wanted to educate the public on the importance of physical activity for BCS, any activities/interventions that may be offered to them, must consider, that any perceived or real risk of injury, or particularly the development of lymphoedema, may lead to non-participation or non-adherence. Breast cancer survivor's concerns about safety were also reported by Whitehead and Lavelle (2009) and Sander et al (2012) in relation to breast cancer survivor's perception of exercise and physical activity in general. A further message to the charity and to potential providers of activities/interventions for BCS, concerns the need to consider and address the issue of affordability. Maintaining DBR as an affordable activity was raised directly by some participants and by others on behalf of fellow team members. The financial impact of cancer in general (Amir et al 2012), and how it may influence participation in BCS interventions/activities (Whitehead and Lavelle 2009) has only been considered in recent years.

Competition events, as reported in the stories, could be regarded as an intensified version of the everyday experience of DBR except that it is experienced as part of the national or international community of breast cancer survivors. The fun, joy, camaraderie, connectedness, inspiration, pride, exhilaration, support, and new identity as a breast cancer survivor and sportsperson the participants experienced at these events, was reported in such terms as *'it was just amazing, just to be in a park, with hundreds of ladies, who'd all gone through the same thing, and everybody was so happy and cheery'* (DB 13)

Competition events also facilitated goal setting, and future planning, and appeared to restore some elements of the temporality lost as a result of their cancer diagnosis. They were also credited with strengthening the team bond. The significance of participating in competition events to support the quality and sustainability of the DBR experience of the team, as well as ensuring team members were not excluded because of their financial status, was an important message to the charity.

While the overall impact of competition events on the BCS was extremely positive there was a tension as to the level of competition in which the team should engage in. However, in keeping with the dyadic nature of their relationships a number of compromise solutions were put forward to reconcile the needs of those who wanted more competition with those who wanted less.

Three important limitations of the study are that it included only a Caucasian female population of breast cancer survivors – male BCS, other cancer survivors, or BCS from other cultures or backgrounds are not represented, therefore the results may not be applicable to these other populations. That the researcher was an insider presented the risk of one-sidedness in the results as the participants may have been reluctant to share certain aspects of their experience with her or believe that she "knew what they meant" and therefore did not elaborate as much as they might have done with a stranger. However, that the researcher had this existing relationship with the participants and knowledge of the sport enabled the participants to focus on their story without having to digress to check that the researcher understood aspects of the sport, or the experience of DBR, as they arose during the storytelling encounter. They were all motivated to participate in the study, and tell their story, for its potential to benefit other BCS, and as such, appeared to include the positive and negative aspects of their experiences.

Through this study of the impact of DBR on the lives of BCS I have come to appreciate the power and potential of storytelling within health care and share the opinion of Portelli (1997) cited by Frank (2010, p.113) as described in the following quote:

‘And one creative storyteller, a brilliant verbal artist, is as rich a source of knowledge as any set of statistics’

7.1 Recommendations

1. For the breast cancer survivors who were experiencing unmet need at the point of joining the team there appeared not to have been any assessment of those needs by health or social care professionals. Additionally, some breast cancer survivors expressed both ambivalence and uncertainty about the role the breast cancer care team could, or should, play in their care beyond the primary treatment phase. This suggests the urgent need for health professionals to implement the recommendation to introduce the ‘Structured Holistic Needs Assessment and Care Planning (DOH 2013), at the end of primary treatment, as a priority, and to be aware of interventions/activities that may support BCS in addressing BCS related needs.
2. Considering the potentially powerful positive impact challenge events, such as DBR competition events have for BCS, it may be helpful to have these opportunities available, where they are not directly linked to a particular cancer cause, or to a requirement to raise a large amount of money. Currently many people may be excluded from the experience because of cost.
3. Any activities/interventions that are recommended will need to be safe and be perceived as safe by BCS. (Safe in this context refers to, the prevention or exacerbation of lymphoedema, or other upper-body-morbidities).
4. Activities/Interventions should be affordable.

5. Interventions aimed at addressing the needs of cancer survivors may benefit from finding ways to capture the connectedness, integration, and camaraderie, that generated a strong sense of commitment to the team and was so important to the storyteller's attendance and adherence to DBR, and therefore to their participation in a physical activity programme.

Appendix A Dragon Boat Racing Literature Review

Author(s) (In alphabetical order)	**Title**	**Method**	**Findings**	**Critique**
Bodner, S. (2010)	Riding the Dragon: Powerful in Pink!	An account of one BCS experience of DBR	The author is an academic who wrote an account of her own experience of participating in DBR after a breast cancer diagnosis. She is a founder of a dragon boat team and also initiated several programmes to promote the well-being of BCS.	Although this is one person's accounts it encapsulates the experiences of BCS as perceived by the author.

Author(s) (In alphabetical order)	Title	Method	Findings	Critique
Harris, S.R. (2012)	"We're All in the Same Boat": A Review of the Benefits of Dragon Boat Racing for Women Living with Breast Cancer	A narrative review of all the quantitative and quantitative data published over the previous 15 years	The review findings suggest that exercise and physical activity have recently emerged as mainstream complementary therapies. Also that the research supporting the safety and positive effects of dragon boat racing and other forms of resistance exercise supports making all women who have been treated for breast cancer aware of this wonderful recreational opportunity.	The review method was not stated.
McDonough, M.H., Sabiston, C.M., Crocker,	An Interpretative Phenomenological Examination of Psychological	An interpretative phenomenological approach was used to gather and	Themes: Perception of increased strength and fitness, a shift towards body image with	A self-selected sample increased the risk of one-

Author(s) (In alphabetical order)	Title	Method	Findings	Critique
P.R.E. (2008)	Changes among Breast Cancer Survivors in their first season of Dragon Boat Racing	analyse the data. Semi structured interviews x2 one in the first two weeks of the new season and the other at the end of the season. 14 self-selected novice recruits participated in the study	respect to fitness rather than weight and appearance, an emerging athletic identity, social benefits including connecting with women who understood the breast cancer experience and could share first-hand information. Some reported struggling with the constant reminder of being a survivor. Author suggested that work should be done to explore how participants cope with challenges.	sidedness in the results and other participants with alternative views may have been missed.
McDonough, M., Poliseo, M.,	The Difference is More than Floating:	17 female novice members of a	Themes: reasons why women felt dragon boat racing was a better fit for them	An interesting and

Author(s) (In alphabetical order)	Title	Method	Findings	Critique
Ullrich-French, S., Sabiston, M. (2010)	Breast Cancer Survivors' Decisions to Join Dragon Boat Teams and Support Groups	dragon boat team for breast cancer survivors were interviewed to explore their decision to join a dragon boat team and their comparison of that decision to their decision to not join a breast cancer support group. Interview transcripts	included: the physical activity focus, de-emphasizing cancer, taking action and moving forward, community involvement, and getting a combination of physical, emotional, and social benefits. Reasons for not joining or continuing with a support group included: a perceived negative focus on cancer, and not feeling a primary need for support.	informative study. Choosing novice paddlers supported the credibility of the findings as they had only recently gone through the decision making

Author(s) (In alphabetical order)	Title	Method	Findings	Critique
		were analysed using content analysis.		process to join the team. Themes rather than narratives.
McDonough, M.H., Sabiston, C.M., Ullrich-French, S. (2011)	The development of social relationships, social support, and posttraumatic growth in a dragon boat team for breast	An interpretative phenomenological approach was used to gather and analyse the data. Semi-structured	Themes: “developing a feisty spirit”,” I don’t want it to be just about me”, “it’s not about the pink it’s about the paddling” and “hard to get close”. Profiles were discussed in terms of developing social relationships and support, providing support to others,	Larger sized sample and interviews on five occasions provided a good

Author(s) (In alphabetical order)	**Title**	**Method**	**Findings**	**Critique**
	cancer survivors	interviews were conducted with 17 breast cancer survivors on five occasions over their first two seasons of dragon boating.	physicality and athleticism, and negative interactions and experiences.	opportunity to capture rich timely data. Themes rather than narratives.
McKenzie, D.C (1998)	Abreast in a Boat-a race against breast cancer	Case series pilot study. 20 of the 24 paddlers had upper-extremity measurements taken	The paddlers showed a marked improvement in both their physical and mental health and no new cases of lymphoedema were reported. It was from this study that the phenomenon of dragon	Although this study was conducted to assess an aspect of

Author(s) (In alphabetical order)	Title	Method	Findings	Critique
		prior to, during, and after, their first paddling season to assess the risk of developing lymphoedema.	boat racing for breast cancer survivors emerged.	physical health it has been included because the author anecdotally reported the positive impact the experience had on the women's psychological

Author(s) **(In alphabetical order)**	**Title**	**Method**	**Findings**	**Critique**
				health.
Mitchell, T. Nielsen, E.(2002)	Living Life to the Limits. Dragon Boaters and Breast Cancer (2002)	A participatory phenomenological-hermeneutic study designed to describe the experience, meaning, and psychosocial impact of dragon boating on women with breast cancer in which the participants	Themes: Hopeful Mission, Common Base, Paddling and the Environment, Camaraderie, Regaining Control, Embracing Life, Facing the Disease, Having Fun, Being Focused, Moving on.	Small sample size and the significance of their participatory role was not discussed.

Author(s) **(In alphabetical order)**	**Title**	**Method**	**Findings**	**Critique**
		remained involved throughout the research process. 6 participants.		
Mitchell, T.L., Yakiwchuk, C.V., Griffin, K.L., Gray, R.E., Fitch, M.I.(2007)	Survivor Dragon Boating: A vehicle to Reclaim and Enhance Life after Treatment for Breast Cancer :	Open ended and semi structured qualitative interviews with 10 women new to dragon boat racing. Pre and post season interviews. Data analysed using	Themes: awakening of the self; common bond; regaining co troll; being uplifted; and transcending the fear of death. Increased energy, no lymphoedema	Pre and post season interviews were a positive feature of this study. Themes rather than

Author(s) (In alphabetical order)	**Title**	**Method**	**Findings**	**Critique**
		thematic analysis		narratives.
Parry, D.C.(2007)	"There is Life after Breast Cancer": Nine Vignettes Exploring Dragon Boat Racing for Breast Cancer Survivors	A feminist epistemology to explore survivors' perceptions of broadly defined health benefits associated with dragon boat racing. Active interviews described as	The findings revealed that dragon boat racing contributed social, emotional, physical, spiritual, and mental dimensions of health. The author suggests that the significance of the study lies not only in the investigation of the leisure pursuit of dragon boat racing but also its focus on survivorship after medical treatment for breast cancer.	Self-selected sample increasing the risk of one-sidedness in the results and the researcher determined the research

Author(s) (In alphabetical order)	**Title**	**Method**	**Findings**	**Critique**
		conversational in nature with 12 participants. Analysed using creative analytic practice.		agenda through structuring of the questions rather than using a single open question.
Parry, D. C. (2008)	The Contribution of Dragon Boat Racing to Women's Health and Breast Cancer.	In-depth face to face active interviews with 11 participants; analysed using the constant comparison	Main findings: solidarity and emotional benefits, physicality and stress coping and spiritual awakening. Participation in dragon boat racing	Themes rather than narratives

Author(s) (In alphabetical order)	Title	Method	Findings	Critique
		method (Glaser and Strauss 1967) to understand women's lived experiences. The author highlighted the lack of research from the survivors standpoint	represented a form of resistance against the dominant cultural narrative of the sick disabled cancer patient. It was perceived as a demonstration that the women were capable of thriving in their everyday lives, they felt normal and emotionally supported, a source of motivation, an improvement in physical ailments, feeling energetic, less depressed, as well as fostering an appreciation for everyday spiritual awakening. The author suggested that research was needed to compare findings between and	

Author(s) (In alphabetical order)	Title	Method	Findings	Critique
			within different countries, Information was also needed to assess how knowledge about dragon boat racing is currently translated. What are the barriers and facilitators to participation?	

Author(s) (In alphabetical order)	Title	Method	Findings	Critique
Parry, D.C. (2010)	Dragon boat racing for breast cancer survivors; leisure as a context for spiritual outcomes:	The research was guided by feminist epistemology. Active interviews (guided by the researcher's agenda while simultaneously being conversational in nature). Self-selected sample of 11 breast cancer survivors. The main purpose was to explore the interplay	The findings suggest that dragon boat racing transcends participation to bring clarity, purpose and meaning to the lives of breast cancer survivors.	Interviews guided by the researcher's agenda rather than through a single open question.

Author(s) **(In alphabetical order)**	**Title**	**Method**	**Findings**	**Critique**
		of survivorship, spirituality, and health for breast cancer survivors. The data were analysed through the constant comparison method (Glaser and Strauss, 1967).		
Sabiston, C.M., McDonough,M.	Psychosocial Experiences of	Interviews 45-60 minutes about their	The DBR programme facilitated social support from women with common	The experiences

Author(s) **(In alphabetical order)**	**Title**	**Method**	**Findings**	**Critique**
H., Crocker, P.R.E. (2007)	Breast Cancer Survivors Involved in a Dragon Boat Program: Exploring Links to Positive Psychological Growth	experiences as members of survivor dragon boat teams: analysed using grounded theory methods. Semi-structured interviews with questions and probes. The questions centred on what they expected to get from dragon boat racing, their	challenges and a shared understanding of survivorship. It also provided opportunities to (re)gain a sense of personal control, develop new identities as athletes, and overcome physical challenges. The authors suggest that future physical activity interventions targeting breast cancer survivors may benefit from developing strategies that share key characteristics of dragon boating.	recounted by participants were broadly determined by the researcher, other potentially more significant experiences may have been missed.

Author(s) (In alphabetical order)	**Title**	**Method**	**Findings**	**Critique**
		perceptions of themselves physically, and how they would describe their social support network) Self - selected sample.		Self-selected sample therefore risk of one-sidedness in results.
Unruh, A.M., Elvin, N. (2004)	In the Eye of the Dragon: Women's experience of breast cancer and the	Epistemology not explicitly stated. Pilot study. Three women interviewed twice	Seven themes identified: attraction of dragon boat racing; physical and emotional well-being; competition; social support; transcendence/connectedness/oneness;	Small self-selected sample of 3 increased the

Author(s) (In alphabetical order)	Title	Method	Findings	Critique
	occupation of dragon boat racing.	about the meaningfulness of DBR in their lives: analysed using thematic analysis	recurrence of cancer; and public awareness.	risk of one-sidedness in the results. Other participants with alternative views may have been missed. Themes rather than narratives.

Appendix B Questions the Literature Should Ask

Questions the literature should ask

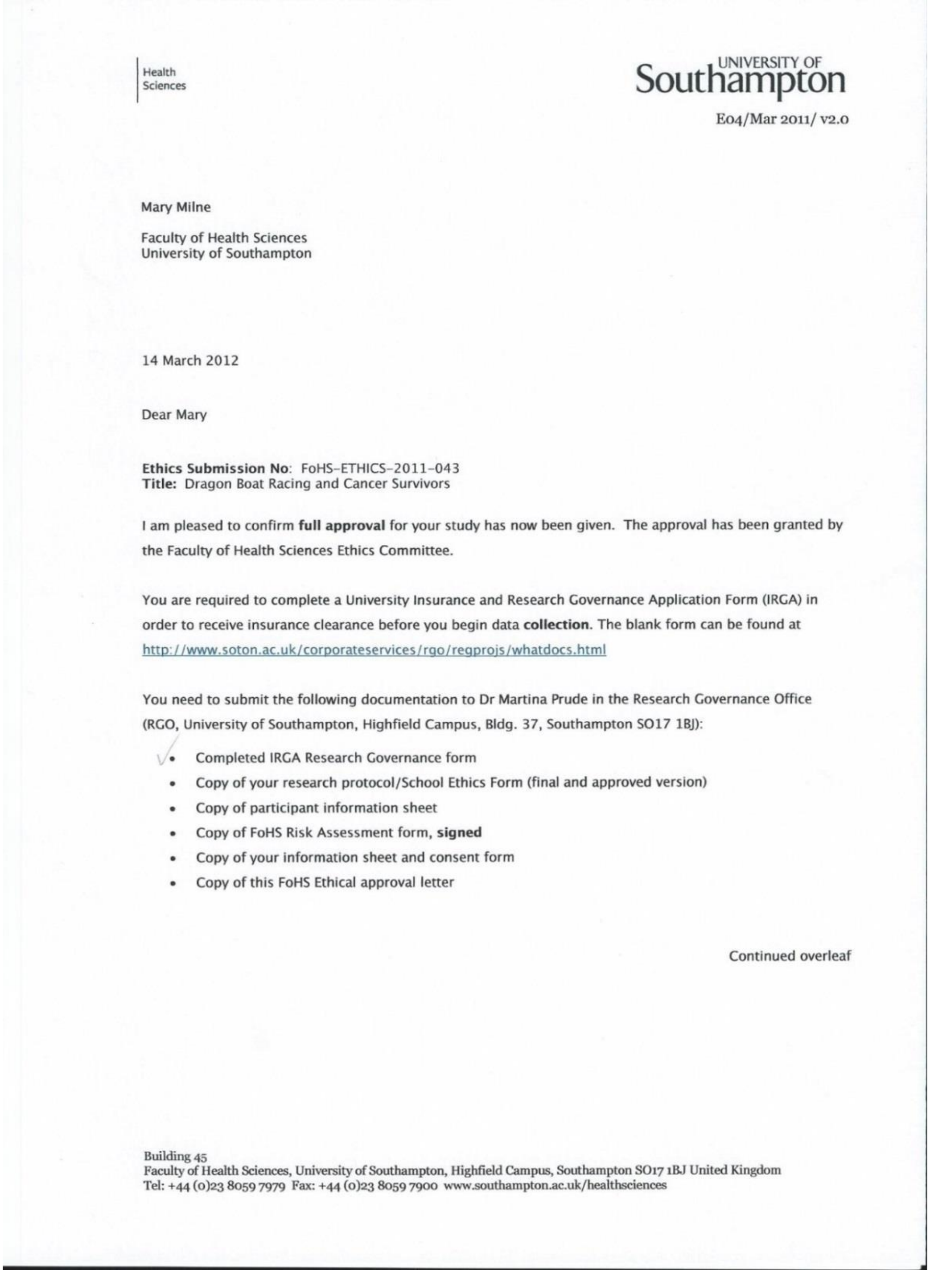
- What were the research aims and objectives?
- What were the outcomes of the research?
- What approaches/methods/strategy were used?
- In what context was the research conducted?
- What was its contribution to the field?
- Does it have any connection to my research question?

Questions a literature review should answer

- Why is this subject important?
- Who else thinks it's important?
- Who has worked on this subject before?
- Who has done something similar to what I will be doing?
- What are the gaps in the research?
- Who is going to use my material?
- What use will my project be?
- What will my contribution be?
- What specific questions will I answer?

(Adapted from Murray 2011, p. 128)

Appendix C Confirmation of Ethics Approval



Health
Sciences

UNIVERSITY OF
Southampton

E04/Mar 2011/ v2.0

Mary Milne

Faculty of Health Sciences
University of Southampton

14 March 2012

Dear Mary

Ethics Submission No: FoHS-ETHICS-2011-043
Title: Dragon Boat Racing and Cancer Survivors

I am pleased to confirm **full approval** for your study has now been given. The approval has been granted by the Faculty of Health Sciences Ethics Committee.

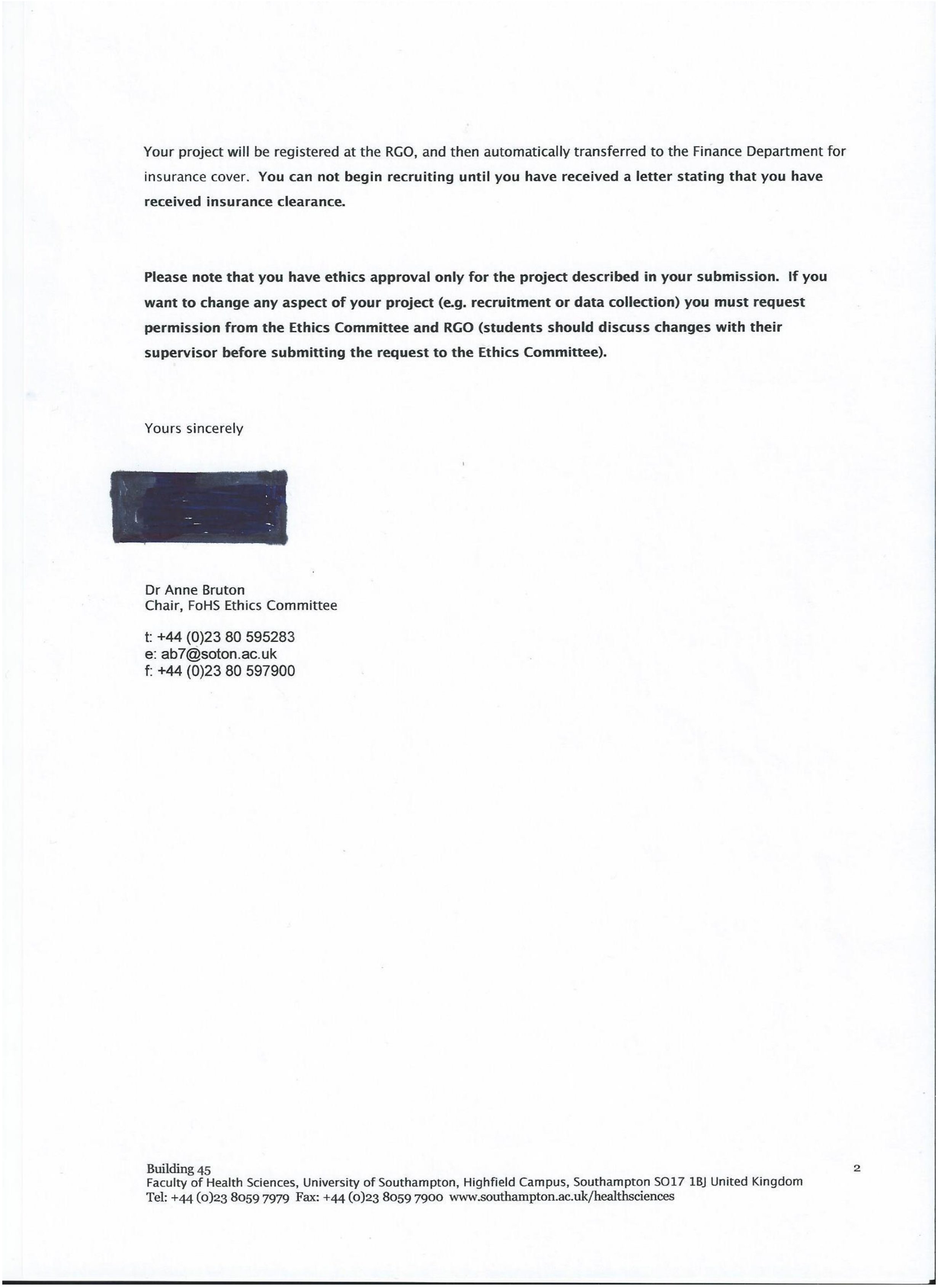
You are required to complete a University Insurance and Research Governance Application Form (IRGA) in order to receive insurance clearance before you begin data **collection**. The blank form can be found at http://www.soton.ac.uk/corporateservices/rgo/regprojs/whatdocs.html

You need to submit the following documentation to Dr Martina Prude in the Research Governance Office (RGO, University of Southampton, Highfield Campus, Bldg. 37, Southampton SO17 1BJ):

- ✓ Completed IRGA Research Governance form
- Copy of your research protocol/School Ethics Form (final and approved version)
- Copy of participant information sheet
- Copy of FoHS Risk Assessment form, **signed**
- Copy of your information sheet and consent form
- Copy of this FoHS Ethical approval letter

Continued overleaf

Building 45
Faculty of Health Sciences, University of Southampton, Highfield Campus, Southampton SO17 1BJ United Kingdom
Tel: +44 (0)23 8059 7979 Fax: +44 (0)23 8059 7900 www.southampton.ac.uk/healthsciences



Your project will be registered at the RGO, and then automatically transferred to the Finance Department for insurance cover. **You can not begin recruiting until you have received a letter stating that you have received insurance clearance.**

Please note that you have ethics approval only for the project described in your submission. If you want to change any aspect of your project (e.g. recruitment or data collection) you must request permission from the Ethics Committee and RGO (students should discuss changes with their supervisor before submitting the request to the Ethics Committee).

Yours sincerely

[redacted]

Dr Anne Bruton
Chair, FoHS Ethics Committee

t: +44 (0)23 80 595283
e: ab7@soton.ac.uk
f: +44 (0)23 80 597900

Appendix D Participant Information Sheet

Participant Information Sheet

The Sport of Dragon Boat Racing as experienced by Breast Cancer Survivors Research Study
Researcher: Mary Milne
Ethics Number:
Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

There is growing interest in the sport of dragon boat racing for breast cancer survivors worldwide. This research intends to explore, what it is like for women, who have completed treatment for breast cancer, to take part in the sport of dragon boat racing. Women who decide to take part would be requested to tell the story of their experience from the time they made the decision to join the team to the present day. The knowledge gained will help to understand how breast cancer survivors, as individuals, experience dragon boat racing.

The study is being conducted by a 'Taught Clinical Doctorate' research student from Southampton University. Funding is not required. The study will be supervised by, academic staff members from the university. The Faculty of Health Sciences Research Ethics Committee has reviewed and approved the study.

Why have I been chosen?

All team members, like yourself, who are actively involved in paddling with the team, are being invited to take part, but only a maximum number of 20 people will be randomly selected to tell their stories. Random selection will be achieved by putting all of the returned envelopes (which will be identical, and have no markings or names, on the outside), into a container, and randomly selecting 70% of that number (up to a maximum of 20). We expect each individual's story will be different and we are interested in knowing what those differences are. A better understanding of those differences will contribute to our knowledge of what it is like for breast cancer survivors to participate in the sport of dragon boat racing.

What will happen to me if I take part?

If you choose to take part in the study you will be requested to sign a consent form and will be given the option to tell your story to the researcher in a one to one interview or to write your own story. With either option please base your story around the following question:

'Please tell me the story of your personal experience of participating in the sport of dragon boat racing, starting with your decision to join the team, and continuing to the present day?'

You will be requested not to refer to any other person or organization, by name, during the interview or in your written account.

Option 1 Interview

You will be invited to meet with the researcher to tell your story at a time and place that is convenient to you. The interview will take approximately one hour but you may finish the interview at any time. With your agreement the story will be audio recorded and transcribed (typed up). Should it be possible to identify you, or any other person or organization – directly or indirectly involved with Dragon Boat Racing - from the recording, this will be omitted by the researcher during the transcription process.

You will be provided with a copy of the recording and requested to reply, within fourteen days of receipt of the copy, if you would like any particular sections to be deleted (you will specify where the deletion should begin and end). A copy of the amended recording will be returned to you for your approval.

Option 2 Story-writing

You will be invited to write the story of your experience of participating in the sport of dragon boat racing beginning at the time you made the decision to join the team and extending to the present day. Completed stories will need to reach the researcher no later than XXXX (one month from the date the consent form is signed). The story may be typed or hand written. You may email the story, or send it to the Research Office, University of Southampton, for the attention of the researcher. Should it be possible to identify you, or any other person or organization – directly or indirectly involved with Dragon Boat Racing – from the account, this will be deleted from the text, by the researcher, before the analysis of the data begins.

Are there any benefits in my taking part?

There may be no benefit to you as an individual.

Are there any risks involved?

It is possible that telling the story may bring back memories of the diagnosis and treatment and this may cause emotional upset. The breast care nurses at both local hospitals have been approached and have agreed to offer a consultation to any participant who wishes to discuss issues, they may have identified, as difficult.

Will my participation be confidential?

We will follow ethical and legal practice and all information that is collected about you during the course of the research will be kept strictly confidential in accordance with the Data Protection Act (1998) and

University Policy. You will be requested to choose a new name for the purpose of the study.

Things that participants say in the interview, or write in their written stories, may be quoted in reports of study findings, however, names and personal details will be removed to protect the participants, and other people's, identity. Where the participant, or the researcher, have any concerns that it may be possible to identify an individual, or organisation, referred to directly, or indirectly, within the story, it will deleted by the researcher to protect the privacy of the individual or organisation, concerned. The participant will be given a copy of the recording of their story and may request that sections of the recording, or the whole recording, be deleted.

Your personal data will be securely stored separate from your stories. The recordings and the data will be securely stored for 10 years in a password protected system in accordance with the University of Southampton regulations.

What happens if I decide not to take part?

Participation is completely voluntary choosing not to take part will not affect the participants membership of the team, now, or in the future.

What happens if I change my mind?

Participants may change their mind at any time without giving any reason and without it affecting your membership of the team, now, or at any time in the future. The information provided up to that point will be destroyed if that is the participants wish.

What happens if something goes wrong?

"If you have a concern or a complaint about this study you should contact Martina Prude, Head of the Governance Office, at the Research Governance Office (Address: University of Southampton, Building 37, Highfield,

Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 5058; Email: rgoinfo@soton.ac.uk . If you remain unhappy and wish to complain formally Martina can provide you with details of the University of Southampton Complaints Procedure."

What happens to the research?

Once the stories have been analysed the findings will be shared with the participant, and may be published in academic journal articles, book chapters, and presentations, to share the knowledge gained as widely as possible. In signing the consent form the participant is agreeing to the publication of the research findings, in whatever medium is believed to be the most appropriate; this may include direct quotes from the stories. In all publications the material will be anonymised. Should you have any concerns about this please discuss it with the researcher, or someone else, before signing the consent form.

Researcher's contact details: Mary Milne (email address) or (telephone number) and leave a message with the most convenient number on which to get back to you.

Thank you for taking time to consider participating in this research

Appendix E Guiding Principles for Evaluating Whether a Study Counts as Narrative Research and Assessing the Quality of Such Research. (adapted, Greenhalgh and Wengraf 2008).

1. Narrative research may include 1 or more of the following activities:
    - **A.** Story gathering (e.g. collecting stories that have already been told or written for a different purpose).
    - **B.** Story eliciting (asking participants to tell a story)
    - **C.** Story interpreting or analysis (drawing meaning from stories
    - **D.** Story collating (selecting and combining stories)
2. The above activities should be classified as research for the purposes of ethical approval if they are undertaken with the explicit intention of furthering a body of knowledge (e.g. through an academic paper, conference presentation, or book).
3. Narrative research must meet the general criteria of high-quality research. These would generally include:
    - The originality, clarity and importance of the research question.
    - The appropriateness of the study design to the research question.
    - The size and representativeness of the sample chosen.
    - The robustness of the data collection process, including choice of instruments or tools, experience, and training and supervision of research staff.
    - The rigour and transparency of the analysis (including the coherence of the theoretical framework and an identifiable unit of analysis).
    - The logic and coherence of the links made between

findings and conclusions
    - The researcher’s awareness of the possibility of error and the steps taken to minimize or take account of this throughout the research process.

4. Storytelling is an art, not a science. The storyteller uses rhetoric and other literary devices to give a version of events from his or her own perspective. In narrative research, the story should therefore be anchored in some way, for example, by:
    - Collecting multiple stories about the same event or comparable experiences.
    - Linking the story to other sources of empirical data (e.g. biomedical data about the severity and time-course of a person’s illness).
    - Linking the story to a thorough review of the literature.

5. Storytelling is a communicative act, involving inter-subjectivity (i.e. an overlap in peoples individual understandings of something held in common) In story-eliciting research, the inter-subjective role of the researcher should be acknowledged and commented upon, usually as part of a more general statement of reflexivity.
6. When a story is sought as (or becomes) research material, the researcher takes on ethical duties towards the storyteller. These include:
    - Honesty: to be explicit and transparent about the purpose of the work.
    - Non-maleficence: to do no harm (unless the potential harm is balanced by a greater benefit).
    - Consent: in relation to the story, to undertake only those activities to which the storyteller has consented.
    - Confidentiality: to protect the identity of the storyteller if

that is his or her desire.

Appendix F Sensitivities and Safeguards concerning the complexity of roles held by the researcher in relation to: Power Imbalance and the Researcher as Insider.

Potential Conflict	**Issues**	**Response**
Power imbalance	• The Charity's Financial Decision Making	The researcher no longer holds any position within the charity and therefore has no involvement with financial decision making.
	• Researchers' position within the Team.	The researchers' role has no involvement with the team's fitness training, coaching, selection, or any element of the teams' activity on the water other than as a fellow paddler. These roles are the responsibility of other team members and two non-breast cancer survivors.

Researcher as Insider		1. The researcher: • recorded her views and feelings about DBR before collecting the stories. • developed an audit trail. • maintained a reflective journal. 2. Participants checked their stories for accuracy. 3. The researcher's supervisors independently reviewed the data.

Appendix G Notation used during the transcription process.

Oh::	Colons are used to indicate prolongation of the prior sound; the number of colons indicates the extent to which the sound is prolonged
EH	Underscoring indicates stress on the word and capitalization indicates louder or shouted talk.
[	Left square bracket indicates where one person's speech is interrupted by the next person's speech.
(())	Double parentheses enclose non-verbal and other descriptive information.
=	Equals sign link utterances by different speakers showing there is no pause between them.
?	A question mark indicates rising intonation as a syllable or word ends

Adapted from Elliott 2005, p.53/54

Appendix H Analysing the Content of the Stories

Stage 1

Analysing the Content of the Stories

Immersion (reading/listening scripts/stories) (gained sense of storyteller's experience)

Fit with Frank's (1995) Narrative Types (movement between narrative types was noted**)**

Reading/Listening (content – immersion) (narrative types identified, grid used as crude match, text highlighted)

Crystallization (Quest Narratives dominant)

Reading/Listening again

3 Facets of Quest Memoir/Manifesto/**Automythology (dominant)**

Reading/Listening again

4 Ideal Typical Bodies (Disciplined, Mirroring, Dominating, **Communicative Body Type (dominant)**

Inspirations (DBR (in the boat), Social Support/Social Support Network/Competition Events, Team/Group Membership, Physical and Psychological Changes)

WEAVE (Pre DBR, DBR, Competition Event**)**

Appendix I Narrative Analysis

(My analysis was driven by understanding the content of each story).

Mishler's Framework (1995) Based on what are commonly understood as the three functions of language, namely meaning, structure, and interactional context	**Content** **Structure** **Performance**	**Content** **Structure** - …. Structural Analysis (Labov and Waletzky 1967) – Abstract, Orientation, Complicating Action, Evaluation, Resolution, Coda. This structural model of narrative form can be useful in analysing short sections of interviews in which narratives occur, but is arguably of less utility when examining an interview more holistically (Elliott 2005). **Performance** – It interrogates how talk coming from speakers is interactively produced and performed as narrative (influence of investigator, setting, and social circumstances on the production and interpretation of narrative. It asks why was the story told *that* way? (Riessman 1993).

Lieblich et al (1998)	Analyses can be characterized by whether they examine **'the form'** or '**the content'** Whereas some readings focus on the explicit content of an account, i.e. what happened and why, other readings pay less attention to the content and concentrate on **the structure of the plot, its coherence or complexity, the style or genre of the narrative, and the choice of metaphors and other images that are invoked**. (In contrast to the typology provided by Mishler (1995), Lieblich et al (1998) do not include a discussion of approaches to narrative analysis which focus on the social context or functions of narrative but do introduce the **distinction between holistic and categorical analysis**.	Lieblich et al 1998 suggests that two main strategies have been outlined in relation to a more holistic analysis of the form of narratives. The first involves categorizing narratives using a typology or genre borrowed from the literature (such as epic, comedy, or tragedy). The second focuses on the direction of the plot whether it is progressive, regressive, or follows a steady line (Elliott 2005).

Chamberlayne and Rustin, 1999, Chamberlayne et al , 2000)	**Content and Structure**	Biographic Narrative Interpretative Method (BNIM) This method advocates producing a summary of the content of a biographical interview and a separate summary of the form of the biography as told in the interview and then requires the analyst to examine the connection between these analytic documents in order to produce a case history documenting theories about how the two are related (Elliott 2009).
Shaw (1966)	**Content**	Shaw's work on the life histories of delinquents provides a good example of research that focuses solely on the content of narrative because he makes no comment on how the life history is structured. He does not provide any analysis of the material he presents rather the life story is allowed to speak for itself.
Bertaux, D. and Bertaux-Wiame, I. (1981)	**Content**	These researchers also focus on the content of the life history of the bakers and the baker's wives in their research study. They are explicit in stating that they did not subject the biographies they collected to any formal analytic techniques. They chose to interview a number of participants and created a collective story which represented the common elements in the trajectories of the different bakers that they interviewed.
Riessman	**Content**	Interested in how a speaker or writer

(2008)	**Structure** **Performance**	assembles and sequences events and uses language to communicate meaning. Interrogate intention and language – *how* and *why* For whom was *this* story constructed. What cultural resources does the story draw on or take for granted. What plots does it call up? What does the story accomplish? Are there gaps and inconsistencies that might suggest preferred, alternative, or counter-narratives?

Appendix J Frank’s Narrative Types

The Four Sections of Frank’s Narrative Types (Plot, Action Problems of Embodiment, Self-Story, Power/Limitations (Frank (1995)

Narrative Types	Plot	Action Problems of Embodiment				Self-Story	Power/Limitations
		Control	Body-Relatedness	Other-Relatedness	Desire		
Restitution	‘Yesterday I was healthy, today I’m sick, tomorrow I’ll be healthy again’	The body’s predictability desired and a need to stave off the contingency of mortality	Dissociation	Monadic	To return to health.	No, in the sense that restitution stories bear witness not to struggles of the self but to the expertise of others (health professionals etc.).	The cultural power of these stories is that their telling reflects one of the best impulses in modernity: the heroism of applied science as self-overcoming. Restitution stories no longer work when the person is dying or when impairment will remain chronic.

Chaos	Imagines life never getting better	The body telling chaos stories defines itself as being swept along without control, by life’s fundamental contingency.	Dissociation	Monadic	Lacking. .	Non self-story.	Chaos stories show how quickly the propos that other stories depend on can be kicked away. The limitation is that chaos is no way to live.
Quest	‘Quest stories meet suffering head on; they accept illness and seek to use it’	The quest narrative affords the ill their most distinctive voice,	Association	Dyadic	Yes	Yes. Three ethics of self-story: Recollection, Solidarity, Commitment and Inspiration.	The genesis of the quest is some occasion requiring the person to be more than she has been, and the purpose is becoming one who has risen to that occasion.

Appendix K Participant Covering Letter

UNIVERSITY OF
Southampton

Letter to Participants

Participant Name

<Date>

Dear

It was a great privilege to hear the story of your experience of dragon boat racing. For so enthusiastically embracing the study, and giving so generously of your time, my sincere thanks.

It was a revelation to hear so many very different stories, yet, during the analysis it became clear that they shared many common elements, such as; your passion for dragon boat racing, your strong desire to encourage other women to take part, and to give them the support that you believe, dragon boat racing, and membership of the team, has given to you.

At the end of the project I will be inviting all the team members who took part in the study to attend a focus group. The purpose of this focus group will be to discuss the key issues raised during the storytelling, and agree the recommendations that you would like to be presented to the charity's trustees, to support their decision making.

Just as each story is precious and greatly valued so too will your contribution to the focus group. I will therefore try to arrange a date and time that is convenient for as many people as possible.

When the final thesis is completed I will be sending you a research summary detailing the study's findings.

Along with this letter you will find a smaller envelope which contains a paper and digital copy of your story. I appreciate that you may prefer not to listen to, or read your story, so I have adopted a system whereby they can remain sealed unless you choose to access them. You will only need to open the smaller envelope if you would like to check that it is an accurate reflection of the story you told, or just for interest. It has no other purpose, so please do not feel that you have you read it, if, for any reason, you would prefer not to.

If you do read or listen to the story I would be grateful if you could reply with any comments before August 31st please.

Thank you.

Yours sincerely,

Mary Milne
Doctorate of Clinical Practice Research Student

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