UNIVERSITY OF DERBY

TREATMENT BEYOND TREATMENT: EXPLORING THE EFFECTS OF TWO COMPLEMENTARY INTERVENTIONS ON PATIENT REPORTED OUTCOMES OF GYNAECOLOGICAL CANCER

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Glossary

AH Abdominal Hysterectomy

AIC Akaike Information Criterion

ANOVA Analysis of Variance

ASA American Society of Anaesthesiologists

BMI Body Mass Index

BPS British Psychological Society

BWY British Wheel of Yoga

CAM Complementary and Alternative Medicine

CIS Carcinoma in Situ

COR Conservation of Resources

CNS Clinical Nurse Specialist

CQC Care Quality Commission

DNA Deoxyribonucleic Acid

DoH Department of Health

EMCN East Midlands Cancer Network

EORTC QLQ C30 European Organisation for Research and Treatment of Cancer - Quality of Life Questionnaire – Core 30

ERAS Enhanced Recovery After Surgery

ERP Enhanced recovery Programme

ERPP Enhanced Recovery Partnership Programme

FDA Food and Drug Administration

FIGO International Federation of Obstetricians and Gynaecologists

FACT G Functional Assessment of Cancer Therapy – General

FT Fast Track

GAM Generalised Additive Model

GASPI General Anaesthetic vs SPInal Anaesthetic

GHS Global Health Status

GLS Generalised Least Squares

GP General Practitioner

HRQoL Health Related Quality of Life

IPA Interpretative Phenomenological Analysis

IV Intra Venous

KS Kolmogorov-Smirnov

LAVH Laparoscopically Assisted Vaginal Hysterectomy

LH Laparoscopic Hysterectomy

LOS Length of Stay

MDT Multi-Disciplinary Team

MLM Multi Level Modelling

NAO National Audit Office

NCAT National Cancer Action Team

NICE National Institute for Health and Clinical Evidence

NSAIDs Non-Steroidal Anti-Inflammatory Drugs

OFTS Open Fast Track Surgery

PCA Patient Controlled Analgesia

PCT Primary Care Trust

PREC Psychology Research Ethics Committee

PROMs Patient Reported Outcome Measures

PRPT Partially Randomised Preference Trial

QoL Quality of Life

REC Research Ethics Committee

RCT Randomised Controlled Trial

SFC Strategy for Cancer

SGO Senior Gynaecological Oncologist

SPSS Statistics Package for the Social Sciences

TAH Total Abdominal Hysterectomy

TLH Total Laparoscopic Hysterectomy

TAP Tranversus Abdominis Plane

VAS Visual Analogue Scale

VH Vaginal Hysterectomy

SHA Strategic Health Authority

WHO World Health Organisation

Abstract

Gynaecological cancers (which include cancers of the ovary, cervix, uterus, vagina, endometrium, vulva and fallopian tube) account for 19% of all female cancers, and there are approximately 942,000 new cases diagnosed per year worldwide. Treatment for gynaecological cancer is often multi modal and consists of surgery, radiotherapy and chemotherapy. Current government policy has highlighted the need to focus on improving patient reported outcomes, including the patient experience of all aspects of cancer (including treatment), and the quality of life (QoL) of patients living with and beyond a cancer diagnosis.

This thesis focuses on the effects of two different complementary interventions available to patients who were undergoing active treatment for gynaecological cancer at the Royal Derby Hospital between 2010 and 2012. Patient reported outcomes were explored in terms of the patients’ experience of the interventions and their reported levels of quality of life. The first study in this thesis explores the patient experience of an enhanced recovery programme (ERP) which was implemented for gynaecological cancer patients undergoing surgery at the Royal Derby Hospital in 2010. Previous research has found that ERPs (which complement traditional surgery) can decrease length of hospital stay, and they are now being implemented nationwide. However, there is a paucity of research into the patient experience of ERPs, especially in the field of gynaecological cancer. This study utilised a qualitative methodology to explore the experiences of 14 gynaecological cancer patients who took part in the ERP at Derby. Each patient was interviewed using a semi-structured format and the transcripts were analysed using Interpretative Phenomenological Analysis. The analysis highlighted that patients highly value the programme, and four main themes, fundamental to their experience, emerged from the data: taking part in the programme, the role of home, managing expectations and individual experiences outside of the programme.

The second part of this thesis explores whether yoga can improve the quality of life (QoL) of patients undergoing treatment for gynaecological cancer when used as a complementary therapy. Previous research has found that participation in yoga can improve QoL in the breast cancer population, although there have been no similar studies conducted with UK gynaecological cancer patients to date. The study presented here utilised a randomised controlled design; 44 patients receiving treatment for gynaecological cancer were randomly allocated into a control group or a 10 week yoga intervention group. Outcomes were measured using the EORTC QLQ C30 questionnaire pre and post trial alongside visual analogue scales that were incorporated into a weekly diary. The results suggest that there was no significant effect of yoga on QoL, although there was encouraging data from one set of tests within the analysis, which suggested that patients on the yoga arm were seeing more improvement in QoL over time compared to the controls. Methodological improvements to clinical trials investigating complementary interventions are discussed in light of the results of this study.

The overall findings of these two studies highlight that the utilisation of mixed methods is efficacious when exploring the effects of complementary interventions on the patient reported outcomes of those with gynaecological cancer. The use of qualitative methods to explore the patient experience of the ERP allowed for an in-depth, unique analysis to take place which was specific to the service delivered at The Royal Derby Hospital. The findings and recommendations from this part of the research have been incorporated into the on-going development of the pathway; it has indicated that more use of qualitative methods is needed in health services research to ensure that the patient experience is being fully explored, in line with the current government policy. Similarly, the second part of the research reported here indicates that further research in the area of yoga and gynaecological cancer is warranted. This requires a narrower focus with regards to both cancer type and point of treatment, to ensure that the number of variables is controlled. In addition, appropriate measurement and analysis techniques need to be considered (such as the generalised additive model used in this research) to preserve the richness of the data as this has not been considered (or utilised) in the many previous pieces of research in the area.

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Chapter 1: Introduction

There are more than 200 types of cancer, and each has different causes, symptoms and treatments. In 2010, 324,579 new cases of cancer were diagnosed in the UK (around 890 people every day), and in the same year, about 1.8 million people are living with and/or beyond a cancer diagnosis (Cancer Research UK, 2010). The following thesis focuses on one group of cancers called gynaecological cancer. This chapter will introduce some of the relevant government literature that is pertinent to the diagnosis and treatment of cancer, with an extended section on the importance of patient reported outcomes. The chapter will then introduce the topic of gynaecological cancer and the different treatments that are commonly used; some of the psychological issues associated with the diagnosis and treatment of cancer will be discussed. Finally, the literature surrounding stress (and subsequent coping) that is relevant to gynaecological cancer is explored, and an overview of the research questions answered within this thesis will be presented.

# Government policy surrounding the provision of cancer services

In 2007 the Cancer Reform Strategy set a clear direction for the development of cancer services in England over the following five years (DoH, 2007). The 2007 strategy highlighted that it was essential for patients and survivors of cancer to have access to services that would improve their experience of both living with and surviving cancer. Although many of the main delivery targets of the Cancer Reform Strategy are still in place, the UK coalition government developed a new set of government directives in relation to health and social care. The three main principles are:

* To put the patient at the heart of the service,
* To orientate the NHS, public health and social care services towards delivering improvements in outcomes that matter,
* To empower local organisations and professionals to innovate and drive improvements in services which deliver care.

These core principles require “every possible penny of money the NHS has to be spent on improving the quality of care and outcomes that patients experience” (DoH 2011a, p.2). Further to this, the “Transparency in Outcomes: NHS Outcomes Framework 2011/12” (DoH, 2010a) provides direction for the NHS. It includes a high-level set of national outcome goals covering the responsibilities of the NHS. It is available to support NHS, and was fully implemented in April 2012.

There are five domains in the framework:

* Preventing people from dying prematurely;
* Enhancing QoL for people with long-term conditions;
* Helping people to recover from episodes of ill health or following injury;
* Ensuring people have a positive experience of care;
* Treating and caring for people in a safe environment and protecting them from avoidable harm.

The principles and domains set out in these two key government documents are reflected in the Strategy for Cancer (SFC), which is a direct replacement for the Cancer Reform Strategy. The SFC (DoH, 2011a) was published in 2011 and aims to help the NHS deliver cancer outcomes that are amongst the best in the world. The Strategy for Cancer highlights that the NHS is required to provide services to those living with and beyond cancer for long periods of time to ensure that they live as healthy a life as possible. To do this, the SFC suggests that “we need to make sure that feedback on patient experience informs the design and delivery of services so they reflect what is important to all patients” (p. 8).

# Improving outcomes

One chapter of the SFC specifically focuses on the QoL of patients and the patient experience. It notes that “although there have been significant improvements in support for people living with and beyond cancer, more needs to be done so that patients have the care and support they need to live as healthy a life as possible, for as long as possible” (DoH, 2011a, p.47). One way that the SFC identifies a wider scope for improving cancer services outside of the NHS is through academic institutions, and it suggests that these must continue to undertake research into all aspects of cancer, including basic science, prevention, early diagnosis, treatment and the psycho-social effects of the disease. The SFC highlights that a focus should be taken to reduce the ill health associated with cancer treatment, reduce the risk of recurrent cancer and reduce the proportion of people who have unmet needs (both physical and psychological) after their cancer treatment. It also suggests that more emphasis is being placed on patient reported outcomes than ever before, and that the area that is of most concern with regards to this is the period during and following treatment.

# Patient reported outcomes

Patient reported outcome (PRO) is a broad term that includes direct subjective assessment by the patient of a number of aspects of their health. These aspects include: symptoms, function, well-being, health-related QoL, perceptions about treatment, satisfaction with care received, and satisfaction with professional communication (Rothman, 2007). Acknowledgment of the need to capture the patient’s perspective of the impact of illness and health-care interventions has grown rapidly over the last decade as there has been a fundamental shift in focus to give greater emphasis to the involvement of the patient in the care they receive, which is reflected in a number of recent policies and national initiatives (DoH, 2008a, DoH, 2011a). As a result, PROs are increasingly accompanying the traditional clinical ways of measuring health and the effects of treatment on the patient (Meadows 2012, Lipscomb et al. 2007). PROs may be collected in a number of ways, including (but not exclusively limited to) standardised patient reported outcomes measures (PROMs) and information about patients’ experiences.

# PROMs and patient experience

There is a clear distinction between patient-reported outcomes measures (PROMs) and questions about patients’ experience of the care process. PROMs are standardised validated questionnaires which may measure any of the aspects of health described above. There are many instruments available, some focusing on specific diseases or conditions, while others are designed to obtain a generic measure of health outcome (Coulter, Fitzpatrick & Cornwell, 2009). The primary reason for using PROMs is to assess treatment effects that are known only to the patient and can provide deep insight which is not routinely collected in a clinical setting (Meadows 2012). Advocates of PROMs (usually completed pre/post intervention) report that these questionnaires are “a remarkably sophisticated measure of whether a treatment has worked in the rather important sense of whether the patient feels better, and how much better” (Timmins, 2008, p.1464).

The use of PROMs is becoming more prevalent in the NHS; all licensed providers of unilateral hip replacements, unilateral knee replacement, groin hernia surgery and varicose vein surgery are expected to invite patients undergoing these procedures to complete a pre-operative and post-operative PROMs questionnaire. The PROMs “will fill a gap in the set of information available on the care delivered to NHS funded patients and will complement existing information” (DoH, 2008b, p.5). These PROMs include the EQ-5D, which is a standardised instrument used as a measure of health outcome. It also includes a condition specific measure which is more sensitive to the individual procedure, allowing for measurement of essential procedure specific outcomes.

A structured review by Marshall, Hayward & Fitzpatrick (2006) looked at 38 research papers which used PROMs such as the General Health Questionnaire, the Zung Self-Rating Depression Scale (ZSDS) and the EORTC QLQ-C30 (a quality of life scale for cancer patients). The review highlighted that the majority of PROMs were being conducted in primary care settings (66%), and the majority of patients were being treated for mental health issues (34%), primary care treatments (24%) or cancer treatment (13%). The review indicated that the administration of recurrent PROMs had a positive impact on provider behaviours, especially in the mental health setting, but there was less of an impact on health status. It was concluded that PROMS can inform the process of hospital care as well as the standard clinical outcome measures – in this instance it is reported that there was a “fairly substantial positive impact on some processes of care, particularly the diagnosis and management of patient conditions” (Marshall et al., 2006, p.559).

In terms of experience as a PRO, there has been a shift from the use of traditional patient satisfaction surveys (which raised a number of concerns with regards to the measurement of quality care) to measuring patients’ experience as a form of outcome (Cleary, Edgman-Levitan, McMullen, Delbanco, 1992; Cleary, 1998). Often, patient experience measures are used alongside PROMs to produce a more rounded picture of patients’ views on both the process and the outcome of care (Coulter, Fitzpatrick & Cornwell, 2009). The patient’s illness experience is influenced by internal standards, intrinsic values, and expectations, and as such the use of this type of PRO provides information unavailable from other sources. The resulting data reflects how the patient interprets the experience and the conditions not observable by others and are distinct from proxy measures (Rothman, 2007), giving a unique insight into the views of the patient.

# Integrating Government Policy with Psychological Theory

Evidence suggests that many psycho-social patient outcomes (including emotional well-being and QoL) is related to their cognitive, emotional and behavioural responses to diagnosis and symptoms (Costanzo, Lutgendorf, Rothrock, & Anderson, 2006; Lutgendorf et al., 2002; Stanton, Danoff-Burg, & Huggins, 2002; Thompson & Shear, 1998). This link between psychological states, coping and disease outcomes suggests that theoretically guided investigations into the ways in which people understand and cope with illness may yield benefits in terms of developing ameliorative programmes (Gould, Brown & Bramwell, 2010). In light of this, the following section includes some details about the treatment for gynaecological cancer, the psychological implications of diagnosis and treatment and a discussion of relevant psychological theories of stress and coping.

# Gynaecological cancer

Gynaecological cancers include cancers of the ovary, cervix, uterus, vagina, endometrium, vulva and fallopian tube. Gynaecological cancer also includes trophoblastic disease which is a type of cancer linked to the placenta (International Federation of Obstetricians and Gynaecologists Committee on Gynaecologic Oncology, 2000). In 2006 it was reported that gynaecological cancers account for 19% of all female cancers, and that there were 942,000 new cases per year worldwide, with ovarian cancer having the highest mortality rate of all female cancers, and approximately 204,000 worldwide diagnoses each year (Sankaranarayanan & Ferlay, 2006). Ovarian cancer patients have a particularly poor prognosis, with a 5 year survival rate of 46%; this is reduced to 31% for advanced stage disease. Other gynaecological cancers have a higher rate of incidence (e.g. uterine cancer), but a lower rate of mortality (Siegel, Naishadham & Jemal, 2012).

# Treatment for gynaecological cancer

Treatment for gynaecological cancer is frequently multimodal, requiring co-ordination of surgical care with chemotherapy and radiotherapy. A Cochrane review by Woo, Kyrgiou, Bryant, Everett & Dickenson (2012) concluded that women may have more favourable outcomes if they are treated by specialist gynaecological oncologists in cancer centres. Gynaecological cancers were one of the first cancer sites to have the centralisation of care recommended by the Calman-Hine report (DoH, 1995). Furthermore, gynaecological oncology has become a subspecialty within obstetrics and gynaecology departments in many countries, with the development of specific advanced training programmes to meet the technical challenges of gynaecological cancer surgery (Morrison, 2012).

During surgery, doctors aim to remove the cancerous tissue. Operations for gynaecological cancer can range in size – from a knife cone biopsy (which is used to treat early stage cervical cancers) to a total abdominal hysterectomy / bilateral salpingo oophorectomy (removal of the uterus, both of the ovaries and fallopian tubes). Optimal debulking (tumour removal) and positive lymph node dissection (removal of any cancerous lymph nodes) is also used for stage III or stage IV ovarian cancer. Chemotherapy involves the use of drugs to stop or slow the growth of cancer cells. These drugs may cause side effects which in many cases subside when treatment finishes. Chemotherapy can be given in several forms, including oral pills or intravenous (IV) injection, and can be delivered as adjuvant or neo-adjuvant therapy (after or before surgery). Radiotherapy uses high-energy rays (similar to X-rays) to try to kill the cancer cells and stop them from spreading. The rays are aimed at the part of the body where the cancer is (external radiotherapy), and due to the nature and location of gynaecological cancers, radiotherapy can also be delivered internally (brachytherapy). Radiotherapy is often given post-operatively in the area from which the primary tumour has been removed.

# Psychological impact of the diagnosis and treatment of gynaecological cancer

The diagnosis of cancer and the subsequent onset of treatment is known to be a time of great stress for patients (Cordova. & Andrykowski, 2003; Wigger, O’Donovan, Redman, & Sanson-Fisher, 1990; Watson, Greer, Blake, & Shrapnell, 1984). The diagnosis is often shocking, as many gynaecological cancers (ovarian cancer in particular) are asymptomatic, or linked to abdominal symptoms which are often attributed to other causes such as irritable bowel syndrome (Goff, Mandel, Melancon, & Muntz, 2004). A number of other factors surround the diagnosis of cancer, such as loss of control, the potential risk/harm of the disease itself and the associated treatment, the threat to identity as a woman and the threat to role as a wife and a mother. There are also more ‘long term’ factors which surround life change, i.e. the fear of reoccurrence and the change of identity to always being a cancer patient. Rosenbaum et al. (2004) states that recently diagnosed cancer patients are faced with an uncertain future and “their physical and emotional wellbeing is continually threatened by fear, isolation, anxiety, depression, fatigue, disfigurement and pain” (p.293).

As with many other physical illnesses, there is a high prevalence of psychological problems that go alongside a diagnosis of cancer due to the physical changes in the body, and these have been found to be strong predictors of depressed mood and anxiety, which in turn can lead to poorer functional ability (Pasacreta, 1997). Prevalence studies have estimated that in the first 100 days following diagnosis, 47%–70% of women experience psychological symptoms of sufficient degree to merit a diagnosis of moderate or severe depression or anxiety (Petersen, & Quinlivan, 2002; Evans et al., 1986; Cain, Kohorn, Quinlan, Schwartz, Latimer & Rodgers, 1983). Some patients may also experience post-traumatic stress disorder (PTSD) symptoms. Cancer manifests critical attributes of a traumatic life event and it fulfils the criterion of a major threat to health and life (Banou, Hobfoll, & Trochelman , 2009; Deimling, Kahana, Bowman, & Schaefer, 2002). Some research has shown that cancer is capable of generating symptoms that approximate or indicate PTSD (Kangas, Henry, & Bryant, 2002), with around 26% of gynaecological cancer patients reporting symptoms indicative of PTSD (Matulonis et al., 2008).

After a diagnosis of cancer has been established, a treatment regimen or specialist care plan for the patient is put into place, either with curative or palliative intent. The treatments included in these care plans vary depending on the type of cancer, and the stage and grade of the disease (see Appendix 1 for details of stage and grade). The period of time between diagnosis and the start of treatment is purposefully short, as swift initiation of treatment is beneficial, and is associated with better disease outcomes (Jacobs & Menon, 2004; Tubiana & Koscielny, 1999). Surgical treatment for gynaecological cancer has been linked with a number of negative side effects, some of which are temporary (such as loss of functionality i.e. heavy lifting and exercise), whilst others are more permanent, such as lymphoedema and loss of sensation (Rob, Halaska & Robova, 2010; Smith, Del Priore, Coleman & Monaghan, 2011; Beesley, Janda, Eakin, Obermair & Battistutta, 2007). Chemotherapy has a number of negative outcomes, such as nausea, vomiting, insomnia and fatigue, and is also responsible for the loss of hair (Jenkins, Catt, Banerjee, Gourley, Montes, Solis-Trapala, Monson & Fallowfield, 2013; Lazlo, & Lucas, 1981). Similarly, radiotherapy also has a number of both long term and short term side effects, which again include fatigue, diarrhoea and incontinence; radiotherapy treatment has also been linked to sexual dysfunction (Nout et al., 2012). The combination of these deleterious side effects leads to a number of negative psychological outcomes which include reduced quality of life (QoL); including emotional, social, physical, cognitive and role functioning. Other difficulties, such as sexual dysfunction and loss of the ability to reproduce, are common outcomes of treatment which might result in anxiety, depression and loss of control. These factors, which are associated with the early stages of a patient’s cancer journey (i.e. diagnosis and treatment), contribute to the stress experienced by many patients.

# Stress and coping – The transactional model of stress

The transactional model of stress developed in the 1970’s (Lazarus & Folman, 1986; Lazarus & Folkman, 1984; Lazarus & Launer, 1978; Lazarus, 1966) and further developed in the 1990s (Lazarus, 1993; Smith & Lazarus, 1993; Lazarus 1991) proposes that “psychological stress refers to a relationship with the environment that the person appraises as significant for his or her well-being and in which the demands tax or exceed available coping resources” (Lazarus and Folkman, 1986, p. 63). In light of this, stress can be viewed as a subjective experience which is affected by individual differences in motivation and cognitive variables. It is the appraisal of the particular event by the person that determines whether the individual experiences a stress response (Aldwin, 2007). These stress appraisals are separated into two parts, primary appraisal and secondary appraisal. The primary appraisal results in the classification of the type of stressor, which could be harm, threat or challenge (if an event is not able to be classified as one of these, then it is treated as benign and discarded). In the case of a cancer diagnosis, the ‘threat’ classification of stressor would be most appropriate, as it is concerned with the expectation of future harm (for example fatalism, which has an established link with cancer diagnoses (Powe & Finnie, 2003; Tomaka, Blascovich, Kelsey, & Leitten, 1993; Weisman, & Worden, 1976)). Secondary appraisal consists of an assessment of personal ability to deal with the stressor (i.e. coping potential). Later work conducted by Lazarus and colleagues (Smith & Lazarus, 1993; Lazarus 1991) added to the early model, suggesting that 15 basic emotions (anger, fright, anxiety, guilt, shame, sadness, envy, jealousy, disgust, happiness, pride, relief, love, hope and compassion) were associated with appraisals, establishing a link between the type of emotion and the original stressor classification and coping resources available. For example, threat appraisals with low coping resources would lead to anxiety and fear.

From the literature surrounding the diagnosis and treatment of cancer, it is known that many patients experience both anxiety and fear throughout this early part of their cancer journey (Hulbert-Williams, Neal, Morrison, Hood, & Wilkinson, 2012; Gil, Costa, Hilker & Benito, 2012), suggesting that they appraise cancer as a threat, and may not believe that they have the appropriate resources to be able to ‘cope’ with the demands of the disease. The transactional model of stress suggests that when there are internal and external resources available to cope with the stressor, then the levels of stress are reduced. This indicates that interventions which aim to increase the available resources for patients would be beneficial in reducing the amount of stress, and the negative emotions that ensue. Lazarus (1993) also distinguishes between two different types of coping, emotion-focused coping and problem-focused coping. Emotion-focused coping arises when an individual changes the way that they think about the stressful situation. This could involve not thinking about the threat at all or reappraising the stressful event to allow it to appear less stressful. Alternatively, problem-focused coping is based on the individual’s approach to ‘coping’ with the stressor. Problem-focused coping includes action that will change the individual’s interaction with the environment or stressor, potentially resulting in reduced psychological stress. Lazarus (1993) further suggests that if appraisals suggest that something can ‘be done’ about a situation, then problem-focused coping is most often used, whereas if an individual appraises that nothing can be done, then emotion-focused coping is most often adopted. Other categories of coping have been added to the original problem-emotion model, such as meaning-based coping which includes re-appraising events, revising goals, making use of spiritual beliefs as well as focusing on positive events. This was included to account for the positive emotional states often found during stressful situations (Folkman, 1997). Other forms of coping include avoidance (Carver, Scheier & Fulford, 2008), religious coping (Aldwin, 2007), anticipatory coping where an individual attempts to prevent a stressful event from occurring (Coyne & Gottleib, 1996), and pro-active coping where individuals prepare for the outcome of a stressful event (Aspinwall & Taylor 1997).

Research suggests that it may be advantageous to possess a range of coping strategies to draw on when recieving a recent diagnosis and treatment for gynaecological cancer (Taylor, 1999). With regard to the efficacy of specific coping responses, unless the cancer is severe with a poor prognosis, problem-focused coping and acceptance enhance positive long-term outcomes (Harcourt, Rumsey, & Ambler, 1999; Holland & Holahan, 2003; Osowiecki & Compas, 1998), and may be seen as adaptive. Maladaptive responses, including, emotion-focused coping, avoidance, disengagement and denial coping, may provide short-term benefits (Stanton, Danoff-Burg & Huggins, 2002; van Elderen, Maes, & Dusseldorp, 1999), but appear to lead to poorer long-term psychological adjustment (Hack & Degner, 2004; McCaul, Sandgren, King, O’Donnell, Bransetter, & Foreman, 1999; Stanton et al., 2002). Studies of coping and psychological outcomes in gynaecological cancer follow a similar pattern, with better outcomes for adaptive and poorer outcomes for maladaptive coping (Costanzo et al., 2006; Lutgendorf et al., 2002). Research by Costanzo et al., (2006) found that women frequently made use of both engagement and avoidant strategies including active coping, seeking social support and mental disengagement if they were undergoing extensive treatment for their gynaecological cancer. Further to this, Costanzo et al. found that the use of engagement coping strategies such as active coping and seeking social support were not significantly related to QoL or mood, whereas avoidant coping strategies, including disengagement and cognitive avoidance, were strongly associated with poorer well-being and more distressed mood. These findings are consistent with earlier research by Lutgendorf et al., (2002) who found that patients who coped using greater acceptance and positive reframing at their initial visits reported better QoL.

# Stress and coping – Conservation of resources

Other models of stress suggest that significant stressful events lead to a loss of resources. Hobfoll’s conservation of resource theory (1989, 2001) is linked to instances of traumatic stress. Traumatic or extreme stressors are defined as “those that occur unexpectedly and that fall outside of the field of events that are developmentally expected” (Hobfall, 1991, p.187), such as a diagnosis of gynaecological cancer as described previously. Conservation of resource (COR) theory is based on the idea that ‘”ndividuals strive to obtain, retain and protect that which they value”, and these valued items are termed as resources (Hobfoll, 1991, p.198). Hobfoll proposes that stress occurs that when resources are threatened, lost, or are not replenished after being invested. Hobfoll suggests that the most severe stressor events are those that are linked to loss; a diagnosis of cancer would fit within this bracket with individuals experiencing a loss of health and also fearing a loss of life. There are, however, other aspects of a cancer diagnosis and subsequent treatment that have previously been discussed which also apply to this ‘loss’ category, including loss of identity, control, physical functioning (associated with treatment for cancer) and other aspects which link to QoL. These resources are often lost, perceived to be lost or are threatened to be lost throughout the earlier stages of a patient’s cancer journey.

In a similar way to the transactional model of stress proposed by Lazarus, Hobfoll (1989) suggests that there are a number of ways that individuals can appraise the stressor. Hobfoll suggests that one type of appraisal is shifting the focus of attention, reinterpreting threat as a challenge and thinking about the stressor in terms of what they may gain rather than what might be lost. Alternatively, the re-evaluation of resources focuses on the value that is placed on a particular resource, mediating the potential sense of loss that is experienced by the individual. If a resource is re-evaluated and less value is placed on that particular resource, then its loss is less upsetting. This is similar to the emotion focused coping suggested by Lazarus & Folkman (1984). However, Hobfoll also suggests that coping in itself is stressful, because individuals must invest resources in order to cope, and the use of resources in the coping process (which is necessary according to the Lazarus model) further impacts the stressful event, leading to an ongoing depletion of resources. This is termed as a loss spiral – when stress is encountered after an initial loss of resources, more resources are invested to offset that loss, leading to an ever decreasing set of resources and associated stress.

## Summary

In light of these two models, the diagnosis and treatment of cancer can be seen as a stressful event for many patients who perceive that they do not have the internal and external resources available to be able to overcome the threat that is posed by this course of events. Additionally, the onset of cancer and its subsequent treatment threatens or removes available resources from patients (i.e control, physical functioning), which are viewed as losses. Interventions that specifically target these areas, (i.e. improving internal and external resources available to individuals to facilitate coping) and also interventions that target the loss of resources (i.e. to prevent the initial loss of resource or to replenish deleted reserves of resources), are required to reduce the stress surrounding this time in the patient’s cancer journey. Although the SFC focuses on improving outcomes for cancer patients, there is no mention of supporting patients in coping with cancer, only that “there is now a greater recognition of the need for rehabilitation to deal with the late effects of treatment or the physical effects of the disease itself” (DoH, 2011a, p.52). This suggests that the government policy in the UK has little focus on patient’s coping strategies, and that the predominant focus for success is the measure of improved patient outcome and experience. However, psychological theory suggests that equipping patients with resources and strategies required to cope with the diagnosis and treatment of gynaecological cancer can help facilitate better patient outcomes.

# Research questions:

* Can the experience and QoL of patients be improved through the implementation of complementary treatment interventions?
* Are patient reported outcomes useful in exploring patient experience of these treatments?
* In relation to the diagnosis and treatment of gynaecological cancer, what role, if any, can complementary treatment interventions play in the facilitation of coping?

# This thesis

In this thesis I focus on provision of ‘treatment beyond treatment’. Earlier in this chapter it was seen that government policy calls for an improvement in patient reported outcomes of treatment for cancer. In the second half of this introduction, evidence was presented that suggests that traditional treatment for gynaecological cancer in the form of surgery, chemotherapy and radiotherapy has a number of negative outcomes which, alongside a diagnosis of cancer, lead to considerable stress for the patient (a negative patient reported outcome). In light of this, interventions that work outside of the traditional model of care have the potential to both improve outcomes for patients undergoing treatment for gynaecological cancer and assist with coping. The potential of two interventions to improve both patient experience and QoL (with efficacy being measured through patient reported outcomes), and their role in facilitation of coping and resource re-establishment is explored.

Firstly, I explore the patient experience of the enhanced recovery programme (ERP) which was implemented for gynaecological cancer patients at the Royal Derby Hospital in 2010 (study 1). ERPs are linked to the surgical treatment for gynaecological cancer, and are now being rolled out nationwide in a number of different areas as they have been found to decrease length of stay. Increased knowledge gathered from the current research on PROs through exploration of the patients’ experiences of this programme is crucial for the development and evaluation of new and existing enhanced recovery services, as well as the on-going development of the gynaecological oncology service at the Royal Derby Hospital. Additionally, this exploration of the patient experience will be conducted with a view to establishing whether this has any utility in providing patients with greater internal and external resources to be able to ‘cope’ with the surgical treatment for their cancer, and what, if any, benefit this has on replenishing depleted reserves of resources.

In the second study, I look more specifically at replenishing lost resources, many of which are facets of QoL, through the development of an complementary therapy intervention. The focus is on whether a mind/body intervention, yoga, can improve the QoL of patients undergoing treatment for gynaecological cancer (study 2). It is acknowledged that health-related QoL is one of the most frequently reported patient outcomes in the cancer population, and it is rapidly becoming an important treatment outcome (alongside improving cure rate and lengthening survival time). It is also acknowledged that many of the resources that contribute to QoL (i.e. physical functioning), are lost during the diagnosis and treatment of cancer. Additionally, there is increasing evidence that complementary therapies, such as yoga, are useful as a tool for improving QoL both during and after treatment (explored further in Chapter 6). In light of this, the information gathered from this research will give further insight into whether interventions such as yoga are efficacious in improving QoL as a patient reported outcome for patients undergoing treatment for gynaecological cancer, and what, if any, benefit this improvement may have in the replenishment of resources.

The strength of this thesis lies in the combination of studies included. Though each study uses a different methodological approach, both aim to facilitate the delivery of better care for patients undergoing treatment for gynaecological cancer through the measurement of patient reported outcomes. Additionally, both studies explore the potential impact new interventions have on patients coping with treatment for gynaecological cancer. As this thesis explores services offered to cancer patients being treated at the Royal Derby Hospital, a brief overview of the gynaecological oncology services at the Royal Derby Hospital is included in Appendix 2. Additionally, each section of this thesis is preceded by an extract from Sheila’s diary of her journey through cancer. Sheila is a patient who took part in both studies; these extracts have been included to give an overview of her experience and to contextualise the research.

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# An extract from Sheila…

*I realised something was wrong when I began to bleed and developed quite a lot of pain. I visited my GP (July 2010) and she immediately referred me to Derby Royal Hospital. After a series of diagnostic tests, I was seen by a doctor in clinic who gave us the dreaded and devastating news. I had endometrial cancer and would have to have a hysterectomy. A chest X-ray and MRI scan followed and arrangements were made for me to be admitted very quickly. Prior to the diagnosis my husband and I were leading a very busy and active life – walking, the theatre, holidays, socializing, etc. We are both retired and have been married for 44 years. My husband has been with me and there for me every step of the way and we have attended all consultations and meetings together and have shared everything. Things had to then go on hold. The news had a huge impact on both of us and also on our son and daughter-in-law and our close friends. The hardest thing was telling our son and at that stage not knowing the outcome. I felt I was letting everyone down and why should this awful thing be happening to me. I felt very angry, bitter, upset and that life was unfair – so many different emotions came flooding through my head. It changed our perspective of life and made us focus very much on what the priorities are. My husband’s feelings were a mixture of emotions, first of all shock and the feeling of helplessness.*

*When I had my pre-operative assessment I was informed about the enhanced recovery programme, my doctor told me he thought I was a suitable patient for this. Going straight in to the enhanced recovery programme plus just finding out I had cancer was very daunting and frightening – I didn’t know what to expect or what the outcome would be.*

Study 1

# Exploring the patient experience of enhanced recovery programmes

Chapter 2: Introduction

This chapter introduces aspects of the surgical intervention, hysterectomy, which is the most common procedure for treating gynaecological cancer. The enhanced recovery intervention offered to patients undergoing this type of surgery is then described and literature from other disciplines is reviewed. The chapter then reviews some of the literature that has been conducted exploring the patient reported outcomes of these programmes, and expands on why the study included in this thesis is necessary.

# Treatment for Gynaecological Cancer

Treatment for gynaecological cancer is often multi-modal (i.e a combination of surgery, chemotherapy and/or radiotherapy). Many women who have gynaecological cancer undergo surgery for their cancer to remove the cancerous (and surrounding) tissue. Most gynaecological cancer surgery consists of some form of hysterectomy, although conditions such as cervical cancer may be treated with a less radical form of treatment (Cancer Research UK, 2010). Hysterectomy is a widely performed gynaecological procedure, and is concerned with the removal of the uterus (Garry 2005). There are three main types of hysterectomy: Abdominal Hysterectomy (AH), Laparoscopic Hysterectomy (LH) and Vaginal Hysterectomy (VH). AH has traditionally been used for the removal of the uterus and is performed through a laparotomy under general anaesthetic, with a mean length of stay (LOS) ranging from 2-11 days (Nieboer et al., 2009). LH is a procedure that has at least part of the surgery performed using laparoscopic techniques. In laparoscopic techniques for hysterectomy, instruments are inserted through small incisions made in the abdomen, and the operation is carried out with the aid of an internal telescope and camera system (NICE Guidelines, 2006).

The use of laparoscopic techniques in gynaecology have been gaining in popularity since the 1990s (Garry, Reich & Liu 1994) and patients who undergo LH are reported to have less blood loss during surgery, require less pain relief, have less infectious morbidity and experience a better post-operative QoL (Pather, Loadsman, Mansfield, Rao, Aroroa, Philp & Carter, 2011). Mean LOS for patients undergoing LH has been reported as 2-5 days (Nieboer et al., 2009). VH was originally used for repairing a prolapse of the vagina. However, it has now become more widely used in procedures as it is regarded as being less intrusive for the patient, and has a reduced LOS in hospital for the patient, reported at 1-5 days (Nieboer et al., 2009; Harris & Daniell, 1996). One intervention that is designed to reduced patients LOS further still is enhanced recovery.

# Enhanced Recovery

‘Enhanced’ or ‘fast track’ recovery is a relatively new concept that combines several peri-operative interventions to reduce the length of in-patient stay in hospital and promote early recovery after surgery (Wilmore & Kehlet, 2001). Enhanced recovery programmes (ERPs) are intended to help patients recover sooner from their operation, whether treatment was for cancerous or non-cancerous disease. Other benefits of ERPs include increased utilisation of beds as well as reduced health care expenditure (Delaney, Fazio, Senagore, Robinson, Halverson, & Remzi, 2001). The fundamental aspects of ERPs were originally proposed by Kehlet in his 1997 paper titled “Multi modal approach to control post-operative pathophysiology and rehabilitation”. The paper concludes that pain control and reduction of surgical stress are key factors in patient recovery, alongside other factors such as nutrition, heat loss and mobilisation. These factors are just a selection of those that have been built into the ERPs that have been developed in the past 15 years.

Several papers, predominantly focusing on colorectal surgery, followed Kehlet’s original paper suggesting that the use of ERP could reduce length of stay (LOS) from anywhere between 6 and 12 days to 2 days (Basse, Hjort, Billesbolle, Werner & Kehlet, 2000; Delaney et al. 2001). The research highlighted that there was an inconsistency in the use of ERPs (i.e. the number of interventions used) and the reported outcome measures. In response to this, the ERAS (Enhanced Recovery After Surgery) collaboration group was formed in 2001, including 5 surgical centres throughout Europe (Sweden, Berlin, Scotland, Norway and the Netherlands). The ERAS collaboration aimed to establish some regulation between the selected establishments and identify suitable methods of reporting the outcomes of the ERPs implemented at their institutions, which mainly focused on colorectal surgery. The collaboration worked on the development of a protocol that was based on evidence provided from the studies carried out in their institutions, and this was finally published in 2005 (Fearon et al., 2005). A diagram of the original protocol is shown in Figure 1.

The protocol identifies the areas of ERPs that are thought to reduce surgical stress, ultimately promoting a return to function (Fearon et al., 2005). The protocol was originally developed as guidance for colorectal surgery only, but has provided the basis for other areas of ERP. The Fearon et al. (2005) protocol covers the three main areas of surgery (pre-operative, intra-operative and post-operative) and suggests a number of evidence based interventions to improve these areas with an overall view to reducing surgical stress for the patient.

Figure 1 – Original ERAS protocol (Fearon et al., 2005).

Please note: diagram removed for copyright reasons, please see caption for reference information.

The pre-operative areas of the protocol include enhanced patient information, pre-operative bowel preparation and pre-operative fasting. The intra-operative areas of the protocol include minimally invasive surgery, intra-operative warming to prevent heat loss and amended anaesthetic protocols. Post-operative aspects of the protocol include areas such as planned early mobilisation and nutrition as well as the early removal of catheters, the use of non-opiate oral analgesia and non-steroidal anti-inflammatory drugs or NSAIDs (Fearon et al., 2005).

In 2006 it was thought that without the ERAS group’s on-going studies and audit, there was little research being conducted in the area. This presented questions about the general applicability to the wider hospital population (Walter, Smith & Guillou, 2006). However, a more recent paper by Varadhan, Lobo & Ljungqvist (2010) suggests that enhanced recovery is being widely accepted within the area of colorectal surgery, and that other areas of surgery such as gynaecological, thoracic, vascular, urological, oesophageal, pancreatic and liver, have started to explore the adoption of ERPs.

# ERPs in Gynaecology

A number of publications in the area of enhanced recovery for non-malignant gynaecological problems suggest that ERPs may be a useful tool for reducing LOS for patients undergoing hysterectomy through vaginal, laparoscopic and open abdominal surgery. Research by Kroon, Radstrom, Hjelthe, Dahlin & Kroon, (2010) identifies that there are several issues with gynaecological surgery that impact on the length of recovery including nausea, pain, bowel paralysis and organ dysfunction. This was previously discussed in the paper by Chase, Lopez, Nguyen, Pugmire and Monk (2008) who identified that patients stay in hospital because they need assistance with pain management and nausea. In addition, emesis needs to be controlled, difficulties with illius need to be resolved and ambulation needs to be instigated and maintained. The research from the colorectal discipline illustrates that these areas can be targeted by the interventions included in an ERP, making gynaecological surgery a good candidate for the implementation of ERPs. As a reflection of this, the number of papers published discussing the use of ERPs in gynaecology has steadily increased.

Moller, Kehlet, Friland, Schouenberg, Lund & Ottosen in 2001, explored the use of fast track surgery for hysterectomy in both open abdominal hysterectomy and laparoscopically assisted vaginal hysterectomy (LAVH). The study reports on a fast track programme which utilised improved patient information, bowel preparation (in the form of an enema), no pre medication offered and use of antibiotics for the wound (cefuroxim). All patients also received 30mg of ketorolac (a type of NSAID used for pain relief) and 4mg of ondanseteron (an antiemetic/sickness drug) as well as bupivacaine into the wound. Patients in the open abdominal surgery group were also administered bupivacane and morphine through an epidural catheter for 2 days and the bladder catheter was left in situ until the next day (<24hrs). All patients in both groups were encouraged to mobilize and take on food and fluids as soon as possible. Pain relief was managed locally on the wards avoiding the use of opiates. This fast track regimen (which does not incorporate all of the acknowledged aspects of an ERP) was found to be beneficial in both the open abdominal surgery group and the LAVH group reducing LOS from 5 days to 2 for open hysterectomy and from 3 days to 1 following LAVH. The authors concluded that the use of fast track programmes for surgery can be useful in reducing LOS for open and LAVH patients, but that consistency depended on staff and surgeons providing a rigourous and standardised service as this is an important aspect of the delivery of successful care (Moller et al., 2001).

Aspects of this research have also been confirmed by Carter et al. (2010) who found that a fast track surgery protocol can be beneficial for patients undergoing open hysterectomy. In addition to the findings by Moller et al. (2001), Carter et al. found that several other factors were associated with early discharge – those being patients who had a lower BMI, had a performance status of 0, had vertical midline incision and were aged 35 years or younger. However factors such as type of incision, use of COX inhibitor (an NSAID), health insurance status, performance status and successfully completing an early feeding plan were statistically significant in reducing the LOS of patients when results were analysed using a stepwise regression. Carter et al. (2010) also highlight the importance of patient information in setting expectations for patients, and the effect this may have on their LOS.

Research conducted by Pather et al. (2011) compared the use of open fast track surgery (OFTS) with standard total laparoscopic hysterectomy (TLH) for both cancer and non-cancer patients. The OFTS consisted of the following aspects: no bowel preparation, increased patient information, perioperative antibiotics, limited opioid use through the administration of oral painkillers, regional analgesia at the time of surgery through a transversus abdominis plane (TAP) block, early oral feeding and mobilisation, as well as early catheter and patient controlled analgesia (PCA) removal. The authors found that those undergoing OFTS still had an increased LOS in comparison to the TLH group with mean LOS for the TLH group being 1.82 days and the OFTS group being 3.38 days. This suggests that even when using fast track surgery the resulting reduced LOS is still longer than the LOS of laparoscopic procedures.

Earlier research by Ottesen, Sorensen, Rasmussen, Smidt-Jensen, Kehlet & Ottosen (2002) explored fast track vaginal surgery for vaginal repair and hysterectomy. The fast track programme in this instance focussed on an increased and improved level of pre-operative information for patients, pre-operative nutrition (including the addition of pre-operative protein drinks and reduced fasting). The programme also included alterations to standard anaesthesia and post-operative pain control, as well as early mobilisation and planned discharge 24 hours post operatively. A total of 8 different procedures were carried out by 8 surgeons on 41 women. The procedures ranged from an anterior repair of the vagina to a full vaginal hysterectomy with anterior and posterior repair. Results from this study indicated that the median LOS was 24 hours across all patients, but a proportion of patients (14.6%) felt that they had gone home too soon. In addition to this, 8 patients (19.5%) chose to go home after 48 hours of surgery for a number of reasons, the most common being insecurity about going home. This raises a number of questions in relation to the desired LOS for patients and the psychosocial factors which may prevent early discharge. The research did report that the majority of patients commented that “the best thing about the whole program, was the short need for hospitalisation” (Ottesen et al., 2002, p. 145), however it is unclear how this additional qualitative information was collected and recorded, and in what context this quote was given.

Research by the Swedish GASPI group (General Anaesthetic vs SPInal Anaesthetic) into the use of alternative spinal anaesthesia as a form of fast track recovery programme for 162 gynaecological patients also found that the use of spinal anaesthesia resulted in a shorter LOS for patients, as well a reduced number of ‘sick days’ off work. The results published in a number of papers identified that spinal anaesthesia (with or without morphine intrathecally) could allow a patient to return home in less than 50 hours post operatively, with less opioids being used in the spinal anaesthetic group (Borendal Wodlin, Nillson & Kjolhede, 2011a, Borendal Wodlin, Nillson & Kjolhede, 2011b, Borendal Wodlin, Nillson & Kjolhede, 2011c). Additionally, those in the spinal anaesthesia group also reported lower intensity of pain, drowsiness and fatigue in comparison to the general anaesthetic group.

# ERPs in Gynaecological Cancer

In addition to the papers that focus on gynaecological surgery for non-cancerous diagnoses, there has been a small amount of research about the use of ERPs in the area of gynaecological cancer. Chase et al. identify that if results could be validated in the area of gynaecological oncology the benefits of ERPs may reduce the cost of health care whilst allowing patients to recover in “a more familiar and safe environment” (Chase et al., 2008, p.541).

A Cochrane Review published in 2010 (Lv, Wang & Shi, 2010) aimed to evaluate the beneficial and harmful effects of ERPs in gynaecological cancer care, but found that there were no eligible randomised controlled trials (RCTs) to include in the review, and only three papers were identified as suitable for a brief discussion of the topic. The three papers included in the review all focused on ovarian cancer patients, and the papers highlighted that only a selection of the enhanced recovery aspects identified in the protocol published by Fearon et al. (2005) were adopted. The review concluded that more research in the form of RCTs needs to be carried out in gynaecological cancer care.

Marx et al. (2006) identified that ERPs that provided patients with an enhanced level of pre-operative information, increased pain relief through the utilisation of continuous epidural analgesia as well as enforced early nutrition and mobilization, led to a significant reduction in hospital stay of patients undergoing surgery for an ovarian malignancy. The median LOS of patients dropped from 6 days (in the control group) to 5 days (in the ERP group). It was also found that patients had a reduced medical morbidity.

This is further supported in a paper by Geradi (2008) which explored a fast track recovery programme for patients undergoing rectosigmoid colectomy as part of primary cytoreductive surgery for advanced ovarian or peritoneal cancers (all patients were FIGO stage IIIC or above – see Appendix 1 for a description of this). This paper, which focused primarily on the feeding habits of patients after surgery, concluded that enhanced recovery pathways for this specific type of surgery significantly reduced patient LOS by 3 days (from a mean of 11.4 days for the control group to 8.7 days for the fast track group). In addition to this, the pathway also significantly reduced the cost to the hospital, with fast track patients costing a mean of $23,912 for their care in comparison to the control group whose mean care cost was $30,205. Although the fast track group consisted of a small number of patients (n=19), the research provided encouraging results for the use of ERPs (with regards to both LOS and cost) in late stage gynaecological cancer patients undergoing complicated surgery for their cancer.

Although the Cochrane reviewers were unable to source the original paper by Eberhart et al. in 2008 (this may have been because the paper was only published in German), the findings from the paper indicate that the ERP implemented for the study made a significant difference to patients recovery and QoL after undergoing surgery for ovarian cancer, without increasing post-operative complications. QoL was measured using the PPP3-questionnaire and a significant improvement in patient autonomy, physical symptoms and post-operative pain was found. These areas have previously been highlighted by Kroon, Radstrom, Hjelthe, Dahlin, & Kroon (2010) as important outcomes for gynaecological cancer patients. Eberhart et al. (2008) also acknowledge that it should be expected that there will be some deviation between individual outcomes in relation to both LOS and QoL, but overall the research identified a clinically relevant improvement. The authors of the research also highlight the importance of multi discipline working in the success of fast track (FT) programmes – the communication between nurses and physiotherapists is important in the success of the study.

A review of an ERP service in gynaecological oncology was conducted by Chase et al. (2008) regarding the treatment of 880 patients over 6 years who had been on a clinical pathway modeled on the colorectal ERP. The pathway included increased patient counseling and information, early mobilisation and catheter removal, removal of the PCA on day one, early enteral feeding, reduced opioid pain control and early discharge. The audit of services included collection of a number of patient characteristics (age, BMI, co-morbidities and prior abdominal surgeries), hospitalisation (pre and post op diagnosis, procedure, estimated blood loss, in-patient complications and LOS) and post hospitalisation admissions. The authors found that 71% of the patients had co-morbidities with the most common being hypertension, diabetes and mental illness. The patients included in the audit had undergone a variety of procedures, with the most prevalent being total abdominal hysterectomy +/- bilateral salpingo oopherectomy and benign adnexal surgery.

The median LOS for patients on the pathway was 2 days. After entering the data into a regression analysis, Chase et al. found that there was a weak correlation between age and LOS. It was also found that the readmission rate was 5%, of which 2% accounted for readmission for wound infections. The median interval time for readmission was 4 days. When comparing those who were readmitted to those not needing readmission, there were no significant single patient characteristics that were indicators of readmission. However, those who had a longer LOS and increased estimated blood loss were more likely to be re-admitted. Patients who were readmitted were also likely to have co-morbidities and had undergone prior abdominal surgery. Older age, higher BMI and greater estimated blood loss were all statistically significant factors which led to an increased LOS. Patients who were diagnosed with cancer also had a significantly increased LOS in comparison with a benign neoplasm.

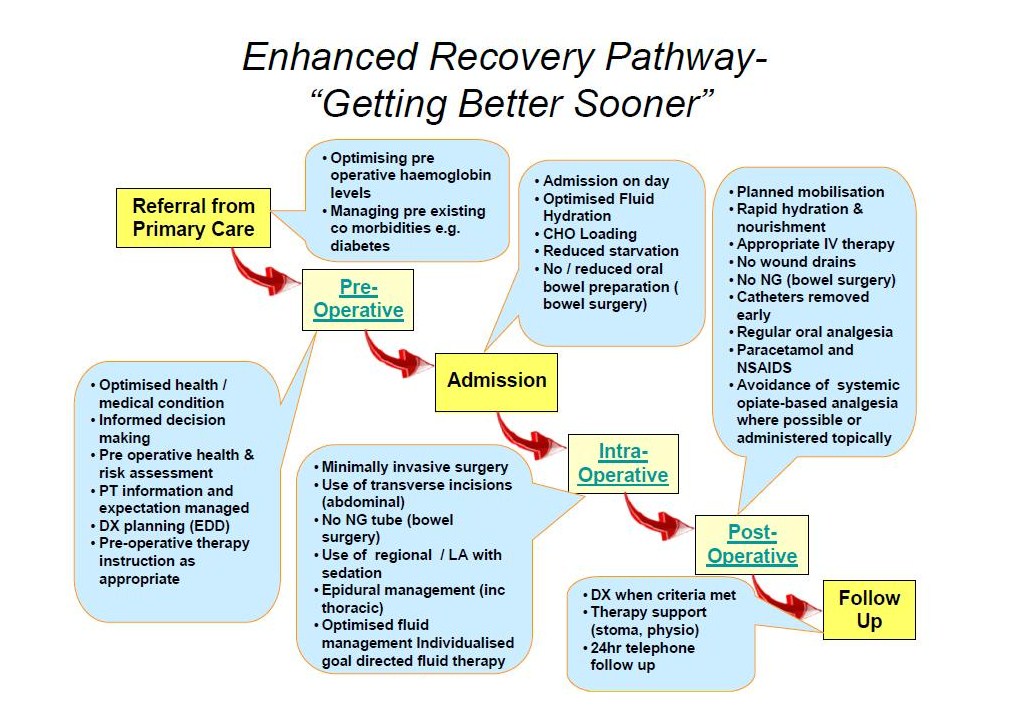
The research into areas outside of the colorectal discipline indicate that fast track or ERPs utilise a number of the aspects published by the ERAS group for enhanced recovery after surgery. However, it appears that many of the research papers outside of the colorectal domain do not adhere to the protocol produced by Fearon et al. in 2005. Several of the papers were published before the 2005 protocol, which may imply that the term ‘fast track’ or ‘enhanced recovery programme’ is not used in the same manner, or does not refer to the same number or types of intervention that are included in the published protocol. It may also be that not all institutions have the ability to perform all parts of the pathway proposed by Fearon et al. due to a lack of resources, or because the protocol does not ‘fit’ with current service. This raises a question around the amount of intervention that is required for a programme to be classified as ‘fast track’ or ‘enhanced recovery’, and also suggests that models of care may be inconsistent between departments or institutions offering ‘fast track’ or ‘enhanced recovery’ services. The Department of Health (2011b) has stated that 80% of the relevant elements should be adopted for an ERP, although this is difficult to enforce when ERPs are determined locally in the UK.

Alternatively it may be that individual interventions proposed for the treatment of colorectal patients would not be suitable for use with other types of patients (i.e gynaecological patients). The paper by Kroon et al. (2010) identifies that nausea, pain, bowel paralysis and organ dysfunction are the most problematic areas for gynaecological patients, so it is unsurprising that the focus of their ERPs is on reducing these complications for patients which leads to a decrease in LOS. In addition to this, the use of ERPs with gynaecological cancer patients still requires further exploration as the effect of ERPs on the overall treatment of cancer is unknown (as surgery may be only one form of treatment, and may include several procedures).

# ERP in the UK at present – Enhanced Recovery Partnership Programme (ERPP)

Initiatives such as Lord Darzi’s High Quality Care for All (DoH, 2008a), the Cancer Reform Strategy (DoH, 2007), the Strategy for Cancer: Improving Outcomes (DoH, 2011a) and the Quality, Innovation, Productivity and Prevention Challenge (DoH, 2010b) have all resulted in the need for the NHS to deliver more services without compromising on quality. ERPs were identified as programmes that would be beneficial both in improving care, and in saving money. In light of this, the national Enhanced Recovery Partnership Programme (ERPP) was designed and rolled out in 2009. The ERPP is a partnership between the Department of Health (DoH), NHS improvement, the National Cancer Action Team (NCAT) and the NHS Institute for Innovation and Improvement. The programme was designed to span a 2 year period (April 2009 – March 2011) and was to focus on four main surgical pathways (colorectal, musculoskeletal, gynaecology and urology).

The aim of the programme was to “improve the quality of patients’ care, through improving their clinical outcomes and experience, and to reduce the length of elective care inpatient pathways across the NHS by utilising good practice principles of the enhanced recovery model of care” (DoH, 2011b, p. 8; Roberts, Mythen & Horgan, 2010). The core pathway for NHS implementation is shown in Figure 2 (NHS Improvement, 2009). The delivery of the programme was split into two years; year one consisting of learning about enhanced recovery best practices and developing resources for the implementation of the programme at 15 innovation sites. Enhanced recovery leads were also nominated in each strategic health authority (SHA) to facilitate local implementation. Year two included the allocation of funding to support networking, events and clinical leadership. A focus on best practice was also encouraged in year two. Innovation sites were encouraged to share best practice with each other with a view to informing and supporting the role of ERP in other sites and surgical pathways in the future (DoH, no date).

Figure 2 – NHS care enhanced recovery pathway. **

During the roll out of the programme an enhanced recovery toolkit was developed which provides a resource for institutions using ERPs to enter and monitor progress with their ERP through a live database. This resource is used alongside Health Episode Statistics (HES) to provide up to date data on activity, LOS and readmissions. The information from the toolkit is supported by two additional reports (an evaluation of year one in May 2010, and two surveys of spread and adoption in November 2010 and February 2011). The tool has shown that the number of ERP projects has steadily grown over the two years, with there being approximately 43 speciality based projects in May 2010, increasing to the 178 teams reporting full implementation in February 2011. It is thought that in 2011, approximately 86% of acute provider organisations had implemented an ERP in at least one speciality (DoH, 2011b).

The report issued at the end of the project by the Department of Health (2011b) states a number of findings. No correlation was found between LOS and readmission rates; as LOS decreased, the number of readmissions did not increase. In addition, ERP had neither a positive nor negative impact on the readmission rates. In relation to Patients Recorded Outcome Measures (PROMs), information had been collected from the musculoskeletal pathways since April 2009 using the EQ-5D (The Euro-QoL Group, 1990), the Oxford hip and knee scores (Dawson, Ftitzpatrick, Carr & Murray, 1996) and some general questions about the surgery and its results. It was reported that “none of the health gains for providers reporting to have fully implemented ERP for these operations are significantly different from the all provider average” (DoH, 2011b, p. 19). With regards to patient experience, it was reported that the providers who had completed the tool kit were encouraged to include the four questions included in the Care Quality Commission (CQC) in-patient survey (shown in Figure 3). Those in the ERP group reported a higher level of satisfaction in comparison with the CQC average (CQC, 2011). Based on the data collected from the enhanced recovery toolkit, it was thought that 17% more patients were happy with the service they received.

# Taking ERP forward – Moving on from the ERPP

Several lessons have been learned from the initial implementation of the ERPP. The 2011 report identifies that it is essential to have support from trust executive and that clinical leadership is required for successful implementation. The report also supports the discussion about the effect that a new pathway may have on staff, and further highlights the importance of a supportive steering group for the project and a supportive and functional MDT.

Figure 3 – Questions taken from the Care Quality Commission Inpatient Survey.

Were you involved as much as you wanted to be in decisions about your care and treatment?

How much information about your condition or treatment was given to you?

Did you feel you were involved in decisions about your discharge from hospital?

Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

Overall, it is surmised that the ERP in the UK is allowing the NHS to generate capacity which in turn releases productivity gains. This is achieved primarily though reduction in LOS. Although the reduction is LOS is not as great as was first anticipated, there has been no evidence of increased readmission rates, or decreased PROMS, but there has been a significant increase in the number of patients reporting positive patient experiences.

# Measuring the efficacy of ERPs

The original protocol published in 2005 by Fearon and colleagues also highlighted that it was important for the process to be audited and recorded. Fearon et al. (2005) state that “audit is an inherent and essential component of every enhanced recovery programme” (p. 473) as it provides feedback on areas of the programme that may need further development. Further to this, Kehlet & Wilmore (2008, p.194) identify that “it is crucial to currently discuss the implementation and results, because the establishment of a fast track programme per se is not enough to secure a successful outcome”.

The majority of research surrounding ERP utilises LOS as an outcome measure. There is on-going discussion about what type of measures should be used to assess quality of surgical care. The NHS definition of quality is that services should be clinically effective, personal and safe (DoH, 2008a). Three measures exist: structure, process and outcome. Structural measures include the setting or system in which care is delivered. These are physical aspects of care such as facilities (i.e. number and type of theatres), and also include factors such as number of procedures, with increased volume of procedures being indicative of high surgical quality (Birkmeyer, Dimick & Birkmeyer, 2004).

Process measures are described as the care that patients actually receive (Birkmeyer et al., 2004). Process measures are often strongly associated with outcome measures, in as much as the process is changed and the outcome measures will be different. One form of process measurement looks at how many people experience the process; so in the case of ERP, how many patients successfully complete the ERP pathway - being on the pathway and following the process should have the impact on the outcome (reduced LOS). If evaluation of process was undertaken for ERP, the focus would be on the delivery of the pathway i.e. how many patients received all aspects of the pathway? The DoH (2011b) identify that patients should be receiving 80% of the interventions involved in the pathway within the UK. Without measuring the process it would be impossible to know whether this was achieved. Process evaluation within the NHS of the ERP will allow some accurate, valid and reliable measure of the hospital provided aspects of the programme, however there is little measure of the compliance by the patients in relation to the patient centred aspects of the programme (such as taking pre-operative drinks and early mobilisation). If patients do not comply with the instruction to consume the pre-operative drinks, knowledge of this may highlight the need for a change in the process to ensure that this happens.

Outcome measures are the product of the process; simply the end results. The measurement of outcome currently dominates the assessment of quality care (Crombie & Davies, 1998). Outcome measures have obvious face validity, resulting in the greatest buy-in from surgeons (Birkmeyer et al., 2004). Some literature suggests that measurement of surgical outcomes alone is enough to prompt surgeons to amend their processes to ensure that outcomes improve, indicating improved quality (Khuri, Daley & Henderson, 2002). However, there are difficulties when using outcome measures as large sample sizes are required to establish statistical power during analysis (Birkmeyer et al., 2004). Surgical outcomes are particularly important for institutions that are spending, or trying to save money. Grocott (2010) identifies that the need for reliable and valid measures of outcome is now at the centre of the UK health agenda. Furthermore, it is suggested that three main areas should be explored to get a holistic view of the quality of care: clinical effectiveness and personal experience.

Outcome measures associated with clinical effectiveness include mortality, emergency readmission and LOS (Massen, Goldacre & McGuiness, 2002), with LOS being the most widely reported outcome measure for ERPs (Fearon et al., 2005). One other important factor to consider in the use of LOS as an indicator of success is the cost implication associated with the treatment of cancer patients, and specifically the focus placed on a reduction in the number of bed days used by each patient. In 2008/09, it was estimated that NHS expenditure on cancer services was over £5.1 billion, and the National Audit Office (NAO, 2010) has estimated that expenditure was actually around £6.3 billion, and the total cost of cancer to society as a whole has been estimated at £18.3 billion for the same period of time (Featherstone & Whitham, 2010). These costs are set to rise further as incidence increases; people live longer with cancer and new treatments become available. The NAO report (2010) identifies that the average LOS for inpatient cancer admissions varied from 5.1 to 10.1 days between Primary Care Trusts (PCTs) in 2008/09. These figures suggest that if every PCT could perform at the average LOS for the best performing PCT, 566,000 bed days could be saved, equivalent to around £113 million each year.

The cost effectiveness of enhanced recovery has only been explored in a small number of research studies compared to research published in the area of LOS reduction. With one of the main motivations for implementing an ERP being the reduced LOS, this will, in turn, have an impact on the overall cost of that hospital stay. It is estimated that a national implementation of enhanced recovery procedures would save between 140000 – 200000 bed days. If each bed day is estimated at between £250 per day, this could equate to savings of between £35 million and £52 million per annum (Roberts et al., 2010).

Although cost implications of the success of ERPs are important factors in the measurement of outcome, the aim of an ERP is to reduce medically unnecessary hospital stays; the days at the end of a stay that are typically of lower care intensity (Massen, Dejong, Kessels & von Meyenfeldt, 2008; Massen et al., 2007). LOS has been suggested as an outcome measure that is suitable for ascertaining the effectiveness of quality improvement activities and is a recognised outcome measure for performance improvement outcomes (Brasel, Lim, Nirula & Weigelt, 2007). It is thought that as LOS decreases, care is more efficient and more effective, with patients using fewer resources as they are in hospital for a shorter amount of time.

There is, however, some discussion around the effectiveness of LOS with regards to measuring outcome. Research by Massen et al. (2008) explored the appropriateness of LOS as an outcome measure. Their research used the defined discharge criteria set out by the ERAS group in 2005 and the Dutch Appropriateness Evaluation Model to assess the appropriateness of hospital stay in the case of delayed discharge. The study identified that up to 90% of pre-ERAS and 87% of ERAS patients were not going home on the appropriate day of discharge; the day that they become medically able to go home. Of these, 69% ERAS and 59% pre-ERAS of stays were labelled as ‘inappropriate’ (the median extended stay for patients in the ERAS group was 1 day). This identifies that there may be a discrepancy between the discharge criteria defined by the ERAS group and what is seen as medically appropriate for an extended stay (the main issues were wound leakage and symptoms indicating an anastomotic leak in both groups). This raises a point about where the care of wounds should take place – in the hospital, in the home or in the outpatient setting. Patients could have gone home earlier and been monitored outside of the hospital environment; however, if there is the requirement for additional wound care outside of the stay in hospital, additional funds need to be associated with care of the patient, impacting on the potential cost savings associated with ERPs.

In addition to this, a number of other issues are highlighted. LOS may not be indicative of recovery; patients may be well enough to go home, but may not be discharged accordingly. Brasel et al. (2007) found that patients who were being discharged to a location other than home had a significantly higher LOS. The research was based in America where there is a marked change in health care provision, and as a result, Brasel et al. also found that patients paying for medical insurance themselves, or having their medical care supplied by medic-aid had an increased LOS. In total these factors accounted for between 25-30% of increased LOS. However, these are not the only factors that have been found to affect LOS. Research by Schoetz et al. (1997) in the colorectal discipline found that patients who were over the age of 65 and those who needed a stoma placing post operatively had an increased LOS, whilst those undergoing elective procedures had a decreased LOS. In addition, factors such as age, ASA grade, physical and functional status scored have also been indicative of increased LOS (Collins, Daley, Henderson & Khuri, 1999). Massad, Volger, Herzog & Mutch (1993) looked at correlates of LOS in gynaecological cancer patients and found that increased LOS was associated with decreased albumin and haemoglobin, increased age and operative blood loss. Previous platinum based chemotherapy was also indicative of a longer LOS. In addition, Holloway et al. (2002) explored the impact of pre-operative QoL on LOS for colorectal cancer patients; finding that patients who had low scores on the FACT-G (indicating a lower QoL on a cancer specific QoL scale for patients with colorectal cancer) had an increased LOS. It was concluded that QoL should be accounted for when considering risk adjustment for estimating LOS. In summary, these papers suggest that factors outside of the hospital control (and those accounted for on the ERP) may have an influence on LOS, bringing into question the appropriateness of this as a measure of success for such programmes as it is hard to adjust for risk and non-clinical factors.

Brasel et al. (2007) acknowledges that for LOS to be a comparable measure between establishments, patients included in the analysis need to be from a similar population, undergoing a similar procedure and have similar clinical and non-clinical factors, as this is the only way LOS can be used as a comparative measure. Further to this, the paper by Massad et al. (1993) raises another important point in relation to methodology. Those who had an excessively long LOS were not included in the statistical analysis, meaning that only those who had a LOS that fell within +/- 3 standard deviations of the mean were included in the analysis, giving an inaccurate representation of the population suitable for inclusion in the sample. Grocott (2010) also highlights that the use of outcomes as a measure of quality may result in clinicians or academics misreporting outcomes or omitting certain patients from data analysis. This could have a significant impact on clinical decision making as data has been modified; or in a worst case scenario result in patients not being offered processes or procedures if they may skew the data for the population. This is a serious point for consideration when exploring the use of LOS as an outcome measure.

The previous discussion has highlighted that although there may be some flaws when using LOS as an outcome measure, even though LOS is the most common measure of outcome for ERPs. Other performance and experience measures are valued as outcome measures. The Royal College of surgeons has advocated the collection and use of both patient and surgeon reported outcome measures.

# Patient Reported Outcome Measures (PROMs) in ERP

A number of papers have explored the impact of ERPs on PROMs measuring QoL (King et al. 2006b; Delaney, Zutshi, Senagore, Remzi, Hammel & Fazio, 2003; Anderson, McNaught, MacFie, Tring, Barker & Mitchell, 2003). These used a range of PROMs, including general QoL questionnaires (EORTC QLQ-C30/CR38, and CGQL), general health status questionnaires (SF-36) specific validated questionnaires (MGPQ), as well as visual analogue scales (VAS) to measure pain and fatigue. Although the papers measure the PROMs at different time points pre and post ERP, all the papers by Delaney et al. and King et al. found that there was no significant difference in QoL, health status and pain/fatigue of ERP and conventional care groups over time. In the Delaney et al. paper there was a difference in MGPQ scores for pain on discharge (with ERP patients experiencing more pain) – but this was expected as ERP patients were going home earlier; however pain scores had equalled out between the 2 groups by post-operative discharge day 10. The Anderson et al. paper found that there was an increase in pain post operatively for the conventional care group, whereas the ERP group’s pain levels did not differ significantly from preoperative levels, and pain levels in the conventional care group were higher on post-operative day 1. There was a difference in pain on coughing which remained higher in the conventional care group at day 7. It was also found that both groups had an increase in fatigue after surgery, but that fatigue scores were significantly higher in the conventional care group on post-operative day 7.

A systematic review conducted by Khan, Wilson, Ahmed, Owais & MacFie (2010) notes that ERPs may adversely affect HRQoL and patient satisfaction and that there has been little measurement of this to date. The review highlighted that any RCTs that had been run in the area were relatively small with only 11-33 patients per arm. Additionally, it was identified that a range of measures were used to measure the multidimensional construct of QoL, but also that studies were only measuring single dimensions of QoL such as pain and fatigue. The review concluded that there was little difference of HRQoL between conventional care groups and ERP groups, but that studies utilised inconsistent and unreliable data collection. Further to this, the review indicated that ERPs were not routinely applied, with different interventions being included in protocols and programmes. This combined with the heterogeneity of the samples used makes a systematic review impossible. In addition the review also highlights that HRQoL is not the main focus of any trial, it is an additional outcome measure – normally recorded alongside LOS.

The existing literature on HRQoL does raise some important points. If there is no significant difference between groups, it may suggest that current measures are not sensitive enough to detect subtle differences in the two groups. If patients are undergoing surgery as a treatment for cancer (which is frequently reported in the colorectal literature) it may be the case that the HRQoL scales reflect measures surrounding general HRQoL rather than specific measures associated with surgery. Also, in the majority, published papers find no difference between conventional care and ERP groups, allowing clinicians to infer that there is no detriment to HRQoL when using ERP. The main focus and outcome measure for ERPs is LOS, so the idea that HRQoL is not reduced when ERPs are implemented may merely be a neutral outcome of the programme. In addition, there have been some small effects of ERP on factors of HRQoL, but these are not consistent over time – raising issues around the best time for measurement of HRQoL. Any effect found in post-operative days 1 and 2 favouring ERP has diminished by post-operative day 7, suggesting that any benefits of ERP on HRQoL are not long term.

There have been a number of papers exploring the differences in HRQoL between open and laparoscopic procedures utilising an ERP (Basse et al., 2005; King et al. 2006a; King, Blazeby, Ewings & Kennedy, 2008); finding no differences between open and laparoscopic surgery. This suggests that ERP could be the contributing factor to HRQoL rather than the delivery of the procedure (even though the papers identify that an effect on HRQoL dependent on procedure has been reported in other areas not using ERP). The King et al. (2006a) found similar results in HRQoL as both groups had a decrease in HRQoL after 2 weeks, but levels had improved by 6 weeks. Further to this, King et al. (2008) found that more patients in the laparoscopic group reported feeling fully recovered at 12 months in comparison with the open surgery group (90% and 58% respectively). In addition, Basse et al. (2005) suggest that patients in the laparoscopic ERP group had no significant improvement in HRQoL in comparison to an open surgery group, but 30% of patients in the laparoscopic group and 17% of patients in the open surgery group felt that their hospital stay had been too short resulting in a reduced level of satisfaction. Delaney et al. (2003) report that there were no differences in patient satisfaction and readiness to go home between the conventional care and the ERP group. This suggests that further work in the area of patient satisfaction needs to be explored with patients.

A systematic review of the literature surrounding the measurement of patient satisfaction by Crow et al. (2002) identifies that satisfaction is hard to define, but the term is still widely used. More information is required to establish factors that affect satisfaction with an aim to improving patient services. The review identified 37 studies which looked at patient satisfaction. It was found that interview methods generated a 30% higher response rate than mail surveys, although it was surmised that mail methods may result in a higher level of reported dis-satisfaction as people are more open if they are not in a one to one situation. The review highlights that research in the area of patient satisfaction is “patchy and ad hoc” (Crow et al., 2002, p.4) as some patients are hard to contact and it is difficult to get a full representation of the diverse population receiving services (i.e. the elderly and those with language problems). It is acknowledged that qualitative research requires a greater resource provision but generates more in-depth data than questionnaire methods and should be used more widely. The review also identifies findings that suggest that satisfaction is linked to prior satisfaction and that psychological factors may also have an impact.

# Patient Experience

The term ‘personal experience’ has been associated with the understanding of patient satisfaction with quality of caring (Grocott, 2010). Kearney, Hubbard, Forbat & Knighting (2007) define patient experience in their work on developing services for cancer patients as “the knowledge and understanding on cancer and cancer care which is derived through actually living with cancer. It acknowledges the totality of the experience and includes survival, morbidity (physical and psychological), social and family issues” (p.10). The Enhanced Recovery Partnership Programme published a document around measuring and improving patient experience. It indicated that clinical teams need to use a variety of approaches including discovery interviews and patient stories to explore the experience of ERPs (NHS Improvement, no date). As “patient experience and quality care permeate everything” (Roberts, Mythen & Horgan, 2010, p.138) it is not surprising that patient experience is an outcome measure of the success of ERPs. There are currently only a small number of papers that specifically explore patients’ experiences of ERP; three papers looking at patients with colorectal cancer, and two papers exploring patients’ experiences of hysterectomy.

The experience of ‘going home’ is explored by Blazeby, Soulsby, Winstone, King, Bulley and Kennedy (2010) reporting the experience of ERP with 20 colorectal cancer patients. Patients expressed that they wanted to be at home because they wanted to be away from infection, and that it suited them to be at home in a more relaxed environment. Patients were initially apprehensive about going home, but felt that overall their recovery was improved at home as there was less interruption in the day. This could be interpreted as they were less likely to comply with a plan given at the time of discharge for use at home, but this is not explicitly stated in the article. Only 9 participants felt that they would recommend the ERP to other people. The other 11 patients in the group felt that once they had returned home it was hard to contact health care professionals, resulting in a sense of vulnerability, especially when experiencing minor complications. Patients also expressed concern about their carers as they had been discharged early: in some cases they felt like a burden.

Although this study does go some way to explore the experiences of colorectal cancer patients taking part in ERP programmes, it offers little more insight than an open ended questionnaire as information about the actual lived experience available from the paper is minimal. This may be attributed to the analytical approach or be a result of the writing style of the authors. There are other papers that focus on a more phenomenological approach to analysis, which report a richer and more insightful view of patients’ experiences of ERP. Papers published by Wagner, Carlsund, Sorensen & Ottosen, (2005) and Wagner, Carslund, Moller & Ottosen (2004) explore the experience of patients taking part in an ERP after hysterectomy. Both papers focus on exploring the experiences of 10 patients through the use of observations (during interactions between health care professionals and patients) and interviews. Patients taking part in the research were generally in good health and were not included in the study if they had received a diagnosis of a life threatening disease (including gynaecological cancer) “because the supplementary diagnosis can have an impact on the women’s experiences of the admission to hospital” (Wagner et al., 2005). The aim of the research was to explore whether the ERP facilitated enough discussion between patients and clinicians to prevent any negative aspects associated with a quicker discharge from hospital. In the main paper (Wagner et al., 2005), inductive analysis of the observations and interviews revealed 3 themes – or three types of women; intervening, cooperative and unsure.

Intervening women knew a lot about the intervention and the process of hospital admission, and patients reported wanting to stop the flow of information from clinicians. These patients also reported an awareness of physical being and engaged in direct discussion with health care professionals. In addition, they were self-motivated and active in following hospital advice. When discharged home, patients were aware and alert for signs and symptoms but would seek information from resources or health care professionals when required.

Co-operative women would only react in consultations if there was a disagreement with the clinician, and would ask for more information if needed after reading the literature supplied. Any questions were linked to confirmation of understanding and were only related to the information that was given. Patients would co-operate with requests from health care professionals when asked, and when patients returned home they were slow to test the body’s functions. They also felt comfortable taking more sick leave if it was required.

Unsure women asked lots of questions during consultations in an apologetic manner, and felt the need to raise and re-raise issues they were unsure of, which according to Wagner et al. (2005), indicates that they were overwhelmed or that they were looking for alternative answers. Patients reported being surprised at 1-2 day discharge and were not active in mobilising themselves. Patients also reported that they were relying on nurses to be kind rather than the nurses motivating the patients to move. Patients found it hard to decide about discharge and there were lots of doubts about whether to stay in hospital. When returning home patients were fearful to try activity and took a long time to feel ready resulting in extended sick leave.

In addition to the classification of patients, a number of other issues were reported by Wagner et al. (2005), which were clearly extensions of the findings presented in the 2004 paper. Patients expressed concerns around the effects of the operation of their sex life, even though no differences were found in the long term. This highlights that patients need to discuss the sexual side of hysterectomy procedures with clinicians before or after the operation. Patients also reported that they had an unexpected painful experience with regards to regaining normal gut function, which was something that was not accurately described in the patient information literature. Further to this, patients found that there was a considerable amount of fatigue after discharge, but that when returning to work, their situation and experience had been considered.

Furthermore, the study indicated that patients felt that they needed to fulfil the role of “good girl” to ensure they were meeting the expectations of the staff and the programme by complying with the principles of the ERP. This is further supported by research carried out by Norlyk and Harder (2009; 2011) looking at patients experiences of ERPs after surgery for colorectal cancer. Norlyk and Harder found that accounts of the patients’ experiences of ERPs reflected the patients’ belief that they needed to follow the instructions set by the ERP, resulting in a lack of autonomy. Patients believed that they must be ‘good’ and ‘cooperative’ to work towards the early discharge goal. To achieve this they must challenge their own intuition about their bodies to complete the ERP, resulting in the suppression of discomfort and ensuring compliance with the regimen.

The papers by Norlyk and Harder (2009, 2011) are similar to those by Wagner et al. (2005) in as much as both papers are generated from the same information gathered during interviews with a sample of 16 colorectal cancer patients. Interviews were analysed using reflective lifeworld research (RLR), which is a phenomenological approach. RLR questions the essential meanings of experience in order to describe it. Researchers conducting lifeworld research need to have an open attitude to be able to understand patients’ views. The papers published by Norlyk and Harder focus on the experience of participating in a fast track programme (2009) and the experience of recovering at home (2011). The original 2009 paper raises some interesting topics for discussion with regards to taking part in an ERP. Patients diagnosed with cancer face an unpredictable future and in some cases experience a lack of control, resulting in patients wanting to contribute to their own well-being through engagement in the ERP. Patients are actively committed to living up to the expectations of the ERP as well as the expectations of the staff delivering the ERP. Patients wanted to be seen as being co-operative, with the ERP giving structure, resulting in patients regaining some form of control and security. In addition to this, many patients saw that surgery was the first step to recovery - ERP was only part of a larger experience.

It was also found that patients wanted to fully take on the ERP in its entirety with little flexibility in the rules, even when experiencing symptoms such as pain and nausea. Patients felt it was more important to abide by the rules of the ERP, which in turn became rules of the hospital and needed to be complied with. The paper also describes a number of tensions between the patients and the programme. Patients were required to comply with the programme, and in some cases this meant working against natural intuition. A lack of engagement with the staff led to patients feeling pressurised to comply with the programme, as the patients constructed the belief that compliance was the objective of the programme which the staff were enforcing. The relationship with staff was the key to overcoming the discrepancy between intuition and instructions – staff needed to be supportive whilst applying enough pressure to get results.

Patients also needed to experience the success associated with meeting the requirements of the programme. When patients were able to mobilise it gave a feeling of success, resulting in motivation to further comply with the programme. There were instances where patients felt alone, even though they were able to complete tasks, as the amount of effort needed was greater than normal. It was summarised that living up to expectations resulted in patients feeling strong, whereas not living up to expectations resulted in feeling weak. The feeling of being alone was also apparent with regards to the movement from being the centre of attention at the point of diagnosis, to being one of many after the operation when on the ward. Small signs of encouragement gleaned from health care professionals were enough to give an indication of compliance which was seen as a positive acknowledgment of effort. In contrast, if staff were unable to display an appropriate amount of knowledge, patients reported a lack of confidence in the staff; this is partly related to the patients’ need for knowledge to be reassured – allowing patients to maintain confidence in their own ability. It was perceived that if health care professionals believed that patients could complete a task, that they could actually complete it, resulting in a higher level of self-efficacy.

In addition, patients believed in the programme and felt a responsibility to produce a reduction in the waiting list. Patients also reported feeling that they were getting more than they were entitled to if they did not go home on time. It was also noted that although early discharge was a worry at sometimes, patients believed that home was better and more helpful in recovery than being in the hospital environment. The role of staff was also important in this respect as there was a trust in the staff that they would not be allowing patients to go home if they were not able. Staff were treated very much as the experts in regards to discharge, with patients relying on clinicians’ assessment of their suitability to go home.

This notion is further explored in the second paper which focuses on the experiences of being at home after taking part in an ERP (Norlyk & Harder, 2011). Once patients leave the hospital environment it marks the shift in focus – the role is now to actually recover rather than to just overcome the operation. Whilst at home patients continue to feel the discrepancy between intuition and instructions, but feel they have more control over the regime - allowing it to fit in with daily life. Patients set their own signals for recovery rather than continuing to use the indicators supplied by the hospital. Friends and family also have a role in this – they become collaborators in the judgement of symptoms and play an active role in decision making about the need to seek medical advice if there is no clear rationale for a symptom. Relatives also become providers of a suitable environment for recovery as well as being motivators and enforcers of the regime. This leads to frustration in some cases; emotions affect relationships and families become the supportive network.

The authors go on to discuss other areas (patients desiring to return to everyday life and moments of rest and interaction with relatives) which are related more to recovery from surgery in general and coping with the diagnosis of cancer rather than directly with the experience of enhanced recovery. It is not surprising that the topic of patient experience in ERP shifts focus to the experience of recovery in general, as once a patient is home, there may be little difference in the recovery between conventional care and ERP patients after a number of days.

There are areas for exploration in relation to the overall effect of ERPs on the patients’ experience that fall outside of the colorectal discipline. The papers by Wagner et al. have explored the patient experiences of ERPs in terms of hysterectomy, but purposely left out the gynaecological cancer patients as there were too many issues associated with cancer. With this in mind it is important to look at the experiences of gynaecological cancer patients with regards to ERP, as surgery may be only one aspect of a larger experience associated with a diagnosis of cancer. This has been explored within the colorectal discipline by Norlyk and Harder (2009, 2011), however in a similar fashion to the implementation of the programme itself, research needs to be expanded outside of the remit of colorectal cancer. Additionally, other factors which may potentially influence the experience of ERPs (such as coping) should be considered when conducting research.

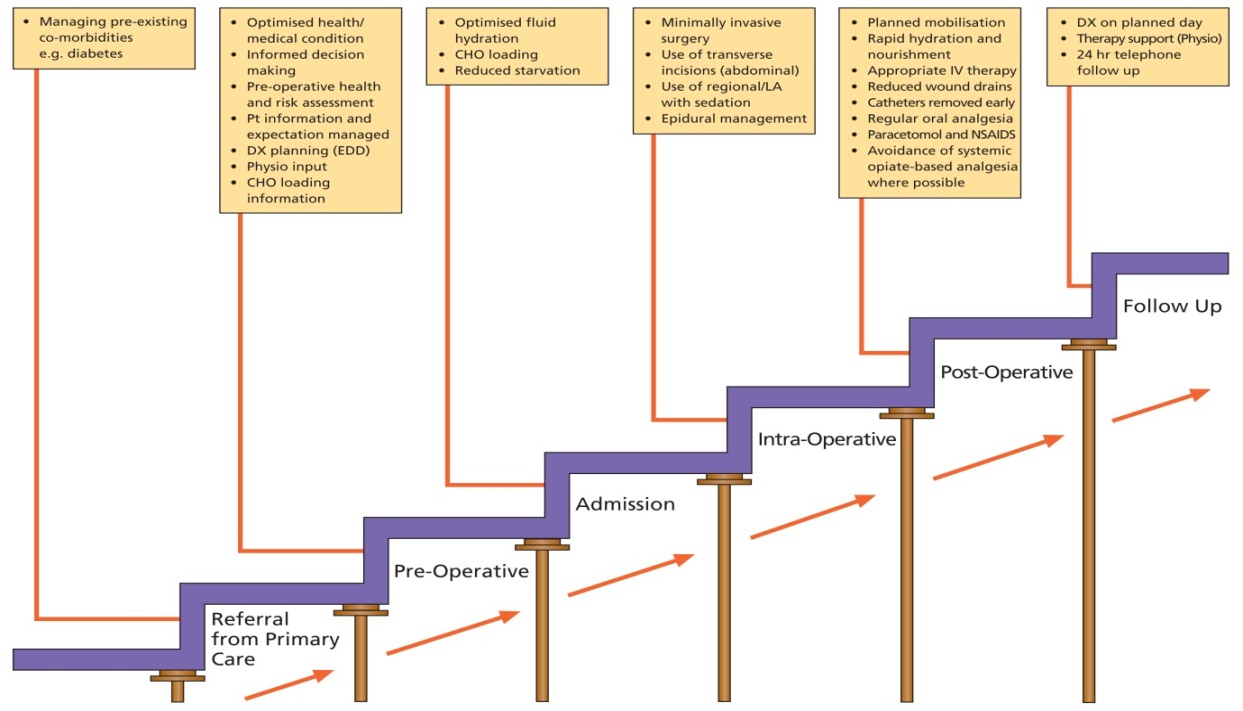
# Enhanced recovery and coping

To date, there has been no published research specifically exploring the link between ERPs and coping. The research by Wagner et al. (2004, 2005) highlights the different coping strategies used by women, expressed in their information seeking and within their interactions with health care professionals concerning their cancer treatment. Women use different types of coping strategies (problem-focused and emotion-focused coping) to help manage their experiences of taking part in the programme and of having cancer in general. Research shows that the different coping strategies influence how they interact with and adopt the programme (i.e. those using problem-focused coping see the ERP as a way of being able to ‘beat’ their cancer). Coping strategies are also alluded to in the research by Norlyk and Harder (2009, 2011). They describe the difficulties that patients experience at home regarding the change in environments and the idea that patients are not physically able to fulfil a role that they associate with being ‘well’, leading to a negative patient reported outcome. This suggests that there may be a loss of resource as a result of the surgery for cancer which in itself is a stressful event. This has important implications for patients overall self-efficacy, not only for the programme but for their overall cancer experience.

# Rationale for the current study

Although the introduction of ERP is a national initiative, the concept of ERP for gynaecological patients was first discussed within Derby Hospitals NHS Foundation Trust during September 2009. The final business case was presented to the directorate management board in November 2009 and subsequently received approval. The implementation of an ERP at Derby Royal Hospital commenced on the 4th of October 2010 and is on-going. Patients undergoing laparotomy (abdominal surgery) for any clinical induction were included in the initial roll out of the trial. A copy of the pathway for Gynaecological Patients undergoing Hysterectomy is shown in Figure 4.

Figure 4 – The Enhanced Recovery Pathway used at the Royal Derby Hospital for patients undergoing hysterectomy.



Many of the papers that have been published to date focus on the individual peri-operative interventions or on the overall effect of the pathway on the LOS and readmission rate of the patient; these have been identified as important clinical indicators of success. These measures were recorded by clinicians at the Royal Derby hospital as a measure of outcome. However several papers identify that patient experience and satisfaction are also important measures in evaluating the success of ERPs (Wilmore & Kehlet, 2001). Research exploring the patient experience of the ERP at the Royal Derby Hospital was therefore identified as being important and timely.

As discussed in the section above, the studies by Wagner et al. (2004; 2005) identify that within the gynaecological patient population different types of patients interact with ERPs in a different manner. Furthermore, Norlyk & Harder (2009; 2011) found that a number of aspects of enhanced recovery were integral to the patient experience. Both sets of studies highlight that the expectations of the programme and the surgery itself influence patient behaviour. In addition, the studies by Norlyk and Harder found that patient experience of the programme may go some way to explaining its efficacy and be of benefit in identifying aspects of the programmes that could be improved. This in turn may have a potential impact on both LOS and the patient experience. Both sets of studies, however, were conducted in Scandinavian health services, thus limiting their relevance to patients on an ERP in the UK.

The following qualitative research aims to explore the experience of taking part in an ERP at the Royal Derby Hospital for patients diagnosed with gynaecological cancer. The information gathered from the research proposed here will allow insight into the lived experience of ERP for patients who have been diagnosed with gynaecological cancer and are being treated by the NHS. It will provide an in-depth and previously unexplored view of the ERP from the gynaecological cancer patients’ perspective which can, in turn, inform the advancement of such programmes in the field of gynaecological cancer surgery and give insight into the efficacy of these programmes in providing mechanisms for coping and replenishing lost resources as a result of surgery.

Chapter 3: Method

Chapter 2 outlined some of the research that has previously been conducted in the area of enhanced recovery, and highlighted the need for further qualitative research in the area. This chapter explores the methodology selected for this study. The use of qualitative methodologies in health research is discussed, and Interpretative Phenomenological Analysis (IPA) is introduced as the methodological framework. This chapter also contains details about the development of the study and the various steps taken in obtaining and analysing the data.

# A qualitative approach

A qualitative methodology was selected for this study. Starks & Brown Trinidad (2007) state that “qualitative research methods enable health sciences researchers to delve into questions of meaning, examine institutional and social practices and processes, identify barriers and facilitators to change and discover the reasons for the success or failure of interventions” (p. 1372). Qualitative research is widespread, and openly accepted in the discipline of psychology – the British Psychological Society has a “Qualitative Research Methods in Psychology Section” which boasts over 1000 members (BPS, 2012).

The introduction of broad humanistic qualitative methods came as a result of the reaction to cognitive experimental psychology in the 1960s and 1970s, (Madill & Gough, 2008). The introduction of qualitative methods, such as discourse analysis (Potter & Wetherell, 1987), challenged quantitative measurement of phenomena through the use of scales and measures (for example, a questionnaire may not directly link to the cognition in question). In contrast, discourse analysis looks at the use of available discourses to describe a cognition based on the current situation or context – how participants use language to describe experiences in a particular situation.

Discourse analysis is categorised as a discursive method of analysis, other methods include thematic, structured and instrumental analysis (Madill & Gough, 2008). One particular type of thematic analysis is interpretative phenomenological analysis (IPA, Smith, 1996). IPA is in some ways similar to discourse analysis, in as much as it explores how people describe experience. However, IPA focuses on how people give meaning to, and make sense of their experience, whereas discourse analysis focuses on the role of the language used, making no attempt to comment on individuals’ ‘inner states’.

As the focus of this project was on patients’ lived experiences of taking part in the ERP at the Royal Derby hospital, IPA was selected as the appropriate approach for this project. Although IPA was selected as the tool for analysis for this piece of research, a number of discursive devices were used by patients in their talk and highlighted as important during the analytic process. Two notable features of discourse which became apparent were the use of three part lists and the use of pronoun switching, both explored in brief here.

The use of three part lists is a recurrent practice in ordinary conversation; it is a culturally available resource for list construction. When people produce lists in conversation, they routinely do so in three parts (Jefferson, 1990); one example of a three part list might be “I’m cold, tired and hungry”. Jefferson (1990) found that three part lists were utilised in many forms of communication, including face to face and telephone communication. Three part lists are used so often in language that when two parts of a list are spoken, the speaker feels compelled to find another factor to add to the utterance, even if they have exhausted their resources (e.g. ‘or something’ or ‘that kind of thing’).

Wooffitt (1992) describes how three part lists can be used to emphasise an experience and provide a narrative account. Hutchby and Wooffitt (1998) describe that “making three specific points can strengthen or affirm a broader, overarching position or argument” (p.233). They further describe that three part lists are often used in political speeches as an aid to persuasion and a way of eliciting applause. In a similar fashion, three part lists are used throughout patients’ constructions of their experiences to add support for an action they had taken or as a justification for not adhering to a particular part of the programme. These are noted and discussed throughout the analysis chapter.

Further to this, throughout the analysis there are instances of pronoun switching, where the women switch between ‘I’ and ‘you’ in their accounts. As pronouns are “part of society members’ jointly held conventional apparatus for achieving orderly and intelligible communication” (Watson, 1987, p.264), it is not surprising that these are utilised to shift the reference from the very personal experience to that of ‘the other’ or ‘the collective’. In talk, individuals have little difficulty dealing with the ambiguities that pronouns present; however, it was only when reading and re reading the transcripts that these ambiguities become apparent.

Goffman (1967) suggests that pronoun use is a tool that is used in conversation to ensure that both parties are involved. It is the social role of the speaker to include the other party or the ‘listener’. This result is that the other party has to attend the conversation more closely to be able to interact and understand what is taking place. Malone (1997) describes three different types of ‘you’: the second person singular (direct reference to ‘you’ as an individual or the listener), the second person plural (‘you’ the collective, which could be substituted for ‘we’) or the indefinite second person (‘you’ used in place of ‘people’ where the speaker is communicating a group experience).

In light of this, the use of ‘you’ may have a number of functions, it may be that ‘you’ is used in the way that Goffman describes, to include the listener in talk, but it also appears that ‘you’ may be used to remove the focus of the account from the ‘I’. Interestingly, this appears in later extracts included in the analysis where individuals are describing their own experience, but when describing an activity that was not proscribed by the programme, the use of the indefinite second person plural (people – collective) acts as a way of diminishing responsibility for their actions (as in ‘everyone does it’, ‘we all do it’). This particular aspect of pronoun switching will be discussed further at pertinent points in the analysis chapter (Chapter 4).

# The basis of IPA

IPA was developed by Jonathan Smith in 1996, with the aim being to “explore the participant’s view of the world and to adopt, as far as possible, an “insider perspective” (Smith, 1996, pp. 264). IPA is informed by phenomenological philosophy and hermeneutics (Smith & Osbourne, 2003).

## Phenomenology

Phenomenology is a philosophical movement which was founded by Edmund Husserl (1859-1938) and further developed by Heidegger amongst others (Landgdridge, 2007). Phenomenology focuses on an individual’s perception of the world – how things appear to them. In essence, phenomenology is based on what we experience (noesis), and how we experience it (noema). The areas, what we experience and how we experience it are linked to two phases: existential and transcendental. Transcendental phenomenology is concerned with how an individual looks at their own experience, allowing them to identify the essential qualities of that experience (Smith, Flowers & Larkin, 2009). This was taken forward by Husserl and developed further into a phenomenological method (with the ability to go back to an experience; specifically focussing on that experience which happened in the conscious of an individual – an experience of “something” or intentionality). To achieve this Husserl identified that we need to bracket off the taken for granted world to be able to focus on the perception of that world – the taken for granted world is a distraction from the essence of the experience. Husserl argues that transcendental phenomenology involves being able to assign essences that are common to an experience – allowing an essence of the phenomenon experienced to develop. The method that Husserl describes uses a number of reductions – each one is used to explore the phenomenon from a different view point, it is that which gives an essence to a phenomenon. In summary, Husserl wanted to be able to transcend everyday assumptions to establish what is at the core of a particular subjective experience (Smith et al., 2009).

Although Husserl offered an important philosophical viewpoint on phenomenology, there is little practical information about how to conduct this type of self-centred phenomenological analysis or the process of the reductions – it is not known whether this is even possible (Smith et al., 2009, p. 16). In addition to this, Husserl was also interested in the first person analysis of an experience, rather than the experience of others - which is an essential aspect of IPA. However, Husserl is not the only philosopher that worked on the phenomenological approach. Heidegger, a student of Husserl, Merleu-Ponty and Sartre moved towards a more existential phenomenology, which instead focuses on the lived experience of individuals. Heidegger grounds his philosophical view point in the lived world “the world of things, people, relationships and language” (Smith et al., 2009), resulting in his philosophy being grounded in a worldly perspective. Heidegger believed that these aspects all had an impact on experience and how we make meaning of this experience. Further to this, Merleu-Ponty focuses on the embodied and individual nature of experience. The individual shapes the experience, so no two people can have the same experiences due to them being fundamentally different (Larkin & Thompson, 2011). Sartre was also concerned with the existential view that experiences are based on interaction and relationship with others, and that individuals are “becoming” rather than “being” (Smith et al., 2009).

To conclude, philosophers such as Heidegger, Merleu-Ponty and Sartre were all interested in the lived experience of phenomena, as it appears to the individual as well as the meaning of this experience. The focus on the existential i.e. the social situation, interactions and relationships with other,s all add to the experience of the individual, and it is this aspect of phenomenology that is addressed in IPA, rather than the transcendental approach identified by Husserl. However, aspects of Husserl’s work are included in modern day IPA, i.e. bracketing and reflecting on experience.

## Hermeneutics

Reenie (2007) describes hermeneutics as “the interpretation of written and oral texts about matters that include human experience and social conduct” (p.3). Hermeneutics were originally used for interpretation of biblical texts, but were later used in the interpretation of other texts. Schleirmacher was one of the first philosophers to use them in a more general sense. Schleiermacher saw hermeneutics as “the primary aspect of social experience, not only for the scholarly interpretation of texts or document of the past, but also for understanding the mystery of the inwardness of the other person” (Gadamer, 1984, pp. 57). Hermeneutic theorists are interested in how we interpret a text to learn about the meaning and production; in particular Schleirmacher was concerned with the meaning of the text and the individuality of the author (Smith et al., 2009).

Heidegger was also an important figure in the development of hermeneutics through phenomenology. Heidegger believed that access to the world experience is always through interpretation. This is particularly important for IPA as it is an interpretative phenomenological analysis of an experience. Smith et al. also note that Heidegger brings a new meaning to the term bracketing which was originally used by Husserl. One must bracket off the fore-structure to be able to let the phenomenon be interpreted, but in some cases it is only after interpretation we realise that we had a fore-structure. This concept is further developed by Gadamer who discussed the distinction of what “we bring to a text and what a text brings to us” (Smith et al., 2009, p.26), but acknowledged that we need to be open as researchers to allow a new object to be presented. This is important for both the interview and analysis stages of qualitative research, and this should form an essential part of reflection. This forms a double hermeneutic – where “participants are trying to make sense of their world, and the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osbourne, 2003, pp.51).

The hermeneutic circle is important when talking about IPA as a methodology (Smith et al., 2009). The hermeneutic circle focuses on both the part and the whole, to understand one, you must look to the other which promotes a “dynamic, non-linear, style of thinking” (Smith et al., 2009, pp. 28). This is reflected in the method of analysis for IPA – it is necessary to move through the data thinking about it in a number of different ways all of which are related – giving different perspectives on the text.

## Idiography

IPA is influenced by idiography in as much as the technique aims to explore the experiences of a homogenous group in one given situation. This has an impact on the sample size required for IPA research. The idea of IPA is not to generalise, rather to explore meaning of shared experience for a very specific group of people (Langdridge, 2007). Whilst IPA focuses on the experience on an individual it can also search for patterns among a group of participants – it highlights both shared and individual experiences (Smith, 2011).

# Summary

IPA is based on the philosophies discussed in this chapter; it looks at the lived experiences of participants, specifically looking at how they make sense of the things that they encounter in their world. It takes into account social interactions of both participant and researcher and their understanding of the experience; it is idiographic in nature and focuses on the interpretative meaning-making aspects of human beings.

# Utilising IPA in research

Since its development in 1996, a substantial body of research has grown which uses IPA (Smith, 2011). In a recent review, Smith (2011) found that the number of papers published using IPA steadily increased from 1996 until 2008, where 71 papers using IPA were published in 2008 alone. Although IPA has predominantly been used by UK researchers, the numbers of papers published outside of the UK is steadily increasing. Research in the areas of patient experience, psychological distress and carers’ experience form approximately half of the 293 papers identified. In the review, it was found that only 5 papers solely focused on cancer. Papers using IPA in cancer studies have surrounded areas such as psychosocial changes when taking part in physical activity (McDonough, Sabiston & Crocker, 2008), follow-up care for childhood cancer survivors (Earle, Davies, Greenfield, Ross & Eiser, 2005) and decisions about final care places for dying children (Hannan & Gibson, 2005).

# Methods

## Participants

Participants were recruited for an overall evaluation of the ERP at Royal Derby Hospital. As part of a larger project, all patients - regardless of their diagnosis - were asked to take part. However, as the focus of this PhD is the experience of those with gynaecological cancer, only a subset of the patients recruited will be included for analysis. Patients were invited to take part in the evaluation if they had taken part in the ERP between the October 2010 and April 2011 and met the inclusion criteria.

### Inclusion criteria for overall study

* Undergone elective open surgery for any gynaecological clinical induction

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### Inclusion criteria for PhD study

* Been diagnosed with a gynaecological cancer (pre or post-surgery)

## Recruitment

Patients were identified by the clinical team using hospital records and contact details supplied by the ERP project lead. In total, 53 gynaecology patients were identified as having undergone elective open surgery; 52 of these patients were asked to take part in the evaluation. One patient was not included in the evaluation as they had returned home to a country outside of the UK and contact details were not available.

Patients were sent an invitation to participate along with a consent sheet. Stamped, addressed envelopes were provided for patients to maximise responses. The patient information sheet included a reply slip asking people to respond whether they would or would not like to take part in the evaluation – those who did want to take part had the option of a face to face interview or a telephone interview. In total, 35 responded to the invitation. 14 responded saying that they did not want to take part in the evaluation at this time, and 21 responded to say that they wished to take part in the evaluation – 15 requesting face to face interviews and 6 requesting telephone interviews. Of the 21 gynaecological patients that took part in the evaluation, 14 were diagnosed with a gynaecological cancer. Four patients took part in telephone interviews and 10 patients took part in face to face interviews (displayed in Figure 5).

# The gynaecological cancer sample - participant characteristics and demographics

All patients taking part in the evaluation had undergone a full open hysterectomy +/- Bilateral Salpingo-oopherectomy, +/- Omentectomy, +/- Pelvic Lymph Node Dissection at the Royal Derby Hospital. Patients were all living in the East Midlands at the time of the operation and spoke fluent English; the sample comprised of women from various ethnic origins. The age range of the patients was 53-80 and the mean age was 66.

Figure 5 – Recruitment for ERP evaluation.



# Data collection - Interviews

After consent was received, patients were contacted by telephone to arrange interviews whether face to face or by telephone. Interviews are often used in qualitative research and are familiar to both researchers and participants. There is a wide variation of interviewing approaches ranging from structured (useful in gaining quantitative data) to unstructured interviews (used in ethnographic research). Semi-structured interviews are widely used in face to face communication providing an opportunity for the researcher to “hear the participant talk about a particular aspect of the life or experience” (Willig, 2001, p.22). This account of experience allows for the meanings of the experience to be qualitatively analysed in a number of ways. Early versions of individual in depth interviews were used by Husserl and the Chicago School sociologists (DiCicco-Bloom & Crabtree, 2006) indicating historical routes with the origins of phenomenological analysis. Semi-structured interviews are pre-arranged with individuals or groups; individual interviews allow the exploration of an individual’s experience, which is normally in depth, whereas group interviews, or focus groups collect a group perspective of an experience, which is more varied and sometimes less detailed.

This study utilised semi-structured interviews as they allow for all participants to be asked the same questions within a flexible framework (Dearnley, 2005); this is important when assessing the reliability and validity of semi-structured interviews as a data collection method. Although it is acknowledged that not all participants will have the same vocabulary or assign the same meaning to words, it is the role of the interviewer to ensure that they convey an equivalent meaning to the participant (Treece & Treece, 1986). In light of this, development of the semi-structured interview schedule is important – it must cover the important areas for discussion as well as taking the participant into consideration (Mann, 1985). The interview schedule developed for the ERP project included a number of open ended questions and prompts that focused on the main topics (Appendix 3). Questions were kept purposefully general at the beginning of interviews to encourage patients to talk openly about their experience, allowing patients to give information and “set the scene” for their participation in the ERP itself. In addition to this patients were encouraged to talk openly about their experience within the hospital, and how it linked to their overall experience of cancer care at the Royal Derby Hospital. This was important to allow the overall impact of the ERP on their cancer experience to be discussed, without patients feeling they had gone off topic.

Time was taken in the interviews to “revisit” terms that were used by the patients for clarification of their meaning. As patients taking part in the study were from a diverse population in regards to ethnic origin and educational status, a number of words or descriptions had to be revisited for further clarification to improve the understanding between patient and researcher. Barriball & While (1994) also note that researchers must clarify the meaning of any ambiguous words that are used by participants to ensure that the meaning of the experience is shared by both participant and researcher this allows for researchers to “validate the meaning of respondents answers” (Barriball & While, 1994: 331).

It was beneficial for the researcher to have some background information about the medical side of gynaecological cancer and in depth knowledge of the ERP itself, as this enabled the researcher to understand and explore some of the medical terms that were used (and forgotten) by the patients. Treece & Treece (1986) argue that the interviewer should have some knowledge of the topic area in order to obtain a relevant and complete data set from the participant. Interviewers should also feel comfortable when discussing the topic in question. Many health related topics may include potentially embarrassing or graphic details of symptoms and procedures – researchers must have the understanding to be able to get the most information possible (Dearnley, 2005). Further to this, DiCicco & Crabtree (2006) also acknowledge that some participants may expect reciprocity for the information that they have provided in the form of clinical information from the interviewer; this is based on the social role of the interviewer and interviewee. Patients may expect to be able to ask clinical questions of a nurse or other health care professional carrying out research, so it is important to define the role of the researcher. In addition the researcher should be prepared to direct patients for advice outside of the interview. Patients were made aware that they were being interviewed by a researcher rather than a health professional and any requests for advice or medical information were directed to the patient’s Clinical Nurse Specialist (CNS).

Patients in the study were asked to take part in a semi-structured interview that would take place at a location convenient for them. Interviews took place in patients’ own homes, at the University of Derby and at the Royal Derby Hospital. Interviews also took place on the telephone. Patients requesting a telephone interview were contacted after consent was received and an appropriate date and time was organised.

There is limited research in the area of telephone interviewing for qualitative research in comparison to the literature available for quantitative telephone research (Barriball, Christian, While & Bergen, 1996; Wilson, Roe & Wright, 1998). The literature that is available reports mixed results in regards to the quality of information generated from telephone interviews, although the few papers which make a direct comparison between telephone and face to face interviews find little difference (Carr & Worth, 2001). Norvic (2008) suggests that mixed results are further supported by the bias that is shown against telephone interviewing in the literature on qualitative methods. Norvic explains that there is little information about the use of telephone interviews in mainstream qualitative text books, and also that there are a limited number of academic papers published in the area. Norvic argues that the common misconceptions about telephone interviewing are unsubstantiated, and that telephone interviewing offers a viable and versatile approach to qualitative data collection.

Research conducted by Sturges & Hanrahan (2004) highlights that there is no difference in the amount and quality of data that is collected via telephone interviews when compared to face to face interviews. Further to this, there was little impact of mode of interview on the depth of the response given. It was also found that participants liked the option of being able to take part in a telephone interview as it allowed them greater flexibility in regards to availability and also eliminated the need for transport. Participants in the telephone interview also acknowledged the increased privacy that was afforded by a telephone interview, which in turn lead to more information being discussed about potentially embarrassing topics. The participants were more comfortable in their own home and were not likely to be over heard; also the telephone interview eliminated the face to face embarrassment of discussing personal problems or taboo topics.

There have been a number of concerns raised about quality of the data i.e. the loss of nonverbal data, the loss of contextual data and the loss or distortion of non-verbal data (Norvic, 2008). In regards to the loss of non-verbal data – many forms of analysis do not record the observations of the conversation. Unless research is ethnographic in nature, analyses rely on transcripts rather than observations. In addition, Sturges & Hanranhan (2004) highlight that other cues replace non-verbal cues when using telephone interviewing, such as pauses and sighs. These are sometimes more telling than non-verbal cues as non-verbal cues are sometimes misinterpreted (Burnard, 1994). Loss of contextual data, where the interviewer cannot see the interviewee can have an impact on ethnographic research as the context and setting of the interview is sometimes unknown. The loss of contextual data in some cases may be beneficial - the loss of settings and surrounding may reduce the information about social economic status, which may in turn have an impact on the interview (Burnard, 1994). The loss or distortion of verbal data, where rapport is lost in telephone interviews is an important consideration in the application of telephone interviews. It is important to foster rapport with an interviewee to ensure that the maximum amount of data is collected on the topic (Fontana & Frey, 2005). Although rapport may be hard to foster on the telephone, the role of informal chat before an interview may be beneficial (Burnard, 1994).

Although all patients had undergone surgery at the Royal Derby Hospital, it was acknowledged that several patients lived outside of Derbyshire – which would result in travel for the participant or the researcher. In addition, patients may have also undergone further treatment after surgery (or it may still be on-going) at another cancer centre and may struggle to be able to commit to a date/time for a conventional face to face interview. Some patients may have returned to work after a period of convalescence and may have found it difficult to allocate time for a face to face interview. In light of this, the decision to include use of telephone interviews was made to minimise disruption of patients’ schedules. An effort was made to establish rapport with the patients in the initial telephone conversation in order to arrange a suitable time and date for the interview. Notes were kept about any information given in the initial phone call (such as holidays and current activities of the patient) to enable the researcher to establish a conversation with the patient before the interview was started. The telephone interviews followed the same interview schedule as the face to face interviews to preserve validity and reliability between the delivery modes. Interviews were recorded via a plug-in from the researcher’s telephone to the same dictaphone used for the face to face interviews, and all sound recordings were transcribed verbatim.

# Ethics

The study met the National Research Ethics Service (NRES) definition of ‘service evaluation’; service evaluations are designed to assess an intervention that is currently in use in an NHS setting (NRES, 2009). Based on this, the study did not require formal NHS ethics approval; however the evaluation of the ERP was approved as an audit of current service by the Women and Children’s Directorate at the Royal Derby Hospital (Appendix 4). Additionally, ethical approval was sought from the University of Derby Psychology Research Ethics Committee (PREC) in line with the BPS Codes of Ethics and Conduct (2009). Approval from PREC for the project and the associated paperwork was granted on the 18th of May 2011 (Appendix 5).

## Consent

Participants were sent (via post) an invitation to participate (Appendix 6) with an information sheet (Appendix 7) describing the study and the study aims. Patients were asked to read the information pack and to contact the researcher with regards to any questions they might have about the research. Included with the information pack was a consent form (Appendix 8) which asked patients who were willing to take part to give full informed consent (based on the information pack and the opportunity to ask questions).

## Debriefing

Participants were issued with a debrief sheet (Appendix 9) after the study, which included information about withdrawing from the study and the process that they needed to follow should they wish to do this. The debrief also included information about support should they need it after taking part in the evaluation. Participants were directed to ask for support from their CNS or their GP if they had any concerns about their health after taking part in the interview.

## Withdrawal from the investigation

Participants were informed of the process for withdrawing their data from the evaluation in a number of documents (Information sheet, informed consent and debrief). If a participant wished to withdraw they had two weeks from the point of debrief to contact the researcher and all information pertaining to them was withdrawn from the study and destroyed (Sound recordings and electronic transcripts were deleted from any computer and any paper transcripts were shredded).

## Confidentiality

Audio recordings from the interviews included data that identified the participants. To preserve participants’ anonymity with those outside of the study team, at the time of transcription all participants were anonymised by use of a pseudonym. Audio data was stored in lockable storage or on a password-protected computer at the University of Derby and was kept separate from transcriptions.

## Protection of participants

The interviews were not expected to cause distress or harm to the participants involved. In the unlikely event that participants did become distressed by the nature of the discussion, the interview would have been stopped and the participant would have been referred to their CNS in the first instance and further advised about advice and counselling services available at the Royal Derby Hospital. This information was also available in the debrief document. Patients were also informed that their participation in the study was completely voluntary and that their participation (or not) would have no influence on the care that they received at the hospital. This was particularly important due to the nature of the research and the sharing of personal experiences of a current service at the Royal Derby Hospital where a patient may still have been receiving treatment. Patients were advised to contact the Patient Advice Liaison Service (PALS) for Derby Hospitals with any areas of concern regarding current service if they wished to talk to someone in a more formal capacity.

## Giving advice

Advice was not given to participants within the study. Although this is a situation where patients may want to seek advice, any requests for advice were directed towards to their healthcare team, in the first instance, their CNS.

# Data analysis

Data was analysed using IPA (Smith, 1996), and followed the steps provided in Smith et al., (2009) and Smith & Osbourne (2003). The guidelines Smith published in 2011 in relation to good IPA research were also followed as closely as possible. The process of analysis began once interviews had taken place and the recordings had been transcribed verbatim. Paper transcripts of the interviews were used for analysis rather than software such as NVivo. Although NVivo has been used extensively in qualitative research and has been recommended for managing large datasets (Leech & Onwuegbuzie, 2008), it has a number of limitations when compared to paper based transcripts. Analysis using paper transcripts allowed the researcher to code without use of a computer and increased the portability of project materials. The use of printed transcripts was also preferred due to the visual presentation of the format; reading paper transcripts allowed for long sessions of coding, these would not have been possible using a screen. Line and page numbers were added to the transcripts allowing for easy reference points to be noted down and easy referencing of quotes. Margins of the pages were also increased to 10 cm either side of the text. This set up is essential for IPA as notes need to be made either side of the text in the process of analysis.

Once transcripts were prepared for analysis, each transcript was worked on individually, in line with the idographic nature of IPA. Each transcript was read multiple times along with listening to the transcripts. Once the researcher was familiar with the transcript, initial notes were made in the left hand margin about the content, language questions that arose from the data. In some cases this was completed in “one go”, but in others notes were made separately about content and language. Once this initial note phase had been completed, the transcript was read again several times and emergent themes were listed in the right hand margin, these were based on both the transcript and the initial comments. The emergent themes were listed chronologically, and given working titles. The working titles of the themes were based on the actual text itself. These were incorporated into a table that combined an extract of the text and the researcher’s comments. Clusters of these working themes were then combined to form main themes.

This process was completed for each transcript. It was important to treat each transcript independently of the last and to analyse each transcript in as much detail. This was difficult in places as it became natural to see themes emerge that had been apparent in other transcripts, and some themes seem completely new. Once each transcript had themes, the tables for each transcript were examined together (at this point the transcripts were discarded as the important information from this process was contained within the table). The researcher went through a process of identifying themes that occurred across cases. This table also allowed the researcher to identify if participants were under-represented in the analysis or if there was a heavy bias towards one aspect of the ERP. This practice is in line with the paper on quality published by Smith (2011).

Smith et al., (2009) highlight that when working with a large group of participants, in this case 14, it becomes more important to look at the reoccurrences across cases. In light of this, to clearly represent the majority of participants, it was initially decided that the themes included in the final presentation of the analysis would be made up of subthemes that appeared in over half of the transcripts. To establish this, a table was drawn up identifying the participants and the themes that had occurred. Themes that had emerged throughout the talk of seven or more of the participants were included in the final analysis. Although this was an effective way of managing a large data set, it was later decided that to preserve the idiographic nature of the IPA analysis, some of the less prominent and more individual aspects of patients’ experiences of the ERP would also be included. This decision was influenced by the case-by-case approach to the analysis of data adopted by the IPA methodology. In his 2004 paper, Smith acknowledges that there are two ways of presenting IPA data; a) the presentation of themes that occur across a number of cases and b) the presentation of the individual’s account through the words that they use. The aim of this approach is that “one should be able to learn something about both the important generic themes in the analysis, but also about the life world of the particular participants who have told their stories” (Smith, 2004, p.42). The incorporation of the less prominent themes allowed for a greater insight into the life-world of the participants in the study, as many of the themes focused around contextual information about their participation in the programme.

# Quality & Validity

Assessing the quality of qualitative research requires different criteria than those for assessing the validity and reliability of quantitative work (Barker, Pistrang & Elliott, 2002). There are a number of available guidelines for doing this (Henwood & Pidgeon, 1992; Elliott, Fischer & Rennie, 1999; Yardley, 2000). The guidelines supplied by Yardley (2000) are recommended by Smith et al. (2009) and have a focus on producing quality qualitative research in health psychology. In their book, Smith et al. go on to describe how the guidelines can be applied to an IPA study. As a result of this, the quality and validity of this study will be based on Yardley’s four principles: sensitivity to context, commitment and rigour; transparency and coherence; and impact and importance.

## Sensitivity to context

Yardley (2000) identifies that the context of theory in regards to both the methodology and the area of interest are important. She states that it is “desirable to have a fairly extensive grounding in the philosophy of the approach adopted and the intellectual history of the categories and distinctions that have been applied to the topic” (p. 220).The philosophical basis behind IPA has been discussed earlier within this chapter. These were considered before analysis began. Yardley also notes that the power relationship between researcher and participant is important, and this had been addressed in the methods section in regards to the use of semi-structured interviews.

## Commitment and Rigour

Yardley describes commitment as involving in-depth engagement with the topic and through developing competence and skill in the method used. Smith et al. (2009) suggest that this may be demonstrated through attentiveness to participants during data collection and taking care over the analysis. By rigour, Yardley refers to thorough data collection and the depth and breadth of analysis. In regards to this, the researcher attended training at IPA workshops and read extensively around the use of qualitative methods including IPA. These steps ensured that the researcher had familiarity with carrying out IPA research. In addition, the researcher provided a selection of transcripts to the supervision team for audit in accordance with guidelines highlighted by Elliot, Fischer & Reenie (1999).

## Transparency and Coherence

Transparency and coherence compliments commitment and rigour. Transparency can be achieved by “detailing every aspect of the data collection process” (Yardley, 2000, p. 222). In light of this, detailed records were kept throughout the analysis stage in the form of a diary. Whilst the diary had no set requirements, it acted as a companion for the analysis and allowed the researcher to move forwards and backwards through iterations of the analysis. This ensured that developing analytical ideas and important areas were followed up. The diary also acted as a reflexive journal, allowing the researcher to see how external factors (i.e. social) may have impacted on the analysis. In regards to coherence, the fit of the data to the purpose is important. Quotes and analysis should reflect the true meaning of the participants, and should fit the research question well. In regards to this project, the researcher constantly referred back to the research question (what are the experiences of people taking part in the ERP?). This inevitably shaped the analysis and the choice of quotations used in the write up.

## Impact and Importance

This factor is concerned with the final analysis, and how it is used, viewed and evaluated. This will be assessed during the discussion chapter (Chapter 5) for this study and in the overall discussion chapter (Chapter 11) of this thesis where implications for care will be highlighted and recommendations will be made.

Chapter 4: Analysis

This chapter details the findings of the IPA methodology that was described in the previous chapter. Table 1 below shows a summary of the main themes and subthemes that emerged from the analysis of the interviews (the full table can be seen in Appendix 10). Throughout the course of this chapter, each of these themes will be discussed in turn, drawing on relevant extracts from the transcribed interviews.

Table 1 - Summary of the main themes and subthemes arising from the interview transcripts.

|  |  |
| --- | --- |
| Main Theme | Subtheme |
| 1. Taking part in the programme | 1a. Receiving information and building knowledge |
| 1b. Getting mobile – keeping to the programme |
| 1c. Intuition vs Instruction |
| 2. Home | 2a. Going home |
| 2b. Being at home |
| 2c. “They are only on the other end of the phone” |
| 3. Managing Expectations | 3a. Expectations built on past experiences |
| 3b. Managing others expectations |
| 3c. Managing their own expectations |
| 4. Individual experiences outside  of the programme | 4a. Time surrounding diagnosis and treatment |
| 4b. Thoughts on cancer |
| 4c. Patient as an individual |

# Theme 1: Taking part in the programme

The main theme of “taking part in the programme” focuses on the integral parts of the ERP identified within these patients’ experience. The theme includes information about the aspect of the programme that they found most important (receiving information and building knowledge), the challenges associated with getting mobile and keeping to the programme, and also covers their constant battle between intuition and instruction.

## 1a. Receiving Information and building knowledge

Receiving information and building knowledge forms a large and important part of these patients’ experience of participating in the ERP. For many patients, this process starts at the point of diagnosis and in this sample the patients were most often diagnosed with cancer prior to their hysterectomy. Some patients did not have a separate pre-operative appointment due to their cancer diagnosis and the need for a speedy course of action (sometimes as little as 24 hours between diagnosis and operation), so their opportunity to receive information about the programme was limited to their diagnosis appointment. As a result of this, the process of receiving information and gaining knowledge about the programme was often combined with the patients learning and gaining knowledge about cancer and their wider course of treatment.

Being on the enhanced recovery pathway is not normally attributed to patient choice - if patients meet the requirements to take part in the programme, they are told that (rather than asked if) they will be on the enhanced recovery pathway. Patients are often given information about the programme after they have been told by the health care professionals that they are to take part.

So you know everything went so smoothly and when he said you are going to go into that fast track programme, I thought well that’s absolutely splendid…. I was absolutely thrilled to bits, you know, and I must admit I had all the details, the information that was given to me was terrific, I felt perfectly confident and happy about everything…. and I took it home anyhow and studied it, because I thought if I am fast tracking I want to be part of this (Betty 42-88).

Betty focuses on her experience of being told she was going into the ERP, and her delight in this course of action. This draws on the traditional biomedical style of hospital care in as much as the patient has little choice, and important decisions about care are made by the health care professionals, this is not unusual, even in a more patient centred environment (Brown, McWilliam & Ward-Griffin, 2007). This is in opposition to the intended role of enhanced recovery which aims to include and empower patients to make decisions and take responsibility for their own care. This empowerment of patients forms one of the four founding principles of enhanced recovery in the NHS where it is believed that patients should “have an active role and take responsibility for enhancing their recovery” (NHS Improvement, 2012, p.6). In Betty’s account of her experience, the decision to be on the enhanced recovery pathway appears favourable and the information is well received. Betty describes that the information given about the programme influenced her happiness and confidence about taking part and, in turn, about her recovery from the operation as a whole. The receipt of information is key in the patients preparation for surgery, and the setting of expectations for both the patient and significant others. Betty uses the information to gain knowledge about what is required of her and what will happen. This is clearly important for Betty as she implies that this is required to enable her to become “part of this”, suggesting that she desires to take a more active role in her own recovery.

Rachel discusses the experience of receiving information about the programme. The extract below highlights that the information is not just beneficial for the patients, but also for the relatives or significant others associated with the patients. This is an important factor considering the role that significant others play in the programme, which will be discussed later on the in the ‘Home’ theme.

The one with the exercises on it, all of them I followed. In fact there was so much information I don’t think anyone could ever complain that they didn’t get enough information. I just found that my husband read it, I read it. I just think, I think it’s good (Rachel 345-349).

Rachel also highlights the amount of information that is available. It is important to patients that they have lots of information available, and that the information that they are given at their diagnosis appointment or their pre-operative assessment is accessible after they return home. In some instances, patients are given lots of information about the operation and the programme on the day of their cancer diagnosis, which in itself is a very stressful event as it can be associated with debilitating and frightening treatment, pain, loss of function and death (Parker, Baile, de Moor, Lenzi, Kudelka & Cohen, 2001). It is not surprising that in some cases patients do not recall any information that is given to them after this point. This highlights the value of written information and a central point of contact in the CNS as being vital for their preparation for the operation. Providing written information at the point of diagnosis as a supplement to oral information is widely reported in the literature as good practice as written information is less easily forgotten and can be accessed again at a later date (Schofield, Butow, Thompson, Tattersall, Beeney & Dunn, 2003; McPherson, Higginson & Hearn, 2001).

The information that is provided at the pre-operative stage, which specifically focuses on the ERP, provides patients with a wealth of knowledge. Patients take comfort in the idea that they know what is going to happen when they go into hospital. Patients also build up knowledge of what they are required to do and educated about why they are being asked to complete various stages of the programme, which in turn may influence their adherence to the overall programme (van Dulmen, Sluijs, van Dijk, de Ridder, Heerding & Bensing, 2007).

I think knowing that I was going to theatre sort of well stocked up food wise. You know with the protein and everything. You’d had a good basis to start before you go into theatre, and the fact that I knew what I was going to have to do when I came round. I knew I was going to have to get up, and I knew that I had to get up and walk. The preparation is good (Lynn 561-567).

Lynn’s account of her experience of enhanced recovery highlights the importance of the information she received, and how this influenced her knowledge of the programme. Lynn implies that the understanding she had about the need to comply with the carbohydrate drink regime, and the effect this would have on her post-operative recovery, had a direct influence on her adherence to the programme. This knowledge impacts on both her confidence in going to theatre and her confidence in the programme itself. In addition to this, it can also be seen how the flow of information as well as the building of knowledge influences the setting of patient expectation with regards to getting mobile after the operation (this is discussed further in the ‘Managing Expectations’ theme). Lynn clearly identifies that the giving of information and the associated knowledge is an important part of the preparation for the operation and also for the recovery from the operation itself.

I think the fact I had the information before I actually went into the hospital, you know you’ve got all the sheets and the paperwork, so it gives you a good idea of what’s going to happen, and what’s expected each day, I suppose it can’t explain to you the feelings of the actual surgery itself, but it does help a lot to know what you can do, do rather than just overstretching yourself or not doing enough is probably more, that you can walk a lot, and to get out of, and to get out and walk a lot, which is probably something that I wouldn’t have thought of (Jane 678-691).

Although information and knowledge are not only given with regards to the practical aspects of the operation and recovery, Jane notes that the literature does not explain feelings of the surgery itself. This omission is justified or excused because there is a lot of information about boundaries of what you can and cannot do after the operation. Jane also highlights the way that the information can affect the expectations of the patient with regards to getting active after the operation. Getting active or early mobilisation after the operation are the biggest changes in expectation for patients with regards to the ERP. Other factors included in the programme are seen as additions to what patients may expect as standard care (such as the addition of the carbohydrate drinks), whereas the early mobilisation is a change to traditional practice and may well go against patients’ previous beliefs or expectations of post-operative care and activity. This process of receiving information prepares patients to have to go against their intuition and follow instructions. This is covered further in the ‘Intuition vs instruction’ theme.

This first set of extracts gives a clear indication of the type of talk that is used throughout the women’s accounts of their experience; the talk comes from a personal perspective. This is confirmed by the use of ‘I’ and conforms to grammatical structure in terms of talk in the first person. However, the extract from Lynn (Lines 561-567) above gives a clear example of the switch from ‘I’ to ‘you’. Lynn moves from ‘I’ to ‘you’ seamlessly from one pronoun to another. The first ‘you’ from “You know with the protein and everything” suggests that Lynn is talking in direct reference to the listener (me) as they share a common set of information, that is, the understanding of why the drinks are given to patients. The second use of ‘you’ where Lynn says “You’d had a good basis to start before you go into theatre” uses either the second person plural (we – inclusive of the listener) or the indefinite second person (people - collective). It is most likely that Lynn is using the indefinite second person as she was aware that the listener had not been in this particular situation or had ever experienced this first hand. She is most likely referring to ‘you’ as in the collective of ERP patients or cancer patients in general.

## 1b. Getting mobile - Keeping to the programme

The subtheme of “Getting mobile - keeping to the programme” explores the need for staff to initiate the post-operative active phase of ERP, i.e. ‘getting moving’. Lynn clearly identifies the role that the ERP had in this “But I think the ERP worked because it made me move, and I understood how to move” (Lynn 396-399). This links back to the previous subtheme about receiving knowledge and information. Lynn places value on the ERP and its benefits, but also identifies how this benefit was partially achieved.

The first opportunity to get out of bed is seen by patients as the beginning of the ‘active part’ of the programme. This process is consistently initiated by the health care professionals. Patients infer that they need to have permission from staff to become active (that this is the right time, and this is what is expected of them). This permission or initiation often comes from the physiotherapists as they are responsible for getting patients safely out of bed and ensuring that they start the programme at an appropriate time (normally on day 1 of recovery). As patients view the success of the programme as being linked to mobility (which they see as being the key to going home) they are often happy to mobilise even though the experience is painful.

It was “get up, come on, let’s have you”, and she helped me. She really made me move, which when you are feeling very sore and very, it’s very painful, you know she was very good (Lynn 88-90).

Lynn demonstrates that the physiotherapist facilitated her getting out of bed, even though it was an uncomfortable experience. Looking back now, Lynn acknowledges that the physiotherapist was ‘very good’ for getting her out of bed, even when she was sore and the experience was painful. Lynn can now see the benefit of something she found uncomfortable at the time. In comparison to traditional care pathways, patients would still be expected to get out of bed at some point on recovery day 1, however it may well just be to sit in a chair next to the bed. In contrast to this, enhanced recovery patients are expected to start a programme of measured walking on recovery day 1.

Patients who have concerns about getting out of bed and mobilising early report a number of barriers to this type of activity. Many patients recount their experience of the early morning routine on day 1, and note that they felt uncomfortable getting out of bed whilst they still have a catheter. Patients in some cases used this as a justification for not getting out of bed; however the health care professionals do not see mobilisation with a catheter as a problem and continue to mobilise patients.

The health care professionals continually initiate the post-operative part of enhanced recovery and provide reassurance for the rest of the programme. This is important for patients as the information that they have had prior to this and the expectations they have set for themselves now need to be ‘put into action’, as the imagined experience has now become real.

Well I think they took the, the drip thing out and then the physios were round quite early, and they got me out of bed, and then I’d still got the catheter in - that was the thing that bothered me the most before I went in, was having a catheter... so the physios came round and sort of helped me out of bed, and made sure I did it the right way. But I’d been practicing at home, but it’s not quite the same is it when you get there. And she took me for a walk along the corridor, and went through things again, what I should be doing (Jane 418-430).

Jane describes that she initially had concerns about getting out of bed. The patient information clearly states how patients should get off the bed, and those patients who see a physiotherapist at the pre-operative assessment will have had a demonstration from the physiotherapist (providing them with the opportunity for vicarious experience through watching the physiotherapists complete the task/movement). Jane states that she has been practicing at home, providing a number of previous accomplishments. This combined with the vicarious experience (watching the physiotherapist) may have improved her self-efficacy in being able to complete the task and therefore adhere to the programme (Lev, 1997; O’Leary, 1984; Bandura, 1982). Jane felt the need to practice getting out of bed at home as a form of preparation for her experience in hospital. To encourage patients to initiate that type of practice at home, patients must identify that getting out of bed will be an important or painful part of the programme and that practice at home may prevent unnecessary pain.

The physiotherapists also use the opportunity when getting patients out of bed on the first day to revisit the main aspects of the ERP. This allows patients to ask any questions about the programme that have arisen since they have been in hospital, which may supplement the information that has already been received pre-operatively. In addition, the physiotherapists also reinforce the expectation that the staff have of the patients with regards to compliance with the programme, early mobility and expected discharge.

## 1c. Intuition vs Instruction

A large part of the patient experience focuses on the on-going battle between patients’ own intuition and the instruction that comes from information leaflets and health care professionals. Over a long period of time we (as a collective) have been told to rest our bodies if things hurt, and after an operation rest is almost seen as synonymous with recovery (i.e. rest and recuperation). Programmes such as enhanced recovery are encouraging patients to become mobile as early as possible after their operations, and provide a number of pre-operative and intra-operative interventions to allow this to take place (such as the carbohydrate loading and the altered anaesthetic regimen).

The receiving information and knowledge subtheme has already highlighted that patients receive lots of information prior to their operation, and a large proportion of this includes instructions that are specific for taking part in the programme. Although patients acknowledge that this is good preparation (the first extract from Lynn above), and that the experience is somewhat different from what they had expected, it does not prepare them for the disparity they experience between what they want to do and what they feel they should do (or are encouraged to do by the health care professionals).

I think there were about three things and I was doing them all the time, to keep everything going. I knew I had got to get off the bed as much as I could, but you really don’t want to. You don’t want to. (Sharon 347-349)

Although Sharon knew she had to get up and off the bed, she did not want to. Some of this was due to discomfort as a result of the operation; some of it may be due to nausea as a result of the pain control. Regardless of the cause, Sharon did not want to mobilise, but felt that she had to get off the bed as much as she could as that is what she had been told - she must comply with the instructions and the programme. There are a number of reasons for this – patients may want to be seen as compliant with the instructions that have been given and the programme, and patients may also wish to appear as the ‘good patient’ (the good patient has historically been defined as passive compliant and inanimate whereas bad patients are thought of as angry, demanding, suspicious and critical) (Raps, Peterson, Jonas & Seligman, 1982).

The transition between ‘I’ and ‘you’ here is a good example of the pronoun switching that has already been discussed. Sharon moves easily between the use of ‘I’ and ‘you’. Sharon uses ‘you’ in the indefinite second person to establish that she is part of a collective and that she is communicating the views of this collective. Sharon implies though her use of ‘you’ that ‘anyone wouldn’t want to get off the bed – not just me’, and that she believes that she is not alone in not wanting to get off the bed. Sharon uses the pronoun shift to justify her desire to not adhere to the programme.

Many patients acknowledge that they have to have a certain amount of trust in the health care professionals and that this is what encourages them to go against their intuition and comply with the requirements of the programme.

I think there is a fright in moving because, well I had a big scar that goes right across my abdomen… but it was this horrible feeling that you are going to burst it or something, because it’s always there I suppose in your mind that are the clips going to hold? But you know, you have to have confidence in all of these things. They have done it thousands of times before, so it’s very rare that you would have a big problem as long as you do, you move how they tell you (Lynn 205-216).

Lynn highlights that there was concern surrounding the wound itself. There is little preparation for what the wound will potentially look like in the patient information. A number of women reported a similar experience describing their concern that the clips in the wound would hold. The resolution for this is to trust in the staff - patients believe that if they follow the directions that are given to them it will prevent there being a problem. The literature highlights that patients are concerned whether doctors have the expertise that they can trust, and that trust is essential alongside quality care and respect. It has been suggested that communication and information sharing are central to the build-up of trust and confidence in medical staff alongside being made to feel ‘at home’ and being treated as an individual (Wright, Holcombe and Salmon, 2004; Walker, Brooksby, McInerny & Taylor, 1998). This indicates that the sharing of information about what women should expect (with regards to their wound) would have a positive impact on the trust that patients have in their health care professionals, and in turn increase the trust in the action that they instruct patients to undertake.

The battle between intuition and instruction is mediated by the instruction that comes from the health care professionals. Patients believe that the staff would not ask them to do something that they were not able to complete.

Yeah, and so yeah, I didn’t really know what to expect as I say I never really had a big operation before, but I assumed that if they tell you that you can get out of bed that you can (Jane 280-281).

Jane highlights the important role that the staff take when dealing with a patient who has never undergone an operation of this type before. These patients have no previous experience to use as a frame of reference and are reliant on the information that comes from others (this is discussed further in the managing expectations theme).

I think the exercise programme, getting up and being made to mobilise yourself quickly, being able to be more independent… The speed at which I really felt more confident - I think confidence was a big thing, making me realise that I could do, that I could walk up and down the corridor as the physiotherapist said I could. They weren’t trying to push me into something I couldn’t do, and every step of the way I was told that if I can’t do it, then I mustn’t do it. But once I’d done one step I wanted to do twenty! And I found that I could really do it, it was wonderful (Sheila 174-190).

Sheila talks about how she was made to mobilise quickly and how this was linked to improved confidence. The staff encouraging her to do the exercise and telling her that she could complete the task improved her confidence and potentially her self-efficacy with regards to being able to mobilise and therefore go home. Sheila also discusses the fine line between encouragement and bullying; where the health care professionals are encouraging patients to complete a task, in comparison to something which may be almost construed as bullying, where patients are told to do something that they are uncomfortable doing. Sheila also acknowledges that this approach acted as a motivation for her to complete the task and that she felt that she could ‘really do it’.

## Conclusion

To conclude this theme, it is evident that the most important aspects of enhanced recovery are those of receiving information and building knowledge. In addition, there are a number of issues that surround becoming mobile or active after the operation itself. The transfer of knowledge and information to patients before, during and after the operation, as part of the ERP, leads to patients being better prepared for surgery and the recovery phase post operatively. This process is integral to the patient experience and is linked to setting expectations. The early mobilisation is an amendment to many existing pathways, and is paramount for patients with regards to early discharge. Enhanced patient information and early mobilisation provide patients with the tools that they require to effectively manage their own (and others) expectations, as well as return home at an earlier time than those on traditional pathways which, for patients, is a desirable outcome. Further to this, the on-going battle between intuition and instruction with regards to getting mobile is one of the most difficult areas of adjustment for patients. Many of these factors relate to coping, and will be dicussed further in the following chapter.

# Theme 2: Home

The main theme of ‘Home’ focuses on the role of home in the patient experience of ERPs. The role of home as a motivator for early discharge is explored together with the essence of home and its role in recovery. Patients’ experiences of returning to a suitable home and the need for other people are discussed alongside the need for the follow up phone call and its role in health surveillance.

## 2a. Going home

The subtheme of ‘Going Home’ includes a number of factors associated with the ‘essence of home’. The theme explores the role that home has on recovery, and in turn the lengths patients will go to in order to be able to go home. The situation where a patient may feel that they want to stay longer is also covered, as this is often seen as ‘opposition’ to the role of enhanced recovery. The ability to go home ‘earlier’ in comparison to traditional pathways is often emphasised to patients when clinicians are discussing the programme and the advantages for the patient.

The analysis highlights that patients clearly associate home with recovery. The previous theme (taking part in the programme) identifies that entering the active phase of the programme and becoming mobile is associated with being able to go home. Many patients feel that until they have reached this point (i.e. being mobile), they would not be able or allowed to return home.

The nurses saw me walking down the corridor, on my own, perfectly alright on the Wednesday morning, and they said oh you’ll be going home today (Rachel 235-238).

Rachel implies that her demonstration of mobility to the nursing staff is a pre requisite for being able to go home. Fulfilling the criteria of being active and completing the prescribed walking routine ‘perfectly alright’ is indicative of success in the programme, and patients perceive that the correct course of action is for them to be discharged. This provides a clear if/then statement for the patients. If the patients complete the programme and the recommended activity, then they should be able to go home. However, this is not always the case. There are a number of clinical indicators that patients must achieve to be able to return home such as being able to pass urine, being able to eat and drink without being sick and being able to pass wind/have a bowel movement (Chase, Watanabe & Monk, 2010).

When I told the nurse she said oh no and then went to the desk and came back, and I felt a bit deflated because I want to go home, I need to go home. I shall be better if I go home (Lynn 452-454).

Lynn describes her desire to go home; not only does she want to go home (desire), she needs to go home (requirement) and she would feel better if she went home (justification). This arrangement of the sentence forms a three part list, and Lynn uses it to reiterate or emphasise her desire to go home.

The extract from Lynn also highlights the ‘reward’ aspect of the programme: being able to go home sooner – and also what happens when this is not possible, or the same view is not shared by the health care professionals. Lynn describes how she felt deflated when the nurse told her that she would not be able to go home. Some patients will go to great lengths to ensure that they are allowed to go home.

On Friday he said I could go home if I wanted to. I didn’t tell them that I was being sick, I was a bit bad I suppose on that, but all I wanted to do was get home, have my own meals, you know, and just get on with life (Lynn 112-114).

Lynn describes how she was a ‘bit bad’ for not telling the health care professionals that she was being sick. Although this symptom may not have been the most problematic to have kept from the health care professionals, it does highlight that patients will be dishonest about any side effects or symptoms they are having in a bid to be able to go home. This may in turn have a detrimental effect on their long term recovery and general health. Patients who are discharged before they are ready have a higher incidence of readmission. Readmission is one of the major concerns with ERPs and forms part of the measures collected for hospital statistics (Varadhan et al., 2010; King et al., 2006a; Fearon et al., 2005). Lynn also provides further justification for her desire to go home, again in the form of a three part list. Home is associated with familiar things like her own food. But more importantly, Lynn indicates that going home is the start of her getting on with life and moving forward. In this sense, home appears to be a catalyst for patients’ long term recovery.

In contrast, a number of patients may initially feel that they would like to stay in hospital past the point when clinicians believe they are fit to be discharged. Some patients are apprehensive about going and being at home. They recognise that they no longer need medical care, so can go home, but do not want to make the transition from the hospital environment to the home environment and a lack of medical care. However, many patients do still make the transition from hospital to home.

Well I did, yes, at that point I have to say yes, you know I was glad, but then when you get home, that first when you get home, I suddenly thought, oh, I don’t know now, I was quite a bit, that was the scariest part I think, when I got home, but just, but just because there was, I was used to having so many people around I suppose and having that back up and support there, and then suddenly you were just at home (Jane 501-507).

Jane infers that although she was pleased when the clinicians said she could go home, the scariest part of the experience was going to be at home due to the lack of support from the medical staff. Having easily accessible health care professionals available in hospital is comforting for the patients even though they may not require care. The transition to home is a stark contrast to the hospital environment. Jane also hints that the transition to home is very quick, ‘suddenly you were just at home’ suggesting that there is little time for the patients to adjust to the change in environment before discharge takes place. Some patients acknowledge that when they actually return home it is not as bad an experience as they first expected.

Erm, well when I got home I realised that I was absolutely fine, but I just had a fleeting panic thinking oh my, I don’t want to go now. But once I was home it was different (Lily 384-386).

Lily explains that although she initially panicked when she was told she could go home, returning home was ‘different’. Further to this, the extract below from Betty describes how she believes she recovered the minute she got home. This implies that returning home had an instantaneous impact on her health and wellbeing, and that for her, home is synonymous with recovery.

The all round business of being able to get and move more easily at home, I mean there is no doubt that I began to recover the minute I got home (Betty 368-370).

This was reflected by several women in the sample. Patients identify a number of factors which are associated with home which lead to their recovery. These factors include feeling more relaxed, having their own food and being in their own surroundings. Many of these are related to the individual and their sense of ‘self’ and can be further associated with patient choice and control. Patients may wish to return home in an attempt to be able to regain control, especially in the bio-medical model where many people find that decision making about their care and treatment regimen has been restricted or removed.

Yes, yes definitely, because I knew that I would be going home quicker and you feel better at home, you feel more relaxed at home, and I just felt better going home, sooner be at home. (Liz 310-313).

Liz describes how being placed on the enhanced recovery pathway was beneficial to her. The speed of discharge home was important as a motivator for taking part in the programme. Liz also provides clear justification as to why home was so important for her through the use of the three part list. Home is more relaxed resulting in her feeling better; this was her motivation for going home as soon as possible. The three part list provides Liz with a suitable rationale and justification as to why she wanted to and should go home sooner.

Alternatively, patients feel that they are not ready to go home and request to stay in hospital longer regardless of whether they are mobile or not. This is generally not because they are fearful of going home, but because they feel that they still require medical attention or would not be comfortable going home without any medical supervision. For patients, the request to stay longer in hospital provides an interesting relationship between patients’ intuition and the instructions that they have received from the health care professionals. It draws on some of the aspects from the earlier discussion on this topic.

No, I was panicking at that point because I felt so rough when I woke up on the Friday morning and I said to him [consultant], well I don’t know if I want to because I didn’t feel well this morning, and he said well I’m happy, I know you are going to be cared for at home, quite well, I’ve met your husband, I know you will be cared for. If you’re up to it, you can go home... and I said can I stay because I really don’t feel too good. (Sharon 455- 460).

Sharon describes that she told her clinician that she was not feeling well, and was unsure as to whether she wanted to go home, but describes how the clinician was keen for her to return home. The clinician focused on there being adequate ‘care’ at home rather than enquiring as to whether the patient felt well enough to return home. Sharon felt that she had to reiterate her request to stay in hospital, and it was only after this she was successful with her request of being able to stay. Although from the account we cannot see the actual exchange between the patient and the clinician, we can infer from the patient’s account of the experience that she felt pressurised into going home, and if it was not for her persistence in saying that she wanted to stay, she would have been discharged. This would be problematic with regards to other patients in the same situation who were not ready to return home and were less insistent than Sharon, as they may well end up being pressurised into being discharged.

## 2b. Being at home

The ‘Being at Home’ sub theme combines two areas; the first being the desire (from the patients) or need (requirement of the hospital) to have someone at home and the role that these individuals play in patients’ experiences of ERPs, and the second being patients concerns that their home is suitable to return home too. ‘Being at Home’ concentrates on the transition from hospital care to home and is concerned about the series of events that follow the decision to discharge the patient.

Going home after a full hysterectomy on day two of recovery means that patients are returning home a full 2 days sooner than they would have done on the traditional care pathway (Moller et al., 2001). Returning to the home environment and unique home orientations is a challenge for some patients as they are returning to a place of care that is not always suitable for their needs. This is a concern for both the patients and the clinicians in terms of discharge, and is something that must be taken into account when discharge planning.

He asked again about the situation at home - was it still the same, had anything changed in the week or anything, and he said no, and he asked about what sort of property we lived in and I said it was a house, and he said what about bathroom facilities? And I said well I’ve got downstairs loo, and he said well if I let you home, he said there’s no reason why you can’t go home hopefully on Saturday, but I’ll confirm it tomorrow, and we’ll see how you go on at home overnight (Sheila 871-880).

The extract from Sheila describes how her discharge was still very dependent on the set-up of her house and how suitable her home was to return to. It also highlights that ‘He’ (the consultant) was very concerned about the set-up of both the physical and emotional home environment. Although patients on traditional pathways will have similar concerns about returning home, they would have had 2 additional days in a purpose built care environment to recover. Sheila notes that her discharge and ability to stay at home was dependant on how she managed at home overnight. This implies that the clinician is keeping avenues open for the patient to return to hospital if the transition is not successful. This may give some comfort to the patients as it reduces the permanency of the decision.

Practical factors such as the availability of bathroom facilities have an impact on discharge planning, as patients are advised to limit the number of times they need to climb the stairs. This is a limitation for some who live in particular home environments.

I had our mum in law, my mum in law live with me for a while so we had got a stair lift, so that was very handy because I would have never took the stairs because we are in an Edwardian house with very steeps stairways, so I wouldn’t have got up and down (Lily 311-316).

Lily describes how having a stair lift in her home was beneficial to her experience of recovery at home. The availability of this specialist equipment meant that she was able to go home, and could recover adequately. The steep stairs would have been a limitation to her mobility, which has already been discussed as being integral to recovery. It is these physical challenges that patients must be able to overcome before they are discharged as well as being ‘mobile’. Lily describes only practical barriers to her discharge and being able to return home, however emotional factors such as adequate care from significant others appeared in other accounts.

The availability of significant others or carers to be at home with the patient, and their confidence in doing this, has an impact on discharge and the feelings patients have about this stage of recovery.

I don’t think they’d have let me out if I hadn’t had anyone here, but I think I could have managed it you know. Yes, definitely. I was very very pleased to get home on the Thursday night (Mary 442-445).

Mary clearly articulates her belief that she would not have been allowed to go home if there was not a suitable person staying with her after discharge. However, Mary notes that she felt she would have managed at home suggesting that she was confident in her own physical abilities. The requirement to have someone at home and patient confidence to return home are important factors for patients who live alone and do not have any family, as they may not have anyone available to fulfil the caring role. In this sample, many women were returning home to their partner, and those who were not had a close family member available to come and stay with them.

And the consultant explained again that if everything was OK he’d check again on the circumstances at home, and that James would be at home for a while, he said that if he was happy to have me home, then there would be no reason why I couldn’t go home (Sheila 111-116).

The extract from Sheila identifies another important factor with regards to going home – that significant others need to be happy to have the patient at home. Significant others take on the role and responsibility of carers when patients return home. For some significant others this is a natural course of events, and all accounts in this sample suggest that significant others were happy to have the patients at home. It is unclear what would happen if the significant other was not happy to have the patient at home, and there is no literature to date that explores the experiences of care givers involved in ERPs. Even in this sample some patients had to ‘draft in’ other family members to help out with care as their significant others were not able to fulfil the role.

In the meantime after I was home a week my husband had a heart attack and he was taken into hospital and I was in the house on my own but I had very good neighbours they coming around you know (Kathleen 367-372).

Kathleen describes how she had to rely on neighbours for support after her husband was taken into hospital following a heart attack. It is impossible to predict what will happen to the home environment or the people that are in it when patients return home, but it is important that patients have an appropriate support structure should the main source of support be removed. Patients rely on their partners (typically a husband) to both take responsibility for the home, but also take responsibility for their care to ensure that they do not do too much.

Yeah, I suppose it depends on peoples circumstances. I mean I am lucky that I have got a husband that is very good and watches what I do, and is good. But I don’t think I’d have liked to have been on my own, you know I think that would have probably been a bit too much (Jane 659-664).

Jane acknowledges that she feels lucky to have the personal situation that she does, and that she has a husband at home to look after her. It is not only care that significant others provide. They are also required to supervise the amount of activity that patients do when they return home. Patients in this sample often reported feeling well and believing that they can do more than they are instructed. Again, this draws on the previous subtheme regarding intuition vs instruction. Jane specifically refers to her husband as being ‘good for watching what she does’ and this is coupled with Jane’s desire to not be on her own. The way that the utterance is structured implies that her husband fulfils the role of police before the role of companion. Within this sample it was not unusual for significant others to be required to ‘police’ activity.

I know they say no lifting for 6 weeks afterwards, you could almost, I almost felt as if I could get, if I didn’t have my husband around saying don’t do that, I’ll lift that and all the rest of it, I did feel extremely well (Rachel 276-287).

Rachel acknowledges here that she felt so well that she believed she could continue with normal activity. It was her husband that prevented her from doing too much. One of the biggest areas of concern for patients is lifting. Patients undergoing hysterectomy at the Royal Derby Hospital are advised to avoid lifting for 6 weeks to allow the body to heal effectively without unnecessary stress. Many of the women involved in these interviews described that lifting was something that they did too soon because they felt so well.

I made a mistake and picked my little tiny granddaughter up and I thought oops shouldn’t have done that. You’re not supposed to anyway, but I felt ok and just picked her up a bit and oh, I think I’ve pulled something (Barbara, 1064-1068).

This raises an interesting point about the outcome of enhanced recovery as a whole. Patients are feeling better sooner, and are allowed to go home earlier. Patients feel better and return to feeling ‘normal’ earlier, but the body’s requirements for rest and recuperation are the same as those on a traditional pathway. When patients were feeling nauseous or were not mobile, there was a protective effect preventing patients from doing too much, thus letting the body heal effectively. The challenge comes now in getting patients to adhere to the rest and recuperation aspects of recovery which impact on their long term health.

## 2c. “They are only on the other end of the phone”

The follow up phone call is an essential part of the ERP. Patients clearly value this aspect of the programme as it helps the transition from hospital care to care at home. The follow up phone call provides a link with health care professionals at the hospital which creates an open dialogue about any problems or questions that the patient may have.

When patients return home from hospital after discharge they become responsible for their own care and in some cases believe that they have a responsibility to look after themselves. The transition from hospital to home is not just one of geography. Patients change role from being an ‘active’ patient in hospital to a ‘recovering’ patient at home. A number of patients reported that once they had been discharged and returned home, they were reluctant to ‘bother’ health care professionals at the hospital.

Yes, yeah, because I think that even though they say that if you’ve got any problems you can ring us, well I know, I don’t know other people but, but me personally you know, I, I know that I tend to leave things a bit too long maybe, and I don’t like to bother people, and I probably wouldn’t have phoned unless I was really really worried, so I suppose it is nice because if I had got any problems then I could have said (Jane 573-580).

Jane describes how she justifies not wanting to bother people, even though the health care professionals had instructed her to call if there had been any problems. Jane sees this as an extension of her general approach to seeking medical assistance – she tends to leave things too long. This is also detailed in Jane’s description of her diagnosis, where it was only at the point of collapse that she sought medical help and subsequently received a diagnosis of ovarian cancer. One of the challenges of the ERP is opening the channel of conversation between patients and health care professionals once they have returned home as a bridge between the two environments. Many patients report feeling isolated once they return home.

I was used to having so many people around I suppose and having that back up and support there, and then suddenly you were just at home (Jane 505-507).

Jane describes the transition between the two environments. The hospital is associated with medical expertise that offers a specialist service with a number of health care professionals which offers a stark contrast to the home environment, even though home is familiar. A number of women describe the transition between the two environments and it appears that the hospital is practical and follows process, whereas the home environment is emotional and lived. One bridge between the two environments is the information that is given to patients which instructs them to contact the ward at any time if they have any problems or questions once they have returned home. Being able to contact the ward after discharge is comforting for some patients. Liz describes that she felt safe and looked after as the hospital staff were easily accessible if she needed them, and that the geographical distance was transcended by the use of telephone communication.

I felt looked after, I felt safe. I remember thinking that they are only on the other end of the phone when I got home, so somebody at some point must have said ring at any time, which obviously I did when there was a problem with the wound, so I felt safe in that way because there was somebody on the end of the phone anyway (Liz 354-359).

Liz describes that she did have the need to call the ward after discharge because she had a problem with her wound. The use of ‘obviously’ suggests that this was a natural course of events for Liz, but the previous extract from Jane highlights that this is not the case for all patients. As part of the ERP patients receive a follow up phone call when they return home, normally one or two days after discharge.

It was nice to know that she was going to ring when I got out of the hospital, because I thought I’ve got the weekend now, and , am I going to be alright, I mean I don’t want to be a nuisance, although the ward had reassured me to ring if there was a problem. But I didn’t want to sort of be a nuisance as such, and I was a bit worried that what would happen just in case they were any problems, but it was nice to know Katy was going to call on Monday (Sheila 1010-1024).

Sheila was clearly worried about how she would get on at home and if she would be ‘alright’ over the weekend. In the earlier extract from Sheila in the ‘Going Home’ subtheme, the consultant has told Sheila that they would see how she got on overnight. The reality here for Sheila is that she has returned home for the whole weekend and to her, the possibility of returning to hospital would be out of the question.

It appears that no amount of reassurance from the ward staff about the availability and readiness of staff to engage in telephone communication would prevent Sheila from feeling like a nuisance. However, Sheila took comfort from the idea that Katy was going to ring on a specific day. This course of events requires some pre planning by the staff, but they must also ensure that they deliver the service that they promise to the patients – the health care professionals must call on the date agreed. If patients are relying on this communication to discuss any problems they are having or are using this as an opportunity to ask questions about their recovery, it is imperative that the health care professionals call as arranged. If patients do not receive their expected phone call, it may have detrimental effects on the communication avenues between health care professionals and patients. Additionally, this may also result in a negative outcome for the patient if problems are overlooked or not discussed with health care professionals when required.

## Conclusion

To conclude the ‘Home’ theme, it can be seen that there are a number of areas that are integral to the experiences of patients on the ERP. Patients feel that they are being rewarded for being able to complete the programme by going home and in some cases the promise of going home leads patients to be dishonest. Further to this, there is a disparity between the emphasis that is put on mobility and the role it plays in the ERP and discharge from hospital. The analysis highlights that further work needs to be done on discharge planning and that the difficulties surrounding patient communication with the ward post discharge need to be addressed through further research. These topics will be explored further alongside recommendations for practice in the following discussion chapter.

# Theme 3: Managing Expectations

The main theme of ‘Managing Expectations’ explores how past experiences influence patients expectations, and how these are managed, as well as managing the expectations of others (including both significant others and staff). The theme also covers what happens when patients exceed or do not meet their own expectations and the possible implications that this may have on the programme.

## 3a. Expectations built on past experiences

This subtheme explores the impact of past events on the patients’ current expectations of surgery and of the ERP and the care associated with it. This combines two different areas which specifically relate to the patient sample – past experiences of gynaecological surgery and past experiences with regards to the care of cancer patients. Both of these areas impact on the setting of patients’ expectation about their current treatment.

A number of women in this sample had undergone gynaecological surgery at an earlier point, and this experience had impacted on their expectations. Unsurprisingly, the patients make direct comparisons from their prior experience of surgery to that of the current surgery. It is this constant referring back to prior experience that influences their beliefs about what may (or did) happen this time. Even looking back retrospectively about their enhanced recovery experience, patients still refer back to their past experience for reference. This suggests that their past experience validates their experience of enhanced recovery, confirming that the programme really is better. The use of nostalgia in talk serves a number of purposes; it may be that an individual is trying to recall a utopian homestead that the current scenario cannot compare with (Gough, 1997). In this case it appears that the nostalgic recollection is providing indirect support for the present, and that the talk demonstrates sympathy for the past. The extract from Liz below confirms that the present is the favourable experience, and that the past is both challenging and influential, but remains redundant in comparison to modern practice.

I had actually had three years previously a cyst on my other ovary, so I had been through a similar kind of thing but before the enhanced recovery was developed... I was only in two nights, which compared to the other one three years earlier, which I suppose was a similar operation because it was a big cut, it was a laparotomy the same, I was in four nights then.... I definitely felt that it was better than the op that I had had three years previously. I was much happier going home earlier (Liz 100-127).

In three years, the length of stay for patients had been reduced by half. For Liz this was a positive improvement and it exceeded her expectations. Liz does however highlight that her comparison may not be valid as it was only a ‘similar kind of thing’. The repetition of ‘similar’ suggests that Liz needs to reassure herself that the two experiences are comparable. Several patients report that the ERP has exceeded the expectations they had built on past experiences.

I was amazed because I’d had an operation previously, a [partial] hysterectomy when I was only thirty something – thirty eight, and I was there for weeks in the hospital and I was worried about home and so on, but this time, I just came home at lunch time and put some clothes in the washing machine (Rosetta 43-48).

Rosetta compares her recent experience to that of a similar operation that took place over 30 years ago. The contrast between ‘weeks’ to ‘days’ in hospital for her is a reflection of both the improvements in hospital care in general but also the impact that enhanced recovery is having on patients. Rosetta was expecting to have an experience similar to before, so the length of stay for her, and the idea that she was feeling better when she left hospital (so much so that she put some clothes in the wash) was beneficial. Rosetta also notes that she was worried about coming home in the first scenario; however the concern is not replicated in the second experience, but is replaced with her completing a routine task on her return home.

A number of patients in this sample had also had prior experiences of cancer. Although many people in today’s society know of someone who has had cancer, the experiences of cancer described by the patients were those of close family, and it is expected that these had a role to play in the setting of patient expectations about their recovery.

[Hospital Name] is bad and my dad had cancer 10 years ago and he had poor treatment there, my Nan was ill and she died in [hospital name], OK she was 93 but she had poor care, and I couldn’t deal with cancer and the worry that I wasn’t being cared for properly. There was no way I would go there (Sharon 555-561).

Sharon describes how her prior experiences of cancer at a different institution influenced her decision to refuse to have care there. Prior experiences of care are clearly very important to those who have cancer as treatment is often intense and lengthy, and it is important to have trust in the institution that is delivering care (Mechanic, 1998). Sharon describes that she could not worry both about cancer and not being cared for properly, implying that good care is integral in cancer treatment.

Alternatively, some patients have had previous experience of lengthy and complicated cancer treatment regimens with members of their family. Edna describes how she felt about her cancer treatment and how the prior experience of her husband was influencing her outlook on her diagnosis and treatment.

So, you know, he, Dr McCann pointed out that I had got that in the back of my mind that I was going to sort of suffer or be in the same kind of process and I think that made a lot of difference. Thinking back, you can’t compare the two (Edna 128-132).

Edna clearly associates having cancer and the subsequent treatment with suffering and that treatment is a long process. Edna transferred these past experiences directly to herself and her very individual situation. Although her husband had a completely different type of cancer, the prior experience had produced a benchmark for expectation. It was the conversation with the GP (Dr McCann) that explored these concerns with Edna. This belief structure about suffering and cancer is also strengthened by negative representations of cancer in the media and society throughout history. Some forms of gynaecological cancer are often portrayed as being lengthy and distressing diseases, and it is not surprising that patients catastrophise with regards to their disease and the treatment, as ovarian cancer has been called the ‘silent killer’ and this term is widely used within the media (Telegraph, 2012).

These personal and relevant experiences impact on a patient’s overall expectations of the service that is delivered. These are challenges that patients are having to face from the time of diagnosis, and are present throughout their journey through cancer. These heavily influence their experience of cancer as a whole, and with that, their experience of the ERP.

## 3b. Managing others expectations

This subtheme explores how patients manage and respond to the expectations of others. When patients exceed the expectations of others it appears that this acts as a positive reinforcement of their actions or behaviour. This theme covers ‘others’ including patients’ significant ‘others’ (family and friends) and ‘others’ as members of staff. Being able to exceed others’ expectations is important to patients and they report this frequently.

Health care professionals often experience new pathways and new initiatives in hospitals for patient care. Many health care professionals are sceptical about the changes that these will have for patients, as many new initiatives do not come to fruition (Mitchell, 2011; Sjetne, Krogstad, Odegard & Engh, 2009). The following extract from Barbara describes how the reaction of the nurses made her feel more determined, and exceeding their expectations had a positive effect on her progress.

It was very very soon and I was standing up straight and even the nurses were saying wow, you know. It made me determined (Barbara 883-885).

Barbara describes how the surprise from the nurses acted as a motivator for her to continue with the behaviour - it made her determined. The staff were able to encourage Barbara to continue with her progress by displaying that she had exceeded their expectations (either of her or of the programme).

The following extract from Sheila describes how other people’s expectations and experiences are always present. People are forthcoming with stories and experiences that aren’t always helpful to the patient. This appears to be consistent across many patient experiences. Patients are constantly told stories by others who may have experienced or heard other accounts of similar operations or forms of treatment. It appears to be socially acceptable for people to share these experiences with prospective patients. It is unclear as to whether these are intended to be positive or negative examples, and the role that they are supposed to play for the patient. It is unknown whether others share these accounts as a way of being able to contribute to the patients’ experience, but these contributions are not always of benefit.

There is always somebody that you speak to that have either had it done or know of people that have had it done, and its oh you’ll be in a fortnight, you won’t be able to put your feet to the floor, you won’t be able to do this, you won’t be able to do the other, so no it, all this which a lot of this I kept to myself for the time being so that when James told most people when they rung up, that’s she’s coming home on Saturday so we won’t bother with visiting, couldn’t believe it because they were all saying well we’ll take you down Saturday, we’ll take you down Sunday and someone else Monday, because she’s bound to be in for a week so, it was tremendous, a lovely feeling that I didn’t have to put on any act, that I had come home in my own right sooner than I thought (Sheila 1053-1070).

Sheila describes how people offer information mostly about physical processes such as, in her case, putting her feet to the floor. These are areas that are directly challenged with the ERP. Sheila notes that she kept the fact that she was on the ERP ‘to herself’. It could be thought that this was to remove or reduce other people’s expectations based on her past experience of people’s reactions. The subsequent communication of discharge to others led to a feeling of disbelief for them, as the new pathway had drastically reduced the amount of time that others were expecting Sheila to be in hospital. The belief that Sheila has exceeded both her own, and others expectations, acts as a positive reinforcement of her behaviour and that returning home sooner was the correct course of action. Sheila describes this as ‘a tremendous lovely feeling’ that she had been able to return home without any ‘act’. This is an interesting concept which implies that patients returning home may feel that they have to put on an act to portray that they were well enough to return home. This can also link back to the ‘Home’ theme where patients keep information from health care professionals to ensure they are able to go home. Sheila also describes that she was able to return home in her own right – suggesting that she had completed all of the tasks that were expected of her and she had earned her right to return home rather than being discharged for another reason.

## 3c. Managing their own expectations

This subtheme explores the way that patients manage their own expectations, whether they exceed or fail to meet them. This is a very ‘self’ orientated subtheme which explores more about what they actually feel about themselves, rather than what is projected onto them by others. Patients refer to ‘I’ and pronoun switching is rarely used by patients in these extracts, indicating that the focus is on the self. There is a greater emphasis on the patient as an individual and that this is very much their individual experience rather than the experience of a collective group of patients.

With regards to patient expectations, most are centred on feelings connected to the body after the operation, and also their expectation about being able to return home earlier than expected. Patients are prepared for surgery at the pre-operative stage, and information is given to them about what to expect after the operation. Patients are also given an expected discharge date. These procedures are put into place to help patients manage their expectations of the service. Even though the setting of patient expectation is facilitated by health care professionals, many patients report that they have exceeded their own expectations.

I don’t feel much worse than I did before the operation, in fact, the fact that I had the operation and I was really pleased with myself, it helps as well. And that was it (Rosetta 232-235).

Rosetta describes how she did not feel ‘much worse’ after the operation. This is something that many women worry about. Those women who are non-symptomatic before they go into surgery expect the operation will make them feel worse than when they went in. For those who were symptomatic (mainly pain), they expect that the pain will not be gone after the operation. This places pressure upon themselves and the operation to exceed their expectations. The addition of the ERP may influence patients and their perceptions of how successful the operation was. Patients’ pain and nausea is controlled and reduced after the operation and their mobility is increased. These factors are perceived as indicators of improved recovery and help patients feel that they have exceeded their expectations.

I didn’t feel sick. I felt great actually. I have to say. I was quite impressed to be honest… it exceeded my expectation because I actually expected to feel a lot sicker and iller after the operation than I did (Rachel 191-198).

The tone of the extract from Rachel demonstrates her surprise at how well she felt after her operation. She was clearly expecting to feel ‘sicker and iller after the operation’, but the absence of these feelings left her feeling impressed. The use of the ‘to be honest’ implies that she is communicating something that other people may find unbelievable, or that she is confessing to something that she would prefer not to admit to. The previous subtheme explored the effect of other people’s expectations on patients’ experiences, and this may be linked to the use of ‘to be honest’ as a way of constructing authenticity of her account. Rachel also clearly states that the experience exceeded her expectations. However this is not always the case. There are times when patients do not meet their own expectations, whether these are pre-existing or have been set in the pre-operative setting.

I don’t think I expected to be as incapable as I was really. I honestly thought, and my husband said, you know, you think you’re going to fly through this operation and be in the garden the next day, and I did, I really did and it was when they walked me down and you’re thinking oh dear, you can’t really do this, you can’t run yet (Sharon 360-367).

Sharon communicates how she felt about not being able to ‘run’ after her operation. Emphasis is placed on the ability to be mobile after the operation, but for Sharon this was not the case. Both her and her husband’s expectations were that her recovery would be faster than she experienced, and the description of being out in the garden the next day is a way for Sharon to demonstrate how unrealistic this expectation was. It appears that Sharon had to reconcile herself to this fact, and it was only when she was actually completing the physical activity that she realised that she ‘really’ couldn’t do it, that she could not fulfil her expectation.

## Conclusion

To conclude the ‘Managing expectations’ theme, it can be seen that there are a number of areas that are pertinent when talking about patients’ expectations of enhanced recovery. Patients are influenced by previous experiences of hospital care, whether that be their own or that of a loved one, regardless of whether this is linked to a gynaecological problem. The analysis also identifies that there are a number of issues surrounding the setting and management of expectation; whether that be expectations of the staff and significant others with regards to the patient, or the personal expectation that the patients have of themselves. These areas will be discussed further in the next chapter of the thesis.

# Theme 4: Individual experiences outside of the programme

The final main theme in this chapter draws together some of the less common, but equally important subthemes that contribute to the idiographic nature of this IPA analysis. The subthemes included focus on some of the individual experiences of women who participated in the ERP. The subthemes cover a wide range of experiences from the point of diagnosis through to patients’ recovery from cancer, resulting in a theme that unites patients’ experiences of cancer and the ERP as a whole, as for some, it is impossible to separate one experience from the other. These themes have been developed from information that falls outside of the patients’ experience of enhanced recovery that was included in patients’ narratives about their experience of the ERP. This suggests that these factors have a role to play in the development and expression of the patients’ accounts of the ERP.

## 4a. Time surrounding diagnosis and treatment

Many patients experience a unique sense of urgency with regards to their diagnosis of cancer, the onset of treatment and, in this instance, their participation in the ERP. There is little time spared between the diagnosis of cancer and the onset of treatment (in this sample it was predominantly surgery that was the first definitive treatment rather than chemotherapy or radiotherapy). This is a challenging time for patients as their world, and everything in it has changed (Hersch, Juraskove, Price & Mullan, 2009; Pearman, 2003). Many patients were not symptomatic when diagnosed, or if they had symptoms, assumed that they were linked to other diseases (such as irritable bowel syndrome) or just to the ageing process in general (Bankhead, Kehoe & Austoker, 2005; Goff, Mandel, Melancon & Muntz, 2004). Many patients, therefore, were shocked at the diagnosis and had little time to adjust to their new state of health before their operation and the onset of the ERP. For example Sharon says:

I went to see, him, in about August time last year, he said he thought it was cancer, and then I had to go in for a biopsy, waited two weeks for that, which was awful because nobody ever says ‘you do know it could be 2 or 3 weeks before you get the result’. Every day I waited for a phone call, and we just, well life just stopped. I don’t know how we lived. I don’t remember August, it was just horrendous (Sharon, 32-39).

For many patients, the time between the suggestion of cancer as a possible diagnosis and the confirmation of this is a long and worrying time (Sagreov & Halding 2004; Clarke-Steffen, 1993).The potential threat of a cancer diagnosis leads patients to worry about what the future holds for them and their families (Hersch, Juraskove, Price & Mullan, 2009). Sharon describes how the waiting time for the diagnosis was “horrendous” for Sharon. She talks of a time of worry and anxiety, where everything in her world ‘just stops’ until the diagnosis is received. Saegrov and Halding (2004) suggest that the period of waiting from the first suspicion of cancer until diagnosis and confirmation of the disease is a period of great stress, and that the period between this and the commencement of treatment is also a very difficult one. Sharon draws on the importance of effective communication from health care professionals that would have assisted in helping her set her expectations about the length of time that was required to process the results. Sharon implies that this information would have helped her. Many women in this study only start to plan their ‘attack’ on the disease after the official diagnosis is received, contrasting with the way they feel during the period of time spent waiting. Although Sharon describes this waiting period as a lengthy one, for others, the whole process from presenting with a symptom to the operation is much shorter.

This was on a Thursday… the next morning I get a telephone call from the doctor to say come down that he wants to see me so I went down and he told me that I had cancer of, he just said you have cancer of the pelvis area, he didn’t say, he didn’t mention the ovaries or anything (Kathleen, 95-102).

The extract from Kathleen highlights the speed of her experience even though there was not an exact diagnosis. She describes the doctor as a powerful other, emphasising the paternalistic model of care: the gender of the doctor is emphasised by the repetitive use of ‘he’ which is followed in a step-by-step fashion following how the events unfolded. Kathleen’s account describes communication from the doctor, but does not talk about her position in the consultation, which suggests she is a passive recipient of information, even when only a partial diagnosis is received. This further emphasises the paternalistic model of care, as Kathleen does not discuss her own part in the interaction with the doctor. It might be assumed that the unconfirmed diagnosis of cancer may have resulted in a number of questions about her potential condition and about the process to follow. The lack of confirmed diagnosis at the point of presentation at the GP surgery leaves patients (including Kathleen) in a state of limbo, knowing in some cases that they have cancer, but not being sure which one and how they will go forward. This is only remedied when patients have an initial consultation with the specialist consultant who is able to give them specific information about their diagnosis and subsequent treatment. Betty, for example, talks about visiting her GP and consultant.

So you know, I wasn’t surprised, I had already come to terms with it, and he said then you will have to come to Derby for this… and when I saw my consultant on the Friday, he said I have booked you in for the Wednesday (Betty, 24-32).

Betty already suspected her diagnosis, and as a result of this, her experience of this stage of her cancer ‘journey’ was very different from the one experienced by Kathleen. The feeling of shock and the unknown was not apparent in her recollection of her experience as she had had longer to adjust to the idea of having cancer. She describes the lack of surprise about the diagnosis and positions herself as the holder of knowledge about her situation which led to her having already ‘come to terms with it’. This is a contrast with Kathleen’s account, where she describes a situation where she is not in control, had no knowledge of her condition before her consultation with the GP, and even after only partial knowledge. Betty felt that she was in control of the situation, after having finally decided to go to her GP, already knowing the probable outcome of her visit. Kathleen’s experience represents a larger proportion of women in this group, setting Betty aside as different from others.

The extract from Betty raises another important issue surrounding a diagnosis of cancer, the need to treat patients as quickly as possible. Early onset of treatment is linked with a better prognosis for many types of cancer (Tubiana & Koscielny, 1999), including ovarian cancer in particular (Jacobs & Menon, 2004). The importance of early treatment and the pressure of the government targets put into place for the treatment of cancer patients such as those included in the ‘two week wait’ pathway (NHS Improvement, 2008), often results in patients being offered surgery when they do not necessarily expect it, and in some cases have not had chance to prepare.

So it was arranged that I would go in in a fortnight, but on the Monday I had a call and he’d had a cancellation and I could go on the Wednesday so I had no time to think about it really (Sheila, 70-73).

Although Sheila states that she did not have any time to think about the start of treatment, she was happy to participate and continue with the surgery, as she ultimately believed that this was the best course of action to treat her cancer. This experience was reported by a number of other women; patients were seen in clinic by their consultants and were offered appointments for a few days later. Many felt that they should take them up as this was something that would help them, and therefore required no thought.

He said I have got an opening tomorrow night, because he said that somebody cancelled or something. So he said but of course you will have to have time to think about it, but I said no. I am quite prepared if you are prepared to help me, I will be there (Rosetta, 14-19).

Rosetta highlights that she was willing to undergo the operation at short notice, and that she was grateful for the consultant helping her with her condition. There could be a number of factors that affect this: Rosetta might be pleased to get her treatment for her cancer underway as quickly as possible; alternatively, she may feel that she has to be grateful for the intervention of a medical professional, echoing the bio medical model of treatment and decision making, with its paternalistic model of care. Alternatively, it may be that Rosetta’s response is a product of gender differences in the physician-patient communication, as the consultant was a man, and the patient was female (with a female-only cancer) and research suggests that this is a generally uncontested gendered construct (Borges & Waitzkin, 1995; Ellingson & Buzzanell, 1999). Although it is uncertain which (if any) of these factors can be attributed to the response of Rosetta to the offer of surgery the following day, they are important factors for consideration in the uptake of late-notice surgery and the subsequent impact that this may have on the patient’s experience.

This subtheme explores some of the unique experiences of patients who have participated in the ERP. It shows the context and the history of some of the patients and gives a greater insight into the factors which may shape the patients’ experience of the programme, and of the treatment of their cancer. The complexities of diagnosis that some women discuss in their accounts of their participation in the ERP clearly underpin their approach to the programme. Time, with regards to the uptake of treatment, is already a factor for many women, which encourages them to both participate in the programme with a view to commencing treatment as quickly as possible.

## 4b. Thoughts on Cancer

For many, the diagnosis of cancer is associated with death, and for a number of years, cancer fatalism has been identified as a barrier to participation in cancer screening, detection, and treatment (Powe & Finnie, 2004). Although this is problematic in itself, cancer fatalism coupled with patients’ ideas about cancer and the way that cancer should be treated has implications for the expectations of patients about the forthcoming treatment and diagnosis. This has strong links with the expectations of patients, discussed in the managing expectations theme. However, not all cancers result in death, and with the development of new treatments and the improvements in treatment package design and efficacy, more people than ever are surviving, and are surviving for longer, after a diagnosis of cancer. This subtheme discusses patients’ individual thoughts and expectations about cancer specifically, rather than their expectations of the programme and of hospital care.

Many patients who are diagnosed with cancer have some idea of what is to follow. This information is collected from a number of sources, including the media, significant others and personal experience. The combination of these external influences (and other factors) leads patients to have an expectation of what will happen after a diagnosis of cancer.

I guessed that they wouldn’t hang around once we had got an idea of what it was. Well he said you will have chemotherapy, you will have a hysterectomy, and you will have 6 cycles of chemotherapy. He just spelt it out really (Liz, 55-60).

Liz discusses her pre-conceptions about what would happen after her diagnosis, which is confirmed by the consultant. Liz refers to one of the most typical responses to a cancer diagnosis – the issue of time. The aspect of time that Liz refers to here specifically is the need or desire for speedy treatment after the diagnosis. Liz casually describes the need for swift action as to not ‘hang around’, using a colloquial term indicating her ease in talking about the topic, which may be indicative of the period of time that has elapsed between her diagnosis and the account she is currently giving. Additionally, Liz also includes the use of ‘they’ and ‘we’ which enables her to position herself and both the passive patient who is on the receiving end of care (she uses ’they’ meaning health care professionals who are responsible for the scheduling of the onset of treatment), and also as ‘we’ with herself, significant others and health care professionals being included in one group that had been enlightened to her new state of health.

The account from Liz highlights individuals’ assessment of the threat of cancer. Liz clearly sees cancer as a threat and associates fast treatment as an essential from the beginning. However, Betty has suspected for some time that she had cancer, and had delayed seeking a diagnosis and treatment. This course of action from Betty is particularly surprising as she was a nurse before she retired and had previously worked in gynaecology. She was fully aware of the symptoms that she had and what the probable outcome of these symptoms were, and she decided to delay seeking diagnosis. The following extract initially describes Betty’s presentation at the GP and goes on to describe her first visit at the hospital.

I had had a bit of bleeding and I think in my heart of hearts I knew it was bad news, and I had sort of put it off like you do, I’ll do it next week, anyhow eventually I went and he [GP] immediately having just done an examination was able to say to me that you need to be seen fairly soon. So he made the appointment and within days I had an appointment at the hospital… [describes hospital]. Before I left the hospital’ clinic, I saw a lovely man once again [consultant], he said this is cancer [describes her specific cancer type] he realised that I also knew (Betty 8-21).

Betty highlights that although it is well known that early detection of cancer leads to better prognosis, and that cancer itself is often linked with negative outcome, she has done little to pursue a diagnosis even though she suspected the cause of her symptoms. Again, the importance of time is highlighted: doctor is immediately able to provide information from her examination which contrasts with the delay that was instigated by Betty. The extract also reinforces her knowledge about her medical situation and the lack of action she had taken to initiate a diagnosis and subsequent treatment.

Though she gives no justification as to why she delayed in seeking assistance for her symptoms, and for delaying the diagnosis of her condition, she was able to talk freely about the delay. It is interesting to note that Betty switches from ‘I’ to ‘you’ in the first extract, highlighting a change in ownership of the situation. The personal tone of the admission of delay signified by the use of ‘I’ is shifted onto the collective ‘you’ when she talks about ‘sort of putting it off’. When Betty says ‘like you do’ it is unclear who is the intended ‘you’, it could be ‘you’ referring to me as a researcher who may be seen by the patients as an expert in the area, indicating that this may be something that I (and she in her past experience) may have encountered before. Alternatively, the ‘you’ may represent women as a whole, suggesting that Betty may be positioning herself as one of many others that delay seeking diagnosis.

For others, the diagnosis of cancer is one of complete shock and the feeling of shock is not one that is restricted to the point of diagnosis. Sharon explores her experience of meeting her consultant for the first time and scheduling her operation.

Then I went to see my consultant who explained what he was hoping to do and then told me how big the tumours were, which he said they were 2cm again now so they have gone back to normal size, and that was before the op. So that was really good, I think it hit me then, what was happening to me. I was very upset then, I had dealt with everything then and then you suddenly think this is it really (Sharon, 137-143).

It was only after the discussion of treatment that Sharon fully understood the implications of her diagnosis. Sharon uses emotive language to describe the sudden realisation of her diagnosis, she describes how the diagnosis ‘hit’ her, which has connotations of being physically assaulted by the diagnosis, leading to her becoming upset. She implies that until she had ‘dealt with everything’, but at the point of deciding on a treatment regimen, everything had suddenly changed. This relates to the previous subtheme, where some patients felt that they were unable to plan their ‘attack’ on cancer until they had a full diagnosis. This seems to be the case here, as it would be at this appointment that the official diagnosis would have been discussed with regards to the initiation of a treatment plan. This point in time has personal significance to Sharon as an individual as she talks in the first person for the majority of the extract, until there is a pronoun switch where she changed to ‘you’ where she extends her thoughts to include everyone who would think the same as she does.

There are a number of contrasting emotions in the accounts of the women. Betty knew about her diagnosis and seemed unaffected by the communication of the diagnosis. Sharon found the diagnosis stressful, and prolonged over time. Although she initially felt that she had been able to cope with it, this was challenged at the point of decision making about her treatment. In the following extract, Barbara describes her experience:

They should have found the cancer then. They didn’t find it. They should have noticed it (Barbara, 990-991).

Barbara describes that she feels bitter and let down by her medical teams as her cancer had not been detected during the extensive treatment that she had received for her kidney stones. Barbara clearly feels let down by the medical establishment, which she had faith in. Barbara disassociates herself from this group and emphasises her dissatisfaction by consistently using ‘they. Additionally, she uses a number of short points to form a three part list, which emphasises her disappointment in the medical team. This feeling is intensified by the stigma that is associated with her final diagnosis of ovarian cancer. Barbara links her diagnosis to a term that is commonly used within the media.

They call it the silent killer… I read it in the paper, you tend to read little bits (Barbara, 549-551).

The term silent killer is a popular concept that has been adopted by the media (Telegraph, 2012), and is widely accepted as a synonym for ovarian cancer. The term silent killer is one that describes the lack of symptoms that are apparent in many ovarian cancer diagnoses, and to some extent, this is why ovarian cancer has such a poor prognosis as patients do not present at their GPs until they have substantial disease, and many GPs do not correctly refer patients to gynaecology, meaning that they go to upper GI clinics first (Chan, 2001; Goff, Mandel, Melancon, & Muntz, 2004). Barbara’s case highlights how media can influence an individual’s understandings about cancer; the media caused her to feel (potentially unnecessarily) anxious about her diagnosis because of the label (emphasis on the ‘killer’) that had been attached. The effect that the media has on patients can be problematic as some research has shown that people with higher levels of cancer fear and fatalism are less likely to learn about positive developments made in the field of cancer control, allowing negative feelings and views to continue (Miles, Voorwinden, Chapman, & Wardle, 2008).

Although the lack of symptoms for some patients is problematic with regards to their presentation for diagnosis and treatment, others report that the lack of symptoms leads to them feeling as if they have not really been ill.

It was weird because having no symptoms I don’t feel as though I’ve had cancer like proper people who have been poorly if you know what I mean (Janet, 192-194).

Janet describes how her lack of symptoms has influenced her cancer experience. She compares herself to ‘proper people’ indicating that she does not identify with that group of patients as she does not have the same shared experience. She invalidates her own experience by comparing it to others who have been ‘poorly’ and describes it as ‘weird’ indicating that this is not the norm. Additionally, Janet also looks for reassurance from the interviewer that this is a ‘suitable’ thought process. Similarly to this, some patients feel as if their experience of illness is not representative of the socially accepted external appearance of illness, and cancer in particular. In the extract below, Barbara describes how she feels about having had cancer.

Really, I just sat there, I sat here. I felt a real fraud you know completely, because I felt I could do things (Barbara, 1292-1294).

Barbara describes herself as a fraud; she felt that she could have done things that had been prohibited by both the nursing staff and her perceptions of what it means to have cancer. This highlights that the stereotypical nature of cancer for Barbara as an individual is one of disability. This idea was challenged by patients’ participation in the ERP. As previously discussed (see Chapter 2), the ERP itself encourages individuals’ recovery after surgery, meaning that they can return to normal life ‘sooner’.

And on the Monday I felt so well I would have gone to Weight Watchers if I could have done. And I felt as though I could drive (Janet, 522-534).

Janet describes her desire to return to normal life as she felt so well after her operation. For her, the removal of the cancerous tissue through a hysterectomy was the only treatment necessary for her disease. Her participation in the ERP facilitated a quick return to normal life post-operation and marked the start of her recovery from cancer as no further treatment was required. Her return to normal life is marked by resuming her day to day routine, which included both physical and social activities that were important to Janet maintaining her sense of self at the time.

This use of the ERP as a tool for returning to normal life (and subsequently survivorship) as quickly as possible was evident in many of the women’s accounts where they did not require further treatment for their cancer. This ‘selling point’ provides some of the motivation for taking part in the programme in the first place. Lynn says:

So I was quite happy and they offered me at the pre-clinic to go on this enhanced recovery programme and I thought well why not? Because anything that will help me recover, I don’t want to be ill. I haven’t got time to be ill. If you understand that. You know I want to be fit and I want to enjoy my life and this is just as far as I am concerned at the moment a blip, and he had given me such a good prognosis, I thought well anything I can do to get better a lot quicker I’ll be fine (Lynn, 61-67).

Lynn describes that she was pleased to be offered the opportunity to participate in the ERP at the time of her diagnosis. This was directly linked to the good prognosis that was given by the doctor. Again, In Lynn’s case, a hysterectomy was the only treatment that was required for her cancer, so the removal of the cancerous tissue and recovery from the operation were directly linked with her recovery from cancer. Lynn highlights that cancer was just a ‘blip’ in her healthy life, and that it was something to be overcome, and that her participation in the ERP was one way of being able to do this.

This subtheme highlights some of the patients’ thoughts about cancer from the point of diagnosis through to their decision to take part in the programme. For many patients, their experience of the programme is one that they cannot separate from their experience of cancer, and, for some women in particular, their participation in the programme is the sum of their treatment for cancer. It appears that patients want to use the programme as a tool for returning to ‘normal’ sooner, allowing them to enter the survival phase if no further treatment is required or allowing them to recover more quickly to facilitate the earlier progression of their subsequent treatment. This directly challenges some of the stereotypical expectations about cancer that are portrayed by the media and reinforced by society and directly links with some of the subthemes within the managing expectations theme.

## 4c. Patient as an individual

A number of the patients in this sample discussed the value of personal and individual care. This was an important factor in their hospital experience as it was independent of the ERP. The consideration of the patient as an individual was something that was applicable to their time in hospital to their overall experience of having cancer. Each patient’s account of what made good care was different, which reflected their individual differences and subsequent experiences of the care that was provided.

The physical aspects of the hospital were important in some women’s experiences of care. The room that women had for the duration of their hospital stay was a significant factor, and many women felt privileged to have been given a private room. Research suggests that the rising levels of patient expectation, together with other factors which include a significant increase in hospital-acquired infection, have led to a recommendation that the proportion of single rooms in acute hospitals should lie between 50 and 100%, and many new hospital have larger proportions of single occupancy rooms (Dowdeswell, Erskine & Heasman, 2004; Gesler, Bell, Curtis, Hubbard, & Francis, 2004). Sheila talks about her experience in the following extract.

I was then taken to my bed of which would remain mine all the while I would be in hospital, which again, I was very privileged, I had a private room with a private bathroom, like a queen! (Sheila, 619-622).

It is clearly important for Sheila to have something that belonged to her throughout her stay. The use of the words ‘my’ and ‘mine’ closely together in the sentence suggests that Sheila appreciated the opportunity to take ownership of an object throughout her stay in hospital, which may have acted as an anchor point (i.e. something familiar) in a rapidly changing environment. Similarly Sheila reiterates the privacy aspect of her surroundings, implying that this was ‘special treatment’ that would be afforded to royalty. As with other themes, this is something that may well be reflected in this particular population (with regards to the patient’s age), as the traditional view of NHS hospital care is associated with large wards with multiple beds, and only private or ‘important’ patients and those who were very ill were given single rooms. The following extract from Rachel describes her experience of care while she was in hospital.

I think the care there was outstanding, it was personal as well. I didn’t feel like I was just a number on a ward or anything. I was in a room on my own, so I could have quite easily felt isolated but I didn’t (Rachel, 425-429).

Rachel describes one of the fears that is commonly faced by patients who are placed into individual rooms - isolation. Research by Florey, Flynn & Isles (2009) found that length of stay was an important factor in patient’s preference of whether they have a single or multiple occupancy room. Their research suggested that those who were staying in hospital for a shorter period of time (mean length of stay 3.5 days) preferred to have a single occupancy room, whereas longer stays (5.5 days or more) preferred a multi occupancy room. This may be one of the reasons that patients on the ERP preferred the single occupancy rooms as their length of stay was between 2 and 4 days. One of the biggest motivators for those who have a shorter length of stay to have a single room is the desire to have a quiet space where there is less chance of being disturbed (Florey, Flynn & Isles, 2009). Sheila talks about this in the following extract.

But the opportunity was there, I never felt rushed, I just felt that they’d got time for me, even though there was a very, I could hear the comings and goings even though I’d got a private room. Even though, I could hear the comings and goings outside, and I saw for myself when I was on the move that it was a busy ward. But they’d got time for me. They were really good (Sheila, 934-940).

Sheila comments on the fact that she had a private room, but her focus moves onto the level of care that she received in a busy ward, which is something that was also reflected by Rachel above. Sheila felt that the care was personal, and that the nursing staff had time for her and her needs, whereas Rachel felt that the care was both outstanding and personal. This contrasts with some of the literature surrounding staff perceptions of what will happen to the level of patient care in ERPs; both Foss (2011) and Mitchell (2011), express their concerns that the implementation of such programmes will reduce the amount of patient/nurse contact time on the ward, and that patient care will become mechanistic.

One aspect of care that was regularly talked about was the amount of time that HCPs (particularly nurses) had for patients. One example of this is the contact time that patients have with their CNS. Each patient who receives a diagnosis of gynaecological cancer at the Royal Derby Hospital is assigned a CNS as a main contact for the duration of their cancer experience. This key contact has a role in every point in the patient’s ‘journey’ from being present at the diagnosis to treatment and follow up visits. This is something highly valued by the patients.

And I had my own cancer nurse as well, Katy, and that was nice. That was really lovely to think that I had got somebody (Lily, 367-369).

Lily describes how having her own cancer nurse, with whom she is able to build a personal relationship, was important for her as she was someone who was there for Lily alone. This suggests that Lily appreciated being the focus of someone’s attention, and found comfort in the idea that she had somebody in case she needed them. It has been suggested that patients with access to a CNS are more knowledgeable about their condition and more proficient in self-care, and that the CNS is a major resource to patients (Smith, 1997).

Carly took us into a room and gave us all the time we wanted, was there anything we needed to know, and this is what happens in hospital. She offered to take me up to the ward so I could see it, but I didn’t because you’re in, and you’ve got to go in, so I didn’t, but she was very good (Sharon, 141-150).

The importance of information giving and the building of knowledge has already been covered earlier in the ‘taking part in the programme’ theme, but the extract from Sharon reiterates that the CNSs play an important role in this process and during this period of time in particular. Research by Booth, Beaver, Kitchener, O’Neill and Farrell (2005) found that women who had initial support from a CNS at the time of diagnosis experienced a clinically significant reduction in their level of psychological distress six months from diagnosis in comparison to those who did not. CNSs are also important in the long term follow up of gynaecological cancer patients and have an important role in the recovery of QoL and sexual functioning after treatment (Maughan & Clarke, 2001). Although the role of the CNS is clearly important, patients also value the approach of the other members of staff. Sheila shares her views about some other important members of staff in her particular experience.

The surgeons and the anaesthetist were so kind, they gave time for any emotions, but because they explained things in such a way, it was just lovely to just have a one-to-one and just be myself. They were really good (Sheila, 1125-1128).

Sheila highlights the fact that two key partners in the ERP (the surgeon and the anaesthetist) left a lasting impression on her. They had significantly contributed to her experience of her overall stay in hospital, and with that her experience of the programme. She highlights a number of qualities that were important for her, including kindness which has been linked to patient satisfaction with hospital medical treatment and has an important role to play in the communication of a diagnosis of cancer (Katić et al., 2001; Hornsten, Lundman, Selstam, & Sandstrom, 2005; Salander, 2002; Pickering, 1997). Another important aspect of Sheila’s experience is that she could be herself. This desire to be herself is a recurrent theme in Sheila’s narrative of her experience. In an earlier extract, when Sheila is describing her discharge from hospital and the expectations of others, she also draws on this idea; she describes that she does not want to ‘put on any act’ (line 168). This sense of self linked to her identity, and being true to herself, is strong in Sheila’s description of her experience of the programme and of her overall ‘journey’ through cancer.

A number of patients also highlighted the importance of them being treated as an individual and considered on an individual basis as patient. Sharon highlights the importance of this in her experience.

It really is fine, and everybody cares, everybody you speak with cares for *you* and what’s happening to *you* and it is totally reassuring and I would never hesitate again (Sharon, 572-573).

Sharon describes that everyone in the hospital environment cares about ‘you’, with this being emphasised in the utterance. Sharon felt that she, as an individual was considered as an individual patient, rather than being classed as one of many cancer patients. This is further explored by Barbara.

Yes and he put in his report at the end of it, he said I don’t want to give this lady because she’s a good golfer and I don’t want her to have a bag because it would not make her golf as good (Barbara, 1213-1216).

Barbara highlights that she thought that her needs as an individual had been considered and appropriately noted by her consultant. This was an important aspect of Barbara’s satisfaction with the care that she received from hospital as many of the concerns she had about her treatment lay in the long term effects rather than the recovery from the operation itself. The desire for the acceptance of individual aspects of patients’ lives was also reflected in other accounts, such as the one from Lily:

Because I’m a Jehovah Witness, there were issues about me not having a transfusion… my consultant actually rang and ordered the cell salvager straight away and that was waiting for me. So that was very positive (Lily, 71-75).

Lily’s religious beliefs meant that she needed additional care and consideration with regards to the equipment that was available for her operation. Lily appears satisfied with the actions of her consultant, and the facilities that are provided to ensure that her autonomous decision was upheld. The consideration of religious belief was important to Lily throughout her treatment experience, including her participation in the ERP.

This subtheme highlights the importance of patients’ perceptions of individual care and the effect that this has on their overall satisfaction with their experience of the enhanced recovery program and of their long term treatment at the hospital. Patients appear to want individual, carefully considered care that is ‘tailor made’ to their requirements and is delivered by both kind and helpful staff. The current analysis suggests that this has the potential to impact on patients’ overall experiences, and that these factors need to be considered when designing health care initiatives (such as the ERP), as they may influence the patient reported outcomes.

## Conclusion

To conclude, it can be seen that there are a number of areas which are important for patients. The time surrounding diagnosis and the onset of treatment was stressful for many women in this sample due to the unexpected diagnosis, and this period is generally an emotional time. The experience for others (one woman in particular) is very different, highlighting some of the variation of the responses to a diagnosis of gynaecological cancer. The theme also explores some of the individuals’ thoughts on cancer, and the preconceptions that shape their experience of cancer, including treatment and the enhanced recovery as a whole. The value placed by patients on individual care is also important for their overall experience of cancer, which also impacts on perception of the ERP.

Chapter 5: Discussion

The following chapter includes further discussion of the findings from the interpretative phenomenological analysis presented in Chapter 4. The current exploration of gynaecological cancer patients’ experiences of ERPs has highlighted that there is a positive view of the programme overall. The interpretative phenomenological analysis has identified three areas which are integral to the overall experience of enhanced recovery, and that a number of individual patient experiences contextualise and add to patient’s perceptions of the programme. These main themes cover the important aspects of the programme and a patient’s journey from diagnosis of cancer to recovery from the operation and beyond. The three main themes of are individual themes in themselves, but also come together to form one overall experience of enhanced recovery, which is contextualised with the experiences within the final, more ideographic theme.

# Taking part in the programme

Overall, the information provided about enhanced recovery is well regarded by the patients, and is informative for both patients and significant others. Patients describe that the information available was useful as it increased knowledge, leading to a greater understanding of why they were being asked to comply with each part of the programme. It is recognised within the wider health psychology literature that the seeking and use of information (or not) can be indicative of or linked to coping style (Ehemana, 2009; Van Der Molem , 1999; Mills & Sullivan, 1999). Literature suggests that those patients who are using a problem focused coping strategy would benefit from the enhanced information that is part of the programme, as it helps them to understand their experience (Lambert, Loiselle, & Macdonald, 2009; Walker, 2007; Suhonen, & Leino-Kilpi, 2006). This is reflected in these patients’ experiences, which suggests that they are using problem focused coping strategies (rather than emotion focused coping strategies which would result in the avoidance of information). Additionally, the patients acknowledge that they were provided with both procedural and sensory information providing them with information about both what would happen before and after surgery with regards to process and also gave indication about how they might feel after the operation (i.e. pain).

Patients acknowledged the benefit of the enhanced information (although they are mostly unaware that it is enhanced), however, it appears that there are some deficits in the information (i.e. what the scar will look like) which would help patients better prepare for the outcome of surgery and help build their expectations. This would be particularly helpful for patients who had never had surgery before or been involved with anyone who has had a surgical procedure. Some women have no idea of what to expect with regards to the wound. At the diagnosis appointment with the consultant at the Royal Derby Hospital, the consultant/surgeon will explain to the patients what will happen in the operation and the topic of wound/scar is covered then. Many women are told whether they will be having a total laparoscopic hysterectomy (TLH) or total abdominal hysterectomy (TAH) and the appropriate wounds. All women in this sample had a TAH so would expect to see a large scar, but in some cases it is unknown at the time whether this will be a lower midline or transverse scar. The knowledge about the orientation of the scar may be important for the patients as it is difficult to prepare for the unknown. However, it appears that patients have concerns about how the wound heals after the operation and whether it will hold whilst completing the prescribed physical activity. More information about how the wound is sutured and the way patients will feel (internally) may be beneficial for patients, and this may reduce part of the conflict between instruction and intuition.

In relation to the ERP itself, receiving information and gaining knowledge are very important for patients with regards to being able to get mobile. The information provided as part of the programme allows patients to understand and gain knowledge about what is expected of them and why, and could be viewed as a way of being able to regain control, which is a resource that is often lost when undergoing surgery (Heike &Mahler, 1990; Taylor, 1979). Receiving information and knowledge allows patients to actively participate in their care; having this sense of autonomy encouraged by staff has been shown to be beneficial with regards to motivation to adhere to a care programme (Williams, Freedman & Deci, 1998).

## Getting active and the role of the physiotherapist

Patients feel that getting active is the most important part of the programme; the rest of the programme is almost ‘a means to an end’. Patients perceive that being active is the key to going home and once this is achieved then they will be allowed to return home. However, the route to being active is not straightforward – there are a number of barriers, the first being getting out of bed. It is not surprising that many patients do not want to get out of bed after the operation; it appears that getting out of bed is the ‘worst’ part of the route to mobility.

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### Mobility

It could be argued that early mobilisation has altered the traditional ‘sick role’ associated with being ill (having cancer) as well as having an operation (Parsons, 1978, 1991). Keeping in mind the age of this patient population (53-80 - mean age was 66), many of these women would be familiar with a more traditional style of recovery, where rest and recuperation are paramount. A number of women in the sample had undergone gynaecological surgery in the past, and most women had had contact with somebody who had undergone a similar experience. These prior experiences influenced the patients’ expectations and also their intuition about the correct course of events post recovery i.e. what is perceived as normal for that situation/group of people (Rimal & Real, 2003). Many patients would expect to be in hospital for 7 or more days after undergoing hysterectomy, with some having previous experience of being in there for up to a fortnight. This stay in hospital would have been mainly filled with bed-rest, with physical activity being phased in slowly until the patients were ready to return home. This may be seen as a historic approach to healthcare, but even before the implementation of enhanced recovery at the Royal Derby Hospital, the length of stay for patients was four days or more due to the anaesthetic/pain control regimen and the lack of pre-operative nutrition.

The deviation from this approach to recovery is nonsensical for some patients; getting out of bed and mobilising early on in their hospital stay (for some women on the day of the operation) goes against their intuition and past experience. Although patients are told that they will be expected to get out of bed, this does not transfer into intention, and subsequently, behaviour. Patients don’t want to get out of bed and mobilise, and this in turn affects their ability to go home. This may be due to discomfort or pain or because they believe that they can’t, or even that they shouldn’t, be getting out of bed so soon.

### The role of the Physiotherapist

The role of the physiotherapist is integral in getting patients out of bed. Patients who see a physiotherapist at the pre-operative appointment are shown how to get off the bed, and are given information to support this. This process was highlighted in the patient’s accounts of their experience and that being able to practice at home was important for them. This is something that should be encouraged as it may improve patient’s self-efficacy about being able to get out of bed and starting to mobilise as they will have had achieved mastery though more successful attempts of that skill (Sirur, Richardson, Wishart & Hanna, 2009; Cheal & Clemson, 2001; Bandura, 1982). It is known that self-efficacy represents a personal resource factor that may facilitate coping both during and after surgery (Knoll, Rieckmann, & Schwarzer, 2005). Patients who do not see the physiotherapist at their pre-operative appointment may be at a disadvantage in comparison to those who do, in as much as they miss the opportunity to be shown how to get off the bed and rely solely on the information that is given to them in the form or written instructions and diagrams. Bandura (1982) described that one of the ways to improve self-efficacy is though vicarious experience (watching someone else who is comparable with the patient). In light of this, it may be worthwhile having a resource available for patients to watch or use that shows patients how to correctly get out of bed (modelled by an appropriate actor), in something as simple as a video that could be distributed on CD, on-line or shown in clinic (Lee, Arthur & Avis, 2008).

The post-operative visit from the physiotherapist is also very important for patients as this instigates the start of the mobility aspect of the programme, the physiotherapist gives the patient an implied permission to mobilise. It is widely reported in the literature that the role of the physiotherapist is integral to post-operative recovery on both traditional and ERPs (Stockton & Mengersen, 2009; Wainwright & Middleton, 2010). Physiotherapists successfully get patients out of bed and encourage them to be mobile. Patients describe that once the first obstacle is removed (getting out of bed), being mobile is not as difficult. Patients who are mobile are able to move towards completing more ‘everyday’ tasks such as getting dressed into their own clothes, brushing their teeth and bathing. These are important activities for patients after the operation as it allows them to return to ‘normal activities’ and take some control of their own care. The accounts from these women demonstrate their belief that these are the first steps in the road to being able to return home, and being able to walk to and from the bathroom is an important step in being able to complete this. Additionally, this may be a useful course of events for patients who may have previously believed that they would be incapable of these types of physical activities (i.e. perceived loss of physical functioning). This rapid resumption of previous physical activities may result in less stress for the women, as they are able to regain potential lost resources that are associated with surgery.

The role of the physiotherapist is therefore central to the delivery of ERPs as they are the facilitator of what patients view as the most important part of the programme and provide the key to going home (there are of course other valuable aspects to the programme, but patients are unaware of these to such an extent). With the current restrictions on spending within the NHS due to the lack of funds available for hospital trusts, the additional time required from physiotherapists to enable the effective delivery of enhanced recovery is a ‘hot topic’ at the Royal Derby Hospital (and no doubt other hospitals). The implementation of enhanced recovery, and the success that follows a well-designed pathway results in an increase in the number of patients put on the pathway when listed for surgery. This means that there are more patients who require additional visits from the physiotherapy team. At Derby, there is currently no provision to increase the number of physiotherapists that are available within the gynaecological-oncology service (although several requests have been made with business cases) and the current financial climate in the NHS means that positions are being cut rather than recruited to. Essentially, there are not enough physiotherapists to go round to see all of the patients, and there isn’t any money available to employ more. This raises concerns about how the long term ‘role out’ of ERPs to the wider population of patients who meet the ERP inclusion criteria will be staffed, and in turn what effect this will have on the patient experience.

### Links to Health Psychology Models

Being mobile after surgery has been identified by the Enhanced Recovery Partnership as a beneficial health behaviour for patients. This suggests that models of health behaviour regularly used by health psychologists may be useful for predicting or explaining the uptake of this behaviour in gynaecological cancer patients. Whilst completing the qualitative analysis, it became apparent that a number of different health models could be linked to parts of the patient experience, such as the Health Belief Model (Janz & Becker, 1984; Rosenstock, 1974), Social Cognitive Theory (Bandura, 1977, 1986, 1997), as well as the Theory of Reason Action and Theory of Planned Behaviour (Ajzen, 1991; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975). Due to the breadth of different experiences, it was difficult to apply just one of these models to patients’ completion of this particular health behaviour (getting mobile). It became apparent that the integrative model of behavioural prediction proposed by Fishbein (Fishbein & Yzer, 2003; Fishbein, Cappella, Hornik, Sayeed, Yzer & Ahern, 2002; Fishbein, 2000) may be the best fit for this group of patients in this scenario. The model is displayed in Figure 6.

Figure 6 - Integrative Model of Health Behaviour (Fishbein, 2000) shown in black text. Italic text indicates the experiences of gynaecological cancer patients on the ERP.

Please note: diagram removed for copyright reasons, please see caption for reference information.

The model recognises that there are three primary determinants of intention as well as other factors that directly influence whether behaviour is performed. Although this evaluation was not designed to ‘fit’ a health behaviour model, it became apparent during the analysis that the experiences fit neatly into the model above. The italic text in Figure 6 contextualises the model and identifies how this specific health behaviour can be predicted by the model. At present, this is only an observation; previous discussion regarding patient mobility highlights how this model may be applicable to this patient population. Further research is warranted in the area of enhanced recovery and mobility, as this model may be beneficial for enhanced recovery pathway design and implementation.

## Home

On day two of recovery, patients are up and out of bed, can eat normally, have been to the toilet and had a shower, they feel that they are ready to go home – and they believe that this is possible. Patients in this sample felt that they had completed their ‘end of the bargain’ so should be given the reward of going home. Home is the desirable place for discharge for most patients, and all patients in this sample were being discharged to their own home. Research in America highlighted that patients on ERPs who were not being discharged to their home (so to a nursing home or to hospital) did not have as reduced a length of stay as those who were being discharged to their own home (Brasel et al., 2007). This suggests that a return to ‘own home’ is a motivator for early discharge. It appears that home has a special significance to people, and it is more than just ‘not wanting to be in hospital’. Home is personal and life carries on at home symbolising a certain amount of normality in a cancer patient’s life, especially after diagnosis.

## The role of home

Toombs (1993) raises an interesting point surrounding phenomenology and studying illness. If we are trying to access an individual’s experience of an illness or an event related to this, we must consider all of the biographical aspects that make up the individual and how these influence this specific experience – included in this will be the home and the hospital environment as well as all other experiences of illness (whether of their own illness or that of others). Both the environment itself and how a patient interacts with it will have an impact on the individual’s experience of enhanced recovery. It is clear from the analysis that patients do not enjoy being in the hospital environment when they feel ‘well’ and express a strong desire to go home. Alternatively, patients feel that the hospital environment is beneficial for their recovery, when they feel that they are not yet recovered.

With regards to home, or the lived space, illness (in this case surgery for cancer) has disrupted the ‘normal’ activity that occurs there. A house or home has both physical and spatial attributes that are identified with the personal and social self (Cooper-Marcus, 1974). After surgery, familiar activities now become difficult and home can be viewed as a restrictive environment, as what was once easily performed in a familiar environment is now difficult (e.g. climbing the stairs). Hospital has traditionally allowed patients to experience the negative aspects of illness (in this case recovery from surgery) in an environment outside of the home, leaving the home and the lived space intact and devoid of the experience of illness. Traditionally, at the point of discharge from hospital, patients would leave behind the hospital which contains the negative experiences associated with surgery, and return to home where ‘normal’ activities could be resumed. This idea is challenged by ERPs. Patients are returning home when they are earlier in their recovery, where everyday tasks are still difficult. The boundaries between hospital and home have become blurred; home is no longer the place where ‘normal’ activities happen as a large proportion of recovery (which would have been completed in hospital previously) is now taking place in the home. Illness is no longer confined to the hospital, and this may have an impact on the role of home for patients.

Research by Boschetti (1990) suggests that there is a close integration between physical and spatial dimensions of home and attachment, centrality and self-identity. Being in hospital separates an individual from these essentials and returning home can be thought of as reuniting an individual with familiar things in the home, and in essence their identity. Further to this, patients regain some control when they return home. It is thought that the hospitalization of patients reduces the sense of control for both patients and family members (Brown & Furstenburg, 1992), and being in hospital is associated with a loss of control over one’s activities (Taylor, 1979). The control is regained in terms of food choice, mobility and availability of familiar objects. Food in the hospital was regularly criticised by the patients during the current analysis, and featured heavily in the discussion about home and what was important about home for recovery. Patients commented that the food choices available to them in hospital were not those associated with recovery and the availability of comforting food at home was essential for them to feel better. The availability of familiar surroundings was also important to patients. Patients were able to relax on their return home, which they believed was integral to recovery.

This concept of control returning to the patients is also important when considering the role of ERPs and their effect on coping. It has been suggested that controllability of an event influences its primary appraisal and indicates appropriate coping strategies (Folkman, 1984). If patients are striving to ‘get home’ to regain control and gain resources that have been threatened or lost (i.e. mobility, food choice), then the ERP could provide both a way of regaining control and replenishing ‘threatened resources’ through early discharge. However, there are concerns about the control exercised by patients when they return home and their early perceived gain of resources that were threatened by surgery. Many of the women feel physically well enough to complete tasks which are potentially harmful to their bodies (i.e. heavy lifting), which may be detrimental to overall recovery. This indicated that although patients perceive that returning home will be good for them with regards to controlling (and subsequently reducing) a stressful situation, a balance needs to be found between activity and rest to ensure that recovery from surgery is the central focus.

On return home, patients become the ‘recovering patients’ in comparison to the ‘active patients’ that they are in hospital. These patients believe that the transition from ‘recovering from the operation’ to ‘recovering from cancer’ also occurs in the home environment. The symbolic action of going home for many of these women marks the start of their recovery from cancer as well as their recovery from the operation, especially for those that do not have extended treatment regimens (chemo or radiotherapy)

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## Practicalities of being at home

The balance between activity and rest is difficult as home is not just a singular thing; it involves both people and place. The place that individuals want to ‘return home’ to needs to be suitable and the people who are at home or are associated with home need to be ready to receive the patients. With regards to the first of these, the home itself is not always suitable for the patient to return to; although patients are up and able to walk, obstacles and challenges such as stairs, cupboards and everyday tasks come to light. Assessment of the ‘at home needs’ of the patient, needs to take place at the pre-operative appointment so that an accurate discharge plan can be made, which is agreeable for both patients and social care services. Although social care services should be integrated into hospital care to make a seamless transition from hospital to home (Direct.gov.uk, 2011), this is often not the case. Social care services are often an afterthought and getting assistance for patients at home is often left to the last minute, resulting in delayed discharge as patients do not have an adequate social care plan. Modifications to the home environment and organisation of care in the home are the responsibility of the social care team and the health care team in the hospital (Derby Hospital NHS Foundation Trust, 2010). These are easily put into place, but the short time frame (as a result of ERP) puts pressure onto an already fragile relationship. The analysis suggests that more emphasis needs to be placed onto the social care needs of the patient at the pre-operative stage, to ensure that the transition to home is as easy as possible for the patients.

## The role of significant others within the home

Significant others receive little or no preparation regarding their involvement in, and the practicalities associated with, having a patient at home who is in the early stages of recovery. The analysis revealed that significant others associated with home are required to fulfil a number of functions including carer, enforcer of rules and companion. In some circumstances this is a significant change or reversal of roles within the household. This research has focused mainly on patients who were going home to their husbands, and they were often called on to assist the patient in everyday tasks such as cooking and shopping. Research by Schröder, Schwarzer, & Konertz, (1998) found that having a partner was associated with more activities in the days following surgery, such as reading, washing oneself, ambulating, and exercising. This suggests that the partner is useful in facilitating activity that is associated with actively coping with the after effects of surgery.

However, when looking at ERPs, at the time when this sample of patients return home, the on-going struggle to reconcile intuition and instruction becomes apparent again. Patients generally feel well when they return home and are able to complete many ‘everyday’ tasks, without having the support from their partner or significant other. This is reinforced by the idea that they have completed the tasks set by the hospital and have been rewarded with discharge. Patients must continue to remember that they are recovering from a major operation and that rest and recuperation need to be balanced with activity and mobility. Patients often feel that they can do more than they are ‘supposed to’ resulting in partners or family members policing them to prevent them from doing things that they shouldn’t.

The information detailing what patients can and cannot do after the operation is contained in the literature given to patients at the pre-operative stage and is also confirmed on discharge. As long ago as 1999, researchers found that physicians overestimate patients' understandings of the post-discharge treatment plan, and that steps should be taken to improve communication about post-discharge treatment (Calkins, et al., 1999). However, there is an absence of research available that explores the experience of significant others that caring for patients who are on ERPs, and what (if anything) may be useful for them. In the hospital environment, trained health care professionals are well aware of the abilities of patients after the operation and what tasks are suitable/not suitable for them to be carrying out. Significant others do not have this type of training, and the literature provided is not sufficient to educate the significant others as to what is an appropriate level of activity for patients. Research conducted by Mahler and Kulik (2002), found that husbands who were asked to watch videotaped information designed to assist patients in their recovery after surgery were more successful in increasing patients recovery, probably due to their improved support. This would suggest that additional information, specifically written for significant others with guidelines for recovery (how recovery should happen and what are the important things to avoid), may be of benefit to assist significant others with this process if they are expected to take on this role.

## Communication – A bridge between home and the hospital

When patients return home there is also the problem surrounding continuing communication with the hospital. The analysis revealed that there was a clear break of communication between patients in the hospital environment and when these patients returned home. When patients return home many feel as if they are alone, and do not want to call for assistance from the hospital if it is required, even if it is to ask advice. Patients are instructed to call the hospital if they have any questions or queries while they are at home. This avenue of communication is one of the reasons that ERPs work – the care is transferred from the hospital to the home, and communication is available to ease the transition from one to the other (Department of Health, 2011b). The current analysis suggests otherwise – there is little communication between the two, and patients feel uncomfortable contacting the hospital. This suggests that the relationship is not working, and therefore not effective (this notion is reinforced by the patients feeling that they cannot call even if there is a problem).

The project lead for the ERP at the Royal Derby Hospital initiated the use of follow up phone calls to ease the transition from one environment to the other, and found some success, which is supported by research in other areas (Mistiaen & Poot, 2008; Dudas, Bookwater, Kerr & Pantilat, 2001). The analysis clearly highlights that patients value the follow up phone call and believed that this was beneficial in their transition to home. The use of telecommunication is not new, but is a resource that is becoming increasingly beneficial for those in the medical profession (Jennett et al., 2003; Miller, 2001; Hersh, Helfand, Wallace, Kraemer, Patterson, Shapiro & Greenlick, 2001). The ability to be able to contact patients outside of the hospital environment is of benefit to both the patient and the hospital as it means that valuable bed days are saved for the hospital and that patients get to return home sooner than before. The follow up phone call has a number of roles; Cox & Wilson (2003) highlight that “information can be reinforced thereby increasing compliance, and ensuring the physical and emotional comfort of the patients” (p. 59). The follow up phone call acts as a two way stream of information, with both sides being given the opportunity to give and receive information.

The downside of the implementation of follow up phone calls is that the calls must happen – patients must have that contact with the hospital if they are expecting it, in the same way as if a visit from a doctor was promised at the hospital. Health care professionals should take this into account when building resources such as this into pathways, as deviation from the expected can lead to a negative experience for patients. Patients may well be relying on the follow up phone call from the hospital to discuss any difficulties or to ask any questions that they may have after discharge. If these phone calls do not take place, the current analysis highlights that these avenues of communication are not currently utilised fully (with regards to patients contacting the hospital). This may result in other healthcare providers having to see patients in clinic or in the home (GP practices or district nurses) when a follow up phone call may have answered a question, and dealt with the question in a more timely and efficient manner.

The follow up phone call is not the answer to all of these problems of course. An intervention that would encourage patients to call the ward when necessary would be beneficial and has been partially implemented at the Royal Derby Hospital. This may include some sort of prompt sheet in the discharge material that details the type of problems to look out for (i.e. with wounds or bowel movements). This would be beneficial for both patients and significant others as it would raise awareness of some of the issues that are associated with this type of surgery and which ones are problematic and require hospital intervention. In addition to this, it may be beneficial for those completing the discharge to emphasise the availability of contact with the ward to the significant other who is staying with the patient on their return home. The significant other often becomes the main carer and is on occasion faced with the decision about whether to seek medical care (Norlyk & Harder, 2009). The availability of communication with a health care professional on the ward may well reduce some of the worry or stress associated with caring for a patient at home who is on day two of recovery from surgery.

# Managing Expectations

Managing the expectations of others is one of the biggest areas of concern for enhanced recovery patients and is a factor throughout the enhanced recovery journey (as well as the cancer experience in general). The expectations of others begin at the point of diagnosis. Others have expectations of both the disease and of the treatment itself through personal experience, the experience of others or through the media. This is often communicated to the patient and is in some ways unhelpful. A number of the patients described how the expectations of others about their surgery were unhelpful, and in one instance resulted in a patient actively keeping information from others so that she did not have to justify her actions and the success of the ERP. It is unlikely that this situation can be removed or can be resolved by an intervention. It appears that it is socially acceptable for people to share expectations and experiences with patients regardless of whether these are helpful, and until society deems this as inappropriate behaviour it is unlikely that this will change.

The expectation of the patients and others also has an impact on the patient’s stress appraisal. The perceived impact or outcome of surgery for cancer influences an individual’s stress appraisal, and informs their decision about whether they have the internal and external resources to be able to cope with the stressor. This information also provides the basis for an individual’s appraisal of what resources are threatened or will be lost. Within the analysis, the women talk about many different sources of information, but personal prior experience and the experience of others appear to be the most influential. Women describe their concern about the quality of care from the institution, which is an external resource that women rely on. Additionally, their own previous experience of care of both themselves and others sets a ‘benchmark’ for their experience on which they base their coping appraisal. These previous experiences also indicate what resources might be lost or are threatened through surgery.

The current analysis surrounding patients’ expectations reflects research that explores the attitudes surrounding cancer dependent on their previous of experience of the disease. Early research by Berrenberg (1989), found that cancer patients held the most positive attitudes about cancer, followed by those with minimal cancer experience. Individuals with a history of cancer in their family hold the most negative attitudes. These findings were consistent with the predictions of the dual process model which was proposed by Berrenberg. In the present study, many of the women who had little experience of cancer had a positive attitude towards the disease and high expectations of themselves and subsequent treatment, which suggests that those who have had experience of cancer through a close relative have negative attitudes. This may be due to the aversive social interactions they have experienced with the cancer patient i.e. “the awkward nature of interpersonal contact with cancer patients may heighten negative feelings and thus increase the tendency to derogate the patient” (Berrenberg, 1989, p.235). These negative social interactions lead to the family member developing a negative outlook concerning cancer, presumably in the service of avoiding a sense of personal failure. This would be appropriate for those who could only report a negative experience of cancer, without having had cancer themselves (i.e. where Sheila talks about people’s attitude toward cancer surgery). However, some aspects of the current research deviate from the proposed model; those women who had previously encountered cancer with a close relative have had prior experience of pain and suffering and in some instances poor care.

## Staff expectations of the programme

The patients and significant others are not the only ones who have expectations; the staff (mainly nurses) also had expectations, not of the patients, but of the programme itself. The timing of the current research project may have amplified this feeling or captured it at its worst; this patient sample were amongst the first to complete the ERP, and staff may not have fully adjusted to or accepted the new pathway into their way of working. Regardless of this, the expectations of the staff impact on the patient through their nursing practice. Nurses have an important role in the delivery of enhanced recovery and this is reflected in several research papers which discuss the impact ERPs have on nursing practice.

### Implications for nursing practice

Foss (2009) reports that there have been initial concerns about the implementation of enhanced recovery from long term nurses, who have been caring for patients for a number of years. Research conducted in a gynaecological cancer department in Norway by Sjetne et al. (2009) identify that there may be slow implementation of new regimens, as current staff do not like change and it can be viewed as a move away from professional autonomy. Results from Sjetne et al.’s research comparing levels of nursing care pre and post implementation of ERP suggested that the total time used for nursing related activity and the amount of time to attend to physical needs of the patient decreased over time. Although these differences weren’t significant, it was suggested that ERP decreased the amount of nurse to patient contact time. This in turn led to a fear of opportunity to deliver individual care, and this concern is supported by Mitchell (2011) who states that the structure of ERPs may give a mechanistic feel to care.

Foss (2009) identifies that reduced contact time between patient and nurse may be problematic and lead to a lack of opportunity to ask questions, meaning that the patient and their family may be discharged with unanswered questions. This combined with the lack of communication between the home environment and the hospital may result in patients feeling alone and unprepared for their recovery. Further to this, Foss notes that there is an increased need for nurses to deliver a variety of care, both physical and psychological, and that time constraints will add further pressure to communication. The wider remit of nurses also requires nurses to be more knowledgeable, resulting in a greater need for training to ensure that skills are adjusted for new practice (Mitchell, 2011).

# Individual experiences outside of the programme

The individual experiences of women outside of the programme allowed their participation in the ERP to be contextualised and underpinned their interaction with the ERP. The data in this section of the analysis gave a greater understanding of the experience of the women with regards to the period of diagnosis and treatment of gynaecological cancer, and also highlighted a number of general care practices that were highly valued by the patients.

## Time surrounding diagnosis and treatment

The initial time surrounding the diagnosis of cancer and the onset of treatment is a period of great stress for a number of reasons, and this is reflected in the coping literature discussed in the introduction to this thesis. Many of the women in this sample talk about their diagnosis and explain that for them, the period of ‘waiting’ which came before the diagnosis was problematic due to the uncertainty of their future, consistent with other research (Drageset, Lindstrøm & Underlid, 2010; Saegrov & Halding, 2004; Gurevich et al. 2002; Green et al.1998). Lazarus and Folkman (1984) suggest that the presence of uncertainty makes it difficult to decide whether anything can be done to evade, master, or even tolerate the harm or to decide on the forms of action that are likely to lead to a desired outcome. The women highlight that the quick onset of treatment offers a contrast to this period of time; at the point of diagnosis they were told about a subsequent treatment plan, and for the majority, surgery was their first definitive treatment (scheduled within a two week period). For many in this sample, the wait for surgery was much shorter in comparison to the wait for a diagnosis, with some women having as little as 24 hours between diagnosis and surgery.

The experience from the point of diagnosis onwards could be likened to getting on a conveyor belt of care, i.e. once a diagnosis had been obtained there was little to stop the treatment process. ERP is the first part of the treatment process for many and these women felt that that the programme is built for speed, in both terms of admission into hospital and returning home after surgery. This is further highlighted as women do not distinguish between ‘normal’ hospital process and the ERP. These women see that enhanced recovery includes the early admission into hospital for their operation as part of the programme rather than as the standard amount of time that women undergoing surgery for gynaecological cancer would have to wait. This adds to the overall perception of the programme, and reinforces the accelerated nature of the programme.

Many of the women in this sample feel pleased and/or relieved to start on the treatment journey. It allows them to take action about the threat that they have appraised from a diagnosis of cancer. Research by Stanton & Snyder (1993) suggests that distress and perceived threat were most pronounced shortly after diagnosis for cancer patients, and that after the surgery, stress levels lower significantly. The women view enhanced recovery as a way of being able to approach the problem that has been presented to them in the form of a diagnosis of cancer and give themselves the best possible start to treatment. Problem-focused coping is associated with greater personal control than emotion-focused coping (Folkman & Moskowitz 2004). Although these women were in a situation in which solving the problem, i.e. ‘getting rid of the cancer’, was objectively beyond their control, they were in a position to be able to regain the control of their recovery from the surgery itself. The women are thankful for the opportunity to take part in the programme, as they believe that this is the fastest route to recovery; whether that be from cancer on the whole (for those who only require surgical treatment) or in preparation for the next stage of treatment (for those who are yet to undergo chemotherapy or radiotherapy).

## The individual nature of care

The analysis suggests that the personal care is important to patients and this must be preserved if ERPs are rolled out. Although patients enjoy having their own space in the hospital in the form of single occupancy rooms, patients acknowledge that they do not want to be treated like a number or just ‘another patient’. HCPs need to be aware of the experiences and preferences of patients to ensure that other standards of care do not slip when ERPS are implemented. This is related to the previous discussion about implications for nursing practice. The role of the CNS is one that patients felt particularly strongly about; this appears to be essential for overall cancer experience, and may become particularly important for those on enhanced recovery whose care may become de-personalised in the ward environment. It is widely acknowledged that nurses and health care professionals are important sources of information for cancer patients and they provide support for patients throughout the cancer journey (Koutsopoulou, Papathanassoglou, Katapodi, & Patiraki, 2010; Rutten, Arora, Bakos, Aziz & Rowland, 2005; van Der Molem, 1999). However, when specifically looking at cancer care surrounding surgery and the change in focus for ward staff, it may be that the CNS needs to be involved more in the provision of information than previously expected. This may be beneficial, as research by Booth, Beaver, Kitchener, O’Neill and Farrell (2005) found that women who had initial support from a CNS at the time of diagnosis experienced a clinically significant reduction in their level of psychological distress six months from diagnosis in comparison to those who did not. Other research has also found that CNSs are important in the long term follow up of gynaecological cancer patients and have an important role in the recovery of QoL and sexual functioning after treatment (Maughan & Clarke, 2001).

It is conceivable that the increasing number of CNSs could assist in resolving some of the shortfalls in relation to the provision of enhanced patient information that is necessary as part of the ERP. Research by Luker et al. (1996) found that patients consider breast care nurses (a form of CNS) to be a better source of information than general staff. There is no universal agreement about the exact role of CNSs; however, it is generally accepted that one of the key aspects of the role is educator, in conjunction with advanced practitioner, researcher, consultant and change agent (Chuk, 1997; Smith, 1997). Although it has been suggested that patients with access to a CNS are more knowledgeable about their condition and more proficient in self-care, and that the CNS is a major resource to patients (Smith, 1997), it has also been recognized that it is difficult to confirm this through research (Smith, 1997). More research is required to establish the role of the CNS in patients coping with the diagnosis and treatment of cancer outside of the provision of information, and specifically with regards to the role out and facilitation of ERPs.

# ERPs and coping

Patients taking part in the ERP in this sample had recently been diagnosed with a gynaecological cancer at the time of their participation in the programme, and for the majority, their hysterectomy is their first definitive treatment. It can be seen from the analysis that many patients had little time between diagnosis and the commencement of treatment. Although this was preferable for many patients due to the prior knowledge about early treatment that is available from a number of sources, they reported that in some cases they had little time to prepare.

The conveyor belt approach to care after the receipt of a diagnosis raises a number of issues about how these patients cope with their cancer diagnosis. The patients in this sample suggest that they have little time to think about their long term plans, and that surgery is the immediate response to the threat of cancer. The early uptake of the programme and the focus on the physical aspects of preparation for surgery gave patients little time to adjust to the diagnosis and associated identity. It appears that the patients in this sample accept the diagnosis after a period of uncertainty associated with awaiting a diagnosis, and quickly move onto the treatment phase of their cancer ‘journey’, which is navigated with the help of health care professionals (such as the CNS).

Throughout the women’s talk about the ERP, there is little emphasis placed on the role of enhanced recovery with regards to patients’ coping style, which had previously been alluded to in other pieces of research (Wagner et al., 2004, 2005; Norlyk & Harder, 2009, 2011). Patients do not directly acknowledge that the immediacy of their treatment allows them to approach the threat ‘head on’, but some women do recognise that they do not want to be ill, and the ERP is a tool which they can use to return to a state of ‘normal’ more quickly. This drive to return to ‘normal’ is facilitated through the seeking out and use of information, the adherence to the programme and acknowledgement of their role in, and control of, their own outcome. This suggests that these women are using the programme as a form of problem focused coping as they desire to return to ‘normal’ more quickly, where ‘normal’ is embodied as the return to their home environment. This process is also indicative of patients desire to re-establish lost resources (e.g. mobility, food choice), and this is enabled through participation in the programme and an early discharge from hospital. Research suggests that the use of problem solving, seeking social support, and self-controlling strategies would be perceived as useful in ameliorating stressful situations such as surgery. Information seeking and use is seen as being helpful in making correct choices about how to proceed with events in a stressful situation (Hilton, 1989), and information seeking behaviours and maintaining control over the stressful situation are important strategies for decreasing any feelings of helplessness and hopelessness (Lazarus and Launier, 1978; Schmale, 1972).

Some women acknowledge that it is only when returning home that recovery from cancer begins (if they only require treatment in the form of an operation), suggesting that adjustment to the ‘new normal’ can begin when they return home. For other women in this sample, they view the ERP as a stepping stone to be able to go onto to have further treatment. Based on this, it appears that many women in this sample use the ERP as a tool for coping with the diagnosis and surgery for cancer. The programme provides them with a platform on which to base their approach to, and recovery from, their cancer diagnosis. Research by Stanton, Danoff-Burg &. Huggins (2002) suggests that early acceptance of a diagnosis of cancer prepares patients for taking an active approach to treatment and recovery and thus bolsters adaptation and adjustment. This process of acceptance may be crucial in the engagement of patients with the programme, where they are expected to take an active role in their own recovery, in turn increasing their adherence. If patients want to use the ERP as a form of problem focused coping, then the likelihood of them completing all of the steps for the ERP are high, as these are prerequisites to going home (i.e, early mobilisation was seen by some women as they key to going home). However, for others who have not accepted their cancer diagnosis and wish to adopt a more avoidant coping strategy, non-adherence to the programme may well become a way of prolonging their return to ‘normal’ (i.e. going home); however, this was not evident in this particular sample.

Within this study, the topic of adherence predominantly featured in the ‘getting mobile – keeping to the programme’ subtheme. Although the integrative model of health behaviour (Fishbein & Yzer, 2003; Fishbein, Cappella, Hornik, Sayeed, Yzer & Ahern, 2002; Fishbein, 2000) has already been identified as a potential model to explain why patients do not adhere to the instruction in terms of intention and behaviour for mobilisation, there is also the need to explore why patients may not adhere to the programme in terms of coping with their overall experience of cancer. On a practical note, improving patients’ adherence to the programme is particularly important for the institution since 80% of the relevant elements must be included by the institution to facilitate successful enhanced recovery (Department of Health, 2011b). Although this is a good benchmark figure for the institutions to work towards, this analysis has highlighted that even when the elements are provided for patients, the potential for poor adherence in areas such as carbohydrate loading, early mobility and early nutrition may well be influencing the number of elements that are received by patients. Similarly, the actions of the patients regarding being at home and their unwillingness to rest is also problematic for the role out of such programmes, and may affect the service outcomes that are currently measured in terms of length of stay and readmission rates.

In light of this, further research into the connection between ERPs and coping with the diagnosis and treatment of cancer needs to be explored to establish whether patients are using ERPs as a form of problem focused coping. Additionally, it would also be beneficial to further explore the impact of ERPs for women who have adopted emotion-focused styles as it is unclear how this style of coping may influence patient’s participation in and adherence to ERPs.

# Previous research

This interpretative phenomenological analysis has revealed a number of themes that are consistent with previous research from Norlyk and Harder (2009, 2007). Their research was conducted in a colorectal cancer patient population and utilised Reflective Lifeworld Research. Although their overall themes were slightly different, the main findings of the research were consistent with the themes discussed in this study. Both colorectal and gynaecology patients found the ERP to be beneficial; they highlighted that participating was a way of regaining control after a diagnosis of cancer and they wanted to take an active part in the programme. Both sets of patients also experienced the on-going battle between instruction and intuition. It appears that many patients on ERPs, regardless of their type of operation, found keeping to the ‘rules’ of enhanced recovery difficult. The findings of the research conducted by Norlyk and Harder had a greater emphasis on other parts of the ERP such as post-operative nutrition, whereas the main area that concerned gynaecological cancer patients was mobility. The post-operative nutrition and pain control was of little concern to the gynaecological cancer patients when asked about their experience, but many implied that it was because they were pain free that they were able to mobilise.

Norlyk and Harder found that the colorectal patients required more reassurance from the staff that they were correctly adhering to the programme. This was not reflected in the gynaecological sample. This may be because the gynaecological patients were mainly concerned with mobility, which was something that could be easily measured and recorded in order for patients to see their own achievements. The project lead for enhanced recovery at the Royal Derby Hospital encouraged patients to complete the milestones chart that was developed alongside the ERP. This detailed a daily list of tasks that the patient should aim to complete, and gave them reassurance that they were adhering to the programme. One of the milestone markers was the amount of time the patients spent being active, and the number of times they managed to walk a 60 meter distance (10 meter segments were marked out on the corridors of the ward). Patients used this as a prompt to be able to track their own progress and see that they were adhering to the programme.

Similarly to the colorectal patients, the gynaecological sample wanted to impress the staff and exceeding the expectations of staff acted as a motivator to continue with the programme. This was further extended in the gynaecological sample to include exceeding the expectations of significant others. The social pressures that Norlyk and Harder discuss with regards to reducing the waiting times was not reflected in the gynaecological sample – patients were more focused on their own experience, and that they would be able to go home sooner and start their recovery earlier than expected. There was little consideration of others, apart from the concern that some patients felt for those who were on the ERP who didn’t have a significant other to go home to, as they believed it would be difficult for them to manage.

The trust in the staff was also a concept that was apparent in the two samples. Both analyses identified that having trust in the staff was an integral part of the ERP for patients; they felt that they would not have been allowed to go home if they couldn’t manage. There was no mention of at home communication with the staff in the colorectal sample (perhaps because they are actually in hospital longer so go home with fewer questions and are further into their recovery), and this may be something that is unique to the programme at the Royal Derby Hospital. Once patients return home, the experiences of the two groups are reportedly similar.

# Limitations of this research

With regards to the study reported in these chapters, there are a number of limitations. Patients included in the analysis were recruited from a larger sample of women. All patients on the ERP within a given time frame were asked to take part, and out of 52 patients, only 21 wanted to participate (14 with gynaecological cancer). The group included in the present analysis is a self-selecting sample. These may have been the patients who have ‘something to say’ about the programme and chose this evaluation as an avenue for discussion. Further to this, the interviews were conducted after a considerable period of time for some patients (up to 8 months after the operation). For future research it may be beneficial to interview patients closer to the time of surgery. However, for this study it was difficult to interview participants who were still on active treatment, as they did not have time to participate, and in some cases, did not feel ready to explore their experiences of surgery.

This sample also consisted of older women. With a mean age of 66, there was little reflection of the breadth of ages of patients with gynaecological cancer. Younger patients were invited to take part but declined the offer. It would be interesting to compare the experience of young patients (i.e. those with cervical cancer) with that of the older generation to explore the impact of age on the perception of the programme and their expectations. In addition to this, all patients in this sample were returning home rather than an alternative place of discharge such as a nursing home or a long term hospital bed. Research by Brasel et al. (2007) suggests that patients who return to a destination other than home experience longer lengths of stay than those who return home. As the current analysis had such a large focus on home and the role of home in enhanced recovery, additional research with a diverse patient group is required to effectively explore other experiences outside of this particular group.

# Further research

The limitations of this study have highlighted a number of issues for further research in the area, for example, the need for a patient information intervention with regards to getting out of bed, post operation exercises and what to look out for if there is a problem. This suggestion is based on the outcome of this study and regular consultation with the gynaecological cancer support group (One Voice). It is intended that this will be generic for gynaecology patients – rather than just gynaecological-oncology. It may be a cost-effective addition to the bank of resources available, as funds to increase the provision of services are limited within the Derby Hospitals Trust.

There is also a need for research to be carried out to explore the experiences of carers and/or significant others who are responsible for patients on ERPs. There is little research about the experiences of the patients themselves, and no research to date on the lived experience of the significant others. This is important research to establish what is happening to these people, and if there are any interventions that would be beneficial to assist them. I have speculated about some of the issues in this analysis based on the experiences of the patients themselves, but research with the individual in this unique situation would yield more pertinent results.

There is a gap in the literature relating to the role of home with regards to recovery from cancer. It is unclear what it is about home that makes it synonymous with recovery. There has been some research into space, place and identity, but this is mainly with regards to environmental and building design, or about delivering formalised care in the home. There is little research available that is specifically in the remit of health, specifically the role of home in the recovery from illness, unless it is regarding transition from home to a care home. As a result of the current findings it appears to be an ‘obvious’ area for research, that would give a greater insight into the role of home for cancer patients and allow for more detailed intervention planning for social care services.

The idea that patients will be going home sooner with the possibility of having unanswered questions or having not been psychologically prepared fully for discharge, implies that greater resources may well be called in from the community nursing team, leading to an increased workload for district nurses (Foss, 2009). This requires on-going research to establish the impact of enhanced recovery on district nurses, social workers and GP services. If ERPs are pushing care out of the hospital into a community setting that cannot cope, then the overall impact of the programmes on health (and cost) may not be as beneficial as first thought.

Finally, it would be beneficial for research to be conducted into the patient experience of on-going ERPs. This sample was taken from the point of the intervention going live, and explores the experience of patients in a relatively new programme. It would be interesting to explore the changes in the patient experience after 2 years of implementation, when the programme is more established. Studeis might focus on what the standard of service still the same, and what the implications may be for patient experience. ERPs are being rolled out across the UK in a number of different disciplines, so evaluations of established programmes may be valuable to institutions currently implementing similar initiatives.

# Conclusion

Through this study, a number of areas have been highlighted which give insight into the lived experience of patients taking part in ERPs and as a result there is now a previously unseen view of gynaecological cancer patients on ERPs in the UK. The role of ERPs in the facilitation of coping has also been explored, and has highlighted that further research is required to fully explore the role of ERPs with regards to the overall patient journey and how women cope with cancer diagnosis and treatment. In light of these findings, this research has provided a number of recommendations for practice that have been developed from patient reported outcomes of participation in the programme. These may have previously remained unnoticed without the implementation of qualitative research.

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# An extract from Sheila…

*During my time in hospital both myself and my husband have never felt alone (we knew there was always someone there if we needed them). We are both very grateful for this. It boosted my morale and confidence to have been selected for the enhanced recovery programme. I cannot praise the team enough for all that has been done for me and for giving me this opportunity. It was only later that I found out that I was the first patient to undergo the Enhanced Recovery Programme in Derbyshire. I have since taken part in the making of a DVD at the hospital as part of the team to promote Enhanced Recovery for gynaecological cancer patients. The DVD was put forward as one of 100 entries in the hospital’s “Celebrating Success” and it won the category “Putting patients first”.*

*When I was in hospital, I was asked if I would like to take part in a research study to explore the use of yoga as a complementary therapy for patients with gynaecological cancer and the impact practicing yoga can have on quality of life. I told them that I was more than happy to take part. I thought it sounded interesting, and I wanted to help in any way that I could.*

Study 2

# Yoga and quality of life for patients receiving treatment for gynaecological cancer:

# A randomised controlled trial

Chapter 6: Introduction

The following chapter firstly introduces complementary and alternative medicine, and the extent to which these are used within the wider cancer and gynaecological cancer populations. The chapter then goes on to discuss one particular complementary therapy – yoga. The use of yoga, and its links to quality of life (QoL) are explored through the presentation of relevant previous literature. Finally, the rationale, aim and objectives of this research are presented along with the hypothesis for this study.

# Complementary and Alternative Medicine

There is no universally accepted definition for Complementary and Alternative Medicine (CAM) (Research Council for Complementary Medicine, 2012). The World Health Organisation (WHO) states that the terms "complementary medicine" or "alternative medicine" are used inter-changeably with traditional medicine in some countries. They refer to a broad set of health care practices that are not part of that country's own tradition, and are not integrated into the dominant health care system (WHO, 2012). The Cochrane Collaboration defines CAM as “a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period” (1997, p.50). This definition is broader and more encompassing of the holistic nature of CAM.

Although referred to as one entity, CAM includes two distinct areas – complementary therapy/medicine and alternative medicine. A standardised definition of complementary medicine is "diagnosis, treatment and/or prevention which complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy or by diversifying the conceptual frameworks of medicine" (Ernst, Resch, Mills, Hill, Mitchell, Willoughby, & White, 1995, p.2551). In contrast to complementary therapies/medicine, “alternative therapies are promoted not to complement mainstream medicine, but to substitute for it” (Ernst & Cassileth, 1998, p.777). To put it simply, complementary therapy/medicine typically works alongside, whereas alternative medicine actively replaces conventional medical treatment. This introduction will focus on complementary medicine, which is in line with this study, rather than alternative medicine.

Since CAM is difficult to define, there are a number of practices recognised as CAM by many governing bodies and institutions. In general there are seven major categories of CAM which include: Mind-body interventions, traditional or folk remedies, special diets or nutritional programmes, herbal medicine, manual healing, chemical or pharmacological agents, and bio-electromagnetic applications (Von Gruenigen, White, Kirven, Showalter, Hopkins & Jenison, 2001). Although the definition of CAM is wide to encompass as many approaches as possible, Ernst and Cassileth (1998) highlight that many research papers include anything that occurs outside of mainstream treatment as CAM. In some cases this is problematic, since any wellness regimen or other non-CAM activity may be regarded by patients as CAM.

# General characteristics of CAM users

In a review of the characteristics of all users of CAM (regardless of any specific health concern or demographic), a comprehensive narrative review of published papers (n=110) by Bishop and Lewith (2008) identifies a number of characteristics of CAM users worldwide (the majority of the papers (64%) were reports of research carried out in America). Users of CAM are predominantly female, which is not surprising as it is widely acknowledged that females utilise healthcare services more than men. Higher levels of education were also linked to increased CAM use, although income was not an associated factor. Bishop and Lewith highlight that further research needs to be carried out to explore the link between ethnicity and CAM use, as there is not enough established data available to fully understand the association between the two. In addition, they also state that there is little consensus between CAM use and age. The body of literature suggests that CAM use is associated with people who have chronic conditions rather than life threatening ones; specifically, there is no established link between having cancer and CAM use. To conclude, it appears that there are some characteristics that are consistent amongst CAM users world-wide, but more research is required to establish these within particular cultural contexts and in particular disease populations.

# CAM in the UK

There has been a rapid increase of CAM use across the world since the 1970’s, and the UK is no exception, although usage figures are lower than those in the United States of America, Germany, Australia or Japan (Ernst & Cassileth, 1998). In 2010, Hunt et al. attempted to update previous UK data collected in 1998 (Thomas, Nicholl & Coleman, 2001), but found that the 12 month prevalence estimate and the lifetime prevalence estimate was similar to the original figure. The research, which used a large sample (n=7630), was able to identify a more detailed description of the individuals who use CAM in the UK. Users of CAM in the UK are more likely to be female, white, well educated, own their own home, have above average income and be active in employment. In addition to this, the health characteristics of CAM users are that they are obese, have no mobility problems, have pain, anxiety or depression and have a longstanding health issue. CAM users also perceived that they had lower levels of social support and poorer psychiatric health in comparison to non-users. With regards to lifestyle characteristics of those who use CAM, individuals are more likely to be religious, non-smokers who eat the recommended 5 portions of fruit and vegetables per day and also take vitamins.

Research by Thomas et al. (2001) indicated that over 1 in 3 people in the UK have visited a CAM practitioner in their lifetime. Visits to acupuncture, chiropractic, homeopathy, medical herbalism, hypnotherapy and osteopathy practitioners were for musculo-skeletal problems (71%), other health problems (24%) and general health maintenance (5%). Visits to reflexology and aromatherapy practitioners were for musculo-skeletal problems (25%), other health problems (15%), general health maintenance (8%) and relaxation (39%). The remaining 13% of aromatherapy and reflexology users described their appointments as non-health, indicating that these were included as part of a beauty regimen or spa day experience/gift. Thomas et al. also estimate that expenditure on CAM was approximately £108 per CAM user, per annum, which equates to between 450-580 million pounds being spent on the previously mentioned 8 CAM therapies (with a proportion of this being paid for by the NHS – estimated at £50-55 million).

# Cancer and CAM

Lorenc, Peace, Vaghela & Robinson (2010) identified that the number of cancer patients using CAM in the UK ranges from 7% to 64%, other articles report up to 80% (Brigden, 1995). Further research by Yates et al. (2005) states that over 90% of cancer patients in their sample (n = 752) were using at least one form of CAM, and 80% were using between one and four different types of CAM during their treatment period. Most patients use CAM as complementary to conventional treatment regimens rather than as a viable alternative. However, McGinnis (1991) suggests that approximately 5% of cancer patients choose an alternative method of treatment over a conventional treatment regimen. Ernst and Cassileth (1998) suggest that the view of CAM in cancer care is changing; CAM is becoming more familiar in the mainstream setting and oncologists are more willing to explore CAM as a method of treatment. Ben-Ayre, Schiff, Steiner, Keshet & Lavie (2012) suggest that patients expect their family doctors and oncologists to refer patients to CAM services, and that oncologists are becoming increasingly expected to build CAM into their treatment regimen as an integrated care package.

There have been a number of observations made about the use of CAM and of the expectations of the users. Vincent and Furnham (1996) suggest that people choose to participate in CAM because they believe in the value of alternative care (i.e. care available outside of the NHS), their previous experiences of conventional medicine have been ineffective, and they are concerned about the associated side effects of treatment. Additionally, patients may have experienced poor communication with conventional health care practitioners/providers. Further to this, a number of papers have highlighted that the need for personal control is a motivator for using CAM (Astin, 1998; Warwick, Irish, Morningstar & Gilbert, 1999), as many patients report that they feel they have reduced control of their health and its treatment. Research by Davidson, Geoghegan, McLaughlin & Woodward (2005) suggests that those who opt to use CAM possess an internal locus of control with regards to their recovery, meaning that patients’ decision making and subsequent responsibility for their overall recovery is important to them.

A number of research papers have indicated that CAM use in cancer may be predetermined by those who have later stage disease as a last attempt when conventional methods of treatment have been unsuccessful (Burstein, Gelber, Guadangoli & Weeks, 1999; Kao & Divine, 1999). Later research by Davidson et al. (2005), suggests that there is no association between the use of CAM and the stage/outcome of disease, and that CAM use is a pro-active choice to “improve general well-being and relaxation” (p.193).

# Provision of CAM services for cancer patients in the UK

There is little provision of CAM services for cancer patients on the NHS, with only 142 CAM centres being distributed throughout the whole of the UK (Egan, Gage, Hood, Poole, McDowell, Maguire & Storey, 2012). The national survey by Egan et al. highlights that the distribution of CAM centres is weighted towards larger cities, with a deficit in the centre of the country meaning that a “significant number of people” live far from a CAM unit (p. 79). It is widely reported (Thomas et al., 2001) that users of CAM (including cancer patients) access and pay for CAM services that are outside of the NHS (around 90%). This is supported by Gage et al. (2009) who suggest that only 15.8% of cancer patients utilise a specialist NHS integrated cancer treatment centre located in the South East of England, although estimated numbers of patients using CAM is much higher.

## Demographics of cancer patients who use CAM

When specifically looking at cancer patients who use CAM, Gage et al. (2009) and Wyatt, Friedman, Given, Given & Beckrow (1999) identify that these are predominantly young, female, live local to the treatment centre and have a higher level of education (with the majority having been to college or University). Further to this, a number of studies have identified that breast and gynaecological cancer patients use CAM most out of the cancer patient population (Kimby, Launso, Henningsen & Langgard, 2003; Gage et al. 2009). Other researchers, such as Markovic, Manderson, Wray & Quinn (2006), suggest that factors such as higher social economic status and marriage are indicative of CAM use, as well as “a longer history of illness and a disease which has poor prognosis from medical treatment” (p.210).

## CAM use in gynaecological cancer patients

Although it is acknowledged that gynaecological cancer patients are the most frequent users of CAM after breast cancer patients (Kimby et al., 2003; Gage et al., 2009), there is relatively little research in this area; what has been conducted is based mainly in the USA, Australia, the UK and Israel. Research conducted by Molassiotis, Browall, Milovics, Panteli, Panteli, Patiraki & Fernandez-Ortega in 2006 looked at the patterns of CAM use in gynaecological cancer patients within Europe, covering 11 different countries. Over 40% of patients in the sample (n=72) used CAM, and on average used 2 different types, with herbal medicine being the most popular. The main justification for using CAM was to increase the body’s ability to be able to fight cancer, to improve both emotional and physical well being as well as increasing hope/optimism. They found that patients who did not use CAM were happy with the prospects of their current treatment (Molassiotis at al., 2006). This is consistent with the findings of Vincent and Furnham (1996) who looked at cancer patients with a variety of diagnoses and cancer sites.

A number of other papers have been published in relation to gynaecological cancer patients and their use of CAM; Molassiotis et al.'s (2006) paper is the only one to focus on gynaecological cancer in Europe – others focus on other westernised populations outside of Europe (mainly America and Australia). Research from a number of sources suggests that gynaecological cancer patients use CAM to control or alleviate side effects from conventional medical treatments and to boost the immune system; use is also attributed to poor prognostic outcomes from conventional treatment (Stewart, Duff, Wong, Melancon & Cheung, 2001; Von Gruenigen et al., 2001). Research carried out by Markovic et al. (2006) in Australia suggests that around one third of gynaecological cancer patients use some form of CAM. Those who do not use CAM list reasons such as cost, lack of information, recent diagnosis, and reluctance to discuss their illness with strangers. However, the large proportion of ovarian cancer patients (with a late stage diagnosis) in this study, meant that patients “entrusted themselves to gynaecological oncology treatments more readily” (p.212).

Further to this, Markovic et al. (2006) identified four different types of CAM user in their sample (N=53). Some women linked their past life experiences (both physical and emotional - i.e. diet, stress & exposure to chemicals) to their diagnosis of gynaecological cancer, and used CAM to address these experiences because they felt that conventional medicine offered little reason or treatment for their cancer. These patients were labelled as consequential users of CAM. Therapeutic users sought CAM to alleviate the side effects of conventional medical treatment. Informed users are similar to consequential users but spent less time analysing the cause of their cancer and linking it to past experiences. Instead, they spent more time focusing on the future and preventing reoccurrence. These patients generally believed in the efficacy of conventional medical treatments, but wanted to maximise their health outcomes through the use of CAM. Finally, exploratory users were those that had received a late stage diagnosis and were focusing on the use of CAM to combat a poor prognosis and the limitations of conventional medical treatments.

Research in America by Von Gruenigen et al. (2001) looked at perceived effectiveness, monetary investment and insurance reimbursement in gynaecology patients (including those with cancer). Over half of the total sample (both benign and cancer groups) (n=529) used CAM and only 36.1% of those that were using CAM had communicated this to their doctors. The most common therapies were nutritional supplements, prayer as medical therapy and green tea. It was reported that 72% of the cancer patients using CAM believed that the therapies were helpful. These patients were more likely to communicate their use of CAM with the health care professionals (39.3%), although this is not a large increase compared to the group as a whole. This paper highlights the high prevalence of CAM use in the area of gynaecology (both benign and cancerous). Use in gynaecological cancer is relatively high in comparison to some estimations (Lorenc, Peace, Vaghela & Robinson, 2010). The number of patients not communicating their CAM use with their health care professionals is especially concerning, since using herbal or nutritional CAM may be contraindicative to mainstream medical treatment (Shannon, 1993; Ernst, 2000; Swisher, Cohn, Goff, Parham, Herzog, Rader, & Mutch, 2001).

Swisher et al. (2001) found that CAM use in gynaecological cancer patients was characterised by previous CAM use (pre diagnosis), and that CAM users were more religious. Having cervical cancer was a strong predictor of non CAM use, and the authors attribute this to lower income and lower education of patients with this cancer type, although this finding has not been reported in any other literature surrounding gynaecological cancer and CAM. Swisher et al. found that 46% of their sample of CAM users (n=56) had used ingestible CAM (herbs, vitamins and teas) and 79% had used some form of psychological therapy. Many patients wanted to directly fight their cancer with CAM and had a desire to increase the body’s ability to fight cancer. There is some consistency here with the ‘types’ of users found by Markovic et al. (2006). Swisher et al. also found that patients’ perceived benefit of these two desires was significantly lower – suggesting that patients’ experiences of CAM were not meeting their expectations, but they still continued to use it. Patients found that they were getting the most perceived benefit in terms of emotional well-being, and only 4% of patients felt that they were getting no benefit from CAM.

Navo et al. (2004) looked at CAM use in breast and gynaecological cancer patients. Although they only looked at a small range of CAMs in comparison to what is available for patients, they found results consistent with other studies (just considering their gynaecological cancer patient results). It was found that over 45% of patients in their sample (n=250) used CAM, and that the most popular CAMs were the ingestion of Glucosamine and Chondroitin and the use of vitamin E as a mega-vitamin (sometimes up to 10 times the recommended daily allowance). Patients were using CAM alongside conventional medical treatment and other over the counter remedies, but no patients were using CAM as an alternative treatment for their cancer. The use of CAM was significantly associated with disease status, with newly diagnosed patients using CAM the least, those in remission the most, and those with relapsed or recurrent disease falling between the two extremes. The research found that there was an association between level of education and CAM use, with the more educated using more CAM - this is consistent with other literature (Bishop and Lewith, 2008). It was reported that 60% of patients using CAM believed that it was safe and effective, but only 28% of the total sample considered CAMs as a type of medication. Patients’ main motivations for using CAM were to improve overall health and wellbeing, and to treat cancer.

Research conducted in Israel by Ben-Ayre et al. (2012) supports previous research in the gynaecological cancer patient population; they suggest that over 40% of patients are using CAM and use continues through chemo and radio therapy treatment. The research also highlights that the expectation for integrative care has now evolved, and patients actively seek the integration of services into their standard medical care. The study found that CAM use was significantly higher in their gynaecological cancer population (67/106) when compared to the population of breast cancer patients (73/166). Touch/movement and healing/energy therapies as well as traditional Chinese medicine were the top modalities of CAM used in both groups. CAM focused nutritional counselling was also popular in the gynaecological cancer group. The study found that ‘younger’ patients were more likely to use CAM, but that a lesser degree of self-assessed religiosity was associated with CAM use. Ben-Ayre et al. highlights that complementary and integrative approaches to CAM are dominant, and that the alternative approach is not supported by the patient population in Israel. The patient focus was on avoiding harm as well as improving coping and well-being rather than a curative treatment for cancer.

To conclude, the literature that surrounds CAM use in gynaecological cancer is varied, and demonstrates the different approaches to studying this patient population. The definitions of CAM are inconsistent throughout the literature. Many pieces of research do not access information about the specific aspects of gynaecological cancer (rather than cancer in general) that patients are trying to target with CAM. Patients appear to use CAM for a variety of reasons and the perceived benefit is varied. The review of the literature also identifies that there is very little research into CAM use by gynaecological cancer patients in Europe, and especially in the UK. As the USA and Australia have different models of health care, the results from these studies may not be valid or applicable to a UK gynaecological cancer population.

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# Yoga

Yoga is the 17th most frequently used CAM therapy offered by the NHS in the UK, (behind other CAMs such as aromatherapy, relaxation and acupuncture), and it is offered in 14.1% of NHS cancer CAM centres (Egan et al., 2012). Yoga is becoming increasingly popular in the health domain as it is a mind and body intervention that is easily accessible, and can be practiced without any specialist equipment on an individual basis or in a group setting (Hagins, Morre & Rundle, 2007). The literature suggests that gentle exercise such as yoga may help to promote regular participation in physical activity, and reduce some of the barriers that are experienced by those with chronic health conditions (Culos-Reed, Carlson, Daroux & Hately-Aldous, 2006; Brawley, Culos-Reed, Angrove & Hoffman-Goetz, 2002).

The Sanskrit word ‘yoga’ is translated as ‘union’. The British Wheel of Yoga (BWY) states that “The practice of yoga helps to co-ordinate the breath, mind and body to encourage balance, both internally and externally and promote feelings of relaxation and ease” (BWY, 2012). The BWY is an umbrella organisation for a number of different schools of yoga and is recognised as the ruling body by the British Sports Council (De Michelis, 2004). Yoga includes a number of different aspects; the physical aspects of yoga encourages users to perform a number of postures or *asanas* (seat), and classes also include breath work/exercises or *pranayama* (*prana* = life force or energy source, *ayama* = to control), and as meditation or *dhyana*. Yoga is described as “a rich treasure of physical and mental techniques that can be effectively used to create physical and mental well-being” (Jayasingha, 2004, p.369).

Yoga for health usually focuses on ‘hatha yoga’. The term 'hatha yoga' covers all types of physical yoga which places an emphasis on postures with breathing and relaxation. Hatha yoga is suitable for all ages and levels of ability and is an ideal starting point for beginners. Ancient texts regarding ‘*hathayoga*’ are explicitly anti-sectarian and Universalist, and state or imply that anyone can practice yoga (Malinson, 2012). Modern day classes that are described as 'hatha' tend to involve slow-paced stretching with some simple breathing exercises and meditation (BWY, 2012).

## Using yoga for health

It is estimated that around 15 million Americans have used some style of yoga in their lifetime, and over half of these have used yoga to manage their health problems, prevent ill health or to improve wellbeing (Saper, Eisenburg, Davis, Culpepper & Phillips, 2004). There are no current figures for the number of people practising yoga in the UK. However, the Chief Executive Officer of the BWY estimates that there are over 11.8 million 'people sessions' delivered by British Wheel teachers per annum; although the BWY is the largest yoga organisation in the UK, it is probable that a similar number of teachers are affiliated to other organisations. In total, this suggests that there may be 24 million 'people sessions' of yoga delivered to UK residents per annum (Bibby, 2012).

Yoga has been linked to a number of health benefits including increased strength and flexibility (Raub, 2002; Tran, Holly, Lashbrrok & Amsterdam, 2001), decreased perceived stress and lower levels of salivary cortisol (West, Otte, Geher, Johnson & Mohr, 2004) as well as reduced anxiety (Smith, Hancock, Blake-Mortimer & Eckert, 2007). Further to this, yoga also appears to improve subjective measures of fatigue, pain and sleep in both healthy and ill populations (Ross & Thomas, 2010). In addition, yoga has had encouraging results surrounding reduction of depression and depressive symptoms (Uebelacker, Epstein-Lubow, Gaudiano, Tremont, Battle & Miller, 2010). One of the biggest areas of benefit for yoga practitioners is in relation to increased QoL in both healthy and ill populations (Goncalves, Souza Vale, Barata, Varejao & Dantas, 2011; Woodyard, 2011; Sharma, Gupta & Bijlani, 2008; Mastangelo, Galantino & House, 2007).

# Quality of Life

QoL is defined by the World Health Organisation (WHO) as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to the goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment” (WHO, 1997, p. 1).

## Quality of life as a patient reported outcome measure

Since the 1960’s, QoL has been emerging as a useful outcome measure by which to judge the efficacy of psychological interventions (Cummins, 1997; Rapley, 2003). Health-related QoL is a multi-dimensional dynamic concept that encompasses physical, social and psychological aspects associated with a particular disease or its treatment (Guyatt, Feeny & Patrick, 1993). For the purposes of this research, the discussion will focus on health related QoL. In 1985, the Food and Drug Administration’s (FDA) decision to require QoL data as one of the ‘Key efficacy parameters’ in a clinical trial for new anti-cancer agents paved the way for QoL measurements to be used as important trial outcome indicators. QoL is particularly important in relation to the approval of new medical treatments for cancer. Without adequate measures for baseline QoL pre-treatment, it is difficult to establish whether any change in QoL is due to the treatment or simply due to the disease itself (Jones, Ledger, Bonnett, Radley, Parkinson & Kennedy, 2006).

## QoL and Cancer

Improving QoL is one of the three goals of cancer treatment (alongside improving cure rate and lengthening survival time), and is becoming increasingly important in the cancer and healthcare literature (Penson, Wenzel, Vergote and Cella, 2006). This literature review focuses on the QoL of those on ‘curative’ or ‘active’ treatment. For patients, managing of the active treatment has been termed the ‘acute survival’ phase – here, patients attempt to manage existential concerns and aggressive treatment. This is followed by an ‘extended survival’ phase where patients manage the late effects of treatment and social re-entry (Walton, Reeve, Brown & Farqhar, 2010; Mullan, 1985).

## QoL concerns for gynaecological cancer patients

Research suggests that gynaecological cancer patients’ emotional well-being and QoL is related to their cognitive, emotional and behavioural responses to diagnosis and symptoms (Gould, Brown & Bramwell, 2010). Both the diagnosis and treatment of gynaecological cancer is stressful for women, resulting in a reduction of both physical and psychological functioning (Costanzo et al., 2006). A diagnosis of gynaecological cancer is particularly distressing for some patients as it involves an area of the body that is internal and particularly intimate; the body parts involved are “emotionally charged” as they are associated with femininity, sexuality and reproduction (Hersch, Juraskove, Price & Mullan, 2009, p.795).

A systematic review by Chase and Wenzel (2011) highlights that QoL data is an important outcome measure for RCTs looking at gynaecological cancer. Further research by Hess & Stehman (2012) showed that whilst there were only 12 studies exploring QoL issues in ovarian cancer patients in 1996, in 2011 this had risen to 139, suggesting a cumulative increase in published research (and subsequent knowledge) in this area.

## Treatment of gynaecological cancer and QoL

Research suggests that gynaecological cancer patients’ QoL is most negatively affected from the point of diagnosis through to the completion of treatment (Pearman, 2003). Treatment for gynaecological cancer is often multi modal and includes surgery, chemotherapy and radiotherapy, all of which have been linked to decreased QoL. Common side effects of treatment include: fatigue, pain, hair loss, nausea, peripheral neuropathy, taste alteration, increased stress and anxiety, decreased mood, and diarrhoea; it is not surprising that many of these side effects impact on a patient’s QoL (Gamper et al., 2012; Klatersky & Lossignol, 2011).

It has been suggested that decreased QoL is relative to the amount of treatment received (Costanzo et al. 2006). Ovarian cancer patients receiving multiple chemotherapy courses are more likely to show depression, anxiety and reduced social and emotional well-being in comparison to patients who receive a single course of chemotherapy (Bodurka-Bevers, Basen-Enquist, Carmack, Fitzgerald, Wolf, de Moor & Gershenson, 2000; Lutgendorf, Anderson, Rothrock, Buller, Sood & Sorosky, 2000). Patients who have ongoing courses of chemotherapy report a continued deterioration in QoL (Guidozzi, 1993). As with many studies regarding QoL and treatment modality, further research is needed to clarify the varying results found in the literature (Zhao, Kanda, Liu, Mao, 2003). In general, chemotherapy is thought to improve the QoL of gynaecological cancer patients over a single course of treatment. However, this is dependent on the type and combination of chemotherapy drugs or medicines given to combat side effects of treatment (Le, Leis, Pahwa, Wright, Ali, Reeder, Hopkins & Fung, 2004; Smyth, Bowman, Perren, Wilkinson, Prescott, Quinn, & Tedeschi, 1997).

Radiotherapy results in patients feeling worse at the end of the treatment, with problems mainly manifesting in diarrhoea, appetite loss, nausea and fatigue; however these effects are not long lasting (Klee & Machin, 2001; Bye, Ose & Kaasa, 1995) and are reduced or even completely removed at 3 months post treatment (Klee, Thranov & Machin, 2000). With regards to surgery for gynaecological cancer, Sood, NyGaard, Shahin, Sorosky, Lutgendorf & Rao (2002) describe that many women report a decrease in physical functioning up to 6 weeks after surgery despite the new techniques that are being integrated into surgical procedures (such as nerve saving surgery) to preserve function in the pelvic area (Rob, Halaska & Robova, 2010; Smith, Del Priore, Coleman & Monaghan, 2011). This is due to the restrictions in movement and requirement for rest and recuperation after surgery. Sood et al. (2002) describe that between the operation and the 6 week follow up patients reported an increase in emotional well-being but no significant increase in social well-being, due to a significant increase in anorectal dysfunction associated with flatus and fecal incontinence.

There is a need for further research into the effects of treatment on patient QoL (Jones et al., 2006) and this is supported by this updated review of the literature. On the whole it appears that patients experience an increase in QoL after treatment, and it is the treatment regimen itself that has the negative effect on QoL (multi-modal treatment had a greater negative effect on QoL in comparison to those treated with surgery alone). The negative effects of treatment are generally reduced to that of other cancer survivors and healthy women after 1-2 years (Pearman, 2003). In addition, there is research to suggest that there is little difference between QoL in cancer patients in comparison to healthy controls after 5 years (Li, Samsioe & Iosif, 1999). This would suggest that interventions to improve QoL for gynaecological cancer patients should target the period of time where patients are undergoing treatment and for the year post treatment (Chase, Watanabe & Monk, 2010). After this period of time, patients’ QoL begins to return to a level that is consistent with other cancer patients and healthy women (Wenzel, Donnelly, Fowler, Habbal, Taylor, Aziz & Cella, 2002; Greimel, Thiel, Peintinger, Cegnar & Pongratz, 2002).

## CAM, Quality of Life and Coping

The use of complementary therapy is widely acknowledged as a tool for coping with the diagnosis and treatment of cancer. Widely available resources from Macmillan state that complementary therapies “can be a good way of helping you cope with some of the stresses caused by cancer and cancer treatments” (Macmillan Online, 2013). The research evidence available in the health literature is generally supportive of this view, suggesting that complementary therapies can be useful in reducing the symptoms of cancer, as well as reducing the side effects of treatment (Deng & Cassileth, 2005). Other research suggests that CAM use is also beneficial to cope with the rigour of clinical trials (Sparber, Bauer, Curt, Eisenberg, Levin, Parks & Wootton, 2000). Sparber et al., (2000) suggest that nurses should evaluate patients' use of CAM with a view to providing QoL therapies such as relaxation, imagery, or healing touch, and that the discussion about these health practices will add to the assessment of patients' coping skills and ability to make decisions about their health care.

The relationship between coping strategies and QoL has been established in a number of studies, with more active coping strategies generally being associated with better QoL (Avis, Crawford & Manuel, 2005 ; McCaul, Sandgren, King, O’Donnell, Bransetter, & Foreman, 1999 ; Sears, Stanton & Danoff-Burg, 2003 ; Sehlen, Hollenhorst, Schymura, Herschbach, Aydemir, Firsching, & Dühmke, 2003 ; Stanton et al., 2000). Previous findings suggest that women with breast cancer who use strategies such as positive cognitive restructuring (i.e. positive reappraisal), acceptance, emotional processing, or emotional expression have better QoL than those who use more passive coping strategies such as avoidance or minimizing importance of their cancer (Avis et al. 2005 ; Lazarus and Folkman, 1984 ; McCaul et al. 1999; Sears et al. 2003 ; Sehlen et al. 2003 ; Stanton et al. 2000). With regards to gynaecological cancer, coping strategies are thought to play an important role with respect to managing the physical and psychological outcomes of cancer diagnosis and treatment (Costanzo, Lutgendorf, Rothroack & Anderson, 2006). Early research by Lutgendorf and colleagues suggests that coping strategies that could be characterised as engagement or attentional coping are associated with positive outcomes, including improved QoL, improved social well being, improved doctor patient relationships, reduced distress, improved functioning status and improved clinical status (Lutgendorf, Anderson, Larsen, Buller & Sorosky, 1999; Lutgendorf, Anderson, Rothrock, Buller, Sood & Sorosky, 2000).

Other research has indicated that instrumental or active coping techniques are associated with better outcomes when patients perceive better control over the stressor in question (Costanzo et al., 2006). Previous research by Osoweicki & Compass (1998) suggests that adult cancer patients who use problem-focused coping strategies and perceive more control of the progression of their cancer report less anxiety and depression. Later research by Sollner, Maislinger, DeVries, Steixner, Rumpold & Lukas (2000) suggests that the use of information seeking and active problem-focused coping styles were the strongest independent predictors of interest in or use of CAM; cancer patients may regard the use of CAM as a way of actively and independently contributing to the treatment of their disease, allowing them to take control of one aspect of their treatment (Montbriand & Laing, 1991; Fryback & Reinart, 1997). In view of this, it could be thought that the uptake of CAM may be the result of patients adopting an active, problem-focused coping style, which in turn may have a positive effect on their QoL.

# Yoga and QoL in Cancer

As yoga has been identified as beneficial to both psychological and physical well-being, it is not surprising that there is a body of research which explores the impact of yoga on QoL and its associated factors in the cancer population. One of the first published studies (Joseph, 1983) exploring the use of yoga as a psychological therapy for cancer patients found that patients reported increased appetite, improved sleep, improved bowel habit and a feeling of peace and tranquillity. Although the yoga intervention (run alongside a Transcendental Meditation class and a group therapy programme) was not the most popular of the three interventions, it did highlight that several issues surrounding QoL for cancer patients (both then and now) could be addressed through the practice of yoga.

Other, more recent papers looking at cancer patients and yoga have suggested that yoga is a feasible intervention for a wide range of cancer patients and survivors (Bower, Woolery, Sternieb & Garet, 2005). Research conducted by Duncan, Leis & Taylor-Brown (2008) explored the use of Iyengar yoga with cancer patients (any individual diagnosed with cancer). They found that that a 10 week course of yoga for patients who were on active treatment had a significant reduction in their most bothersome symptom, increased QoL and spiritual well-being, and decreased levels of mood disturbance. In addition, QoL improved and mood disturbance was reduced at 6 week follow up, suggesting that yoga may have a long term effect, although the mechanism for long term efficacy has not been explored. As well as this, research by Sohl, Danhauer, Schnur, Daly, Suslov & Montgomery (2012) found that women with ovarian cancer (n=7) who participated in up to three 15-minute sessions of yoga skills therapy (consisting of awareness; body movement and breathing/relaxation) during regularly scheduled chemotherapy for ovarian cancer, reported decreased anxiety and increased relaxation (pre-post individual session measures). Sohl et al. argue that these preliminary results support the feasibility of implementing a yoga skills intervention, although the small sample size and subsequent lack of rigourous statistical analysis makes this somewhat difficult to justify.

# Research into the efficacy of yoga for cancer patients

It has already been established that out of all cancer patients who use CAM, breast cancer patients utilised services outside of the traditional treatment regimen most often (Kimby et al., 2003; Gage et al., 2009). With this in mind, it is not surprising that the largest body of literature surrounding the efficacy of yoga for cancer patients looks at the breast cancer population. Recent systematic reviews of the literature surrounding yoga for cancer patients highlight the paucity of research into the efficacy of yoga for patients who do not have breast cancer. Separate systematic reviews by Smith and Pukall (2009) and by Lin, Hu, Change, Lin & Tsauo (2011) both highlight that only 3/10 papers suitable for inclusion in their publications were conducted outside of the breast cancer population. Although more research is underway or in preparation for publication, there is still a deficit in comparison to the amount of literature surrounding yoga and breast cancer. As a result, much of this review will draw on research conducted in the breast cancer population.

# Yoga use for cancer survivors

There have been mixed reports about the benefits of yoga for those who have completed their treatment for cancer (Culos-Reed et al., 2006; Blank, Kittell & Haberman, 2005; Littman, Bertram, Ceballos, Ulrich, Ramprasad, McGregor & McTiernan, 2012). However, a recent piece of cross sectional research by Lowe, Andersen, Sweet, Standish, Drescher & Goff (2012) looking at the use of yoga for ovarian cancer survivors (n=219) suggests that yoga, combined with a traditional exercise regime, has a positive impact on QoL. Patients classified themselves into one of three groups: either taking part in no exercise, regular exercise or regular exercise and yoga. Results from the postal questionnaire (analysed using a multivariate linear regression) were used to assess the association between each exercise category and the QoL scales. This indicated that survivors who reported participating in both regular exercise and yoga tended to have higher scores on measures of physical functioning than survivors who reported only participating in regular exercise. Survivors who participated in regular exercise and yoga also reported fewer limitations associated with physical health, fewer limitations associated with emotional health, less pain, and more vitality. The two exercise groups had similar scores for social functioning. Survivors who reported participating in both regular exercise and yoga tended to have higher scores on measures of general health than survivors who reported participating only in regular exercise, suggesting that the addition of yoga to a regular exercise regimen may well be beneficial for improving ovarian cancer survivors’ QoL. As the focus of this research is on those who are currently undergoing treatment for their cancer, the following review of the literature include studies that focus on patients who are on active treatment for their disease.

# Yoga for cancer patients on active treatment

## Physical benefits of yoga

There have been a number of physical benefits attributed to the practice of yoga for those patients who are being actively treated for cancer. These include reduction of treatment-induced side effects (e.g. nausea) and relief of symptoms of the disease itself (e.g. pain). Research by Carson, Carson, Porter, Keefe Shaw and Millar (2007) indicated that patients who practiced yoga for longer periods of time on a given day were more likely to experience lower pain and greater invigoration. Additionally, the research also suggested that patients who completed the trial had higher levels of fatigue and other treatment related symptoms, and that amelioration of these symptoms was their main motivation for taking part in the trial. With regards to patients’ perception of the physical benefits of yoga, later research by Chandwani, Thornton, Perkins, Arun, Raghuram, Wei & Cohen, (2010) found that women who were allocated to a yoga group reported significantly better health perception and physical functioning one week after radiotherapy in comparison to those in the wait-list control group.

When looking specifically at treatment related side effects, Raghavendra et al. 2007 conducted a trial exploring the use of yoga and the effect it has on nausea and vomiting (which is a common side effect of chemotherapy) in stage II & III breast cancer patients (n= 62). Results from their research suggest that those in the yoga group had reduced chemotherapy related nausea and anticipatory nausea, compared with those who were randomised to supportive therapy and coping intervention.

A number of pieces of research have also been conducted exploring the links between yoga practice and cancer patients’ physiology. Research by Banerjee et al. (2007), found that patients in the yoga arm of a trial had significantly less radiation-induced DNA damage in comparison to the control group, and that levels of DNA damage correlated with the levels of stress reported by patients. This suggests that patients who are less stressed, as a result of yoga practice, have less DNA damage. In addition to these findings, later research by Rao, Nagendra, Raghuram, Vinay, Chandrashekara, Gopianth & Srianth, (2008) found that lower levels of serum Immunoglobulin A were also present in the yoga group and there was a smaller drop in CD56 following surgery. These results suggest that there may be some benefits to immune system functioning for those taking part in yoga. However, as with many physiological mechanisms, it is difficult to confirm whether this is directly caused by participation in yoga, or whether it is an alternative activity which is generating this change.

Based on the stress reduction qualities of yoga it is not surprising that it has a physiological benefit, since there is an established link between stress and cortisol levels (Mason, Brady & Tolliver, 1968; Kirschbaum et al., 1995). Although this body of literature is growing, and provides valuable insight into the physical and physiological benefits of yoga practice, the majority of literature available focuses on psycho-social patient outcomes such as anxiety, fatigue and QoL.

## Psycho-social benefits of yoga

There is a much larger body of research exploring the psycho-social benefits of yoga in comparison to the physiological benefits. A large proportion of this research focuses on or around that construct of QoL. Some research has found that yoga is a beneficial intervention for improving overall QoL for patients undergoing treatment for breast cancer (Ulger & Yagli, 2010; Rao et al., 2008) and for those who have completed their treatment (Culos-Reed et al., 2006). However, the majority of research has found that yoga is beneficial for improving particular aspects (or subscales) of QoL.

Galantino, Greene, Daniels, Dooley, Muscatello & O’Donnell (2012) found that a yoga intervention for cancer patients on chemotherapy reduced the number of errors when completing a cognitive test, indicating an improvement in cognitive functioning. This built on earlier research by Hosakote et al. (2009) who found that those in the yoga intervention had a significant improvement in positive affect, emotional functioning and cognitive functioning whilst also reporting decreases in negative affect when compared to a control group. It has also been found that yoga is associated with beneficial effects on social functioning (Levine & Balk, 2012). Those in the yoga intervention also reported improvements in emotional well-being, and a decrease in distress, whereas the control group reported deterioration in social well-being, spiritual wellbeing and an increase in distress (Moadel et al., 2007). This finding is supported by later research by Danhauer, Mihalko, Russell, Campbell, Felder, Daley & Levine (2009) which indicates that yoga was more beneficial to women who started the classes with higher negative affect and lower emotional wellbeing in comparison to the control group.

Research into the efficacy of a yoga intervention in the reduction of stress, anxiety and fatigue are also encouraging in both post treatment (Blank et al., 2005; Culos-Reed et al., 2006) and active treatment groups. Ulger & Yagli (2010) found a reduction in state/trait anxiety levels in patients on active treatment assigned to a yoga intervention, and Rao et al., (2008) found that there were significant decreases in state and trait anxiety as well as decreases in depression and distress for those in a yoga group compared to the controls. Similarly Banergee et al., 2007 found that breast cancer patients on active radiotherapy (+/- chemotherapy) on the yoga arm of a trial had a significant decrease in anxiety, depression and stress – the opposite to those in the control condition who had significant increases.

Research looking at restorative yoga for women with breast (n=17) or ovarian (n = 37) cancer found encouraging evidence to suggest that yoga decreased both depression and negative affect, over the course of a 10 week intervention (Danhauer, Tooze, Farmer, Campbell, McQuellon, Barrett & Miller, 2008), although these results were not compared to a control group. Additionally the authors found that there were increases in overall QoL scores and mental health scores over the 10 week intervention and 2 month follow up period. The increase in QoL scores was influenced by changes in physical and functional well-being. Physical functioning increased after the intervention, and fatigue improved significantly over the course of the intervention. There were significant interactions between adherence (number of classes attended) and scores for physical functioning, suggesting that class attendance increased the scores of the physical functioning scale at both post intervention and 2 month follow up. The number of classes attended was also associated with decreases in anxiety, depression, negative affect and fatigue, but these were not significant over time.

Comparing treatment modalities of the participants, there were no significant differences in QoL between those on chemotherapy or radiotherapy during the trial. There was however a significant difference in QoL dependent on the type of cancer. Patients with breast cancer reported a larger change in QoL score (they started with a lower QoL than the ovarian cancer patients and completed the 10 week yoga course with a higher rated QoL). This suggests that the majority of the significant change found in the trial was actually down to the breast cancer patients rather than the ovarian cancer patients. Danhauer et al. attribute this to ovarian cancer patients either having longer to adjust to their diagnosis (they had generally been diagnosed longer than the breast cancer patients) or because the ovarian cancer patients have a poorer prognosis and perceive less of an increase in QoL. Although initially encouraging, this paper gives little indication of the benefits of yoga for the ovarian cancer population.

A trial consisting of a 7 week Tibetan yoga intervention for lymphoma patients found that there was a significant difference in sleep related measures at the three month follow up period. The yoga group had significantly better overall sleep quality, fell asleep more quickly and slept longer with fewer sleep medications when compared to the control condition (Cohen, Warnke, Fouladi, Rodriguez & Caoul-Reich, 2004). Similarly, Rosenbaum et al. (2004) found that restorative yoga (offered as part of the Stanford Cancer Supportive Care Programme) was the most popular class (yoga was offered alongside QiGong, a fatigue management programme and other classes), with over 96% of attendees reporting a reduction in stress; 94% felt an increase in wellbeing, 74% felt an increase in energy, 65% reported more restful sleep and 51% noted an improvement in pain.

Other benefits have been found with regards to psycho-social functioning of breast cancer patients taking part in yoga interventions. Carson, Carson, Porter, Keefe Shaw and Millar (2007) found that patients reported levels of invigoration and increased acceptance of their cancer on the day of and the day following the intervention class. In contrast to this, other research suggests that participants in a yoga group had a significantly greater score for benefit finding, although those in the yoga group experienced more intrusive thoughts one month post radiation compared with those in the control arm of the trial (Chandwani et al., 2010).

## Yoga and the conservation of resources

In Hobfoll’s 2001 paper regarding conservation of resources (COR) theory, a comprehensive list of 74 resources was provided, all of which are valid in Western contexts. These include ‘feeling I have control over my own life’, ‘feeling independent’ and ‘personal health’, amongst others. Many of the facets of QoL are included in, or can be linked to, the resources that have been identified (Taylor, Kulkarni & Shiraishi, 2006). During the introduction chapter of this thesis, the outcome of a perceived loss or threat to resources was discussed, with the links between loss of resources and stress being established. In short, the prevention of the depletion of resources and secondarily maintenance or gain of existing resources are essential in maintaining healthy functioning in adaptation to stress (Hobfoll, 1998; Hobfoll, 1989).

Research has been conducted exploring the links between COR and QoL in areas such as chronic fatigue syndrome and colorectal cancer (Taylor, Kulkarni & Shiraishi, 2006; Hou, Law, Yin, & Fu, 2010). Research by Taylor et al. (2006) found that both resource loss and gain emerged as significant predictors of overall QoL independently of fatigue severity and symptom severity. The research goes on to suggest suggests that the gain, or re-establishment of lost or threatened resources (such as self efficacy and work place support) could improve QoL, whereas loss of resources (such as seniority at work and physical functioning) could decrease reported levels of QoL. At present, there has been no research exploring the use of CAM with a view to gaining or re-establishing resources that are lost or threatened during the diagnosis and treatment of cancer. Both the theory itself and previous research in the area of COR would suggest participation in yoga would result in the re-establishment of lost or threatened resources (i.e. flexibility, physical functioning, social functioning) and improve QoL for patients.

# Conclusion

It is evident from this review of the literature that there has been little research regarding yoga for gynaecological cancer patients and what little does exist focuses on ovarian cancer patients. Some studies focusing on gynaecological cancer patients include yoga as a tool within a programme for increasing physical activity or as part of a larger mindfulness based stress reduction programme, and these general programmes report varying success (Conroy, Sattelmair, Cook, Manson, Buring & Lee, 2009; Carlson, Speca, Patel & Goodey, 2003).

Although the published work presented throughout this review suggests that yoga may be beneficial for gynaecological cancer population, there are a number of limitations to this research. Studies range from small, non-randomised trials with as little as four participants (Galantino et al., 2012) to larger (n=128) RCTs (Moadel, Shah, Wylie-Rosett, Harris, Patel, Hall & Sparano, 2007). A number of papers do not report replicable statistical methods (Blank et al., 2005) and the combination of small sample size and the use of non-validated measures bring the findings of some of the research into question. These factors highlight the need for larger RCTs which are commonly thought of as the gold standard for research, although there is debate in the literature regarding this ideal for designing research in complementary medicine (Walker, 2010; Grossman & Mackenzie, 2005; Kaptchuck, 2001).

# Rationale for current study

The review of the literature has highlighted that there is a dearth of worldwide research into the use of CAM by gynaecological cancer patients, and that there is little research carried out in this area in the UK. Despite this, the literature review has indicated that yoga may be beneficial for cancer patients. The systematic review by Smith and Pukall (2009) highlights that there is variability across the studies that have aimed to explore the use of yoga with cancer patients, with regards to quality of methodology, use of appropriate outcome measures and sample size. The review also highlights that many of the studies have been conducted with breast cancer patients and that there is a need to “examine the use of yoga with non breast cancer female patients” (p.473), and that there is little research conducted in the area of gynaecological cancer. This is surprising as the research by Gage et al. (2009) suggested that gynaecological cancer patients were the most common users of CAM after breast cancer patients. This highlights that an RCT looking at the potential benefits of yoga for gynaecological cancer patients is required. The available body of literature suggests that gynaecological cancer patients may find considerable benefit from a mind body intervention such as yoga, as it may be beneficial for controlling both illness and treatment related side effects.

# Aims, objectives & hypothesis

## Aim

* To explore if yoga can improve QoL for gynaecological cancer patients.

## Objectives

* To assess the QoL of gynaecological cancer patients on active treatment who are randomized to a 10 week yoga intervention or control group.
* To establish whether there are any differences between the two groups (yoga and control) at pre intervention, post intervention and follow-up time points.

## Hypothesis

* There will be a significant difference between the QoL of those who take part in a yoga intervention in comparison to those who do not.

Chapter 7: Method

The following chapter outlines the methodology used to achieve the research aims and objectives defined in the previous chapter. The chapter covers the design of the study, information about the intervention and details of the recruitment strategy. The chapter also includes a discussion of the ethical implications of conducting an RCT in a gynaecological cancer patient population, and also gives an overview of some of the more unusual methods of analysis used within this study.

# Design

The previous literature review highlights that an RCT exploring the efficacy of yoga for gynaecological cancer patients is both timely and necessary. Based on this, an RCT was designed to test whether a yoga intervention is beneficial for improving patients' QoL over a 10 week period. Previous interventions using yoga range in length, some lasting as little as eight days (Warner, 2006), whereas others cover the whole of an individual’s chemotherapy cycle (Raghavendra et al., 2007). The majority of studies (Banerjee et al., 2007; Blank et. al, 2005 and Cohen et al. 2005) use interventions that are 6-8 weeks long. Culos-Reed et al. (2006) identify that a 7 week intervention may be too short to find any significant differences between the two groups, whilst Moadel et al. (2007) found a number of significant results after a 12 week intervention. Based on this literature it was decided that a 10 week intervention would be implemented to balance both cost and effectiveness (classes were costed at £55 per week for room hire and tuition).

Within the RCT patients were recruited to three levels of consent. Patients who did not wish to participate in a trial but were otherwise willing to complete baseline measures acted as a baseline control. Patients who consented to the trial were randomly allocated to a non-yoga control group or yoga intervention group. Trial participants were asked to complete a questionnaire relating to QoL pre and post intervention, and were given a 10 week diary to monitor pain, fatigue, anxiety and QoL using Visual Analogue Scales (VAS). The diary also included sections for them to note any other comments.

At the end of the 10 week intervention participants in the yoga arm were asked to attend a focus group. Focus groups were run every 6-8 weeks as patients completed their 10 week course (on the same day and at the same venue in a separate room as the yoga intervention). The role of the focus group was to capture participants’ experiences, attitudes and thoughts about the intervention. The findings of the analysis will not be discussed within the remit of this PhD due to word count and size of the analysis.

Additional follow-up questionnaires were administered 4 months after the end of the trial to patients in both groups. This follow up was included within the trial to explore if there are any long term benefits to practicing yoga, however it will not be discussed in the body of this thesis due to time constraints. The overall trial design is shown in Figure 7.

Figure 7 - Diagram of RCT design.



# Intervention - yoga classes (Hatha yoga)

Hatha yoga can be adapted for all kinds of needs and is holistic in principle. When the intervention was constructed, the classes were composed in the style of a standard class, incorporating all aspects of what yoga practitioners would expect from a “normal class”. Yoga practice is inclusive of all physical abilities, and designing the class for the cancer patients was no different, although there were a greater number of health considerations to be accounted for. An additional focus on awareness was included in the class to ensure that patients/participants were working at their own level with something that they found comfortable. This is no different from standard practice, but was accentuated in the intervention class. Patients were encouraged to explore their own expectations and to not judge themselves against others in the class, due the range of physical ability.

Teachers were not recruited from a particular school of yoga, but were teaching diploma holders with the British Wheel of Yoga (recognised as the umbrella body by the Sports Council of England), which is an institution where the focus is on the safety of those participating in the class (BWY.org, 2012). Patients were encouraged to try to do different things, but adaptations were available to encourage inclusivity in the class, for example, postures were adapted for those who did not have a full range of movement. The challenge for teachers was to incorporate these participants in the class without the practice of those who were more “able bodied” being affected. Patients were also taught that the principles remained the same, i.e. good posture and attention to physical detail in regards to alignment, even if they were not able to complete all physical aspects of the class.

The use of breathing and breath awareness was a focus for the class, however the teachers decided that this was not to be delivered in structured pranayama (breathing exercises) in every class, as being aware of breath was considered enough to be beneficial for patients. In some classes it was intended that patients move up from basic breathing awareness into pranayama as part of an extended exercise. The focus on breathing was included in the intervention to encourage patients to work with the breath during the class, and to also foster controlled breathing and relaxation outside of the classes, whether that was through breath awareness or more formal pranayama. One of the areas where breathing practice took a focus was during the breathing and relaxation opening to the sessions. This had two functions; to rest and remove patients from the 'goings on' of the world outside and to focus on the self. The teachers wanted to emphasise that the focus of the class was on the self and that the class and the hour of yoga belonged to them, and for them, and therefore required a focus on the individual.

With regards to the postures, these were chosen so that patients would be able to progress within the class itself rather than over the course of a period of time. Postures were chosen for their accessibility and also based on the participants who were in the class each week and their abilities. The postures were graduated within the class environment to allow patients to go as far as they wanted within a safe environment. The aim was to produce a programme where the participants would feel some benefit, and over the 10 weeks achieve some variation. The need for breath-work while attempting postures was not the main focus and no pressure was put onto the participants to combine breathing and posture work. The focus of the class was on the physical aspect, but if patients were able to combine the two aspects this was also incorporated. Participants were encouraged to choose their own style of practice and work with what they felt comfortable. This was of benefit to some patients as they did not feel pressurised into completing something that they were unable to achieve.

Guided relaxation and visualisation was used as part of the closing ceremony or relaxation section at the end of this class. Relaxation was a focus for the group as this was a skill that could be used (and was suggested would be useful) outside of the class. Patients were not encouraged to fully empty the mind, but were encouraged to practice control, and be able to let go of thoughts that may be problematic. This also drew on the skills that were fostered in the breathing awareness throughout the class, highlighting that this could became a tool that patients could use in their everyday life.

# Participants

## Sample Size

The systematic review by Smith and Pukall (2009) highlights that many papers do not report effect sizes for their studies. Moadel et al. (2007) and Culos-Reed et al. (2006) found medium to large effect sizes when measuring the effect of yoga on QoL in the breast cancer population. Effect sizes (Cohen’s d) were reported at 0.28 and 0.83 respectively, indicating variation in the size of effect found in this type of research. Cohen’s d is a measure of effect size for a t-test; ANOVA uses *f* as a measure of effect size. To calculate the prospective sample size for a 2x2 mixed methods ANOVA an equivalent effect size (*f*) needed to be estimated. A medium to large effect size in *f* ranges between 0.25 and 0.40 respectively (Cohen, 1988). These figures were used in a sample size calculation conducted in G\*Power (Erdfelder, Faul & Buchner, 1996). With the α error probability set at 0.05, and a power of 0.95, it was estimated that a sample size of between 54 and 24 was required to achieve a medium or large effect (respectively).

5-7 patients per week are diagnosed with a form of gynaecological cancer and undergo treatment at the Royal Derby Hospital. Of these, some will subsequently be found to have benign disease, and some may not meet the inclusion criteria. As a conservative estimate it was thought that it would be feasible to approach 2 patients per week, over 78 weeks. Based on this it was predicted that we would have invited over 156 participants to take part in the trial.

Due to the exploratory nature of this study, the inclusion criteria were minimised to allow as many people as possible to be included in the trial.

## Inclusion Criteria

* Aged 16 or above
* Diagnosed with cancer of the ovary, cervix, vulva, uterus, fallopian tube or peritoneum
* Ability to engage with a gentle programme of yoga
* On active treatment (within 6 weeks of surgery or on active chemo or radiotherapy)

## Exclusion Criteria

* Diagnosed with a benign condition such as an ovarian cyst
* Patients with mental incapacity unable to give informed consent
* Patients unable to understand verbal and written information in English
* Patients who already practice yoga who would be unwilling to enter the control arm of the trial. This group of patients would be eligible to enter the baseline control group.

Those currently taking part in yoga were included in the trial, but only if they were willing to refrain from practicing yoga if randomised to the control group (this situation did not occur, but it was thought that this may have resulted in current yoga practitioners not wishing to take part in the study). It was identified that if current yoga practitioners were to be excluded, then other practitioners of mind/body techniques such as Tai Chi and Pilates may have also needed to be excluded as they have similar methodologies.

# Procedure

## Recruitment

Patients meeting the inclusion criteria (judged by the clinical staff) were approached for the study by a member of the research team (CNSs, Doctors or the researcher). Some patients may have already been undergoing treatment for their disease, or about to embark on treatment. A patient information sheet (Appendix 11) along with a covering letter (Appendix 12) was given to patients in the clinic (this may have been the initial appointment at the point of communication of diagnosis, or at the pre op appointment). If this was deemed as an unsuitable time by the research team (due to the nature of the visit to clinic), patients were contacted via post and information was sent to their home address after the appointment, or included with their standard clinical letter after the surgery. Potential participants were invited to contact one of the researchers by telephone or email if they had any questions about the trial or wanted further information.

If the patient was willing to participate in the study (by either providing baseline data or taking part in the RCT), they were asked to sign a consent form (Appendix 13) by a member of the research team. All staff taking consent had completed appropriate training to do so (ICH Good Clinical Practice training). A copy of this consent sheet was given to the patient, a copy was kept in the patient notes and the original kept by the research team.

Those consenting to take part in the RCT were randomised to either the intervention group or the control group by an independent person (one of the medical secretaries who played no part in the recruitment or consenting of patients). Patients were allocated to a group based on a list of random numbers generated by an internet programme on a first come first served basis. After randomisation each participant was given a unique identification number and this was entered into a recruitment log which was kept for all patients taking part in the trial. The data collection form (Appendix 14) was completed by the medical team for all patients at the point of consent (if patients did not complete the consent in hospital and returned their consent by post, patient information was collected before randomisation took place). Participants were informed by letter of the outcome of the randomisation (Appendix 15 & 16). The recruitment process diagram given to staff can be seen in Figure 8, and the final recruitment for the trial can be seen in Figure 11.

Figure 8 – Recruitment process diagram given to staff involved in the trial.



Figure 9 – Final recruitment for the trial.



# 

# Data Collection

## Baseline

Participants who consented to providing baseline information only were given a set of questionnaires (either in person or by post) as soon as consent was received. When the questionnaire had been completed and returned a debrief letter (Appendix 17) was sent to the participant and their participation within the study was completed.

## Full RCT

Once informed consent had been given and randomisation had occurred, patients randomised to the yoga condition were invited to take part in the 10 week course of yoga (the 10 week course is based on 10 calendar weeks of yoga, rather than 10 sessions). The yoga sessions ran between 17.45 and 18.45 on a Thursday evening at the Multi-Faith Centre at the University of Derby. The Multi-Faith Centre was chosen as a venue as it is away from the hospital (a point raised by the gynaecological patient support group as being of vital importance), it has free car parking, and there was a comfortable area for carers to wait.

The yoga sessions were run by 2 qualified teachers and were designed to be of a similar standard each week, but also flexible to the characteristics of that particular group. Patients were told that the yoga classes could be taken up by the patient at any time during the course of their treatment, for example, 2 weeks after surgery during radiotherapy, or at the beginning of their chemotherapy. This was to ensure that the patient could access the classes at a time when they felt able to complete the sessions and gain maximum benefit from any positive effects of the classes.

After the patients had made contact with the research team confirming that they wanted to start the yoga, they were asked to complete the QoL questionnaire. It was requested that questionnaires were returned to researchers either directly in a sealed envelope before their first class, or via the post. Diaries were also given to patients to complete over the 10 week period. The end of intervention questionnaires were given to the participant at the last session of the 10 week intervention, or posted out to the participant. An invitation containing information and consent for the focus groups was given to the participants at this point.

Patients in the control (no yoga) arm were asked to complete the QoL questionnaire before and after a 10 week period as well as a 10 week diary. Questionnaire and diary packs were sent via post to the participants with the notification of randomisation letters, with the follow up questionnaire being sent 9 weeks later to ensure that they were available for the end of the 10 week period (Appendix 18). Once received, patients were sent an interim thank you letter and debrief for their participation in this part of the trial (Appendices 19 & 20). All participants were also invited (by post) to complete a follow up set of questionnaires after a 4 month period, and these were sent by post with a covering letter (Appendix 21). After these were received, patients were sent a debrief letter (Appendix 22).

The 10 week diary contained VASs to measure QoL, pain, anxiety and fatigue, as these have been shown to be some of the most problematic symptoms associated with treatment for gynaecological cancer, and are known to influence QoL (Smith, Gomm & Dickens, 2003; Bower, Ganz, Desmond, Rowland, Meyerowitz, Belin, 2000; Visser & Smets, 1998; Hurny et al., 1993; Aaronson et al., 1993). The diary also provided space for participants to write down their thoughts and feelings on a daily basis (Appendix 23). These diaries were sent out with the questionnaire packs (Appendix 24) to those on the control arm, or given to individuals during their first yoga class if allocated to the yoga arm. It was requested that these were returned to the researchers alongside the post intervention questionnaires.

# Materials

## EORTC QLQ C30

The primary study outcome for this research is QoL. Jones et al. (2006) found in their meta-analysis of measures used to quantify QoL during treatment for gynaecological cancer patients, that the two most used questionnaires were the European Organisation for Research and Treatment of Cancer’s Quality of Life Questionnaire Core 30 (EORTC QLQ C30, Aaronson et al., 1993) and the Functional Assessment of Cancer Therapy – General (FACT G, Cella et al., 1993). Although there are a number of other questionnaires available, results from the meta-analysis suggest that the QLQ-C30 and the FACT-G would be the most suitable measures for this study and after consulting patients with regards to their preference of questionnaire, the QLQ C30 was selected (data not shown). The QLQ C30 is a 30 item questionnaire developed to assess the QoL of cancer patients. It is used regularly in cancer research and is regarded as one of the best tools for measuring QoL (Okamoto et al., 2003; Bottomley et al., 2002).

The EORTC QLQ C30 can be made module specific (i.e. specifically for cervical cancer), however this was decided against as patients taking part in this research had several different types of gynaecological cancer, and not all of these have their own specific module. The QLQ-C30 incorporates nine multi-item scales: five functional scales (Physical, Role, Cognitive, Emotional and Social Functioning); three symptom scales (Fatigue, Pain and Nausea/Vomiting); and a Global Health Status(GHS)/QoL scale. Six single item scales are also included (Dyspnoea, Insomnia, Appetite Loss, Constipation, Diarrhoea and Financial Difficulties). The QLQ-C30 has been reported as both reliable and valid. It achieves a Cronbach’s alpha of 0.82 when tested with a heterogeneous sample of cancer patients (Ringdal & Ringdal, 1993), and also with site specific cancers (including ovarian cancer), and at different stages of treatment (Aaronson et al., 1993; Osoba , Zee, Pater, Warr, Kaizer & Latrielle, 1994; Kaasa et al., 1995).

## Weekly Diaries

Carson et al. (2007) utilised daily diaries in their study with breast cancer patients, and found significant increases in invigoration and acceptance, as measures taken more frequently had a greater sensitivity to change than pre/post measures alone. Based on Carson et al.'s methodology, it was decided that a similar approach would be adopted as a method of collecting an additional weekly measure of QoL, pain, anxiety and fatigue within this study. It is acknowledged that collecting repeated measures of patients’ experiences is a useful technique in the social science field (Stone & Shiffman, 1994). Obtaining information outside of the laboratory or hospital setting may be more indicative of people’s daily routines and may better represent the “average level and typical variability that people experience in everyday life” (Schwartz & Stone, 1998, p.6). One of the biggest advantages of using diary methods is that they allow researchers to more accurately examine reported life events as they happen, and reduce the likelihood of retrospection (Reis, 1994).

There are a number of issues surrounding the use of diaries; one being the difficulty in deciding how often to measure the desired outcome. There are two broad designs of diary measurement, time-based designs and event based designs. Time-based designs focus on fixed or variable schedules but in general are orientated around a period of time between diary entries. Event based designs focus on the frequency of a given event, and diary entries are only made when an event occurs (Bolger, Davis & Rafaeli, 2003). As the current research was designed to look at differences in QoL over time, a fixed schedule, time based design was the most appropriate for this study. The fixed schedule design was beneficial as it allows for a set protocol to be implemented with the individual completing the diary. In this case, the protocol was ‘fill in the dairy once a week on the same day every week’. This was preferable to the variable schedule design which would have required additional input from the research team and a method of signalling or notification from the researcher to the participant (i.e the researcher contacts the participant when they want them to fill in the diary measures and this may be seen as obtrusive to daily life).

The current study utilised a weekly fixed-schedule paper and pen diary over a 10 week period (11 entries in total with a baseline). Weekly entries (on the same day each week) were chosen rather than daily entries to reduce the amount of burden experienced by patients, especially as these patients were on active treatment and some were attending daily radiotherapy treatments. Additionally, as yoga was a weekly intervention and at home practice was not required, it appeared appropriate to use a weekly measure. Paper and pen diaries were also used as these are more flexible than other forms of diary (handheld/electronic diaries methods), and allowed patients to take their diaries with them on holiday and into the hospital environment. The diary included visual analogue scales for QoL, pain, anxiety and fatigue as well as a space for patients to write down any comments or feelings about the last week (Appendix 23).

### Visual Analogue Scales

Visual Analogue Scales (VASs) have been described as practical, reliable and valid, and are “particlalry suitable for the measurement of change and the observation of its significance” (Zeally & Aitken, 1969, p.996). VASs typically consist of a 10cm line with a positive and negative anchor at each end. Respondents are asked to mark a line between the two anchor points to indicate their feelings. This can then be transferred into a 100 point scale (i.e. 100 millimetres). Scott and Huskisson (1976) originally identified a number of steps in the constructions of VASs, including the definition of the sensation or response that is to be observed, and subsequent anchoring end phrases which are short and readily understood. Later research by Scott and Huskisson (1979) indicated that there was no significant difference between horizontal and vertical presentation of VASs, and that there was a high correlation between scoring on the two scales (r=0.99), but indicated that scores on the horizontal scales tended to be slightly lower on the vertical scales, highlighting the need for a standardised presentation within individual research projects. Additionally, Revill, Robinson, Rosen & Hogg (1976) note that uni-polar VASs (i.e. ‘Not at all anxious’ to ‘Extremely anxious’) are more easily understood than bi-polar VASs (i.e. ‘Extremely calm’ to ‘Extremely anxious’) and that this should be factored into VAS design.

VASs have been used to assess QoL since 1976 (Priestman & Baum, 1976; Hauser & Walsh, 2008), and have been widely validated in the oncology setting as both a single and multi-item tool. With regards to QoL measures, single item VASs have a number of advantages in comparison to multi item QoL measures; it is regarded as one of the simplest approaches to measuring QoL, and as they are easy to administer, they are regarded as being less burdensome to patients (Selby, Chapman, Etazadi-Amoli, Dalley & Boyd, 1984). Alternatively, single item measures do not measure the individual domains of QoL, meaning that an individual must consider all of the facets of QoL before completing the scale (Fayers & Machin, 2000). Research by deBoer, Lanschot, Stalmeier, Sandick, Hulscher, deHaes & Sprangers (2004) found that a single item QoL VAS achieved high correlations with a number of health perception scales (0.70+), and also achieved a high test-retest reliability intra-class correlation (0.87), suggesting that the VAS is both valid and reliable in comparison to multi-item questionnaires. Scores for reliability and validity for VAS in the pain domain have been found to be between 0.71-0.94 (dependent on literacy) and 0.78-0.91 (Hawker, Mian, Kendzerska & French, 2011), and have also been tested within the oncology literature (Ahles, Ruckdeschel & Blanchard, 1984). VASs have been proven to be a valid method for the measurement of anxiety and fatigue and are highly sensitive for measuring change (Williams, Morlock & Feltner, 2010; Lee, Hicks & Nino-Murcia, 1991; Gift, 1989; Hornblow & Kidson, 1976).

# Ethical Considerations

The research project received NHS Research Ethics Committee (REC) approval from the East Midlands (Nottingham, REC2) on the 11th of November and local R&D approval from the Derby Hospitals NHS Foundation Trust on the 9th of December 2010 (Appendix 25). Some of the important ethical issues are described below.

## Consent

Participants were asked to give full informed consent to one of two levels of participation:

* consent to baseline measures only
* consent to baseline measures and RCT yoga intervention

Consent was sought from patients after a ‘cooling off period’ once they had received the information for the trial, which is recommended by the National Research Ethics Service (NRES, 2010). None of the patients were consented to take part on the same day that they were given the information pack. All members of the research team who took consent from patients had undergone mandatory NHS ‘good clinical practice training’.

Patients were asked to contact a member of the research team if they had any questions about the trial or their potential participation, and in many instances, this is when patients communicated their desire to take part and a consent form was sent to them in the post (unless they had already been given a copy in clinic). In addition to this, at the time of information being given to the participants, they were asked whether they would be happy to receive a call from one of the research team to follow up on the information that was given. If a period of one week had passed without the research team receiving contact from the patient, one of the research team made contact with the patient (by telephone or in clinic) to ask about participation, and if at this point the patient did not consent (or give indication of consent at a later date i.e. after surgery), then their name was added to a list held centrally to prevent them being re-issued information or called again about participation in the trial.

## Debriefing

Patients were fully debriefed after each stage of the trial in line with BPS ethical guidelines (BPS, 2009). Patients received a full debrief after their initial completion of the trial (after 10 weeks) and also a thank you letter (and mini debrief) after they had completed the four month follow up. The debrief included information about the study and what the study hoped to find, information about how to contact the research team and also information about how to withdraw their information from the trial.

## Confidentiality

The data collection form contained no patient identifiable information and was recorded using patient ID rather than name. Only information contained within the data collection form was transferred from the Royal Derby Hospital to the University of Derby. Researchers from the University of Derby did not have access to full patient notes at any point. All anonymous information was transferred to a database on a University or NHS computer and was password protected.

All questionnaire data and diaries were marked with the patient’s unique identifier (a number that corresponded to their position on the randomisation list), and any linked data with the ability to identify participants was stored separately (i.e consent sheets and focus group recordings and transcripts). Data from the questionnaires was stored separately from the consent sheets, as were the data collection forms to preserve anonymity at each level.

Audio recordings from the focus groups included data that identifies the participants, and so to preserve participant’s anonymity with those outside of the study team, at the time of transcription all participants were made anonymous and suitable pseudonyms were allocated. Audio data was stored in lockable storage at the University of Derby and was kept separate from transcriptions. In accordance with NHS ethics approval, only the research team members had access to the research data for purposes of analysis. All study documents, patient information sheets and consent forms will be retained for 10 years.

## Withdrawal from the Study

The patient was free to withdraw their consent at any time without giving any reason. A participant may have wanted to completely withdraw from the study and ask for any data pertaining to them to be withdrawn from the study. In this case, any information pertaining to the participant would have been destroyed, and any information that had been divulged in focus groups would not have been sampled in any write up or publication of findings (although other information obtained from a focus group they had participated in may have been used). Alternatively, participants may have wanted to withdraw from the study for a number of reasons but still gave consent for any anonymised data that had been collected up to that point to still be used within the study. The patients were not expected to withdraw if they were unable to attend all 10 sessions.

## Protection of participants

All research was carried out in line with the BPS guidelines for ethical research. All materials and procedures were passed by the University of Derby’s Psychology Research Ethics Committee and the NHS ethics committee. Participants were informed that their participation in the research was voluntary and that their participation (or not) would have no effect on the treatment that they would receive from the NHS service. This was particularly important as patients were recruited from the clinical setting, and often the CNS or consultant was included in the initial discussion about participation in the trial.

## Giving advice

No advice was given as part of this study. If patients had any questions that arose from their perception in the study about their medical condition or any other factors relating to treatment for their disease they were signposted to their CNS (in the first instance) or their GP who would be able to refer them to appropriate sources. Clinical staff were informed of patients participation in the trial through the use of a marker in the patients clinical notes, and important information about the study was included in case any questions did arise from patients. The yoga teachers were also briefed about not giving advice with regards to medical treatments and given the contact details of the medical team at the hospital should any patients attempt to seek advice from them.

# Data Analysis

Information collected on demographics of patients (from the data collection form) and the pre/post intervention data from the EORTC QLQ-C30 were analysed using SPSS version 19 (IBM Corp, 2010). Analysis consisted of a mixture of parametric and non-parametric tests which was dependant on the type of data and the individual data assumptions required for each test. Data collected from the QoL, pain, anxiety and fatigue VAS was also entered into SPSS, to establish whether there were any main effects of intervention. As the VAS data contained repeated measures for 11 time points, several different models were used in the analysis of the VAS data to determine which approach was best for analysing this information. This analysis was conducted using ‘R’ (R Development Core Team, 2008). As these methods are not regularly used within the field of health psychology a brief description of the method and the rationale for its use has been included below.

## Generalised Additive Models

A Generalised Additive Model (GAM) is a form of non-parametric regression (Hastie and Tibshirani, 1986). It has greater flexibility than traditional regression methods (such as linear and non-linear regression). GAM enables the user to establish whether there is a trend where it may have been ‘missed’ by other methods (i.e. there may not be a straight line relationship between the two variables). When using GAMs, it is assumed that the mean of the dependent variable is dependent on an additive predictor through a nonlinear link function; the usual linear function of the covariant is replaced with an unspecified smoother function (Hastie and Tibshirani, 1986). The degree of smoothing is dependent on the span of the points in each neighbourhood (in this case, time point or week); resulting in the ‘smooth’ trend of the response variable (QoL) as a function of the predictor variable (time). If appropriate, separate smoothers over time can be derived for the different levels in the nominal predictor variable (intervention). In this research, the GAM was used to establish how the intervention (yoga), affected QoL over time. In addition, GAMs enable the user to visualise the relationship between the dependent and independent variables which is a benefit of using GAM methodology.

### Rationale for using the model

One of the outcomes of the analysis was to establish how QoL is linked to time for each arm of the intervention; in other words, was there a trend in time for each arm of the intervention? Standard regression would assume that QoL has a linear relationship with time. With regards to this particular intervention, it was unknown whether there would be a linear relationship between time and QoL. As the sample for the intervention included a high proportion (40.90 %) of participants on active treatment (chemo or radio therapy), it was proposed that their outcomes over time may be cyclical (in line with their chemotherapy) or be variable depending on their individual treatment regime (some patients may have been 5 weeks post-op and started chemotherapy/radiotherapy two weeks later resulting in a drop in QoL). Based on this and initial data exploration, the use of GAM was judged to be suitable for full exploration of the data.

## Generalised Least Squares

Autocorrelation determines the level of association in a variable between two time points, e.g. the association of QoL scores at time point 0 and time point 1. In many data, values that are closer to each other in time are more likely to be similar to each other than those that are further apart in time. Auto correlation statistics allow us to estimate the lag, i.e. the amount that the current measures have been influenced by previous activity i.e. so how much of the QoL reported at time point 1 is related to the score that was given at time point 0. When using additive models or normal regression techniques, it is assumed that there is no autocorrelation, and that the residuals are independent. However, if there is autocorrelation, and it is not accounted for, it can lead to a number of type 1 errors.

### Rationale for using the model

In the current research it would be reasonable to assume that an individual’s QoL at a given time may be related to a measurement taken at a previous point, meaning that there would be autocorrelation. Based on this it was deemed appropriate to extend linear regression modelling to incorporate the possibility of autocorrelation within the data and to allow for this within the model. To fulfil this requirement a Generalised Least Squares (GLS) extension was used that models the variance-covariate structure, and thereby accounting for autocorrelation in the residuals (Pinheiro & Bates, 2000).

## 

## Multilevel Modelling

Multilevel Models (MLMs) contain variables that are measured at different levels. These levels are nested within each other and form a hierarchy. MLMs explicitly model the hierarchical nature of data at each individual level within the hierarchy, starting with the lowest level. MLMs can also be used to analyse repeated measures data where the data from each individual is analysed (in this case over the 11 weeks) on the individual level and then incorporated into a higher level analysis (in this case intervention group). MLMs fit a straight line to each individual’s data from the dataset based on a simple linear regression, allowing for the intercepts to vary dependent on the individual, but assume that these intercepts fall within a normal distribution (Kreft & de Leeuw, 1998).

### Rationale for using the model

In the current research it is clear that the data is grouped or nested in a hierarchical structure. Variation at the individual level is likely to be nested within the intervention level. Thus the random component (individual level) needs to be modelled within the fixed component (intervention level), making the MLM framework highly applicable. Additionally, this type of analysis has also been used in previous research using diary methods when exploring the efficacy of yoga for patients with cancer, which highlight its potential use in this research (Carson et al., 2007).

# Analysis of the Data

GAM, GLS and MLM analyses were conducted separately on visual analogue raw scores and change scores. The first set of analyses was conducted using the visual analogue scale scores over the 11 weeks. The raw scores were used for this analysis allowing us to account for actual variation between the two intervention groups. Change scores were computed by subtracting the week 0 score from the week in question, so for week 4, the equation was (VAS week 4 score – VAS week 0 score = Week 4 change score). Use of the change in VAS scores relative to week 0 (as week 0 was a baseline control) allowed for observation of any trends/relationships between the intervention and time, and the effect it had on the change in QoL from week 0. This analysis allowed us to see if there were any differences between the groups taking part in the intervention independent of their starting QoL.

Chapter 8: Results

The following chapter details the results generated from the RCT methods described in the previous chapter. Results from the pre/post/follow-up data from the EORTC QLQ-C30 are presented after the initial exploration of patient demographics; mixtures of parametric and non-parametric tests are used. The information gathered from the 11 week VAS data is then explored using a number of methods.

# Data Input & Demographics

Data from the EORTC QLQ-C30 questionnaire and patient diary were inputted into SPSS version 19 (IBM Corp, 2010) in accordance with the instructions given for each individual scale (Fayers, Aaronson, Bjordal, Groenvold, Curran & Bottomley, 2001). Information from the data collection form (a summary of key information from the patient notes such as cancer stage) was collated and entered for both baseline-only and RCT participants (Table 2). Analysis of this demographic data was carried out to ascertain if there were any differences or associations between the baseline-only, intervention and control groups using Chi Squared tests (for categorical data). The data collected for patients’ age was continuous data which was normally distributed and was subjected to analysis using a one way analysis of variance (ANOVA).

Table 2 shows the frequencies for each demographic category and also the test statistic (F value for ANOVA and X2 value for Chi Squared) and p value. None of the X2 tests were significant (p> 0.05), suggesting that there was no significant association between a particular group and the categorical demographic data. The ANOVA showed that there was no significant difference in age between the three groups (F(2,53) = 1.50, p>0.05). The post- hoc bonferroni tests also indicated that there were no differences between pairs of groups. The use of these preliminary tests on the demographic data indicated that the groups were at a similar level in terms of age, cancer type and other demographics at the beginning of the trial.

# Analysis of pre/post/follow-up intervention (EORTC QLQ C30)

Data collected from the EORTC QLQ C30 was tested for normality of distribution as a whole sample (n=56). The means, medians and standard deviations are displayed in Table 3. Normality of distribution was assessed using measures of skewness, kurtosis and boxplots. The boxplots identified that there were no outliers from the dataset so all data was included for analysis. Skewness and kurtosis for the majority of subscales on the EORTC QLQ C30 fell within the acceptable range of –2.00 to +2.00 for skewness and –5.00 to +5.00 for kurtosis (Kendall & Stuart, 1958), however when visually checking the distribution of the data, all histograms (apart from the General Health Question at time point 1 on the QLQ – C30) indicated that the data was not normally distributed (generally being leptokurtic and heavily skewed).

The visual check was further supported by results from the Kolmogorov–Smirnov (KS) test which had significance values of <0.05 for all sub scales other than the GHS at time point 1. In the KS test normally distributed data achieves a significance of >0.05 (Field, 2009). Based on this, it was decided that data would be analysed using non-parametric tests, and not the mixed methods analysis of variance (ANOVA), since this assumes that data is normally distributed. Although ANOVA is robust in many situations, (even where normality is violated), the small sample size for this analysis would not have been adequate to ensure that an accurate and significant effect was found from any statistical tests (Clark-Carter, 2004). In light of this, a combination of Kruskal-Wallis, Wilcoxon’s signed ranks, and Mann-Whitney U tests were used in place of the mixed methods ANOVA.

## Baseline data

At the point of consent, patients who were not willing to take part in the full RCT were asked if they would complete a one off questionnaire. This was added to the protocol to establish whether there were any differences in baseline measures between those who would take part in a full RCT and those who would not. A Kruskal-Wallis test was used to explore differences between baseline, control & yoga groups for the EORTC QLQ C30 at time point 1. The Kruskal-Wallis test did not produce any significant results for the subscales suggesting that patients across the three groups reported similar levels for each scale and subscale at time point one. Test statistics and p-values are displayed in table 4. The baseline group data was not used in any further analysis.

## Testing for differences between groups at time points 1, 2 and 3

A Mann-Whitney U (non-parametric between measures t-test) test was used to explore whether there were any differences between the scores of control patients and yoga patients at time points 1, 2 and 3. As there was only a small sample included for analysis we were able to calculate the exact p-value for the test (Field, 2009). This is displayed along with the U statistic and z score in Table 5.

Table 2 – Means, standard deviation & frequencies for demographic data (including test statistics).

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | Baseline (n=13) | Control (n=25) | Yoga (n=19) | Test  Value | p value for Test  at Time 1 |
| Age - Years Mean (Age - Years SD) | 67.25 (11.70) | 61.36 (11.49) | 60.16 (12.15) | 1.50 a | 0.233 a |
|  |
| Type of Cancer |  |  |  | 4.19 b | 0.123 b |
| Primary | 10 | 24 | 19 |  |  |
| Recurrent | 2 | 1 | 0 |  |  |
| Cancer Site |  |  |  | 3.46 b | 0.749 b |
| Ovarian/PPC | 6 | 7 | 7 |  |  |
| Endometrial | 6 | 15 | 11 |  |  |
| Vulval | 0 | 1 | 0 |  |  |
| Cervical | 0 | 2 | 1 |  |  |
| Vaginal | 0 | 0 | 0 |  |  |
| Stage |  |  |  | 3.00 b | 0.809 b |
| I | 9 | 13 | 13 |  |  |
| II | 1 | 3 | 1 |  |  |
| III | 1 | 6 | 4 |  |  |
| IV | 1 | 3 | 1 |  |  |
| Grade |  |  |  | 1.20 b | 0.879 b |
| I | 4 | 12 | 8 |  |  |
| II | 4 | 5 | 5 |  |  |
| III | 3 | 6 | 6 |  |  |
| Radio Therapy Treatment |  |  |  | 1.68 b | 0.482 b |
| Internal Only | 0 | 2 | 0 |  |  |
| External Only | 0 | 0 | 0 |  |  |
| Both Internal and External | 1 | 4 | 4 |  |  |
| None | 11 | 19 | 15 |  |  |
| Chemotherapy Treatment |  |  |  | 0.55 b | 0.761 b |
| Chemo | 6 | 10 | 7 |  |  |
| No Chemo | 6 | 15 | 12 |  |  |
| Surgery |  |  |  | 6.92 b | 0.329 b |
| Laparoscopy | 3 | 14 | 7 |  |  |
| Laparotomy | 7 | 10 | 11 |  |  |
| No Surgery | 1 | 1 | 1 |  |  |
| Other | 1 | 0 | 0 |  |  |
| Active treatment (CT/RT) on Trial |  |  |  | 0.25 b | 0.844 b |
| Yes | 4 | 10 | 8 |  |  |
| No | 8 | 15 | 11 |  |  |

Note: (a = ANOVA, b=X²)

Table 3 - Mean, median & standard deviation for EORTC QLQ C30 sub scales at T1 and T2.

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Time 1 | | | | | | | | | Time 2 | | | | | |
| Baseline | | | Control | | | Yoga | | | Control | | | Yoga | | |
| N=12 | | | N=25 | | | N=19 | | | N=25 | | | N=19 | | |
| EORTC QLQC30 | Mean | Median | SD | Mean | Median | SD | Mean | Median | SD | Mean | Median | SD | Mean | Median | SD |
| Global Health Scale | 72.22 | 66.67 | 15.62 | 72.33 | 75.00 | 16.96 | 69.30 | 75.00 | 21.70 | 73.99 | 83.33 | 18.99 | 74.12 | 83.33 | 21.14 |
| Physical Functioning | 82.22 | 83.33 | 13.43 | 80.00 | 83.33 | 19.85 | 85.26 | 93.33 | 17.15 | 82.40 | 93.33 | 20.89 | 86.32 | 93.33 | 12.27 |
| Role Functioning | 79.17 | 66.67 | 16.09 | 62.50 | 66.67 | 27.03 | 71.92 | 83.33 | 32.89 | 78.67 | 100.00 | 31.74 | 80.70 | 100.00 | 27.92 |
| Emotional Functioning | 76.39 | 83.33 | 22.43 | 79.33 | 83.33 | 19.11 | 75.88 | 91.67 | 26.91 | 84.00 | 91.67 | 21.91 | 82.46 | 83.33 | 18.40 |
| Cognitive Function | 91.67 | 100.00 | 11.24 | 83.33 | 100.00 | 25.00 | 85.09 | 100.00 | 20.71 | 84.00 | 100.00 | 21.90 | 82.46 | 83.33 | 21.86 |
| Social Functioning | 76.39 | 75.00 | 21.86 | 65.33 | 66.67 | 30.40 | 71.05 | 83.33 | 35.94 | 77.34 | 83.33 | 23.01 | 84.21 | 100.00 | 24.52 |
| Fatigue | 33.33 | 33.33 | 19.53 | 34.22 | 33.33 | 23.99 | 35.09 | 33.33 | 27.03 | 25.34 | 22.22 | 20.91 | 23.98 | 22.22 | 20.04 |
| Nausea | 5.56 | 0.00 | 10.86 | 8.00 | 0.00 | 13.71 | 4.39 | 0.00 | 7.54 | 3.34 | 0.00 | 9.62 | 6.14 | 0.00 | 16.86 |
| Pain | 8.33 | 0.00 | 11.24 | 20.00 | 0.00 | 29.27 | 16.67 | 0.00 | 21.52 | 11.33 | 0.00 | 15.75 | 18.42 | 16.67 | 19.95 |
| Dyspnoea | 8.33 | 0.00 | 15.08 | 4.17 | 0.00 | 11.26 | 7.02 | 0.00 | 13.96 | 9.33 | 0.00 | 18.05 | 12.28 | 0.00 | 16.52 |
| Insomnia | 27.78 | 16.67 | 34.33 | 34.67 | 33.33 | 35.33 | 36.84 | 33.33 | 34.95 | 25.33 | 33.33 | 27.69 | 24.56 | 33.33 | 29.06 |
| Appetite | 22.22 | 33.33 | 21.71 | 14.67 | 0.00 | 25.60 | 12.28 | 0.00 | 19.91 | 13.34 | 0.00 | 28.89 | 5.26 | 0.00 | 16.71 |
| Constipation | 5.56 | 0.00 | 12.97 | 16.00 | 0.00 | 29.06 | 21.05 | 0.00 | 29.84 | 22.67 | 0.00 | 31.51 | 8.77 | 0.00 | 24.45 |
| Diarrhoea | 11.11 | 0.00 | 29.59 | 4.00 | 0.00 | 11.06 | 12.28 | 0.00 | 25.36 | 12.00 | 0.00 | 30.25 | 8.77 | 0.00 | 18.73 |
| Finance | 8.33 | 0.00 | 28.89 | 4.00 | 0.00 | 11.06 | 7.02 | 0.00 | 13.96 | 1.33 | 0.00 | 6.67 | 5.26 | 0.00 | 22.94 |

Note: Mean and Median have both been reported alongside the standard deviation as non-parametric tests were used in the analysis.

Table 3a - Mean, median & standard deviation for EORTC QLQ C30 sub scales at T3.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Time 3 | | | | | |
| Control | | | Yoga | | |
| N=17 | | | N=14 | | |
| EORTC QLQC30 | Mean | Median | SD | Mean | Median | SD |
| Global Health Scale | 77.06 | 79.00 | 18.13 | 83.21 | 83.00 | 12.27 |
| Physical Functioning | 81.63 | 93.00 | 25.96 | 91.79 | 93.00 | 8.76 |
| Role Functioning | 83.38 | 100.00 | 24.37 | 92.93 | 100.00 | 14.05 |
| Emotional Functioning | 80.25 | 83.50 | 23.40 | 88.07 | 57.50 | 11.02 |
| Cognitive Function | 82.25 | 91.50 | 21.47 | 94.00 | 100.00 | 10.57 |
| Social Functioning | 85.50 | 100.00 | 29.97 | 90.50 | 100.00 | 19.27 |
| Fatigue | 29.06 | 27.50 | 25.69 | 45.07 | 16.50 | 96.52 |
| Nausea | 2.13 | 0 | 5.81 | 2.42 | 0.00 | 6.17 |
| Pain | 9.38 | 0 | 16.02 | 8.33 | 0.00 | 15.68 |
| Dyspnoea | 8.25 | 0 | 14.76 | 7.14 | 0.00 | 14.19 |
| Insomnia | 31.13 | 33.33 | 37.45 | 30.95 | 33.33 | 27.62 |
| Appetite | 6.25 | 0 | 18.17 | 9.52 | 0.00 | 15.62 |
| Constipation | 12.50 | 0 | 29.53 | 14.29 | 0.00 | 25.20 |
| Diarrhoea | 16.63 | 0 | 29.81 | 14.29 | 0.00 | 28.39 |
| Finance | 2.06 | 0 | 8.25 | 7.14 | 0.00 | 14.19 |

Note: Mean and Median have both been reported alongside the standard deviation as non-parametric tests were used in the analysis.

Table 4 - Kruskal-Wallis test for differences between subscales at T1 for baseline, control & yoga.

|  |  |  |
| --- | --- | --- |
| EORTC QLQC30 | *H (df=2)* | p value |
| Global Health Scale | 0.031 | 0.985 |
| Physical Functioning | 1.227 | 0.541 |
| Role Functioning | 4.171 | 0.124 |
| Emotional Functioning | 0.370 | 0.982 |
| Cognitive Function | 0.573 | 0.751 |
| Social Functioning | 1.220 | 0.543 |
| Fatigue | 0.075 | 0.963 |
| Nausea | 0.462 | 0.794 |
| Pain | 0.930 | 0.628 |
| Dyspnoea | 1.159 | 0.560 |
| Insomnia | 0.584 | 0.747 |
| Appetite | 2.398 | 0.302 |
| Constipation | 2.458 | 0.293 |
| Diarrhoea | 1.563 | 0.458 |
| Finance | 0.977 | 0.613 |

Table 5 - Mann-Whitney U test for differences between the control and yoga groups at T1, T2 and T3.

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Time 1 | | | Time 2 | | | Time 3 | | |
| EORTC QLQC30 | *U* | z score | exact p | *U* | z score | exact p | *U* | z score | exact p |
| Global Health Scale | 232.50 | -0.120 | 0.910 | 224.00 | -0.328 | 0.750 | 139.00 | -0.375 | 0.717 |
| Physical Functioning | 190.50 | -0.932 | 0.358 | 232.00 | -0.133 | 0.900 | 140.50 | -0.072 | 0.950 |
| Role Functioning | 174.00 | -1.361 | 0.179 | 234.00 | -0.092 | 0.935 | 117.00 | -0.784 | 0.479 |
| Emotional Functioning | 235.50 | -0.048 | 0.967 | 213.50 | -0.591 | 0.562 | 142.50 | -0.258 | 0.804 |
| Cognitive Function | 233.50 | -0.106 | 0.926 | 222.00 | -0.399 | 0.696 | 118.50 | -1.174 | 0.258 |
| Social Functioning | 202.00 | -0.872 | 0.390 | 190.00 | -1.211 | 0.230 | 139.00 | -0.500 | 0.944 |
| Fatigue | 230.50 | -0.168 | 0.873 | 232.50 | -0.120 | 0.912 | 129.50 | -0.460 | 0.656 |
| Nausea | 216.50 | -0.623 | 0.542 | 227.50 | -0.397 | 0.842 | 142.50 | -0.383 | 1.000 |
| Pain | 234.00 | -0.090 | 0.941 | 186.50 | -1.306 | 0.196 | 121.00 | -0.849 | 0.454 |
| Dyspnoea | 206.50 | -0.820 | 0.541 | 210.50 | -0.806 | 0.507 | 133.50 | -0.425 | 0.709 |
| Insomnia | 228.00 | -0.236 | 0.821 | 234.50 | -0.077 | 0.959 | 129.50 | -0.738 | 0.480 |
| Appetite | 23.00 | -0.101 | 0.933 | 205.50 | -1.129 | 0.310 | 146.00 | -0.242 | 1.000 |
| Constipation | 209.00 | -0.803 | 0.441 | 172.00 | -1.886 | 0.068 | 144.00 | -0.273 | 0.968 |
| Diarrhoea | 202.00 | -1.256 | 0.205 | 230.50 | -0.247 | 0.955 | 142.50 | -0.316 | 0.808 |
| Finance | 216.00 | -0.804 | 0.680 | 234.00 | -0.230 | 0.749 | 147.00 | -0.249 | 0.748 |

The Mann Whitney U test did not yield any significant results suggesting that there were no significant differences between those in the control group and those in the yoga group at time points 1, 2 or 3. However, the p-value for a difference in constipation at T2 was approaching significance (p = 0.068), indicating that patients in the control arm reported more constipation at time 2 compared with the yoga arm. The estimated effect size of this, calculated with the equation given by Rosenthal (1991, p.19), was r=-0.20, indicating a small effect size (under the 0.3 cut off).

## Testing for differences between time points for each group.

A Friedman’s ANOVA (a non-parametric equivalent of a one way ANOVA) was used to establish whether there were any significant changes over the three time points for each subscale of the EORTC (calculated separately for each group). The analysis indicates that there is a significant improvement in role functioning (X2 (2) = 10.89, p<0.05), Social Functioning (X2 (2) = 11.81, p<0.05) and Insomnia (X2 (2) = 7.41, p<0.05) in the control group. No significant changes over the time points were seen in the yoga condition, however the subscale for constipation was approaching significance (X2 (2) = 5.16, p=0.08). The X2 value and exact p value for each subscale are displayed in Table 6 (again, the exact p value is displayed as this was a small sample).

Table 6 – Friedman’s ANOVA changes over time for EORTC QLQC30 subscales for control and yoga groups.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Control | | Yoga | |
| EORTC QLQC30 | X2 value | exact p | X2 value | exact p |
| Global Health Scale | 1.583 | 0.472 | 2.302 | 0.339 |
| Physical Functioning | 2.426 | 0.192 | 0.044 | 0.994 |
| Role Functioning | 10.882 | 0.003\* | 2.313 | 0.341 |
| Emotional Functioning | 1.333 | 0.547 | 1.143 | 0.588 |
| Cognitive Function | 1.474 | 0.508 | 3.586 | 0.165 |
| Social Functioning | 11.808 | 0.002\* | 2.000 | 0.520 |
| Fatigue | 4.80 | 0.094 | 3.862 | 0.145 |
| Nausea | 2.364 | 0.317 | 0.353 | 0.907 |
| Pain | 2.130 | 0.371 | 1.400 | 0.525 |
| Dyspnoea | 2.240 | 0.398 | 2.818 | 0.274 |
| Insomnia | 7.409 | 0.023 | 2.837 | 0.263 |
| Appetite | 2.348 | 0.331 | 2.235 | 0.401 |
| Constipation | 1.086 | 0.629 | 5.158 | 0.085 |
| Diarrhoea | 1.333 | 0.547 | 0.692 | 0.747 |
| Finance | 1.600 | 0.630 | 0.667 | 1.000 |

Note: p values marked with \* are significant at the 0.05 level

## 

## Post hoc tests for the Friedman’s ANOVA.

A series of Wilcoxon signed ranks tests (non-parametric within group t-test) were used to establish whether there were any significant differences between combinations of time points (T1 & T2, T1 & T3 and T2 &T 3) for each group. A Bonferonni correction was applied and so all effects are reported at a 0.0167 level of significance. There were significant changes in the control group between T1 and T3 in role functioning (z=-2.675, r=-0.09), social functioning (z=-3.025, r=-0.10) and insomnia (z=-0.012, r=-0.07). There were no significant changes between any of the combinations of time points for those in the yoga condition.

# Testing relationships between EORTC QLQ C30 & VAS scores

Firstly, the data was analysed to ascertain whether there was a significant correlation between the EORTC QLQ C30 scores at T1 and T2 and the VAS QoL scores at week 0 and week 10 (results shown in Table 7). As these scales measure the same outcome, it was expected that there would be a highly significant positive correlation between the scales. Since the data was non-normally distributed and also had a number of outliers (when looking at box plots), a Spearman’s rho correlation was used. This test is less sensitive to outliers and is suitable for use with non-parametric data (Field, 2009).

Table 7 - Spearman’s Rho correlations between EORTC QLQ C30 and VAS QoL.

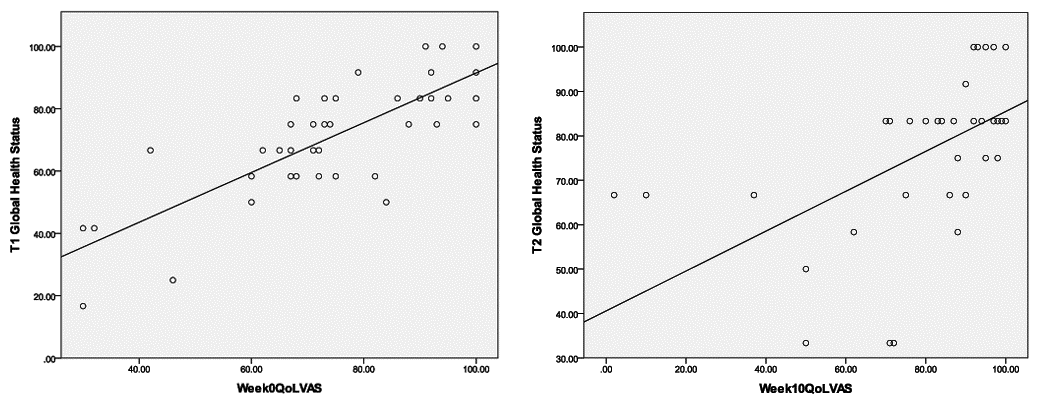
|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | QLQ C30 GHS at T1 | Week 0 VAS QoL | QLQ C30 GHS at T2 | Week 10 VAS |
| QLQ C30 GHS T1 | 1 | 0.758\*\* | 0.428\*\* | 0.343\*\* |
| Week 0 VAS QoL |  | 1 | 0.454\*\* | 0.485\*\* |
| QLQ C30 GHS at T2 |  |  | 1 | 0.640\*\* |
| Week 10 VAS  QoL |  |  |  | 1 |

Note: Correlation marked with \*\* are significant at the 0.001 level (2 tailed)

The Spearman’s Rho correlations indicate that there is a highly significant strong positive correlation (Graph A) between patients global health status at T1 and their VAS QoL scores at week 0 (rs= 0.76 p<0.001). Additionally, there is a highly significant positive medium-strong correlation (Graph B) between patients' health status at T2 and their VAS QoL scores at week 10 (rs = 0.64 p<0.001). Graphs A & B from these correlations are shown in Figure 10.

There were also significant positive small - medium correlations between QLQ C30 GHS T1 and QLQ C30 GHS T2 (rs = 0.43 p<0.001), QLQ-C30 GHS T1 and Week 10 VAS QoL (rs = 0.34, p<0.001) and between week 0 VAS QoL and QLQ C30 GHS T2 (rs = 0.45 p<0.001), suggesting a relationship between all combinations of time points for both measures.

Figure 10 - Spearman’s Rho correlations between EORTC QLQ C30 and VAS QoL. Graph A is on the left, and Graph B is on the right.



# Analysis of VAS data

Data was screened for normality using the methods described for the EORTC QLQ, and showed similar outcomes – falling within acceptable skew and kurtosis values, but demonstrating non normal distribution when inspected visually and examined using the KS test (p< 0.05). Means, medians and standard deviations for individual conditions are shown in Table 8.

## Testing for differences between groups at time points 1 and 2

A Mann-Whitney U test was used to explore whether there were any differences between the scores of control patients and yoga patients at week 0 and week 10. Again, the exact p value is displayed along with the U statistic and z score in Table 9.

Table 9 - Mann-Whitney U test for differences between the control and yoga groups at weeks 0 and week 10.

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Week 0 | | | Week 10 | | |
|  | *U* | z score | exact p | *U* | z score | exact p |
| VAS QoL | 153.50 | -1.825 | 0.069 | 138.00 | -1.576 | 0.117 |
| VAS Pain | 155.50 | -1.798 | 0.073 | 167.00 | -0.992 | 0.328 |
| VAS Anxiety | 182.50 | -1.118 | 0.269 | 155.50 | -1.297 | 0.199 |
| VAS Fatigue | 195.50 | -0.796 | 0.434 | 180.00 | -0.638 | 0.632 |

The Mann Whitney U test did not yield any significant results, suggesting that there were no significant differences between those in the control group and those in the yoga group at time week 0 and week 10 for any of the VAS measures, although the scores at week 0 in the QoL measure were approaching significance (p=0.069), suggesting that those in the yoga group had a lower baseline QoL than those in the control group.

Table 8 - Means, medians and standard deviations (SD) of VAS QoL, Anxiety Pain and Fatigue scores.

|  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Control (n=22) | | | Yoga (n=17) | | |  | Control (n=22) | | | Yoga (n=17) | | |
| VAS QoL | Mean | Median | SD | Mean | Median | SD | VAS Anxiety | Mean | Median | SD | Mean | Median | SD |
| Week 0 | 79.81 | 83.00 | 19.85 | 72.12 | 73.00 | 16.90 | Week 0 | 77.71 | 82.50 | 22.63 | 70.32 | 71.00 | 24.09 |
| Week 1 | 81.59 | 86.00 | 20.37 | 70.88 | 70.00 | 16.59 | Week 1 | 83.92 | 90.50 | 22.57 | 71.00 | 74.00 | 22.27 |
| Week 2 | 83.32 | 89.50 | 17.87 | 70.47 | 72.00 | 20.35 | Week 2 | 84.46 | 94.00 | 21.97 | 74.84 | 77.00 | 24.24 |
| Week 3 | 81.14 | 86.50 | 16.87 | 68.00 | 67.00 | 17.96 | Week 3 | 85.20 | 94.50 | 18.91 | 76.36 | 89.00 | 27.26 |
| Week 4 | 84.00 | 92.50 | 19.36 | 68.82 | 71.00 | 17.60 | Week 4 | 89.00 | 99.00 | 16.96 | 76.32 | 83.00 | 20.02 |
| Week 5 | 26.50 | 88.50 | 76.45 | 64.82 | 67.00 | 24.57 | Week 5 | 85.04 | 99.50 | 23.42 | 76.00 | 82.00 | 22.10 |
| Week6 | 81.50 | 87.50 | 20.15 | 68.94 | 75.00 | 21.33 | Week6 | 87.17 | 92.50 | 18.16 | 74.05 | 84.00 | 25.31 |
| Week 7 | 77.36 | 91.50 | 26.57 | 69.88 | 72.00 | 19.03 | Week 7 | 87.67 | 98.00 | 19.93 | 76.66 | 84.00 | 23.29 |
| Week8 | 85.91 | 92.50 | 16.45 | 73.53 | 75.00 | 22.16 | Week8 | 87.17 | 97.00 | 18.72 | 27.37 | 85.50 | 73.89 |
| Week 9 | 84.14 | 89.50 | 17.81 | 75.00 | 80.00 | 18.91 | Week 9 | 87.71 | 97.00 | 16.96 | 78.41 | 87.00 | 20.08 |
| Week 10 | 80.73 | 91.00 | 25.11 | 76.65 | 84.00 | 21.91 | Week 10 | 83.21 | 96.50 | 25.43 | 83.23 | 90.00 | 16.75 |
| VAS Pain | Mean | Median | SD | Mean | Median | SD | VAS Fatigue | Mean | Median | SD | Mean | Median | SD |
| Week 0 | 82.96 | 97.00 | 29.18 | 77.37 | 82.00 | 20.41 | Week 0 | 66.75 | 74.00 | 28.85 | 59.74 | 58.00 | 27.81 |
| Week 1 | 87.96 | 100.00 | 23.86 | 80.53 | 91.00 | 21.20 | Week 1 | 82.13 | 93.00 | 22.72 | 59.42 | 70.00 | 24.70 |
| Week 2 | 91.08 | 100.00 | 18.70 | 84.84 | 95.00 | 18.67 | Week 2 | 77.74 | 91.00 | 23.53 | 67.84 | 79.00 | 25.38 |
| Week 3 | 87.29 | 96.50 | 19.33 | 85.47 | 90.00 | 15.42 | Week 3 | 78.67 | 84.00 | 21.30 | 63.32 | 70.00 | 23.98 |
| Week 4 | 88.78 | 100.00 | 18.74 | 86.53 | 94.00 | 14.70 | Week 4 | 79.95 | 93.00 | 21.56 | 24.33 | 77.00 | 66.00 |
| Week 5 | 81.83 | 99.00 | 31.04 | 80.05 | 88.00 | 22.91 | Week 5 | 74.00 | 68.00 | 27.88 | 66.79 | 68.00 | 29.36 |
| Week6 | 85.78 | 96.00 | 24.37 | 78.05 | 87.00 | 24.19 | Week6 | 76.57 | 83.00 | 24.01 | 70.31 | 72.00 | 24.50 |
| Week 7 | 85.50 | 95.50 | 21.30 | 83.11 | 87.50 | 17.96 | Week 7 | 77.43 | 87.00 | 27.71 | 68.50 | 72.50 | 22.76 |
| Week8 | 89.62 | 98.00 | 17.07 | 84.28 | 88.00 | 16.04 | Week8 | 83.87 | 92.00 | 19.89 | 75.39 | 81.00 | 22.75 |
| Week 9 | 87.12 | 97.50 | 20.50 | 87.59 | 93.00 | 16.24 | Week 9 | 81.91 | 92.00 | 21.66 | 79.47 | 86.00 | 16.67 |
| Week 10 | 86.66 | 97.00 | 18.83 | 84.00 | 89.00 | 17.39 | Week 10 | 75.95 | 74.50 | 28.29 | 76.00 | 87.00 | 25.04 |

## Testing for differences between week 0 and week 10 by group

A Wilcoxon signed ranks test was used to establish whether there were any significant differences between week 0 and week 10 for each individual group. The z score and exact p value for each scale and subscale are displayed in Table 10 (again, the exact p value is displayed as this was a small sample).

Table 10 - Wilcoxon signed ranks test for differences at Week 0 and Week 10 for all patients (overall, yoga and control groups).

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Control | | Yoga | |
|  | z score | exact p | z score | exact p |
| VAS QoL | -0.567 | 0.587 | -1.042 | 0.312 |
| VAS Pain | -0.457 | 0.662 | -0.931 | 0.368 |
| VAS Anxiety | -1.489 | 0.142 | -2.042 | 0.040 |
| VAS Fatigue | -1.218 | 0.231 | -1.941 | 0.052 |

The results from the Wilcoxon signed ranks test indicate that there were no significant differences between week 0 and week 10 for the individual arms of the intervention for QoL and pain, or for anxiety and fatigue at week 0. However, at week 10, there was a significant difference between the two time points with regards to anxiety and fatigue for those in the yoga condition. This suggests that there was a significant improvement in both anxiety and fatigue for those in the yoga group over the 11 week period. Figure 11 shows the mean VAS score over the 11 time points for each arm of the intervention.

## VAS QoL data analysis using time as a linear variable

The VAS QoL data was analysed using the GAM, GLM and MLM methods introduced in the previous chapter. Analysis was conducted using the R statistical programming language (R Development Core Team, 2008). The change score analysis will be presented separately following a presentation of the overall QoL data. Median QoL score with time and by condition are shown in Figure 12.

### GAM

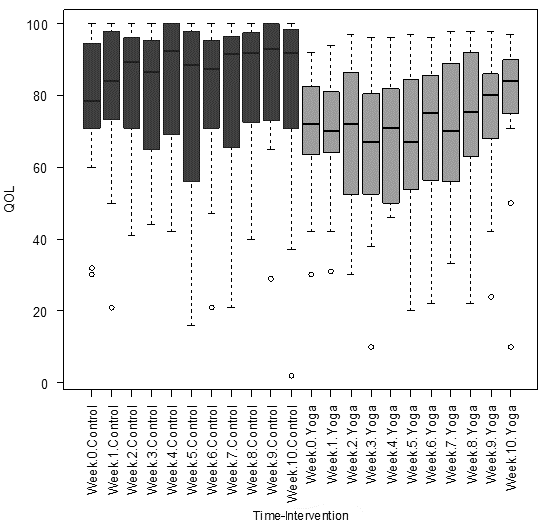
The GAM was modelled using two approaches described by Zuur, Ieno & Smith (2007) and Wood (2006); both use the ‘mgcv’ package in the R repository. Although both techniques were used for the modelling, only the results from the technique described by Wood will be presented – after running the model, it was considered that this technique produced the model which was the best fit for the data (using explained deviance and standard residual diagnostics).

Figure 11 - Mean QoL, pain, anxiety and fatigue VAS scores over time.

# 

The diagrams below (Figure 13) are a model visualisation. The first diagram gives the overall shape of the whole dataset (ignoring effects of condition) over time. The solid line shows the model prediction across time, without any effect of condition. The shaded area represents +/- 2 standard errors, and the dots represent data points. It can be seen from this diagram that the overall trend is positive over time, i.e. that as time goes on, QoL increases, although this effect was not significant (see below). The second plot is a visualisation of the effect of the yoga condition with time. Again, the shaded area represents +/- 2 standard errors.

Figure 12 - Box plot of the median QoL score with time and by condition, with the inter quartile range (IQR; boxes) and the maximum scores (whiskers). Dark grey boxes represent the control condition and light grey boxes represent the yoga condition.



The GAM indicated that time alone was not a significant contributor to the model (QoL), suggesting that time was not a better predictor of QoL than the median score. There was however, a highly significant interaction between time and intervention (yoga) – suggesting that time and intervention (yoga) combined significantly contributed to the QoL of patients, i.e. there is a statistically significant upward trend in QoL over time. These results are displayed in Table 11 and represented in Figure 13.

Figure 13 –The GAM model showing the trend of time for the whole group (left) and those on yoga (right).

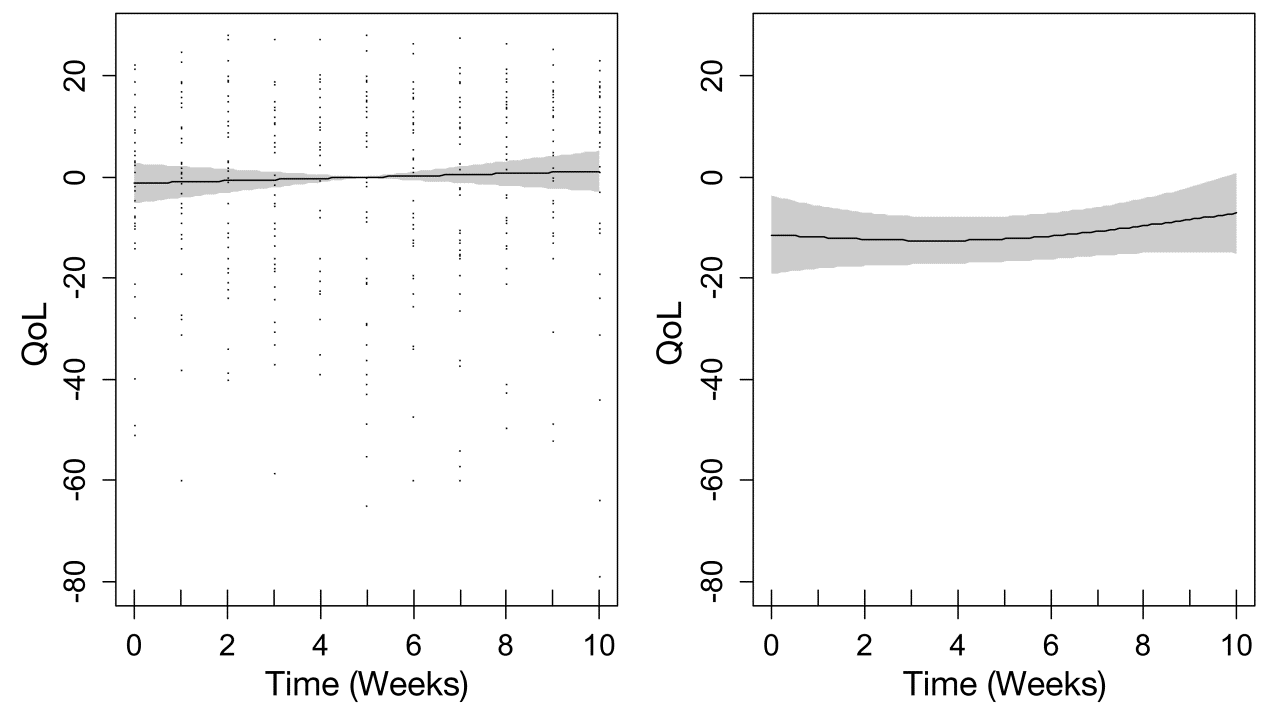


Table 11 – Results of the F-ratio test.

|  |  |  |  |
| --- | --- | --- | --- |
|  | DF | *F* | P Value |
| Time | 1 | 0.37 | >0.05 |
| Time\*Intervention | 2.97 | 12.38 | <0.0001 |

The overall model summary provided an Adjusted R Square of 0.07, and indicated that the time: intervention (yoga) interaction explained 7.79% of the deviance in QoL scores (displayed in Table 12).

Table 12 - Fit of the Model.

|  |  |  |
| --- | --- | --- |
|  | Adjusted R Square | Deviance Explained |
| GAM 1 | 0.07 | 7.79% |

### GLS

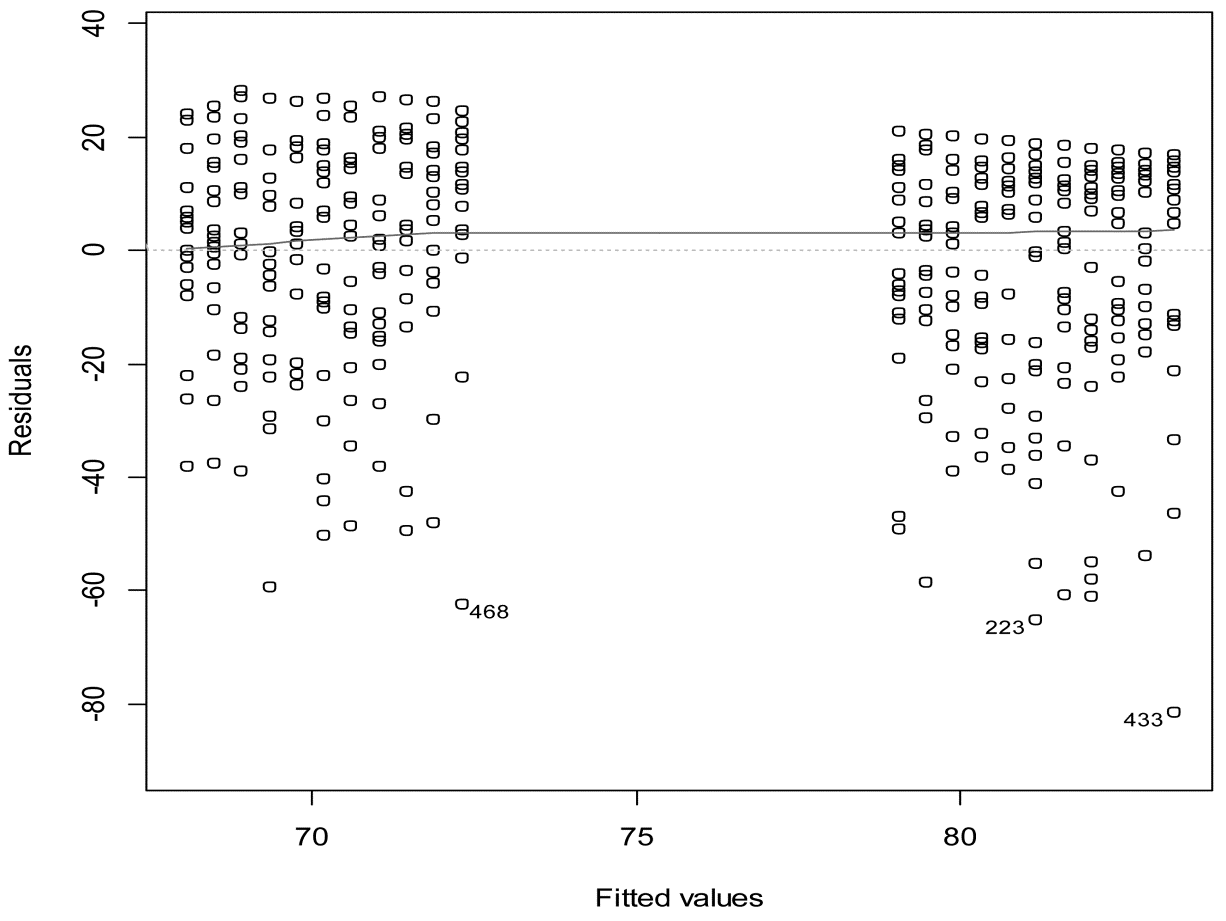
The second analysis of the VAS QoL data was the GLS method, which allows for a lack of independence in the data through autocorrelation (temporal in this case). This utilised the methodology outlined by Zuur et al.(2007) and Bulling et al. (2010) (both the GLS and MLM use the ‘nlme’ package in R). The most appropriate random component (modelling of the autocorrelation using a variance-covariate matrix) was determined first using the Akaike Information Criterion (AIC) scores and residual diagnostics. The AIC is a measure of ‘goodness of fit’ (Akaike, 1973 & 1974) and is based on the number of parameters in the statistical model (k) and the maximized value of the likelihood function of the estimated model (L). When this information is computed (AIC = 2k – 2lm(L)), it provides an overall score for each model. The preferred model is the one with the lowest AIC score. The random components used were compound symmetry and an auto-regressive structure.

The AIC scores for each random structure were compared with the baseline linear regression model (Table 13). It can be seen from the table that the linear regression analysis achieved the lowest AIC, and therefore represented the best random component structure (i.e. no temporal autocorrelation). The residual diagnostic plot for this model assessing homogeneity of variance is shown in Figure 14. The results of the linear regression are presented below.

Table 13 - AIC scores for the GLS modelling procedure.

|  |  |
| --- | --- |
| GLS Technique | AIC Score |
| Linear Regression | 4109.79 |
| Compound Symmetry | 4111.24 |
| Auto-regressive Model | 4111.40 |

Figure 14 – Distribution of residuals from the linear model – yoga on the left, control on the right.



The linear regression indicates similar findings to the previous GAM analysis, although the interaction between yoga and time is lost (this is likely to be because we are now looking at linear relationships rather than allowing non-linear relationships). There was also no significant interaction between time and intervention, so this was removed from the model. The linear regression indicated that there was a significant effect of intervention, and that those in the yoga group were on average 10.97 points lower on the VAS scale (at any given time point) when compared to the control group (Figures are displayed in Table 14); this difference is represented in the distribution of residual graph (Figure 14). As with the GAM, the linear regression indicated that time alone was not a significant predictor of QoL. The overall model explained 6.97% of the deviance in QoL scores, and the *F*-test was highly significant (Table 15), suggesting that the model was a better predictor of QoL than using the mean scores alone (Table 16).

Table 14 – results of the linear regression with time and intervention as predictors of QoL.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Coefficient | Beta Value | Standard Error | t-value | P Value |
| Intercept | 79.04 | 1.92 | 41.08 | <0.001 |
| Yoga | -10.97 | 1.88 | -5.82 | <0.001 |
| Time | 0.42 | 0.29 | 1.43 | >0.05 |

Table 15 – Results of the F-test.

|  |  |  |  |
| --- | --- | --- | --- |
|  | DF | F | P Value |
| Model | 2, 462 | 18.20 | <0.001 |

Table 16 - Fit of the Model.

|  |  |  |
| --- | --- | --- |
|  | Adjusted R Square | Deviance Explained |
| Linear | 0.07 | 6.97% |

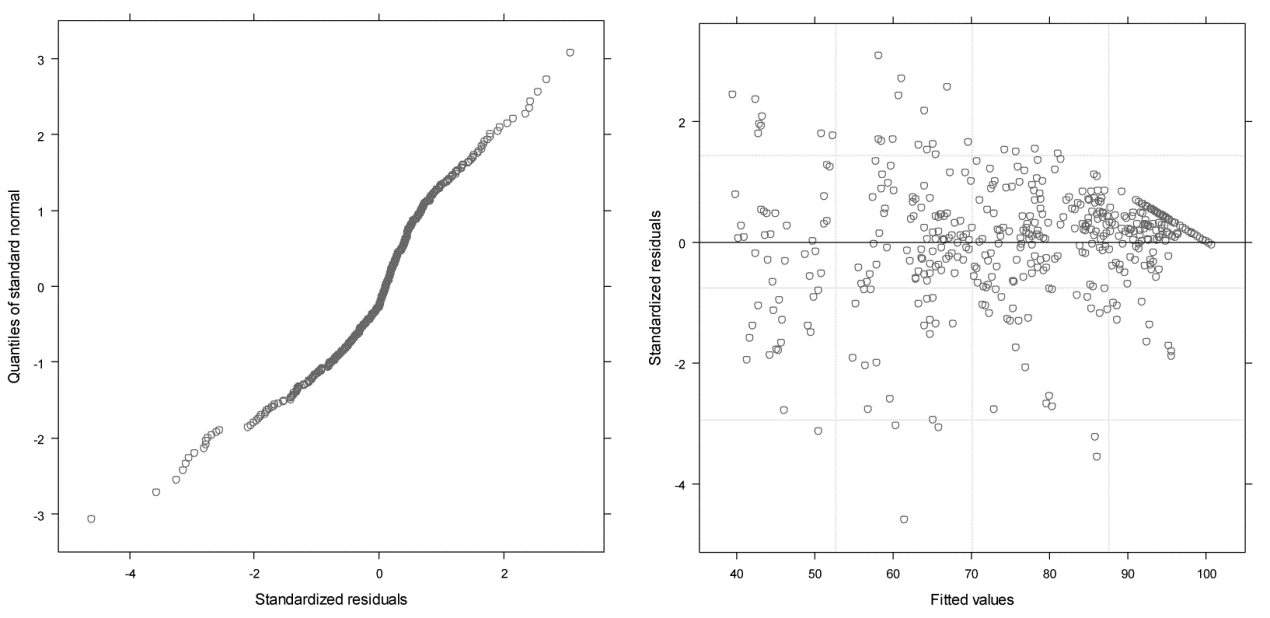
### MLM

The third method of analysing the VAS QoL data, the MLM, allowed the individuals to be added to the model as a random component (using a variance-covariate matrix as with the GLS models). Adding these into the model increased the heterogeneity of variance within the model (shown in Figure 15), indicating that the MLM was not a suitable framework for analysis in this instance.

### **Adding pain, anxiety and fatigue to the models**

As there was a significant time x intervention interaction effect on QoL, it would have been ideal to conduct additional analysis to explore if any of the other VAS measures (pain, anxiety and fatigue) had an effect, either on this interaction or in their own right (e.g. could the patient’s fatigue be the reason for improved QoL). However, this would have required a substantial increase in the number of independent variables, with interactions and, as the sample size for this study was small (n=44), this method of analysis was not achievable. Therefore an intermediate framework was constructed in which time, pain, anxiety and fatigue were used as potential independent variables with QoL as the dependent variable. This was conducted independently for the two sets of data; those patients who took part in the yoga and those who were in the control group.

Figure 15 – QQ-plot assessing normality (left) and a plot of fitted versus standardised residuals (right) from the MLM.



As the analysis was now being conducted on subsets of the data, the number of data points in each subset fell to a level where the application of regression splines in the form of a GAM analysis would be inappropriate (Hastie and Tibshirani, 1986). Therefore, in the first instance linear regression was applied. To allow for the non-linear relationship between time and QoL identified in the earlier GAM analysis, time was treated as a factor rather than a continuous variable.

Potential correlations between the three variables (pain, anxiety and fatigue) had to be accounted for as, if significant, they would break the assumptions of the regression. Thus, Pearson’s correlations were conducted to assess the relationship between each of the variables, and each of the variables and QoL. The results from the Pearson’s correlation can be found in Table 17.

Table 17 – Pearson’s (and spearman’s) correlations between the VAS variables.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Pain | Anxiety | Fatigue | QoL |
| Pain | 1 | 0.58 (0.62)\*\* | 0.54 (0.57)\*\* | 0.64 (0.67)\*\* |
| Anxiety |  | 1 | 0.66 (0.69)\*\* | 0.78 (0.76)\*\* |
| Fatigue |  |  | 1 | 0.78 (0.79)\*\* |
| QoL |  |  |  | 1 |

Note: Correlation marked with \*\* are significant at the 0.001 level (2 tailed).

As there were medium to large correlations (0.5 - 0.8) between the variables, data needed to be isolated (to prevent over fitting the model) before they were entered into the model. The partition method described by Zuur, Ieno, and Smith (2007), was used to achieve this isolation. This partition method involves identifying the variable with the highest correlation with the dependent variable (in this case, fatigue), and this variable remains unchanged. The remaining explanatory variables (pain and anxiety) are then individually regressed against this main independent variable to ascertain the effect that is independent of that caused by fatigue. The residuals from each of these regressions then represent information that is independent of the main explanatory variable (fatigue), and it is these residuals that are put into the regression framework instead of the original variables in raw data form.

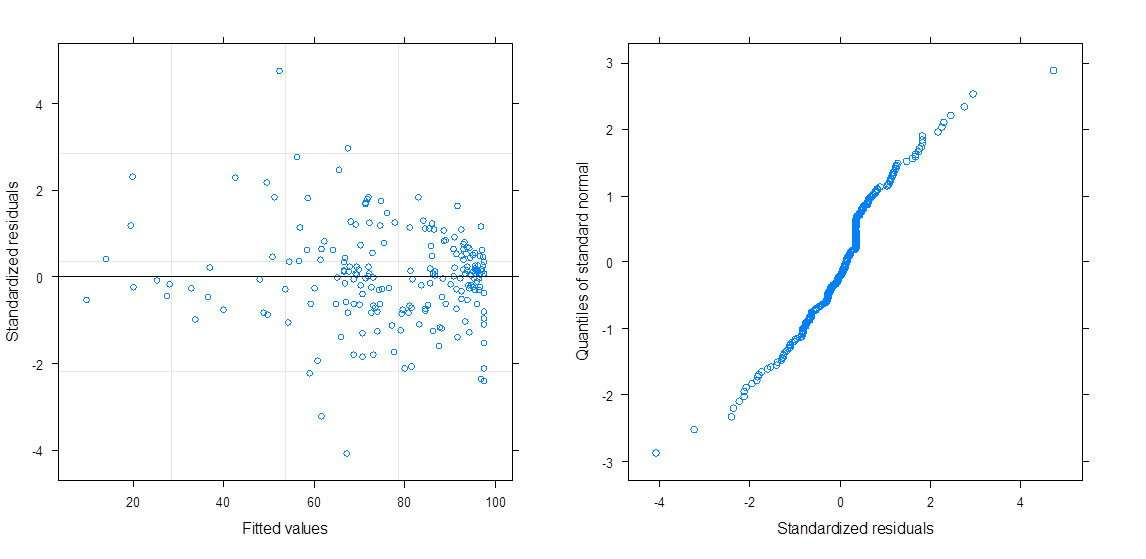
The linear regression analysis was then conducted with the starting model involving each of the four independent variables as additive components. Model assumptions were tested using boxplots and QQ-plots (Figure 16). There was evidence of a strong heterogeneity of variance and non-normality (Figure 16). In light of this, a generalised least squares (GLS) component was added to the linear regression framework in order to model the heterogeneity of variance.

Figure - 16 Plots showing distribution of data from the GLS model for the overall data.

|  |  |
| --- | --- |
|  |  |

**Note:** In all of the following analysis, all terms were put in in an additive manner. It was felt that given the minimal amount of data, including interactions with so many potential independent variables would be inappropriate. Additionally, it was decided to treat time (week) as a factor to allow for the possibility of non-linear changes with time.

The preliminary analysis using the GLS method reduced the homogeneity of variance and the data was closer to being normally distributed (Figure 17), so full analysis of the data continued.

Figure 17 – Plots showing distribution of data from the GLS model for the control group. 

In the following GLS models, all starting independent variables (time, anxiety, pain and fatigue) were put into the starting model together in additive form. A backwards selection process was then applied following the method described by Zurr et al., (2007), dropping the most insignificant terms sequentially until all remaining terms were significant (this was to ensure that true significant effects from the data were not masked by non-significant effects as there was such a small data set).

#### Control Group

In the control group, all variables were included in an additive manner. At the first selection step, it was found that the variable of time was non-significant, and it was subsequently removed from the model. This may have been due to the reduction in the size of the data set after the breaking down in to separate conditions, reducing the statistical power to identify more subtle patterns in the data. The GLS model was run again, and the resulting analysis suggested that all other variables (pain, anxiety and fatigue) significantly affected QoL (Table 18).

The results for the GLS in the control group suggest that all three variables predict the QoL of patients. The strongest predictor of QoL, based on the size of the beta values, was fatigue, with pain and anxiety having around one third of the impact compared to fatigue.

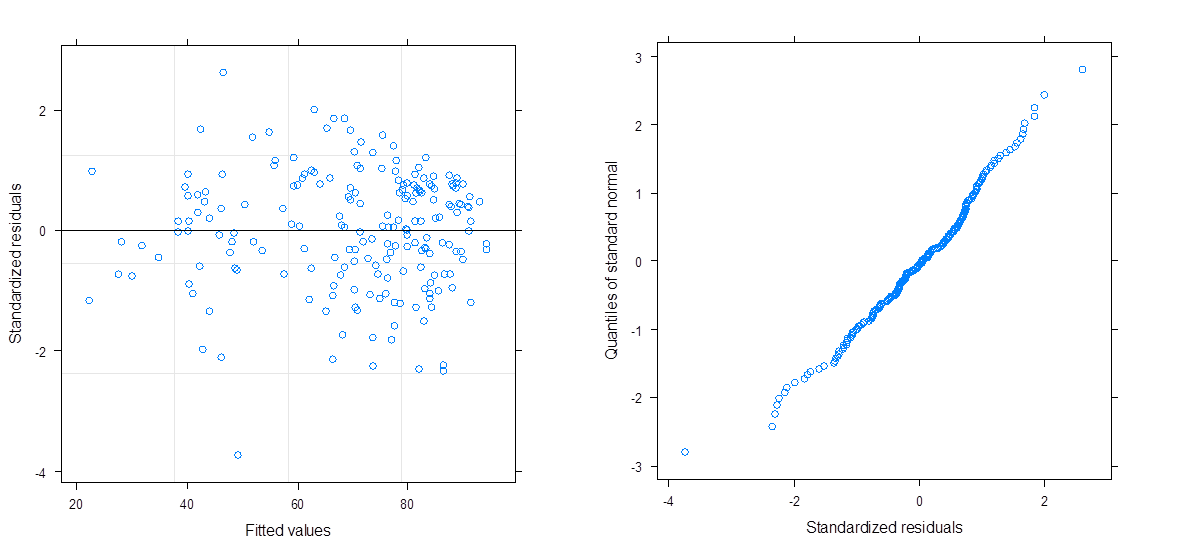
Table 18 – Results of the GLS with fatigue, anxiety and pain as predictors of QoL for the control condition.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Coefficient | Beta Value | Standard Error | t-value | P Value |
| Intercept | 23.43 | 2.31 | 10.15 | <0.001 |
| Fatigue | 0.72 | 0.03 | 27.68 | <0.001 |
| Pain | 0.27 | 0.05 | 5.21 | <0.001 |
| Anxiety | 0.28 | 0.04 | 7.12 | <0.001 |

#### Yoga group

Analysis for the data collected from the yoga group was conducted in the same manner as for the control group. The basic linear regression model suggested heterogeneity of variance and non-normally distributed data which was similar to the control group (see Figure 18).

Figure 18 – Plots showing distribution of data from the GLS model for the yoga group.



As with the control group, data from the yoga intervention was analysed using a GLS model in an attempt to reduce some of the heterogeneity of variance and to improve the distribution of data points. The preliminary analysis using the GLS method effectively reduced the heterogeneity of variance and the data was close to being normally distributed (Figure 18), so full analysis of the data continued.

In the yoga group at the first selection process, it was found that the variable of time was non-significant (as was the case with the control group), and it was subsequently removed from the model. The GLS model was run again, and results suggested that all other variables (pain, anxiety and fatigue) significantly affected to QoL (Table 19).

Table 19 – Results of the GLS with fatigue, anxiety and pain as predictors of QoL for the yoga condition.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Coefficient | Beta Value | Standard Error | t-value | P Value |
| Intercept | 26.91 | 2.36 | 11.43 | <0.001 |
| Fatigue | 0.64 | 0.03 | 20.43 | <0.001 |
| Pain | 0.13 | 0.05 | 2.87 | <0.01 |
| Anxiety | 0.32 | 0.05 | 6.72 | <0.001 |

As with the control group, the strongest predictor of QoL was fatigue, with anxiety having around half of the effect strength, and pain having around one quarter of the effect strength compared to fatigue.

The overall findings of this additional analysis suggest that factors such as anxiety, fatigue and pain do contribute to the QoL of patients on both arms of the trial. However, due to the small number of participants, it is difficult to ascertain whether there is a significant difference in the levels of contribution that these factors make for each individual group (i.e. control and yoga) as not all factors (time and intervention group) can be added into one overall model.

## VAS QoL Change Data

The VAS QoL data was analysed using the GAM, GLM and MLM methods introduced in the previous chapter. Change scores were computed by subtracting the week 0 score from the week in question, so for week 4, the equation was (VAS week 4 score – VAS week 0 score = week 4 change score). Use of the change in VAS scores relative to week 0 (as week 0 was a baseline control) allowed for observation of any trends/relationships between the intervention and time, and the effect it had on the change in QoL from week 0. This analysis allowed us to see if there were any differences between the groups taking part in the intervention independent of their starting QoL. From earlier analysis conducted in SPSS we know that those in the yoga group had a lower starting QoL than those in the control group (Table 8), and the analysis that was previously conducted in R (the GLS) suggests that this is consistent over time. Median QoL change scores with time and by condition are shown in Figure 19.

### GAM and GLS analyses

The GAM and the GLS analyses were conducted using the same methodology as used with the overall QoL data. The models (GAM, GLS with compound symmetry and GLS with the Auto-regressive model) did not include any significant predictors, so have not been presented here. However the basic linear model showed an effect of yoga approaching significance, p = 0.09), indicating that there was an effect of intervention (yoga) and that patients in the yoga group achieved, on average, 3 points less of a change in QoL over each time point (displayed in Table 20). However, the R-squared value for the model was very small; indicating that the model only explained 0.40% of the variance in QoL change scores (Table 21). Additionally, the *F*-test was non-significant, suggesting that the model was not a better predictor of the QoL change when compared to the median (Table 20). Note: time was removed from this model as it was a non-significant predictor of QoL change.

Table 20 – Results of the linear regression with intervention as a predictor of QoL.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Coefficient | Beta Value | Standard Error | t-value | P Value |
| Intercept | 2.49 | 1.27 | 1.97 | <0.05 |
| Yoga | -3.18 | 1.92 | -1.66 | >0.05 |

Table 21 – Test statistics from the linear regression.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | Adjusted R Square | Deviance Explained | F Statistic | P Value |
| Model | 0.004 | 0.40% | 2.751 | >0.05 |

### MLM

The third method of analysing the VAS QoL Change data, the MLM, allows the individuals to be added the model as a random component. This analysis showed a marginal effect of time (p = 0.07), suggesting that as time went on, there was an increase in QoL change, with the QoL change increasing by 0.40 for each time point (displayed in Table 22). Note: at present, there is no statistically robust method for generating an R squared value for MLM, and therefore an *F*-test could not be conducted.

Figure 19 - Box plot of the median QoL change score with time and by condition, with the inter quartile range (IQR; boxes) and the maximum scores (whiskers). Dark grey boxes represent the control condition and light grey boxes represent the yoga condition.

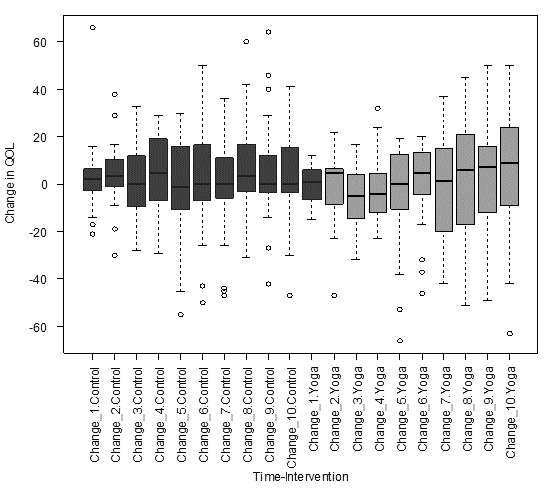


Table 22 – Results of the MLM with intervention and time as predictors of QoL.

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Coefficient | Beta Value | Standard Error | t-value | P Value |
| Intercept | 0.37 | 3.39 | 0.11 | >0.05 |
| Yoga | -2.94 | 4.77 | -1.83 | >0.05 |
| Time | 0.40 | 0.22 | 1.83 | >0.05 |

### 

### **Adding pain, anxiety and fatigue to the models**

It would be inappropriate to perform the additional analysis using the pain, anxiety and fatigue variables with the change data. The change data arises from a calculation involving two time points, and difficulties arose in the more ‘straight forward’ of the two data sets for the original raw data that had not been transformed in any way. The difficulties with the original dataset were due to the low ratio of data records to independent variables, and large variance, and it was decided that these would be exacerbated by including a calculation based on two such data sets which would be required for the change data (i.e. time point 2 – time point 1 = amount of change).

Chapter 9: Discussion

In this chapter the results from the EORTC QLQ-C30 data will be discussed first, followed by discussion surrounding the analysis of the VAS data. This chapter also includes discussion surrounding the methods and recruitment to the trial and some of the difficulties and limitations encountered with this type of research. Areas worthy of further research are presented and alternative methods of research are proposed.

# Establishing differences between the groups at baseline

There were no significant differences or associations between any of the individual demographics (e.g. age, cancer site, stage, grade or treatment type) and the baseline, control and yoga groups. This is encouraging as any effect that came from subsequent analysis could be attributed to the difference between groups based on the intervention, rather than differences in the patients themselves. Analysis of the baseline data (T1) from the EORTC QLQ C30 for the three groups (baseline only, control and yoga) found that there were no significant differences between any of the groups at time point 1, suggesting that there were no differences in overall quality or life or any of the associated subscales between those who wanted to be randomised into the full trial and those who only wanted to complete the baseline questionnaire.

Originally it was thought that there may be difference between those who were willing to take part in the full trial, and those who wanted to take part in the baseline only. It was unknown whether this would be due to cancer type or other factors. These factors may have resulted in a worse/better QoL than those who only wanted to take part in a one-off questionnaire. For example, some patients who did not want to participate in the full trial may have had a better perceived QoL than those who consented to take part, and felt that they did not need an intervention to improve their QoL. However, as seen above, there were no differences in perceived QoL in any of the groups at T1.

# Findings from the RCT

## Testing for differences between groups with the EORTC QLQ C30

There were no significant differences between the yoga and control group at baseline, post intervention or at the 4 month follow up. The only measure on the EORTC QLQ C30 that was approaching significance was the score for constipation at T2, with the control group having a greater amount of constipation post intervention than those in the yoga group. It is accepted within the literature that cancer treatment (both chemotherapy and radiotherapy) can result in constipation, and it is listed as a known side effect (Gibson & Keefe, 2006; Andreyev, 2005). It is also widely acknowledged that physical activity can be used as a remedy for constipation generally (Dukas, Willett & Giovannucci, 2003; De Schryver, Keulmans, Peters, Akkermans, Smout, De Vires & Van Berge-Henegouwen, 2005) and also for those with cancer (Brown et al., 2003; Mancini & Bruera, 1998). Widely accessible cancer charity websites advise patients to take part in gentle physical activity (amongst other things) when experiencing constipation (Macmillan.org, 2012). Although there is no research at present, a number of anecdotal observations specifically link yoga to reduced constipation. These refer to general health or specifically in cancer patients, and the results of the current study may reflect this.

## Testing for differences over time

The analysis indicates that there is a significant improvement in role functioning, social functioning and insomnia in the control group over time. The Bonferroni test suggests that the main difference was seen between T1 and T3. These results were initially surprising,as it was expected that those in the yoga condition would have found a benefit in social functioning and role functioning based on their participation in the yoga classes (Speed-Andrews, Stevinson, Belanger, Mirus, & Courneya, 2010; Moadel et al., 2007). However, when looking closer at the median scores (as non-parametric tests were used), it became apparent that there were benefits over time for both groups, even though the results for the yoga group were not statistically significant. Overall, it appears that the statistics highlight a significant change in the control group which was not present in the yoga group. However, this is due to a lower starting point (although the difference was not significant) with regards to social and role functioning, and a longer period of time to reach the highest possible score in comparison to the yoga group. With regards to the insomnia scores, both groups had the same median score for all three time points, suggesting that the significance came as a result of the change in standard deviation over time. This may be a result of the small sample size for each group. No significant changes over the time points were seen in the yoga condition, however the subscale for constipation was approaching significance supporting the previous discussion about the use of yoga and its potential use in the reduction of constipation.

## Using VAS for baseline (week 0) and post intervention (week 10)

Analysis exploring the difference between the groups at baseline (week 0) and post intervention (week 10) indicated that there was no significant difference between those in the control group and those in the yoga group at week 10. However, the scores at week 0 were approaching significance (p=0.069), suggesting that those in the yoga group had a lower starting QoL than those in the control group (this was not reflected in the EORTC QLQ C30 scores). This was explored further when using time as a linear variable (discussed below). When using the VAS scores to test for differences between the two time points for the overall group and for each individual arm of the intervention, it was found that there were no significant differences between week 0 and week 10 on the VAS. These findings were consistent with those found in the EORTC QLQ C30 pre and post intervention measures; i.e. that yoga had no significant effect on QoL. However when looking at the results for anxiety, pain and fatigue, it is apparent that there was a significant improvement in both anxiety and fatigue for those in the yoga group over the 11 week period. This is consistent with previous research in the breast cancer population that suggests yoga (both hatha yoga and iyengar yoga) is efficacious in reducing fatigue and anxiety (Banasik, Williams, Haberman, Blank, & Bendel, 2011; Ulger & Yagli, 2010; Rao et al., 2009; Moadel, 2007; Bower, Ganz, & Aziz, 2005).

## Using time as a linear variable

The main analysis with the VAS data treated time as a continuous variable. The rich data that was collected from the diaries allowed for more complex data analysis to take place which supplemented the pre/post intervention data.

### The overall QoL data

The QoL GAM analysis indicates a significant upward trend in QoL with time for those in the yoga condition, which may be increasing in rate. There may be a positive effect of yoga (in comparison to the control group), but more time measures (i.e. weeks of yoga), are needed before the benefits are seen in terms of a significant difference between pre and post intervention. There was lots of ‘noise’ or variance within both sets of data (QoL and QoL change), and so the fact that a trend is seen suggests that the trend is fundamental i.e. there is a ‘real’ effect of yoga.

The results from the GLS for both groups suggest that pain, anxiety and fatigue are factors that significantly contribute to patients’ overall QoL, t is difficult, however, to ascertain how much of an influence these factors were having on the primary endpoint (QoL) due to the small sample size and the lack of an usable r2 value (Zurr et al., 2007). However, what is evident from the analysis is that fatigue is the biggest contributor to QoL, followed by anxiety and finally pain, and this is consistent in both the control and yoga groups. This suggests that as these factors decrease, QoL improves, which is consistent with the available literature (Smith, Gomm & Dickens, 2003; Stark, Kiely, Smith, Velikova, House & Selby, 2002; Bower, Ganz, Desmond, Rowland, Meyerowitz, Belin, 2000; Bodurka-Bevers, Basen-Engquist, Carmack, Fitzgerald, Wolf, de Moor & Gershenson, 2000; Visser & Smets, 1998; Hurny et al., 1993; Aaronson et al., 1993). The analysis also suggests that when these factors are added to the original model, time is not a significant predictor of QoL, which was consistent with the original model (although a significant time x intervention (yoga) effect was found in the original GAM). Although these results are useful in determining which factors contribute to patients’ QoL, the small sample size resulted in limited modelling of the data, preventing the exploration of interactions between the independent variables and the two intervention groups.

When returning to the original linear regression (exploring only QoL) the results suggest that those in the yoga group have consistently lower QoL than those in the control arm. This indicates two things; firstly, working with linear regressions (or straight lines) with the type of data generated from this style of measurement (weekly diaries) does not preserve the intricacies of the data set or allow for variation between the groups, meaning that important effects may well be lost (e.g. the significant trend that was found using the GAM). Secondly, it adds weight to the results of the Mann-Whitney U test which explored the differences between groups at time point 0. Although the difference between the groups at week 0 was only ‘approaching’ significance, the results of the linear regression confirm that those in the yoga condition have a lower QoL at the start of (and throughout) the trial.

With regards to the lower levels of QoL in the yoga group, there were 17 patients allocated to the yoga group who did not take up the classes, compared with only 1 patient in the control group who discontinued the intervention. Although this attrition may be due to patients being allocated to the ‘wrong group’ (i.e. were hoping to be allocated to the control group), Danhauer et al. (2009) note that women with a low health related QoL and greater fatigue at baseline were more likely to drop out of a trial. If Danhauer et al.’s findings were also true in this sample, and these patients were the ones with the better QoL, then it would suggest that those who were in the yoga group who did not attend the classes and subsequently dropped out of the trial may have had a lower QoL than those who took part. Alternative research by Carson et al. (2007) suggested that patients who completed their trial had higher levels of fatigue and other treatment related symptoms, resulting in a lowered QoL as well as lower levels of relaxation, and that amelioration of these symptoms was their main motivation for taking part in the trial. If Carson et al. were correct, this would suggest that those who continued with the yoga intervention may have been the patients who were experiencing the worst symptom related side effects, and were those that had the worst QoL. At present, it is unknown which of these schools of thought is correct, as there is no baseline data for those who did not take up the trial. This highlights a need for baseline measures at consent (discussed in more detail later in the chapter).

### The QoL change data

When exploring the change in QoL relative to patients’ starting QoL (which is now established as lower for those in the yoga group when compared to those in the control group), it was found that there were no significant trends with regards to time or condition using the GAM or GLS methods. The general linear model did indicate that there was difference between the two groups over time, although this difference was only ‘approaching’ significance. These results suggest that those in the yoga group experience on average 3 points less change in QoL than those in the control group for each time point (week). This suggests that those in the yoga group do not accumulate positive change in QoL at the same rate as the control group; meaning that those in the yoga group would take longer to get to the same point of QoL (i.e. 100%) than those in the control group. This result should be taken with caution due to the lack of significance and the small sample size.

The MLM showed an effect of time that was ‘approaching’ significance, indicating that as time went on, there was a greater overall change from baseline QoL in the group as a whole (regardless of which group participants were in). This suggests that change was cumulative, and that there was a linear effect of time – as time continued, there was more improvement in QoL (because it built on the increase from the week before). This may have been influenced by the group of patients that took part in the trial; there were not any patients that were receiving palliative treatment, and there were not any recurrent cancer patients. Previous research suggests that those receiving multiple courses of treatment or those receiving palliative treatment see less of an increase in QoL, if any is seen at all (Pearman, 2003; Capelli, VIncenzo, Addamo, Bartolozzi, Braggio & Scambia, 2002).

# Conclusion of the interpretation of findings

Although change statistics were incorporated into the analysis to look at the rate of change in QoL regardless of their starting point, it is important to look at the analysis as a whole. Those in the yoga group started off with a worse QoL than those in the control group, and they had a slower rate of change as well. This rate of change may have been influenced by their poor QoL at the start. The increase in overall QoL towards the end of the trial could be attributed to taking part in yoga, or it could be that they have come to the end of their treatment and have started to improve. Research by Pearman (2003) indicates that QoL is most negatively affected during the period from diagnosis until the end of treatment in gynaecological cancer patients (other than those who are receiving palliative treatment whose QoL progressively gets worse), suggesting that QoL starts to improve at the end of treatment. Further to this, a meta-analysis by Smith and Pukall (2009) suggests that Cohen et al.’s (2005) study was unable to evidence any significant positive effect for yoga participants in terms of distress, anxiety, depression and fatigue, since patients in this group were not receiving any active treatment during the trial. In light of this, the large number of patients within the yoga arm of the current intervention (11 out of 19) who were not on active treatment (in terms of recieveing chemo or radiotherapy but were recovering from surgery) may have contributed to the lack of effect. Therefore, future research should examine effects on patients with the different treatment modalities separately.

# Implications of the research

The findings of this research indicate that there is no significant benefit of taking part in a 10 week course of yoga for gynaecological cancer patients with regards to improving QoL. It could be that 10 weeks of yoga for this patient sample is not long enough to see significant improvements in their QoL, or that the timing of the intervention was not appropriate. This research adds to the existing literature, and although it may not support all of the existing information, it has gone a way to adopting rigourous RCT methodology to test the hypothesis. Additionally, further research with larger sample sizes is warranted in this area to establish the full potential of yoga for this group of patients, as there were some encouraging results from the GAM analysis. This research provides a number of recommendations for future research in the area; for example, the methodology employed in the RCT has implications for the number of patients recruited to the trial, and also adds to the discussion about using yoga for gynaecological cancer patients with regards to coping.

## Yoga for gynaecological cancer patients and coping

The transactional model of stress and coping (Lazarus & Folkman, 1984) and the conservation of resource (COR) theory (Hobfoll, 1989) suggest that participation in yoga would be beneficial for improving the QoL of gynaecological cancer patients through the facilitation of active, problem-focused coping styles, and the re-establishment and gain of threatened or lost resources (Avis et al., 2005; McCaul et al., 1999; Sears et al., 2003; Sehlen et al., 2003; Stanton et al., 2000; Costanzo, Lutgendorf, Rothroack & Anderson, 2006; Lutgendorf, Anderson, Larsen, Buller & Sorosky, 1999; Lutgendorf, Anderson, Rothrock, Buller, Sood & Sorosky, 2000; Osoweicki & Compass, 1998; Taylor, Kulkarni & Shiraishi, 2006; Hou, Law, Yin, & Fu, 2010). Previous research suggests that patients who seek out and take part in CAM use active problem-focused coping styles. This may go some way to accounting for the high level of attrition (45%) from those who were allocated to the yoga group; it could be argued that those who did not want to participate in yoga may not have adopted this coping style in favour of emotion focused or avoidant styles – taking an active role in their recovery was not consistent with their approach to coping. However, this is speculation, as no measures of coping style were taken from the participants in this part of the research.

Additionally, the findings from the VAS QoL scale data which indicated a poorer QoL for those who were in the yoga intervention at week 0 (i.e. those who completed the trial), suggests that it was women with a significantly poorer QoL who were attending the classes. Previous research has suggested that amelioration of symptoms such as fatigue and anxiety are the biggest motivation for patients to take part in yoga (Carson et al., 2007), and it may be that the re-establishment or gain of these resources (in line with COR theory), such as stamina/endurance, are motivating those with the worst QoL to attend the classes. Again, this is speculation as measures of QoL from those who did take up the trial initially after consent were not collected (due to the design of the study); this limitation will be discussed in more detail in the following sections.

# Discussion of the methods

## Discussion about the different types of data collection

The different types of data collection (traditional pre/post intervention measures and longitudinal repeated measures) highlighted the range of approaches that can be taken to measuring QoL, with varying results. Hess & Stehman (2012) in a systematic review found “that some aspects of HRQoL may improve both during and after treatment, whereas others may be expected to decline and the direction of these differences may vary by the instrument used” (p.1278). The current study also highlights the variation between measures. Using the VAS to generate longitudinal data allows for a more detailed view of what was happening over the time period, whereas the pre and post data from the EORTC QLQ C30 is designed for testing the different domains of QoL, and was useful for establishing whether there was any significant difference between the groups at the two time points. The combination of both approaches here worked well. The pre/post measures did not show a significant improvement in QoL in the yoga group, which alone would have indicated that the intervention was unsuccessful. However, the addition of longitudinal data and the GAM analysis indicated that there was an upwards trend in QOL for those in the yoga group, and that with a longer intervention, yoga may have had a significant effect on gynaecological cancer patients' QoL.

## Consistency between measures

VASs have been used for a number of years to measure QoL (Priestman & Baum, 1976; Hauser & Walsh, 2008). The use of a single item VAS in this research allowed patients to easily record their weekly QoL with little burden (Selby, Chapman, Etazadi-Amoli, Dalley & Boyd, 1984). However, it is important to remember that the single item scale did not measure the individual domains of QoL in the same manner as the EORTC QLQ C30, meaning that individuals completing the VAS must consider several different areas before giving a global QoL score (Fayers & Machin, 2000). The two scales may also measure QoL in different ways. Research by deBoer, Lanschot, Stalmeier, Sandick, Hulscher, deHaes & Sprangers (2004) found that a single item QoL VAS achieved high correlations with a number of health perception scales (0.70+) which suggests that using VAS is valid in comparison to multi-item questionnaires. In the current research, similar correlations were found between the two scales when compared at their respective time points. There was a significant strong positive correlation between patients’ global health status at T1 and their VAS QoL scores at week 0 (r = >0.70), and a significant positive medium-strong correlation between patients’ health status at T2 and their VAS QoL scores at week 10 (r= 0.64).

## Discussion of the research design

This study was designed as a RCT, as a rigourous test of the benefits of yoga was (and still is) urgently needed within the field. However there was a high rate of attrition, with over 27% of patients who had given consent in the current study not completing (or even starting) the intervention, and a further 6% lost to follow up. This is comparable with other studies in the area; Moadel et al. experienced a 22% attrition rate, and Raghavendra et al. (2007) experienced a 29% attrition rate. It is thought that the rate of attrition in this research was due to the strict randomisation of the trial. Many patients reported that they were hoping to be allocated to the ‘other’ arm of the trial and as a result dropped out of the study (many did not formally withdraw from the study – they just disengaged with the study and any further communications). The majority of the attrition (94%) came from the yoga group, and many women described that their drop out was due to them being randomised to the yoga arm of the trial rather than the control arm. Patients reported that they were hoping to be either allocated to the control arm, or that they would be feeling well enough to start the classes by the end of their treatment, and that this did not occur.

Culos-Reed et al. (2006) attributed the lack of significance between the groups in their trial to the high rate of attrition and subsequent small sample size. Many patients in their study withdrew as those in wait-list control group reported that they had begun to “engage in their own physical activity because they had not been randomised to the yoga participant group” (p.896). A number of patients in the current research (who were randomly allocated to the yoga group) reported that they would have been disappointed if they had not been allocated to that group, and would have ultimately decided to not take part in the RCT at all (which would have resulted in an even higher level of attrition). Many patients reported that as a result of their invitation to participate in the trial, they wanted to participate in physical activity, and the invitation to take part in a trial looking at yoga had encouraged them to try a similar activity. Being randomised to the control group would not have been a satisfactory outcome for them, and they would have gone on to find an equivalent class elsewhere, making them ineligible for the trial in line with the exclusion criteria. Based on this, it became clear that the sample in this RCT was more of a self-selecting sample than one randomly allocated to a group. Patients only took part in the intervention if it suited their needs, raising a question about the efficacy of the RCT in this instance. The use of RCTs in CAM research and their use in this research will be explored further below.

### RCTs

RCTs are widely used in biomedical research and the random assignment of participants to each condition is an essential part of the gold standard method for establishing causation in medical studies (Aickin, 2002). Randomisation is argued to be the only way to establish balance between treatment groups, and that there is no other way of creating comparison groups that have been distributed in an unbiased way (Kleijnen, Gotzsche, Kunz, Oxman & Chalmers, 1997). The increase in CAM in mainstream medicine coincides with the call for evidence based practice. As a result, CAMs are expected to demonstrate efficacy, effectiveness and safety to assure their place in modern medicine practice (Carter, 2003). As there is a shared understanding of the term RCT between members of the medical community, and the fact that RCTs are widely used and have become the norm in this setting, it is assumed by many in the medical community that RCTs are the most appropriate and only effective way of testing the efficacy of CAM (Walker & Anderson, 1999).

Ernst (2001) argues that RCTs for CAM are both hard to design and expensive due to the individual nature of therapy. Subsequently, medical research funders do not provide enough funding to allow fully powered RCTs for CAM, which may result in organisations not integrating CAM into their healthcare guidelines (Walker, 2010). Further to this, CAM practitioners argue that the patient/practitioner relationship and the therapeutic environment play a central role in the efficacy of CAM (Verhoef, Lewith, Ritenbaugh, Boon, Fleishman & Leis, 2005), and any research which uses randomisation as a method of allocation is interfering with the joint decision making between patient and practitioner (Carter, 2003). Some literature goes as far as saying that the reductionist scientific paradigm is not suitable for application to a ‘real’ world practitioner providing therapeutic care, and that the integrative holistic paradigm is more suitable for CAM research (Vickers, 1996a; Visintainer, 1986). However, others argue that the only reasons for not conducting RCTs in CAM research are down to practicalities, and that there are no valid theoretical arguments (Vickers et al., 1997).

Vickers (1996b), states that solutions need to be found for the practical problems regarding methodology in CAM research. Much discussion exists in the CAM literature about appropriate methods for use in CAM research, and whether RCTs are appropriate for use in this field. A number of suggestions have been made about amending the traditional aspects of RCTs to make them more suitable for use in the field of CAM, and that the focus should be on adapting current research methodologies rather than inventing new ones (Vickers, 1996b). Based on this, if research is to focus on and use RCTs, a number of recommendations have been highlighted to improve their efficacy and application in CAM research. It has been suggested that those contemplating using a RCT might pilot test their assumption before proceeding with the RCT. These pilot tests come in the form of feasibility studies which assess whether engagement and subsequent recruitment is feasible for a full RCT (Orwin, Cordray & Huebner, 1994). They also allow further insight into the use of an intervention with a particular group. This addition would have been particularly useful before the current study, as it would have highlighted some of the difficulties in recruitment prior to its roll out. Other strategies improving the overall enrolment and engagement in the RCT have been highlighted as potential areas for improvement to counter some of the difficulties previously mentioned (Corrigan & Salzer, 2003); however, this generally refers to problems with overall engagement, and in this study it was mostly those who were allocated to the yoga group who disengaged.

Aspects such as recruitment (discussed in a separate section below) and subsequent randomisation of patients into the trial were the biggest methodological issues, highlighting a number of areas that need careful consideration before future CAM research is conducted. Solutions or adaptations of traditional randomisation have been suggested by a number of CAM practitioners, and many seem to revolve around variations of the classical RCT design, including pragmatic trials, factorial designs, preference trials and n-of-1 trials (Verhoef et al., 2007). There are two designs which can act as a substitute for randomisation; the first being Zelen’s design (Zelen, 1979, 1990). Zelen’s design can address some of the previously discussed difficulties by randomising patients before consent – consent is then only sought from those randomised to the treatment group in order to bolster recruitment or avoid stress at not receiving a preferred therapy (Edwards, Lilford, Braunholtz, Jackson, Hewison & Thornton, 1998; Torgerson & Roland, 1998). Zelen’s design has been much discussed and for most medical trials is considered highly controversial, and in some cases unethical; however, Walker & Anderson (1999) believe that it could be potentially useful in CAM research.

The second design that may be appropriate for CAM research is the partially randomised preference trial (PRPT) proposed by Brewin and Bradley (1989). PRPTs were suggested as a method of allocating patients to clinical trials where participants are required to “sustain an effortful and demanding role and those in which they are likely to have strong treatment preferences” (Brewin & Bradley, 1989, p.313). It would be reasonable to believe that this would be the case for many patients asked to take part in CAM research – some patients in this research were current (or previous) yoga practitioners or held a strong belief about the use of yoga, so would only have been satisfied with being allocated to the yoga condition. Others were already users of other forms of CAM or were pleased to see that it was being tested with this particular population – these people were happy to be allocated to either condition. Some patients were more conservative about its use in the oncology setting and preferred to stay with the traditional medical treatment alone, but still wanted to take part in research – these people would have only been happy to be in the control condition. PRPTs give patients the opportunity to show a preference for which treatment arm they are allocated to, and if there is a preference then they are allocated to that group but are not included in the RCT. Those who have no preference are randomised into the trial in line with traditional protocol (see Figure 20).

If all patients have a strong preference, then a feasibility study will result – whereas if all patients have no preference, an RCT will take place. If there is a mixture of responses and there is a large enough sample, both studies can be run concurrently. It is argued that an RCT with this design will have a reduced level of motivational disruption (i.e. the ones who take part in the hope of being randomised to one intervention arm over the other) compared to traditional RCTs, increasing the amount of internal validity (Bradley-Gilbride & Bradley, 2010). Additionally, there are likely to be more participants, as those who would not have previously taken part in an RCT due to the prospect of being randomised to a non-preferred group would now have the opportunity to take part. In some cases, PRPT designs have resulted in 99% recruitment levels (Henshaw, Naji, Russell & Templeton, 1993).

Retrospectively, it appears that the PRPT may have been a suitable design for this research – it would have allowed individuals to contribute to their allocation of condition, and may have resulted in a higher rate of participation, and less attrition than the current design. There are however, still issues surrounding the validity of this type of research design, and also how it is regarded by the medical community. If the PRPT methodology had been used in this trial, the project may have been classified as a ‘feasibility study’. One of the criticisms highlighted in the literature review in Chapter 6 with regards to research in the area of CAM, was the lack of rigourous methodology and the small sample sizes (Smith & Pukall, 2009). By forfeiting the gold standard status of an RCT, it may have been possible to increase the numbers of participants, however the quality of the research may well have been compromised, and it may have been less widely accepted by the medical community.

Figure 20 – A visual representation of the PRPT design proposed by Brewin & Bradley (1989).

Please note: diagram removed for copyright reasons, please see caption for reference information.

# Discussion of recruitment

## Staff Engagement

There were a number of factors that impacted on the recruitment for the RCT, the first being the challenge of engaging staff in the research, and building a good working relationship within a multi-disciplinary team (MDT) at the Royal Derby Hospital. The structure of the gynaecological-oncology department is included in Chapter 1 of this thesis, and this structure had both positive and negative effects on recruitment. The support for this trial within the gynaecological-oncology department came predominantly from the Senior Gynaecological-Oncologist (SGO) within the department, and the CNSs. Although the SGO saw, or was responsible for the care of approximately one third of all gynaecological-oncology patients seen at the Royal Derby Hospital, a high proportion were seen by other consultants, registrars and nurses within the department. The SGO was involved in the trial from the early planning stages and was aware of much of the literature surrounding the efficacy of certain types of CAM with the cancer population, in particular the literature surrounding yoga. This was also similar with regards to the CNSs – they were included early on in the planning phase and were asked for input about the design of the trial.

One issue for lack of ‘buy-in’ from the medical staff was their attitude towards CAM. Research in this area has highlighted a number of different perspectives. Milden & Stokols’ (2004) qualitative research into physicians’ attitudes towards CAM highlighted that clinicians in America felt that they did not have enough knowledge about CAM, and that they believed more education was required before they could make a decision about recommending it to their patients. Further to this, research by Astin, Marie, Pelletier, Hansen & Haskell (1998) described the variation in practitioner beliefs about CAM efficacy, and found that it was dependant on the individual therapy with figures raging from over 50% (acupuncture) to 13% (herbal approaches). Clinicians have also raised a number of concerns about the safety and evidence base surrounding CAM, and the lack of statutory regulation (Botting & Cook, 2000). A qualitative study conducted within the NHS found that there were three broad groups of views in the academic doctor population; briefly the ‘enthusiasts’, the ‘sceptics’ and the ‘undecided’ (Maha & Shaw, 2007).

In the medical team associated with the trial at the Royal Derby Hospital, only the SGO and the CNSs would fall within the ‘enthusiast’ category, and the majority of the other team members at the start of the trial fell into the ‘sceptics’ or ‘undecided’ category. The number of staff that were either undecided or sceptical about the trial was particularly problematic in this instance as it became difficult to ensure that patients who were suitable for the trial were a) being given information during their clinical visits with the consultants, and b) that they had opportunity to ask any questions that might arise about their participation in the trial.

As well as individual clinician’s perspectives of CAM as a whole, it became apparent that there were also some pre-conceived ideas about yoga practice. Although the whole MDT and other clinical staff had been invited to take part in a sample yoga class, many did not engage. This resulted in the misunderstanding of the set-up of the classes and what the classes would include. Many clinicians failed to see how ‘standing on one leg’ could have the potential to improve patients’ QoL, and even when given the opportunity to read the available literature or attend a presentation given by the research team about the intervention, many were not interested in learning more. Furthermore, all staff were given copies of the recruitment process diagram displayed in Chapter 7, but there was on-going lack of knowledge about the set-up and procedure for the trial.

One of the other factors that contributed to the difficulties in recruitment was the structure of the gynaecological-oncology department with regards to staffing (see the staffing diagram in Chapter 1). The continuous rotation of junior medical staff within the department meant that staff were constantly needing to be updated about the trial and the research activities of the team. Each individual member of staff needed to be briefed, and due to their work schedules this happened on an individual basis. Ideally, it would have been advantageous to restrict the number of individuals who could give information about the trial to the research team, the three consultants and the CNSs, but this was unachievable as gynaecological-oncology registrars (from ST1 through to ST7) also saw a high proportion of the patients in the clinic. It was also important for all of the registrars to have knowledge of the trial and what was included, as a large proportion of patients still appeared to subscribe to the “paternalistic” model of care, where the patient complies with the instructions that they are given by their healthcare professional. Many patients reported that they had taken part in the research because it had been suggested to them by their doctor or their CNS.

As time went on, these problems became less of an issue. The positive feedback from patients about the classes encouraged clinicians to reassess their beliefs about this intervention, and the amount of information getting out to patients increased steadily over time. Additionally, the approach to deciding which patients were suitable for the trial was transferred to the MDT meeting. The researcher attended every MDT meeting and patients were identified at the point of team diagnosis. This was particularly efficacious as each new patient passes through the MDT for a review of their diagnosis. Once patients were identified, the relevant information forms and consent sheet were inserted into the patient notes attached to the MDT form, which is reviewed before seeing a patient in clinic. The information was made more noticeable for clinicians by including a red sheet of paper with brief instructions and information about the trial, as well as signposting them to other documents that were held centrally. The role of the MDT in recruitment was central, as it allowed for a greater research presence to be felt, and resulted in the team taking a more unified approach to recruitment.

## Timing of the Intervention

There were a number of discussions around this at the planning stage of the intervention. The SGO and the CNSs were asked for feedback about the best time for recruitment for the trial. Due to the nature of the cancer, there is often little time wasted between the point of diagnosis and the start of the first course of treatment, whether that be surgery or chemo/radiotherapy. Both the CNSs and the SGO thought that it was most suitable to approach patients in the clinical setting on the day of their diagnosis, or soon after their appointment. This allowed the most time for patients to read and understand the information, and when appropriate give consent before the start of any treatment. Normally, patients receive their first definitive treatment within 31 days of their diagnosis (NHS Improvement, 2008).

Approaching patients about taking part in the trial was judged on an individual basis depending on the patient’s reaction to the diagnosis. Some patients (maybe those with an internal locus of control) approached their cancer diagnosis in a positive manner, and wanted to do everything that they could to beat/combat/recover from the cancer. These patients were given information at the point of diagnosis, and were asked to think about taking part. If they wanted to participate, they were asked to bring their signed informed consent sheets to their next appointment, or to contact the research team if they had any further questions. Alternatively, some patients did not respond well to the diagnosis of cancer and were overwhelmed by the amount of information that was presented to them at that time. If the clinical staff deemed that this was not a ‘good time’ to give the participant information, then the information was sent out in the post.

On reflection, it was mainly patients who had received the information in the clinical environment that responded to the invitation to take part in research. The diagnosis appointment with both the consultant and the CNS was a good opportunity for patients to ask questions, and the individual counselling session with the CNS after the diagnosis allowed for patients to discuss participation in a more informal environment. Even if ladies were uncertain about whether they wanted to participate at that point, they reported that they were pleased to have been given the information and the opportunity to take part.

Many patients were happy to take the information, but did not follow up on the offer to take part. Follow up phone calls to these patients were useful, but they generally weren’t able to make a decision until they were in the post-operative period, and even then, it was sometimes difficult to catch them at an appropriate time. One of the best times to approach patients about their participation was during their hospital stay after their operation, where patients enjoyed having someone to talk to, or when patients were waiting to see the medical/clinical oncologist about their planned treatment. Patients who had received information about the trial were identified from their notes, and the researcher attempted to follow up each patient while they were an inpatient or while they were waiting for an outpatient appointment. With lengthy waiting times in clinic, many people were happy to discuss the trial, and this was where many of the baseline participants were recruited from, as patients were happy to receive information, be consented, and return the completed questionnaires on consecutive weeks (many patients will see the clinical/medical oncologist weekly while they are on chemo or radiotherapy).

There were, however, some drawbacks about recruiting patients from waiting rooms. Many patients who had already started treatment did not want to take part in the research – they found that treatment in itself was taxing, and the thought of being randomised into a trial where they may have been allocated to a yoga intervention, which would have resulted in another trip outside of the home was too discouraging (this further highlights the potential benefits of the PRPT design). Many asked if they would be able to think about it and consider it after treatment had been completed. A number of ladies were disappointed that they were not eligible for the trial once they had completed their active treatment. However, some women did report that they would pursue the idea of doing yoga or some other type of physical activity, as a result of the invitation to participate.

## Other design issues

After data analysis, it was noted that there may have been a considerable difference in the starting point for the trial between the control group and the yoga group. Most of those in the control group filled in the baseline form and started the trial straight after consenting and receiving the participant pack. The yoga group however, consented to take part in the trial and then contacted the research team when they felt that they were ready to undertake the intervention – which had to be while they were still in the ‘active treatment phase’ (within 6 weeks of surgery or while still receiving chemotherapy or radiotherapy). As many patients received information about the study prior to their operation, and consented (or were given consent forms to return by post) at their 2 week follow up appointment with the consultant/CNS, it would be reasonable to believe that those in the control group commenced their active participation in the study earlier in the treatment phase than those in the yoga group, even though they both consented at similar points in their cancer journey. This was not something that was considered by the research team, but at the point of analysis it became apparent that a) this would have been useful information to have collected as it may have been a confounding variable, and something that we could have controlled for in analysis, and b) that patients had a great amount of variation in when they wanted to start the trial – it could be as much as 18 weeks different (comparing surgery only to chemotherapy patients).

Additionally, there was no regulation in the day the diaries were completed for those in the control group. Patients were simply asked to start the diaries on any day, and to make sure that they completed them on the same day each week. Yoga patients were directed to fill in the diaries on the day of the class (before attending) or the day prior to attending; this was to ensure that patients were reporting how their week had been prior to the intervention. However, this was not the case in the control group – they had the opportunity to complete the diary at any point. Although this may at first seem an irrelevant point, it became apparent over the course of the trial that reports may have been influenced by day of treatment. Patients receiving chemotherapy were given their three-week treatment cycles on a Thursday (the same day as the yoga class). Therefore, one week out of three, some of the yoga participants had spent up to 6 hours at the hospital receiving chemotherapy. Not surprisingly, they reported that they felt a large amount of fatigue on this day (more so than any other) which may have influenced their responses in the diary and whether they came to the yoga class that week.

# Discussion of the Analysis

There were a number of different types of analysis that would have been useful for this project, and as with any research project, it is important to use the appropriate statistical test (Levin et al., 1997). The use of alternative or ‘non typical’ methods of analysis (GAM & GLS) have been utilised in this study, as the research design warranted and required this type of analysis. Another analysis that was considered was time series analysis, which is used for analysing longitudinal data and would have been suitable for research of this type. However, it is widely acknowledged that time series analysis requires over 50 time points to be effective (Tabachnick & Fidell, 2005). In the present study, the diaries provided 11 time points for analysis (i.e. a baseline week and 10 further weekly measures). It is unlikely that the number of time points would have reached 50, even including an extended baseline and follow up period. Alternatively, daily measures of QoL over the time period would have resulted in 77 time points, and an extended baseline and follow up could have resulted in over 166 time points (with three weeks either side of the intervention). However, weekly measures were chosen over daily measures to reduce the amount of burden that patients may experience while on the trial, and based on experience from this trial, weekly measures were not intrusive to patients.

With regards to the use of the current analysis techniques (GAM, GLS etc), future research would benefit from more data points (people) as this would decrease the uncertainty and increase the accuracy of the model. Additionally, it may give the data enough power to detect a significant effect over this shorter period (11 weeks).Retrospectively, it would have been beneficial to have included weekly measurements over a greater period of time either side of the intervention to allow for a better baseline to be set; one baseline measure may not have been representative of how they were feeling over a longer period of time (i.e. their baseline measure could have just been a ‘bad day’, especially seeing as it was potentially a chemotherapy treatment day). Additionally, the extended follow up would allow us to explore what happened to patients QoL after completing their 10 classes.

In relation to the design of the diary and the information received from it, Bolger et al. (2003) discuss some additional analytical benefits of a more detailed diary. Earlier in this chapter, it was proposed that it would be beneficial for patients to complete a more detailed diary that included their specific treatment regimen and schedule details. Bolger et al. highlight the potential use of this type of data; it would allow researchers to develop an exploratory model of the factors which affect in-person variability in the data. Essentially, recording treatment data alongside QoL data for that week would allow researchers to build a more detailed model based on a multi-level data array (an extended form of the multi-level modelling conducted in this research), potentially allowing researchers to explore a number of contributing variables (e.g. treatment week) that are currently unmeasured and unaccounted for in the analysis (Bolger, DeLongis, Kessler & Schilling, 1989; Mason, Wong & Entwistle, 1984).

Returning to the topic of baseline measures, there may have been some benefit in including an additional baseline measure as soon as patients had consented to take part. It has already been acknowledged earlier within this chapter that some patients had extended periods of time between giving their consent and actually starting the intervention (particularly those is the yoga group), but the inclusion of an additional baseline measure (at the point of consent) may also have enabled us to look at a different type of analysis. Moadel et al. (2007) found that 71% of patients attended no classes and supplied baseline data only. Having this information allowed them to complete an intention to treat analysis. This may have been beneficial for this study, as questionnaires (EORTC QLQ C30) administered soon after the point of consent may have been completed by all patients, and this would have allowed for additional analysis to take place based on this data alone that would have given a greater insight into the participants who did not engage with the trial. Additionally, Moadel et al. also found that nearly one third of intervention participants did not attend a single class but still provided follow up data. Considering this information before the design of this trial may also have been of benefit to the current research project, although it would have meant that patients would have had to communicate their decision to not take up the classes to the research team. In the current research project the majority of people who dropped out of the yoga arm of the trial did not communicate their decision even though the instructions were to contact the research team when they felt that they were ready to take up the classes.

# Further research - Recommendations for the future

Based on this experience, future trials investigating yoga as an intervention for gynaecological cancer patients should consider the following:

* More detailed information about the participants and their individual treatment schedules would allow researchers to construct a better map or timeline of activity and fluctuations in QoL.
* It would be beneficial to have set a day for patients to complete the diary that was not closely aligned to the day that patients receive their chemotherapy treatment. The fact that classes in this trial were held on a Thursday may have been a contributor to the high levels of attrition within the yoga arm of the study.
* This research showed that there was a significant yoga dependent positive trend in QoL, which is encouraging. However the analysis would have been more powerful with a larger sample and a longer intervention – this would have allowed the interactions between independent variables such as anxiety, pain and fatigue, as well as both intervention groups, to be entered into one model to explore the interactions between these variables.
* Future trials could consider adopting the intervention to cover the post-treatment phase, rather than concentrating only on the active treatment phase.
* Future research could also work towards establishing the number of classes that patients would have to attend to see a significant increase in QoL.
* Restricting analysis to one type of gynaecological cancer rather than including them all would have been beneficial (this research project could not do this due to the small sample recruited). QoL is based on a patient’s type of cancer, age, health status/prognosis and treatment regimen, and it would be beneficial to look at one aspect more fully. If research was to be restricted to one cancer type or area, it would be difficult to recruit from only one cancer centre as the slow recruitment would not allow for this on a financial basis (not enough people per class to make it cost effective), and would not allow enough power for appropriate statistical tests. One way of resolving this would be to combine the resources and the patient base from a number of hospitals; maybe even all institutions within a cancer network, however cost may then become a factor.
* Research explicitly exploring the links between yoga and coping alongside QoL for patients for patients undergoing treatment would be beneficial in understanding this period in patients’ lives and the potential benefits of yoga.

Although these seem like basic issues, they highlight the need for extensive planning surrounding trial design, and that patient input is essential. These issues could be resolved by using pilot studies as described by Orwin et al. (1994). The research team consisted of researchers, the CNSs and the Gynaecological Oncology Consultants, but these issues were not considered. The patient group were consulted in the planning stage of the current intervention to gauge interest, and as a result of their comments, the yoga intervention was moved to its current venue. In future, it may well be beneficial to include an option to present the final research proposal to a patient group (maybe a support group or other established forum) to receive feedback from patients.

## Future research outside the area of yoga

As an aside from the main aim of this research, a number of women commented on the efficacy and usefulness of diary writing. Some participants reported that completing the weekly diary in itself was a useful intervention, and is something that should be explored further. Women reported that they had photocopied their diaries before returning them to the research team, as they found that they used them to look back on and see how far they’d come, and also to use as an outlet, or as a point of reflection. Kellogg (1994) notes that “expressively writing about upsetting life events seems to help people adjust to current difficulties and appears to improve health” (p.215); research in the area has shown that expressive writing has seen some success with subsequent investigations testing the impact of expressive writing in clinical populations, including people with chronic illnesses such as asthma, pelvic pain, arthritis, and cancer (Morgan, Graves, Poggi & Cheson, 2008; Norman, Lumley, Dooley & Diamond, 2004; Schwartz & David, 2002; Smyth, Stone, Hurewitz & Kaell, 1999). Based on this it appears that diary writing may be a useful intervention to explore with gynaecological cancer patients.

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# An extract from Sheila…

*I had never undertaken any yoga before but I really enjoy it and use this experience in my everyday life. I’ve learnt a great deal about breathing exercises, relaxation, posture, etc. and meeting other people who have other forms of gynaecological cancer. I have also taken part in a focus group and I am delighted to have been given the opportunity to take part and would like to express my thanks to all concerned. At the end of my 10 week course (of which I completed a diary on a weekly basis) I was told that I could carry on attending and I still go along each week. My husband comes too and uses the time to read and relax as well.*

*As part of the yoga group we are looking at the possibility of producing a book whereby each of us will write a piece about our own cancer experiences (maybe in the form of a poem of a favourite piece of prose) and this will be illustrated by a photograph of each of us. We are also thinking about the possibility of forming a Choir. For two weeks in November this year (whilst the yoga tutor is on holiday) we are going to try some Drama / Art therapy which we are looking forward to.*

*Yoga is ‘me’ time. It is so relaxing and the tutor makes it very clear to all of us that if we can’t do any of the exercises then we don’t do them. Yoga has increased my muscular strength and increased my energy levels, my sleep quality and reduced my stress and anxiety levels. The ladies that attend are all at different stages of ‘recovery’ (some have undergone chemotherapy/ radiotherapy). All of us who attend feel we are part of a team and we have so much in common and so much to share. The social interaction and support is excellent and we try to help each other through our different experiences. We also feel we can be open and talk about sensitive issues.*

Chapter 10: Overall Conclusions

The following chapter concludes the two studies and refers back to the questions initially posed at the beginning of this thesis. The strengths and limitations of the research included in this thesis are then explored and recommendations for further research are given.

# Summary of the research findings

In the introductory chapter, a number of research questions were posed to help give direction to the thesis, and in the following section these questions will be addressed.

## Can the experience and quality of life of patients be improved by the implementation of complimentary treatment interventions?

This thesis focused on two aspects of complementary treatment for gynaecological cancer. Firstly, it explored the patient experience of an ERP and found that it was highly valued by patients. The analysis highlighted that more information was required in particular areas (i.e. location of the scar), to assist patients' preparation for certain aspects of the surgery. In general, patients felt that they had enough information to partake in the programme. This is important because information was a key component of building the knowledge which allowed patients to actively participate in their own care. Patients clearly wanted to return home sooner, and going home was a big motivator for patients to become mobile, even though this was something that they expected to be both difficult and uncomfortable. It was also apparent that the role of the physiotherapist is integral to the onset of this behaviour, and that the patients benefit from seeing the physiotherapist both before and after their surgery.

When returning home, patients made the transition from the active patients they were in hospital to being recovering patients at home. Patients found that going home was not as easy as they had expected since they were no longer in a ‘tailor made’ care environment. Significant others played an important role in the transition from hospital to home, with regards to assistance in everyday tasks, but also as moderators of behaviour. Patients referred to their significant others as ‘police’ as they were responsible for preventing them from doing too much when they felt that they ‘could’ do things that they ‘shouldn’t’ have been doing. Patients also highly valued the follow up phone call. This provided a bridge between the home and the hospital and removed some of the barriers that patients experienced regarding contact with health care professionals. Patients felt that they did not want to be a ‘nuisance’ to staff once they had returned home, and were unlikely to call the hospital for assistance or advice, but the scheduled phone call from the hospital alleviated some of these issues, and opened a dialogue between the home and the hospital.

Patients found that managing expectations of both themselves and others was one of the on-going challenges throughout their experiences. Patients felt that others were happy to pass on their expectations through the process of storytelling about their own and others' past experiences, and this was something that patients struggled to manage that ultimately influenced their own expectations of care. Managing their own expectations was problematic for some patients as they believed that they would be able to progress faster than they were, resulting in them feeling disappointed in their own progress. Patients also were aware of the expectations of staff, and the effect that this had on their care. Patients wanted to exceed the expectations of the staff, with a desire to be a ‘good patient’ and to prove themselves to others.

In terms of the patient experience of care outside of the programme, the women felt that the wait for the diagnosis of cancer was slow in comparison to the urgency that they felt, and this contributed to their feelings of distress. This was a stark contrast with the perceived speed of care associated with the ERP. The women valued ‘things’ that they could call their own during their experience; many women appreciated their own room and own bed that were allocated to them in the hospital, and they acknowledge that having their own cancer nurse (CNS) was integral to the receipt of information throughout their cancer journey. Patients also associated these factors with the individual nature of care, which was important to their overall cancer experience. Their participation in the ERP resulted in some women feeling that they had not really ‘had cancer’, as they had few symptoms before the diagnosis, and surgery was their only definitive treatment. As their stay in hospital and surgical side effects had been reduced as a result of the ERP, women did not identify with the role of ‘cancer patient’. This had implications for balancing active recovery with appropriate rest to ensure full recovery after surgery.

The second part of this thesis explored whether yoga could improve the QoL of patients undergoing treatment for gynaecological cancer. The results suggest there was no significant effect of yoga on QoL; however, there was encouraging data from the GAM analysis, suggesting that patients on the yoga arm of the trial were improving over time. Yoga patients started with a worse QoL than those in the control group and had a slower rate of change than patients in the control group. There was a significant increase in social functioning in the control group over the intervention period, although it only allowed them to achieve the level of social functioning displayed by the yoga patients at the start of the intervention. Yoga appears to have some positive effects on constipation, which is consistent with the literature on physical activity and cancer, although it has not been explicitly explored. The analysis also highlighted that factors such as fatigue, anxiety and pain influenced patients QoL, though the limited numbers within the study did not allow for full exploration of these relationships in one complete model. Further research in the area of yoga and gynaecological cancer is warranted, but requires a narrower focus with regards to both cancer type and point of treatment to ensure that the numbers of variables are controlled; appropriate measurement and analysis techniques also need to be considered to preserve the richness of the data.

## Are patient reported outcomes useful in exploring patient experience of these treatments?

Throughout this thesis, information collected in the form of patient reported outcomes has been integral to the research conducted. The interviews conducted with patients to explore the patient experience of ERPs allowed a previously unseen view of gynaecological cancer patients participation in perioperative interventions, and highlighted a number of findings that would not have been available through the conventional outcome measures currently in use by the hospital and UK government. Similarly, the use of varied methods of collecting QoL measures in the yoga study (pre/post/follow up measures and longitudinal weekly VAS measurements) gave different views of the yoga intervention. Without the use of these measures, the valuable information about the efficacy of the interventions included within this study would not have been possible. However, in the case of the yoga intervention, little information could be collected about the patients’ experience from the standardised QoL questionnaires. Qualitative data collected about patients’ experience of their participation in the intervention through the facilitation of focus groups, and written information in the form of diary entries collected at the same time as the weekly VAS measures will allow greater insight into the experience of women taking part in the intervention, highlighting the important of mixed methods research.

## In relation to the diagnosis and treatment of gynaecological cancer, what role, if any, can complementary treatment interventions play in the facilitation of coping?

Although coping was not the focus of this thesis, the potential role that complementary treatment interventions can play in the facilitation of coping is an important and under-researched topic. From study 1, which explored patients’ experiences of ERPs, it appears that perioperative programmes foster problem focused coping for patients during their initial cancer treatment (surgery). Patients are actively encouraged to participate in their own care and recovery from surgery, which for several women in this research was their only treatment for cancer. The ERP also fosters a sense of control over their situation, which is a contrast to the uncontrollable and stressful diagnosis of cancer. The ERP encouraged women to gain or re-establish resources that were lost or threatened by the diagnosis and surgery for cancer, which may be beneficial for preventing further stress. The women in this sample highly valued the ERP as this approach to surgery fitted with their overall view and approach to coping with the diagnosis and treatment of gynaecological cancer. However, it still remains unclear whether this would be the case for all patients participating in ERPs after a diagnosis of cancer.

With regards to the yoga study, the findings highlighted that the yoga intervention may have been used by patients who had active problem-focused coping styles and poorer QoL, with a view to re-establishing or gaining resources that have been threatened or lost throughout the course of diagnosis and treatment for cancer. However, without specifically measuring coping and coping styles (which was not the focus of this thesis), it is difficult to make specific links between the findings in the current study and established models of coping. This would, however, be a useful area for further research, as the integration of CAM, especially mind/body interventions such as yoga, have the potential to improve the overall experience of patients living with and beyond cancer in terms of coping, QoL and other psychological benefits.

# Strengths and Limitations

The research included in this thesis had a number of strengths and limitations. These are discussed at length at the end of each study, but are also summarised here.

## Study 1

Some of the major strengths and limitations of the enhanced recovery study came from the use of qualitative methodology to explore the patient experience. After speaking with Annelise Norlyk, the co-author of the other pieces of comparable research in the area (Norlyk & Harder, 2009, 2011), it became apparent that these two projects are (to date) the only ones to adopt the use of qualitative methods (such as IPA) with an aim of exploring the patient experience of ERPs. One of the major strengths of using IPA was the insight and structure it gave to the research. IPA is well established in the field of health psychology and has been used in a number of different areas of health (Brocki & Wearden, 2006; Chapman & Smith, 2002; Smith, 1996). The use of IPA in this project was particularly useful as the results were specific to the women taking part in that specific ERP. Based on this, the Royal Derby Hospital has been able to use the information about these patients' experiences of the programme, and incorporate it into the on-going development of the pathway.

The strength that comes from the individual nature of IPA also contributes to its limitation. The use of qualitative methods such as IPA is seen as unscientific and anecdotal to many medical scientists and clinicians (Green & Britten, 1998). As a result, many clinicians are uncomfortable with the use of qualitative research, and are somewhat biased toward the use of quantitative research and the output of hard numbers. In the hospital environment, the findings of this research are frequently combined with quantitative analysis of length of stay figures, which in some ways is disappointing as qualitative research is not valued on its own merits, but only as an overall view of the programme. A further limitation of the use of IPA in this research was that the analysis of the data is highly focused on these individuals and the experience that they had on the ERP pathway used at The Royal Derby; these results cannot be generalised to other patients on other pathways. In addition to this, each pathway for enhanced recovery has different components, and at present there are few conventions that govern the elements of enhanced recovery that must be present in any given pathway. As a result, each institution’s pathway is at best slightly different in its delivery, and it is reasonable to believe that any change to the pathway would potentially change the outcome of the patient’s experience.

## Study 2

As with the enhanced recovery projects, the strengths and limitations of the yoga study were tied to the research methodology. The use of the RCT to explore whether yoga could improve the QoL for gynaecological cancer patients was both timely and necessary due to the large number of non-randomised trials that have been conducted in the breast cancer population. The use of the randomised trial methodology allowed for a rigorous research protocol to be put into place, thereby reducing the amount of potentially confounding variables. The benefits of randomised allocation to control and yoga groups should have reduced a number of the difficulties surrounding selection bias for treatment. However, the decision to use this form of allocation became a limitation due to the high level of attrition, and highlighted the need to explore other methods of allocation which may be more suitable for CAM research.

The use of the RCT conforms to the standard expected by the medical community with regards to the methodology, however some of the statistical tests used are challenging to interpret due to their unusual or non-typical application (outside of their normal field). Although this may initially be seen as a limitation, it can also be viewed as a strength, since this research has challenged some of the established boundaries with regards to statistical methods used in health research. There are few papers which use techniques such as GAM in mainstream health research, and those that do exist focus on air pollution and public health (Dominici, McDermott, Zager & Samet, 2002), or the impact of genital warts on health-related QoL (Woodhall, Ramsey, Cai, Crouch, Birks, Edmunds, Newton & Lacey, 2008). This is not a comprehensive list, but it does demonstrate the variety of topics in which this type of analysis could be of use.

The sample size of the current study was a limitation; a greater number of patients would have allowed for increased power in the statistical testing of the data. With regards to the number of participants, initial recruitment to the trial was not an issue and the high rate of attrition was the main contributor to the reduction in numbers. The number of patients that participated in the trial was enough to be able to complete the planned analysis, but a larger sample would have assisted in building a more accurate model (for the GAM/GLS/MLM analysis) as there was a lot of ‘noise’ and variance within the VAS data. With regards to statistical analysis, the lack of information gathered from patients about their individual treatment plans and life events limited the analysis to an extent; this information would have been beneficial for more sophisticated analysis, which may have allowed for further control of variables.

# Recommendations for future research

Now more than ever, government policy is focusing on the patient’s experience of care and their experience of cancer and survivorship as a whole. Traditionally medical care has been judged on treatment efficacy and outcomes such as length of stay, however this is changing, and the approach taken to exploring these factors needs to change too. The increase in qualitative research in the field of health is indicative of this – one of the most effective ways of exploring the patient experience is to talk to people. Qualitative research is unique in its ability to investigate practitioners’ and patients’ attitudes, beliefs, and preferences, and the whole question of how evidence is turned into practice (Green & Britten, 1998). The qualitative analysis methodologies currently available to researchers mean that evidence can be analysed in a number of ways depending on the outcome (and influences the questions that are asked). Qualitative research is widely accepted in the field of health psychology and current government policy highlights the need for better recognition of qualitative work by the medical community. Some health care professionals and those involved in the NHS may have to move away from the purely quantitative measurement of patient outcomes. Although PROMs are starting to become more commonplace within the health arena, their content is still quantitatively based.

The integration of a mixed methods approach to the measurement of patient outcome may be an agreeable compromise. The mixed methods approach which combines both quantitative and qualitative feedback is often criticised in research, as it is argued that the two techniques draw on different philosophical paradigms (Johnson & Onwuegbuzie, 2004). However, the use of both approaches allows for their individual strengths to be utilised and their limitations to be reduced (Creswell & Plano Clark, 2011). Furthermore, combining the use of quantitative and qualitative research results in methodological triangulation, allowing the most comprehensive answer to be found to the proposed research question (Morse, 1991). Qualitative methodology has generally only been utilised in health services research over the last 15 years (Mays & Pope, 1995), and the integration of qualitative and quantitative research followed soon after (Barbour, 1999). It is reported that there has been a growing recognition of the importance of understanding the impact of the delivery and organisation of health services, with a focus on processes as well as outcomes. There are a range of methodological approaches required to do this which consist of quantitative, qualitative and mixed methods (Wisdom, Cavaleri, Owwuegbuzi & Green, 2012; Palinkas, Horowitz, Chamberlain, Hurlburt & Landsverk, 2011; O’Cathain, Murphy & Nicholl, 2007), but at present this does not appear to extend to the delivery of ERPs.

Similarly, the current government policy calls for healthcare professionals to improve the QoL of patients living with and beyond cancer. The extension of current services within the NHS (such as the holistic needs assessment) and integration of non-medical services, such as CAM, are one way of providing a more holistic or integrative package of care which is now expected by patients (Ben-Ayre et al., 2012; Fouladbakhsh, Szczesny, Kowalewski & Blair, 2012; Shuval, Gross, Ashkenazi, & Schachter, 2012; Omar & Merrick, 2009). Research surrounding the optimal number of sessions required to achieve a significant increase in QoL using mind-body interventions (such as yoga) is required in a variety of cancer populations. Research of this type should be pursued alongside ongoing research into the use of CAM in the gynaecological cancer patient population in general.

This thesis, in part, aimed to rigorously test the findings of previous research that had suggested that use of yoga improved QoL for cancer patients (outside the area of gynaecological cancer). This study found that a 10 week course of yoga did not improve the QoL of gynaecological cancer patients receiving treatment. Although at first this appears to be a ‘non-effect’ finding, the use of alternative statistical techniques highlighted that there was a significant upward trend of QoL for those in the yoga condition. The analysis also highlighted that factors such as pain, anxiety and fatigue contributed to patients change in QoL over time, but the limited numbers prevented further modelling. This should be pursued further in future research in the area to establish what role these factors play in the change in QoL for those utilising CAM. The results of this study also contributed to the current literature with regards to the reduced QoL of those who were willing to take part, and the promising effect of yoga on their QoL. Without embracing new statistical techniques, this would have potentially been viewed as a failed intervention. Although it is somewhat scary to those who are used to using standard parametric tests for pre/post intervention measures, there is much more to be learnt about the use of innovative statistical methods and their application to medical and health psychology research.

This thesis has also linked together two important areas: government policy and psychological theory. Although the focus of this thesis was on complementary treatment interventions and their effects on patient reported outcomes, it has also become evident that the outcomes of these interventions are linked, or can be linked to prominent psychological theories such as coping. It is evident throughout this thesis that when exploring the period of time surrounding diagnosis and treatment of cancer, models of coping are important when considering patients’ reported outcomes of their treatment. The way that patients cope with the diagnosis of cancer can influence their approach to treatment, and this should be considered when designing interventions for patients accessing services during this time period. Further research exploring government policy and its links to psychological theory would be beneficial in the design and delivery of holistic models of care. This would be well suited to researchers from the health psychology discipline, as one of the aims of health psychology in the UK is to inorm the formulation and development of healthcare policy (Division of Health Psychology, 2013).

# Conclusions of the Thesis

Cancer is not a one size fits all disease – interventions that have been completed in other areas of cancer cannot and should not always be directly applied to the area of gynaecological oncology. This is evident for both ERP, where research had primarily been conducted in the colorectal cancer population, and yoga, where much of the research has been conducted with breast cancer patients. The current research found similar outcomes to the research conducted in the area of enhanced recovery (although few other studies existed prior to this), but could not replicate the findings of the research conducted using yoga as an intervention to improve QoL in the breast cancer population. Many other cancer disciplines generally have more money to spend on research than that seen in gynaecology departments (due to the greater incidence of these types of cancer). For example, Cancer Research UK are currently funding 103 projects looking at breast cancer, whereas there are only 83 projects being funded for all 5 gynaecological cancers combined. This figure highlights that breast cancer continues to be a focus for funding in cancer, however, it does not mean that researchers should not continue to complete research (and be applying for funding) in gynaecological cancer.

In addition, when looking at the proportion of research funding that is allocated across the different types of cancer research by Cancer Research UK, in 2008/2009 approximately 58% of the available funding was spent on basic research into the biology and understanding of cancer. In comparison, only 9% was allocated to population and behavioural sciences research (Cancer Research UK, 2008). This highlights that there may be a deficit between the amount of money that is spent on the ‘people side’ of cancer research, and the amount of influence that is placed on this area in the current government policy. It is becoming increasingly difficult to get funding to complete research in the area of patient experience and QoL in the current economic climate, and research into lesser known, or more controversial methods of treatment for cancer (i.e. CAM) is often underfunded, thus preventing research from being adequately completed (Walker, 2010).

As gynaecological cancers include a number of individual (and very different cancers) it is difficult to complete research in some areas when looking at the group as a whole. There are major differences between a stage I cervical cancer and a stage IV ovarian cancer. The treatment and outcome of the diseases are very different, and there is a large variation in the demographics of patients who have gynaecological cancer since women with cervical cancer are generally younger (aged 24-45) than those with ovarian cancer (50+ years). As a result of this, patients who have these types of cancer often have very different experiences. For example, a young woman with cervical cancer who loses her ability to reproduce or has reduced sexual functioning for the rest of her life has a very different experience to a post-menopausal 65 year old lady who has successfully had four children and has a stage I endometrial cancer. In many ways, these experiences are not comparable and should not be treated as such. If the government wants to take a greater focus on the patient’s experience, it is important that gynaecological cancers are treated separately, and that researchers consider the difference between each cancer and the impact that disease and subsequent treatment may have on experience.

In light of this, the approach to researching gynaecological cancers has to change. The number of gynaecological cancer patients seen by each institution over the course of a year is greatly reduced in comparison to patients with diseases such as breast cancer and colorectal cancer. In the East Midlands, breast cancer is responsible for 30.9% of the new female cancer diagnoses, whereas gynaecological cancers account for only 13.1%. Colorectal patients account for 10.8% of the new cancer diagnoses in women and 14% in men (East Midlands Cancer Network, 2012). If these figures are correct for Derby, and the known number of newly diagnosed gynaecological cancer patients is 230 (13.1%) – using the previous figures supplied by the EMCN, this would suggest that the number of new breast cancer patients at Derby is somewhere around 542 per year. Access to a large number of breast cancer patients is one of the benefits of completing research within the breast cancer population.

If the current RCT had been conducted in the breast cancer population, based on the numbers recruited for the gynaecological cancer trial, over 100 patients would have taken part in the intervention - adding much needed power to the results. However, it is increasingly difficult to get this type of number in the gynaecological cancer population. The patients are generally older (most are post-menopausal), and depending on the type of cancer, have a worse prognosis (with regards to ovarian cancer). Trying to access the equivalent number of patients within one institution is difficult. This would be an apt use of the EMCN. Across the EMCN there are approximately 1420 new gynaecological cancer patients each year (NHS Trent Cancer Registry, 2012). If research could be organised and developed from a network point of view, it would be more feasible to achieve highly powered quality quantitative research alongside creating a larger and more diverse population from which to gather information and complete research on patient experience.

# Final Comments

The studies conducted in this thesis have provided a unique insight into the lives of gynaecological cancer patients in the UK; this is the first study looking at the patient experience of an ERP in an NHS hospital. Furthermore, this is the first RCT to take place in the UK exploring the use of yoga as an intervention to improve gynaecological cancer patients’ QoL. Both studies highlight the potential for research within this patient population, which is essential to allow on-going improvement in patient outcomes (such as patient experience and QoL), and development of the potential links with psychological theories such as coping, alongside policies such as the SFC.

# An extract from Sheila…

*I have found all aspects of the Enhanced Recovery Programme and the Yoga programme beneficial to aiding my recovery both physically and emotionally. I am now a much calmer person and do not let things worry me to the same degree. My spirits have lightened and I am more optimistic. After the initial shock of coming to terms with the diagnosis I have found the whole overall experience (from being at first a very negative one) both challenging and positive. I get on with life and enjoy every day to the full. It stops you worrying about things you can’t change or do anything about. My husband still finds one of the hardest things is to know when to give me my own space and not to fuss too much. We are now getting our lives back to how things were before, holidays etc. and we both take every opportunity we can to thank everyone involved in my on-going care. We continue to say thank you to everyone for giving me the opportunity to share my experiences which I hope come across as very positive. I feel very lucky, very proud and privileged to have been given all these opportunities and it has given me confidence to speak to groups and all sorts of people about my experience. I have spoken to students at the University of Derby, to medical staff at a Doctors’ surgery in Derby and to a group of medical professionals at a hotel in Kegworth both about the Enhanced Recovery Programme and my Yoga experience. I have also been interviewed on Radio Derby recently when the programme was being broadcast live from Derby Royal Hospital as part of a NHS day re endometrial cancer from the patient’s perspective.*

*To date, my feeling is one of hope for the future for anyone in my situation. As well as the medical staff I owe so much to my husband, son and daughter-in-law, friends and family for all their love and support and I cannot thank them enough. It has been phenomenal.*

Chapter 11: Reflection

# Introduction

The following chapter includes some of my personal reflections on the process of completing this PhD. It focuses on a number of different areas and draws on particular moments in the PhD process that have shaped or influenced my progression throughout this programme and through the completion of this research in general. Some of the information contained in this chapter is very personal to me, but I have written this for both myself and for anyone who reads this thesis. As this piece of reflection is written both by me and for me (and you the reader), it is written in my personal voice, rather than my academic voice, so the tone in places is very different from what you may have experienced throughout the rest of this thesis.

# Getting to this PhD

When applying for this three year, fully funded PhD studentship, I was in the last year of my part-time MSc in health psychology. The post had previously been advertised for ‘biology students only’ as it was originally designed to combine 2 areas: the first being an RCT exploring yoga and its effects on quality of life, and the second being to investigate the identification of specific molecular markers in the progression of gynaecological cancers using tissue microarray (TMAs). After the university had advertised and gone through an unsuccessful round of applications, my MSc dissertation supervisor (who was at the time one of the supervisors on the package) told me about the project in casual conversation as she was surprised that the post remained unfilled.

I asked her to contact the director of studies for the package to ask whether they would consider taking a psychology student rather than a biology student, and that I would be willing to learn the biological side to it, as I had studied biology at A-level. This appeared to be a favourable compromise, and the post was re-advertised to include ‘social sciences’ as well as ‘science’ based degrees. Although I was concerned about the TMA aspect of the PhD, I was fairly confident about the yoga and quality of life study. I had always been interested in health and general well-being, and from an early age have experienced life in the hospital environment – my mother was a radiographer, and my father has Ankylosing Spondylitis (a form of inflammatory arthritis, which meant having the fluid build-up on his joints drained weekly). One of my earliest memories was sitting next to my dad’s bed in the local community hospital (run by the nuns) while he was having the fluid drained from his leg. As a result – I grew up feeling comfortable in the hospital environment, and working in the health domain was something I knew I wanted to pursue.

I completed the application form and was subsequently invited for interview. For the interview I had to prepare a 10 minute presentation about the use of TMAs in cancer research. I was very nervous about the presentation, as it was something that was far out of my comfort zone. I asked members of the psychology department to give me some feedback on my presentation, and their feedback helped me reorganise my thoughts (and slides), and gave me a lot of confidence for the interview.

After completing the interview for the post (there were other candidates, not just me), and finding out I was successful, I had the challenge of balancing the last semester of my MSc and the start of my PhD. As the PhD studentship had been co-funded by the charity (The gynaecological cancer fund) and the University, and was only for 3 years, I had to take up the post at the start of 2010. I started the PhD with some knowledge about quality of life (what I had done over the course of the MSc), and I knew nothing about gynaecological cancer. I could name a few of the parts that gynaecological cancer could affect, but had no real understanding of the physiological aspects (other than what I had learned in A-level biology during lessons on reproduction). As the interview for the PhD had included the presentation on TMAs I had done a lot of reading around that area. I knew this was the weaker of the two areas, and it was something that I had to learn, rather than something that I had experienced or had a working knowledge of. When it came to cancer, I knew nothing. I was in the lucky position (in some respects) to have never known anyone close to me who had had cancer. I was not one of the people who had a tenuous link to a cancer story. I had recollections of a teacher having ‘CANCER’ at school once, but they returned after treatment and continued as before – I didn’t even know what type of cancer it was.

The last semester of my MSc consisted of 2 modules and the independent study/dissertation. I completed as many of the assessments as I could and tailored them to the area of cancer. I changed my independent study to look at the role of online forums in the delivery of social support to ovarian cancer patients. I tried to make everything as streamlined as possible. Studying for the MSc and going through the process of applying for NHS ethics was difficult. Both aspects slowed as a result. It took us over a year to get the NHS ethics for the yoga study, and there were further delays in getting the TMA protocol ready for submission due to the working relationship between departments at Derby and Nottingham University. I finally finished the MSc in the September of 2010, and NHS ethics approval for the yoga trial was received shortly after. I immersed myself into the psychological aspects of cancer, and ‘parked’ the biological aspects until I had the extra brain resources to cope with it – it was planned for after the MSc submission. When I had finally handed in the MSc, we found out that it would not be possible to conduct the TMA research as the move from the old Derby Royal Infirmary to the Royal Derby Hospital meant that the tumour samples we needed had been put into long term storage, and the fees to recall the samples were outside the allocated budget for the PhD. This left a big hole in my thesis. My Director of Studies had been informed that completing the yoga trial alone would not be enough to fulfil the requirements of a PhD and that another study was necessary to ‘beef up’ the project and subsequent thesis (who said this, I don’t know – I would like to have serious words with them…).

So the hunt was on to find another project to complete alongside the yoga project. Of course, I was looking for something more aligned to health psychology. I was approached by Anish (my clinical supervisor who is a gynaecological oncologist at the Royal Derby Hospital) to become involved in the evaluation of the Enhanced Recovery Programme that was about to be rolled out at in the gynaecology department. Originally, it was thought that I would be able to contribute to the questionnaire that was given to patients on their exit from the hospital; but at the time I felt that this project needed more than an item on a questionnaire. After completing a literature search, it became apparent that there was little research that existed which explored the patient experience of these programmes. To me it seemed strange that nobody had asked these patients how they felt about this process, and what impact it was having on their care. I approached the Enhanced Recovery Steering Group (ERSG) with my proposal for the study, and it decided that this would be a suitable method of audit of the patient experience. Originally, I had planned to use the project as the consultancy aspect of my Stage 2 qualification for health psychology, however over time, it became clear that this project was a suitable addition to the original yoga project, and that many patients who took part in the yoga intervention had also been on the enhanced recovery programme after their surgery (Sheila being one example). Finally, the projects for the overall thesis were decided, and the research and subsequent thesis went from there.

# Working with the patients

Working with this group of patients has been one of the most enjoyable aspects of this PhD. Along the way, I have met some truly incredible people who have inspired me, and influenced how I think about things, including how I will deal with things in the future. At the start of this PhD journey I was a bit nervous about working with people who had *cancer.* I felt slightly uncomfortable talking to patients as I didn’t know quite what to say. I wanted to tell them that everything would be OK, and that they would recover, but the truth was that I knew that this wasn’t true, and that many of them would not live past 5 years. I now realise that many patients fear people feeling like that when they are talking to them, that they know that people don’t quite know what to say, but that they can’t or don’t want to make it right, or easy for people. I don’t think that they want people to feel uncomfortable, far from it, but I think that they don’t have the energy to overcompensate for other people’s awkward reactions. They are adjusting to having or surviving cancer, and so should other people.

I have learned over the course of this PhD that the patients I work with are still people, everyday people, and that for many *cancer* does not completely take over their lives. Early on in my research I was lucky enough to be introduced to Sheila (the Sheila that has written the overview for each section). She had been diagnosed with endometrial cancer, and was completely shocked at the diagnosis, but I have never seen her have a bad day. That’s not to say she doesn’t have them, I know she does, but her outward appearance is so happy and so jolly, and after 2 years, I don’t think this is an act. From the very start, she was open about her condition and her feelings about having *cancer* (I put *cancer* in italics as it is still very much treated like that with the patients that I have met over the last three years, it’s not quite the whisper that I originally associated with the word, but it is still that slightly comical over exaggerated mouthing of the word). Sheila and her husband James were very open and honest about how they both felt, and were willing to share their experiences with anyone who was interested. And I was interested. I wanted to know how people dealt with this, and not from the academic point of view, but from the real life point of view – real people. Shelia explained to me how she felt, and over the course of time I built up a better view of what was really happening to her. I know that everyone else’s experiences are different, and the type of cancer people have influences this too, but I still gained insight into a world that I had never known.

After talking at length with Sheila I learned a number of things. Firstly that these people were ‘normal’ and that cancer was just part of them for the time being. They had pasts, and some would have futures. Secondly, that just because people had cancer, it didn’t mean they had lost their sense of humour. I have always enjoyed using humour as a way of breaking the ice with people, and I would like to think that I am quite jovial. But I found that when I started working with cancer patients I tried to hide this away, I felt that it was inappropriate to be my ‘normal self’ around them, that cancer was serious and that a serious attitude was needed when talking to patients. After a time though, I felt that I could be myself around people and that they appreciated it. I think it was a contrast to the healthcare professionals that they would see in clinic, it made me different. I was a researcher who worked with people and was interested in people. In some ways, using humour made me more human or maybe easier to interact with. I don’t know what it was, but I know that as time went on I felt more of me coming through in my conversations with people, and that they responded better, or maybe more freely.

Talking and working with patients also made me confront some of my own fears. I had to learn to have some difficult conversations with people. The conversation about death. This was something I had always previously felt uncomfortable with. Someone once said to me that I got so upset at funerals and the like because I was mourning for myself rather than for the person that had died. I don’t know how much truth there is in that but it is something that stayed with me. Was I sad for them or was I being sad for me? I’m still not sure, but I know now that I have had to get used to having difficult conversations with patients. They are frank with their views and in some cases very much to the point. Because I wear a hospital badge and work in the hospital environment they seem to assume that they can talk to me about anything, in the greatest of detail, death included.

There was one occasion where I was sat in the pub with the ladies on a ‘Christmas do’ after the last yoga session of the year. One of the late stage ovarian cancer patients asked me if I would visit her in the hospice, when the time came. I think she knew that she didn’t have long left – I think she knew more than us. On the spot, I said yes, and shortly after New Year her case came to multi-disciplinary team meeting. Her tumour had metastasised further, and she was to be moved from the ward to the ‘Mac unit’. At this point our conversation came back to me – and I went to visit her; she was so pleased to see me. She was pleased to see someone that wasn’t her family and that she felt that she could talk to freely. She explained that she had made her will and left her house to her three daughters. We talked about her drugs and joked that she was getting her ‘money’s worth’ out of the NHS. Although I was having my final conversation with her, it wasn’t bad, it was sad. It was sad that she was ending her life in a hospital bed when all she wanted to do was go and die at home, but couldn’t because she didn’t want her daughters to have that memory of her dying there; where they lived. There were times I think when we both just sat in silence, as it seemed like the right thing to do; it wasn’t because things were difficult to say, I think it was just that there was no need for words. Her family arrived at her room and I left, I said that I would go and visit her again, but I think I knew deep down that I wouldn’t, that we had said what we needed to say. She died a few days later; I didn’t see her again. Some people from the unit went to the funeral, I didn’t go. I didn’t really know her and it wouldn’t have felt right being at such an intimate gathering. I felt that I had done my bit, what she had asked me to do while she was there.

I think that experience is something that will stay with me. It was the first time I had one of ‘those’ conversations with people, and I made it through. I didn’t cry, and I listened. I listened to what was happening to them and how they felt, and that was enough. It wasn’t about me. It was about them. One of the things I have come to realise throughout this PhD is that completing this research may mean that I become Dr Archer; however the things I have been part of while completing this PhD have made a difference to people’s lives, and often at a point in their life when everything is changing. I feel very humble to have been a part of that, and that being part of this research may have made people’s lives better while they have had cancer.

# Professional Relationships

There have been two distinct aspects to the professional relationships that I have built up through my PhD; the academic side and the healthcare professional side. The academic side happened more easily, I went from being student to being a ‘helper outer’ to being a lecturer. I was accepted by the academic community fairly easily (discussed further in the teaching section). I found that I enjoyed working and moving into a family of people that I had become familiar with over the previous four years as a student. I felt comfortable asking questions and freely took advice. I tried to be open and approachable, and also to be respectful of people in the department who had been teaching for a long time and learn from them, even though I may not have appreciated their teaching style when I was a student. I was lucky enough to belong to two research groups while completing my PhD, and these relationships and forums for discussion were very useful. The health psychology cluster and its members were particularly useful to me as it felt like a safe space for discussing all things ‘health’. The range of more experienced members through to PhD students fostered a learning environment; it resulted in open discussion about a number of projects and the experiences that came along the way. It allowed us to grow as a health team, and meant that we all strengthened our network and increased our skills. I was one of the first to go through the new IRAS form (NHS ethics form), and I found that I was being called upon for advice about completing it. As a fairly new PhD student I felt that I had something to offer to the group, and that my experiences, although different, were contributing to a whole.

The healthcare side of the professional relationships was more difficult. I was moving into a world when I had only ever been the receiver – I had only ever known the role of patient. The transition into working with people at the hospital was made much easier by a few key introductions early on. I was lucky enough to have Anish (the senior gynaecological oncologist) as my third supervisor on my PhD package. He knows lots of people which was good for introducing me to people. His secretary (Sarah) was one of the first people I met at my time at the hospital, and she was the person to know if you wanted anything done. She knew who was doing what and when and this was a good thing to know.

I think I was surprised at how disorganised the hospital was, or at least appeared to be; it was very different from how it looked on the ‘other side’ as a patient. The influx of new patients and temporary clinics and the rotations of medical staff and the number of bank nurses meant that I felt that I was always one step behind. At the start I felt like I didn’t know what was going on. It was hard to keep up with everyone and to know who I’d spoken to about particular aspects of the research. I felt like I needed a strategy, and that strategy was to get to know people who were going to be there for a while. The consultants and the clinical nurse specialists had been there for a long time, and they knew how things would go. I found that asking the two clinical nurse specialists for their advice about things helped massively, and that they were open and honest about what they thought about my plans and the research in general and they wanted to be involved. The ward sisters had the same approach, but they always seemed busy; which they were. I found that I asked them less ‘information finding’ questions, and only went to them when I needed to specifically ask them a question.

My relationship with the doctors was slightly different. To be honest, I lost track of the medical students, and they were not really interested in the research aspect of things. Sometimes, there would be one or two who were interested in research and who would ask questions, and I was more than happy to answer as well as taking any ideas that they had on board. In general they were not interested in what I was doing and I had plenty of others to keep up with (seeing as they were on a 10 week rotation). The early career registrars were good to talk to about ideas. They had enough time to be able to get into a conversation with; there are a couple who were really interested in my research and wanted to get involved more in the research side of things. It seemed as if we were having an information ‘swap’. They would teach me about the medical and biological side of gynaecological cancer, and I told them about the psychosocial side. This was a good opportunity for all involved, and I enjoyed learning more. I also felt that I was on the same ‘level’ as them, many of us were of a similar age, and had been in higher education for a similar amount of time – we saw each other as equals, just in different fields.

This was something that was not shared with many of the senior registrars and some of the consultants. Although most people were very nice, and polite, it was clear that there were some differences between me as a PhD student and trainee health psychologist and them as consultants or ‘waiting to be consultants’. On the whole, I don’t think it was anything personal, I just think that they don’t value health psychology; after talking to a number of other health psychologists, I don’t think I’m alone with this view. To start with, I thought it was just because I was new, and a little unsure of myself in the environment, but three years later there are still problems with a couple of consultants. Some of the consultants weren’t bothered either way – if I was there, they would talk to me and make conversation, but I was not missed when I wasn’t there. For others, it appeared that having a PhD student around who wasn’t studying medicine was unnecessary. I don’t think it helped that I was studying something that wasn’t ‘real science’ (‘real scientists’ get more respect), but I think the fact that I was trying to run a CAM intervention made it worse. Some of the more senior staff did not see the value in running the yoga intervention, and made their thoughts clear. This made working relationships hard. I tried my best to include people in the intervention and to share knowledge with them in the hope of trying to get them to be neutral, but even this was too much for some people. In time, it became less of an issue. The success of the ERP project and having a paper accepted at the National NHS ERP event in London helped with some of the consultants. I think it lifted my reputation, and made some people see that the work and the projects that I work on are of value, and that they may benefit from being involved in my research.

Overall, the three years spent in the hospital environment have been good. I have enjoyed working there, and although building up a network of people to call on has been hard, and slow – I now feel that I am part of the team. Through persistence and different tactics, I have got people to ‘come round’ to the idea of doing patient focused research in the department and after the ERP event and the feedback that came to the hospital, they offered me a job.

# Teaching

I had a year out after my A-levels (working as an events co-ordinator, which on reflection made me extremely organised), I came to the University of Derby in 2005 and haven’t really left since. I completed my undergraduate degree in psychology and then moved onto study the MSc in health psychology part time over two years. During my time as an undergraduate I worked in the student union bar and then moved into working in the IT department at the University while completing my MSc. I spent a lot of time with academics, and people got to know me well. I was fortunate enough to always be ‘around’ when things needed doing, and it meant that I got a lot of opportunities, I was offered my first teaching post because I was ‘around’ and was happy to help out – I was taken on as a lecturer to run seminars for the first years, and I really enjoyed teaching. My boss at the time said he had heard good things about me from the students, and I enjoyed seeing that moment when people understood what you were trying to tell them.

One of my favourite topics for teaching was statistics. The dreaded statistics. I found this most fulfilling. I think it was because so many people came with preconceived ideas about the topic, and thought that it was going to be really hard. But that moment when people understand how to work out the degrees of freedom using a rugby team analogy made it for me. It made me confidentthat I could do this, and that I could teach a topic that not many people wanted to do. I felt that I was a teacher, that I could one day be an academic and work in the university environment. In some ways, this further inspired me to apply for the PhD, especially as it was a Graduate Teaching Assistant (GTA) post. Although it meant moving department, to the school of Biology, Sport and Forensic Sciences, I felt that I would fit in.

I did fit in even though I felt on occasion that I was the wrong shaped piece for their puzzle. I knew I fitted into a puzzle, but I am not sure that it was theirs, but over time this changed. I had a different way of doing things, and I taught topics that I would never have taught before. I have shown people how to build all of the muscles in the shoulder rotator cuff in clay and have learned all of the major bones in the skeleton. I enjoyed the challenge of teaching different things to undergraduates, and felt that my confidence was building. I had to change the way that I taught, to be more imaginative teaching in the biological sciences. I couldn’t rely on what felt natural, and use the examples that I had maybe heard before. I changed my examples from people to frogs and plants, and got used to doing box and whisker plots instead of histograms when doing stats. I delivered two years worth of stats lectures from start to finish; it was good, I enjoyed it.

On occasion I gave lectures to the MSc health students on the chronic conditions module and I gave a series of three lectures on the psychosocial aspects of cancer. I have taught sports students (it had a tenuous link to yoga), radiographers, nurses, and public health students. I have delivered online and on-campus lectures. Sitting in my pyjamas recording my online lectures in my living room made me feel a bit odd the first time, but after a few practices it became easier, and I started to relax – I wanted to be able to give the online students that same type of lecture that the on-campus students get. Sometimes, delivering online content is better. Burning board (an interactive forum for students) meant that I could set tasks that encouraged debate, and meant that people didn’t feel so on the spot as in the classroom when they have a discussion task. I enjoy teaching and the ongoing challenge of making things interesting. I like learning and developing and I want to inspire that in other people.

Facilitating a debate on the use of stem cells in genetic research has been one of my favourite topics – and at first I thought that it was far removed from my comfort topic of health psychology, but it wasn’t. In the end, it all boiled down to ethics, and what we thought was right, just the same as any other topic that we discuss in health. Writing on the windows of the classroom with a board marker due to the absence of a real whiteboard (the interactive one was broken) made it fun and interesting for the students, it livened up the conversation and broke the ice. It made the students ask about my perspective as someone who was outside of their field, which encouraged a cross discipline debate, with people moving from one side of the room to the other to join the for or against team depending on the swing from that round. People broke out of their ‘real science’ bubble: they expressed their opinions and their own thoughts on the topic. It was a great debate, and reading the essays that resulted from it was enjoyable, as I could see how the discussion had influenced their writing, and how we as a group had navigated through a difficult topic. I think I would miss not being able to teach, and I hope that it is something that I can continue with while I still have the enthusiasm for it.

# The academic side of things

The academic side of things has not been easy over the three years. I have found that my writing style and my approach to research has changed. At times I have felt that I shouldn’t have been doing a PhD, and in comparison to some of the other PhD students, I wasn’t doing something theoretical enough. I felt out of my depth talking about epistemologies and ontologies, and I didn’t know whether I was a realist or a social constructionist (it turns out that I am a realist). I found it hard to write long pieces of work, and to put the information that I wanted to say into academic style. I suppose I would say that I felt incompetent. But I kept at it; I knew that this was something that I wanted to do and that I needed to find a solution to the problem. After having a few late nights discussing the problem with my partner (who is also doing a PhD), I decided that I was going to learn how to write a PhD, and that I could learn a lot of the information about the philosophical aspects of research. This came from reading; I did a lot more reading. I talked – I joined in with the conversation about epistemologies and ontologies and I learned along the way. I asked lots of questions, and found that the knowledge started to plug holes in the information that I already had. I had enjoyed completing my MSc, but I didn’t feel that it had given me enough of the academic side of things. I felt a bit let down by the course, but in the end it turned out that it was me that was at fault. I thought I would be able to take the same approach to my PhD as I had for my MSc, that I could read what I needed to and I would be fine.

When I started my ‘new approach’ to the PhD, I found that I had what we now call the ‘snowball’ problem. I would read one piece of literature, and identify another 5 journal articles that ‘looked interesting’ and would read one of those and find another 5 articles that looked ‘interesting’ and so on. I ended up with more articles that I could cope with, but I had classified them all as ‘interesting’. I had to get organised, and work on some sort of grading scale. Once this was established I felt a lot more organised and I found that I had more knowledge than ever. I went through a period of not being able to find anything, and it was frustrating when I knew I had ‘read it somewhere’ and I couldn’t remember where, so I started keeping a bibliography and noting on the printed out journals whether it had been used in my writing. I also found talking about things a great help, it helped me connect the information in my head, and it made writing easier. I also found that thinking about how I was going to phrase things before writing them helped as well, I found that my thoughts changed. I was thinking about writing more and more, and when I actually came to sit and write, it was a lot easier and less of a chore. Sometimes it felt like welcome relief to get the information out of my head and onto paper; as time went on more ‘stuff’ came out in an academic tone and needed less correction to make it academic.

I quite enjoy writing now. I wrote a reflective journal for my Stage 2 qualification in health psychology and found it to be very helpful; I have used some of it as a reference for this piece of reflection. It allowed me to see how far I have come, and that my writing style has changed over time. One thing that hasn’t changed is my passion for research and finding the answer to questions that interest me. I have enjoyed that part of the PhD the most, and it’s something that I still continue to enjoy now.

# Moving forward from the PhD

Completing this PhD has led to a number of opportunities for me. I have been offered a post-doctoral research fellow post in the gynae-oncology department at the Royal Derby Hospital for two years. I am very lucky as I have been given an open remit to conduct research into any area relating to ‘patient experience of gynaecological cancer’. One of the areas that I hope to do more research on is the role of home for gynaecological cancer patients. I really enjoyed writing about home for the enhanced recovery project, and I am exploring the possibility of conducting a qualitative/‘photo-voice’ project to see how the role of home changes over time for patients. I am also interested in the area of drama-therapy and its use as an intervention for those newly diagnosed with cancer. I am also involved in another project at the hospital exploring the differences in knowledge and understanding of palliative care for those who work in the gynae-oncology department in comparison to those who work specifically in palliative care. I enjoy working in the area of gynae-oncology, and working with that group of patients is something that I think will continue (hopefully) for some time, but I am also branching out of gynae cancers and am currently working on a project (outside of my hospital post) with one of my supervisors (Jane Montague) exploring why patients choose not to have breast reconstruction after mastectomy. Moving outside of my area is daunting, but interesting, and I am excited about what the future holds for me in terms of research.

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Appendices

Appendix 1 Information about Stage and Grade

Appendix 2 Overview of the gynaecological oncology services at the Royal Derby Hospital

Appendix 3 Focus Group/Interview Schedule for ERP Evaluation

Appendix 4 Audit Approval Letter for ERP

Appendix 5 Approval Letter: PREC

Appendix 6 Patient Invitation to participate in ERP Evaluation

Appendix 7 Patient Information Sheet for ERP Evaluation

Appendix 8 Statement of Informed Consent for ERP Evaluation

Appendix 9 Thank you/Debrief Letter for ERP Evaluation

Appendix 10 A summary table of the main themes and subthemes that emerged from the IPA

Appendix 11 Participant Information Sheet – Yoga intervention

Appendix 12 Invitation to Participate – Yoga intervention

Appendix 13 Statement of Informed Consent – Yoga intervention

Appendix 14 Data Collection Form – Yoga intervention

Appendix 15 Confirmation of Group Allocation Letter (Control) – Yoga Intervention

Appendix 16 Confirmation of Group Allocation Letter (Yoga) – Yoga Intervention

Appendix 17 Thank you letter/Debrief (Baseline) – Yoga intervention

Appendix 18 Follow-up Sheet (Control) – Yoga intervention

Appendix 19 Thank you letter/Debrief (Control) – Yoga intervention

Appendix 20 Thank you letter/Debrief (Yoga) – Yoga intervention

Appendix 21 4 Month Follow-up Letter – Yoga intervention

Appendix 22 4 Month Thank you letter/Debrief – Yoga Intervention

Appendix 23 Your Diary – Yoga intervention

Appendix 24 Yoga and Quality of Life Study Questionnaire Booklet – Yoga intervention

Appendix 25 R&D Approval Letter – Yoga intervention