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The effects of guided written disclosure on perceived stress and quality of life in women with ovarian cancer and their partners

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by

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ABSTRACT

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES
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THE EFFECTS OF GUIDED WRITTEN DISCLOSURE ON DISTRESS AND QUALITY OF LIFE IN WOMEN WITH OVARIAN CANCER AND THEIR PARTNERS

By Emily J. Arden-Close

High levels of distress are often reported among women with ovarian cancer, and among spouses of cancer patients. However, very few interventions have been tested on women with ovarian cancer, and those that are available rarely involve partners. Recent evidence suggests that writing for 15 minutes a day over three days is effective in improving physical and psychological health across a variety of illnesses, and may benefit cancer patients. However, very few studies have tested the effectiveness of guided writing. The aim of this thesis was to test the effectiveness of writing about the patient's diagnosis and treatment of ovarian cancer according to a structured protocol (the GDP) on reducing distress and improving quality of life in women with ovarian cancer and their partners. A second aim was to test two theories that may account for the beneficial effects of written disclosure, the cognitive processing hypothesis and the social interaction hypothesis.

Two studies and a systematic review were completed. A pilot study used an AAB design to test the efficacy of the GDP plus stress management in 27 women with ovarian cancer. The intervention led to reductions in perceived stress and intrusive thoughts at one month follow-up, which were related to word usage. A randomized controlled trial comparing the GDP to control writing (about what the patient did the previous day), demonstrated no main effects on any of the outcomes, except an increase in intrusive thoughts for partners. However, certain moderators and moderated mediators of the intervention were identified. Patients in the GDP group had improved quality of life if they improved in illness-related couple communication, and if their partners had higher levels of intrusive thoughts at baseline. Within the GDP group, use of positive emotion words was related to improvements in illness-related couple communication for patients and partners.

Overall, these findings suggest that the GDP was not effective at improving quality of life or reducing perceived stress in partners of ovarian cancer patients, nor for the majority of patients. However, there was tentative evidence that it may benefit patients in certain circumstances. Possible mechanisms of improvement include changes in communication (in line with the social interaction hypothesis), and increased benefit-finding Further research is needed to determine whether writing about positive events is associated with improvements in health, whether patients benefit from interventions to improve illness-related couple communication, and for whom the GDP may be effective.

LIST OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

DECLARATION OF AUTHORSHIP

I, Emily Arden-Close, declare that the thesis entitled ‘The effects of guided written disclosure on perceived stress and quality of life in women with ovarian cancer and their partners’ and the work presented in the thesis are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;

- where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has clearly been stated;

- where I have consulted the published work of others, this is always clearly attributed;

- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;

- I have acknowledged all main sources of help;

- where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself

- parts of this work have been published as: Arden-Close, E., Gidron, Y., & Moss-Morris, R. Psychological distress and its’ correlates in ovarian cancer: A systematic review. *Psycho-Oncology,* in press.

Signed: ……………………………………………………...

Date:…………………………………………………………..

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ABBREVIATIONS

BDI	Beck Depression Inventory
CA 125	Cancer Antigen 125
CES-D	Center for Epidemiologic Studies - Depression Scale
COPE	Coping Orientation to Problems Experienced
CR	Cross-sectional
EORTC-QLQ C30	European Organization for Research and Treatment of Cancer – Quality of Life Questionnaire
FACT-G	Functional Assessment of Cancer Therapy - General
FACT-GP	Functional Assessment of Cancer Therapy - General Population
FACT-O	Functional Assessment of Cancer Therapy - Ovarian
FLIC	Functional Living Index - Cancer
GDP	Guided Disclosure Protocol
HADS	Hospital Anxiety and Depression Scale
IES	Impact of Event Scale
IPQ-R	Illness Perception Questionnaire-Revised
LN	Longitudinal
MHI	Mental Health Inventory
POMS	Profile of Mood States
PSS	Perceived Stress Scale
QoL-CS	Quality of Life – Cancer Survivors
RCT	Randomized Controlled trial
SCL-90	Symptom Checklist-90
SM	Stress Management
STAI	State Trait Anxiety Inventory
WHO QoL Scale	World Health Organization Quality of Life Scale

Chapter 1: Introduction to the thesis

1.1 Thesis Outline

The current research was designed to test the efficacy of guided written emotional disclosure in reducing perceived stress and improving quality of life in women with ovarian cancer and their partners. It starts by describing biological, epidemiological, diagnostic, treatment and prognostic factors in ovarian cancer. From this it can been seen that ovarian cancer is often diagnosed at an advanced stage, which means that treatment is aggressive, the prognosis is poor, and risk of recurrence is high. In addition, there is preliminary evidence that psychiatric morbidity is associated with worse survival. Not surprisingly, research has shown that ovarian cancer patients often experience significant levels of distress. However, since this is not uniform, it is important to identify demographic, illness-related and psychological correlates of psychosocial adjustment. Identification of demographic and illness-related correlates of distress enhances the accuracy of judgements about whom to target when designing psychological interventions. Identification of psychological factors enables the design of hypothesis-based interventions to target those factors. The following chapter is a systematic review on correlates of psychological distress and quality of life in ovarian cancer, in which study quality is assessed, in order to draw more definite conclusions about the evidence available. In addition, several studies that did not meet the strict inclusion criteria for the systematic review but were considered highly relevant to the thesis are discussed, in order to assess the influence of coping strategies on adjustment, and the psychological interventions for patients with gynaecological cancer that have been carried out to date.

Evidence also suggests that not only are individual differences important when understanding cancer-related distress, but that partner and couple related factors are also important influences on adjustment to a cancer diagnosis. Chapter 3 is a literature review on cancer in the context of marriage. It addresses the prevalence of psychological distress and correlates of psychological adjustment in partners of cancer patients, the influence of partners' distress on patients' adjustment to cancer, and the relation between couple communication and adjustment in both members of the couple. Psychological interventions for couples in which the woman has cancer are discussed and evaluated, in order to assess the strengths and limitations of interventions that have been carried out to date. Finally, methodological factors to be taken into account when conducting research on couples in which one partner has cancer are examined in detail.

Couples in which one partner has cancer experience significant demands on their time and ovarian cancer patients are often too ill to travel to participate in interventions. Thus, brief interventions involving little contact with the health services may be appropriate for them. One such intervention that has been shown to be effective in improving physical and psychological health in a number of populations is written emotional disclosure of traumatic events for 15 minutes a day over three days. However, many such interventions have been unstructured, whereas evidence from theory regarding cognitive processing of trauma suggests that guided writing interventions may be more effective. In addition, the effectiveness of guided writing has been tested in very few studies. Chapter 4 reviews the literature on written disclosure studies. The basic paradigm and the rationale behind the written disclosure intervention are explained and evidence for its effectiveness is presented. The Guided Disclosure Protocol (GDP), which will be used in this thesis, is described, with an explanation of its rationale, and evidence for its effectiveness. Written disclosure studies on populations with chronic illness, with a focus on studies involving cancer patients, and studies using written disclosure in the context of relationships are discussed, in order to provide a reasoned argument for why written disclosure would be effective for couples where one partner has ovarian cancer.

Theoretically, it is important to understand why written disclosure may be beneficial for health. Therefore, in Chapter 4, several theories developed to explain this are discussed, including the emotional inhibition hypothesis, exposure/emotional processing theory, the cognitive processing hypothesis and the social interaction hypothesis. Previous studies have assessed single theories in isolation, although recent research recommends that multiple models are assessed simultaneously. Since the GDP was developed based on research regarding cognitive processing of trauma, it was deemed appropriate to test the cognitive processing hypothesis, by assessing intrusive thoughts and use of insight, causality and emotion words when writing. Also, since the intervention involved patients and their partners, it was decided to test the social interaction hypothesis, which holds that writing about a traumatic event changes the way in which people interact with others, by assessing marital communication. Finally, methodological issues are discussed, to provide justification for the specific methodology regarding the intervention used in this thesis.

The feasibility and effectiveness of the GDP in conjunction with 30 minutes of stress management over the telephone in reducing distress and improving quality of life in women with ovarian cancer is tested in a pilot study which utilizes an AAB design. The main study, a randomized controlled trial, assesses the efficacy of the GDP compared to control writing on reducing perceived stress and improving quality of life in women with ovarian cancer and their partners, at three and six month follow-ups, and identifies predictors, mediators and moderators of improvement. Involving partners serves two purposes: first, it enables a test of whether involving partners in a writing intervention is beneficial for both the patients and their partners, and second, it provides an opportunity to test the social interaction hypothesis. The hypotheses are discussed in more detail in Chapter 6.

In the final chapter, the results of the pilot study and the main study are discussed and compared with regards to their strengths and limitations. Theoretical and clinical implications of the research are also discussed, to describe the unique contribution it has made to the fields of health psychology and psycho-oncology.

1.2 Medical aspects of ovarian cancer

Cancer can be defined as any malignant growth or tumour caused by uncontrolled cell division. Ovarian cancer can be defined as cancer of the ovary. This section provides background medical information about ovarian cancer. The biology, epidemiology, risk factors, diagnosis, treatment and prognostic factors are discussed.

Ovarian cancer is the most common gynaecological cancer in UK women. There are over 6600 new cases per year (Office for National Statistics, 2007), and over 4400 deaths (Office for National Statistics, 2006). The five year survival rate in the UK was 29% for women diagnosed with ovarian cancer between 1991 and 1993 (Office for National Statistics, 2008). Although survival is over 70% if patients are diagnosed with early stage disease, only 20% of patients are diagnosed at early stages. The rate of survival for metastatic disease is 15%, and one third of patients are diagnosed with distant metastases (Engel et al., 2002) since most patients are asymptomatic until the disease has metastasized (Pan, Ugnat, Mao, Wen, & Johnson, 2004). Even when symptoms are present, they are generally non-specific, including abdominal bloating, increased urinary frequency, and diarrhoea. Hence, they may be misdiagnosed as other conditions. Ovarian cancer is the leading cause of death from gynaecologic malignancies. During the last 20 years, survival time has been prolonged, mainly for patients diagnosed with early stage disease, but there has been no improvement in the cure rate (Engel et al., 2002). However, the rate of survival is higher in younger women, reflecting the fact that they are more likely to be diagnosed with early stage disease (Engel et al., 2002).

1.3 Epidemiology

Ovarian cancer is predominantly a disease of perimenopausal and postmenopausal women - 85% of cases are diagnosed in women over 50 (Office for National Statistics, 2007). Onset is very low in the under 40s, and rises through the fifth decade. However, the rate of increase slows down after 50 years. Incidence is most common in the 55 to 59 age group, with the median age at diagnosis being 61 years (Barber, 1993). Incidence is highest in western industrialized countries and lowest in Japan and developing countries (Coleman, Esteve, Damiecki, Arslan, & Renard, 1993). The majority of ovarian cancers are sporadic – only about 5-10% are familial.

Epithelial ovarian tumours, which account for 90-95% of ovarian tumours, arise from the germinal epithelium on the surface of the ovary. This forms invaginations into the ovarian stroma during adulthood, which are the earliest developmental stage of serous tumours. Epithelial tumours generally arise where the surface epithelium has penetrated into underlying stroma, forming cysts.

Several theories have been developed regarding the aetiology of ovarian cancer. Fathalla (1971) hypothesised that incessant ovulation, which involves repetitive disruption and repair of the ovarian surface epithelium, may lead to increased likelihood of spontaneous mutations and thereby increase the risk of ovarian cancer. According to this theory, risk decreases with increasing number of births because pregnancy interrupts the tearing of ovarian cancer surface epithelium (OSE) with each ovulation. However, this model does not explain why infertility is associated with increased ovarian cancer risk. More recently, studies of ovaries removed prophylactically from high-risk patients have shown a wide variety of histologic changes, leading to the speculation that these changes are characteristic of a premalignant phenotype (Salazar et al., 1996). In an attempt to suggest why the rate of increase in the incidence of ovarian cancer slows down after menopause, Pike, Pearce, & Wu (2004) hypothesised that (sex) hormones affect cancer incidence through their effect on mitotic rates in the stem cell compartment, partly by increasing the probability of a DNA-damaging event being fixed as a mutation, partly by promoting such an effect. Since the menopause reduces mitosis (and sex hormones), it slows down the rates of spontaneous and environmentally induced mutations in the relevant stem cells.

1.4 Risk Factors

The most significant risk factor for ovarian cancer is a family history of the disease. It is estimated that 5–10% of epithelial ovarian cancers are hereditary or familial. The risk of ovarian cancer depends on the number of affected first- and second-degree relatives, and their age at diagnosis with ovarian or breast cancer (Holschneider & Berek, 2000). A mutation in the genes BRCA 1 and 2 is responsible for approximately 90% of familial ovarian cancers.

Nulliparity has been consistently reported as a risk factor for ovarian cancer. However, after controlling for voluntary nulliparity, many studies suggest that infertility is a significant risk factor in ovarian cancer (Bristow & Karlan, 1996). It has been suggested that the use of fertility drugs is a risk factor for ovarian cancer. However, across a wide variety of studies, women who used fertility drugs and then became pregnant did not have an increased risk of ovarian cancer, whereas an increased risk has been reported in infertile women who received prolonged treatments with fertility drugs (Harris, Whittemore, & Itnyre, 1992; Rossing, Daling, Weiss, Moore, & Self, 1994). Based on these observations, it is plausible that, rather than fertility drugs being a cause of ovarian cancer, futile use of fertility drugs may be a marker of an underlying pathology leading to both ovarian cancer and refractory infertility.

There are several important protective factors against ovarian cancer. These include parity, with each delivery conferring a 16-22% risk reduction, independent of the age of first pregnancy (Adami et al., 1994), lactation (Hankinson et al., 1995), and oral contraceptive use - the risk of ovarian cancer declines with increased usage and the protective effect appears to persist after discontinued use (Schlesselman, 1995). In contrast, large-scale epidemiologic studies have demonstrated that hormone replacement therapy (HRT) is a risk factor for ovarian cancer (Salehi, Dunfield, Phillips, Krewski, & Vanderhyden, 2008).

A variety of environmental factors have been investigated as risk factors for ovarian cancer, since the highest incidence occurs in industrialized countries. The evidence is based on case-control studies. However, only limited conclusions can be drawn from these studies, since they are usually retrospective. Where possible, the evidence given here is based on systematic reviews, to control for this. Still, there are a number of contradictory findings, which may be partly due to confounding factors. Factors associated with increased risk of ovarian cancer include cigarette smoking, with a particularly strong relationship for mucinous tumours (Pan et al., 2004), and high intake of animal fat (Zhang, Yang, Binns, & Lee, 2002). Protective factors include increased physical activity (Zhang, Lee, & Binns, 2003), and increased consumption of fruits and vegetables (Zhang et al., 2002). The evidence regarding the relation between body weight and ovarian cancer risk is inconclusive, with one review concluding that there is a direct, but weak association between increased BMI and ovarian cancer risk (Purdie et al., 2001), but another study demonstrating an inverse relationship between body mass index and ovarian cancer, such that increasing body weight may offer protection (Lukanova et al., 2002). Research has suggested that talcum powder may increase the risk of ovarian cancer if it ascends the genital tract. However, further studies are required to explore this relation (Muscat & Huncharek, 2008). Tavani et al. (2004) found that a family history of ovarian cancer leads to moderate increase in risk when hormonal and lifestyle risk factors are low, but excess risk when they are high, pointing at synergism between risk factors.

Finally, it is important to examine risk factors that are directly related to psychiatric morbidity. An association has been demonstrated between self-reported use of psychotropic medication for six months or longer and increased risk of ovarian cancer, primarily for medications that operate through dopaminergic systems (Harlow, Cramer, Baron, Titus-Ernstoff, & Greenberg, 1998). This evidence supported the hypothesis that psychotropic medications increase gonadotropin secretion. However, no association was found in two more recent studies, one based on medical records (Dublin, Rossing, Heckbert, Goff, & Weiss, 2002) and one based on self-reports (Moorman, Berchuck, Calingaert, Halabi, & Schildkraut, 2005). Importantly, none of the studies found increased risk of ovarian cancer from selective serotonin reuptake inhibitors, which are currently the most commonly used class of antidepressants. Medicines that operate through dopaminergic mechanisms are not widely used nowadays.

1.5 Diagnosis

Ovarian cancer is usually diagnosed at an advanced stage (Stage III is most common) due to non-specific symptoms or lack of symptoms. Although ovarian cancer is often described as ‘the silent killer,’ previous studies have shown that 79-84% of women had symptoms prior to diagnosis (Chan, Ng, Lee, Ngan, & Wong, 2003). These symptoms included abdominal/pelvic pain, increased abdominal girth, change in bowel habits, urinary frequency/dysuria, a sense of abdominal pressure and decreased appetite. In Chan et al.'s study, only 10% of patients were asymptomatic prior to diagnosis, and the participants generally sought medical advice within 2 weeks of the onset of symptoms. However, it can take up to a year after receiving medical advice for patients to receive a diagnosis. Reasons for treatment delays attributable at least in part to the doctor include non-investigation of symptoms, treatment for non-cancer causes and lack of follow-up (Evans, Ziebland, & McPherson, 2007). Koldjeski, Kirkpatrick, Swanson, Everett, and Brown (2005), found that primary care was characterized by misdiagnosis and ineffective management, whereas specialist care was characterized by specialized examinations, tests and definitive diagnoses. Based on communication with ovarian cancer patients, it is likely that these factors significantly impair the patient's relationship with their GP, although this has not been researched scientifically. This is particularly important with regard to patients in the UK, since under the National Health Service the GP is always the first point of contact.

Routine pelvic examination can detect asymptomatic ovarian cancer. However, this is rare – examination of only one in 10,000 women will reveal an ovarian cancer, because the majority of palpable adnexal masses in premenopausal women are not malignant (Whittemore et al., 1989).

Radiologic imaging can be very useful if the patient has an adnexal mass or symptoms of ovarian cancer. Abdominal ultrasound can provide information on characteristics of a mass which are suggestive of a malignancy, such as bilateral ovarian involvement, irregular borders, presence of solid components with papillary projections, multiple dense irregular septae, and the presence of ascites and involvement of other organs (Dershaw & Panicek, 1993). Transvaginal sonography is commonly used both in screening and to evaluate adnexal masses (van Nagell, DePriest, Gallion, & Pavlik, 1993). Computed tomography (CT) scans are frequently used in the diagnosis or preoperative evaluation of ovarian cancer. They can be useful in identifying liver or lung nodules, and are used in routine follow-up appointments to monitor pelvic and abdominal masses for response to therapy (Bragg & Hricak, 1993).

Tumour markers have been investigated in the detection and treatment of a variety of cancers, as they have the potential to contribute to screening, diagnosis and progress, and provide a means of monitoring response to treatment and indicating relapse during follow-up (Meyer & Rustin, 2000) with relatively simple and inexpensive tests. With regard to the diagnosis and treatment of epithelial ovarian cancer, evidence has shown CA 125 to be the most useful marker currently available. Bast et al. (1983) developed an assay to detect serum levels of CA 125. The initial results of this assay found that only 1% of 888 healthy individuals and 6% of 143 individuals with benign diseases had levels of CA 125 above 35U/ml, compared to 82% of 101 ovarian cancer patients. Further, among 38 individuals with ovarian cancer monitored on 2-18 occasions over a period of 2-60 months, rising or falling levels of CA 125 correlated with progression or regression of disease in 93% of instances. However, when there is only minimal disease present, serum antigen levels are frequently undetectable.

1.6 Treatment

There are a wide variety of factors involved in considering the approach taken in treatment of ovarian cancer, and it is important to involve the patient in the decision-making process (Stewart et al., 2000). The majority of ovarian cancer patients are aged between 40 and 60, and require aggressive treatment, which usually consists of cytoreductive surgery, followed by combination chemotherapy. Originally, a staging laparotomy is performed to diagnose the malignancy and determine the extent of disease. To determine the volume and distribution of disease, the peritoneal surfaces of the abdominal cavity are explored systematically. Cytoreductive surgery then aims to remove as much of the tumour as possible without undue surgical morbidity, and is important because, firstly, it can result in mechanical and metabolic improvements in the patient, and secondly, it can convert a patient from a poor prognostic group to a more favourable one.

With regard to chemotherapy, the NICE guidelines (National Institue of Clinical Excellence, 2003) recommend a choice of either paclitaxel in combination with a platinum therapy (cisplatin or carboplatin), or platinum drugs alone as standard initial therapy. The standard treatment in the UK is 6 cycles of therapy – more than that is associated with an increase in toxicity experienced, and does not significantly improve median survival (Hakes et al., 1992). However, if the patient is older and has medical problems, or if cytoreductive surgery is not possible, then treatment may be aimed at palliation of symptoms. Evidence suggests that adding paclitaxel to standard platinum-based chemotherapy prolongs life by a median time of 10-11.5 months. Addition of paclitaxel is associated with a greater occurrence of side effects, but research has documented quality of life to be comparable to that associated with use of platinum-based chemotherapy alone. For a recurrence of ovarian cancer the NICE guidelines (National Institue of Clinical Excellence, 2005) recommend drug treatment with a combination of paclitaxel (Taxol) and a platinum drug if the cancer comes back more than a year after treatment, a choice of either Taxol and a platinum drug or Liposomal doxorubicin (Caelyx or Doxil) if the cancer comes back within 6-12 months, or a choice of Taxol, Liposomal doxorubicin or Topotecan (Hycamtin) for platinum refractory (the cancer coming back within 6 months) or platinum resistant cancer.

1.7 Prognostic Factors

One of the most important prognostic factors in ovarian cancer is disease stage at diagnosis – a large-scale US study based on the National Cancer Institute's Surveillance, Epidemiology and End Results reported the following five-year survival rates: Stage I (93%), Stage II (70%), Stage III (37%) and Stage IV (25%) (American Joint Committee on Cancer, 1997). Staging is based on surgical pathological findings, following exploratory laparotomy, peritoneal washings, total abdominal hysterectomy, bilateral salpingo-oophorectomy, omentectomy, multiple peritoneal biopsies, and pelvic and para-aortic lymph node staging. In 1971, the International Federation of Gynecology and Obstetrics developed the first classification system for staging ovarian cancer. This is commonly used by gynaecologic oncologists worldwide and regularly updated in the light of new information. According to this system, Stage I disease is defined as the tumour being limited to the ovaries, Stage II is defined as the tumour involving one or both ovaries with pelvic extension, Stage III is defined as the tumour involving one or both ovaries with microscopically confirmed peritoneal metastasis outside the pelvis and/ or regional lymph node metastases, and Stage IV is defined as there being distant metastasis.

In advanced ovarian cancer, the size of the remaining tumour at the end of the operation is the most important prognostic indicator - remaining tumours ≤ 1cm have been associated with a better prognosis (Hoskins, 1993). Eisenkop, Friedman, and Wang (1998) in a study of women with Stage IIIc and Stage IV ovarian cancer reported a significant effect of completeness of the cytoreductive operation on the probability of five year survival.

Following initial treatment, CA 125 has been found to correlate with disease stage and amount of residual disease. In 93% of the patients originally studied, CA 125 correlated well with disease progression or recurrence. Sensitivity for detecting nonmucinous ovarian cancers after treatment was found to be 88% (Meyer & Rustin, 2000). If CA 125 has fallen to normal within three months of chemotherapy, second-look surgery is likely to be negative, whereas if it takes longer than three months to fall to normal range, residual disease is generally found at second-look laparotomy. To illustrate this, Fayers et al. (1993), who used values of CA 125 before the third course of treatment, with a cut-off of 70 U/ml, found that 57% of participants in their study with levels above this were correctly predicted to show cancer progression or die within 12 months, whereas 80% with a level below this were alive and progression-free. More recently, Markman, Federico, Liu, Hannigan, & Alberts (2006) found that concentrations of CA 125 eight weeks after initiation of chemotherapy was an independent prognostic factor in patients with suboptimal residual Stage III and Stage IV ovarian cancer, with median survival being 26 months for those with a CA 125 < 35 U/ml but 15 months for those with CA 125 > 35 U/ml.

CA 125 is one of the only serological markers with such strong prognostic importance. Certainly, many ovarian cancer patients take it very seriously - Parker et al. (2006) found that in patients with lower levels of knowledge about ovarian cancer, greater preoccupation about CA 125 levels was associated with increased levels of depression; and that increased anxiety was associated with lower levels of knowledge about ovarian cancer, and higher levels of preoccupation with CA 125. Recent research has shown significant relations between CA 125 levels and psychological factors. de Moor et. al (2006) in a longitudinal study of women with ovarian cancer undergoing chemotherapy, found that optimism was negatively associated with CA 125 at follow-up, and that dispositional optimism at baseline predicted CA 125 level at follow-up, after controlling for baseline CA 125. Based on this evidence, it was decided to assess CA 125 levels in the current research, to explore the impact of the intervention on a biological factor.

Very few studies have assessed the prognostic importance of socio-medical risk factors after diagnosis. One study of 704 patients with ovarian cancer followed up for a mean of 6.2 years post chemotherapy found that psychic disorders were associated with a worse prognosis, as was higher parity (von Georgi, Schubert, Franke, & Munstedt, 2002). This evidence suggests that it is important to develop psychological interventions for ovarian cancer patients, as they may improve survival. However, psychological problems were assessed by GPs using a yes/no question, which means that the measure may have been influenced by GP characteristics. Further research is required to explore this issue.

1.8 Summary

The current section has addressed biological, epidemiological, diagnostic, treatment and prognostic factors in ovarian cancer, in order to provide a background and explain why ovarian cancer patients might experience high levels of distress. Chapter 2 is a systematic review that expands this information by identifying correlates of psychosocial adjustment in ovarian cancer.

Chapter Two: Correlates of psychological adjustment in ovarian Cancer: A systematic review

In order to understand factors affecting psychological adjustment (defined as anxiety, depressive symptoms and quality of life) in ovarian cancer, a systematic review of the literature was carried out. The rationale behind the review is explained, methodology is reported, quality assessment criteria are set out, and the results are reported. Findings, limitations and implications for future research are discussed. In addition, several relevant studies that did not meet the inclusion criteria for the systematic review are discussed and evaluated.

2.1 Introduction

A number of studies have found elevated levels of anxiety and depression in patients with ovarian cancer (Miller, Pittman, Case, & McQuellon, 2002; Norton et al., 2004; Norton et al., 2005). However, one longitudinal study found that 23% of patients experienced little or no distress (Kornblith et al., 1995). Thus, the psychological sequelae of ovarian cancer are quite heterogeneous. Identifying systematic and reliable research-based risk factors of psychological distress and reduced quality of life could help to guide psychological support and/ or interventions to those who require them the most.

This is a significant issue. A study of 143 women diagnosed with ovarian cancer found that although 55% of participants had experienced some depressive symptoms, very few had been offered counselling (Norton et al., 2004). Failure to participate in mental health services may be due to lack of availability and awareness rather than choice. Gynaecological cancer survivors report positive attitudes to psychological services such as individual counselling, support groups and couple counselling, with over half saying that they would have used psychological services when they were diagnosed if such services had been available (Pistrang and Winchurst, 1997; Wenzel et al., 2002). Desire for such services is likely to be greater in patients experiencing increased levels of distress, as they desire more information about the psychological aspects of cancer and coping strategies (Stewart et al., 2000). Given this evidence, it is plausible to assume that psychological interventions may be well received by ovarian cancer patients, particularly those experiencing high levels of distress.

However, despite the increased prevalence of distress in ovarian cancer, very few psychological interventions have been developed for patients. A search of the literature from 1980 – 2007 revealed only seven psychological intervention studies for patients with gynaecologic cancers (Cain, Kohorn, Quinlan, Latimer, & Schwartz, 1986; Capone, Westie, & Good, 1980; Chan et al., 2005; Manne et al., 2007b; Petersen & Quinlivan, 2002; Wenzel, Robinson, & Blake, 1995; Worden & Weisman, 1984). Furthermore, these studies found mixed results, possibly because they did not screen for levels of psychological distress. To further this research, it is necessary to identify correlates of psychological distress and quality of life. This will allow us to improve the screening for these interventions, guide their therapeutic contents and improve their efficacy, which has not been done until recently – a search of four major scientific databases revealed no studies assessing levels of psychological distress in ovarian cancer (and very few on other gynaecologic cancers) before 1995.

Research suggests that five main factors are associated with anxiety and depression following a diagnosis of cancer: demographics, degree of disease severity, optimism/ pessimism, stress-response symptoms of avoidance and intrusive thoughts, and use of engagement and disengagement coping strategies (patient responses to the stress of their cancer diagnosis) (Epping-Jordan et al., 1999). The results and discussion will therefore be structured according to these five factors.

When assessing the literature, it is important to consider study quality, as this can vary widely. Montazeri, Ewen, and McGillis (1996) in a review on quality of life in ovarian cancer based on 20 studies published between 1976 and 1994, noted several important issues related to study design. First, the absence of a clear-cut definition of quality of life led to uncertainties in theoretical and operational concepts. Second, very few studies controlled for disease stage and other prognostic factors. Third, many studies modified valid versions of psychometric instruments. Fourth, many studies used small samples, with possible insufficient statistical power. Fifth, some studies included patients with a variety of cancers, without presenting ovarian cancer results separately, meaning that inferences about ovarian cancer could not be made. Since many different measures were used, it was not possible to do a meta-analysis. Overall, only limited conclusions could be drawn.

However, study quality has been improving since the previous review. For example, as quality of life is now routinely assessed in drug trials, there are a number of reliable and valid measures available. Quality of life is now more routinely assessed using standardized measures, which break it down into physical, social, emotional and functional well-being. Cella (1995) has defined health-related quality of life as the extent to which one's usual physical, emotional and social well-being is affected by a medical condition and its treatment. In addition, during the past decade, there has been a substantial increase in research assessing levels of psychological distress and factors affecting psychological adjustment in ovarian cancer. Although Pearman (2003) carried out a review on quality of life and psychosocial adjustment in gynaecologic cancer survivors, several issues limit the conclusions that can be drawn from this review. First, no specific period for the literature search was provided. Second, the only database searched was Medline. Third, gynaecologic cancer patients were not differentiated, although factors that may play a role in psychological adjustment can differ considerably, depending on diagnosis. For example, ovarian cancer generally has a worse prognosis than cervical and endometrial cancers, since it is more likely to be diagnosed at a later stage. Fourth, studies were not quality assessed, and therefore the strength of evidence could not be assessed. Furthermore, in recent years new articles on psychological distress and quality of life in ovarian cancer have been published.

The purpose of this review was to assess correlates of psychological adjustment, conceptualized as levels of distress (anxiety and depression) and quality of life in ovarian cancer. This review covered the period from January 1994 (to include any articles missed by Montazeri et al.'s review) to December 2007 (when the systematic review was conducted). The studies were quality assessed, and divided into good, average and poor quality, in order to assess the strength of evidence.

2.2 Method

2.2.1 Search strategy

I used four methods to locate relevant studies: a keyword search, a backward search, a manual search of relevant journals, and a manual conference program search. Using the keyword search method, I conducted a search of the databases Medline, PsycInfo and Embase for articles covering the period from January 1994 (to ensure I included any articles missed by the previous review, which had searched only Medline) to December 2007 (when the search was carried out) with the provision that any articles published in 1994 and included in the previous review were not included. The search included the following terms: *ovarian cancer, ovarian carcinoma, gynaecologic cancer, gynecologic cancer, psych$, depression, major depression, anxiety, anxiety disorders, quality of life, distress, coping, coping behaviour and stress.* After each term had been entered into the keyword function, the cancer-related terms were combined using the OR function, and so were the psychological terms. A further search was then conducted, whereby the results of the previous searches were combined using the AND function. This generated 1887 hits. Since a search through the titles revealed that a number of the articles dealt with drug trials or genetic testing (not relevant to my research question), the cancer-related terms were narrowed down using the NOT function. Using the words NOT *genetic* NOT *drug trial* reduced the number of hits to 1572. Genetic testing was not of relevance, since this review aimed to identify corrrelates of psychosocial adjustment in women who had been diagnosed with ovarian cancer, not women who were at risk of developing the disease. Drug trials were not of relevance, since I aimed to identify non-chemotherapeutic correlates of psychosocial adjustment. This search obtained 96 articles.

Following the keyword search, I carried out a backward search, in which I located papers by examining the reference lists of all papers obtained from the first step (as well as a recent non-systematic literature review; Pearman, 2003). This identified three further articles. I then carried out a search of the journals *Gynecologic Oncology* (from which I had identified a number of articles) and *Psycho-Oncology* for the period January 1994 – November 2006. This identified one further article. Following this, I contacted the authors of unpublished dissertations, to enquire whether they had written any relevant articles based on their dissertation. This method identified two unpublished manuscripts. Overall, 100 published studies and two unpublished studies were identified and obtained.

2.2.2 Inclusion and exclusion criteria

Once the studies had all been identified and obtained, I examined the papers to determine eligibility for inclusion in the systematic review. To be included, studies had to meet the following criteria:

1) Either include ovarian cancer patients only, or present the results for ovarian cancer patients separately. Thirty-seven studies were excluded according to this criterion, either because they were concerned only with patients with cervical and endometrial cancer (five studies), or because ovarian cancer results were not presented separately (32 studies).
2) Be a quantitative study with standardized or validated measures of psychological distress and/ or quality of life. Eleven studies with qualitative methods and one case study were excluded.

3) Present new data not already reported in an earlier source. Sixteen review articles were excluded according to this criterion.

2.2.3 Coding procedure

The following information was extracted from each study: report information (authors, year of study, source of study), ovarian cancer sample size, age of participants, disease stage at diagnosis, time since diagnosis, measures used (including whether they were standardized), design and major findings.

2.2.4 Ratings of study quality

A methodological quality assessment list was used to assess the studies. This was devised based on reviewing existing quality assessment lists (Ariens, van Mechelen, Bongers, Bouter, & van der Waal, 2001; Gardner, 2003) extracting those criteria that were considered relevant, and devising further criteria based on consultation, to cover all stages of the article. Since quality assessment was generic, the criteria could be applied to a variety of different types of study design. These criteria are summarized in Table 1. To reduce subjectivity in ratings, most criteria (10/12) could be assessed objectively with little interpretation. Each criterion was assessed out of 3 points. Assessment is elaborated on below.

Table 1. Criteria for quality assessment

	Item definition
Rationale	Was there sufficient theoretical background to justify the study aims?
Disease variables	Was time since diagnosis reported?
	Was disease stage reported?
	Were background biomedical and demographic variables reported?
Study design	Was the study cross-sectional/ case-control, prospective or a RCT?
	Was the choice of design adequate for the research question
Analysis and data presentation	Were adequate statistical tests carried out (of sufficient complexity)?
	Were the descriptive and inferential statistics presented adequately?
	Was the sample size sufficient in relation to the number of independent variables (at least 10 times the number of IVs in the analysis)?
Measures used	Were reliable and valid measures used to assess quality of life and psychological distress?
Discussion	Were the conclusions justified based on the design and research findings?
	Were the limitations reported?

2.2.4.1 Overall assessment

The studies were assessed out of 36 points (3 given to each criterion). Studies that scored 30 points or more were classified as good, those that scored 26-29 points were classified as average, and those that scored 25 points or fewer were classified as poor. According to these criteria, 19 studies were classified as good, 15 studies were classified as average, and 5 studies (mainly published prior to 2000) were classified as poor.

When collating the findings, the strength of evidence for a relationship between demographic and other factors and psychological adjustment was assessed by defining four levels of evidence. Levels of evidence were based on those set out by Ariens et al. (2001), and related to both quantity and quality, and are as follows.

1. Strong evidence: Consistent findings across two or more good studies;
2. Some evidence: Consistent findings across two or more studies, provided one is average;
3. Inconclusive evidence: Consistent findings in multiple poor studies, inconsistent findings, or only one study is available, irrespective of quality.

2.3 Results

Overall, 38 studies carried out by 27 research groups were included in this systematic review. The majority of the studies were carried out in the USA (18 studies) or Canada (5 studies). Other studies were carried out in Australia (3 studies), Austria (2 studies), Hong Kong (3 studies), China (2 studies), Germany (1 study), Italy (1 study), Norway (1 study), the Sudan (1 study) and the UK (1 study). Twenty-seven of the studies dealt with ovarian cancer patients only (4 of those studies focused on survivors), and 12 dealt with women with a variety of gynaecological cancers including ovarian cancer, for which the pertinent results could be interpreted.

The quality assessment brought up a number of limitations with the studies. First, some medical studies failed to report disease stage at diagnosis. Second, psychological studies were less likely to report biomedical variables, such as type of treatment, and medical studies were less likely to report other demographic variables, such as socioeconomic status (SES), and marital status. Third, some studies that compared the prevalence of anxiety and depression in ovarian cancer patients to that of the general population did not have a control group. Related to this, some studies did not use appropriate control groups.

Table 2. Data extraction and quality assessment

Ref no.	Article reference	Design	Ovarian cancer (N)	Disease stage	Time since diagnosis (months)	Measures used to assess QoL/ distress	Findings	Quality Assessment score
1	(Awadalla et al., 2007)	CR	18/181	Not reported	3.6 years (SD=5.2)	WHO QoL scale	1)Higher QoL than general population, psychiatric and diabetic patients 2) Higher QoL a/w being married, medium/ high skill occupation, at least high school education, duration of illness, feeling well, having radiotherapy 3)No differences between cancers 4) Being cared for by spouse a/w higher social QoL	30 disease stage; sample size
2	(Bodurka-Bevers et al., 2000)	CR	246	181: III/ IV 65: I/II	0.3-364 (median 28.5)	FACT-O; CES-D; STAI – state anxiety	1) 21% depression scores > 16 – indicates clinical diagnosis 2) Poor performance status a/w high depression, anxiety, low QoL 3) Younger age a/w greater likelihood of depression, poorer physical, ovarian-specific and overall QoL 4) Active treatment a/w poorer emotional and functional wellbeing 5) 30 months or more since diagnosis and evidence of disease a/w more ovarian cancer specific concerns 6) Being divorced/ separated a/w better SWB	30 disease stage/ time since diagnosis, study design, limitations
3	(Boscaglia, Clarke, Jobling, & Quinn, 2005)	CR	100	60: I; 11: II; 28: III; 1: IV	Less than 1 year (Mean 22.21 weeks, SD=14.58)	BDI for Primary Care; STAI – state anxiety	1) 24% symptoms of depression, mean anxiety higher than general population 2) Younger age, later stage of disease, more negative religious coping: a/w higher level of depression 3) More negative spiritual coping a/w higher levels of anxiety	30 sample size, data, demographics
4	(Canada et al., 2006)	CR	125	110: III/ IV	Not reported	FACT-O;	1) Age positively correlated with QoL 2) Greater level of religion/ spirituality a/w greater use of active coping, better QoL 3) Greater use of active coping a/w better overall QoL, social and functional well-being 4) Association between religion/ spirituality and functional well-being, overall QoL mediated by active coping	30 intro, time since diagnosis, demographics, limitations

Ref no.	Article reference	Design	Ovarian cancer (N)	Disease stage	Time since diagnosis (months)	Measures used to assess QoL/ distress	Findings	Quality Assessment score
5	(Capelli et al., 2002)	CR	48/ 115	Ovarian: 38: III/IV, Overall: 56 III/IV	Not reported	SF-36 (QoL)	1) HRQoL scores lower for progressive/ recurrent disease than primary disease 2) Ovarian cancer better QoL scores than cervical carcinoma 3) Lower scores a/w older age 4) Ovarian cancer: lower physical functioning, physical role and emotional role	26 time since diagnosis, demographics, design, data, sample size, limitations
6	(Chan, Ng, Ngan, & Wong, 2003)	LN	17	All IIIc/ IV	Newly diagnosed	EORTC QLQ-C30	1) Overall QoL improved after chemotherapy and continued to improve until 6 months (but role and cognitive functioning declined at 3 months after chemotherapy)	26 intro, demographics, design, stats, data, sample size, conclusions
7	(Chan et al., 2005)	RCT	39 intervention (T), 36 control (C)	88: I 18: II; 40: III; 9: IV	Newly diagnosed	BDI; Beck Anxiety Inventory;	1) No effect of the intervention 2) Lower educational level a/w less anxiety 3) No significant differences between ovarian cancer and other gynaecologic cancers in levels of anxiety / depression	31 intro, data, sample size, limitations
8	(Costanzo et al., 2005)	CR	61	45: III, 16: IV	Newly diagnosed	FACT-G; POMS-SF; CES-D;	1) Elevated levels of distress 2) History of depression a/w higher levels of IL-6 in ascitic fluid 3) Poorer physical and functional well-being and greater fatigue a/w higher levels of IL-6 in peripheral blood	33 demographics
9	(de Moor et al., 2006)	LN	90 (completed follow-up)	8%: I 7%: II 66%: III, 17%: IV	Mean 2.60 years (SD=3.11)	PSS; STAI; CES-D; FACT-O;	1) Optimism negatively a/w anxiety, stress and depression at baseline and follow-up 2) Optimism positively a/w QoL at baseline, dispositional optimism a/w social and functional well-being at follow-up 3) CA 125 a/w anxiety at baseline but not follow-up	35
10	(Ding, Zhu, & Zhang, 2007)	LN	75 (61 at follow-up)	19% - I 20% - II 47% - III 14% - IV	Newly diagnosed	FACT-O	1)All reported good QoL by T3 2)Overall, physical, additional concerns – went up over time 3) Predictors of QoL at T1 – economic status, extra-family support 4) Predictor at T2, T3 – intra-family support	33 demographics, stats, sample size

Ref no.	Article reference	Design	Ovarian cancer (N)	Disease stage	Time since diagnosis (months)	Measures used to assess QoL/ distress	Findings	Quality Assessment score
11	(Donovan, Greene, Shuster, Partridge, & Tucker, 2002)	CR	151 (81 initial cancer, 70 recurrent)	77%: III/ IV	Recently diagnosed, (being treated)/ being treated for recurrent ovarian cancer	FACT-O; POMS-SF;	1) No differences in QoL, POMS or spirituality/ religion 2) Meaning and peace a/w QoL 3) Faith a/w QoL in recurrent cancer 4) Those in highest quartile on FACIT-Sp and SBI-15R had better QoL (no group differences) 5) Religious beliefs a/w QoL in recurrent cancer, support a/w quality of life in both groups	28 intro, time since diagnosis, demographics, stats, sample size, limitations
12	(Ersek, Ferrell, Hassey Dow, & Melancon, 1997)	CR	152	Not reported	Mean 59.8 months (SD=69.9)	QoL-CS	1) Active disease a/w worse physical, psychological and social well-being, and total quality of life 2) Quality of life was moderately high	22 intro, disease stage, demographics, design, stats, data, questionnaire, conclusions, limitations
13	(Ferrell et al., 2005)	CR	1347	12%: I, 10%: II 64%: III 11%: IV	Mean 4.1 years Range 0-22 years	QoL-CS	1)87% had symptoms pre-diagnosis 2)Higher QoL if Stage II, married, employed, higher annual income, older, lower if active treatment 4)Social QoL higher if higher annual income, employed	29 intro, questionnaire, conclusions, limitations
14	(Gil, Gibbons, Jenison, Hopkins, & von Gruenigen, 2007)	CR	33/157	36%: I/II 64%: III/IV	Newly diagnosed	SF-36; FACT-G	1)Physical and mental health , older age, educational level – lower BMI a/w physical QoL 2) Physical and mental health , lower BMI a/w functional QoL, 3) Mental health, lower BMI, lower educational level a/w social QoL 4) Physical and mental health, older age a/w emotional QoL	27 intro, disease stage,design, means & SDs, sample size, conclusions

Ref no.	Article reference	Design	Ovarian cancer (N)	Disease stage	Time since diagnosis (months)	Measures used to assess QoL/ distress	Findings	Quality Assessment score
15	(Gioiella, Berkman, & Robinson, 1998)	CR	11/18	Not reported	Not reported	FLIC	1) Older patients - higher spiritual well-being, better QoL 2) Married patients - higher level of spiritual well-being, but lower QoL 3) Catholic patients - higher levels of spiritual well-being, QoL 4) Ovarian cancer patients: lower QoL and spiritual well-being	22 time since diagnosis, disease stage, demographics, stats, data, sample, conclusions, limitations
16	(Greimel & Freidl, 2000)	LN	33/98	79%: III/IV	Newly diagnosed	Psychological well-being index (standardized);	1) Ovarian cancer had lowest psychological well-being before surgery, but increased by 3 months 2) Psychological well-being improved significantly from T1 to T3 3) Age had no influence on functioning or well-being 4) No differences between early and advanced stage cancer	29 intro, demographics, stats, data, conclusions, limitations
17	(Greimel, Thiel, Peintinger, Cegnar, & Pongratz, 2002)	LN	64/ 248 (25.8%)	Ovarian 76.6% III/ IV	Newly diagnosed	EORTC QLQ-C30; Quality of Life Index	1) Global QoL, emotional and role functioning more affected than physical, social and cognitive functioning 2) Physical, social and role functioning decreased after initial treatment 3) Emotional and global QoL improved pre-post treatment 4) During chemo ovarian cancer patients had higher levels of emotional functioning than breast cancer patients 5) At 6-8 weeks ovarian better role functioning than cervical 6) Before treatment higher physical and role functioning and global QoL if early stage disease; during chemo emotional functioning higher if advanced disease 7) Severity of surgery and Karnofsky performance status accounted for most variance in QoL	31 intro, limitations

Ref no.	Article reference	Design	Ovarian cancer (N)	Disease stage	Time since diagnosis (months)	Measures used to assess QoL/ distress	Findings	Quality Assessment score
18	(Guo, Sheng, Liu, & Hua, 2004)	LN	65/146 (44.5%)	Ovarian 70.7% III/ IV	Newly diagnosed	FACT-O	1) Physical QoL lower if ovarian cancer, lower education, better if surgery only 2) Advanced stage cancer a/w poor physical, emotional and functional well-being 3) Social well-being was lower if age over 70, no help at home. 4) Emotional well-being was higher if over 70, and lower if less education and no help at home, ovarian cancer 5) Functional well-being was higher if college education, no radiation therapy, and home help. 5) Overall QoL lowest in ovarian cancer patients, those with less education, and without help at home, better in older people	28 intro, demographics, questionnaire, conclusions, limitations
19	(Hipkins, Whitworth, Tarrier, & Jayson, 2004)	LN	57	65%: III/ IV	Mean 6.1 months	HADS; IES	1) Anxiety at T1, perceived emotional support and younger age a/w anxiety at T2 2) IES-intrusions at T1, perceived emotional support and younger age a/w anxiety at T2 3) Depression at T1, perceived emotional support associated with depression at T2 4) Increase in anxiety, decrease in depression over 3 months	28 demographics, data, questionnaire, limitations
20	(Hodgkinson et al., 2007)	CR	54 (27%)	59%: I, 17%: II, 22.6%: III 1.5%: IV	Mean 3.7 years SD=2.3	SF-12; HADS	1) 5.5% cases of depression, 14% anxiety 2)Correlates of distress: poorer physical and mental QoL, PTSD, higher total needs 3) Extended survival a/w lower anxiety	31 intro, time since diagnosis, limitations
21	(Kornblith et al., 1995)	LN	151 at start	86%: III/ IV	Not reported	FLIC; MHI;	1) In 1/3 of patients, symptoms of anxiety and depression occurred at levels of moderate to very severe intensity 2) High distress a/w more physical symptoms, worse physical functioning, worse current well-being, advanced disease, being inpatient on study entry 3) Physical symptoms, physical functioning, Karnofsky performance status predictors of psychological distress 4) 23% - little or no distress	25 intro, time since diagnosis, disease stage, demographics, stats, data, sample, questionnaires, limitations

Ref no.	Article reference	Design	Ovarian cancer (N)	Disease stage	Time since diagnosis (months)	Measures used to assess QoL/ distress	Findings	Quality Assessment score
22	(Lakusta et al., 2001)	CR/LN	60 (38 cross-sectional, 26 longitudinal	81% III/ IV	Not reported	EORTC QLQ-30	1) As age increases, fatigue decreases 2) Advanced stage associated with more sleep disturbance 3) Recurrent disease associated with slightly lower levels of fuctioning 4) If newly diagnosed, QoL declined over treatment, but if recurrent disease, QoL improved over the course of treatment	29 intro, time since diagnosis, demographics, design, stats, sample
23	(Le, Hopkins, & Fung Kee Fung, 2005)	LN	253 (94 chemo, 159 follow-up	Chemo: 82% III/IV, Follow-up: 54% III/IV	Not reported	FACT-O	1)Salvage chemo a/w worse overall and emotional QoL, more ovarian-cancer specific concerns, than first-line adjuvant chemo 2) Follow-up: better than chemo in the physical, functional and ovarian cancer domains, and overall QoL	27 time since diagnosis, disease stage, demographics, design, data, conclusions, limitations
24	(Le et al., 2004)	LN	72	60.2%: III 16.3%: IV	Not reported	FACT-O	1) Exposure to 1 or fewer chemotherapy regimen a/w better QoL 2) Older age a/w better physical and emotional QoL. 3) Stage II disease a/w fewer ovarian-cancer specific concerns than Stage IV, Stage 1 a/w better emotional QoL than Stage IV. 4) Better performance status a/w better functional, physical QoL	28 intro, time since diagnosis, disease stage, demographics, data, sample, limitations
25	(Liavaag, Dorum, Fossa, Trope, & Dahl, 2007)	CR	189	43%: I 17%: II 40%: III	6.3 years (sd 6.0)	HADS; EORTC-QLQ-C30;	1)QoL, anxiety a/w chronic fatigue 2)Being on treatment a/w lower QoL 3)Higher anxiety but lower depression than controls 4)Worse QoL, physical and mental health, more fatigue than norms	32 intro, sample size
26	(Lutgendorf et al., 2002b)	CR	24	19: III/IV	New diagnosis (2-14 days before surgery)	FACT-G; POMS;	1) Greater social well-being a/w lower levels of VEGF 2) VEGF > 380 pg/ ml (associated with poorer survival) – a/w lower levels of social well-being 3) Higher levels of helplessness a/w higher VEGF	31 sample size, data

Ref no.	Article reference	Design	Ovarian cancer (N)	Disease stage	Time since diagnosis (months)	Measures used to assess QoL/ distress	Findings	Quality Assessment score
27	(Lutgendorf et al., 2005)	CR	42	83% III/ IV	Newly diagnosed (following surgery)	POMS (SF)	1) No significant differences in distress, depressed mood or social support between groups 2) Higher levels of social support a/w higher NKCC in PBMC and TIL, whereas greater distress a/w poorer NKCC in TIL 3) Greater social support a/w greater NKCC, greater distress a/w more impaired NKCC	33 sample size
28	(Meden, Metz, & Monkeberg-Tun, 1994)	CR	85	5- I 15 –II 51 –III 14 –IV	28 months (range 3-116) – tested after surgery and at least 3 cycles of chemo	Heidelberg 'Sense of well-being' questionnaire	1) Middle aged patients best QoL, then oldest, then youngest 2) Patients with an illness lasting 2-3 years had the highest somatic QoL, those diagnosed less than 1 year had the lowest 3) Those with an illness lasting 1-2 years had the highest psychological QoL, illness lasting more than 5 years - lowest 4) Those with a secondary carcinoma had lower QoL 5) 2 operations - highest QoL, 1 operation - lowest 6) Lower somatic QoL after a partial resection of the intestine or colostomy, higher if less than 6 cycles of chemotherapy 7) Somatically, QoL deteriorated in proportion to size of tumour residue after surgical treatment 8) Oral chemo a/w higher psychosocial QoL than intravenous	20 intro, demographics, data, design, stats, questionnaires, conclusions, limitations
29	(Miller et al., 2002)	CR	10 (12%)	Not reported	39 months (6-145)	FACT-G	1) Lower levels of physical well-being a/w lower level of education, longer time of treatment, 2) Lower social well-being a/w no help at home, age over 71 3) Emotional well-being higher if older, lowest in ovarian cancer 4) Functional well-being lowest in ovarian cancer, a/w lower levels of education, no home help, higher if no radiation therapy 5) Overall QoL lowest if no help at home, less than high school education, only surgery, higher in older patients	29 disease stage, demographics, sample
30	(Molassiotis, Chan, Yam, & Chan, 2000)	CR	35 (56.5%)	3- borderline 21 –I, 19 –II, 3 –III, 1 –IV	52.3 months (***SD*** 45.1, range 6 months – 13 years)	WHO QoL scale; POMS;	1) Lower levels of mood disturbance, depression in ovarian than cervical cancer 2) Younger age a/w better social relationships, psychological health 3) Early stage disease a/w better psychological health 4) Depression accounted for 45% of the variance in QoL	30 intro, study design, sample size, questionnaire

Ref no.	Article reference	Design	Ovarian cancer (N)	Disease stage	Time since diagnosis (months)	Measures used to assess QoL/ distress	Findings	Quality Assessment score
31	(Norton et al., 2004)	CR	143	39% - III	Mean 22 mths (49% under 6 mths)	BDI (somatic items excluded); MHI; IES;	1) Higher levels of depression than community samples 2) Higher levels of anxiety than depressive symptoms 3) Younger age, less time since diagnosis and more advanced disease stage a/w greater levels of psychological distress	31 design, questionnaire, limitations
32	(Norton et al., 2005)	CR	143	46%: III	18 months (***SD*** = 2.3 years)	MHI	1) Older age a/w less anxiety and depression, greater behavioural and emotional control, greater self-esteem 2) Higher levels of physical impairment a/w lower perceived control over the illness and in turn with greater psychological distress 3) Higher levels of unsupportive behaviours from family and friends a/w lower self-esteem, and in turn with greater psychological distress	33 questionnaire
33	(Parker et al., 2006)	CR	126	85%: III/ IV	Mean 2.7 years (sd = 3.4)	CES-D; STAI;	1) 25% scored above clinical cut-off for depressive symptoms 2) Age significantly a/w depressive symptoms and anxiety 3) CA125 preoccupation significantly a/w anxiety; lower knowledge scores and higher CA125 scores a/w more depressive symptoms 4) Knowledge moderated relationship between CA125 preoccupation and depressive symptoms 5) Current anxiety negatively a/w knowledge, but positively a/w CA125 preoccupation	31 demographics, questionnaires, conclusions
34	(Petersen, Graham, & Quinlivan, 2005)	LN	9 (35%)	61%: I 12%: II, 27%: III	Newly diagnosed	SCL-90; Perceived Social Support	1) Levels of symptoms did not differ across first 6 weeks 2) No significant differences in levels of symptoms between ovarian cancer and other sites 3) More symptoms a/w poor perceived social support	26 intro, disease stage, demographics, design, stats, data, sample, limitations
35	(Stevinson et al., 2007)	CR	359	108-I, 55-II 112-III 26-IV	Not reported (only more/ less than 60 mths)	FACT-O	1)If met guidelines for physical exercise, higher QoL than if insufficiently active/ sedentary (not dose-response relation) 2)Advantage greater for women with current disease	31 intro, time since diagnosis, stats

Ref no.	Article reference	Design	Ovarian cancer (N)	Disease stage	Time since diagnosis (months)	Measures used	Findings	Quality Assessment score
36	(Stewart, Wong, Duff, Melancon, & Cheung, 2001)	CR	200	Not reported	7.2 years (SD= 4.9)	MHI ; QoL-CS	1) Mental health not a/w age, education, time since diagnosis	26 intro, disease stage, stats, data, questionnaires, limitations
37	(von Gruenigen, Frasure, Jenison, Hopkins, & Gil, 2006)	LN	42	13: I/II 29: III/ IV	Newly diagnosed (1/2 recruited pre-operatively, ½ post-operatively	FACT-G; SF-36,	1) Questionnaires post-op: lower physical QoL and fatigue scores, and lower SF-36 physical summary, but all improved over 6 mths 2) Questionnaires pre-op: physical QoL and fatigue scores lower at 3 months, returned to baseline at 6 months; functional scores no change baseline-3 mths, but higher at 6 mths	32 intro, data, sample
38	(Wenzel et al., 2002)	CR	49	38: I; 11: II	5-10 years	QoL-CS; SF-36; IES-R; CES-D;	1) Abdominal symptoms, gynaecologic symptoms, neurotoxicity and co-morbid illness a/w physical well-being 2) Neurotoxicity a/w physical and psychological well-being, depression 3) Illness intrusiveness a/w overall QoL, survivor-specific distress, 4) Emotional well-being a/w confidence managing illness, depression 5) As physical and social well-being declined, increase in sexual discomfort 6) Spiritual well-being a/w personal growth, capacity to integrate cancer experience	26 demographics, stats, data, sample, questionnaires, conclusions, limitations

Third, there were a few issues with the statistical tests - dividing data into quartiles to address the issue of skew, rather than transforming variables (1 study), not using inferential statistics (1 study), doing Pearson correlations only, rather than regression (2 studies), and not explaining the statistical tests used (1 study). Fourth, means and standard deviations were not always reported. Fifth, a number of studies had rather small samples, and very few met the criterion of 10 participants per independent variable required for three points. Finally, some of the studies used non-standardized assessment tools (that had not been validated and published) to assess secondary outcomes.

2.3.1 Psychological distress

Anxiety and depression were assessed in 20 studies. Thirteen of these were good, six were average, and one was poor. Levels of depression in ovarian cancer groups tended to be higher than in community samples, with percentages of those scoring above the clinical cut-off ranging from 21-25% in the good studies, to 33% in the poor study (Kornblith et al., 1995) (though, interestingly, this study found that 23% of individuals experienced little or no distress). Notably, the prevalence of depression decreased after the three month period following completion of treatment (Hipkins et al., 2004), although it does not appear to differ across the first 6 weeks post-diagnosis (Petersen et al., 2005). However, in studies involving patients who were at varying stages of their cancer journey approximately 25% of participants scored above the clinical cut-off, suggesting that depression may remain a significant problem for some patients. Studies that looked at ovarian cancer survivors, defined as those who had been 2 years or more without evidence of active disease, found that 6% scored above the clinical cut-off for depression (Wenzel et al., 2002), which is comparable to the general population and that they scored higher on the Mental Health Inventory than population norms, indicating better mental health than the general population (Stewart et al., 2001). Overall, levels of anxiety tended to be higher than levels of depressive symptoms (Norton et al., 2004). For example, Liavaag et al. (2007) reported that ovarian cancer survivors experienced higher levels of anxiety than the general population. Hipkins et al. (2004) reported that the prevalence of clinical levels of anxiety was 47% three months after finishing treatment, and that anxiety increased from completion of treatment to three month follow-up, in contrast with a decrease in levels of depression in the same period. They suggest that following completion of treatment, women are more likely to attend to physical symptoms and internal states, in an attempt to understand whether they are remaining well. This is likely to accentuate somatic symptoms, and thereby lead to increased anxiety. Correlates of levels of anxiety and depression are reported in Table 3.

Table 3. Correlates of levels of anxiety and depression in ovarian cancer

Factor	Most frequently observed association	Congruent with observations	No relation	Incongruent with observations	Level of evidence
Age	Younger – more distress	Good: 5 Average: 1	Average: 1 (survivors)	Good: 1	Strong
Disease stage	More advanced – more distress	Good: 3 Poor: 1	Average: 2 (1 on survivors)		Strong
Time since diagnosis	Shorter – more distress	Good: 3	Good: 1 Average: 1 (survivors)		Strong
Disability status	Worse – more distress	Good: 1 Poor: 1	Average: 1		Some
Physical symptoms	More symptoms – more distress	Good:2 Poor: 1			Strong
Active chemotherapy/ follow-up	Chemotherapy – more distress		Good:1		Inconclusive
Phase of treatment: initial/ recurrent	Recurrent – more distress		Average: 1		Inconclusive
Site of cancer	Ovarian – more distress		Good:1 Average: 1	Good: 1	Inconclusive
Perceived social support	More social support – less distress	Good:1 Average: 2			Some
Previous levels of depression	More – more distress	Average: 1			Inconclusive
Previous levels of anxiety	More – more distress	Average: 1			Inconclusive
Previous levels of intrusive thoughts	More – more distress	Average: 1			Inconclusive
Quality of Life	Poorer quality of life – more distress	Good: 2	Average:1		Strong

2.3.1.1 Demographics

One factor constantly associated with increased levels of depression in ovarian cancer patients included younger age, where evidence was found in five good studies (Bodurka-Bevers et al., 2000; Boscaglia et al., 2005; Norton et al., 2004; Norton et al., 2005; Parker et al., 2006) and one average study (Hipkins et al., 2004).

In contrast, one average study (Stewart et al., 2001) found no relationship between age and depression in ovarian cancer survivors, and one good study (Molassiotis et al., 2000) found lower levels of distress in women under 45 years old (who were diagnosed with early stage disease). The weight of the evidence therefore strongly suggests that younger patients experience more anxiety/ depression. Chan et al. (2005), in a good study, found that a lower educational level was associated with less anxiety.

2.3.1.2 Degree of disease severity and treatment

Being diagnosed with advanced stage disease was associated with increased levels of psychological distress in three good studies (Boscaglia et al., 2005; Molassiotis et al., 2000; Norton et al., 2004) and one poor study (Kornblith et al., 1995), although two average studies found no relationship between disease stage and levels of distress (Hipkins et al., 2004; Stewart et. al, 2001 – ovarian cancer survivors). Based on these results, there is strong evidence that having advanced stage disease at diagnosis is associated with higher levels of psychological distress. Shorter time since diagnosis was associated with increased levels of distress in three good studies (Chan et al., 2005; Hodgkinson et al., 2007; Norton et al., 2004), although, importantly, this could not be assessed in a large number of studies where participants were recruited at diagnosis. Thus, there is strong evidence that longer time since diagnosis is associated with lower levels of distress.

Worse disability status was associated with increased levels of psychological distress in one good study (Bodurka-Bevers et al., 2000) and one poor study (Kornblith et al., 1995), although one average study (Hipkins et al., 2004), found no relationship between disability status and levels of depression/ anxiety. Thus, there is inconclusive evidence for a relationship between disability status and levels of psychological distress.

Increased levels of physical impairment were related to increased levels of psychological distress in two good studies (Hodgkinson et al., 2007; Norton et al., 2005) and one poor study (Kornblith et al., 1995). Related to this, 1 average study on ovarian cancer survivors (Wenzel et al., 2002) found that increased levels of self-reported neurotoxicity was associated with increased levels of depression. From these findings, it was concluded that there is some evidence for a relationship between increased levels of physical symptoms and increased levels of psychological distress Phase of treatment (active/ follow-up) was not associated with levels of depression/anxiety, in the one good study that addressed this issue (Boscaglia et al., 2005). Also no differences in psychological distress were found between those with newly diagnosed and recurrent cancer in one average study (Donovan et al., 2002), suggesting that both cancer phases are psychologically equally difficult.

2.3.1.3 Type of cancer

Three studies assessed several different types of gynaecologic cancers. Two good studies (Boscaglia et al., 2005; Chan et al., 2005) and one average study (Petersen et al., 2005) found no differences between patients with ovarian cancer and those with other types of gynaecologic cancers. However, one good study (Molassiotis et al., 2000) found that women with ovarian cancer experienced lower levels of depression than those with cervical and endometrial cancer. The majority of the ovarian cancer patients in this study had early stage disease, which may account for this difference. These results do not suggest any clear relation between cancer site and levels of psychological distress.

2.3.1.4 Social support

Poor perceived social support was associated with increased levels of anxiety and depression in one good study (Norton et al., 2005) and two average studies (Hipkins et al., 2004; Petersen et al., 2005). This was assessed in different ways across the studies i.e. perceived social support (Petersen et al., 2005), perceived emotional support (Hipkins et al., 2004), and perceived unsupportive family/friend behaviours (Norton et al., 2005), which adds to the robustness of the evidence. These findings suggest moderate evidence for a relationship between perceived social support and levels of psychological distress.

2.3.1.5 Immune factors

Finally, some interesting issues were assessed in single studies. The relationship between levels of distress and immune factors was assessed in three good studies (Costanzo et al., 2005; Lutgendorf et al., 2002b; Lutgendorf et al., 2005). Costanzo et al., (2005) found that a history of depression and increased depressed mood were associated with higher levels of interleukin-6 in ascitic fluid. Lutgendorf et al. (2002b), found that higher levels of helplessness were associated with higher levels of vascular endothelial growth factor, a pro-angiogenic factor which is associated with poorer survival. Lutgendorf et al. (2005), found increased levels of distress were associated with lower levels of natural killer cells in tumour-infiltrating lymphocytes. Thus, various indices of distress are correlated with biomarkers of important prognostic factors in ovarian cancer.

2.3.1.6 Coping strategies

Parker et al. (2006), in a good study, found that lower levels of knowledge about ovarian cancer and higher CA 125 levels were associated with increased levels of depression. Furthermore, the latter association was moderated by knowledge levels, such that it did not occur if knowledge about ovarian cancer was low, suggesting that depth of understanding of the illness moderates the link between CA125 and depression. Increased anxiety was associated with lower levels of knowledge about ovarian cancer, and with higher levels of preoccupation with CA 125. Boscaglia et al. (2005), in a good study, found that increased levels of negative religious coping (i.e., confusion and dissatisfaction with God, redefining the illness as a punishment) were associated with higher levels of anxiety and depression. Wenzel et al. (2002), in an average study, found that survivor-specific distress was significantly correlated with levels of depression in ovarian cancer survivors. The results from these studies point at possible complex relations between information-seeking, coping and distress in ovarian cancer.

2.3.1.7 Miscellaneous factors

de Moor et al. (2006), in a good longitudinal study, found that CA 125 level (a tumour marker with high prognostic value in ovarian cancer) positively correlated with anxiety and depression at baseline, but no prospective relations were found and that levels of optimism were negatively associated with levels of anxiety and depression at both baseline and follow-up. Depression at time of diagnosis was a significant predictor of depression 3 months later, and levels of anxiety and intrusive thoughts at time of diagnosis were significant predictors of levels of anxiety 3 months later in one average study (Hipkins et al., 2004). Similarly, Hodgkinson et al. (2007), in a good study, found that post-traumatic stress disorder was associated with more distress. Increased levels of distress were associated with worse quality of life in two good studies (Hodgkinson et al., 2007; Molassiotis et al., 2000) and one average study (Gil et al., 2007), suggesting strong evidence for this relation. Finally, Liavaag et al. (2007), in a good study, found that anxiety was associated with increased likelihood of being diagnosed with chronic fatigue syndrome in ovarian cancer survivors.

2.3.2 Quality of life

Quality of life was assessed in 29 studies. Thirteen of these were good, 13 were average and three were poor. Correlates of quality of life are reported in Table 4.

Table 4. Correlates of quality of life in ovarian cancer

Factor	Direction of Association	Positive Correlation	No relation	Inverse Correlation	Strength of evidence
Age	Older-better QoL	Good:2 Average: 6 Poor: 1	Average: 1 Poor: 1 (unclear)	Average: 1	Strong (subscales other than social)
Educational level	More education: better QoL	Average: 2 Average: 1 (physical)		Average: 1 (social)	Some
Disease stage		Good: 1 (at diagnosis) Average: 3 Poor: 1	Average: 1	Good: 1 (during chemotherapy)	Some
Disability status		Good: 2 Average: 1 Poor: 1			Strong
Active treatment		Good: 2 Average: 2			Strong
Phase of treatment – intial/ recurrent		Average: 4 Poor: 1	Average: 1		Some
Active disease (longer-term survivors)		Good: 1 Poor: 2			Some
Surgery only	Surgery only – better QoL	Average: 1	Poor: 1	Average: 1	Inconclusive
Radiotherapy	Radiotherapy: worse QoL	Average: 2		Good: 1 (developing country)	Some
Site of disease	Ovarian cancer: worse QoL	Average: 3 (1 prior to treatment) Poor:1	Good: 3	Average: 1	Inconclusive
Being married	Married – better QoL	Good: 1 Average: 1 Poor: 1		Good: 1	Some
Having home help	Home help – better QoL	Average: 2			Some
Spirituality	Greater levels of spirituality: better QoL	Average: 2 Poor: 1			Some

2.3.2.1 Demographics

Older age was associated with better quality of life in two good studies (Bodurka-Bevers et al., 2000; Canada et al., 2006) five average studies (Ferrell et al., 2005; Gil et al., 2007; Guo et al., 2004; Le et al., 2004; Miller et al., 2002) and one poor study

(Gioiella et al., 1998), although one average study (Capelli et al., 2002), found that younger age was associated with better quality of life, one poor study (Meden et al., 1994), found that middle-aged people had the best quality of life, then oldest, then youngest, and one average study (Greimel & Freidl, 2000), found that age had no influence on functioning or well-being. Based on these findings, it was concluded that there is strong evidence for a relationship between older age and better quality of life. Regarding individual dimensions, older age was associated with better physical quality of life in one good study (Bodurka-Bevers et al., 2000) and two average studies (Gil et al., 2007; Le et al., 2004), four average studies found that older age was associated with better emotional quality of life (Gil et al., 2007; Guo et al., 2004; Le et al., 2004; Miller et al., 2002) one good study found that older age was associated with fewer ovarian-cancer specific concerns (Bodurka-Bevers et al., 2000); and two average studies found that older age was associated with worse social quality of life (Guo et al., 2004; Miller et al., 2002). One average study (Lakusta et al., 2001) found that older age was associated with less fatigue, and one average study of ovarian cancer survivors (Stewart et al., 2001), found that older age was associated with more positive perceptions of body image. Taken as a whole, these findings suggest there is moderate evidence that older age is associated with better quality of life with regard to every dimension except social.

Educational level was not assessed in many studies. However, three average studies found that a low educational level was associated with lower physical quality of life (Gil et al., 2007; Guo et al., 2004; Miller et al., 2002), two found evidence that a lower educational level was associated with lower functional and overall quality of life (Guo et al., 2004; Miller et al., 2002), and Guo et al. (2004) found that low educational level was also associated with worse emotional well-being. Based on these studies, it was concluded that there is some evidence for a relation between lower educational level and worse quality of life. However, Gil et al. (2007) found evidence that a lower educational level was associated with better social quality of life. With regard to economic status, Ferrell et al. (2005), in an average study, reported that a higher annual income and being employed were associated with better social and overall quality of life, Ding et al. (2007) in a good study, found that higher self-reported economic status was associated with better quality of life, and Awadalla et al. (2007) in a good study, reported that having a medium or high skill occupation was associated with better quality of life.

2.3.2.2 Degree of disease severity and treatment

With regard to disease stage, the evidence is varied. Le et al. (2004), found that those with Stage II disease had fewer ovarian-cancer specific concerns than those with Stage IV disease, and those with Stage I disease had better emotional quality of life than those with Stage IV disease. Lakusta et al. (2001), found that advanced stage disease was associated with more sleep disturbance. Guo et al. (2004), found that advanced stage disease was associated with poor physical, emotional and functional quality of life. Greimel et al. (2002) found that patients with early stage disease had higher physical and role functioning at diagnosis, but during chemotherapy those with advanced stage disease had better emotional quality of life. Finally, Greimel & Friedl (2000), found no differences in quality of life between those with early and advanced stage disease. From these findings, it was concluded that there is some evidence for a relationship between more advanced stage disease and worse quality of life.

Worse disability status was associated with worse quality of life in two good studies (Bodurka-Bevers et al., 2000; Greimel et al., 2002) one average study (Le et al., 2004) and one poor study (Kornblith et al., 1995). When this was broken down by subscale, Le et al. (2004) found that worse disability status was associated with worse functional and physical quality of life. Based on these findings, it was concluded that there is strong evidence that worse disability status is associated with worse quality of life. However, such relations may be spurious due to item overlap – measures of physical and functional quality of life often include items related to disability.

One good study (Bodurka-Bevers et al., 2000) and one average study (Le et al., 2005) found that being on active treatment was associated with worse functional quality of life. Further, one good study (Liavaag et al., 2007) and two average studies (Ferrell et al., 2005; Le et al., 2005b) found evidence for a relation between being on active treatment and worse overall quality of life. Being on active treatment has also been associated with worse emotional quality of life (Bodurka-Bevers et al., 2000) and worse physical well-being and more ovarian-cancer specific concerns than being on follow-up (Le et al., 2005). These findings suggest strong evidence for a relation between being on active treatment and worse quality of life.

Several studies examined whether there was a difference in quality of life between those with primary and recurrent disease. However, this could not be assessed in studies where all the participants were newly diagnosed. Recurrent disease was associated with worse quality of life in four average studies, (Capelli et al., 2002; Lakusta et al., 2001; Le et al., 2004; Le et al., 2005) and one poor study (Meden et al., 1994). One average study (Donovan et al., 2002) found no differences in quality of life between those with newly diagnosed and recurrent cancer. Specifically, being on salvage chemotherapy was associated with worse overall and emotional well-being and ovarian-cancer specific concerns (Le et al., 2005); recurrent cancer was associated with lower levels of functioning (Lakusta et al., 2001); and having had more than 6 cycles of chemotherapy was associated with worse somatic quality of life (Meden et al., 1994). Thus, these findings suggest some evidence for a relationship between being on chemotherapy and worse quality of life. However, it is important to note that recurrence/ disease stage is often confounded with treatment – individuals who experience a recurrence will have more treatment – and therefore it is difficult to be sure whether it is the recurrence or the extra chemotherapy treatment that is associated with worse quality of life. However, Awadalla et al. (2007) found that longer time since diagnosis was associated with better quality of life, suggesting that the time of diagnosis is the point at which quality of life is most impaired.

The relation between active disease and quality of life in longer-term survivors was assessed in several studies. One good study (Bodurka-Bevers et al., 2000) and two poor studies (Ersek et al., 1997; Meden et al., 1994), found that active disease was associated with worse quality of life. Specifically, Bodurka-Bevers et al. (2000) found that more than 30 months since diagnosis and evidence of active disease was associated with more ovarian-cancer specific concerns; Ersek et al. (1997), found that active disease was associated with worse physical, psychological and social well-being and total quality of life, compared to no evidence of active disease; and Meden et al. (1994), found that psychological quality of life was worst in individuals with an illness lasting more than five years. Thus, there is some evidence that active disease in long term survivors is associated with worse quality of life.

With regard to other types of treatment, two average studies found that functional quality of life was better in individuals who had not experienced radiation therapy (Guo et al., 2004; Miller et al., 2002), but one good study found that having radiotherapy was associated with better quality of life (Awadalla et al., 2007). The authors suggest this unusual finding is due to the patients' appreciation of being able to receive radiotherapy in a country with limited economic resources. With regard to surgery, the evidence is unclear. Guo et al. (2004), found that physical quality of life was better in patients who had surgery only, but Miller et al. (2002), found that quality of life was worse overall in patients who had surgery only, and Meden et al. (1994), found that quality of life was best in individuals who had had two operations, but lowest in individuals who had had one operation. Interestingly, Meden et al. (1994), also found that somatic quality of life was lower in individuals who had had a colostomy or a partial resection of the intestine; those who had oral chemotherapy had higher psychosocial quality of life than those who had intravenous chemotherapy; and that somatic quality of life deteriorated in proportion to size of tumour residue after chemotherapy treatment. Overall, the only conclusion that can be drawn from these findings is that there is some evidence that having radiation therapy is associated with worse quality of life in industrialized western nations.

2.3.2.3 Immune factors

Costanzo et al. (2005), found that higher levels of IL-6 in peripheral blood were associated with poorer physical and functional well-being, and greater fatigue. Lutgendorf et al. (2002b) found that lower levels of vascular endothelial growth factor (VEGF) were related to better social well-being, and that VEGF > 380 pg/ ml (associated with poorer survival) was associated with lower levels of social well-being. This evidence suggests that the relation between immune factors and quality of life should be explored further.

2.3.2.4 Type of cancer

Among the studies on patients with gynaecologic cancer, having ovarian cancer tended to be associated with worse overall quality of life than having other types of gynaecologic cancers. This finding was reported in one poor study (Gioiella et al., 1998) and three average studies (Greimel & Freidl, 2000; Guo et al., 2004; Miller et al., 2002), although Capelli et al. (2002) found that those with cervical cancer had worse quality of life than those with ovarian cancer. Three good studies found no difference in quality of life as a function of diagnosis (Awadalla et al., 2007; Hodgkinson et al., 2007; Molassiotis et al., 2000). When these results were broken down by subscales, Greimel and Friedl (2000) found that patients with ovarian cancer had the lowest quality of life prior to surgery. Three studies found that those with ovarian cancer had lower emotional and physical quality of life (Capelli et al., 2002; Guo et al., 2004; Miller et al., 2002) and one found evidence for lower functional quality of life also (Miller et al., 2002). Finally, Greimel et al. (2002), found that patients with ovarian cancer had better emotional quality of life during chemotherapy compared to those with breast cancer, and those with ovarian cancer had better role functioning than those with cervical cancer at 2 months follow-up. However, these findings may reflect the willingness of patients with advanced stage ovarian cancer to endure higher levels of toxicity in the hope of enhancing survival, due to its worse prognosis. Although at face value these findings suggest having ovarian cancer is not necessarily associated with worse quality of life, when examined more carefully there is evidence that ovarian cancer may be related to worse emotional and physical quality of life relative to other gynaecologic cancers, possibly due to more aggressive treatment and fears of recurrence because it is often diagnosed at an advanced stage.

2.3.2.5 Social support

Several studies found that social factors were related to quality of life. One good study (Awadalla et al., 2007), one average study (Ferrell et al., 2005) and one poor study (Gioiella et al., 1998) found that being married was associated with better quality of life. In contrast, one good study (Bodurka-Bevers et al., 2000) found that being divorced/ separated was related to better social/ family well-being. Two average studies found that having home help was related to better social, functional and overall quality of life (Guo et al., 2004; Miller et al., 2002), and Miller et al. (2002), also found that having home help was related to better emotional well-being. From these studies, it was concluded that there is some evidence being married is associated with better quality of life, and some evidence that having home help is associated with better quality of life. With regard to levels of social support, Awadalla et al. (2007) found that being cared for by a spouse was associated with better social quality of life, and Ding et al. (2007) found that extra-family support was associated with better quality of life at the start of a course of chemotherapy, but intra-family support was associated with better quality of life as the course progressed.

2.3.2.6 Coping strategies/ optimism

There has been very little research on coping strategies and personality factors in ovarian cancer. de Moor et al. (2006), in a good study, found that optimism was positively associated with quality of life at baseline, and dispositional optimism was positively associated with social and functional well-being at follow-up. Canada et al. (2006), in an average study, found that more active coping was associated with better overall, social and functional quality of life. Spirituality (which can be viewed as a coping strategy) and quality of life was assessed in three studies. One poor study found that being Catholic was associated with better quality of life (Gioiella et al., 1998). More broadly, one average study (Canada et al., 2006), found that a greater level of religion/ spirituality was associated with better quality of life, and in the case of functional and overall quality of life this effect was mediated by active coping. One average study (Donovan et al., 2002), found that a higher level of spirituality was associated with better quality of life. Meaning and peace were associated with better quality of life in all their participants, and faith was associated with quality of life in recurrent cancer. Stronger beliefs were associated with better quality of life in recurrent cancer, and support was associated with quality of life in both groups. Importantly, there were no differences between those with newly diagnosed and recurrent cancer with regard to levels of spirituality. Overall, these studies provide some evidence for a relation between a greater level of religion/ spirituality and better quality of life.

2.3.2.7 Miscellaneous Factors

Some interesting issues have been assessed only in single studies. Stevinson et al. (2007), in a good study, found that meeting guidelines for physical exercise (150 minutes of moderate intensity activity per week) was associated with better quality of life than being insufficiently active or being sedentary, and that the advantage was greatest for women on active treatment. Gil et al. (2007), in an average study, found that a higher body mass index (BMI) was associated with lower physical, functional and social quality of life. Liavaag et al. (2007) found that worse quality of life was associated with increased likelihood of caseness of chronic fatigue.

2.4 Discussion

To identify correlates of psychological distress and quality of life in ovarian cancer, a systematic review of the literature was carried out. The results showed strong evidence for a relationship between younger age, being diagnosed with more advanced disease, more physical symptoms and shorter time since diagnosis with increased levels of anxiety and depression; some evidence for a relationship between low perceived social support and worse disability status and increased levels of anxiety/depression was also found. There was inconclusive evidence for a relationship between being on active chemotherapy, having a recurrence and having ovarian cancer (compared to other gynaecologic cancers) and levels of anxiety/depression. While the evidence for a relationship between quality of life and distress could be viewed as strong based on our criteria, the issue of item overlap (quality of life instruments often include measures of mood) spuriously inflated this relationship.

With regard to quality of life, there was strong evidence for a relationship between worse disability status , being on active treatment, and younger age (regarding subscales other than social) and worse quality of life. There was some evidence for a relationship between lower educational level, being diagnosed with more advanced stage disease, having recurrent disease, having active disease (in longer-term survivors), and having radiotherapy and worse quality of life. There was some evidence that being married, increased levels of religion/ spirituality and having home help were associated with better quality of life. There was inconclusive evidence for a relationship between having surgery only with quality of life, and inconclusive evidence that having ovarian cancer was associated with worse quality of life. With regard to both psychological distress and quality of life, these results are discussed in relation to the factors considered to be associated with psychological adjustment in ovarian cancer: demographics, degree of disease severity and treatment-related factors, social support, optimism/ pessimism, avoidance/ intrusive thoughts and use of coping strategies.

2.4.1 Demographics

Overall, a constant relationship was found between younger age and increased levels of anxiety/ depression, in line with previous literature. Individuals diagnosed when they are younger have a number of issues to contend with, including the impact of their diagnosis on those around them, issues about childbearing, and the possibility of an early death. This finding was repeated for quality of life, with regard to all subscales except social well-being. In general, elderly people, whether they have cancer or not, may be lonelier than younger people. Although younger women are more likely to be married (as opposed to widowed), and possibly have a wider social network, the disease is more likely to impact on their everyday lives. This evidence suggests that younger women should be carefully assessed for symptoms of anxiety and depression. However, older people may also benefit from access to interventions, as a way to increase their social network.

A low educational level was associated with worse quality of life, possibly because less education may hinder patients in attempts to make sense of their disease and treatment, or to seek medical information in order to reduce uncertainty. To reduce this problem, it is important that doctors assess the educational level of their patients, and in general, explain disease information in simple language, with the use of visual aids where necessary. In contrast with this idea, Chan et al. (2005) found that a low educational level was associated with less anxiety. Individuals with less education may have limited awareness about the seriousness of their condition. Alternatively, low educational level is often taken as a proxy for low socioeconomic status, and this relates to the finding that unemployed individuals and those with a lower income reported worse quality of life. Individuals on a lower income are less likely to have access to private healthcare, meaning that they have to wait longer for treatment, and do not necessarily have access to the best treatments. Overall, demographic factors appear to have a significant impact on quality of life. Although most are not modifiable, the way in which they are appraised can be altered, and appraisal should therefore be tested in future studies.

2.4.2 Disease severity and treatment-related factors

More advanced disease was associated with increased levels of psychological distress and worse quality of life in newly diagnosed patients. Advanced stage disease is associated with poorer survival and more symptoms, and patients are obviously aware of these threats - fear of recurrence is one of the major issues affecting ovarian cancer patients (Ferrell, Smith, Cullinane, and Melancon (2003)). This evidence suggests that individuals diagnosed with advanced disease should be carefully assessed for anxiety and depression. Similar findings were reported for quality of life. However, interestingly, Greimel et al. (2002) found that patients with advanced stage disease experienced better emotional quality of life during chemotherapy than those with early stage disease. In these patients chemotherapy may eliminate symptoms, whereas some patients with early stage disease are asymptomatic at diagnosis. Alternatively, they may be willing to tolerate a higher level of toxicity in expectation of treatment benefits (Balmer, Thomas, & Osborne, 2001) or it may provide patients with advanced stage disease with more hope than those with early stage disease. However, these results were based on questionnaires that are not disease-specific, so may not have addressed specific experiences related to living with gynaecologic cancer. Alternatively, it is possible that patients with some early stage cancers receive more aggressive treatments than those with advanced disease, impairing the quality of life of the former more than the latter.

As in other cancers (Helgeson, Snyder, & Seltman, 2004), levels of anxiety/ depression tended to decrease as time since diagnosis increased. A cancer diagnosis is a traumatic event, and coming to terms with it requires a significant shift in perspective, which could explain these findings. This may reflect an adaptation process. However, there was some evidence that active disease was associated with worse quality of life in longer-term survivors. Such individuals generally undergo several regimens of chemotherapy. However, quality of life may improve over the course of treatment (Lakusta et al., 2001), as patients become accustomed to the side effects of the treatment, and chemotherapy reduces disease symptoms. The impact of time since diagnosis on quality of life is difficult to assess, since it is often confounded with receipt of treatment. Ideally, separate analyses should be performed on disease-free individuals and those who have experienced a recurrence, but if this is not possible, recurrence status should be controlled for in all analyses.

Physical symptoms/ impairment were also associated with increased levels of anxiety and depression, possibly because they are viewed as indicators of disease progression. In addition, some treatment-induced physical symptoms (e.g., nausea) may either induce or be associated with altered mood state as part of the “sickness response” (Reichenberg et al., 2001). Similarly, worse disability status was associated with increased levels of anxiety/ depression, and worse quality of life – reduced ability to perform daily activities may reduce enjoyment of life. This evidence suggests that individuals with limited ability to perform daily activities may benefit from psychological interventions. Since this is a common problem, it is important to ensure psychological interventions are easily accessible to a wide variety of patients, and that these interventions are tailored to accommodate patient limitations (i.e., over the phone for people who are unable to travel). Alternatively, depression or anxiety may lead to poorer performance status because depressed patients have reduced motivation (Beck, 1967) leading to reductions in energy expenditure required for daily activities. It is also plausible that relations between self-reported physical symptoms and distress may reflect the underlying personality trait of neuroticism (Watson & Pennebaker, 1989), manifested by corresponding scores on both outcomes. Objective assessment of physical symptoms would enable a test of the true relation between impairment and distress.

There was some evidence that being on active chemotherapy treatment was associated with worse quality of life, but not increased risk of anxiety and depression. This was surprising since chemotherapy can cause a number of unpleasant side effects, often greatly reducing life satisfaction and inducing the sickness response. Patients on active chemotherapy are recommended to restrict their activity, since the immune system is weakened, explaining in part the impaired functioning. However, a number of the studies that assessed anxiety and depression included only newly diagnosed individuals. Patients undergoing chemotherapy are aware that their condition is being treated, which may reflect an important source of medical support. Upon completion of treatment, some patients experience anxiety that their progress is not being monitored, and that they will be unaware of a recurrence (particularly since ovarian cancer can be asymptomatic). Similar “separation anxiety” is found in patients leaving the intensive coronary care unit for less intensive monitoring and care in other parts of hospitals (Sarantidis et al., 1997). Also surprisingly, having a recurrence was not associated with increased levels of anxiety and depression, and although the majority of the evidence suggested that having a recurrence was associated with worse quality of life, this was not always the case. In this context, it is important to note that quality of life scales tend to assess levels of physical symptoms, rather than the impact of such symptoms on everyday life. To illustrate the difference, in a qualitative study of women receiving palliative chemotherapy, many participants reported that the impact of nausea and vomiting on their quality of life had significantly diminished relative to their initial chemotherapy (Houck, Avis, Gallant, Fuller, & Goodman, 1999). This research tends to suggest limitations of quality of life scales with regard to addressing the impact of illness on each individual.

With regard to the findings on anxiety and depression, individuals who had a recurrence were compared with newly diagnosed patients. Comparing patients who had a recurrence with disease-free individuals at a similar time since diagnosis may yield different results. Alternatively, this result could be explained in the following way: by the time of recurrence, some individuals have been living with their illness for several years, and may have come to terms with their diagnosis and treatment – news of a recurrence may be less surprising than the initial diagnosis. This issue requires further research. Alternatively, experiencing recurrences may lead to modifications in the idea of what is necessary for good quality of life (Lutgendorf et al., 2002a). On the other hand, recurrence could be worse than an initial diagnosis since it generally means that the disease is not curable, and therefore may induce greater responses of hopelessness.

Having radiotherapy was associated with worse quality of life. Radiotherapy is not a common method of treatment in ovarian cancer, and tends to be given only when individuals refuse chemotherapy. Therefore, this finding may reflect the prognosis of the individuals given radiotherapy, rather than effects of the treatment. The study finding a relation between having radiotherapy and better quality of life was carried out in the Sudan, a developing country, and the authors suggested that the patients were grateful for the opportunity to receive treatment that was not widely available. However, radiotherapy can impair sexual functioning (Andersen, Woods, & Copeland, 1997), and individuals treated in this way should be given advice on coping with these issues.

Although it was expected that having surgery only would be associated with better quality of life, the evidence was inconclusive. Individuals who have surgery only may worry more about recurrence, which impacts on other aspects of their quality of life. However, the impact of treatment on quality of life is likely to be influenced by the response of the individual to the treatment they receive. Overall, disease and treatment related factors significantly impact on quality of life and distress, although treatment-related concerns are likely to diminish as the disease-free interval increases. More longitudinal studies are needed across the course of treatment, in order to examine correlates of psychosocial adjustment following multiple recurrences.

2.4.3 Immune factors

A few well-designed studies found that various indices of distress and quality of life were correlated with biomarkers of prognostic factors in ovarian cancer (e.g., VEGF, IL-6). Since distress may lead to altered immune function, interventions to reduce distress need to be made a priority. These studies are important, since they point to potential mediators linking psychological factors with prognosis in ovarian cancer (von Georgi et al., 2002). However, this needs to be tested in longitudinal studies and randomized controlled trials, which would provide a better understanding of the direction of the relation between immune factors and psychological distress. It is important to test this relation, since future studies may examine whether blocking biomarkers improves prognosis in distressed patients.

2.4.4 Type of cancer

The evidence assessed here suggests no differences in levels of anxiety and depression between patients with ovarian cancer and those with other gynaecologic cancers. Similar findings were observed in two excluded studies (Chan et al., 2001; Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Ovarian cancer has a worse prognosis as it is more likely to be diagnosed at an advanced stage, and consequently requires more aggressive treatment, both of which are distressing. However, provided disease stage was controlled for in these studies, this lack of difference is expected since cancer can be life threatening and all gynaecologic cancers may affect sexual relations and intimacy. Thus, other factors related to the disease mentioned above, rather than the mere diagnosis of ovarian cancer, should be considered when assessing anxiety and depression (Kornblith et al., 1995). However, the evidence suggests that having ovarian cancer may be related to worse emotional and physical quality of life relative to other gynaecologic cancers, possibly due to more aggressive treatment and fears of recurrence because it is often diagnosed at an advanced stage.

2.4.5 Social support

As expected, given previous studies on other types of cancer, i.e., Helgeson & Cohen, (1996) poor perceived social support was associated with increased levels of anxiety and depression. This may result from patients not receiving sufficient emotional or instrumental support from close friends/ relatives. Alternatively, high patient distress may lead to reduced social support due to significant others not having the skills to manage such distress. Similarly, being married (which is often viewed as proxy for social support) was associated with better quality of life. Also, with regard to instrumental support, not having home help was associated with worse quality of life. Women generally play a considerable part in the running of their household, which is likely to be greatly impaired while they are receiving treatment.

2.4.6 Quality of life and depression

As expected, poorer quality of life was significantly associated with increased levels of anxiety/ depression. Experiencing more physical symptoms and reduced ability to engage in leisure activities/ work is likely to decrease self-esteem, possibly leading to greater distress. Future studies need to test whether self-esteem mediates such a relation. This evidence suggests that interventions targeting quality of life are a high priority area for future research, and should be made widely available, particularly given the relations between quality of life and distress/ survival (Hoodin & Weber, 2003; Mainio et al., 2006). However, as mentioned above, these relations may partly stem also from item overlap and need to be tested by removing questions assessing distress from quality of life instruments.

2.4.7 Religion/ spirituality

The evidence assessed suggests that a greater level of religion/ spirituality was associated with better quality of life. Religion and spirituality may give individuals a purpose in life, and some framework for making sense of their illness, thereby enabling them to confront the illness. Supporting this rationale, Canada et al. (2006), found that the relation between spirituality and functional and overall quality of life was mediated by active coping. This finding echoes that of Holland et al. (1999), that reliance on spiritual and religious beliefs was related to active coping in patients with malignant melanoma. However, it is important to understand how the patient conceptualizes spirituality/ religion or what it does with its contents: Boscaglia et al. (2005) found that increased levels of negative religious coping (i.e., redefining the stressor as a punishment from God) were associated with higher levels of anxiety and depression.

2.4.8 Optimism/ pessimism

There have been very few studies on levels of optimism in gynaecologic cancer patients. One good study (de Moor et al., 2006) found that optimism was negatively associated with anxiety, stress and depression at baseline and follow-up; and positively associated with quality of life at baseline. Further, dispositional optimism was associated with social and functional well-being at follow-up. This may be related to coping strategies. High levels of optimism at the time of diagnosis have predicted less psychological distress up to 12 months later in women with early stage breast cancer, an effect that was mediated by acceptance, denial and behavioural disengagement (Carver et al., 1993). The relation between optimism and subjective distress may also be partially mediated by negative affectivity (Watson & Pennebaker, 1989).

2.4.9 Avoidance/ intrusive thoughts

Avoidance and intrusive thoughts have been assessed in very few studies on patients with ovarian cancer. In ovarian cancer patients who have completed chemotherapy, levels of intrusive thoughts at baseline have been associated with symptoms of anxiety at three month follow-up (Hipkins et al., 2004). Related to this, Hodgkinson et al. (2007) found that PTSD symptoms were associated with increased levels of distress. It is likely that the combination of lack of knowledge and being diagnosed with advanced-stage disease causes increased levels of distress in ovarian cancer patients. A longitudinal study of 80 women newly diagnosed with breast cancer found that younger age was associated with levels of anxiety/ depression at baseline, and this relation was mediated by magnitude of intrusive thoughts. At three months post-diagnosis, intrusive thoughts was the only predictor of changes in symptoms of anxiety/ depression (Epping-Jordan et al., 1999). This is important because intrusive thoughts are typically reported at high levels at time of diagnosis, and may persist for years following the initial diagnosis and treatment. Therefore, interventions need to be developed to reduce intrusive thoughts.

2.4.10 Health-related factors

A few interesting issues have been assessed in single studies. Stevinson et al. (2007) found that being insufficiently active or sedentary was related to worse quality of life, and that this relation was particularly strong for individuals on treatment. As over 70% of their participants were not sufficiently active, this evidence is cause for concern. Gil et al. (2007) found that a higher body mass index (BMI) was associated with worse quality of life, possibly because it puts the individual at increased risk of co-morbidity and is associated with increased fatigue following exercise. Related to this, Liavaag et al. (2007) found that increased levels of anxiety and worse quality of life were associated with caseness of chronic fatigue syndrome in ovarian cancer survivors. Anxious individuals may be particularly in need of graded exercise interventions, as their anxiety may have been related to reduced levels of activity. Overall, the evidence from these preliminary studies suggests that the relation between exercise and quality of life should be tested longitudinally in order to gain increased awareness about the direction of causality, and assessed in randomized trials.

2.4.11 Limitations and directions for further research

Regarding methodology/ reporting, several issues need to be addressed in future studies. First, information should be collected on whether the individual is living alone or with a partner, socioeconomic status, type of treatment received and whether the patient has had a recurrence. Second, more prospective studies and randomized-controlled trials are needed, the latter enabling causal inferences and having potential clinical value. In addition, longitudinal studies should test trajectories of change in distress following diagnosis and treatment. Third, more attention should be given to sample size. Fourth, questionnaires should be validated prior to usage if possible. Fifth, importantly, studies should use models to structure their research questions – most studies have not been based on theory regarding adjustment to illness. Finally, limitations and possible future directions for research should be provided. Although the majority of these conclusions echo those of Montazeri et al. (1996), which would suggest lack of progress in recent years, the studies published in the current decade were rated ‘average’ or better, in contrast with the studies published in the 1990s. It is also encouraging to see that the volume of published research on ovarian cancer has been increasing in recent years – over half the studies included in this review were published after 2003. In addition, the studies revealing relationships between distress and disease biomarkers indicate promising avenues and call for testing whether treating distress could alter such biomarkers and improve prognosis in ovarian cancer. Also, some studies point to a number of modifiable factors affecting levels of distress and quality of life, such as levels of knowledge and coping strategies, which were not assessed in the ovarian cancer literature before the late 1990s. Given recent reviews on psychological interventions and prognosis in cancer (Coyne, Stefanek, & Palmer, 2007), future studies need to design alternative interventions for modifying psychosocial factors.

This systematic review had a few limitations. The studies were quality assessed by only one author, so inter-rater reliability could not be assessed. However, since nine out of the 12 criteria could be assessed objectively with little interpretation, this is unlikely to seriously impact on the results. Some correlates of distress (e.g., immune factors, coping) were tested in too few studies to enable firm conclusions to be drawn.

Overall, this review has provided a first step towards identifying factors that may impact on psychological distress and quality of life in ovarian cancer, a disease that has often been neglected in psycho-oncology research until recently. This is also the first review to quality assess studies, and therefore provides a more stringent test of the evidence than previous reviews on ovarian cancer. The evidence here can be used as a preliminary guide when deciding which patients to assess for anxiety and depression and whom to target when designing psychological interventions.

2.5 Evidence excluded from the systematic review

The following section discusses studies that failed to meet the strict inclusion criteria for the systematic review, mainly because ovarian cancer results were not presented separately. This research helps to clarify the relation between coping strategies and quality of life in cancer with regard to similar populations, and examine the effectiveness of psychological interventions for gynaecological cancer patients.

2.5.1 Coping strategies

Greater use of active coping has been related to better social well-being and less overall distress cross-sectionally (Lutgendorf et al., 2000) and greater use of positive reframing and acceptance has been associated with better functional well-being in gynaecological cancer patients (Costanzo, Lutgendorf, Rothrock, & Anderson, 2006) and greater functional, emotional and physical well-being in newly diagnosed gynaecological cancer patients one year later (Lutgendorf et al., 2002a).

On the other hand, avoidant coping has been associated with poorer emotional and physical well-being, and greater anxiety, depression, fatigue and total mood disturbance, in women extensively treated for gynaecologic cancer (Lutgendorf et al., 2000). Use of behavioural disengagement in patients newly diagnosed with gynaecological cancer has been associated with poorer functional and emotional well-being and overall quality of life, greater distress and total mood disturbance, and less vigour one year later (Lutgendorf et al., 2002a). More specifically, greater use of mental disengagement has been related to poorer emotional well-being, greater anxiety and greater depressed mood; use of behavioural disengagement has been related to poorer functional well-being, and denial has been associated with greater anxiety (Costanzo et al., 2006). Overall, the evidence suggests that active coping is associated with better quality of life, whereas denial, avoidance and behavioural disengagement are associated with worse quality of life and increased levels of distress. Thus, interventions designed to increase levels of active coping may be beneficial.

2.5.2 Psychological interventions

The few intervention studies involving gynaecologic cancer patients are reviewed here. Cain, Kohorn, Quinlan, Latimer, and Schwartz (1986), found that participation in group or individual thematic counselling led to lower levels of depression and anxiety at post-test and follow-up in gynaecologic cancer patients than standard personal counselling. Among early stage gynaecologic cancer patients, Wenzel, Robinson, and Blake (1995) found that five weekly group counselling sessions did not lead to greater improvement relative to a control condition regarding adjustment to the illness at five week follow-up. However, participants reported low levels of distress prior to participation. Petersen and Quinlivan (2002) found that a one hour relaxation and counselling interview performed by a medical practitioner involved in the patient's care led to significant reductions in levels of anxiety and depression relative to usual care. However, these studies used small samples, the interventions were un-standardized, medical and demographic factors were not taken into account, intention-to-treat analyses were not carried out, and there was no comparison of treatment approaches. Therefore, only limited conclusions can be drawn.

Manne et al. (2007b), in a manualized RCT that controlled for medical and demographic factors, found that coping and communication skills led to significant reductions in levels of depression at six and nine months relative to usual care in 239 patients with gynaecologic cancer (over 80% had ovarian cancer). Such evidence provides support for the use of psychological interventions in gynaecologic cancer patients. However, given that mutual partner support may be critical in adjustment to cancer, it should be noted that the interventions addressed here did not involve spouses. Couple-related interventions will be discussed in Chapter 3.

2.6 Review of the chapter

This chapter has drawn together the main findings from the literature to identify demographic, illness-related and psychological correlates of psychosocial adjustment (quality of life, anxiety and depression) in ovarian cancer. Chapter 3 discusses cancer in the context of marriage, in order to identify couple-related correlates of psychosocial adjustment in the patient and correlates of psychosocial adjustment in the spouse. This evidence is required in order to determine what type of intervention may be effective for couples where one partner has cancer.

Chapter 3: Cancer in the context of marriage

3.1 Outline of chapter

When looking at adjustment to cancer, it is helpful to consider the patient's relationship with their spouse/ partner as this can be a very important determinant of the patient's psychological adjustment. This chapter therefore addresses the impact of cancer on couples. Studies assessing levels of patient and spouse distress are reviewed, with the aim of estimating the extent of disruption the cancer causes to the couple. Predictors of patient and spouse distress are then discussed, in order to determine ways in which distress might be modified. Next, observational studies of couple communication are examined in detail, so that the impact of perceived negative spouse behaviours on patient adjustment can be examined in more depth. The few interventions that have been carried out on couples experiencing a diagnosis of cancer are discussed and assessed, to provide a clear picture of what has been done previously. Finally, methodological issues to be taken into consideration when conducting studies with couples are addressed, and the way in which these issues will be dealt with in the main study is explained.

3.2 Introduction

Marriage can be distinguished from other relationships by its intensity, duration and interdependence (Coyne & Fiske, 1992). Individuals are likely to depend most on their spouses for assistance in times of crisis. There is a general assumption that spousal support for seriously ill individuals increases to meet their partners' needs. However, serious illness can produce marked stress for the spouse, and makes some marriages vulnerable to deterioration. Chronic illness involves the disruption of 'normal' life experience. Patients and their families are plunged into an unknown environment, with limited opportunity or control to remove or act on the stress target. It is an experience with no predictable end, and inability to justify or explain the pain and suffering is often associated with experience of stress. This chapter starts by describing levels of distress and adjustment in couples experiencing cancer.

3.3 Levels of distress and adjustment in the healthy spouse and patient

A number of studies have attempted to quantify differences in psychological distress between patients and spouses. However, the results reported are contradictory, with some reporting that patients and spouses experience similar levels of distress, others reporting that patients experience higher levels of distress than spouses, and yet others reporting that spouses experience higher levels of distress than patients. The diversity of results in this area has led to little advance in the specification of mechanisms, development of theory, or empirical exploration of mediator and moderator variables. The role of patient versus partner has been confounded with gender. In fact, in studies of 'mixed' cancer patients, results are often discussed without reference to gender. A meta-analysis of 43 studies with sample sizes of at least 20 couples clarified the contradictions by finding a significant effect for women reporting more distress than men, regardless of whether the woman was the patient or the partner (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008).

Another correlate of patient and spouse distress is type of cancer (Baider and De-Nour, 1988). Levels of distress are likely to be affected by factors such as prognosis of the particular cancer and its impact on everyday life. The research carried out in this thesis involves only ovarian cancer patients (who are all female) and there are therefore no confounding factors due to type of cancer or gender. Ovarian cancer has a poor prognosis, and research has shown that many patients experience significant levels of psychological distress (see Chapter 2). There is very little research on partners of ovarian cancer patients. However, it is expected that many experience significant levels of distress, partly because the disease has a poor prognosis, and partly because of the impact on sexual functioning and fertility, which is likely to be particularly important for younger couples.

Patient distress does not appear to differ between studies of patients assessed alone and studies of couples. Those who do not have a partner may have alternative sources of support whereas those who have a partner may not always get the support they need (Hagedoorn et al., 2000b). Some studies have compared couples coping with cancer to community samples. Hagedoorn et al. (2000a) reported higher levels of distress among women in couples coping with cancer than women in healthy couples. However, these differences in distress tended to decrease over time (Hinnen, Hagedoorn, Sanderman, & Ranchor, 2007). Comparisons with gender-specific norms reveal a modest elevation in distress in couples coping with cancer. However, this finding should be treated with caution as differences between American and Israeli norms on the Brief Symptom Inventory are larger than differences between couples coping with cancer and the community (Hagedoorn et al., 2008). Having established that women experience more distress than men, it is now important to understand the correlates and predictors of psychological distress in couples experiencing a diagnosis of cancer.

3.4 Correlates/ Predictors of Psychological Distress and Quality of Life in Patients

Correlates of psychological distress in ovarian cancer are discussed in Chapter 2. This section therefore focuses on relationship-related correlates of distress in patients, with particular reference to female patients. When experiencing elevated mood disturbance and trauma symptoms, most people turn to their partners for increased support. The support of a partner increases motivation to seek more aggressive treatment and have better health habits, and may buffer women coping with the psychological stresses and physiological changes of disease progression.

3.4.1 Marital satisfaction

Poor marital satisfaction at the time of diagnosis is closely related to future distress, whereas perception of inadequate intimacy and support during stressful times is closely related to mood disturbance. Higher levels of marital quality have been associated with less anxiety and depression (Hannum, Giese-Davis, Harding, & Hatfield, 1991; Pettingale, Burgess, & Greer, 1988) and better quality of life (Swensen & Fuller, 1992) across a variety of cancers.

However, marital status is sometimes used as an index of social support without assessing the extent to which partners in the relationship perceive their marriage as supportive. This is important as research discussed later in this chapter has shown that negative aspects of close relationships are better predictors of quality of life than positive aspects. Giese-Davis, Weibel, and Spiegel (2000), in a study of 125 metastatic breast cancer patients (57% married), found no differences in levels of mood disturbance between married and single women, and between women with partners involved in the study, and partners not involved in the study. However, married patients who rated their relationship as having greater cohesion and expression were less distressed.

3.4.2 Coping Strategies

Several studies have assessed patient and partner use of coping strategies, and their relation with patient distress. Evidence from small cross-sectional studies suggests that spouse coping is related to quality of life (Zacharias, Gilg, & Foxall, 1994) and marital satisfaction (Ptacek, Ptacek, & Dodge, 1994), with self-blame, emotional venting and wish-fulfilling fantasy being highlighted as particularly maladaptive strategies (Zacharias et al., 1994). Examining this issue in more detail, Ben-Zur, Gilbar, & Lev (2001) found that high psychological distress and low psychosocial adjustment were related to high levels of emotion-focused coping in both patients and spouses. In particular, emotional ventilation, denial and reliance on religion by the spouse were related to patient psychological distress and poor psychosocial adjustment. Such reactions may be perceived by the wife as indicating helplessness and therefore lack of support. Since this was a cross-sectional study, it is not possible to be clear about the direction of causality: high levels of distress may prevent efficient use of problem-focused coping by both spouses. Alternatively, spousal distress may be dependent on patient distress and coping. Nevertheless, these findings suggest that if spouse coping influences patients' distress, interventions to reduce more maladaptive emotion-focused coping may be effective in reducing psychological distress in patients and spouses.

3.4.3 Social support in the context of the marital relationship

When researching social support in the context of the marital relationship, one important issue to consider is the amount of support sought by the patient, and disclosure of concerns to the partner. Harrison, Maguire, & Pitceathly (1995) in a study of 520 recently diagnosed cancer patients found that men tended to name only one confidant, their spouse, whereas women had a wider circle of family and friends to whom they confided information about their cancer. Based on this finding, it is expected that improvements in marital communication will lead to greater improvements in quality of life in partners than in female patients, who may be less dependent on their spouses for emotional support. Nevertheless, spouse support may have a significant impact on patient psychological distress. Several studies found that spouse support was related to lower levels of distress in cancer patients, across a variety of diagnoses (Baider, Ever-Hadani, Goldzweig, Wygoda, & Peretz, 2003; Northouse, Dorris, & Charron-Moore, 1995).

Given the strong relation between spouse support and patient distress, and the lack of spouse support in some couples, it is important to examine whether support from friends/ family can compensate for poor partner support. Pistrang and Barker (1995), in a study of 113 breast cancer patients in adjuvant treatment, found that helpfulness of disclosures to partners was significantly correlated with well-being even among those who had a good helping relationship with someone else, showing that a poor partner helping relationship was a risk factor in the psychological response to breast cancer. However, patients were required to report on their helping relationship with one person, rather than their overall social network. More recent research has suggested that support from family and friends may compensate for unsupportive partner responses by reducing maladaptive coping and counteracting self-appraisals that result from partner unsupportive behaviours. For example, Helgeson, Cohen, Schulz, and Yasko (2000) found that a peer discussion group was helpful for breast cancer patients who lacked support from their partners. Manne et al. (2003) found that among women with breast cancer who reported low family and friend support, partner unsupportive behaviours were indirectly related to patient distress via increased patient avoidance and reduced coping efficacy, whereas among those with high levels of family and friend support, partner unsupportive behaviours had a direct relation with patient distress. This research suggests that interventions to reduce partner unsupportive behaviours may be effective in reducing patients' distress, but the type of interventions required may differ depending on the level of family and friend support the patient has.

It is also important to investigate the pattern of spouse support across different phases of treatment, as this may vary according to the demands of the situation. The erosion hypothesis holds that social support declines over time as a stressor becomes chronic and members of the social network become tired and overwhelmed by the individual's need for support. This idea has been supported by evidence suggesting that support remains high in the first month post-surgery, but then decreases over the following few months (Bolger, Foster, Vinokur, & Ng, 1996). This appears to be the case whether the support is emotional (Northouse, 1988) or instrumental (Neuling & Winefield, 1988). Bolger et al. (1996) found that an increase in physical impairment was associated with a relative increase in support, but that an increase in emotional distress was associated with a decrease in support provision. This is important, as it suggests that distressed cancer patients are not receiving the support they require. Overall, the evidence addressed here suggests that more spouse support is related to reduced patient distress, but that support from other family and friends may compensate for poor spouse support. However, overall support appears to decrease as time since diagnosis increases, suggesting that individuals several months post-diagnosis may be more at risk of distress than those who are newly diagnosed. However, if the spouse is experiencing significant levels of distress, he/ she is less likely to be able to provide support to the patient. The following section therefore addresses correlates of distress in the spouse.

3.5 Correlates/ predictors of psychological distress in the spouse

A cancer diagnosis can have a considerable impact on the patient's spouse, who is burdened with many difficulties including uncertainty about treatment outcome (Coe & Kluka, 1988; Zahlis & Shands, 1991), a sense of helplessness and isolation, providing care and support (both instrumental and emotional) to the ill partner (Zahlis & Shands, 1991), shifting of role responsibilities and disruption in social and recreational life resulting from the partner's disability (Zahlis & Shands, 1991), coping with the partner's emotional distress (Northouse, 1989) and need for information and support from medical professionals (Coe and Kluka, 1988). These stressors place the healthy spouse at risk of greater psychological distress and physical disorders. As an indication of the greater impact of a cancer diagnosis on spouses relative to other family members, Cassileth, Lusk, Brown, and Cross (1985), in a study of relatives of cancer patients, found that spouses reported greater mood disturbance on the Profile of Mood States than other relatives. Research has shown that spouses have elevated levels of distress during the initial phase of treatment, and recurrent and late stages of the disease (Blanchard, Albrecht, & Ruckdeschel, 1997). This is important because the spouse is a key source of social support for the patient, and elevated levels of distress may interfere with his/ her ability to provide emotional and practical support to the patient. Therefore, understanding factors that contribute to spouse distress can lead to ideas for ways to reduce this distress, and thereby improve both spouse and patient quality of life.

Patient physical impairment appears to be associated with spouse distress (Ell, Nishimoto, Mantell, & Hamovitch, 1988; Northouse et al., 1995). Perceived social support may be another important factor (Baider et al., 2003; Northouse, Mood, Templin, Mellon, & George, 2000). It may be that spouses fail to make their needs for support known. If this is the case, an intervention asking spouses to write about the impact of their partners' cancer on their lives may prompt them to seek help and/or discuss their needs with the ill partner and could constitute a covert method for spouses to "legitimately" seek help. Northouse et al. (1995) also found a significant correlation between partner health problems and psychological distress in the partner, suggesting that this should be taken into account when examining the impact of illness on couples. In a longitudinal study, Northouse et al. (2000) found that baseline role problems and level of marital satisfaction were the best predictors of role adjustment in spouses one year post surgery. Baseline emotional distress had a significant direct effect on emotional distress at one year follow-up, suggesting that emotional distress may remain a problem for a significant minority and early identification is therefore crucial.

3.6 Correlations between patient and partner distress

Studies have assessed the correlation between patient and spouse distress, and factors that modify such reactions. Correlations have been found between patient and spouse distress (Fang, Manne, & Pape, 2001; Northouse et al., 2000), patient psychological distress and spouse reports of marital quality (Fang et al., 2001), patient and spouse quality of life (Chen, Chu, & Chen, 2004), and spouse depression and patient quality of life (Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999). Such correlations have been reported longitudinally, over multiple assessments and across several types of cancers. Segrin et al. (2005), addressing this issue in a longitudinal study of distress in dyads of women with cancer and close others (children, friends, intimate partners) reported significant correlations over time, and similar trajectories in distress within dyads. However, these trajectories could have been tied to trajectories in the course of the woman's active treatment, such that both members of the couple experienced more distress when the woman was being treated. The evidence reviewed here suggests that partners' distress reactions appear to be closely linked, a finding that has been supported by two reviews (Hagedoorn et al., 2008; Manne, 1998). Hagedoorn et al. (2008), in a meta-analysis, found a correlation between patients' and partners' distress of .29, which was not moderated by gender. However, there was significant heterogeneity across studies, with some finding no such correlations at some time points (Baider, Koch, Esacson, & De-Nour, 1998), and others finding significant correlations only for certain genders (Baider, Perry, Holland, Sison, & Kaplan De-Nour, 1995). Although contradictory, these findings suggest that the ways in which couples adapt to their situation and respond to the stress created by illness may in some cases be influenced by the gender of the patient and spouse. In this context, it is important to note that concordance between patient and partner distress fluctuates considerably – according to Northouse et al. (2000), correlations in psychological adjustment between couples where the woman had breast cancer varied from 33% agreement for baseline emotional distress to 57% for role problems at 1 year post-diagnosis. However, distressed couples tended to remain distressed over time. Gustavsson-Lilius, Julkunen, Keskivaara, and Hietanen (2007), after finding that patient and partner distress and sense of coherence were related at 14 month follow-up, though not baseline, suggested that the reactions of one partner to the disease affected the other partner's reactions, and over time the psychological status of patients and partners increases in similarity.

Overall, there are several questions that need to be explored further: how distress is transmitted, whether there are gender differences in transmission and communication of distress, and whether improvement in the psychological condition of one partner would be transmitted to the other. Further, it is important to examine adjustment across the course of cancer i.e., diagnosis, treatment, post-treatment, as different time periods may be associated with specific psychological processes. The answers to these questions have important implications for the development of psychological interventions. Nevertheless, the evidence suggests that interventions designed to help reduce distress and manage negative emotions in patients may also be useful in alleviating spouse distress, as patient and spouse distress appear to be at least moderately correlated.

One issue that should be examined in this context is the role of information exchange, as that may provide reassurance and uncertainty reduction, particularly to the spouse. Bar-Tal, Barnoy, and Zisser (2005) found that female patients attributed greater information needs to spouses than the spouses expressed, and relied heavily on perception of their own knowledge when assessing their spouse's knowledge, which was not accurate. This suggests the importance of good communication between partners – if the patient has an inaccurate understanding of their partner's knowledge, mis-communication is more likely to occur. Evidence suggests that female partners have a more accurate understanding of their husbands' experience with prostate cancer than male partners do of their wives' experience with breast cancer (Carlson, Ottenbreit, St Pierre, & Bultz, 2001). Thus, it is hypothesized that the current study will provide a context for improving couple communication, by enabling each partner to reflect on their story regarding the woman's ovarian cancer, and thus acting as a springboard for the couples to discuss the illness and thereby reach a common understanding of it. In support of this idea, Skerrett (2003) has shown that in counselling sessions for couples where one partner has a chronic illness, requiring each partner to tell their illness story provides couples with an insight into the different narratives they may have about the illness, and thus aids them in reaching a common understanding.

3.7 Impact of cancer on the marital relationship

The correlations observed between patient and partner distress suggest that distress in one partner may negatively impact on the marital relationship. However, the empirical evidence needs to be reviewed. Research assessing the impact of cancer on the marital relationship is therefore assessed here. However, it is important to note that the patients in the research reported here were not assessed until after their diagnosis. A true assessment of the impact of cancer on the marital relationship can only be gained by assessing the couple prior to the patient's cancer diagnosis. Retrospective ratings of marital satisfaction have been strongly correlated with perceptions of subsequent marital satisfaction, and a longer period of time spent on chemotherapy has been associated with worse marital satisfaction in women with breast cancer (Lichtman, Taylor, & Wood, 1987). Overall, the evidence suggests that a cancer diagnosis or recurrence may lead to communication difficulties in a significant minority of couples, particularly when patient reports are taken into account, even if their marital satisfaction does not differ from the norm (Hoskins, 1995; Lichtman et al., 1987). Patient-reported problems include the husband's failure to talk about cancer-related issues, and patients' need for more opportunities to express fears about cancer recurrence (Lichtman et al., 1987). However, it is important to note that cancer does not always lead to marital dissatisfaction. For example, Kuijer, Buunk, and Ybema (2001) found that cancer patients and partners are as satisfied with their relationships as healthy couples. The evidence suggests that at least 40% of cancer patients report that their relationship has become closer compared to pre-diagnosis (Dorval et al., 2005; Swensen & Fuller, 1992).

3.8 Effects of positive partner support and negative responses on patient distress

The evidence addressed above suggests that emotional support provided by spouses and greater marital satisfaction are associated with general psychological adjustment. This is particularly important, since support provided by partners may not be compensated for by other sources of support (Helgeson & Cohen, 1996). Further, there is a positive relationship between spousal support and marital satisfaction in both healthy couples and couples in distress (Abbey, Andrews, & Halman, 1995). Active engagement, which includes involving the patient in discussions, and inquiring about how they feel and what help they need, has been positively associated with marital satisfaction (Kuijer, Ybema, Buunk, & DeJong, 2000).

However, partners can display a variety of unsupportive responses to a diagnosis of cancer, including excessive worry/ pessimism, underestimating the severity of the illness, avoiding/ withdrawing from the patient, criticizing the way the patient is coping with the illness, conveying lack of interest in patient concerns, changing the topic when the partner is talking about the cancer experience and behaving in an unkind manner, either intentionally or unintentionally (Manne, Taylor, Dougherty, & Kemeny, 1997). The evidence suggests that critical and avoidant responses from husbands of female cancer patients are associated with both distress and well-being, whereas perceived support is associated only with well-being (Manne et al., 1997; Vinokur & Vinokur-Kaplan, 1990). These findings are important as they mean that those most in need of spousal support are least likely to receive it.

Unsupportive responses may have a stronger association with psychological distress than supportive responses, as they impact on coping strategies (Lepore, Ragan, & Jones, 2000). This idea is based on cognitive processing theory, which holds that successful processing of an event can occur through sharing thoughts/ concerns. If individuals feel constrained in attempts to talk about their experience with others, they may be more likely to engage in avoidance, which may then lead to intrusive thoughts. In support of this hypothesis, Manne (1999), in a longitudinal study of 129 married individuals with cancer (87 female) found that intrusive thoughts were associated with greater spouse avoidance, and that individuals who perceived their partner as critical and/or avoidant of cancer discussion were more upset by intrusive cancer-related thoughts. Overall, this evidence suggests that perceived spouse negative behaviours are significantly associated with patient distress. The impact of one of the most common negative spouse behaviours, protective buffering, on patient distress will now be examined in more detail.

3.8.1 Protective Buffering

One of the most extensively studied negative behaviours performed by spouses is protective buffering. This consists of hiding concerns, denying worries, concealing discouraging information and preventing the patient from thinking about their cancer, and is a commonly used strategy, particularly among spouses of patients with lower physician-rated life expectancy (Manne et al., 1997). However, it has been associated with more distress in male survivors of myocardial infarction (Coyne & Smith, 1991). Research on cancer patients has shown that protective buffering is viewed as unhelpful (Lichtman et al., 1988), is related to increased distress in women reporting low levels of marital satisfaction (Manne et al., 1997), and is associated with lower marital quality in patients experiencing high levels of psychological distress, and those with high levels of physical impairment (Hagedoorn et al., 2000b). The relation between protective buffering and marital quality is particularly strong for patients experiencing high levels of physical impairment, possibly because physical limitations are more noticeable. It is likely that protective buffering impacts so negatively on patient psychological adjustment because it undermines feelings of control.

3.8.2 Determinants of negative responses

Given the association between partner negative responses and patient distress, it is important to understand why partners interact in such ways, so that interventions can be developed to reduce negative responses. Several studies on determinants of protective buffering have been carried out. Partners tend to use more protective buffering if they are more distressed (Coyne & Smith, 1991; Hinnen et al., 2007), and score higher in neuroticism (Hinnen et al., 2007). In addition, Hinnen et al. (2007) found that among those scoring low in neuroticism, less distress was associated with more active engagement over time, whereas there was no such relation for those scoring high on neuroticism. Thus, neuroticism and distress are both risk factors for less active engagement. Although neuroticism is a fairly stable variable, interventions to reduce distress may be effective at increasing active engagement. Written disclosure may help to increase active engagement by providing a context for the partner to think about his wife, or may reduce his distress, which may then lead to discussion between the couple, and could subsequently reduce patients' distress also.

3.8.3 Moderators of the impact of negative responses

Manne et al. (1997) found that physical impairment moderated the relation between spouse withdrawal and patient well-being, such that among those with less impairment, spouse withdrawal was associated with lower well-being, whereas among those who were more physically impaired, withdrawal was not associated with patient well-being. This finding suggests that as the magnitude of their illness increases, patients may attend less to the responses of others. For those with more impairment, higher levels of spouse support were associated with more distress. While seemingly counter-intuitive, these results suggest that if the patient experiences more disability imposed by the illness, significant others are more likely to respond negatively. This can be explained with reference to the caregiver stress model (Pearlin, Mullan, Semple, & Skaff, 1990) which holds that a primary stressor (i.e. limitations in the patient's ability to complete daily activities) may lead to a secondary stressor (role strain associated with constriction of social and recreational activities) for the caregiver. Manifestations of stress in spouses may increase as the patient becomes more impaired, and could result in withdrawal from the ill partner and criticism of their way of coping with the illness.

However, patients' attitude to negative responses may partially depend on the quality of the relationship. Manne, Alfeiri, Taylor, and Dougherty (1999) found that patients with cancer who reported low marital satisfaction reported more negative spouse behaviours, but that there was no direct link between patient functional impairment and spouse negative affect. However, among those high in marital satisfaction, patient functional impairment was related to spouse negative affect both directly and indirectly through interference in spouse activity. Partners experiencing less marital satisfaction may have had fewer supportive exchanges with their spouse in the past, and therefore be less willing to provide assistance to the patient. Also, partners with low marital quality may be distancing themselves from their ill spouse, such that they do not react emotionally to the spouse's morbidity. However, it is unclear whether these results would generalize to significantly maritally distressed couples – 76% of those in the low marital satisfaction group were not considered to be maritally distressed. Also, the quality of the marital relationship before the onset of illness could not be assessed prior to the diagnosis of cancer. Furthermore, patient related variables were not assessed – if the patient was irritable or hostile (possibly due to increased physical symptoms), this may have elicited criticism from their spouse.

3.8.3.1 Moderators of the impact of protective buffering

Manne et al. (2007a) found that increases in protective buffering by partners were associated with increases in distress only among patients who rated their relationships as more satisfactory. Partners were more likely to hide their negative feelings and avoid conflict than patients, probably because they had more motivation to shield the ill partner from additional stress. Protective buffering led to more distress over time for the person engaging in it, which is in line with research that hiding concerns and less disclosure is detrimental to mental health (Pennebaker & Susman, 1988). Written disclosure may therefore be beneficial as it provides a stimulus for couples to discuss issues relating to the illness. Protective buffering by the patient was significantly related to more patient distress, possibly because the healthy spouse needs to know the patient's emotional needs and concerns in order to provide support.

3.8.4 Positive support and coping: relations with patient distress

Given the significant relation between spouse negative behaviours and patient psychological distress, it is important to understand ways to enhance positive social support. There are several ways in which positive social support exchanges can occur. First, advice and guidance may alter harmful and/or threatening appraisal of a situation to more benign appraisal, if realistic in the context of cancer. Second, open communication can provide a safe context for patients to discuss their concerns. Manne et al. (2004c), in a study of 162 women with breast cancer and their partners, found that patients experienced more posttraumatic growth than their partners over a period of 18 months post-diagnosis if their partners were above average in emotional expression. They suggest that interventions should facilitate engagement in affective expression, which is the case in the GDP. Third, partners can help identify adaptive coping strategies by providing feedback about the efficacy of particular coping efforts, and provide a positive evaluation of coping (Holahan & Moos, 1987). Manne, Pape, Taylor, and Dougherty (1999) in a cross-sectional study, found that positive reappraisal coping mediated the relation between spouse support and psychological well-being. Conversely, avoidant coping mediated the relation between spousal criticism/ avoidance and psychological distress. Unsupportive behaviours may damage the individual's perceptions of mastery/ control, possibly because they are detrimental to appraisals of coping efficacy. This is important because higher perceived control over the consequences of cancer has been associated with lower psychological distress (Thompson, Sobolewshubin, Galbraith, Schwankovsky, & Cruzen, 1993).

Manne & Glassman (2000) found that more perceived negative spouse behaviours were associated with lower coping efficacy, less perceived control over medical and emotional aspects of treatment, and greater use of avoidant coping (which was associated with higher levels of distress). Conversely, higher levels of coping efficacy were associated with less psychological distress. Furthermore, coping efficacy and avoidance mediated the association between spouse negative behaviours and psychological distress. A further longitudinal study showed that avoidant coping mediated the relation between unsupportive partner behaviour and patient distress (Manne, Ostroff, Winkel, Grana, & Fox, 2005). These findings help suggest ways in which perceived negative spouse behaviours may impact on patient coping. When the spouse is overtly critical or shows a lack of interest in the patient's concerns, this may lead to increased avoidance. Fewer opportunities to vent concerns are associated with attempts to avoid thinking about cancer and/or dealing with feelings about it, and therefore reduced opportunity to accomplish cognitive processing. Further, if the spouse is not available to talk or gives negative feedback, patients may evaluate coping efforts regarding the demands of their cancer in a more negative light. Therefore, it is recommended that clinical interventions involve partners, particularly those who are rated by patients as unsupportive. The current research aims to reduce perceived negative spouse behaviours by using an intervention to moderate appraisal of the cancer in both patients and their partners. Writing about the cancer enables individuals to reflect on their appraisal of it, and may lead to them being more open about it. In this way, if the partner changes his/her appraisal of the cancer, this may lead to reduced psychological distress in the patient. However, the evidence here is based on questionnaires. It is important to understand the type of spouse utterances that are perceived as negative, so interventions can be developed to reduce such utterances.

3.9 In-depth analysis of couple communication

The inability to communicate openly within a marital relationship may lead to physiological distress, increased illness and further compromise immune functioning (Kiecolt-Glaser & Newton, 2001). Although questionnaires are the mostly commonly used method of assessing patient and spouse behaviours, they do not provide an insight into the nature of couple communication (Baider & Kaplan De-Nour, 2000). This section therefore addresses the relation between partner responses and patient distress in detail.

3.9.1 Informal helping relationships

Pistrang and Barker (1995) looked at the quality of informal helping relationships (dyadic communication where one partner is experiencing emotional distress and the other attempting to alleviate that distress) in women recently diagnosed with breast cancer. Patients who reported their partner as being more helpful reported less distress. Partner empathy was positively correlated with helpfulness, but negatively correlated with partner withdrawal. However, there was no relation between partner criticism and partner withdrawal, possibly because criticism was sometimes experienced positively, as a sign of partner engagement. However social support research often fails to address what social support consists of when it occurs between two people, or include the perspectives of both members of the dyad (Pistrang, Barker, & Rutter, 1997). Pistrang et al. (1997) used tape-assisted recall (where a recording of the conversation is played back to the participants, and they are asked a series of questions about it) to examine conversations with three couples in which the woman had recently been diagnosed with breast cancer. This revealed that lack of empathy/ change of focus from the helper (partner) was seen as unhelpful, whereas the helper responding to the essence of the discloser's (patient's) concerns was seen as helpful. The main issue regarding this type of analysis is ecological validity – the only way to determine whether conversations are typical of how the partners talk is by patient report. Another limitation is that reports of helpfulness from patients may be positively biased to enable maintenance of a positive image of the relationship.

3.9.2 Large-scale observational study

The study carried out by Pistrang et al. (1997) discussed communication in only three couples. In order to gain more generalizable insights into communication patterns in dyads, Manne et al. (2004b) carried out an observational study where 148 couples in which the woman had breast cancer had to participate in two ten-minute discussions, one of a cancer-related issue and a one of a mutually agreed relationship problem. Patients experienced higher levels of both general and cancer-specific distress if partner self-disclosure was less likely to follow patient self-disclosure. One important model for understanding these findings is the interpersonal process model of intimacy (Reis & Shaver, 1988). According to this model intimacy is a process where one person expresses important self-relevant feelings and information to another person, and as a result of the other's response, comes to feel understood, validated and cared for. The key components include self-disclosure and the speaker interpreting the listener's statements as responsive. According to this model, both patient disclosure and spouse disclosure predict perceived partner responsiveness, which predicts intimacy. Manne et al. (Manne et al., 2004a) found that in support of this model, findings based on spouse self-report revealed that perceived partner responsiveness mediated the association between patient self-disclosure and intimacy. However, findings based on patient report also revealed a direct association between perceived spouse disclosure and intimacy. Disclosure by the ill partner may not set the tone for perceived intimacy due to high general levels of self-disclosure by patients. Importantly, there was a very strong association between perceived responsiveness and intimacy, and in both the general and cancer-related topics, greater intimacy was associated with patient self-disclosure being followed by partner self-disclosure. However, the laboratory nature of the discussion may have changed intimacy processes, and there were no pre-morbid measures of intimacy, or control group of healthy couples.

3.9.3 Cancer-related discussion

In the observational studies patients did not report the frequency of cancer-related discussions in general. Even in close relationships, cancer is not necessarily discussed frequently (Boehmer & Clark, 2001). As discussed above, protective buffering has been associated with more distress in female patients (Manne, Alfieri, Taylor, & Dougherty, 1999) and lower marital satisfaction in distressed patients (Hagedoorn, Buunk, Kuijer, Wobbes, & Sanderman, 2000a). Certainly, qualitative interviews with couples in which one partner has breast cancer have demonstrated that couples who discuss the cancer openly tend to view it as a couple-related stressor, which enhances coping, whereas couples where one or other partner avoids discussing the cancer tend to view it as an individual stressor (Kayser, Watson, & Andrade, 2007; Skerrett, 1998). Further, avoidance of discussing the cancer tends to spread to other family members (Kayser et al., 2007). Relationship awareness (thinking about the impact of the disease on the partner and the relationship (Badr & Acitelli, 2005), authenticity (honest self-disclosure) and mutuality (ability to empathize), appeared to be important in the coping process. The evidence from these studies points to the importance of open communication about the illness within couples in promoting a united outlook and thus enhancing its manageability.

Examining this issue in more depth, Manne et al. (2006), in a longitudinal study, found that more mutual constructive communication (discussion of issues, expression of feelings, understanding of views, feeling that the issue has been resolved) was associated with lower levels of distress and higher relationship satisfaction in patients at nine month follow-up. Conversely, more avoidance of discussing problems and more use of demand-withdraw communication (where one partner pressed the other to talk about a problem, and the other withdrew) was associated with higher levels of distress and lower levels of relationship satisfaction in patients. Cancer-related relationship communication did not change significantly over nine months, indicating that couples experiencing communication difficulties are in need of interventions. The transition to survivorship poses relationship-related challenges which continue to require couples to negotiate solutions together. However, the lack of change in cancer-related relationship communication over time may be because maladaptive strategies are infrequently used, or because couples rated how frequently they used each strategy when they encountered an issue rather than the overall use of each strategy. The finding that demand-withdraw communication was maladaptive among non-maritally distressed couples dealing with a medical stressor, indicates that interventions to help improve couple communication and adjustment to illness may benefit a significant percentage of couples. Two major limitations of this study include that relationship communication prior to diagnosis and general, non-cancer related communication among couples were not assessed.

3.10 Interventions for couples facing cancer

The previous section attempted to identify communication patterns that were associated with psychological adjustment in patients. Taken together, these results suggest that open communication and partner empathy are associated with improved adjustment in patients, whereas greater use of avoidance and withdrawal by partners are associated with higher levels of distress in patients. Interventions for couples experiencing a cancer diagnosis are now discussed, in order to assess their methodology, quality and effectiveness. Martire, Lustig, Schulz, Miller, and Helgeson (2004), in a meta-analysis of psychosocial interventions for chronic illness which involved families (five on cancer patients), found reduced depressive symptoms in spouses, but no effect on anxiety. Interventions that focused on relationship issues led to a reduction in depressive symptoms in patients, possibly through helping the spouse to be more supportive and less critical of the patient. Also, spouse participation may be considered an act of support. A further meta-analysis of twelve studies has demonstrated that couple-focused interventions are more effective than interventions for patients alone (Martire, 2005). This evidence suggests that intervention studies for individuals with chronic illness should involve partners where possible.

Very few intervention studies for cancer patients have involved both members of the couple, and the majority of those suffered from several methodological flaws.

However, a few good quality studies are discussed below.

One important theory that may explain adjustment to cancer is equity theory (Walster, Walster, & Berscheid, 1978), which holds that when relationships are out of balance, both partners feel inequitably treated. A serious illness leads to a change in the balance of give-and-take between partners - as patient contributions to the relationship decrease, their rewards increase, whereas the opposite is true for the spouse. The lack of equity may remain long after the necessity for it has ended. In healthy couples, lack of equity is associated with lower relationship satisfaction. Kuijer, Buunk, and Ybema (2001) found that cancer patients and healthy partners who perceived themselves as underbenefited reported less satisfaction with their relationships when the patient experienced few physical limitations. These studies suggest that inequity in couples may partly account for the impact of a cancer diagnosis.

Kuijer, Buunk, de Jong, Ybema, and Sanderman (2004) tested this idea by carrying out a randomized controlled trial where couples were assigned to a biweekly, CBT oriented counselling programme focusing on the exchange of social support and help or a wait-list control group. The intervention led to a decrease in perceptions of inequity in both patients and partners, which was directly related to improvements in relationship quality and remained at 3 month follow-up. However, although distress decreased in patients and remained stable to follow-up, the intervention had no effect on partner distress, possibly because the partners were still worried about their spouses. One major limitation was that this study had a small sample of 59, which meant it was not possible to study gender differences. Furthermore, couples experiencing marital dysfunction unrelated to cancer were excluded, which limits the generalisability of the findings.

One school of thought holds that better patient adjustment may increase partner support, whereas patient distress may increase partner withdrawal and negativity. Couples' individual responses to stress interact, and their social support is mutual. Effective couple coping develops through empathic communication which develops emotional connection and a shared realistic and positive appraisal of stress. Scott, Halford and Ward (2004), found that an intervention designed to focus on helping couples to cope conjointly with the cancer and support each other (CanCOPE) led to improved couple-focused coping with the cancer and reduced partner withdrawal in response to patient communication (as assessed by a 10 minute video where the couple discussed the patient's cancer) post-intervention and at six month follow-up, in 94 couples where the women had early stage breast or gynaecological cancer. Psychological distress, avoidance and sexual problems reduced in patients, but there were no significant benefits for their partners. However, those who did not complete the study reported lower levels of relationship satisfaction, and may have dropped out due to poor partner support and poor adjustment to their cancer. This study has been commended by Manne and Andrykowski (2006) as being one of the best trials of recent years, meeting 16/21 of the Consort guidelines, and with a 94% participation rate. However, Coyne and colleagues (Coyne, Lepore, & Palmer, 2006a) criticized it on the grounds that the level of effort made by the researchers in this trial to recruit participants and deliver the intervention would not be feasible in general practice. For example, the intervention was home-based and tailored to the schedules and preferences of the women and their husbands.

Manne et al. (2005) carried out a randomized controlled trial comparing six sessions of couple-focused communication and coping skills (CG), with an emphasis on the psychological impact of cancer on the couple and relationship, and enhancing communication and support, to usual care on adjustment to early stage breast cancer in 238 couples. The rate of acceptance was only 33%. However, 19/21 CONSORT guidelines were met. Intention-to-treat analyses showed that CG led to significant reductions in depression and anxiety relative to usual care and had a greater impact on distress and positive well-being among women who rated their partners as unsupportive pre-intervention. (Manne, Ostroff, & Winkel, 2007) found that those who began the couple-focused group intervention with higher levels of emotional processing (attempting to explore the meaning of cancer and come to an understanding of their emotions) and emotional expression regarding their reactions to cancer experienced lower levels of depressive symptoms at follow-up. Thus, asking participants to express emotions was beneficial for individuals who naturally select emotional expression to cope with stressors. Similarly, those who are more emotionally expressive may be more likely to benefit from written disclosure (Stanton et al., 2000). However, such effects are unlikely to be as strong, as written disclosure is carried out in a less engaging and less interpersonal context. Overall, evidence from well-designed studies suggests that interventions with a focus on couple-related communication may be effective in reducing distress in patients, and improving couple communication. However, uptake rates tend to be low, possibly due to the level of commitment required from the couple. The current study therefore tests the effectiveness of written disclosure, a brief intervention which can be carried out at home with minimal inconvenience, but may nevertheless stimulate couple communication regarding the cancer.

3.11 Methodological issues

There are a number of methodological issues to consider when conducting research with couples, which are discussed below. These may account for the contradictory results to date.

3.11.1 Recruitment - sample size and rate of uptake

Although sample size is important for sufficient power, it is equally important to consider the rate of uptake, which has not been reported in many studies (Hagedoorn et al., 2008), and is especially low among individuals with advanced stage cancer experiencing active medical treatment. Spouse refusal is generally higher than that of patients. However, it is difficult to determine whether refusal is due to the patient, spouse, or both partners. This is particularly important, as couples experiencing higher levels of marital conflict/ difficulties may be less likely to participate in such studies, and could be those most in need of interventions. Patients are likely to refuse to participate in research if they believe their partner will not cooperate, and it is not therefore possible to compare patient and partner response rates (Manne, 1994). In some studies, partners were not asked to participate until the patients had given consent (Hagedoorn et al., 2008). In the current study, patients will be provided with the option to participate alone if their partners are not interested, which enables comparison of patient and partner response rates.

3.11.2 Study design

The majority of the studies to date have been cross-sectional. Although the issue of dropout increases in longitudinal studies, such research is necessary in order to understand how patient and spouse distress vary and reciprocally affect each other across the course of the cancer journey and predict patient outcomes. This is particularly important as longitudinal studies often only present data for couples who have completed all assessments, leading to a biased sample. Intention-to-treat analyses will therefore be carried out in the current research.

3.11.3 Type of cancers studied

Most studies have been carried out on breast cancer patients and their husbands, and it remains uncertain whether these results can generalize to other cancers. This is important as a high percentage of ovarian cancer patients are diagnosed with advanced stage disease - Hagedoorn et al. (2008) note a lack of attention to cancers with poorer prognoses. However, breast cancer research can to some extent be generalized to ovarian cancer, a disease which has been under-researched. In addition to breast cancer, a number of studies have been carried out on patients with 'mixed' cancer diagnoses. The conclusions that can be drawn from such studies are limited, particularly since patient and partner characteristics and medical details such as current treatment, duration of treatment, frequency, and additional treatments are not often recorded (Hagedoorn et al., 2008). In future studies, it is necessary to specify criteria for sample selection, diagnosis, and stages of illness, select a variety of sociodemographic variables, and analyse refusals and dropouts. All these factors have been taken into account in the current study. Furthermore, it focuses solely on ovarian cancer, a disease which affects only women.

3.11.4 Assessment

Self-report is the main method of assessment in studies of couples experiencing cancer. In recent years there has been a shift from assessing psychopathology to assessing psychological distress, and studies have found more evidence of non-pathological levels of distress in physically ill patients (Baider & Kaplan De-Nour, 2000). The most common measures are the Symptom Checklist-90 and the Brief Symptom Inventory. The current research assesses perceived stress and quality of life. Perceived stress was considered to be an appropriate way of assessing current distress. However, low scores on a distress measure do not indicate satisfaction with life, and it was therefore decided to assess quality of life as a primary endpoint. With regard to spouse support, many studies have used different measures, making comparisons limited. In fact, there are many aspects of marital relationships that are not addressed in the chronic illness literature, and for the purpose of the research in this thesis, four items were developed to assess illness-related marital communication.

Self-report scales have been administered by interview, mail and telephone. Baider and Kaplan de-Nour (2000) recommend the use of interviews for in-depth insight into patients' psychological state and response to their illness. However, since the current research recruited from a wide geographical area, and many of the patients had advanced stage cancer, it was decided to send out questionnaires patients could complete at home.

3.12 Conclusions

This chapter addressed the impact of a cancer diagnosis on couples. The key findings are summarized below. First, women experience more distress than men, whether they are the patient or the spouse. Second, the main factors associated with patients' psychological distress are marital satisfaction, use of emotion-focused coping by their partners and partner support (which may be compensated for by support from friends, though). Third, similar factors are associated with psychological distress in spouses, with the addition of levels of patient and spouse physical symptoms. Fourth, there is a small correlation between patient and spouse distress. Fifth, perceived spouse negative behaviours have a greater impact on patient well-being than perceived positive behaviours. Negative behaviours that are particularly detrimental for patient well-being include protective buffering (especially in individuals experiencing high levels of marital satisfaction), and withdrawal from cancer-related discussion, both of which are used by partners reporting higher levels of distress. On the other hand, partner empathy and engagement with patient concerns are positively associated with patient well-being. Finally, interventions involving cancer patients and their partners have tended to show positive effects, but the few well-designed studies involved procedures that would be too time-consuming to implement widely. Hence, it is important to test the effectiveness of brief interventions.

The evidence reviewed in this chapter suggests that couples reporting both low and high levels of marital satisfaction may benefit from written disclosure, as it provides a context to openly discuss the patient's illness and its impact on their lives. Following a pilot study to test the feasibility of carrying out a written disclosure intervention with ovarian cancer patients (Chapter 5), the effectiveness of written disclosure as a stand-alone intervention for couples will be tested (Chapters 6-8).

Chapter Four: Written disclosure: Evidence for effectiveness, theory and methodology

4.1 Introduction

The previous chapters have demonstrated that many ovarian cancer patients and partners of cancer patients experience significant levels of distress, and identified individual and couple-related correlates of distress in ovarian cancer patients and their partners. Given that the current research is a randomized controlled trial assessing the effectiveness of written emotional disclosure, this chapter assesses the current evidence of its benefits for physical and psychological health. The results of three meta-analyses are discussed, the most recent of which found a significant effect size and identified a number of moderators. As the current research assesses the effectiveness of guided written disclosure in women with ovarian cancer and their partners, the rationale for using guided rather than standard writing is addressed, and previous studies assessing the effectiveness of written disclosure in patients with a variety of chronic illnesses are summarized and discussed, with particular attention given to studies on cancer patients. Studies on written disclosure in the context of relationships are summarized and discussed. The current research aims to test two theories developed to explain the beneficial effects of written disclosure: the cognitive adaptation hypothesis and the social interaction hypothesis, and these theories are therefore critically evaluated. However, other competing theories are also evaluated, including the original theory (the emotional inhibition hypothesis) and the exposure/ emotional processing hypothesis, to set the context. Finally, methodological issues in carrying out a randomized controlled trial assessing the effectiveness of written disclosure are discussed, to justify the procedure used in the current study.

4.2 Introduction

There is a variety of evidence to show that traumatic events are associated with increased likelihood of mental and physical health problems (e.g., Kartha et al., 2008). However, the majority of individuals who experience a trauma do not develop post-traumatic stress disorder (PTSD) symptoms (Keane, 1998; Wortman & Silver, 1989). Evidence suggests that not disclosing traumatic events to a social network is associated with elevated risk of illness (Cole, Kemeny, Taylor, & Visscher, 1996; Ullrich, Lutgendorf, & Stapleton, 2003). Related to this, there is considerable evidence indicating that repressive coping (avoidance of negative affect) is associated with worse health (Niaura, Herbert, McMahon, & Sommerville, 1992), and some psychological interventions encouraging expression of thoughts and feelings have been associated with reductions in stress (Spiegel, Bloom, & Yalom, 1981). From the above evidence it is possible to extrapolate that writing about thoughts and feelings related to traumatic events may lead to improved health. This may happen because the act of repression is associated with increased stress, or because writing enables the individual to habituate to aversive emotional stimuli.

4.3 Written Disclosure – evidence for health effects

Numerous studies have shown a positive effect of writing about trauma on health. Originally, Pennebaker and Beall (1986) found that writing about traumatic events led to reduction in healthcare centre visits and fewer physical health complaints in healthy students. This result has since been replicated in a wide variety of populations, and the evidence suggests that writing about important personal experiences for 15 minutes per day over three days brings improvements in mental and physical health, across age, gender, culture and social class (Pennebaker & Seagal, 1999). Writing has similar results to psychotherapy in healthy participants (Esterling, L'Abate, Murray, & Pennebaker, 1999). Smyth (1998), in a meta-analysis of 13 randomized controlled trials assessing the effectiveness of written disclosure (mainly on healthy students), found the mean weighted effect size to be Cohen’s d = .47., which was significant at $p < .0001$, with a fail-safe N of 117, and concluded that writing about trauma leads to improved health, and psychological, physical and general functioning. Two variables moderated the effect size, the length of time between writing sessions (1 week led to greater effect than 1 day) and gender (males showed more change in response to written disclosure than females).

Writing may yield its positive effects by leading to greater cognitive change, understanding of the problem, and awareness of alternative explanations for the event (Esterling et al., 1999). This suggests a cognitive mediation for the beneficial effects of written disclosure. However, in a recent meta-analysis, Meads, Lyons, and Carroll (2003) criticize Smyth’s meta-analysis, on the grounds that first, he excluded four randomized controlled trials that were available, and second, the results were aggregated across wide-ranging categories, meaning that the results of trials and outcome measures were largely incompatible, and thus the overall effect size was not easy to interpret quantitatively in relation to benefits that emotional disclosure may bring about. Finally, this earlier meta-analysis included only 13 trials. Meads et al.'s analysis included 61 trials assessing the effectiveness of written disclosure across a variety of populations, with numerous unpublished trials with null results, and they concluded that there is no or little effect of writing about trauma, and further studies need to be carried out to establish the true effects.

However, until recently, many such interventions have been unstructured. Typically, participants are instructed to write about the most traumatic experience of their lives and describe their deepest thoughts and feelings (Smyth & Helm, 2003). More recently, Frattaroli (2006), in a meta-analysis of 146 randomized controlled trials assessing the effectiveness of written disclosure across a variety of populations, found a mean effect size of 0.075, which was significant at $p = 3 * 10^9$. Although this effect size is smaller than previous meta-analyses, it did include a number of unpublished studies, which are more likely to have null findings. This high-quality, comprehensive review was published in a peer-reviewed journal, and there has been an exponential increase in the literature in recent years. Such a small effect size points to the existence of moderators. Based on theory regarding cognitive processing of trauma, one hypothesized moderator is type of instructions given (cognitive processing or standard). Although Frattaroli (2006) did not find a significant effect for cognitive processing instructions, they were used in only six studies, compared to 110 studies that used standard instructions. Of the three studies in this meta-analysis that compared cognitive-processing and standard instructions, two (possibly underpowered), found no differences, and Broderick, Stone, Smyth, and Kaell (2004), who used a larger sample, found a significant effect for using cognitive-processing instructions. More large-scale studies assessing the effectiveness of guided writing are therefore needed. The current research therefore aimed to assess the effectiveness of the Guided Disclosure Protocol (GDP) (Duncan & Gidron, 1999) which is discussed below.

4.3.1 The Guided Disclosure Protocol

Duncan and Gidron (1999) developed the GDP, where participants are required to write in a structured way about a trauma, for 15 minutes per day over 3 days. The content and theoretical basis for this form of writing are discussed below. On day 1, participants are asked to describe the event in chronological order, without expression of emotions, and to write the causal links between what happened. It is likely that this increases comprehensibility. Foa, Molnar, and Cashman (1995) found that describing a rape chronologically predicted better prognosis. This may be because memories of trauma are fragmented and intrusive, because they may be encoded in a somato-sensoric and affective limbic (amygdala) memory mode (Shin et al., 2004; Van der Kolk & Fisler, 1995). Linguistically labelling emotionally negative stimuli reduces amygdala activity and increases prefrontal cortex (PFC) activity, whereas processing such stimuli in an affective and sensory manner alone increases amygdala activity (Hariri, Bookheimer, & Mazziotta, 2000). Elevated amygdala activity, and reduced prefrontal cortex activity have been correlated with increased severity of PTSD symptoms (Shin et al., 2004). Thus, disclosing the event chronologically may help individuals to process the event cognitively and fit it into the framework of their lives.

On day 2, participants are asked to describe their thoughts and feelings at the time of the event in words, and whether the event affected their life, to increase their insight about it. The precise verbal labelling and processing of unpleasant emotions may first reduce amygdala activity and increase PFC activity (Hariri, Bookheimer, & Mazziotta, 2000), thus enabling cognitive restructuring, and together with describing the event's impact on their lives, this allows individuals to think about the event more explicitly, and thus reflect on what they have learned from the event, and how they have developed as a result of it. In support of this idea, Pennebaker and Francis (1996) showed that participants who used more insight words when disclosing trauma experienced greater health benefits.

On day 3, participants are required to write how they currently think and feel about the event, and reflect on what they would do in the future if they encountered a similar event. This enables them to consider coping strategies and to undergo self-regulation, which is likely to enhance the effectiveness of the intervention - recent research suggests that written disclosure may be more effective for those with good physiological self-regulation. In a study of bereaved adults, O'Connor, Allen, and Kazniak (2005) found that within the disclosure group, higher first session repiratory sinus arrhythmia (an indicator of vagal control of the heart) was related to a better outcome. This could reflect greater vagal withdrawal during disclosure-induced sympathetic arousal, possibly leading to a faster desensitisation response later.

Gidron et al. (2002) found that the GDP reduced visits to general practitioners (GPs) in frequent attendees, an effect that was maintained at a 15-month follow-up. This contrasts with a study by Schilte et al. (2001), which found that typical non-guided writing did not reduce GP visits in frequent attendees. However, it is not possible to compare Schilte et al.'s (2001) study directly with other writing studies, since the writing in that study was a summary of two 45-minute one-to-one sessions with a GP who invited participants to disclose important events in their life. Duncan et al. (2007) found that the GDP reduced PTSD symptoms in parents of children with cancer. However, this finding needs to be treated with caution, as this study was based on a sample of only 8 parents, and it therefore utilized an AAB design as opposed to a randomized controlled trial. The GDP has also improved sense of coherence in individuals writing about a controllable event, possibly because it raises their awareness of a sense of control in their lives (Arden-Close, Gidron, & Duncan, 2005). However, at the moment there is only tentative support for the effectiveness of cognitive-processing instructions. Gidron et al. (2002) had a small sample, which reduces generalizability of their results. More large-scale studies assessing the effectiveness of the GDP are therefore required.

In a study examining the impact of cognitive-processing instructions, Lutgendorf and Antoni (1999) found a decrease in levels of intrusive thoughts one week following completion of the writing, but no changes in avoidance. Greater involvement in the disclosure and more negative mood arousal were associated with greater insight by the end of the session. They suggest that written disclosure may be more effective in stimulating changes in cognitive processing for those who ruminate about their problems, and that high levels of intrusive thoughts at study entry may have relevance to populations dealing with traumas such as life-threatening diagnoses. The participants in the current research are patients with ovarian cancer, which has a poor prognosis, or their spouses. The fact that they have joined a support group suggests a willingness to engage with their illness, and it is therefore expected that levels of avoidance will be low.

4.3.2 Written disclosure in chronic illness

Originally, many written disclosure studies were carried out on healthy students. However, results of these studies have limited relevance for individuals with life-threatening illnesses outside their contribution to theory. Therefore, this section focuses on studies of written disclosure carried out on people with physical illness. The majority of such studies have been carried out in individuals with rheumatoid arthritis, asthma and fibromyalgia, which are chronic, rather than life-threatening. Nevertheless, such studies provide valuable insights into methodological issues, and can be compared to cancer when addressing the impact of the illness on lifestyle, and the impact of writing on illness-specific measures.

Several studies have been carried out on individuals with rheumatoid arthritis (RA) (Broderick, Stone, Smyth, & Kaell, 2004; Danoff-Burg, Agee, Romanoff, Kremer, & Strosberg, 2006; Kelley, Lumley, & Leisen, 1997; Smyth, Stone, Hurewitz, & Kaell, 1999; Wetherell et al., 2005). Those considered to be most relevant to the current study are discussed in detail. Kelley et al. (1997) required their participants to talk into a tape, as RA causes difficulty with writing. Disclosure led to reductions in physical dysfunction and affective disturbance from baseline to three month follow-up, and larger increases in negative affect after disclosure (possibly caused by recalling and experiencing affective memories, and thus suggesting a greater depth of processing) were correlated with greater improvement in joint condition. However, the participation rate was low, suggesting that many patients may be reluctant to engage in such research - perhaps only those accepting or capable of deeper emotional processing remained in the study. Smyth et al. (1999) found that written disclosure led to improvements in forced expiratory volume in patients with asthma and improvement in overall disease activity in patients with RA. Interestingly, health improvements in the trauma writing group were not mediated by quality of sleep, substance use, medication use, affect, stressful experiences or social contact with others (Stone, Smyth, Kaell, & Hurewitz, 2000), possibly because the variables were measured over an inadequate time frame, there was inadequate statistical power to detect small changes in potential mediators, or other variables mediated the effect of writing on clinical outcomes.

Hamilton-West and Quine (2007) found that written disclosure led to improvements in functional status at 3 month follow-up in patients with ankylosing spondylitis (similar to rheumatoid arthritis), which were related to word usage. Improvement in disease activity was associated with an increase in use of positive emotion words, and a decrease in the use of sadness/ depression words. Improvement in functional status was associated with a decrease in sadness/ depression words, an increase in tentative words, and a decrease in certainty words. Improvements in psychological health were associated with a questioning approach characterised by a move away from the use of words relating to certainty and towards the use of words relating to tentative possibilities. This evidence highlights the importance of assessing word usage as a potential moderator of improvement.

Broderick et al. (2004) compared standard writing with enhanced meaning writing (similar to the GDP – individuals were required to consider a traumatic event in a comprehensive, integrated way, and relate it to effects and changes in their beliefs and life views), and had two control groups, one for time management writing, and one for attention. Those in the enhanced meaning group showed an improvement in disease activity relative to the other groups at 4-6 month follow-up. However, only 49% of those who volunteered to participate completed the task, and the results were non-significant when intention-to-treat analyses were carried out. These results suggest that further research should be carried out in order to identify who benefits from writing. Broderick, Junghaenel, and Schwartz (2005) carried out a study of written disclosure in fibromyalgia patients. The writing in this study followed a format similar to the Guided Disclosure Protocol, with the only difference being that on the first day, participants were required to use emotional expression and cognitive reappraisal after they had retold the story factually. Written disclosure led to decreases in pain and depression, and an increase in psychological well-being, whereas the control groups (a neutral writing group, and a usual care group), worsened on all measures. The effect sizes were similar to those found in pharmaceutical clinical trials. Thus, evidence from this study suggests that the GDP could benefit people with chronic illness.

Very few studies have been carried out on patients with life-threatening illnesses. Petrie, Fontanilla, Thomas, Booth, & Pennebaker (2004) in a study of patients with HIV, found that written disclosure led to an immediate reduction in viral load, which was followed by increases in the CD4+ lymphocyte count over the following six months, compared to no change in the control group. They suggest that written disclosure may lead to a reduction in catecholamine/cortisol elevations that result from an unresolved stressor, and may therefore be more useful for those who are socially isolated and lack a close confidant. In support of this view, Esterling, Antoni, Kumar & Schneiderman (1990) found that repressors who wrote expressively had higher levels of Epstein-Barr virus after writing. In the current study, it is expected that the intervention will provide an opportunity for partners to disclose concerns in a non-threatening environment.

Nine studies of written disclosure in clinical populations were reviewed in a meta-analysis (Frisina, Borod, & Lepore, 2004). The mean weighted effect size was d = .19, which was significant at p <.05. Further analyses found the effect to be significant for physical health outcomes, but not psychological health outcomes. However, the reasons given for excluding several studies were unclear. Further, the review failed to include several relevant articles. Thus, only limited conclusions can be drawn.

4.3.3 Written disclosure in cancer patients

It is important to note that the underlying response to writing may vary across patient groups. As there are very few studies per patient group, it is difficult to determine if the medical characteristics of samples or small procedural differences are responsible for the varying impact of written disclosure (Harris, Thoresen, Humphreys, & Faul (2005). To illustrate this, Smyth et al. (1999) found improvement by two weeks in patients with asthma, whereas for patients with rheumatoid arthritis there was a clear improvement only after four months. However, to date, only five studies have looked at written disclosure in cancer patients. These studies are discussed in detail in Table 5, and quality assessed based on the number of CONSORT guidelines (developed to assess the quality of randomized controlled trials) they met (Moher, Schulz, & Altman, 2001).

First, possible reasons for some pertinent results reported in Table 5 are addressed, in order to put them in context. The lack of positive outcomes in Walker et al. (1999) may have been due to low statistical power and failure to assess physical outcomes, which generally show more robust effects than psychological outcomes (Frisina et al., 2004). Further, positive mood was close to ceiling level, meaning that it was not possible to detect improvement. The results from this study should not therefore be taken as evidence that written disclosure is not helpful for cancer patients. Zakowski et al. (2004) suggested that a possible mechanism for their findings regarding avoidance and social constraint is that written disclosure provided the participants with a stimulus to begin speaking more effectively and with less distress about their emotions, whereas high levels of social constraints may have been associated with continued cognitive avoidance of cancer-related thoughts and stimuli in the control group at follow-up. Avoidance may be detrimental in the long-term, because it prevents the individual from confronting and processing threat and possibly acting to solve it. Based on these findings, the current study aims to reduce avoidance by asking both the woman and their partner to write about her cancer, which may then enable them to discuss it more openly.

Table 5: Studies of written disclosure in cancer patients

Study	Sample population (size)	Design	Findings	CONSORT score (/22)
(Walker, Nail, & Croyle, 1999)	Breast cancer patients completing radiotherapy (44)	T: Write deepest thoughts and feelings about cancer C: Usual care	No effect on any of the measures	11
(Rosenberg et al., 2002)	Prostate cancer patients (30)	T: Write about deepest thoughts and feelings regarding cancer C: Usual care	Reduced pain Trend towards improvement in health care utilization	12
(de Moor et al., 2002)	Stage IV renal carcinoma patients (42)	T: Write about cancer C: Write about health behaviours	Improved sleep (Pittsburgh Sleep Quality Index) (4, 6, 8 and 10 wk follow-ups)	13
(Zakowski, Ramati, Morton, Johnson, & Flanigan, 2004)	New diagnosis of prostate/ gynaecological cancer (13.5% ovarian) (104)	T: Write about parts of cancer experience they found hard to share with others C: Describe daily activities non-emotionally	T: Decrease in distress (BSI) if high levels of social constraint (Compared to increased symptoms and avoidance in among those with high social constraint in control group)	12
(Stanton et al., 2002)	Women with Stage I/ II breast cancer within 20 weeks of completing treatment (60)	T1: Write about deepest thoughts and feelings regarding breast cancer T2: Write about positive thoughts and feelings regarding cancer C: Write facts about cancer	Decrease in physical symptoms Fewer medical appointments for cancer-related morbidity Decrease in distress if low cancer-related avoidance Both treatment conditions beneficial	20

The implications of the extent to which the studies in Table 5 met CONSORT guidelines are now discussed, in order to assess the strength of the evidence and how this affects the conclusions that can be drawn. Both Walker et al. (1999) and Rosenberg et al. (2002) failed to meet requirements related to randomization and blinding, which have been shown to impact seriously on trial outcomes. However, since these studies found few significant results and are more like pilot studies, due to small sample size, these results are unlikely to significantly bias scientific opinion. Similarly, de Moor et al. (2002) defined their study as a pilot study and note that their results need further exploration. Further, this study had some strengths - effect sizes were reported and the method of randomization was explained. The study by Zakowski et al. (2004) however, suffers from several serious flaws - requirements related to randomization and blinding were not met, and the findings were reported in a way that led readers to believe process variables were primary outcomes. The lack of significant results was glossed over. This was possible as trial protocols are not published for written disclosure studies. Further, pre-post differences in distress within the intervention group were smaller than initial differences between the intervention and control groups (Coyne, Lepore, & Palmer, 2006b). However, the fifth study (Stanton et al., 2002) was well designed, with the main limitations being the number of primary outcomes, and failure to mention the start and end dates of the study.

Overall, only limited conclusions can be drawn from the research assessed above, due to small sample sizes, and failure to report details of randomization and blinding. Further, there were considerable differences between the studies regarding type of cancer investigated, writing content and outcomes, which limit the extent to which they can be compared. Nevertheless, positive findings from a high quality study (Stanton et al., 2002) provide an impetus for further studies testing the efficacy of written disclosure in cancer patients. The evidence for assessing the efficacy of written disclosure in couples is now addressed.

4.3.4 Written disclosure in the context of relationships

Although traumatic events are often interpersonal, the research literature tends to emphasize intrapersonal processes and consequences. The occurrence of a traumatic event to someone may have important implications for his/her partner. However, the written disclosure literature has mainly considered people in isolation, although there are some exceptions. Snyder, Gordon, and Baucom (2004) carried out a study of written disclosure in couples where one partner had experienced an extramarital affair. Treatment led to decreases in depression and PTSD-related symptoms, reductions in state anger and global marital distress, decreases in negative assumptions, and increases in forgiveness towards the partner for affected/hurt spouses. The effect sizes were moderate to large, exceeding the average for effective marital therapies not targeting affair couples. However, here the written disclosure was carried out as part of a structured intervention with a therapist, whereby the partners were required to write letters to each other. Thus, it is not clear whether written disclosure facilitated the other interventions or required the other treatment components to achieve its benefits. Further, it is not clear what individual relationship processes moderated or mediated the effects of written disclosure.

Other studies, despite addressing relationship processes, have only involved one member of the couple. For example, Slatcher and Pennebaker (2006) found that among undergraduates who had been in a committed heterosexual relationship for an average of 1.3 years, those who wrote their deepest thoughts and feelings about their current romantic relationship were significantly more likely to still be dating their partners at three month follow-up, relative to those who wrote about their daily activities. Analysis of instant messages before and after the writing, and at three month follow-up revealed that both members of the couples increased the use of positive emotion words in their text messages at similar rates, even though only one member had participated in the expressive writing manipulation. It appears that the effects of writing transferred to the non-participant partners, possibly through changes in the way in which the participant interacted with them after the intervention. Lepore and Greenberg (2002) found that among members of couples who had experienced a relationship break-up approximately six months previously, those who wrote their thoughts and feelings about the relationship were more likely to reunite with their ex-partner, and felt significant decreases in resentment towards their ex-partner, guilt over the break-up, and symptoms of intrusions and avoidance at 15 weeks follow-up. In contrast, the control participants, who were told to develop rational arguments about impersonal topics, experienced higher levels of intrusive thoughts and avoidance, which were associated with increases in upper respiratory symptoms.

Overall, the few studies available suggest that writing is beneficial with regard to feelings about romantic relationships. There are several differences between the studies discussed above and the current research – they were carried out on undergraduates, who had been in relationships for a much shorter period of time, they involved only one member of the couple, and the writing focused on the relationship. The current research will require both partners to write and will focus on the wife's cancer. Nevertheless, the evidence suggests that writing leads to positive benefits for couples, possibly initiated through changes in the way in which the member of the couple who participated in the expressive writing intervention interacts with his/her partner, following reflection on their relationship. Although the participants in the current research will not be required to write about their relationship, diagnosis and treatment of cancer in women impacts heavily on male partners (Baider & De-Nour, 1999) and may have led to changes in marital interactions. Writing may provide a framework for couples to explore issues surrounding the diagnosis and how it has impacted on their relationship, thereby reducing any constraint they may previously have felt regarding such issues.

4.4 Theory: Why does written disclosure work?

Several theories have been developed to explain the positive outcomes following written disclosure. These include the emotional inhibition hypothesis, the cognitive adaptation hypothesis, the exposure/emotional processing theory and the social interaction hypothesis.

4.4.1 Emotional inhibition hypothesis

According to the emotional inhibition hypothesis, those who inhibit their emotions may be more prone to physical impairments and disease than if they are emotionally expressive (Cohen & Herbert, 1996). Inhibited anger and hostility have been linked to hypertension and CHD (Barefoot, Larsen, von der Lieth, & Schroll, 1995). Also, emotional inhibition may be linked to cancer progression (Garssen, 2004). Suppression of emotion increases sympathetic activation (Gross, 1998), and chronic sympathetic activation (caused by increased stress) leads to adverse physical and psychological outcomes, particularly infectious illnesses (Cohen & Williamson, 1991). Pennebaker (1989) hypothesised that disclosure may lead to reduction in stress, and thus improved immune functioning and health. In support of this hypothesis, written disclosure has led to improvement in immune function i.e., proliferation of T-helper cells, antibody response to the Epstein-Barr virus (Esterling, Antoni, Fletcher, Margulies, & Schneiderman, 1994), immune response to hepatitis B vaccinations (Petrie, Booth, Pennebaker, Davison, & Thomas, 1995), and enhanced wound healing (Weinman, Ebrecht, Scott, Walburn, & Dyson, 2008).

However, there is no evidence that decreases in inhibition mediate the relationship between writing about traumatic events and improved health. For example, Greenberg and Stone (1992) found no differences in reported health or physician visits at two month follow-up between those writing about undisclosed and previously disclosed traumas. In addition, Greenberg, Wortman, and Stone (1996) found that writing about deep emotions regarding imaginary traumas produces the same effects as writing about deep emotions related to experienced traumas. Further, evidence suggests that emotional expression and cognitive assimilation may be more effective than emotional expression only (Ullrich & Lutgendorf, 2002). Overall, the evidence does not provide support for the emotional inhibition hypothesis. It is therefore necessary to explore other theories to explain the beneficial effects of written disclosure.

4.4.2 Cognitive adaptation hypothesis

The cognitive adaptation hypothesis holds that processing of a traumatic experience requires changing of existing schemas (Janoff-Bulman, 1992). According to this hypothesis, information processing regarding specific events is guided by schemas that are relatively stable. Affectively overwhelming experiences interfere with the cognitive integration of traumatic events to an inner model, and may result in the storage of memory as sensory perceptions/obsessional ruminations/behavioural ruminations without integration into mental schemas. Since such memories lack linguistic components, they cannot be effectively communicated or organized (Horowitz, 1986).

Horowitz (1986) hypothesised that resolution of a traumatic event is characterized by alternating cycles of intrusion and avoidance. According to this model, avoidance protects individuals from being overwhelmed by their emotions. However, intrusions, which lead to continual activation of the nervous system and HPA axis, pave the way for the assimilation of new information. These alternating cycles allow disturbing information to be assimilated and worked through in manageable doses. Being able to confront a stressful event that has been avoided increases the chance of resolution of that event. Decreased avoidance leads to a change in cognitive-emotional processing, and decreased intrusive thoughts lead to a greater sense of integration with the stressful event. Activation of relevant cognitive-emotional schemas accompanied by new information incompatible with previously existing cognitive-affective schemas brings about psychological change. Reprocessing may involve returning to traumatic memory repeatedly in attempts to achieve integration with the existing mental schema, which is necessary for complete recovery. Cognitive change requires the integration of thoughts and feelings. Once the meaning of the event makes sense, the emotional effects associated with it are more manageable.

According to the cognitive adaptation hypothesis, written disclosure may provide a context for the controlled activation of trauma schemas enabling the logical restructuring of illogically stored memories into a coherent narrative (Lutgendorf & Antoni, 1999; Pennebaker, 1997; Smyth & Pennebaker, 1999; Smyth, True, & Souto, 2001). The facing of avoided topics in a nonthreatening context helps individuals reorganize and integrate thoughts and feelings related to the experience, thereby leading to resolution of the traumatic event and to improved physical health (Lutgendorf & Antoni, 1999). In support of this idea, decreasing disorganization is associated with improvements in narratives from the victims of personal trauma during exposure treatment (DeSavino et al., 1993), and predicts better prognosis (Foa et al., 1995). However, many people may require specific instructions on how to order their memories and reflect on how the event impacted on their life, as in the GDP.

In order to explore these hypotheses further, it is important to look at the correlations between words used in the writing tasks and benefit gained from writing, as this may provide insight into the process by which improvements take place. Pennebaker and Francis (1996) found that use of more positive emotion words and a moderate number of negative emotion words were associated with improved health outcomes. Those who use very few negative emotion words may be repressive copers, whereas those who use high numbers of negative emotion words may be high in neuroticism. Further, Pennebaker, Mayne, and Francis (1997) suggest that labelling emotions reduces the perceived intensity of the experience, and increases sense of control over affective experiences, thereby aiding in integrating emotional reactions into the general understanding of a traumatic event. Studies on relations between content analyses and outcomes support the variability between participants and the need to guide participants, to maximize benefits from writing.

Health improvements have been associated with an increase in causal and insight words over the three days, suggesting that some participants are constructing a story over time whose elements were meaningfully linked, following reflection (Pennebaker & Francis, 1996; Pennebaker, Mayne, & Francis, 1997). Such organization of narratives may have led to health improvements. Those who use high levels of cognitive words throughout the writing may enter the study with a preconceived explanation of their emotional experience. However, the evidence is correlational –

changes in language may be affected by other mechanisms. Also, in many studies, there is cognitive and/or linguistic change in the absence of physical/ psychological improvements. In order to test this theory, Smyth et al. (2001) carried out a study with three groups – control, narrative, and listing the event in a fragmented way. This study included only one session because it was thought that more sessions would lead the fragmented experimental group to form a narrative. The hypothesis that intrusions would be reduced by the narrative was not supported – the narrative group experienced higher levels of avoidant thinking following the writing. However, multiple sessions may be required for increases/improvements in narrative function, as they provide the individual with an opportunity to habituate to the traumatic memory over several days and perhaps achieve reorganisation and greater insight into the event. Alterations in narrative may underlie cognitive and physical benefits from written disclosure. In support of this idea, Greenberg et al. (1996) found that a single writing session led to increases in avoidant thinking.

Lutgendorf and Antoni (1999) found that moderate emotion and a high level of involvement in the disclosure process (from detached to having emerging insight) was associated with positive outcomes. Similarly, an increased level of insight, understanding and involvement has been associated with better immune functioning post-disclosure (Esterling et al., 1994). However, a moderate level of reflection appears to be optimal. Suedfeld and Pennebaker (1997), found that in the essays from Pennebaker et al. (1988), scores closer to the median level of complexity were associated with greater improvements in health, which may have been indicative of allowing enough resources to analyze and come to terms with their memories of severely negative experiences. Higher levels of complexity may have been characteristic of brooding, obsessive rumination, or an attempt to process an unnecessarily large amount of information.

However, it is necessary to address the nature of cognitive complexity in order to understand it fully. In order to do this, Creswell et al. (2007) analysed the essays written by the cancer patients in Stanton et al. (2002) for self-affirmation, defined cognitive processing plus discovery of meaning. They suggest that cognitive processing alone can be construed as rumination, whereas cognitive processing combined with discovery of meaning (enhanced appreciation for life and recognition of its fragility as a result of a traumatic event) is characteristic of successful reconciliation to the traumatic event. In support of this idea, self-affirmation mediated the effects of writing on reductions in physical symptoms, whereas cognitive processing alone had no effects. This evidence suggested an independent psychological pathway by which writing leads to health benefits. However, the writing groups were not compared – the mediation may have been carried by positive correlations in the group writing about perceived benefits of breast cancer. Nevertheless, as a possible mechanism for this pathway, Creswell et al. (2007) suggest that expressive writing may have buffered the stress associated with writing about cancer-related thoughts and feelings. Such reduced defensiveness may have enhanced efforts at maintaining involvement during writing and facilitated efforts to work through difficult cancer-related thoughts and feelings.

Park and Blumberg (2002) assessed cognitive appraisal of the event (uncontrollability, threat, stressfulness, intrusions, avoidance) prior to writing, on the last day and four months later. They hypothesised that the cognitive model would be supported if a positive outcome was associated with change in appraisal of the event. However, although appraisal improved from pre-writing to follow-up for the disclosure group, there were no improvements in self-reported emotional and physical health. Admittedly, it is difficult to measure cognitive changes - content analysis may not necessarily be able to capture the nuances of cognitive restructuring important for positive change. Alternatively, cognitive changes may be an outcome of successful exposure, rather than a prerequisite of positive health outcomes in written disclosure. Overall, there is some evidence suggesting that cognitive processing is associated with improved health. However, this relation appears to be complex, and requires further exploration, particularly of the self-affirmation findings.

4.4.3 Exposure/ emotional processing theory

Alternatively, the positive effects as a result of written disclosure may be explained by the exposure/emotional processing theory. Watson, Gaind, and Marks (1972) found that in phobic clients, exposure to fearful stimuli promoted physiological and psychological habituation, leading to a reduction in the fear response over time. Exposure reduces fear by activating the fear structure through exposure to feared stimuli and providing corrective information about the stimuli, responses and meanings (Foa & Kozak, 1986). Written disclosure allows the individual to be exposed to aversive conditional stimuli (memories) and other cues that were previously avoided. Repeated exposure to these adverse stimuli through several writing sessions may allow for the extinction of negative emotional associations (UCS-CS associations), or activate the fear structure and provide corrective information, thereby leading to beneficial outcome.

Thus, written disclosure may overcome the tendency to avoid or suppress distressing memories/ emotions/physiological sensations.

In support of this hypothesis, research has shown that disclosure is associated with greater salivary cortisol reactivity and more self-reported arousal in response to the first writing session, relative to controls, whereas this difference is not observed at subsequent sessions. These findings hold across both women with moderate levels of PTSD symptom severity (Kloss and Lisman, 2002), and trauma survivors with high levels of psychological distress (Sloan & Marx, 2004a). Disclosure in these studies led to reductions in PTSD symptoms and depressive symptoms. Importantly, in Kloss and Lisman's (2002) study, greater physiological activation in response to the first session was significantly associated with these improvements. However, the participants were only followed for four weeks – effects may diminish over time. Further, the physiological measure is sensitive to novelty – the disclosure participants may not have shown physiological reactivity to the second and third writing sessions because the procedure was no longer novel, although the self-reports suggested this is unlikely. Thus, these studies provide some support for the exposure theory. However, in the instructions, participants were allowed to choose the topic to write about, whereas Foa and Rothbaum (1998) stated that exposure to the same traumatic experience/ memory is critical for extinction/ habituation, an idea that has been supported by both case studies (Sloan & Marx, 2006) and experimental studies (Bernard, Jackson, & Jones, 2006).

Support for this hypothesis was also reported by Sloan, Marx, Epstein, & Lexington (2007) who found that emotional expression (writing with as much emotion and feeling as possible) was more effective than insight and cognitive assimilation (focusing on what the event meant and how it changed their lives, and challenging dissonant thoughts), leading to fewer depressive symptoms, physical health complaints and PTSD symptoms at one month follow-up. Importantly, the relation between experimental condition and changes in PTSD symptoms was fully mediated by changes in self-reported arousal. These results showed a link between confronting emotions related to the event and improvements in physical and psychological symptoms.

Alternatively, the extinction of negative emotions may be achieved through constant elicitation of intense negative affect, regardless of the eliciting stimulus. Watson, Gaind, and Marks (1971), found that in individuals with a phobia, exposure to stimulus-specific cues and fear-specific cues were equally effective at reducing anxiety when the clients were subsequently confronted with stimuli related to their phobia.

According to this theory, the beneficial effects of written disclosure may be partly due to response-related habituation. Emotional expression in a safe context such as written disclosure should attenuate negative affective and physiological responses to stress-related stimuli through repeated exposure (Bootzin, 1997). Habituation may lead to decreases in emotional arousal between sessions. In support of this idea, Greenberg et al. (1996) found no difference in health centre visits at follow-up between students who wrote about past personal traumas and those who wrote about imaginary traumas.

Finally, as evidence to support this theory, there should be changes in posttraumatic stress symptoms following written disclosure. This has been supported by a reduction in intrusive thoughts and images in some studies (Kloss & Lisman, 2002; Sloan & Marx, 2004a), but other studies have shown no effect. However, methodology has varied across studies: some used small samples, meaning that there may have been insufficient power to examine outcome effects; some used a single writing session, which may have been inadequate to extinguish negative emotions; and length of time until follow-up has varied. The final point is important because Nishith, Resick, and Griffin (2002) found that during a course of treatment, female rape victims increased in trauma-related avoidance prior to improving. Also, the study populations have varied widely: some have been individuals seeking treatment, and some have been college students either randomly selected or pre-selected based on their trauma history. The presence and severity of psychological symptoms varied considerably across these populations – written disclosure may work best with low to moderate levels of symptoms. Alternatively, there may be individual differences in ability to chronologically structure disclosed memories, which may influence arousal systems and also account for part of the effects of repeated self-exposure via writing. However, the GDP may reduce these differences, since individuals are given guidance on how to structure their writing, based on cognitive neuroscience principles.

4.4.4 Social interaction hypothesis

When people write about traumatic experiences, they are writing about social issues (Pennebaker, 2004). Rime, Mesquita, Philippot, and Boca (1991) suggest that social sharing is important in processing and resolving trauma. One theory holds that written disclosure is beneficial because it results in changes in social and linguistic behaviours, leading to increased social connections (Pennebaker & Graybeal, 2001)). In support of this idea, Pennebaker, Barger, and Tiebout (1989) asked Holocaust survivors to talk about their experiences during and immediately following WWII.

These emotionally charged interviews were videotaped and a copy of the videotape was given to the participants. Although prior to the interviews, 70% of the participants had not talked to anyone about the Holocaust, at follow-up interviews several weeks later, almost all the participants had viewed the videotapes twice, and shown them to at least three others. Giving these testimonies led to changes in the ways these participants related to others and thought about their pasts, and to important health benefits (reduced physician visits in the months post-interview), even though 40 years had passed since the traumatic event. Pennebaker and Graybeal (2001) suggest that talking about personal experiences helps people in several ways. First, talking helps the person to come to a cognitive understanding of their traumatic experiences, partly because others may put forward more adaptive cognitive perspectives regarding the event. Second, talking alerts others to the person's psychological state, enabling him/her to remain socially tied to others. Written disclosure may help to break down social constraints, thereby providing individuals with a stimulus to talk more about emotions related to traumatic experiences (cf. Zakowski et. al, 2004). Finally, people may actually disclose traumatic memories differently after writing about them, perhaps with greater insight and less chaos, which may be less socially deterring to others. Certainly, most respondents to surveys report the need to share their feelings with others following a traumatic event (Rime, Philippot, Boca, & Mesquita, 1992), and disclosure of trauma helps to resolve stressful experiences.

However, many traumatic experiences are never disclosed. Pennebaker and Susman (1988) found that across a wide range of traumas varying in social acceptability, at least 20% of the respondents did not confide the event to others. Henderson, Davison, Pennebaker, Gatchel, and Baum (2002), in a study of 272 breast cancer patients, found that although over half reported at least a moderate desire to talk with others about their cancer, one third reported that they preferred not to discuss it with anyone in their social network. Factors related to increased disclosure included more severe disease, younger age and being more optimistic. Although this study was retrospective, meaning that recall of disclosure may have been biased, it nevertheless provides insight that disclosure is a coping strategy used in an attempt to develop new insights, find significance in the experience of cancer, and seek and obtain emotional and instrumental support. Those who are more optimistic may anticipate greater receptivity from potential disclosure targets, have interpersonal communication pathways characterized by relatively high levels of collaboration and trust, and have the ability to find personal growth in trauma, factors that may increase social sharing.

Often, since there are no clear social norms for talking about traumatic experiences, friends or even family are unsure about how to respond to disclosure of a traumatic event following the trauma. Further, although disclosing traumatic events may be associated with psychological and physiological benefits, including drops in skin conductance (Pennebaker et al., 1989), watching/hearing about emotional events is associated with adverse biological changes, such as increased skin conductance (Shortt & Pennebaker, 1992). However, it is important to clarify how levels of social support vary following a traumatic event and its disclosure. Pennebaker, Colder, and Sharp (1990), in a study of 40 bereaved parents attending support groups, found that in the first 2-4 weeks after their children's deaths, their friends and acquaintances were very helpful, but then interactions became stilted. To explore post-trauma interaction in more detail, Pennebaker and colleagues have examined mass social reactions to large-scale upheavals, including the Loma Prieta Earthquake of October 1989 and the Gulf War (Pennebaker & Harber, 1993). Social reactions to the events were similar: people talked and thought about them at very high levels during the first two weeks following the event; then there was then a significant drop in talking about the event, but thinking about it remained at high levels and self-reports of physical symptoms, anxiety and arguments increased; and by eight weeks following the event, thinking and talking about it were both at relatively low levels. The first shift appeared to be primarily due to social constraint – from 2/3 weeks after the events onwards, people reported that while they would like to talk about their own experiences, they would not like to hear stories about others' experiences. After a certain amount of time, individuals do not wish others to discuss their feelings about a catastrophe.

With regard to an individual upheaval, lack of interest is particularly hard for the traumatized person, because the event affects them maximally, and the desire to talk about the event remains much greater for them over a much longer period of time than for individuals in their support network. If trauma-related thoughts are not validated by others, people are more likely to consider them inappropriate or abnormal. Thus, social constraints may interfere with the ability to process traumatic events (Lepore, Silver, Wortman, & Wayment, 1996), by increasing arousal.

However, amount of talking is not simply a function of desire to talk, but also depends on the receptiveness of the social network, relative success of cognitive processing of the loss, and degree of emotional recovery. Although on one level trauma victims would be better off by not inhibiting themselves so much, encouraging people to stop inhibiting themselves may adversely affect their social networks. Written disclosure may therefore be effective as an intervention because it enables people to release their deepest thoughts and feelings to an 'implicit audience' without hostile reactions. This may then enable them to interact with others in a more positive way, since they experience lower levels of distress and may have greater self-control. However, this theory has only been tested in a handful of studies. Kim (2008) in a study on bilingual students who wore a computerized tape recorder (EAR) for two days, found that those who were required to switch between writing in their native and acquired languages talked more and spent more time in dyadic interactions at one month follow-up than those who wrote in a single language and control participants. Other studies have shown that participants in written disclosure studies are likely to talk about their traumatic experience more frequently post-disclosure than pre-disclosure (Kovac & Range, 2000; Schoutrop, Lange, Hanewald, Davidovich, & Salomon, 2002). However, to date, there is mixed support for this theory – Frattaroli (2006) in a meta-analysis, found that emotional writing did not lead to greater likelihood of discussing the event, and although it was more likely to improve social relationships, this effect was small, based on a small number of studies, with a fail-safe N of 2. It appears that further research is required.

Alternatively, writing may provide an alternative way to cope with stress, and a new understanding of stressful experiences. In support of this idea, Langens and Schuler (2005) found that written disclosure led to lower levels of negative mood at follow-up in individuals high in fear of rejection, even after controlling for neuroticism, possibly by compensating for the impaired capacity to down-regulate negative mood caused by diminished perceptions of social support. Similarly, Gortner, Rude, and Pennebaker (2006) found that expressive writing led to reductions in depressive symptoms at 6 month follow-up in individuals high in suppression who had experienced elevated levels of depressive symptoms in the past.

4.4.4.1 Implicit audience

Brody and Park (2004) suggest that participants are writing for an 'implicit audience.' Sharing may promote an implicit sense of accountability and a desire to talk. To date, the two studies which allowed participants to retain the writing found no effect (Ames et al., 2005; Broderick et al., 2004). As the writing was not monitored, it is possible that the participants did not follow the instructions (i.e., they may have taken breaks in the middle of the writing, or done it only for a few minutes). Radcliffe, Lumley, Kendall, Stevenson, & Beltran (2007) found that writing shared with researchers led to reduced interpersonal sensitivity, depression, and avoidance, whereas private disclosure led to reductions in avoidance only. When writing with an audience in mind, the participants may have either processed the stressor more fully, or written about secrets. Alternatively, they may have chosen to write about more difficult stressors/ conflicts. However, this would not be possible to test ethically, as it would involve the use of deception in a supposedly 'private writing' group.

Pennebaker (2004) puts forward factors that should be taken into account during the stages in the interval between the written disclosure intervention and outcome. Initially, there are cognitive changes – the individuals have to label, structure and organize the event, present information in a linguistic structure often for the first time, to an implicit audience and themselves. It is often difficult to understand this stage and determine whether it is associated with long-term health. There are also immediate emotional changes such as habituation and extinction, which may reduce the impact of thoughts surrounding the trauma. However, it is also difficult to link this stage to long-term physical health. Thinking less about the trauma enables the individual to devote his/her thoughts to other issues. Alternatively, Lepore (1997) suggests that the immediate emotional arousal associated with writing dissipates over time, leading to fewer emotionally charged thoughts about the writing topic within weeks.

Further studies exploring the experiences of participants in writing studies are necessary, in order to gain insight into how benefit might occur. To date, however, only one study has addressed this issue. Byrne-Davis et al. (2006) reported on the experience of a sub-sample of the participants in Wetherell et al.'s (2005) study of written emotional disclosure in rheumatoid arthritis (nine intervention, six control). Several processes of improvement appeared to be taking place – finding resolution by reliving and releasing emotions and focusing on ability to cope after the trauma. The intervention appeared to be most beneficial for participants who reported that they did not usually discuss the issues with others. Those who reported the greatest benefit had worse mood and higher levels of disease at baseline. Men were reluctant to discuss their experiences of disclosure, and did not report the process as valuable.

Overall, the written disclosure paradigm is complex – Sloan and Marx (2004) suggest that it is possible that a combination of theories may underlie the beneficial effects associated with it. They recommend that multiple models be examined simultaneously. The main study assesses the cognitive adaptation hypothesis, since the GDP was developed based on research regarding cognitive processing of trauma, and the social interaction hypothesis, since couples are participating in the intervention, and it will be possible to test whether their communication changes following the intervention.

4.5 Methodological issues

4.5.1 Efficacy versus effectiveness

Broderick et al. (2004) highlight the distinction between efficacy and effectiveness trials. Efficacy trials involve evaluating novel treatments in rigorously controlled laboratory settings. Inclusion/ exclusion criteria are strict and rigorously applied. Effectiveness research involves testing of such treatments in real world settings. This is important as efficacy research is often carried out at the cost of external validity, and may not represent the range of patients, health care providers and settings observed in clinical practice. Individuals self-selected into research trials may be more motivated and ready for change. Further, research settings may elicit positive expectations from the participants, and furnish attention to the patient that may optimize the treatment outcome. Effectiveness issues include treatment generalizing to all patients and contexts, treatment feasibility in terms of implementation, acceptance, and evaluation of costs and benefits. However, it is often difficult to deliver a specified intervention in a form consistent with the laboratory version, and make it sufficiently appealing to motivate patient participation.

In the current research, due to ethical considerations, recruitment letters will be sent only to patients who have given consent to be contacted by third parties. Further, the participants are members of an ovarian cancer support group, and therefore may be more motivated to participate in research studies than patients with ovarian cancer who are not members of support groups (Grande, Myers, & Sutton, 2006). Also, writing time will be monitored in order to test the effectiveness of writing for a particular period of time. These features of the design are typical of an efficacy study. On the other hand, the inclusion criteria have been kept very broad, and the writing will be carried out at home, as it is easy and inexpensive to implement. It could be argued, therefore, that to a certain extent the current research assesses effectiveness as well as efficacy. Further, since written disclosure has never been tested on patients with ovarian cancer, or on couples as a stand-alone intervention, the current research is exploratory.

4.5.2 Home-based versus lab-based studies

Home-based studies eliminate restrictions caused by limited physical space, increase flexibility, and allow access to a broader range of participants. Also, at home participants undergo exposure to the event in their natural environment, which could facilitate the process of integrating the event into their lives. However, in such studies experimenter control is reduced, and it is therefore not possible to verify that participants have been provided with adequate care during the experiment (Sheese, Brown, & Graziano, 2004). One major issue to consider is limited control over the surroundings where the participants carry out the writing. This is important because, according to Pennebaker (1994), participants should write in an isolated setting, to enable the individual to concentrate and engage in higher-order cognitive processing. To illustrate how this may impact on the results, Schwartz and Drotar (2004) found no effect of writing on adult caregivers of children with a chronic illness, who started the writing while staying with their children in hospital. A high level of cognitive and emotional demand may have meant the participants were unable to engage fully in and habituate to the response of writing, and therefore would have been unlikely to gain sense of mastery and control over emotional responses, making cognitive restructuring unlikely. These issues have some relevance to the present study – research has shown that a diagnosis of cancer in women is a highly stressful experience for their husbands/partners (Baider & De-Nour, 1999). However, in the current study the participants will be advised to write in a quiet place, and will not be distracted by unfamiliar surroundings.

At home, there is also limited control over the extent to which the participants follow instructions regarding when they should write and for how often/long. For example, Sheffield, Duncan, Thomson, and Johal (2002) found that the absence of contact during the intervention meant there was reduced adherence to the task instructions. A method of controlling for this, which will be used in the main study, is to telephone the participants prior to writing, remind them to find a quiet room and write for 15 minutes, and then telephone them again after 15 minutes to tell them to stop writing (Zakowski et al., 2004). Writing at home means it is possible to recruit participants from a wide geographical area, and inconvenience to the participants is reduced, which is extremely important when recruiting people with a chronic illness, such as cancer. For example, Wetherell et al. (2005) in a home-based study on rheumatoid arthritis patients, provided participants with the opportunity to talk instead of write and to take breaks, since RA causes difficulty with writing. This enabled recruitment of patients with varying severities of the illness. Furthermore, Frattaroli's (2006) meta-analysis found larger effect sizes for psychological health in studies where participants wrote at home, possibly because participants felt more comfortable and relaxed, and therefore engaged more with the topic. Overall, it is necessary to adapt methodological issues to health, logistic and ethical issues when researching patients with chronic illnesses.

4.5.3 Time period over which the writing is spread and length of time for writing

A meta-analysis by Smyth (1998) suggested that effect sizes were larger when writing sessions were separated by one week. However, Sheese et al. (2004) found no differences between writing once a week for three weeks, and writing over three consecutive days – both groups improved equally on self-reported health and sick days relative to a control group that wrote about non-emotional topics. Further, Pennebaker (1994) recommends the use of consecutive sessions, based on the observation that once people have started a writing study they tend to think about it every possible moment. Therefore, in the studies which follow, the participants will be required to write over three consecutive days. The time given for writing generally varies from 15 to 20 minutes per day. In the current study, the participants were given 15 minutes to write, as it was thought that 20 minutes would be too long for the control group to remain engaged. Recent research has shown that writing for two minutes is effective in reducing physical symptoms in healthy undergraduates (Burton & King, 2008), suggesting that 15 minutes is unlikely to be too short.

4.5.4 Instructions given to the control group

Generally, participants in the control group are asked to write about neutral, non-emotional topics. This controls for experimenter contact and expectations. However, one major issue with this is that of dropout due to lack of engagement with the task. Although a randomized controlled trial is the only way to prove beyond doubt that benefits are due to an intervention, benefits in a number of studies may have been due to deterioration in the control group following writing about trivial/ meaningless topics, or suppressing their thoughts and feelings, so it is important to select engaging control topics that are perceived as relevant (Danoff-Burg et al., 2006). To engage participants emotionally in the task, in a study of written disclosure in patients with chronic pelvic pain, Norman, Lumley, Dooley, and Diamond (2004) asked the control group to write about pleasant events they had experienced. However, such control groups may be too similar to the writing intervention, in that emotions are also invoked. Therefore, a standard control group, where participants are required to write about what they did the previous day, will be used in the present study. Further, because husbands/partners will write about their wife's diagnosis and treatment of cancer, it was decided that the control group would write about what their wives did the previous day, in order to control for husbands thinking about their wives.

4.5.5 Typing or writing

Brewin and Lennard (1999) reported participants who typed used fewer negative affect words, whereas those who wrote in longhand disclosed more. However, such studies generally take place in the lab, meaning that all individuals are required to write in longhand. Here, since participants were writing at home, it was decided to give them the option to type or write, to make them feel more relaxed.

4.5.6 Interaction with the participants

Pennebaker (1994) advises interacting in a warm and caring yet serious manner with participants. In his studies, they are asked 'warm up questions' at the initial meeting. Following an overview of the study, where its importance is stressed, the participants meet with the lead investigator for the remaining writing instructions. Following termination, they meet with the experimenter for debriefing and to talk about the study and their reactions to it. It has been suggested that these repeated interactions with a warm, experimenter may contribute to improvement in emotional disclosure participants. Rogers, Wilson, Gohm, & Merwin (2007) found that expressive writing participants assigned to a warm experimenter rated their essays as more revealing of emotion and more personal, and were more likely to think about the study and the topics, but experienced more distress at one week than those assigned to a cold experimenter. However, the follow-up was very short – written disclosure often causes an upsurge in negative affect immediately following completion, but benefits in the long run. Interactions with a warm experimenter may be more beneficial in the long term. In the current research, the instructions will be given according to a protocol. However, I will be available to chat with the participants following each writing session, should they have issues they wish to discuss, and will thank them after every session. Further, I will already have established a rapport with the participants by telephoning them to take background details, and will have been willing to answer their queries/ listen to them.

4.5.7 Outcomes

The CONSORT guidelines require clearly defined primary and secondary outcome measures to be reported. Current regulations require trial protocols to be registered at the point of starting a clinical trial, with clearly defined outcome measures. However, to date very few studies have done this. An inflated sense of the efficacy of interventions is presented, due to a variety of factors including post hoc selection of measures that put the efficacy of the intervention in the best light possible, recasting past trials with null effects as positive in subsequent publications, and post hoc dropping of patients from analyses who are likely to show the least positive benefit from having been randomized to an intervention (Coyne et al., 2006b). Several studies have put forward this ‘confirmatory bias’ (Antoni et al., 2001; Classen et al., 2001; Zakowski et al., 2004). The investigators should be prepared to judge the efficacy of an intervention based on effects on pre-specified outcomes. The current research has two clearly defined outcomes – overall quality of life and perceived stress. Secondary outcomes, hypothesized to be process variables, include intrusive thoughts and marital communication. Further, all analyses, whether pre-specified or exploratory, should be reported. Often, trials are stopped based on positive results in interim analyses of data, rather than attainment of a predetermined sample size. For the current research, sample size will be clearly defined, based on a power calculation.

4.5.8 Length of follow-up

It is important to ensure that the time-course of benefits is charted, in order to understand whether an intervention leads to improvements in the short term, and whether such improvements are maintained long-term. One month may be too short for benefits to appear. On the other hand, longer term follow-ups are needed, as interventions with lack of benefit beyond 3 months may not be cost-effective. Gillis, Lumley, Mosley-Williams, Leisen, and Roehrs (2006), in a study of at-home written emotional disclosure in 72 women with fibromyalgia, found improvements in sleep, global health, healthcare utilization and physical disability at three months, relative to the control group, whereas the only outcome that improved at one month was sleep quality. The delay of these benefits indicates that time was required for change, which may have reflected continued emotional processing, extinction of negative emotion, changes in cognitions regarding self and others, and decisions to communicate and approach relationships differently. On the other hand, Broderick et al., (2005) found that effects of written disclosure in fibromyalgia were weakened by 10 months. However, the time course of effects may vary by illness population. In the pilot study, the follow-up will only be one month following the completion of the final intervention, as its main aim is to assess the feasibility of the intervention. However, the main study includes follow-ups at 3 and 6 months, to see whether the GDP leads to short-term benefits, and whether these benefits are maintained in the long term. A one month follow-up was considered to place extra burden on patients, and provide limited further information.

4.5.9 Randomization

The CONSORT guidelines require details of how the random allocation sequence is generated and implemented, and by whom the allocation sequence, enrollment and assignment to groups is carried out. This is important, as researchers may otherwise assign participants based on their suitability for the intervention. Random allocation sequences should be generated using an impartial method, such as a computer program. However, since this may lead to group differences in small trials, it is acceptable to use stratification, whereby participants are randomized after being split based on a significant demographic/ clinical measure. As the main study aims at a sample of 80-100 participants, stratification will be used after consulting the research team and considering variables of prognostic importance. Once the sequence has been defined, it should be concealed from the researcher prior to assigning participants to their groups, as inadequate allocation concealment can inflate effect sizes (Schulz, Chalmers, Hayes, & Altman, 1995). This can be done using number containers or a central telephone. In the current study, details of assignment will be placed in numbered envelopes, which will be kept in a locked drawer to which the principal researcher does not have a key, and opened by another researcher once the participant has been given a number. It is also important to know who generated the allocation sequence, who enrolled participants, and who assigned participants to their groups. Ideally, these tasks should be carried out by different researchers, in order to minimize bias. One limitation of the current study is that it will be carried out by a single researcher, due to economic constraints. However, the allocation sequence will be destroyed once it has been generated, which minimizes the possibility of significant bias.

4.5.10 Blinding

Ideally, participants, those administering the interventions, and those assessing the outcomes should be blind to group assignment, in order to reduce bias. Blinding of participants is important, as knowledge of group assignment may influence responses to the intervention. In line with ethical considerations, participants will be informed that there are two groups. However, they will not be informed about which task the intervention is, and which the control group assignment is. One major limitation is that this study is being carried out by a single researcher, who cannot therefore be blind to condition – this increases the possibility of performance bias. However, the booklet clearly explains how to carry out the task, and the researcher will use a pre-written script, and time every call to 15 minutes by setting an alarm. Lack of blinding is not expected to increase the possibility of observer bias, as the outcomes are all self-reported and the questionnaires are completed at home, apart from CA 125, which is measured by the patients' consultants, who are not aware of the study. Therefore, the risk of bias is considered to be minimal. Further, the return questionnaires will be addressed to my supervisor, who has had no contact with the participants.

4.6 Conclusions

To date, there is some evidence for the beneficial effects of written disclosure in cancer patients. However, written disclosure has mainly been carried out on individuals in isolation, and very few studies have tested the effectiveness of guided writing. Possible theories to explain the beneficial effects of written disclosure include the cognitive adaptation hypothesis, the exposure/ emotional processing hypothesis, and the social interaction hypothesis. There are also several methodological issues that need to be taken into account when planning a writing intervention. The first study aims to test the feasibility of the written disclosure paradigm combined with half an hour of stress management over the telephone in ovarian cancer patients. The reasons for including the stress management will be discussed in Chapter 5. The second study aims to test the effect of guided written disclosure concerning the diagnosis and treatment on stress and quality of life in women with ovarian cancer and their partners. Hypothesized mechanisms for change include reductions in intrusive thoughts and greater insight (assessed by percentages of insight and causality words) in order to test the cognitive model, and changes in social interaction (assessed by a marital communication questionnaire) to test the social interaction hypothesis. This study will therefore extend the written disclosure paradigm to partners, and focus on a relatively unstudied population.

Chapter Five: Pilot Study: The effects of written disclosure and stress management on perceived stress and quality of life in women with ovarian cancer

This chapter discusses the pilot study. The rationale behind the stress management intervention is explained. The aims and hypotheses are stated, the method is described, and the results are reported. Findings, limitations, and implications for future research are discussed.

5.1 Introduction

The main background to this study is discussed in Chapters 1-4. For sake of brevity and comprehensiveness, only the background concerning the rationale behind the stress management intervention is provided here.

Several studies have demonstrated that use of positive approach coping is associated with greater well-being in gynaecological cancer, whereas avoidant coping (behavioural disengagement) is associated with worse outcomes (reported in Chapter two). Avoidant coping may be ineffective in dealing with long-term stressful situations because it only addresses the immediate emotional response, not providing the individual with tools to manage the stressor (Mishel et al., 2002). Greater use of avoidant coping in relation to breast cancer has been related to lower levels of one year survival, which reinforces this idea (Epping-Jordan, Compas, and Howell (1994)). Given such evidence, it is plausible to assume that interventions that increase use of positive approach coping and reduce use of disengagement may be effective in reducing distress and improving quality of life in ovarian cancer.

The Guided Disclosure Protocol (GDP) (Duncan & Gidron, 1999) discussed in Chapter 4**,** may not be sufficient for reducing distress because although it encourages appraisal of a stressful event, it does not teach alternative coping strategies. Thus, cancer patients may require additional guidance in stress-management related approaches, to teach problem focused coping and relaxation techniques.

Many stress management interventions have had a positive impact on cancer patients. For example, Antoni et al. (2001) found that a 10 week cognitive-behavioural stress management programme reduced the prevalence of depressive symptoms and increased benefit finding in breast cancer patients. However, since the writing consisted only of three 15-minute sessions, it was decided that a similar period of time would be appropriate for the stress management session, because its main aim was to enhance any benefits brought about by writing. Further, an intervention requiring a significant time commitment was believed to place considerable response burden on the participants, many of whom had been diagnosed with advanced stage cancer.

As evidence that brief interventions can be effective, Lekander, Furst, Rotein, Hursti, and Fredrikson (1997) found that three sessions of relaxation training led to increased lymphocyte numbers and higher proliferative responses to ConA in patients undergoing chemotherapy for ovarian cancer. Andersen (2002), in a review, concluded that many interventions have shown positive benefits for at least a subgroup of participants. Therefore, it was decided to add a 30 minute stress management session over the telephone, focusing on the use of problem-focused coping in controllable situations and emotion-focused coping in uncontrollable situations. This was based on the 'Goodness of Fit' hypothesis, suggested by Lazarus and Folkman (1984) that problem-focused coping is more effective in controllable situations, whereas emotion-focused coping is more effective in uncontrollable situations. This theory was supported by evidence from Forsythe and Compas (1987) who found a high level of symptoms when there was a poor fit between appraisal and coping strategy (trying to change uncontrollable stressors), but a low level of symptoms when there was a good fit between appraisal and coping strategy.

5.2 Aims and Hypotheses

This study, then, aimed to examine the effects of written disclosure and stress management on measures of well-being in patients with ovarian cancer. Overall, I hypothesized that the GDP and stress management intervention would lead to reduced perceived stress and intrusions, greater use of problem-focused coping and reduced use of behavioural disengagement, and improved quality of life in women with ovarian cancer. I further hypothesized that improvement in levels of intrusive thoughts and perceived stress, and quality of life would be mediated by increase in use of problem-focused coping and reduction of use of behavioural disengagement. I further hypothesized that improvements were expected to occur only due to the intervention, not due to passage of time or exposure to tests, and it was therefore decided to use an AAB design. I further hypothesized that the improvement would not differ according to the order in which the interventions were carried out. However, it was possible that the first intervention would influence the way in which the participants experienced the second intervention. For example, if they did the stress management first, they could then write about coping strategies on Day 3 of the writing. Therefore, there were two groups, to test for an order effect of the interventions.

5.3 Method

5.3.1 Design and Procedure

This pilot study was carried out to examine the combined effectiveness of written disclosure and stress management, and to investigate whether there was an order effect of the interventions. It used an AAB matched prospective design, since there was no control group. Patients with ovarian cancer who were interested in participating contacted the researcher by telephone or e-mail. After 8 participants had contacted the researcher, the participants were randomly assigned to either stress management first or written disclosure first, after matching for time since diagnosis and treatment. Each group of eight participants was divided into two. For each group of four participants, 2 slips marked 'Writing first' and 2 slips marked 'Stress management first' were put into a box. For each participant, the researcher drew a slip from the box. The researcher then posted an informed consent form and the questionnaires to the participants, enclosing a stamped self-addressed envelope. A month after the initial questionnaires had been received, the questionnaires plus the first intervention (either written disclosure or the stress management booklet, depending on which group the participant was assigned to) were sent out. The participants were required to complete the second questionnaires before taking part in the intervention. Two weeks after the first intervention was completed, the second intervention was sent out. A month after this was received, the final questionnaire was sent out.

5.3.2 Participants

The participants were 27 members of the UK ovarian cancer charity Ovacome. Originally, the study was advertised in their quarterly newsletter. From this, six people contacted the researcher to express an interest in participating. Further, I gave a brief presentation at the Ovacome members' day, and eight people approached me to express an interest in participating. Letters were then sent out to 39 members of Ovacome who had participated in a previous study the research team had run, and 13 people contacted me indicating willingness to participate. Further letters were sent out to a sample of Ovacome members living in the south (near Southampton university) who had ticked a box indicating willingness to be contacted by third parties when they joined Ovacome, and eight people contacted me expressing willingness to participate. Thus, originally 35 people were recruited. However, two people who had been disease-free for nearly 10 years since diagnosis felt the questionnaires irrelevant to them, and thus decided not to participate. One person withdrew from the study before participating, due to ill-health. One person died soon after completing the initial questionnaires. A further two dropped out after completing one intervention, due to ill-health. One person was unable to complete the follow-up due to ill-health. One person did not return the follow-up, and repeated telephone calls to her were not answered. Thus, the final sample consisted of 27 participants. Since this was a pilot study and limited psychological research had been done on this population, inclusion criteria were limited to having had a diagnosis of ovarian cancer, being able to read and write English, and being in good enough health to complete the study.

5.3.3 Background information

Background information was collected about the participants' age, cancer stage at diagnosis, time since diagnosis, time since treatment, type of treatment received, highest level of education completed, alcohol and cigarette intake, type and frequency of exercise, and frequency of relaxation (i.e., deep breathing exercises/ progressive muscle relaxation). This was assessed by a 5-point Likert scale ranging from 1 (not at all) to 5 (5 times per week or more). Follow-up data was collected about frequency of relaxation (see Appendices F and K).

5.3.4 Measures

The measures used were completed at both baselines and at follow-up (see Appendices, F, G and K).

5.3.4.1 Brief COPE

The Brief Coping Orientation to Problems Experienced (COPE) (Carver, 1997) assesses dispositional and situational abilities to cope with stress. The Brief COPE contains two items from each subscale. Items are measured on a 4-point self-report scale from 0 (I haven't been doing this at all) to 4 (I've been doing this a lot). For this study, the subscales of active coping, positive reframing, acceptance, emotional support, and behavioural disengagement were used, since previous studies i.e., Lutgendorf et al. (2002a), have shown active coping and positive reframing to be associated with better health, but behavioural disengagement to be associated with worse health. This was deemed to be the most appropriate coping scale for use with a clinical population – normative data was collected from survivors of a hurricane, whereas other measures of coping have been based on student samples.

5.3.4.2 Perceived Stress Scale

The Perceived Stress Scale (Cohen & Williamson, 1988) is a 10-item self-report scale measuring the extent to which individuals felt able to cope with stress in their lives during the past month. Items are rated on a 5-point scale from 0 (never) to 4 (very often). Normative data for this was collected from a sample of 2,387 people who completed a telephone interview. Cronbach's alpha was found to be .78, indicating good reliability. Scores were moderately related to responses on other measures of perceived stress, and numbers of life events experienced within the past year. Scores were also related to self-reported physical illness and utilization of health services. In this study, Cronbach's alpha ranged from 0.88 to 0.91, indicating good reliability. This was considered a suitable measure of appraisal of current stress levels, which the intervention aimed to reduce and correlates correlates highly with anxiety scales. This scale has been used with a wide variety of populations.

5.3.4.3 Impact of Event Scale-Revised

The IES-R (Weiss & Marmar, 1997) was developed to parallel the DSM-IV criteria for PTSD, and consequently includes three subscales of intrusions, avoidance and hyperarousal. It is a self-report measure designed to assess current subjective distress for any specific life event. Items are rated on a 5-point scale from 0 (not at all) to 4 (extremely). For this study, the intrusions subscale (revised version) was used (8 items).

In a study of four different population samples, internal consistency for the intrusions subscale ranged from 0.87 to 0.92 (Weiss & Marmar, 1997). Test-retest correlation coefficients ranged from 0.57 to 0.94. It has been shown to detect changes in clinical status over time, and to be sensitive to differences in response to traumatic events as a function of severity. With regard to content validity, the original intrusions subscale (one item was added for the IES-R), had a high endorsement of up to 85%. The intrusions subscale was used in this study as it was hypothesised that reductions in intrusive thoughts would indicate changes in cognitive restructuring and less need to inhibit unpleasant memories following the written disclosure intervention, and this scale has been used widely with cancer patients. Further, several studies have shown that intrusive thoughts longitudinally predict levels of anxiety and depression (Epping-

Jordan et al., 1999; Hipkins et al., 2004). Cronbach's alpha in this study ranged from 0.84 to 0.88, indicating good reliability.

5.3.4.4 Functional Assessment of Cancer Therapy-Ovarian

The FACT-O (Basen-Engquist et al., 2001) is a self-report scale that was developed to measure quality of life in people with ovarian cancer. There are four subscales that are relevant to any chronic illness (physical well-being, social/ family well-being, emotional well-being, functional well-being), and one scale specific to ovarian cancer (additional concerns). For this study, the physical well-being, social/ family well-being, emotional well-being and additional concerns subscales were used. Each item is rated on a 5-item scale from 0 (not at all) to 4 (very much). There are seven items in the physical well-being subscale, seven items in the social/ family well-being subscale, 6 items in the emotional well-being subscale, and 12 items in the additional concerns subscale.

Normative data was based on 232 outpatients with ovarian cancer (Basen-Engquist et al., 2001). Follow-ups were carried out at one week, to assess test-retest reliability, and at two months, to assess sensitivity to changes in performance status. Internal consistency and test-retest reliability were greater than 0.80 for the physical, emotional, and functional subscales, and for the FACT-O total score, indicating very good reliability, and ranged from 0.70 to 0.80 for the social well-being and ovarian-cancer specific scales, indicating satisfactory reliability. FACT-O scores were significantly correlated with other measures of quality of life, physical symptoms, anxiety, depression and family functioning as expected. FACT-O scores were sensitive to differences in performance status and whether the person was under active treatment or not, and the functional and social well-being and ovarian-cancer specific subscales were also sensitive to differences in disease stage. Change in performance status at two months follow-up was associated with an overall change in FACT-O subscales. Assessing quality of life is now viewed as being of primary importance in randomized controlled trials, and the FACT has been used in the majority of studies focusing on both gynaecologic cancer patients in general, and ovarian cancer patients. In this study, Cronbach's alpha ranged from 0.86 to 0.90 for the physical well-being subscale, indicating good reliability, from 0.79 to 0.85 for the social well-being subscale, indicating good reliability, from 0.62 to 0.80 for the emotional well-being subscale, which raises some concern, and from 0.57 to 0.69 for the ovarian-cancer specific subscale, indicating quite low reliability.

5.3.5 Writing intervention

This study used the Guided Disclosure Protocol, developed by Duncan and Gidron (1999), and tested in Gidron et al. (2002). The researcher telephoned the participants a few days after sending out the writing task, to ask if they had any questions about the task, and remind them about it. The participants were asked to reflect on their diagnosis and treatment of ovarian cancer, by writing for 15 minutes per day over three days, at home in a quiet room free from distractions. There were three parts to the writing. On Day 1, they were asked to describe the event in chronological order, in a 'journalistic manner', without expressing their emotions. On Day 2, they were asked to describe their thoughts and feelings at the time of the event (to enhance cognitive processing and verbal labelling of sensory and affective responses), and whether it affected their life (to enhance self-reflection and insight). On Day 3, they were asked to describe how they currently thought and felt about the event (to enhance perspective-taking), and how they would cope with similar events, should they be encountered in the future (to enhance self-regulation). The full protocol is presented in Appendix J.

The writing was analysed by the computer programme *Linguistic Inquiry and Word Count* (Pennebaker, Francis, & Booth, 2001), to see whether use of affective (positive and negative emotion) and cognitive (insight) words in the written disclosure tasks were related to improvement on the psychological measures. Pearson correlations were carried out to see the relations between the change in the main psychological variables from baseline to follow-up, after controlling for baseline levels of these variables and affective and cognitive words used on days 2 and 3 of the writing.

5.3.6 Stress Management Intervention

I designed the stress management intervention, and it was checked by and pilot-tested on my supervisor. It was also pilot-tested on one of the support staff in the Ovacome office, a nurse who had had training in counselling, and was experienced in dealing with Ovacome members. The topics covered included problem-focused coping (problem solving), emotion-focused coping (deep breathing exercises) and assertiveness when communicating with doctors, with a focus on tailoring coping strategies to the situation. In addition to the session, a booklet explaining the main points was sent out to the participants, for reference during the intervention (see Appendix I).

I telephoned the participants a few days after sending out the booklet, to arrange a convenient time for them to take part in the programme (approximately 30 minutes over the telephone), and to remind them to first complete the questionnaires, and to have the booklet available for the stress management session.

I telephoned the participants at a previously agreed time, to carry out the stress management session. After introducing myself, I explained about the different types of coping strategies that could be used depending on whether the situation was controllable or uncontrollable. I then invited the participant to choose a controllable problem they wished to work on, and to try to solve it according to cognitive-behavioural principles. I then asked the participant to give examples of uncontrollable situations, and taught the participant a method of deep breathing. Finally, I gave the participant some advice on being assertive with their doctor (i.e., asking if there were alternative treatments with less toxicity). I delivered the intervention following an intensive course on Stress Management at the Centre for Stress Management in London, UK. The protocol for this intervention is presented in Appendix H.

5.3.7 Data Analysis

The data was analysed using SPSS for Windows (version 12). Since this was an exploratory study, it was decided to conduct a number of analyses, despite awareness that this could increase the risk of Type 1 error. The aim was to see whether there was an improvement from baseline to follow-up, such that conditions differed in relation to the various psychological measures only at follow-up. To determine the effects of the intervention on the outcome variables, repeated measures mixed analyses of variance (ANOVA) were conducted, with group (GDP first, SM first) being the between-subjects factor and time (first baseline, second baseline, follow-up) being the within-subjects factor. Where appropriate, disease stage was entered as a covariate. Significant effects of time were followed up with planned contrasts comparing the first and second baseline, and the first baseline and the follow-up, in order to see where the differences occurred. A non-significant result when comparing first and second baseline coupled with a significant result when comparing first baseline and follow-up was taken as evidence that the improvement was due to the interventions.

5.4 Results

5.4.1 Participant characteristics:

The mean age of the participants was 56.1 (range 33 to 72). The majority of the participants had advanced stage disease (Stage I: 4, Stage II: 4, Stage III: 16, Stage IV: 3). Demographic characteristics of the groups are presented in Table 6.

Table 6. Baseline demographic information as a function of group

	Stress Management First Mean *(SD)*	Writing First Mean *(SD)*
Age	58.17 (8.68)	54.64 (9.40)
Time since diagnosis (months)	35.75 (13.1)	40.71 (29.1)
Time since treatment (months)	17.42 (13.4)	25.07 (27.7)
Exercise	3.25 (1.06)	4.21 (0.89)
Alcohol consumption (units per week)	4.10 (3.31)	5.0 (3.63)
Relaxation	2.17 (1.02)	2.14 (0.66)
Smoke	0	Yes - 2, No – 12
Disease stage	Early – 42%, Advanced – 58%	Early – 21%, Advanced – 79%

Independent samples T-tests were carried out on the continuous demographic variables. These showed that the groups were well matched with regard to age, time since diagnosis and treatment, alcohol consumption, and frequency of relaxation. However, the writing first group did significantly more exercise than the stress management first group. However, since this was a pilot study, with a small sample, it was decided not to include exercise as a covariate. Chi-square tests were carried out in relation to the categorical demographic variables of disease stage and tobacco consumption. No significant differences were found between the groups. For the ANOVAs, disease stage was controlled for if it correlated with change in scores from baseline to follow-up. One participant in the stress management first group had to be excluded from the analyses, because personal communication revealed that she completed Day 3 of the writing approximately one month after Day 2. All results are reported in Table 7.

5.4.2 Quality of Life

5.4.2.1 Physical

Initial examination of the data revealed high levels of skewness and kurtosis at second baseline. A reflect and logarithm transformation improved the fit of the data to a normal distribution, and therefore all statistical tests were carried out on the transformed data. Since Pearson correlations revealed that change in physical quality of life from first baseline to follow-up was correlated with disease stage (*r* = -.421, *p* = .04), stage was included as a covariate in all subsequent analyses. There was a significant effect of time on physical quality of life: (*F* (2, 46) = 3.32, *p* = .05), but no main effect of group (*F* (1, 23) = 1.49, *p* = .24), and no group-by-time interaction (*F* (2, 46) = 1.21, *p* = .31). Planned contrasts revealed no significant differences from first baseline to second baseline (*F* (1, 24) = .87, *p* = .77); but a trend towards significant differences from first baseline to follow-up (*F* (1, 24) = 2.92, *p* = .10). Examination of effect sizes revealed a small effect for the writing first group, but no effect for the SM first group.

5.4.2.2 Social

There was no effect of time on social quality of life (*F* (2,48) = 2.05, *p* = .14), no effect of group (*F* (1,24) = .62, *p* = .44) and no group-by-time interaction (*F* (2, 48) = .98, *p* = .38). However, examination of effect sizes revealed a small to medium effect for the writing first group only.

5.4.2.3 Emotional

There was no effect of time on emotional quality of life (*F* (2, 48) = .26, *p* = .77), no effect of group (*F* (1, 24) = .995, *p* = .33) and no group-by-time interaction (*F* (2, 48) = .04, *p* = .96). Examination of effect sizes revealed no effect for either group.

5.4.2.4 Ovarian-cancer specific concerns

There was no effect of time on ovarian cancer specific concerns (*F* (2, 48) = .90, *p* = .41), no effect of group (*F* (1, 24) = .19, *p* = .67), and no group-by-time interaction (*F* (2, 48) = 1.00, *p* = .38). However, examination of effect sizes revealed a small effect for the writing first group.

5.4.3 Coping

With regard to coping, it was decided to analyse only the ‘active coping’ and ‘behavioural disengagement’ subscales, to reduce the probability of Type 1 error. Active coping was considered to be the best example of problem-focused coping, and behavioural disengagement was considered to be the best example of an ineffective strategy, based on previous research (Lutgendorf et al., 2002a).

5.4.3.1 Active coping

The mean at baseline was very close to ceiling level. Examination of histograms of the data revealed severe negative skewness at all time points. A reflect and inverse transformation was attempted, but this did not reduce the skewness and kurtosis values. Therefore, this data was analysed using non-parametric statistics. The Friedman test revealed no significant differences in scores between the three time points ($\chi 2$ = 1.50, *p* =.47).

5.4.3.2 Behavioural disengagement

The mean at baseline was very close to ceiling level. Examination of histograms of the data revealed severe negative skewness at all time points. As a reflect and inverse transformation did not reduce skewness and kurtosis, this data was analysed using non-parametric statistics. The Friedman test revealed no significant differences in scores between the three time points ($\chi 2$ = 1.14, *p* = .57).

5.4.4 Intrusive thoughts

Close examination of the data revealed high levels of skewness at follow-up. A square root transformation reduced levels of skewness and kurtosis, resulting in the data being more normally distributed. Therefore, all statistical analyses were carried out on the transformed data. Pearson correlation revealed that change in levels of intrusive thoughts from first baseline to follow-up was not correlated with disease stage (r = -.05, p = .83), and therefore it was decided not to include disease stage as a covariate in subsequent analyses. There was a significant effect of time on levels of intrusive thoughts (*F* (2, 48) = 5.07, *p* = .01), but no effect of group (*F* (1, 24) = .37, *p* = .56) and no group-by-time interaction (*F* (2, 48) = 1.65, *p* = .20). Paired t-tests revealed that there were significant differences from first baseline to follow-up (t (25) = 2.87, *p* = .008), but not from first baseline to second baseline (t (25) = .42, *p* = .68). These results are displayed in Figure 1. Examination of effect sizes revealed a medium to large effect for the writing first group and a small to medium effect for the SM first group.

5.4.5 Perceived Stress

Pearson correlation revealed that change in levels of perceived stress from first baseline to follow-up was not correlated with disease stage (r = -.03, *p* = .91). There was a significant effect of time (F (2, 48) = 5.97, *p* = .005), but no effect of group (F (1, 24) = .24, p = .63), and no group-by-time interaction (F (2, 48) =. 89, *p* = .42). Paired T-tests revealed that there were significant differences from first baseline to follow-up (t (25) = 3.32, *p* = .003), but not from first baseline to second baseline (t (25) = 1.6, *p* =

.12). These results are reported in Figure 2. Examination of the effect sizes revealed a large effect for the writing first group and a small effect for the SM first group.

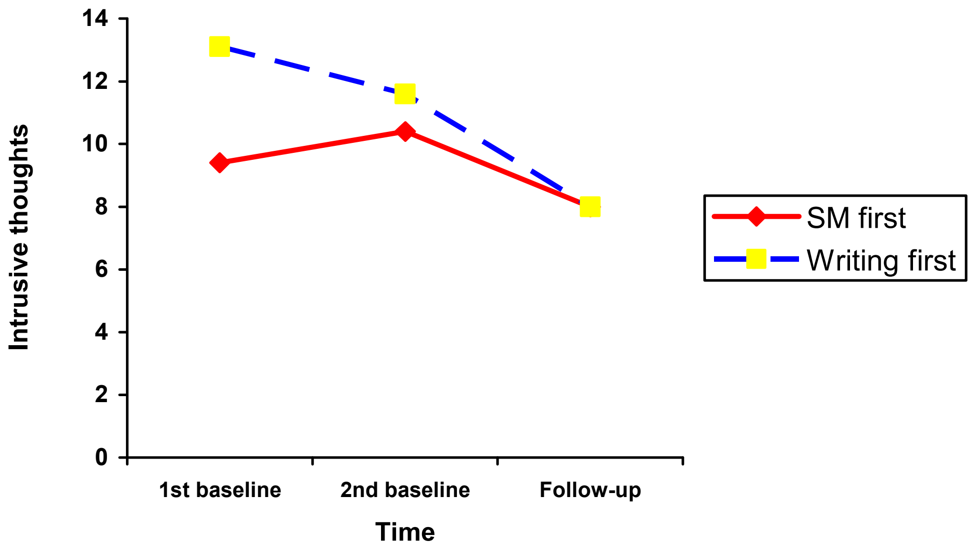

Figure 1. Effects of the GDP plus stress management on intrusive thoughts

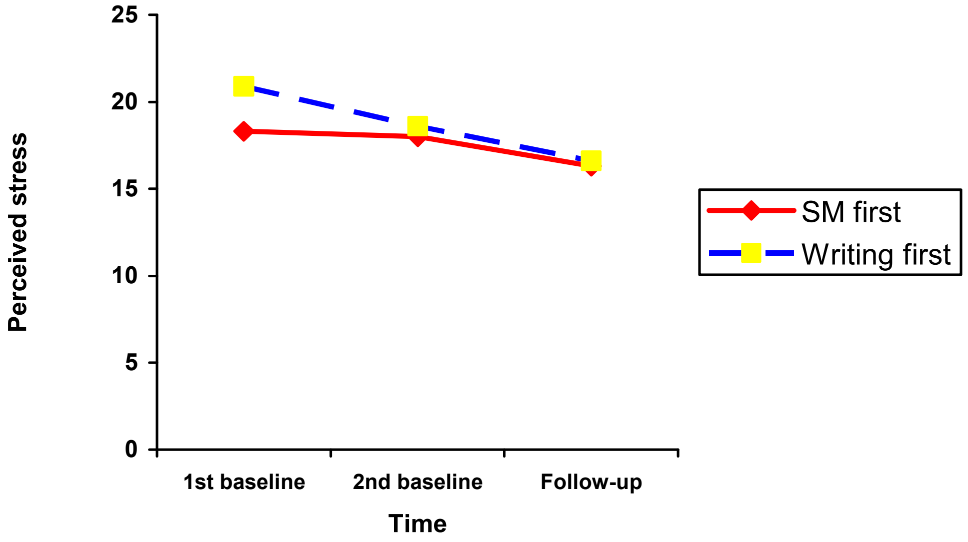

Figure 2. Effects of the GDP plus stress management on perceived stress

Table 7. Effects of written disclosure and stress management on psychological variables

Variable	Group	First baseline	Second baseline	Follow-up	Effect size
		Mean *(SD)*	Mean *(SD)*	Mean *(SD)*	Cohen's D (1st baseline to follow-up)
Physical QoL	Writing first	22.07 (6.02)	22.93 (6.40)	23.93 (5.18)	.32
	SM first	21.41 (5.68)	21.58 (6.05)	21.50 (5.83)	.02
	Overall	21.77 (5.76)	22.31 (6.16)	22.81 (5.52)	.18
Social QoL	Writing first	15.93 (4.05)	16.14 (4.54)	17.64 (4.91)	.38
	SM first	18.33 (5.50)	17.33 (6.23)	18.33 (4.54)	0
	Overall	17.04 (4.83)	16.69 (5.30)	17.96 (4.66)	.21
Emotional QoL	Writing first	14.86 (5.95)	14.79 (4.63)	15.29 (5.04)	.07
	SM first	16.58 (3.20)	16.17 (2.72)	16.67 (2.64)	.03
	Overall	15.7 (4.87)	15.4 (3.86)	15.9 (4.10)	.04
Ovarian cancer specific concerns	Writing first	36.64 (5.37)	37.50 (5.17)	38.21 (5.65)	.29
	SM first	37.0 (6.21)	35.75 (5.31)	37.0 (5.59)	0
	Overall	36.81 (5.66)	36.69 (5.21)	37.65 (5.54)	.16
Active coping	Writing first	6.64 (1.55)	6.93 (0.92)	7.0 (1.47)	
	SM first	6.25 (1.54)	6.08 (1.70)	6.42 (1.31)	
	Overall	6.46 (1.53)	6.54 (1.36)	6.73 (1.40)	
Behavioural disengagement	Writing first	6.93 (1.44)	6.64 (1.78)	7.07 (1.21)	
	SM first	7.58 (1.16)	7.67 (0.65)	7.58 (0.90)	
	Overall	7.23 (1.34)	7.12 (1.45)	7.31 (1.09)	
Perceived stress	Writing first	20.86 (6.20)	18.64 (5.44)	16.57 (6.02)	.70
	SM first	18.33 (7.32)	18.0 (6.52)	16.33 (7.32)	.27
	Overall	19.69 (6.72)	18.35 (5.85)	16.46 (6.51)	.48
Intrusive thoughts	Writing first	13.14 (6.94)	11.57 (7.04)	9.0 (6.78)	.60
	SM first	9.42 (4.58)	10.42 (4.85)	8.0 (3.54)	.34
	Overall	11.42 (6.15)	11.57 (6.04)	8.54 (5.45)	.50

Since there were no changes in coping, the reductions in levels of intrusive thoughts and perceived stress were not due to changes in coping, and therefore no mediation analyses were carried out.

5.4.6 Relaxation

A paired T-test revealed that the participants reported doing significantly more relaxation at follow-up compared to first baseline (t (25) = -4.46, *p* < .001). Whereas the baseline mean was 2.15, indicating that the majority of participants did relaxation once a week or less, the follow-up mean was 3.27, indicating that the majority of participants did relaxation once or twice a week. However, bivariate correlations (controlling for frequency of relaxation at baseline) revealed that increases in frequency of relaxation were not related to improvements in levels of perceived stress (r = 0.15, *p* = .48), intrusive thoughts (r = .08, *p* = .71), quality of life (r = .05, *p* = .80) or behavioural disengagement
(r = .25, *p* = .22). However, there was a trend towards a relation between increase in frequency of relaxation and improvements in active coping (r = .38, *p* = .06).

5.4.7 Content analyses of the writing

Content analyses were carried out to see the percentages of affective (positive and negative emotion words) insight, and causality words used on Days 2 and 3 of the writing, using *Linguistic Inquiry and Word Count* (Pennebaker et al., 2001). Reduction in perceived stress was correlated with greater use of affective words in general (r = -0.42, *p* = .03) and greater use of negative emotion words (r = -0.42, *p* = .03) on Day 2. Reduction in intrusive thoughts was correlated with greater use of negative emotion words (r = -0.37, *p* = .06) and greater use of anxiety/ fear words (r = -0.40, *p* = .05) on Day 2. Reduction in levels of perceived stress was correlated with greater use of cognitive words in general (r = 0.40, *p* = .04), and greater use of causality words (r = -.57, *p* = .002) on Day 3.

5.5 Discussion

The results partially supported the hypotheses. Perceived stress and intrusive thoughts decreased from baseline to post-test, but not from first to second baseline, indicating that the intervention was successful in reducing distress in patients with ovarian cancer. Effect sizes were large for the writing first group and small for the SM first group. These improvements appeared to be related to the words used on Days 2 and 3. This offers tentative support for the cognitive processing hypothesis of written emotional disclosure, and the importance of emotional labelling. It is important to note that frequency of relaxation did not affect outcomes. Reflecting on how they currently felt about their diagnosis and treatment and how they were now able to cope with similar situations (as required on Day 3) may have helped participants to put the event into perspective and to self-regulate. The precise verbal labelling and processing of unpleasant emotions reduces arousal, thereby aiding in integrating emotional reactions into the general understanding of a traumatic event (Pennebaker et al., 1997), and may reduce amygdala activity and increase PFC activity (Hariri et al., 2000). In support of this hypothesis, increased use of negative emotion words was related to greater reduction in levels of intrusive thoughts.

There was also a trend towards improvement in physical quality of life from first baseline to follow-up. However, since this improvement was not related to words used on Day 2 or Day 3, it is not possible to say with any degree of certainty which part of the intervention was responsible for it. Examination of the effect sizes revealed small effects for physical quality of life, social quality of life and ovarian cancer specific concerns, in the writing first group only. Writing prior to talking have may influenced participants' willingness to disclose information in the stress management session, by reducing their distress and increasing their self-control, in line with the social interaction hypothesis (Pennebaker & Graybeal, 2001), and particularly the 'implicit audience' theory (Brody & Park, 2004). However, since the writing first group reported higher levels of stress and intrusive thoughts and worse social quality of life at baseline, these results should be interpreted with caution. Finally, with regard to the FACT-O, there were no effects on emotional quality of life. Examination of the items revealed that they were similar to those assessing clinical levels of depression, such as the CES-D (Radloff, 1977), whereas the presence of clinical levels of distress was not a requirement for participation.

Problem-focused coping improved very little, and change in coping was not related to improvements in other outcomes. This suggests that the mechanism by which improvement occurs is not increased use of problem-focused coping. However, an increase in active coping was correlated with an increase in frequency of relaxation, suggesting that participants who did more relaxation may have also used more problem-focused coping in controllable interventions. Further research is needed to examine moderators of the efficacy of cognitive-behavioural stress management. However, due to the small sample, these results should be interpreted with caution. Alternatively, there are several other explanations for the lack of improvement in coping. First, problem-focused coping was close to ceiling level in this population, leaving little room for improvement. The study population were members of a support group, and thus may have been more likely to use adaptive coping strategies than the general population with ovarian cancer (Grande et al., 2006). Second, the measures may not have targeted outcomes with sufficient sensitivity – it may have been more appropriate to ask participants if they used more problem-focused coping in specific controllable situations, and more emotion-focused coping in specific uncontrollable situations, such as when waiting for CA-125 test results, as this causes considerable anxiety (Parker et al., 2006). Third, the stress management intervention may not have been sufficient for improvements in this population. Although participants increased the amount of relaxation they did from baseline to follow-up, which suggested that they had engaged with the programme, and reported that they liked it, this was not related to improvement on any of the outcome measures, except active coping, which was close to ceiling level at baseline. There are several possible reasons for this result. First, it only took 30 minutes over the telephone – many such interventions take several months, with an hourly meeting every week. Therefore, it may not have been long enough to bring about lasting change. Second, it was carried out by a research student who had no formal training in counselling. However, since there were no follow-ups in between the interventions (partly to decrease response burden, and partly because the full intervention package was deemed necessary for maximum benefit), it is not possible to conclude definitively which part of the intervention was responsible for improvements.

5.5.1 Limitations

This study had several limitations. First, although the participants were told to write for 15 minutes per day over three days, this was not directly monitored. Although personal communication suggested that most participants followed the instructions, it would be advisable to monitor this directly in future studies, by telephoning the participants before and after they write. Second, the participants were only followed up at one month – a longer follow-up may have revealed greater improvement, and would have provided information about maintenance of benefits. This is particularly relevant with regard to CA-125, which will be recorded in the main study – patients are tested more regularly when they are on chemotherapy, whereas those who have been disease-free for several years are tested once every three or six months. Third, the sample size was quite small, which increased the likelihood of the results being skewed by participants with extreme scores. Further, it was not possible to test for U-shaped relations – this is important because writing at a moderate level of complexity is related to greater improvement at follow-up (Suedfeld & Pennebaker, 1997). Fourth, the questionnaires were returned to the principal researcher, which may have increased the likelihood of observer bias. However, the differential effects between the writing first and SM first groups suggest that this is unlikely to be the only reason for the positive outcomes. Finally, the participants in this study were members of a support group, so not necessarily representative of the general population with ovarian cancer. However, since this intervention has never been carried out on ovarian cancer patients before, the main aim was to see whether it could reduce psychological distress – a search of the literature revealed that only seven psychological interventions have been tested on ovarian cancer patients. If the intervention was found to be beneficial, it would need to be replicated on a more representative sample.

Given that this study suggested that benefit obtained was mainly due to the writing, the main study aims to test the effects of written disclosure as a stand-alone intervention on ovarian cancer patients and their partners, using a larger sample, and with a longer-term follow-up. The introduction and method for the main study are presented in Chapter 6.

Chapter Six: The effect of guided written disclosure on distress and quality of life in women with ovarian cancer and their partners: A randomized controlled trial: Aims and Method

6.1 Introduction

The previous chapters have identified several important findings. First, many patients with ovarian cancer experience significant levels of distress. Second, psychological interventions could be beneficial for a large proportion of patients who desire them. Third, partners of cancer patients also experience significant levels of distress. Fourth, partners' distress and couple communication are significantly associated with psychosocial adjustment in both patients and partners. Fifth, written emotional disclosure has been effective in improving health in patients with chronic illnesses, and improving psychological outcomes in studies targeting relationship processes. Further, evidence suggests it may be effective in improving health outcomes in cancer patients. The pilot study found that word usage on days 2 and 3 of the GDP was associated with benefits in patients with ovarian cancer. However, the effects of the GDP on the well-being of patients and spouses of women with ovarian cancer have not been tested. This study therefore aims to assess the effectiveness of the GDP in reducing distress and improving quality of life in women with ovarian cancer and their partners. Before conducting research, it is important to have explicitly defined hypotheses, in order to test theoretical models, ensure that interventions are expected to be effective, and reduce the risk of Type I error. This chapter therefore starts by outlining the aims and hypotheses of the main study, and the rationale for these.

6.2 Hypotheses

6.2.1 Primary Outcomes

6.2.1.1 Aim 1: To evaluate the effectiveness of the GDP compared to control writing in reducing distress and improving quality of life in ovarian cancer patients and their partners

To the best of my knowledge, there are no reported RCTs assessing the effects of written emotional disclosure as a stand-alone intervention for couples or as an intervention for couples where one partner has a chronic illness. Furthermore, very few studies have tested the effectiveness of guided writing. The purpose of the current research was to test the effectiveness of writing about the diagnosis and treatment of the patient's cancer according to the GDP in reducing distress and improving quality of life in women with ovarian cancer and their partners, compared to writing about what the patient did the previous day, which was selected in order to control for experimenter contact, expectations, and the partner thinking about their wife.

In terms of primary outcomes, it was hypothesized that:

- Couples who wrote about the patient's diagnosis and treatment following the GDP for 15 minutes a day over three days would demonstrate significantly greater improvements in quality of life and reductions in perceived stress at three month follow-up when compared to couples who wrote about what the patient did the previous day, for 15 minutes a day over three days.
- Improvements for the GDP group would be maintained at six months

6.2.2 Secondary Outcomes

6.2.2.1 Aim 2: To evaluate the effectiveness of the GDP in reducing visits to health professionals in ovarian cancer patients

Previous written disclosure studies have found significant reductions in visits to health professionals in healthy students (Smyth, 1998), using the GDP (Gidron et al., 2002) and in cancer patients (Stanton et al., 2002). As effects of writing in chronic illness are stronger for physical than psychological health outcomes (Frisina et al., 2004), the current study aimed to investigate the effectiveness of the GDP in reducing visits both to consultants/ GPs and to alternative therapists. Since ovarian cancer is often diagnosed at a late stage, following several misdiagnoses, this tends to impair patients' trust in their GPs, leading them to explore alternative therapies.

It was hypothesised that:

- Patients in the GDP group would show significant reductions in visits to GPs/ consultants and visits to alternative therapists at three month follow-up, relative to those in the control group
- These benefits would be maintained at six month follow-up.

6.2.2.2 Aim 3: To see whether the GDP reduces CA 125 levels

CA 125 is a tumour marker with high prognostic value in ovarian cancer (Bast et al., 1983). Preliminary evidence suggests that dispositional optimism is a significant predictor of CA 125 (de Moor et al., 2006). However, the relation between psychological factors and CA 125 has been investigated in very few studies. Given that psychiatric disorders are associated with worse survival post-diagnosis (von Georgi et al., 2002), the current study aimed to see whether the GDP would lead to improvements in CA 125.

It was hypothesized that:

- CA 125 would be lower for patients in the GDP group at three month follow-up, relative to the control group.
- These benefits would be maintained at six month follow-up.

6.2.3 Aim 4: To examine potential mediators of the efficacy of the GDP

Evidence has suggested that written emotional disclosure is effective in improving physical and psychological health. However, the reason for its beneficial effects is unclear, although several mechanisms have been hypothesised. This study aimed to see whether the cognitive processing hypothesis or the social interaction hypothesis was more effective in explaining the benefits brought about by the GDP.

It was hypothesised that:

- The GDP would lead to reductions in levels of intrusive thoughts and distress about the illness, and improvements in both general and illness-related communication relative to the control group at three month follow-up, and these benefits would be maintained at six month follow-up.
- The GDP would lead to improvements in quality of life and reductions in perceived stress through reductions in levels of intrusive thoughts and distress about the illness, in line with the cognitive processing hypothesis.
- The GDP would lead to improvements in quality of life and reductions in perceived stress through improvements in both general and illness-related couple communication, in line with the social interaction hypothesis.

6.2.4 Aim 5: To identify factors associated with treatment outcomes

One objective of the present study was to evaluate potential predictors and moderators of improvements in quality of life and perceived stress. Specific illness variables, baseline levels of some secondary outcome measures, change in levels of some of the secondary outcomes, and aspects related to the actual intervention were selected as potential predictors, moderators and moderated mediators based on clinical or theoretical rationales. A moderator can be defined as a variable that influences the strength of the relation between an independent and a dependent variable (in this context, the relation between group and quality of life/ perceived stress). Moderated mediation occurs when the process by which treatment leads to the outcome depends on the value of a moderator variable (Muller, Judd, & Yzerbyt, 2005). Thus, it enables understanding of the conditions under which mediation may occur. Although such analyses have often been dismissed as "fishing," Kraemer, Wilson, Fairburn, and Agras (2002) are of the view that 'There has recently been growing recognition ...that carefully and expertly performed hypothesis-generating activities are necessary to foster stronger hypotheses for the next generation of hypothesis-testing studies and to provide the background information necessary to design such powerful studies' (p 882). Thus, although not all the moderators or moderated mediators are directly related to the study aims, they were considered important in order to generate theoretically relevant information through enhancing understanding of those for whom the intervention worked and the processes by which it did so (Hinshaw, 2007).

In Chapter 2, having recurrent ovarian cancer was not conclusively associated with quality of life or distress. Nevertheless, given that recurrence means the disease is incurable, and thus individuals who have experienced a recurrence face different stressors from those who have not, it was important to assess if recurrence status had an impact on the primary outcomes, partly to clarify for whom the GDP might be effective. Moderation analysis was considered a more appropriate way to assess this than sensitivity analysis, as over half the sample had experienced a recurrence.

Given that one expected outcome of the research was improvements in marital communication, it was expected that the GDP might be more effective for those who could be classified as less satisfied with regard to marital communication. Also, based on research regarding communication and psychosocial outcomes (i.e., Manne et al., 2006), it was expected that those who improved more with regard to illness-related couple communication would benefit more from the GDP, and thus change in illness-related communication was selected as a potential moderated mediator. According to the cognitive processing hypothesis, it was expected that those who improved more with regard to intrusive thoughts would benefit more from the GDP, and thus change in intrusive thoughts was selected as a potential moderated mediator. Finally, given that previous research has demonstrated that partner distress is associated with worse outcomes for the patient (i.e., Northouse et al., 1995), the current study aimed to assess whether partners' intrusive thoughts predicted or moderated the primary outcomes.

One predictor was chosen that related to aspects of the actual intervention: views about the intervention. It was important to assess if those who liked the intervention benefited, as this would suggest that the GDP could be offered to those who viewed it positively.

6.2.5 Aim 6: To identify whether word usage was related to treatment outcomes

Previous research has shown correlations between word usage and health improvements (Pennebaker et al., 1997; Danoff-Burg et al., 2006), which have been related to cognitive processing. In line with the cognitive processing hypothesis, it was expected that:

- Participants in the GDP group would use more emotion, insight and causality words on days 2 and 3 of the writing than the control group.
- Use of emotion, insight and causality words would be related to improvements in the primary outcomes.

6.2.6 Aim 7: To identify whether participants in the GDP group reported talking and thinking more about the writing at follow-up relative to the control group

According to the social interaction hypothesis, written disclosure changes the way in which participants interact with others, leading to increased discussion of the traumatic event (Pennebaker & Graybeal, 2001). Such increased discussion of the event is likely to be related to thinking more about it. It was therefore hypothesized that:

- Participants in the GDP group would report thinking and talking more about what they wrote, relative to those in the control group

6.2.7 Aim 8: To evaluate whether patient and partner improvement were correlated

In the current study, both women with ovarian cancer and their partners wrote about the woman's diagnosis and treatment of ovarian cancer. Since it was expected that writing about the woman's illness would provide a context for couples to discuss the illness, and possibly help them arrive at a shared understanding of how to cope with it, it was hypothesized that within the GDP group, patient and partner improvement on the primary and secondary outcomes from baseline to three month follow-up would be correlated, whereas such correlations would not be significant for the control group.

6.2.8 Aim 9: To see whether discrepancy in communication moderated the effects of the primary outcomes

The majority of the hypotheses have focused on each individual member of the couple. However, research has suggested that congruence between couples may be an important influence on psychological adjustment (Sagy & Antonovsky, 1992). The current study aimed to test this by assessing first, whether discrepancy with regard to both general and illness-related couple communication was related to levels of the primary outcomes of perceived stress and quality of life at baseline, and second, if these results were significant, whether change in discrepancy from baseline to three month follow-up moderated the effects of group on quality of life and perceived stress.

6.3 Method

The study was a randomized controlled trial in which the Guided Disclosure Protocol (GDP) (Gidron et al., 2002) for written emotional disclosure was compared to control writing. The study was approved by the School of Psychology Ethics Committee, University of Southampton.

The study followed the Consolidated Standards of Reporting Trials (CONSORT) guidelines for designing and reporting the results of RCTs (Moher et al., 2001). Participants who were eligible and had provided informed consent were randomized to writing for 15 minutes a day over three days, either about the patients' diagnosis and treatment in a structured way (the GDP) or about what the patient did the previous day (control). The control condition was designed to control for experimenter contact, expectations, and the partner thinking about the patient, and has been used in a number of written disclosure studies.

6.3.1 Random assignment, concealment and blinding

Prior to commencement of the study, the program www.randomization.com was used to generate a table indicating assignment to groups. This was carried out twice, as patients were stratified based on whether they had had a recurrence since their initial diagnosis, in order to increase the probability of obtaining two equivalent groups with regard to prognosis. Randomization was then carried out separately for patients with and without a recurrence. As the sample was quite small, randomization was done in blocks of ten. Following this, opaque envelopes were numbered and the appropriate condition was written on a slip inside each envelope. The random numbers table was then destroyed, and the envelopes kept in a locked cabinet to which the principal researcher did not have access. Following return of the initial questionnaire, each couple was given a number based on the order in which they had entered the trial, and this number corresponded with a numbered envelope. An independent administrator who was not connected with the project then opened the cabinet, opened the appropriate envelope, and told me which condition the participant was assigned to, after which I put the appropriate task in an envelope and sent it to the participant.

As this study was carried out by a single researcher, double blinding was not possible. However, several other measures were taken to reduce bias. First, the questionnaires were returned to my supervisor, who had had no contact with the participants and was unaware of their group allocation, in order to reduce the risk of measurement bias. Also, the outcomes were assessed by self-report questionnaires, which the participants filled in at home in their own time, except for CA 125, which was measured by consultants who were unaware of the study and later self-reported by patients. Second, although I telephoned the participants to tell them when to start and stop writing, the instructions were clearly stated on the writing booklet, and I timed the writing in order to reduce the risk of performance bias. The participants were not informed about group assignment. They were merely told in the consent form that a certain type of writing had been shown to benefit health in a variety of illnesses, and that they would be asked to write about events in either an emotional or a non-emotional way.

6.3.2 Participants

The participants were recruited from Ovacome, a UK charity for patients with ovarian cancer. Initially, the study was advertised in the Ovacome newsletter, and interested participants were invited to contact me for further information. Once the advertisement had been placed, letters were sent out to 530 patients who had given prior consent to be contacted by third parties, with the title 'Mrs' to maximize recruitment of couples, at four time points between May 2006 and June 2007, informing them about the study and inviting them to participate. Interested individuals were invited to write their name and telephone number on a slip which was returned to me in an attached stamped addressed envelope. Those who were not interested were requested to fill in a slip where they could tick one of four boxes indicating the reason why from 'I am not interested', 'I am too busy' or 'I am not feeling well' or 'Other (please specify where possible)'. This procedure was carried out in order to determine reasons for non-participation where possible. Those who had further questions were invited either to e-mail me or contact me via the Ovacome office.

I telephoned those individuals who had indicated their willingness to participate, thanked them for returning the slip and asked if they had any questions about the study, and asked several screening questions in order to ensure that they met the inclusion criteria and could be randomized accurately. These questions covered the treatment the patient received when she was diagnosed, whether she had received any treatment since (for stratification purposes), time since initial diagnosis, and whether the patient's husband/ partner would be willing to participate. Once eligibility had been determined, I took the patient's address and posted out the initial questionnaire.

The inclusion criteria were:

- A definite diagnosis of ovarian cancer.
- No more than five years since last treatment. During this period individuals are seen by their consultant once every six months or more, and their CA 125 level is tested at each visit.

The exclusion criteria were:

- Being unable to speak, read or write English.
- Being under 18 years old.

The inclusion criteria for spouses were:

- Having a partner with ovarian cancer with whom they lived full-time.

All those who agreed to participate were sent the initial questionnaire and a consent form. Questionnaires were returned in stamped addressed envelopes to my supervisor. Upon receipt of the initial questionnaire, I sent out the writing task, and telephoned the couple several days later to arrange mutually convenient times for them to do the writing. On each day of the writing, I telephoned the participant at a mutually agreed time, to tell him/her to start writing, and again after 15 minutes to tell him/her to stop writing. After completing the third day of the writing, participants were thanked for their involvement in the task and requested to return the writing to the supervisor in the attached stamped addressed envelope. Follow-up questionnaires were sent out after three and six months and returned to my supervisor, who had had no contact with the participants. Once the final questionnaire had been received from both partners, the couple was sent a debriefing form.

6.3.3 Writing Protocol

In the treatment group, the couples wrote about the patient's diagnosis and treatment for 15 minutes a day over three days within one week. Couples were required to write on the same days, but not at the same times (although a number of couples chose to do so). If both members of the couple chose to write at the same time, I spoke to only one member of the couple (whoever answered the telephone), but if they chose to write at separate times, I spoke to each member of the couple separately. In the control group, the patients wrote about what they did the previous day, and the partners wrote about what their partner did the previous day, in order to control for the partner thinking about the patient. As in previous trials, this controls for experimenter contact and expectations, and for the effects of being required to write. Participants were asked to find a quiet place free from distractions, and were told not to worry about grammar, spelling or sentence structure, and to write continuously for the entire time.

The GDP protocol was as follows: On Day 1 of the study, the participants were asked to describe the diagnosis and treatment chronologically, and to describe what caused what, without mentioning their emotions. Day 2 was divided into two parts. First, the participants were required to describe how they felt and what they thought at the time of the diagnosis. Second, they were required to write about the impact that their diagnosis and treatment had had on their lives, and whether it had caused them to change priorities. On Day 3, they were required to describe how they currently felt and thought about the diagnosis and treatment, whether their thoughts and feelings now were the same as at the time of diagnosis, and whether they would be able to cope with similar situations better because they had experienced it. The protocols for both conditions are included in Appendices R and S.

6.3.4 Assessments and Measures: Background Demographic and Biomedical Information

Demographic information was collected at baseline about age, occupation, highest level of education completed, marital status and length of time married. Medical information about cancer stage at diagnosis, time since diagnosis, time since last treatment, whether the participant had received surgery, chemotherapy (with drugs received mentioned if known) and radiotherapy, number of courses of chemotherapy, and whether the participant was currently undergoing treatment and if so what, were obtained by self-report. In addition, at each follow-up participants were asked if they were currently undergoing treatment and if so what. In addition, information was collected at baseline about whether the participant smoked and if so how many cigarettes per day, whether they drank alcohol and if so how many units per week, and how often they exercised per week, which was answered on a five point scale from ‘5 times a week or more’ to ‘Never’ (see Appendix P).

6.3.5 Outcome measures

Assessments included self-report measures which were collected in questionnaire form, and an objective measure of disease progression which was collected by self-report and later confirmed by oncologists who were unaware of the study. Data based on these measures was collected at each time point.

The primary outcome measures were quality of life measured by the Functional Assessment of Cancer Therapy – Ovarian (FACT-O) (Basen-Engquist et al., 2001) or the Functional Assessment of Cancer Therapy – General Population (FACT-GP) (Cella et al., 2003) and perceived stress measured by the Perceived Stress Scale (PSS) (Cohen & Williamson, 1988). Hypothesized mediators of improvement in the GDP group included cancer-related intrusive thoughts (IES) (Weiss & Marmar, 1997), marital communication, both general (ENRICH Couple Scales – Communication Subscale; Fowers & Olson, 1989) and illness-related (four items developed for the purpose of this study), use of positive and negative emotion words on Days 2 and 3 of the study (LIWC 2007; Pennebaker, Booth, & Francis, 2007), and extent to which participants had talked and thought about the event following the study. Other secondary outcomes included emotional representations of the illness (IPQ-R; Moss-Morris et al., 2002), CA 125 level, visits to the GP/ consultant and visits to alternative therapists. Assessment was completed as baseline (see Appendix P), three months follow-up (see Appendix T) and at six month follow-up (see Appendix V).

6.3.5.1 Primary Outcomes

The FACT-O (Basen-Engquist et al., 2001) was used to assess quality of life. This is the most widely used measure of quality of life in ovarian cancer research, thus permitting comparison with other studies (see Chapter 2). Full justification for use of this scale is presented in Chapter 5. There are four subscales that are relevant to any chronic illness (physical well-being, social/ family well-being, emotional well-being, functional well-being), and one scale specific to ovarian cancer (additional concerns). For this study, the physical, social and functional well-being subscales were used. The ovarian cancer specific concerns scale and the emotional well-being subscales had low reliability in the pilot study, so were not utilized.

There are seven items in the physical well-being subscale, six or seven items in the social/ family well-being subscale (one optional item, assessing satisfaction with sex life, was excluded from this study, as first, it was considered to address a different issue compared to the other questions, and second, approximately 25% of participants failed to answer it), and seven items in the functional well-being subscale. Each item is rated on a 5-item scale from 0 (not at all) to 4 (very much). Details about the reliability and validity of this scale are presented in Chapter 5. In the current study, Cronbach's Alpha for the overall scale ranged from .88 to .91, indicating good reliability. All subscales showed similar levels of internal consistency across the three time points. For the individual scales, Cronbach's alpha ranged from .88 to .91 for the physical well-being scale, from .82 to .89 for the social well-being scale, and from .85 to .88 for the functional well-being scale.

The partners completed the FACT-GP, an equivalent scale for assessing quality of life in the general population. Using a scale with the majority of the same questions meant that patient and partner improvement could be compared. As for the patients, the physical, social and functional well-being scales were used. There are 6 items in the physical well-being subscale, 5 items in the social/ family well-being subscale, and 6 items in the functional well-being subscale. An internet survey completed by 1078 participants from the general population demonstrated good convergent and divergent validity, and Cronbach's alpha was higher than 0.70, across the subscales (Cella et al., 2003). In the current study, Cronbach's alpha for the overall scale ranged from .81 to .84, indicating good reliability. For the individual subscales, Cronbach's alpha ranged from .75 to .78 for the physical well-being subscale, indicating adequate reliability, from .77 to .80 for the social well-being subscale, indicating adequate reliability, and from .80 to .85 for the functional well-being subscale, indicating good reliability.

To assess levels of stress, both patients and partners completed the PSS (Cohen & Williamson, 1988). As mentioned in Chapter 5, this scale has good reliability and validity. It was considered an appropriate measure for the current population, as levels of distress in physically ill patients are generally non-pathological. Improvements on this scale were demonstrated in the pilot study, which were related to percentages of negative emotion and causality words used on days 2 and 3, indicating that written emotional disclosure may be effective in reducing perceived stress and that changes in the PSS are sensitive to the GDP. In the current study, Cronbach's alpha ranged from .90 to .91 for patients, and from .87 to .89 for partners, indicating good reliability.

6.3.5.2 Secondary Outcomes

Both patients and partners completed the IES-R (Weiss & Marmar, 1997). Patients completed it with regard to their cancer, and partners completed it with regard to their partners' cancer. Psychometrics and rationale for use of this scale are described in Chapter 5. In the current study, Cronbach's alpha ranged from .91 to .92 for patients, and from .90 to .92 for partners, indicating good reliability.

Both patients and partners completed the emotional representations scale of the Illness Perception Questionnaire – Revised (Moss-Morris et al., 2002). This questionnaire, which has good reliability and validity, was used as an alternative to the

FACT-O emotional quality of life scale, which had low reliability in the pilot study, as it was considered to more accurately capture the emotional response to the cancer. The patients completed it with regard to their cancer, and the partners completed it with regard to their partners' cancer. This scale consists of six items which are answered on a 5 point scale from 'strongly disagree' to 'strongly agree,' and is scored so that higher scores indicate more emotional distress in relation to the illness. One item is reverse scored. Sample items include 'I get depressed when I think about my cancer' and 'My cancer makes me feel angry.' In the current study, Cronbach's alpha ranged from .88 to .90 for patients, and from .84 to .86 for partners, indicating good reliability.

Both patients and partners completed the ENRICH Couple Scales communication scale, which assesses marital communication (Fowers & Olson, 1989). This measure was used as it specifically assessed communication, in line with the social interaction hypothesis regarding written emotional disclosure, which is evaluated in the current research. This scale consists of ten items which are answered on a 5-point Likert scale from 1 'Disagree Strongly' to 5 'Agree Strongly.' Six items are reverse scored. Sample items include 'I can express my true feelings to my partner' and 'When we are having a problem, my partner often refuses to talk about it' (reverse scored). The scale is scored so that higher scores indicate better marital communication. A study of 15, 522 individuals (7621 couples) demonstrated a Cronbach's alpha of .86. Test-retest reliability data over a period of 4 weeks was .86, based on a sample of 115 individuals (Olson & Olson, 2000). Results from a discriminant analysis based on the ENRICH marital inventory indicated that satisfied and dissatisfied couples could be discriminated with 85-95% accuracy, a finding that was highly relevant for the communication subscale (Fowers & Olson, 1989). Cronbach's alpha in this study ranged from .89 to .91 for patients, and from .87 to .91 for partners, indicating good reliability.

Research has shown that when one member of a couple has cancer, communication regarding the illness is significantly correlated with relationship quality (see Chapter 4). However, a search revealed no questionnaire specifically designed to assess illness-related marital communication, so it was decided to create a brief measure assessing this. The items cover two main domains: how comfortable the individual felt about discussing the illness with their partner and their impression of their partner's willingness/ reluctance to discuss the illness. These domains are explored from both the patient's and the partner's perspective. This measure consists of four items which can be answered on a 5-point Likert scale from 1 ‘Disagree strongly’ to 5 ‘Agree strongly,’ with the wording edited so that the questions can apply to either the patient or the partner. Higher scores indicate better communication. Items include ‘It is hard for me to express feelings about my illness to my partner’ (for patients, reverse scored), and ‘I feel comfortable discussing issues related to her illness with my partner’ (for partners). Cronbach’s alpha ranged from .80 to .85 for patients, indicating good reliability, and from .72 to .80 for partners, indicating adequate to good reliability. Reading ease is at Flesch-Kincaid grade level 7 (Microsoft Word Readability Statistics). Convergent validity was demonstrated by significant correlations with the Enrich couple scales communication subscale for patients and partners; concurrent validity was demonstrated by significant correlations with social quality of life in patients and partners, and with intrusive thoughts and emotional representations of the illness in patients only; test-retest reliability over a period of three to six months was demonstrated in both patients and partners in the control group; and predictive validity was demonstrated in the control group by significant correlations between illness-related communication at baseline and emotional representations of the illness at three month follow-up for patients, and between illness-related communication at baseline and social quality of life at three month follow-up for partners. This scale is presented as the final four items assessing communication (see Appendices P and Q).

Utilization of health care was assessed by asking participants how often they had visited their GP or a consultant for illness, injury or checkup; an alternative therapist for illness, injury or regular treatment; or self-treated with over-the-counter remedies or alternative medicine in the preceding 3 months. Previous research on written disclosure has shown stronger effects for physical than psychological health outcomes, and this study aimed to see whether these results could be replicated. Ovarian cancer patients are often diagnosed with advanced stage disease, following misdiagnoses by their GPs, which can impair the patient-provider relationship, and lead to patients becoming interested in complementary therapies. It was therefore decided to obtain information about visits to alternative therapists as well as GP visits.

CA 125 is a tumour marker with high prognostic value in ovarian cancer (see Chapter 1). Since a previous study found that optimism significantly predicted CA 125 at the end of treatment (de Moor et al., 2006), this study aimed to see whether similar improvements in CA 125 levels could be obtained. Data about CA 125 level and date of last CA 125 test were obtained by self-report. However, following an amendment to approval from the ethics committee, patient consent was obtained for letters to be written to consultants requesting confirmation of the self-reported CA 125 (see Appendices Y-Z). The correlation between self-report and consultant report was 0.995, indicating that these self-reports were highly reliable.

6.3.5.3 Linguistic analysis of the writing

The writing texts were analysed using the computer program Linguistic Inquiry and Word Count (LIWC) 2007 (Pennebaker et al., 2007). This counts numbers of words for a variety of language categories, and reports percentages of words in each category, as well as total word count. In order to do this, all handwritten texts were typed, and all typewritten texts were scanned and checked against the original text. The LIWC analysis served two purposes. First, it was a manipulation check, to see whether the GDP group used more positive and negative emotion, insight and causality words than the control group on Days 2 and 3. Second, it aimed to see whether percentages of positive emotion, negative emotion and causality words used on Days 2 and 3 were related to improvements in the GDP group.

6.3.5.4 Post-writing questions.

Each day, the participants were given several questions to answer immediately post writing. (Pennebaker, 1994). On days 1 and 2, these questions asked how personal the writing was, how revealing they were of emotions, how much the individual had told others about the topic they wrote about, how much they had wanted to tell someone about what they wrote, and how much they had actively held back from telling someone about what they wrote. On day 3, questions were asked about how personal the essays were, how revealing of emotions they were on days 2 and 3, how much they had told others about the topic they wrote about and held back from telling someone about the topics they wrote about. They were also asked about the extent to which they had thought about the study since it began, the extent to which they had thought about the topics since the beginning of the study, and the extent to which they thought about the topics they wrote about prior to the study. These questions were answered on a scale from 1 ‘not at all’ to 7 ‘a great deal.’ They served two purposes. The questions regarding how personal and how revealing of emotions the essays were, and the extent to which the participants had thought about the study and the topics acted as a manipulation check, to see if the GDP group had engaged more with their essays than the control group. The other questions were based on the social interaction hypothesis, which holds that written disclosure can lead to increased social interaction following a traumatic event. At the follow-ups, the participants were asked how much they had thought about what they wrote, and how much they had talked to someone about what they wrote. It was hypothesized that self-report of talking more at follow-up would mediate improved outcomes.

6.3.5.5 Follow-up questions.

At the final follow-up, the participants were asked whether they would recommend the writing to others, and whether they thought they were in the intervention or control group. These questions were designed to assess the acceptability of the intervention, and the effectiveness of blinding the participants to condition.

6.3.6 Sample Size Determination

The sample size calculation for this study was based on the results from the pilot study for perceived stress, which is one of the primary outcomes in the current study. A calculation based on the difference between the means at first baseline and follow-up for the 'writing first' group in the pilot study revealed an effect size of 0.70. With 80% power and $p<.05$, using two-tailed tests, it was calculated that the current study needed 32 participants per group to complete the intervention in order to obtain a significant effect. However, since this estimate was generous, it was decided to recruit approximately 50 participants per group. This calculation was based on the perceived stress results as it was assumed that quality of life would improve more over a longer time period.

6.3.7 Statistical analyses

First, to determine the success of randomization, the GDP and control groups were compared on baseline demographic and biomedical variables, using T-tests for continuous variables, and chi-square for categorical variables. Any variable found to differ between groups at baseline was added as a covariate in subsequent analyses. Second, the writings in the GDP and control groups were compared for use of positive and negative emotion, insight and causality words on days 2 and 3 using T-tests. Also, the extent to which the participants considered their writing to be personal and revealing of emotions was compared across the GDP and control groups, using T-tests, in order to assess engagement with the task.

To determine whether the GDP led to improved quality of life and reduced perceived stress relative to the control group, 2 by 3 mixed ANOVAs were used, with group (GDP or control) as the between subjects factor, and time (baseline, 3 month or 6 month) as the within subjects factor. Mixed ANOVAs were used as they provided an opportunity to compare changes over time in the GDP and control groups. It was hypothesized that there would be a group by time interaction indicating improvement in the GDP group relative to the control group at three and six months follow-ups. If such interactions occurred, changes were examined from baseline to each follow-up point using planned contrasts, to determine the group in which time had had an effect.

Similar 2 by 3 ANOVAs were carried out for the process variables of intrusive thoughts, marital communication and illness-related marital communication. When these were also found to be significant, mediation analyses were carried out using the Sobel test (Preacher & Hayes, 2004) in order to determine whether the improvements in the outcome variables were fully or partially mediated by the improvements in the process variables. Pearson correlations were carried out in order to determine whether percentages of positive emotion, negative emotion, insight and causality words were related to changes in outcomes from baseline to each follow-up. Significant correlations were followed up with multiple regressions in order to test for moderation. Level of the outcome variable at follow-up was entered as the DV, level of the outcome variable at baseline was entered on the first step, and the percentage of i.e. positive emotion words used was entered on the first step. The CA 125 results were dichotomized based on a clinical cut-off of 35 (Bast et al., 1983), and analyzed using nonparametric tests, since they were initially highly skewed.

Intraclass correlations were carried out in order to determine whether patient and partner improvement were correlated. These analyses were hypothesized to provide insight into whether improvements were couple-related or individually based.

Moderation and moderated mediation analyses were carried out based on hypotheses regarding subsets of individuals who might be expected to benefit more from the intervention and mechanisms by which benefits were expected to occur. Although the main aim of randomized controlled trials is to minimize between-group differences at baseline, and determine if the intervention is efficacious for the population as a whole, it is also important to identify moderators (Sherman et al., 2004). As discussed in section 6.2.4, identification of moderators and moderated mediators serves two main purposes. Clinically, it is important for clinicians to be aware of who benefits from interventions, so they know to whom to offer therapies. Theoretically, it provides a greater understanding of the theoretical underpinnings of specific interventions and their processes.

The presence of moderators and moderated mediators was tested in the following way. For dichotomous variables, 3 (time) ×2 (group) ×2 (moderator variable) ANOVAs were used, with the moderator as a between subjects factor. For continuous variables, hierarchical multiple regressions were used. The primary outcome at three months (quality of life or perceived stress) was the dependent variable. It was decided to focus on outcomes at three months, as improvements were expected to be most likely to occur over this period. The measure of the primary outcome at baseline and other relevant covariates were entered in the first step, and group, the moderator, and the interaction term of group × the z-score value of the moderator was entered in the third step. The moderator/moderated mediator was centred in order to reduce multicollinearity. Hypothesized illness-related moderators included experience of a recurrence. Hypothesized moderators/ moderated mediators related to the social interaction hypothesis included change in illness-related couple communication (since the GDP might have been expected to benefit couples who were experiencing problems discussing the patient's illness) and marital communication at baseline. Hypothesized moderated mediators related to the cognitive processing hypothesis were changes in levels of intrusive thoughts (as improvements are indicative of having worked through the event – see Chapter 4). Other moderators included partners' intrusive thoughts at baseline and whether participants would recommend the intervention.

Finally, sensitivity analyses, excluding participants based on certain factors, were carried out in order to see whether these factors impacted on the results. It was decided to check whether the couple completing the intervention together or separately would influence the results, and thus couples who had completed the intervention separately were excluded from these analyses.

Analyses were carried out on both the intention to treat and the completers' samples. The intention-to-treat sample consisted of all participants who were assigned to each group, regardless of whether they experienced the intervention. The analysis on the intention-to-treat sample tested the benefit that could be expected from offering the intervention in practice. Missing values were replaced with participants' baseline values of the measures. The analysis on the completers' sample tested the efficacy of the intervention for those who received it and remained alive to experience the benefits.

Chapter Seven: The effect of guided written disclosure on perceived stress and quality of life: A randomized controlled trial - Results

The following chapter reports the analyses and subsequent results for each hypothesis. Section one describes preliminary analyses carried out to screen the data. In sections two, three and four participant flow and baseline characteristics of the couples are described. Section five focuses on the inter-relationships between baseline factors. Section six addresses whether the participants would recommend the intervention, and the effectiveness of blinding. Sections seven and eight describe the fidelity checks: word usage by group, and the post-writing questions. Sections nine, ten and eleven describe the outcome data for primary and secondary outcomes. Section twelve describes the findings on predictors and moderators of the primary outcomes. Sections thirteen and fourteen describe the correlations between word usage and change in the outcomes, and levels of thinking and talking about the writing at follow-up. The final section discusses couple-related factors: correlations between patient and partner improvement and communication discrepancy as a correlate of outcome.

7.1 Data Screening and preliminary analyses

Statistical analyses were performed using SPSS for Windows (version 15). Prior to analysis all variables were examined using the SPSS explore function. Most variables did not have missing values. If under 25% of the data from a particular scale were missing, the scores were replaced with the means of the other items. This happened in two cases out of the entire sample. If over 25% of the data from a particular scale were missing, the data were treated as missing for the completers analyses, and replaced with the previous observation for the intention-to-treat analyses.

The data were examined for normality of sampling distributions, linearity and homogeneity of variance. These examinations revealed that skewness and kurtosis were less than 1 for most variables, indicating that the assumption of normality was met. However, three of the variables had extreme levels of skewness and kurtosis – CA 125 level, doctor visits, and visits to alternative therapists. Transformations were attempted, but did not normalize the data. It was therefore decided to dichotomize the CA 125 results using the clinical cut-off of 35 u/ml (Bast et al., 1983). Briefly, a score above 35 u/ml is indicative of a possible recurrence, whereas a score below 35 u/ml is within the normal range for the general population. Similarly, as only one third of the participants had visited an alternative therapist at any time point, these results were dichotomized based on whether the patients had visited an alternative therapist or not. However, the variable of doctor visits could not be dichotomized, so it was analysed using non-parametric tests.

All statistical analyses were two-tailed and a 5% significance level was maintained throughout the analyses. Two types of analyses were carried out: completers and intention-to-treat. Intention-to-treat analyses are recommended as they include all randomized participants in the groups to which they were allocated, regardless of whether they completed the intervention (Hollis & Campbell, 1999). Such analyses indicate the effectiveness of a new treatment, should it be implemented in practice, and control for non-compliance and differential dropout between conditions. However, given that, one of the main reasons for attrition in the current research was patient death, whereas the current research did not claim to enhance survival, completers analyses were also carried out.

There is a lack of consensus about how missing responses should be handled in intention-to-treat analysis. However, one of the most commonly used methods is the ‘last observation carried forward’ method (Hollis & Campbell, 1999), which was used in this study. For participants who withdrew from the study without completing the intervention, or before the three month follow-up, three month follow-up scores on the questionnaire measures were obtained by substituting the missing data with their scores obtained at baseline. Similarly, for the participants who dropped out between three and six month follow-up, six month follow-up scores were obtained by substituting the missing data with their scores obtained at the three month follow-up.

7.2 Participant Flow

Figure 3 shows the flow of participants through the trial. Three hundred and thirty six respondents returned a slip or contacted the researcher indicating receipt of the letter. It is important to note that the Ovacome database is not based on hospital records, but updated by members and their families. A number of those who did not respond to the initial letter may have been in hospital, died, moved away or been ineligible to participate. Of those who responded, 203 expressed interest in the study, and 141 couples were found to be eligible. Reasons for ineligibility included being single (28 participants), and too long since their last treatment (34 participants). Of these 141 couples, 102 completed baseline measures and were randomized - the intention-to-treat sample. This represents a response rate of 102/141 (72.3%).

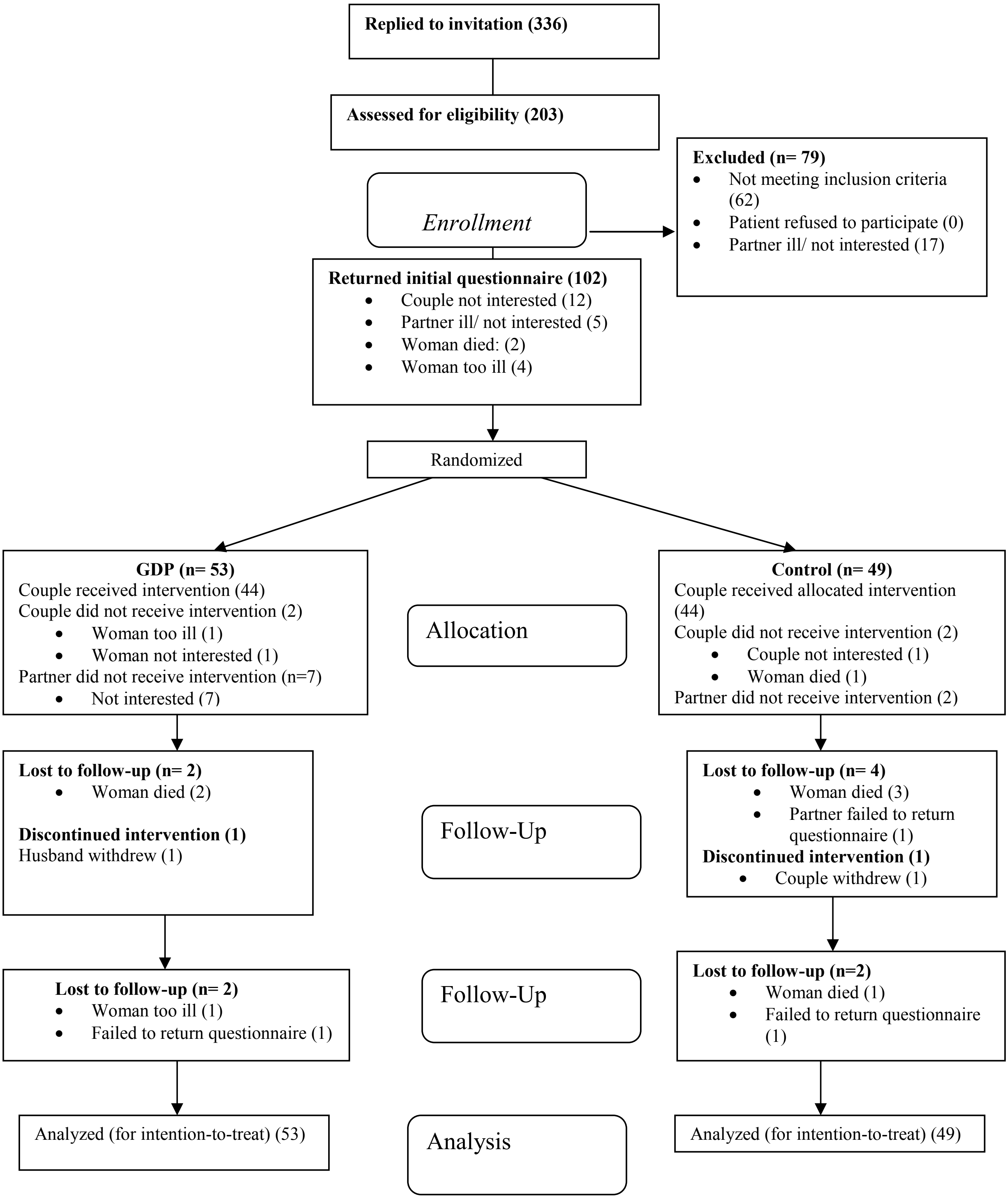

Figure 3: Flow of participants through the trial

Of the 102 couples that were randomized, 13 (12.7%) dropped out without writing. Reasons for dropout included that the partner did not wish to write (GDP: 7 cases; Control: 2 cases), the patient was not interested (GDP: 1 case, Control: 1 case), the woman was too ill (GDP: one case) and the woman died (Control: one case). A further 12 (11.8%) failed to complete one or both of the follow-up assessments. Reasons for this included the patient dying (GDP: 2 cases; Control: 4 cases), the patient being too ill (GDP: 1 case), the couple withdrawing from the study (Control: 1 case); the partner withdrawing from the study (GDP: 1 case), and failure to return the questionnaire, by the partner (Control: 1 case) and the couple (GDP: 1 case; Control: 1 case). Thus, 77 couples (75.5% of those randomized) completed the intervention. Completers analyses were carried out on these participants, in order to determine the effectiveness of the intervention. However, since the moderation analyses were carried out between baseline and three month follow-up, they included all participants who remained in the study to that date (81 couples; 79.4%). In addition, even if the partner withdrew from the study, the patient usually did not do so. Thus, the overall response rate for patients was 88/102 (86.3%), and the moderation analyses for patients included 92 couples (90.2%).

7.3 Baseline demographic characteristics of participants

Baseline demographic and disease-related characteristics of patients randomized to the GDP and control groups are reported in Table 8. The mean age of participants was 55.1 years. The average time since diagnosis across both groups was 37.8 months, and average time since last treatment was 15.1 months. Approximately 2/3 of the patients (63.7%) were diagnosed with advanced stage disease. Thirteen patients (12.7%) were undergoing treatment at the time of recruitment, and 45 (44.1%) had experienced a recurrence of the cancer since their initial diagnosis. Among those who completed at least one follow-up assessment, 44 of those who had not had a recurrence remained disease free, and 10 had a recurrence during the study. All but eight patients had had surgery. The median number of courses of chemotherapy experienced was one (range 0-5). Participants had been married/ cohabiting for 27.08 years on average. Thirty-two patients (19.6%) had a tertiary education. Thirty seven (36.3%) were employed.

There were no between group differences with regard to the health behaviours of exercise, smoking and alcohol consumption. On average, patients exercised 1-2 times per week or more. The average level of alcohol consumption was five units per week, which is well below limits recommended for the general population. Only seven (7%) of the sample smoked.

Table 8: Baseline demographic and illness characteristics and health behaviours of the patients

	GDP (n=53)	Control (n=49)	Statistical comparison
Age (Mean, SD)	53.02 (10.30)	57.39 (8.09)	t = 2.32 (p=.02)*
Disease stage:			
I	12	11	Pearson χ^2 = 3.89 (p=.27)
II	4	10	
III	30	24	
IV	7	4	
Time since diagnosis in months (Mean, SD)	43.29 (34.05)	31.54 (21.22)	t = -2.09 (p=.04)*
Time since last treatment in months (Mean, SD)	16.40 (19.44)	13.65 (15.34)	t = -.78 (p=.44)
Currently having treatment	7	6	Pearson χ^2 = .02 (p=1)
Had a recurrence	26	19	Pearson χ^2 = 1.09 (p=.32)
Number of courses of chemotherapy (Mean, SD)	1.85 (1.35)	1.53 (0.96)	t = -1.36 (p=.18)
Had surgery	51	43	Pearson χ^2 = 2.52 (p=.15)
Had radiotherapy	6	5	Pearson χ^2 = .03 (p=1)
Length of time married/ living with partner in years (Mean, SD)	25.67 (13.66)	28.62 (10.98)	t = 1.11 (p=.27)
Highest level of education:			
Less than secondary school	16	21	Pearson χ^2 = 1.92 (p=.38)
Secondary school/ technical qualification	18	15	
University education	19	13	
Employment status:			
Employed	23	14	Pearson χ^2 =2.42 (p=.15)
Retired/ homemaker	30	35	
Exercise (Mean, SD)	3.28 (1.32)	3.09 (1.21)	t= -.10 (p= .92)
Smoke	4	3	Pearson χ^2 =.39 (p=.58)
Alcohol units per wk (Mean, SD)	5.21 (6.06)	5.09 (5.44)	t= -.77 (p= .45)

*p<.05

Baseline demographic characteristics of the partners are reported in Table 9. Across the whole sample, the mean age of the partners was 57.8 years. Thirty six participants (41.9%) had a tertiary education. Fifty nine participants (57.8%) were employed.

Table 9: Baseline demographic characteristics of partners

	GDP (n=53)	Control (n=49)	Statistical comparison
Age (Mean, SD)	55.34 (10.92)	60.43 (9.22)	t = 2.33 (p=.02)
Highest level of education:			
Less than secondary school	11	10	Pearson $\chi^2 = .15$ (p=.93)
Secondary school/ technical qualification	14	15	
University education	17	19	
Employment status:			
Employed	24	35	Pearson $\chi^2 = 3.04$ (p=.11)
Retired	25	18	

Comparisons were made to determine whether the two groups were equivalent with regard to demographic and biomedical characteristics. Differences were tested using independent samples T-tests for continuous data, and chi-square analysis for categorical data. Results showed that the two groups did not differ significantly in terms of disease stage, time since treatment, whether they were currently having treatment, numbers having experienced a recurrence, number of courses of chemotherapy, time married, educational level and employment status. However, there were significant differences in age and time since diagnosis between the groups. Participants in the GDP group were significantly younger than those in the control group, and it was longer since their initial diagnosis. Because of this, age and time since diagnosis were added as covariates in all subsequent analyses. In addition, it was expected that having treatment at retest would influence the results, so this was also included as a covariate in subsequent analyses. Similarly, although partners did not differ between the groups with regard to educational level and employment status, those in the GDP group were significantly younger than those in the control group.

7.4 Characteristics of baseline outcome measures

7.4.1 Primary Outcomes

The GDP and control groups were compared on their quality of life (FACT-O: patients; FACT-GP: partners) and perceived stress scores at baseline. These results are reported in Tables 10 and 11. For patients, there were no statistically significant differences between the two groups at baseline on quality of life, but the GDP group experienced higher levels of perceived stress than the control group. For partners, there were no statistically significant differences at baseline on perceived stress, but the GDP group experienced worse quality of life than the control group. Comparisons of the subscales showed that these differences were due to partners in the GDP group reporting worse social and functional quality of life. The overall perceived stress scores reported in this sample (Patients: 16.99, SD=8.13; Partners: 14.40, SD= 7.03) were higher than those reported for the general population (13.02) (Cohen & Williamson, 1988). Patients' scores on the FACT-O subscales were slightly lower than the means reported in the validation study (Physical: 22.25; Functional: 20.94; Social (7 item scale): 23.33) (Basen-Engquist et al., 2001) indicating that patients in this sample were slightly less satisfied with their quality of life. The mean score for partners on the FACT-GP (74.0 %) was similar to that of a representative sample of 1400 people from the general population (Cella et al., 2003).

7.4.2 Secondary Outcomes

As shown in Tables 10 and 11, independent samples T-tests revealed no differences between the GDP and control groups at baseline with regard to intrusive thoughts and emotional representations of the illness. In addition, for patients, there were no differences at baseline with regard to marital communication and illness-related couple communication. Further, Mann-Whitney U tests showed no differences between groups at baseline with regard to visits to GPs/ consultants and visits to alternative therapists. However, for partners, the GDP group scored lower at baseline with regard to marital communication and illness-related couple communication.

Table 10: Baseline characteristics for outcome measures - patients (means are presented with standard deviations in brackets unless otherwise specified)

	GDP (n=53)	Control (n=49)	Statistical comparison
Quality of Life (FACT-O)			
Physical	21.30 (5.62)	21.51 (5.99)	t = .18 (p= .86)
Social	17.81 (4.97)	19.57 (4.18)	t = 1.94 (p= .06)
Functional	18.52 (6.16)	18.94 (5.69)	t = .35 (p= .73)
Overall	57.64 (13.40)	60.02 (11.32)	t = .96, (p= .34)
Perceived Stress	18.57 (8.05)	15.25 (7.94)	t = -2.08 (p= .04)*
Intrusive thoughts	11.62 (7.81)	9.82 (7.52)	t = -1.19 (p=.24)
Marital communication	34.79 (9.01)	37.10 (7.87)	t = 1.37 (p=.17)
Illness-related communication	13.64 (3.86)	14.39 (3.76)	t = .99 (p= .33)
Emotional representations	19.70 (5.64)	18.69 (6.13)	t = -.86 (p= .39)
Visits to GP/ consultant (Median, range)	2 (10)	1 (12)	*Mann-Whitney U* Z = -.57 (p= .57)
Visits to alternative therapists (Median, range)	0 (36)	0 (13)	*Mann-Whitney U* Z = -.45 (p = .65)

*p<.05

Table 11: Baseline characteristics for outcome measures – partners (means are presented with standard deviations in brackets)

	GDP (n=53)	Control (n=49)	Statistical comparison
Quality of Life (FACT-GP)			
Physical	20.57 (3.18)	21.69 (3.40)	t = 1.73 (p= .09)
Social	9.60 (3.37)	11.49 (3.52)	t = 2.76 (p= .007)**
Functional	14.15 (4.68)	17.59 (4.92)	t = 3.62 (p < .001)**
Overall	44.32 (8.19)	50.78 (8.60)	t = 3.88 (p < .001)*
Perceived Stress	15.43 (6.84)	13.29 (7.13)	t = -1.55 (p= .12)
Intrusive thoughts	9.15 (7.17)	8.60 (6.73)	t = -.39 (p= .69)
Marital communication	35.15 (8.15)	39.14 (6.92)	t = 2.66 (p= .009)**
Illness-related communication	14.77 (3.54)	16.35 (2.61)	t = 2.57 (p= .012)*
Emotional representations	22.13 (4.68)	20.98 (4.99)	t = -1.20 (p=.23)

*p<.05, **p<.001

Concerning levels of intrusive thoughts regarding the cancer, no group differences were observed. Thirty six patients (35%) and 29 partners (29%) scored above the cut-off of 12 (Creamer, Bell, & Failla, 2003) indicating possible caseness of PTSD with regard to the intrusive thoughts criterion.

Concerning emotional representations of the cancer, no group differences were found. Patients scored higher than the mean of 19.75 reported for chronic pain patients (Moss-Morris et al., 2002), indicating more distress in relation to their illness, and the mean score for partners was similar to the mean reported for chronic pain patients, indicating similar levels of distress.

There were no group differences with regard to marital communication for the patients. However, partners in the GDP group scored lower than those in the control group, indicating worse marital communication. Both patients (35.90) and partners (37.07) scored higher than the mean of 31.6 based on a sample of 21, 501 married couples (Fowers & Olson, 1989), which indicates that they had better marital communication. Based on cut-off scores, 19 patients (18.6%) and 16 partners (15.7%) would be considered to be dissatisfied with regards to marital communication. Concerning illness-related couple communication, there were no group differences with regard to the patients, but partners in the GDP group scored lower than those in the control group, indicating less satisfaction with illness-related couple communication. Patients reported similar levels of satisfaction for general (3.59) and illness-related communication (3.50), when the mean item scores were compared. Partners also reported more satisfaction with illness-related communication (3.88) than general communication (3.71).

Visits to GPs/ consultants and alternative therapists over the preceding three months (for illness, injury and regular treatment combined) did not differ between the GDP and control groups. These results were compared using Mann-Whitney U tests as the data was skewed (a high percentage of the patients reported not visiting GPs/ consultants or alternative therapists at all). The range for visits to alternative therapists was particularly large, as some people visited alternative therapists for weekly treatments.

Overall, the evidence from independent samples T-tests and chi-square tests showed that the patients were equivalent with regards to most of the baseline demographic, medical and outcome characteristics. Out of 23 variables, differences were found on only three (age, time since diagnosis and perceived stress). However, the randomization appeared to be less successful with regard to the partners. Out of six partner-specific variables, differences were found on three (quality of life, marital communication, and illness-related couple communication).

7.5 Correlations between the primary outcomes and other factors at baseline

7.5.1 Background demographic and biomedical variables

Pearson product-moment correlations were calculated to assess the degree to which quantitative demographic and illness variables were associated with the primary outcome measures (quality of life, perceived stress) at baseline. Point-biserial correlations were used for dichotomous variables and Spearman correlations for the other categorical data. These results are presented in Tables 12 and 13.

Table 12: Correlations between the primary outcomes and background biomedical, demographic and health behaviour variables – patients

Variable	Type of Correlation	Quality of Life	Perceived Stress
Age	*Pearson correlation*	.13	-.17
Disease stage	*Spearman correlation*	-.02	.14
Time since diagnosis	*Pearson correlation*	-.001	.003
Time since treatment	*Pearson correlation*	.02	.05
Having treatment	*Point-biserial correlation*	-.10	-.07
Had a recurrence	*Point-biserial correlation*	.07	-.09
No of courses of chemotherapy	*Pearson correlation*	-.09	-.01
Had surgery	*Point-biserial correlation*	-.002	-.07
Had radiotherapy	*Point-biserial correlation*	-.10	-.11
Time married	*Pearson correlation*	.01	-.06
Level of education	*Spearman correlation*	.05	.03
Employment status	*Point-biserial correlation*	-.06	-.05
Exercise	*Pearson correlation*	.10	.05
Smoking	*Point-biserial correlation*	-.02	-.05
Units of alcohol/ wk	*Pearson correlation*	.17	-.18

For patients, none of the baseline demographic and illness variables were significantly correlated with the primary outcome variables at baseline. Correlation coefficients were generally small, ranging between -.18 and .17, with p values >.05. For partners, correlations ranged from -.25 to .35. The majority of p values were >.05. However, there were significant correlations between patients' disease stage and partners' perceived stress, patients' time since diagnosis and partners' quality of life, patients being on treatment and partners' perceived stress, patients having had a recurrence and partners' quality of life and perceived stress, number of courses of chemotherapy patients had had and partners' quality of life and perceived stress, and educational level and quality of life. These findings suggested that partners experienced more perceived stress when the patient was diagnosed with more advanced stage disease, was on treatment, had had a recurrence, and had had more courses of chemotherapy. Partners experienced better quality of life when the patient had been diagnosed more recently (in most cases these patients had not experienced a recurrence), had not had a recurrence, had had fewer courses of chemotherapy, and when they were more educated.

Table 13: Correlations between the primary outcomes and background biomedical and demographic variables – partners

Variable	Type of Correlation	Quality of Life	Perceived Stress
Age	*Pearson correlation*	.13	.03
Disease stage	*Spearman correlation*	-.04	.22*
Time since diagnosis	*Pearson correlation*	-.23*	.12
Time since treatment	*Pearson correlation*	-.13	-.11
Having treatment	*Point-biserial correlation*	-.04	.24*
Had a recurrence	*Point-biserial correlation*	.25*	-.32**
No of courses of chemotherapy	*Pearson correlation*	-.22*	.35**
Had surgery	*Point-biserial correlation*	.01	-.04
Had radiotherapy	*Point-biserial correlation*	.03	-.02
Time married	*Pearson correlation*	.12	.02
Level of education	*Spearman correlation*	.04	.09
Employment status	*Point-biserial correlation*	.24*	-.09

*p<.05, **p<.001

7.5.2 Correlations between the primary and secondary outcome variables

Pearson product-moment correlations were calculated to assess the degree that secondary outcome variables were linearly related to the primary outcome variables of quality of life and perceived stress. Point-biserial correlations were calculated for the dichotomized variables of CA 125 and visits to alternative therapists. These results are reported in Tables 14 and 15.

Pearson product-moment correlations showed that for patients, all the secondary outcome variables except visits to alternative therapists and CA 125 level were significantly correlated with perceived stress and quality of life. For partners, all the secondary outcomes were significantly correlated with perceived stress and quality of life.

Table 14: Correlations between the primary and secondary outcome variables - patients

Variable	Quality of Life	Perceived Stress
Intrusive thoughts	-.50**	.71**
Emotional representations of the cancer	-.50**	.68**
Marital communication	.40**	-.38**
Illness-related communication	.31**	-.22*
Visits to GPs/consultants	-.36**	.30**
Visits to alternative therapists	.02	.06
CA 125	-.09	.05

*p<.05, **p<.001

Table 15 : Correlations between the primary and secondary outcome variables - partners

Variable	Quality of Life	Perceived Stress
Intrusive thoughts	-.31**	.49**
Emotional representations of the cancer	-.23*	.52**
Marital communication	.57**	-.31**
Illness-related communication	.47**	-.40**

*p<.05, **p<.001

7.6.1 Effectiveness of blinding and acceptability of the intervention

7.6.1.1 Effectiveness of blinding

In order to determine the effectiveness of blinding, participants were asked whether they thought they were assigned to the intervention or control group. Among patients, 20 of the control participants thought they were in the control group, three thought they were in the intervention group, and 17 were not sure. Six of the GDP participants thought they were in the intervention group, 21 thought they were in the control group, and 19 were not sure. Pearson chi-square revealed that these numbers were not significantly different between groups ($\chi^2 = .72$, p=.69), indicating that blinding of participants was successful for patients. Among partners, 15 of the control participants thought they were in the control group, eight thought they were in the intervention group, and 12 were not sure. Ten of the GDP participants thought they were in the intervention group, 11 thought they were in the control group, and 18 were not sure. Pearson chi-square revealed that these numbers were not significantly different between groups ($\chi^2 = 1.83$, p=.40), indicating that blinding was also successful for partners. Interestingly, a number of participants assigned to the GDP thought they were in the control group, as they were not given feedback on their writing tasks. Overall, these results suggest that blinding was successful.

7.6.1.2 Acceptability of the intervention

No participants in the GDP group reported any adverse effects of the intervention. Seven partners in the GDP group (13.2%) did not feel comfortable completing the intervention and therefore withdrew from the study without doing so. There was one participant in the control group who reported distress from completing the questionnaires, and therefore withdrew from the study at three month follow-up.

For patients, 32 (69.6%) of the GDP group said they would recommend the intervention and 14 (30.4%) said they would not, whereas 18 (45%) of the control group said they would recommend the intervention, and 22 (55%) said they would not. Pearson chi-square revealed that this difference was statistically significant ($\chi^2 = 5.31$, p=.029), indicating that patients in the GDP group were more likely to recommend the writing than those in the control group. For partners, 22 (56.4%) of the GDP group said they would recommend the intervention and 17 (43.6%) said they would not, whereas 20 (57.1%) of the control group said they would recommend the intervention and 15 (42.9%) said they would not. Pearson chi-square revealed that this difference was not statistically significant ($\chi^2 = .004$, p=1.00) indicating that partners in the GDP group were no more likely to recommend the intervention than those in the control group. Overall, the GDP appeared to be received more positively by patients than their partners.

7.7Word Usage across the three days

7.7.1 Comparing word usage across groups

Percentages of positive emotion, negative emotion, insight, and causality words were computed for each day of writing, using Linguistic Inquiry and Word Count (LIWC; Pennebaker et al., 2007). This had two purposes. First, it served as a manipulation check, to see whether participants in the GDP group used more affect and cognitive words than those in the control group. In order to do this, percentages of words used for each category were compared between the groups using T-tests. These results are reported in Tables 16 and 17. Overall, both patients and partners in the GDP group used more positive emotion, negative emotion, insight and causality words on days 2 and 3 relative to the control group. In addition, participants in the GDP group used more negative emotion and insight words, and fewer positive emotion words on day 1 relative to the control group. This indicated that the experimental manipulation was successful on days 2 and 3, but that participants in the GDP group found it difficult to describe the diagnosis and treatment without reference to emotions.

Table 16: Percentages of word usage categories across groups – patients (means are presented with standard deviations in brackets)

Word Category	GDP (n=49)	Control (n=47)	Statistical comparison
Day 1			
Word Count	359.98 (97.17)	326.72 (107.62)	t = -1.59 (p=.12)
Positive emotion	1.18 (0.70)	2.44 (1.45)	t = 5.36 (p<.001)**
Negative emotion	1.47 (0.95)	0.68 (0.85)	t = -4.30 (p<.001)**
Insight	2.70 (1.21)	0.91 (0.79)	t = -8.62 (p<.001)**
Causality	0.82 (0.55)	0.99 (0.67)	t = 1.37 (p=.18)
Day 2			
Word Count	376.33 (93.40)	325.40 (104.66)	t = -2.52 (p=.014)*
Positive emotion	2.99 (1.43)	2.00 (1.17)	t = -3.70 (p<.001)**
Negative emotion	3.02 (1.02)	0.81 (0.56)	t = -13.24 (p<.001)**
Insight	3.92 (1.32)	1.08 (0.94)	t = -12.12 (p<.001)**
Causality	1.68 (0.81)	0.90 (0.63)	t = -5.25 (p<.001)**
Day 3			
Word Count	356.33 (107.02)	345.68 (133.66)	t = -.43 (p=.67)
Positive emotion	3.43 (1.78)	2.45 (1.50)	t = -2.94 (p=.004)**
Negative emotion	2.53 (1.13)	0.85 (0.76)	t = -8.59 (p<.001)**
Insight	4.18 (1.17)	1.14 (0.90)	t = -14.29 (p<.001)**
Causality	1.65 (0.83)	0.96 (0.62)	t = -4.55 (p<.001)**

*p<.05, **p<.01

Table 17: Percentages of word use categories across groups – partners (means are presented with standard deviations in brackets)

Word Category	GDP (n=44)	Control (n=44)	Statistical comparison
Day 1			
Word Count	300.32 (114.95)	227.64 (98.69)	t = -3.18 (p=.002)**
Positive emotion	1.29 (1.07)	2.14 (1.65)	t = 2.85 (p=.006)**
Negative emotion	1.79 (1.18)	0.29 (0.37)	t = -8.04 (p<.001)**
Insight	2.54 (1.19)	0.77 (0.76)	t = 8.31 (p<.001)**
Causality	1.09 (0.80)	1.11 (0.94)	t = .12 (p=.91)
Day 2			
Word Count	281.77 (89.76)	229.89 (99.39)	t = -2.57 (p=.012)*
Positive emotion	3.09 (1.50)	1.77 (1.34)	t = -4.34 (p<.001)**
Negative emotion	2.95 (1.30)	0.60 (0.72)	t = -10.51 (p<.001)**
Insight	3.62 (1.27)	0.94 (0.84)	t = -11.70 (p<.001)**
Causality	2.20 (1.25)	0.84 (0.75)	t = -6.17 (p<.001)**
Day 3			
Word Count	256.70 (103.13)	243.77 (108.22)	t = -.57 (p=.57)
Positive emotion	3.60 (1.47)	1.81 (1.20)	t = -6.27 (p<.001)**
Negative emotion	2.48 (1.23)	0.68 (0.74)	t = -8.32 (p<.001)**
Insight	3.74 (1.65)	1.21 (1.03)	t = -8.61 (p<.001)**
Causality	1.80 (1.17)	0.82 (0.75)	t = -4.68 (p<.001)**

*P<.05, **p<.01

7.8 Post-writing questions

After each writing session, the participants answered questions regarding their essays. On days 1 and 2, these questions covered how personal and revealing of emotions the essays were, how much they had told other people about what they had written, how much they had wanted to tell others about what they wrote, and how much they had actively held back from telling others about what they wrote. On the final day, the questions related to all three days of the writing. They covered how personal and revealing of their emotions the participants considered the essays to be, how much they had told other people about what they had written, how much they had actively held back from telling others about what they had written, how much they had thought about the study since it began, how much they had thought about the topics they wrote about since the beginning of the experiment, and the degree to which they thought about the topics they wrote about before the experiment began. All the items were answered on a seven point Likert-type scale from 1 (not at all) to 7 (a great deal). These results are presented by group in Tables 18 and 19.

Table 18: Post-writing questions – patients (means are presented with standard deviations in brackets

	GDP (n=49)	Control (n=47)	Statistical comparison
Day 1:			
Personal	5.86 (1.55)	4.51 (2.07)	t= -3.59 (p =.001)**
Revealing of emotions	3.31 (2.16)	2.40 (1.84)	t= -2.21 (p =.03)*
Told others	5.22 (1.99)	2.13 (1.75)	t= -8.07 (p<.001)**
Wanted to tell others	4.82 (2.10)	2.28 (1.65)	t= -6.61 (p<.001)**
Held back from telling others	2.69 (2.07)	2.49 (2.20)	t= -.47 (p=.64)
Day 2:			
Personal	6.59 (0.91)	4.49 (2.03)	t= -6.50 (p<.001)**
Revealing of emotions	5.82 (1.39)	2.68 (1.81)	t= -9.49 (p<.001)**
Told others	4.10 (1.98)	2.28 (1.65)	t= -4.89 (p<.001)**
Wanted to tell others	4.78 (2.06)	2.32 (1.82)	t= -6.18 (p<.001)**
Held back from telling others	3.61 (2.08)	2.00 (1.84)	t= -4.03 (p<.001)**
Overall:			
Personal	6.37 (1.05)	4.49 (2.09)	t= -5.51 (p<.001)**
Revealing of emotions	5.84 (1.39)	2.83 (1.81)	t= -9.10 (p<.001)**
Told others	4.18 (1.94)	2.23 (1.68)	t= -5.24 (p<.001)**
Held back from telling others	3.55 (1.98)	2.47 (2.09)	t= -2.61 (p=.01)*
Thought about study	4.09 (1.69)	3.50 (1.85)	t= -1.33 (p=.19)
Thought about writing topics since study began	4.85 (1.71)	3.7 (1.98)	t= -2.79 (p=.007)**
Thought about topics before study began	4.53 (1.54)	2.87 (1.83)	t= -3.94 (p<.001)**

*p<.05, **p<.01

These analyses are based on the participants who completed the writing and returned it to the researcher (GDP: n=49; Control: n=47). Two participants in the GDP group and two participants in the GDP group did not complete the writing. In the GDP group, the writing from one patient was lost in the post, and another participant failed to return it.

As expected, Table 18 shows that the patients in the GDP group viewed their essays as more personal and revealing of emotions across all three days. This was the case even on Day 1, when the GDP group were required to describe the diagnosis and treatment factually, without reference to emotions. In addition, participants in the GDP group reported having told others more about what they had written and holding back more from telling others about what they had written. Also, the GDP group reported having thought more about the writing topics both before the study began and since it began. However, the GDP group were not more likely than the control group to have held back from telling others about what they had written on Day 1 (when they described the factual details of their diagnosis and treatment), although the difference held for the other two days, nor were they more likely than the control group to have thought about the study since it began.

Table 19: Post-writing questions – partners (means are presented with standard deviations in brackets)

	GDP (n=44)	Control (n=44)	Statistical comparison
Day 1:			
Personal	5.50 (1.65)	4.39 (2.15)	t= -2.73 (p=.008)**
Revealing of emotions	3.48 (2.26)	1.84 (1.26)	t= -4.20 (p<.001)**
Told others	4.43 (2.40)	1.23 (0.64)	t= -8.57 (p<.001)**
Wanted to tell others	4.43 (2.31)	1.59 (1.11)	t= -7.37 (p<.001)**
Held back from telling others	2.59 (1.96)	1.98 (1.99)	t= -1.46 (p=.15)
Day 2:			
Personal	6.39 (0.84)	4.16 (2.28)	t= -6.08 (p<.001)**
Revealing of emotions	5.50 (1.23)	2.18 (1.50)	t= -11.36 (p<.001)**
Told others	3.55 (1.99)	1.25 (0.84)	t= -7.04 (p<.001)**
Wanted to tell others	3.77 (2.23)	1.36 (0.61)	t= -6.91 (p<.001)**
Held back from telling others	3.32 (2.08)	1.80 (1.69)	t= -3.77 (p<.001)**
Overall:			
Personal	6.09 (1.18)	3.95 (2.26)	t = -5.56 (p<.001)**
Revealing of emotions	5.64 (1.12)	2.61 (1.74)	t= -9.68 (p<.001)**
Told others	3.70 (1.92)	1.41 (0.95)	t= -7.10 (p<.001)**
Held back from telling others	3.16 (2.02)	2.32 (2.11)	t= -1.91 (p=.06)
Thought about study	3.29 (1.86)	2.19 (0.79)	t= -2.87 (p=.007)**
Thought about writing topics since study began	4.39 (1.71)	2.26 (1.26)	t= -5.29 (p<.001)**
Thought about topics before study began	4.11 (1.91)	2.07 (1.73)	t= -4.13 (p<.001)**

*p<.05, **p<.01

As expected, Table 19 shows that the partners in the GDP group viewed their essays as more personal and revealing of emotions across all three days. This was the case even on Day 1, when the GDP group were required to describe their diagnosis and treatment factually, without reference to emotions. In addition, participants in the GDP group reported having told others more about what they had written and greater desire to tell others what they had written about. Also, the GDP group reported having thought more about the writing topics both before the study began and since it began, and having thought more about the study since it began. However, the GDP group were not more likely than the control group to have held back from telling others about what they had written on Day 1 (when they described the factual details of their diagnosis and treatment) or overall, though they were on Day 2. Overall, these results demonstrated that both patients and partners had followed the instructions as required, except with regard to writing without emotions on Day 1.

7.9 Results for the RCT outcome data: repeated measures ANOVA

The RCT evaluated the efficacy of guided written emotional disclosure (the GDP) about the patients' diagnosis and treatment of ovarian cancer for improving quality of life and perceived stress in women with ovarian cancer and their partners. The primary outcome measures and the continuous secondary outcome measures were analysed using 2 (group) by 3 (time) repeated measures ANOVA. These analyses were carried out for both patients and partners. In each of these cases, the independent variable (IV), group, included two levels: GDP and control. Covariates included the patient's age, time since diagnosis, and whether the patient had undergone treatment since participating in the intervention. Since it was hypothesized that benefits from the intervention would be greater for patients if their partners completed the intervention also, completers' analyses consisted only of couples where both partners completed the intervention. Intention-to-treat analyses are reported separately. The categorical outcome measures of CA 125 and visits to alternative therapists were dichotomized and analysed using Pearson chi-square tests. Visits to GPs/consultants were highly skewed. However, as over 80% of the sample had visited their GP or consultant at least once, it was not appropriate to dichotomize it. These results were therefore analysed using the Mann-Whitney U test.

The 2 (group) by 3 (time) repeated measures ANOVAs evaluated the effects of group, time and group by time interactions. When significant, the group by time interaction effect was examined further by using *a priori* within subjects' contrasts comparing each time point to the previous one. Repeated contrasts were used to assess when change occurred by comparing three month follow-up data with the baseline scores, and to assess if treatment gains were maintained by comparing the six month follow-up data to the three month follow-up data. In order to understand the group in which change occurred, these analyses were carried out separately for each group. Finally, to understand the influence of disease progression on follow-up results, sensitivity analyses were conducted to examine the effect of recurrence status on the outcome measures.

Before conducting the outcome analyses, tests were conducted in order to assess whether the assumption of sphericity was met. Sphericity refers to the equality of variances of the differences between levels of the repeated measures factor. It is considered to be present when the difference between each pair of scores has equal variance (Field, 2005). Sphericity was measured using Mauchly's test. A significance level of less than $p = .05$ indicates that the condition of sphericity is violated. In such cases, the Greenhouse-Geisser correction was used in order to produce a valid F-ratio.

7.10 Results for the primary outcomes

The primary outcome measures included quality of life (the FACT) and perceived stress (the PSS).

7.10.1 Quality of Life

7.10.1.1 Group Means

Two (group) by 3 (time) repeated measures ANOVAs were conducted to determine whether there were any statistically significant group by time effects on quality of life. The dependent variable was quality of life measured at each of the three time points. The group means across time for both patients and partners are presented in Table 20, with higher scores indicating better quality of life. Figures 4 and 5 are graphs indicating changes in quality of life over time for patients and partners. There were no group by time interaction effects. For patients, effect sizes (Cohen's d) for the GDP group were -0.21 from baseline to three month follow-up and -0.19 from baseline to six month follow-up. For partners, effect sizes for the GDP group were 0.15 from baseline to three month follow-up and -0.03 from baseline to six month follow-up.

Table 20 : Quality of Life Scores for both groups – patients and partners

Group	Baseline (Mean, SD)	Three-month follow-up (Mean, SD)	Six-month follow-up (Mean, SD)	Repeated measures ANOVA	
				F	*p*
Patients:					
GDP	58.87 (12.53)	56.00 (15.30)	56.30 (14.96)	*df* (2, 140)	
Control	60.13 (11.06)	60.26 (11.77)	60.26 (12.58)	*F* = 2.34	.10
Partners					
GDP	45.75 (7.40)	46.86 (7.61)	45.50 (7.63)	*df* (1.81, 119.53)	
Control	50.94 (8.99)	49.57 (8.53)	49.11 (8.90)	*F* = 2.52	.09

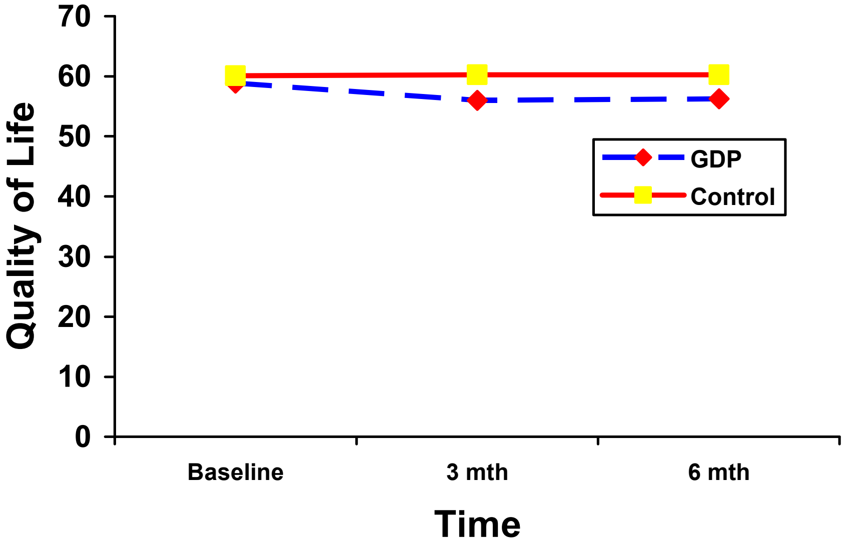

Figure 4: Mean quality of life scores across time for patients

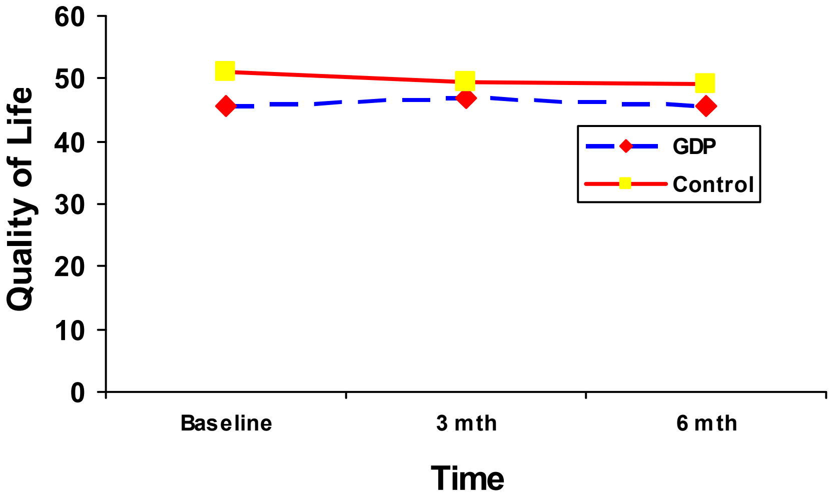

Figure 5: Mean quality of life scores across time for partners

7.10.1.2 Quality of Life: Sensitivity Analyses

Sensitivity analyses were conducted to examine whether changes in factors unique to the ovarian cancer patients and their partners in this study had an impact on quality of life outcome. In the current study, only one such analysis was carried out. The couples were informed that they could either complete the intervention at the same time or at different times. Eleven couples completed the intervention separately (seven in the control group and four in the GDP group). Sensitivity analyses were conducted with regard to quality of life, whereby these 11 couples were excluded from the analysis. For patients, a 2 (group) by 3 (time) repeated measures ANOVA revealed similar results to the analyses for all completers – the group by time interaction was non-significant (*F* (2, 126) = 2.97, *p*=.06). For partners, the results were similar to the analyses conducted on all completers – the group by time interaction was non-significant (*F* (1.80, 106.21) = 1.77, *p*=.18). Thus, sensitivity analyses indicated that in this sample of ovarian cancer patients and their partners, allowing couples to complete the intervention separately did not appear to have a significant impact on the overall outcome for patients or partners.

7.10.1.3 Quality of Life: Intention to treat analyses

The CONSORT guidelines (Moher et al., 2001) recommend that intention-to-treat analyses are carried out, in order to understand the impact an intervention will have in practice. In the current study, these were not the primary analyses, as although the

RCT did not aim to improve survival, a major reason for attrition was patient death. Furthermore, since written disclosure has not been tested as a stand-alone intervention for couples, this study aimed to test the effectiveness of completing the intervention and possible mechanisms for this effect. Nevertheless, in order to ascertain the viability of future research into this topic, intention-to-treat analyses were carried out. These analyses revealed similar results to the completers' analyses with regard to interactions. For patients, the group by time interaction was non-significant (F (2, 168) = 2.56, p=.08). For partners, the group by time interaction was non-significant (F (1.75, 145.45) = 1.30, p = .28). These results suggest that the GDP has no effect on patients' or partners' quality of life.

7.10.2 Perceived Stress

7.10.2.1 Perceived Stress: Group Means

Two (group) by 3 (time) repeated measures ANOVAs were conducted to determine whether there were any statistically significant group by time effects on perceived stress. The group means across all three time points for patients' and partners' levels of perceived stress are presented in Table 21, with higher scores indicating more stress. As shown in Figures 6 and 7, which are graphs indicating changes in perceived stress over time, there was no group by time interaction effect for perceived stress in patients or partners. For patients, effect sizes (Cohen's d) for the GDP group were -0.11 from baseline to three month follow-up and -0.10 from baseline to six month follow-up. For partners, effect sizes for the GDP group were -0.30 from baseline to three month follow-up and -0.21 from baseline to six month follow-up.

Table 21 : Perceived stress scores for both groups – patients and partners

Group	Baseline (Mean, SD)	Three-month follow-up (Mean, SD)	Six-month follow-up (Mean, SD)	Repeated measures ANOVA *F*	*p*
Patients:					
GDP	18.10 (7.70)	18.95 (7.68)	18.85 (7.74)	*df* (2, 140)	
Control	14.17 (7.67)	15.09 (6.92)	16.23 (7.82)	F = .38	.68
Partners					
GDP	15.13 (6.69)	17.13 (6.52)	16.45 (6.19)	*df* (2, 136)	
Control	12.29 (6.92)	12.40 (6.36)	13.29 (7.68)	F = 1.20	.30

7.10.2.2 Perceived Stress: Sensitivity analyses

Sensitivity analyses were conducted to examine whether changes in factors unique to the ovarian cancer patients and their partners in this study had an impact on perceived stress. In the current study, eleven couples completed the intervention separately (seven in the control group and four in the GDP group). Sensitivity analyses were conducted with regard to perceived stress, whereby these 11 couples were excluded from the analysis. For patients, a 2 (group) by 3 (time) repeated measures ANOVA revealed similar results to the analyses for all completers – the group by time interaction was non-significant (F (2, 126) = .52, p=.59). For partners, the results were similar to the analyses conducted on all completers – the group by time interaction was non-significant (F (1.81, 110.25) = .82, p=.43). Thus, allowing couples to complete the intervention separately did not appear to have a significant effect on the outcome for patients or partners.

7.10.2.3 Intention-to-treat analyses

Intention-to-treat analyses were carried out with regard to the perceived stress scores. For patients, the results were similar to the completers' analyses. There was no group by time interaction (F (2, 168) = .30, p=.74). For partners, the results were similar to the completers' analyses. There was no group by time interaction (F (2, 168) = 2.18, p=.12). Overall, these results suggest that the GDP had no impact on perceived stress in either patients or partners when the full sample was taken into consideration.

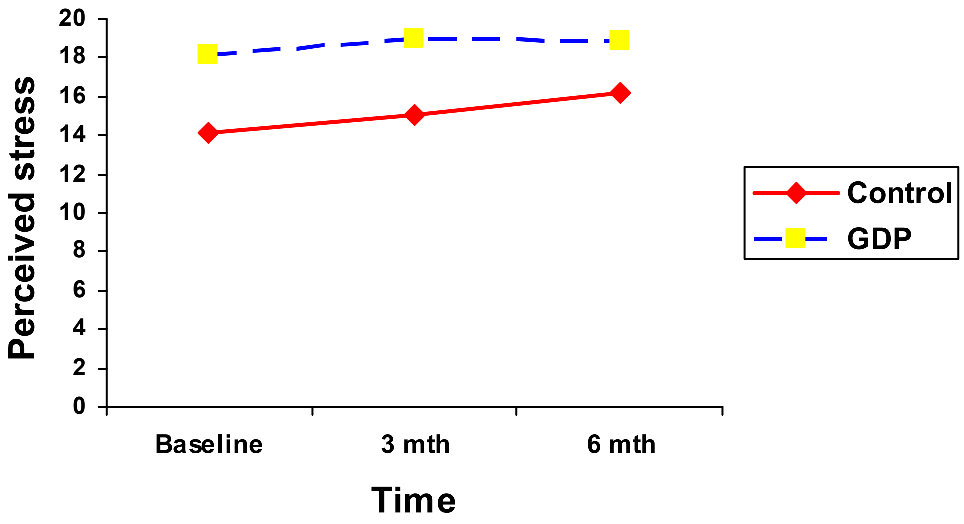

Figure 6 : Mean perceived stress scores across time for patients

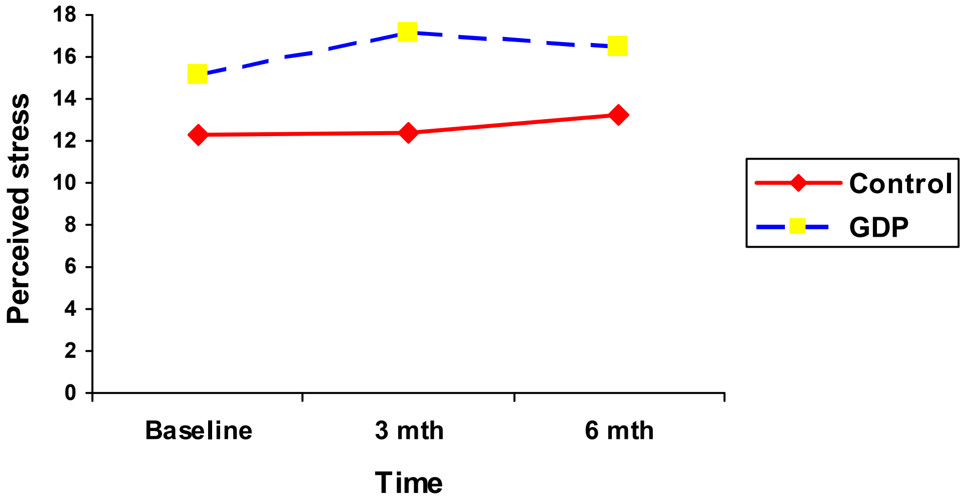

Figure 7 : Mean perceived stress scores across time for partners

7.11 Results for the secondary outcomes

7.11.1 Social Interaction Hypothesis

Two secondary outcomes were assessed with regard to the social interaction hypothesis: marital communication and illness-related couple communication.

7.11.1.1 Social interaction hypothesis – group means

The group means across all three time points for patients' and partners' marital communication in general and illness-related couple communication are presented in Table 22, with higher scores indicating better communication. Figures 8-11 are graphs indicating changes in communication over time for patients and partners. Two (group) by 3 (time) repeated measures ANOVAs were conducted to determine whether there were any statistically significant group by time effects on communication. The dependent variables were marital communication and illness-related couple communication measured at each of the three time points.

With regard to the patients, there was no group by time interaction with regard to marital communication (*F* (2, 142) = 1.50, *p*=.23) or illness-related couple communication (*F* (1.83, 129.91) = .11, *p*=.88). With regard to partners, there was no group by time interaction with regard to marital communication (*F* (2, 134) = .21, *p*=.81) or illness-related couple communication (*F* (2, 134) = 1.58, *p*=.21). These results are reported in Table 15, and depicted in Figures 6-9. For patients, effect sizes (Cohen's d) for marital communication for the GDP group were -0.10 from baseline to three month follow-up and -0.07 from baseline to six month follow-up. For partners, effect sizes for marital communication for the GDP group were -0.04 from baseline to three month follow-up were and -0.09 from baseline to six month follow-up. For patients, effect sizes for illness-related couple communication for the GDP group were 0.10 from baseline to three month follow-up and 0.12 from baseline to six month follow-up. For partners, effect sizes for illness-related couple communication for the GDP group were -0.10 from baseline to three month follow-up and -0.08 from baseline to six month follow-up.

Table 22 : Means and standard deviations of social interaction hypothesis variables for both groups – patients and partners

Variable	Group	Baseline	3 month follow-up	6 month follow-up
Marital communication				
Patients	GDP	35.05 (9.26)	34.15 (9.06)	34.43 (9.18)
	Control	36.00 (8.02)	37.33 (7.04)	37.67 (8.04)
Partners	GDP	35.65 (7.81)	35.32 (8.71)	34.92 (8.57)
	Control	38.91 (7.44)	38.46 (8.31)	37.69 (8.22)
Illness-related couple communication				
Patients	GDP	13.63 (4.10)	14.00 (3.72)	14.10 (3.62)
	Control	13.58 (3.65)	14.39 (3.27)	14.28 (3.34)
Partners	GDP	14.65 (3.58)	14.30 (3.79)	14.38 (3.45)
	Control	16.20 (2.71)	14.86 (3.43)	15.26 (3.27)

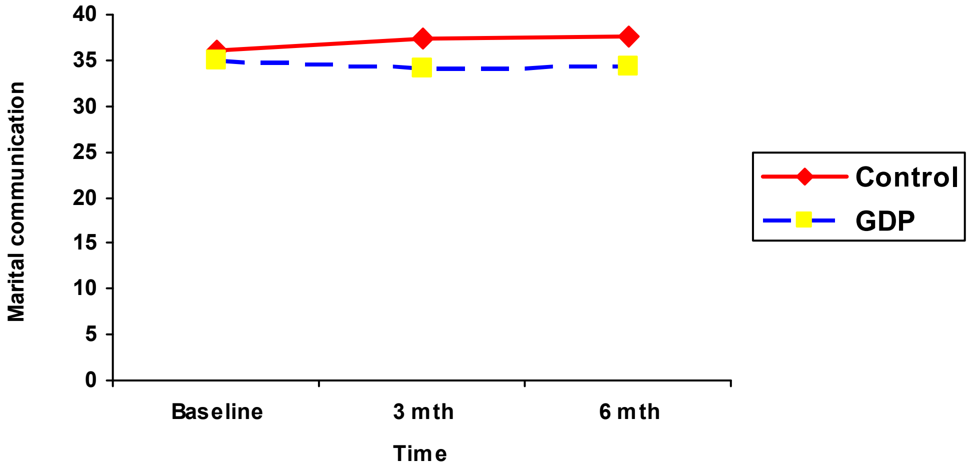

Figure 8: Mean marital communication scores across time for patients

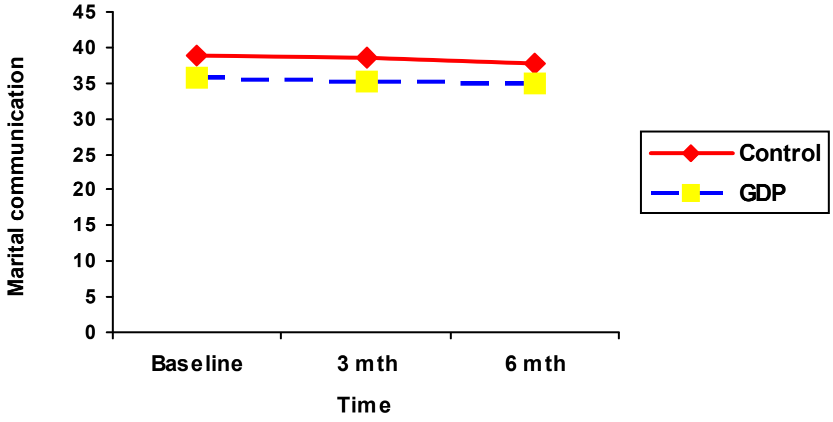

Figure 9: Mean marital communication scores across time for partners

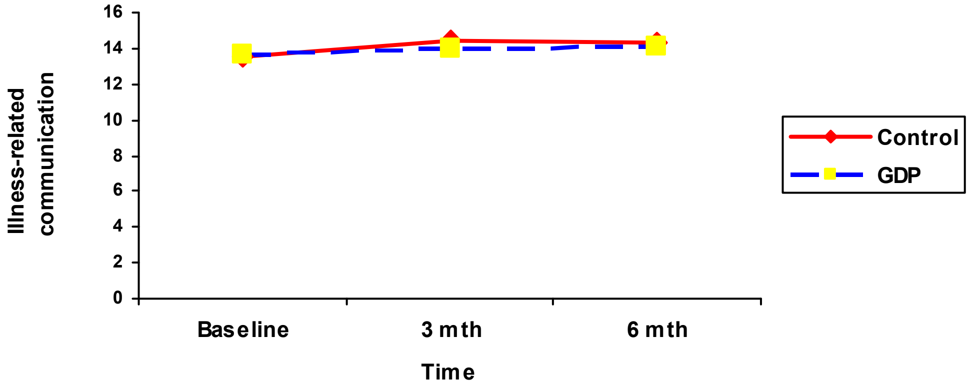

Figure 10: Mean illness-related couple communication scores across time for patients

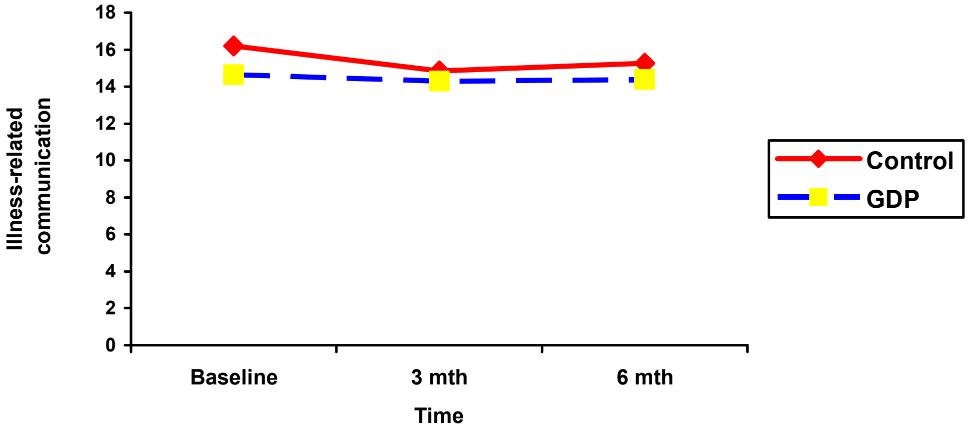

Figure 11: Mean illness-related couple communication scores across time for partners

7.11.1.2 Social interaction hypothesis: intention-to-treat analyses

Intention-to-treat analyses were carried out on the variables of marital communication and illness-related couple communication. With regard to general marital communication, the results were similar to the completers' analyses for both patients and partners. There was no group by time interaction in patients (*F* (2, 168) = 1.62, *p*=.20) or in partners (*F* (2, 168) = .48, *p*=.60). With regard to illness-related communication, the results were similar to the completers analyses - there was no group by time interaction for patients (*F* (1.72, 144.53) = .77, *p*=.45), or for partners (*F* (2, 168) = 2.44, *p*=.09). In summary, there was no effect of the GDP on general marital communication or illness-related couple communication in patients or partners.

7.11.2 Cognitive Processing Hypothesis

Two secondary outcomes were assessed with regard to the cognitive processing hypothesis: intrusive thoughts related to the cancer, and emotional representations of the cancer.

7.11.2.1 Cognitive Processing Hypothesis: Group Means

The group means across all three time points for patients' and partners' levels of intrusive thoughts and emotional representations of their illness are presented in Table 23, with higher scores indicating higher levels of intrusive thoughts/ more distress. Figures 12 to 15 are graphs indicating changes in illness-related intrusive thoughts and levels of distress over time for patients and partners. Two (group) by 3 (time) repeated measures ANOVAs were conducted to determine whether there were any statistically significant group by time effects on intrusive thoughts and emotional representations of the illness. These analyses were carried out for both patients and partners. The dependent variables were cancer-related intrusive thoughts and emotional representations of the illness measured at each of the three time points.

With regard to the patients, there was no group by time interaction for intrusive thoughts (*F* (2, 142) = .035, p=.97) or emotional representations of the illness (*F* (2, 142) = .48, p=.62). With regard to partners, there was no group by time interaction for emotional representations of the illness (*F* (1.78, 121.32) = .11, p=.88). However, there was a significant group by time interaction for intrusive thoughts (*F* (2, 134) = 3.29, p=.04). Planned contrasts of the interaction effect revealed that there was a significant group by time interaction between baseline and three month follow-up (*F* (1, 72) = 7.14, p=.009) but that there was no group by time interaction between three month follow-up and six month follow-up (*F* (1, 67) = .10, p=.75), indicating that the change occurred between baseline and three months. The effect of time from baseline to three months was significant for the GDP group (*F* (1, 39) = 6.92, p=.012) but not for the control group (*F* (1, 38) = .32, p=.57), indicating that this difference was due to an increase in levels of intrusive thoughts in the GDP group between baseline and the three month follow-up. For patients, effect sizes (Cohen's d) for intrusive thoughts for the GDP group were 0.03 from baseline to three month follow-up and -0.07 from baseline to six month follow-up. Effect sizes for emotional representations of the illness for the GDP group were -0.05 from baseline to three month and 0.06 from baseline to six month follow-up. For partners, effect sizes for intrusive thoughts for the GDP group were -0.27 from baseline to three month follow-up and -0.33 from baseline to six month follow-up. This contrasts with effect sizes of 0.11 from baseline to three month follow-up and 0.08 from baseline to six month follow-up. For emotional representations of the illness, effect sizes for the GDP group were 0.13 from baseline to three month follow-up and 0.09 from baseline to six month follow-up.

Table 23: Means and standard deviations of cognitive processing hypothesis variables for both groups – patients and partners

Variable	Group	Baseline	3 month follow-up	6 month follow-up
Intrusive thoughts				
Patients	GDP	10.90 (7.46)	10.68 (8.00)	11.40 (7.59)
	Control	8.92 (6.96)	9.06 (6.55)	9.36 (6.90)
Partners	GDP	8.14 (5.95)	9.95 (7.49)	10.24 (6.92)
	Control	8.54 (6.59)	7.86 (6.28)	8.03 (6.21)
Emotional representations of the illness				
Patients	GDP	19.45 (5.36)	19.70 (5.27)	19.10 (5.63)
	Control	18.58 (5.81)	18.17 (5.41)	18.56 (5.27)
Partners	GDP	21.71 (4.69)	21.13 (4.50)	21.26 (5.07)
	Control	21.14 (4.35)	20.17 (4.96)	20.60 (4.89)

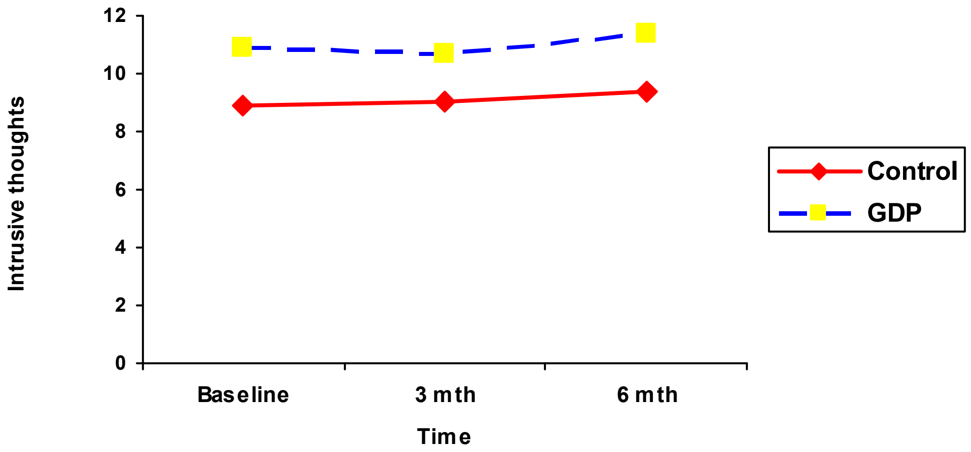

Figure 12: Levels of intrusive thoughts across time for patients

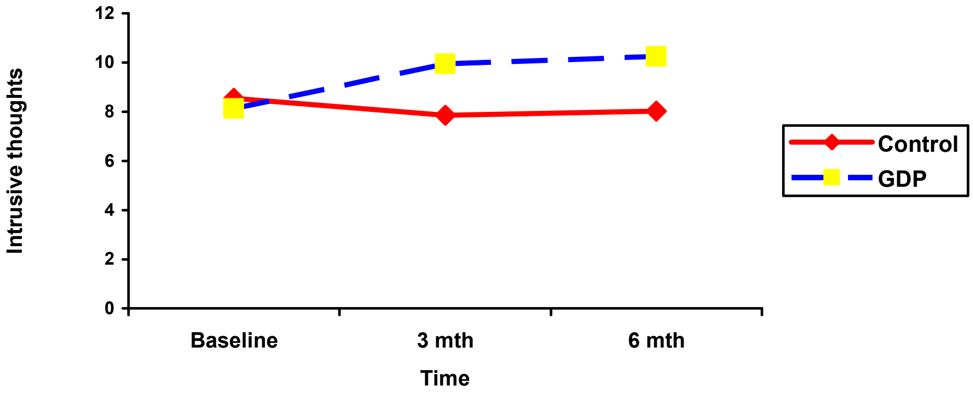

Figure 13: Levels of intrusive thoughts across time for partners

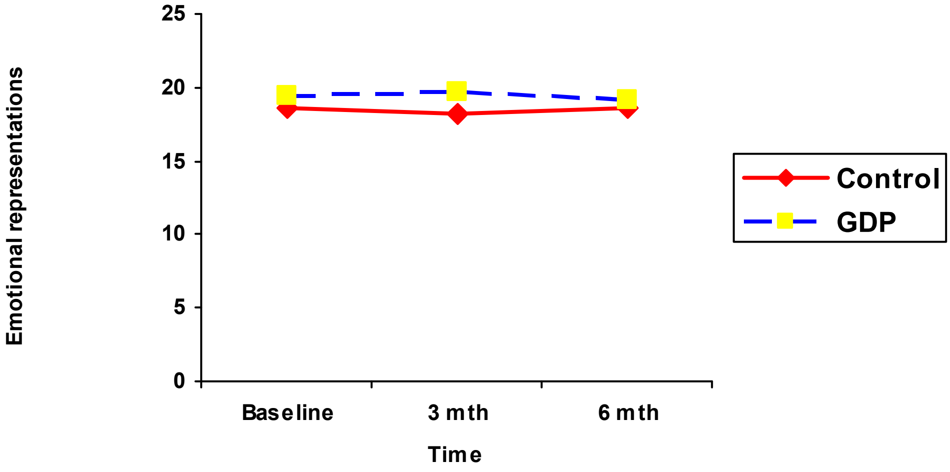

Figure 14: Emotional representations of the illness – patients

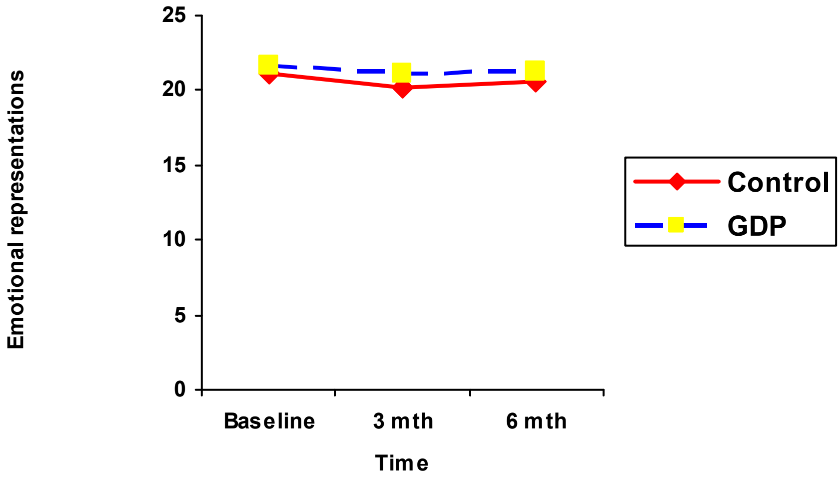

Figure 15: Emotional representations of the illness – partners

7.11.2.2. Intention-to-treat analyses – cognitive processing hypothesis

Intention-to-treat analyses were carried out with regard to the variables of emotional representations of the illness and intrusive thoughts. For emotional representations of the illness, the results were similar to the completers' analyses. There was no group by time interaction in patients (*F* (2, 168) = 0.80, *p*=.45) or partners (*F* (2, 168) = 0.35, *p*=.69). For intrusive thoughts, the results were similar to the completers' analyses. There was no group by time interaction in patients (*F* (2, 168) = 0.46, *p*=.63). However, there was a significant group by time interaction in partners (*F* (2, 168) = 3.76, *p*=.03), which occurred between baseline and three months (*F* (1, 84) = 7.00, *p*=.01), but not between three months and six months (*F* (1, 84) = .57, *p*=.45).

In summary, there was no differential effect of the GDP versus control writing on emotional representations of the illness. There was no effect of the GDP on intrusive thoughts in patients, but it led to increased intrusive thoughts in partners relative to the control group.

7.11.3 Secondary Outcomes: Visits to Health Professionals

Visits to health professionals for the preceding three months were assessed at each time point. These were divided into visits to GPs/consultants and visits to alternative therapists. Both these variables had high levels of skewness and kurtosis at baseline, which were not influenced by transformations. As 67 of the participants had not visited an alternative therapist at baseline, it was decided to dichotomize this variable. Chi-square analyses were then conducted to determine whether significantly fewer patients visited an alternative therapist at follow-up in the GDP group relative to the control group. These results, which are reported in Table 24, revealed no significant group differences at any time point.

Table 24: Number of patients who had visited an alternative therapist at each time point, by group

Visits to alternative therapists	GDP	Control	Chi-square analysis (df = 1)
Baseline (n, %)	17 (32%)	15 (32.6%)	$\chi^2 = .003$, p=1.00
Three month follow-up (n, %)	18 (37.5%)	15 (36.6%)	$\chi^2 = .008$, p=1.00
Six month follow-up (n, %)	17 (37%)	13 (31.7%)	$\chi^2 = .26$, p=.66

The variable of GP visits could not be transformed or dichotomized appropriately, so non-parametric tests (Mann-Whitney U) were used to compare the groups at each time point. As shown in Table 25, there were no significant group differences at any time point.

Table 25: GP/consultant visits at each time point, by group

GP visits	GDP	Control	Statistical analysis (Mann-Whitney U)
Baseline (median, range)	2 (0-10)	1 (0-12)	Z = -.57, p=.57
Three month follow-up (median, range)	2 (0-7)	2 (0-13)	Z = -1.10, p=.27
Six month follow-up (median, range)	2 (1-8)	2 (0-9)	Z = -1.29, p=.20

7.11.4 Secondary Outcomes: CA 125

Since the CA 125 data was highly skewed, it was decided to dichotomize it based on the clinical cut-off of 35 U/ml (Bast et al., 1983). Categorical CA 125 levels did not differ between groups at baseline. Chi-square analyses were conducted to determine whether the percentage of patients with CA 125 levels above 35 U/ ml differed between the groups at each follow-up. Not all participants had this data at each time point, so these analyses are not based on the full sample, and should be considered as exploratory. As shown in Table 26, these results revealed no significant group differences at any time point.

Table 26: Categorical CA 125 levels at each time point and results of chi-square analysis

CA 125 > 35 U/ml	GDP (n, %)	Control (n, %)	Chi-square analysis
Baseline (n, %)	12 (23%)	14 (29%)	$\chi^2 = .48$, p=.50
Three month follow-up (n, %)	15 (37.5%)	12 (37.5%)	$\chi^2 = 0$, p=1.00
Six month follow-up (n, %)	15 (48%)	13 (43%)	$\chi^2 = .16$, p=.80

7.12 Mediators and Moderators

7.12.1 Mediators of change

Mediators identify mechanisms through which an intervention brings about positive change. One of the aims of this study was to investigate potential mediators of the effectiveness of the GDP in reducing distress and improving quality of life in ovarian cancer patients. However, there was no group by time interaction for any of the primary outcomes, so no tests for potential psychosocial mediators were carried out.

7.12.2 Moderators of change in quality of life and perceived stress and conditional indirect effects

Another objective was to evaluate potential moderators of the primary outcomes of perceived stress and quality of life in ovarian cancer patients and their partners. Hypothesised possible illness-related moderators included the presence of a recurrence. Hypothesised psychosocial moderators included baseline marital communication (which was categorised based on published norms) and partners' levels of intrusive thoughts at baseline,. Other moderators included participants' views of the intervention (based on a question asking whether they would recommend it to others) and recurrence status. Since it was also considered important to address the process by which improvements may have occurred for some of the population, change in levels of intrusive thoughts and change in illness-related communication were selected as potential moderated mediators, based on the original theoretical hypotheses (Muller et al., 2005)). Change scores are generally used in mediation analysis (Baron & Kenny, 1986). However, as discussed in Chapter 6, moderated mediation implies mediation for some people or in some contexts. In the current research, as there was no theoretical basis for selecting further moderators the change scores were treated as moderators in these analyses. This was considered more appropriate than splitting the sample based on their change scores and running mediation analyses on each half, as it accounted for the full range of variability in the change scores. Since it was expected that any change would occur mainly between baseline and three months, and any effects demonstrated were present at three months but not six months, these analyses were carried out between baseline and three months.

Possible moderators and moderated mediators were analysed in two ways. Categorical variables were analysed using a 2 (moderator variable, i.e., recurrence) by 2 (group) ANOVA, controlling for baseline levels of the primary outcome (perceived stress or quality of life), with levels of the primary outcome at three months as the DV. Continuous variables (partners' levels of intrusive thoughts at baseline plus the hypothesized moderated mediators (conditional indirect effects)) were analysed using hierarchical multiple linear regressions. This is considered to be a better method than categorising outcomes based on a median split, as it takes into account variability in the moderator. In these regressions, the primary outcome in question at three months (i.e., quality of life) was entered as the DV and level of the primary outcome at baseline, was entered as a predictor on the first step, followed by intervention group, the z-score of the moderator variable and the interaction term of group by the z-score of the moderator variable on the second step. Results for the dichotomous moderator variables are shown in Tables 27 and 28, and results for the continuous moderator/ moderated mediator variables are shown in Tables 29 and 30.

Table 27: Analysis of variance for the dichotomous predictor/ moderator variables – quality of life

Predictor/ Moderator		*F*	p
Recurrence	Patients	.03	.86
	Partners	.09	.76
Recurrence*Group	Patients	.005	.94
	Partners	.006	94
Marital communication	Patients	2.83	.10
	Partners	2.59	.11
Marital communication* Group	Patients	.09	.77
	Partners	.66	.42
Recommend intervention	Patients	.58	.45
	Partners	1.28	.26
Recommend intervention*Group	Patients	4.81	.03*
	Partners	.20	.66

*p<.05

Table 28: Analysis of variance for the dichotomous predictor/ moderator variables – perceived stress

Predictor/ Moderator		*F*	p
Recurrence	Patients	6.12	.02*
	Partners	.92	.34
Recurrence*Group	Patients	.002	.97
	Partners	1.67	.20
Marital communication	Patients	.96	.33
	Partners	.12	.73
Marital communication* Group	Patients	.64	.43
	Partners	.10	.75
Recommend intervention	Patients	2.44	.12
	Partners	.25	.62
Recommend intervention*Group	Patients	1.19	.28
	Partners	.03	.87

*p<.05

Table 27 shows that for patients, views about the intervention moderated the effect of group on quality of life. In the GDP group, there was no effect of views of the intervention on quality of life at three month follow-up, whereas in the control group, those who said they would not recommend the intervention reported better quality of life at three month follow-up. These results are depicted in Figure 16. Having recurrent ovarian cancer was a significant predictor of perceived stress, such that those who had had a recurrence reported lower levels of perceived stress at follow-up. However, no significant interaction was obtained between this predictor and group.

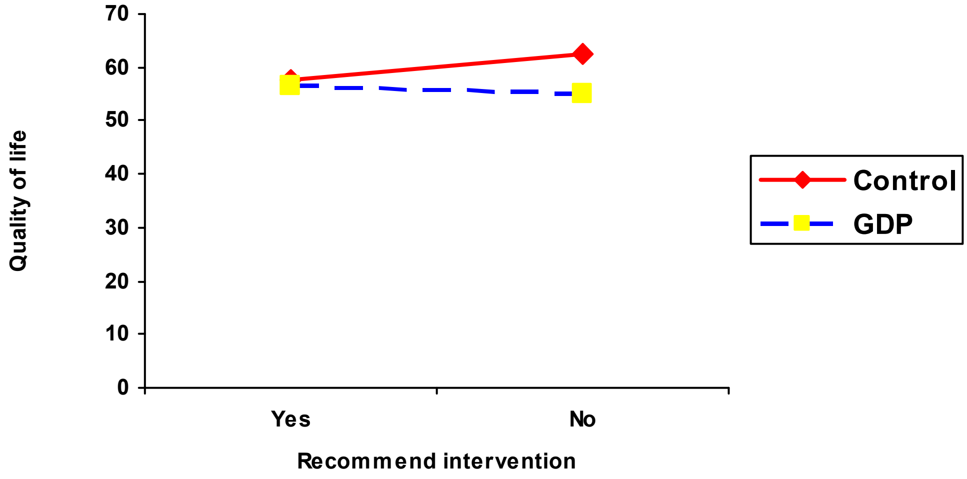

Figure 16: Views about the intervention as a moderator of the effect of group on quality of life

Results for the continuous variables revealed that change in intrusive thoughts predicted quality of life at three month follow-up in partners (see Table 29). The partner’s levels of intrusive thoughts at baseline and change in illness-related communication moderated the effects of the GDP on quality of life in patients (see Tables 29 and 30). Change in intrusive thoughts predicted levels of perceived stress at three month follow-up in patients and partners. It also moderated the effects of the GDP on perceived stress in patients. These results are explained below, with reference to graphs where appropriate.

Table 29: Hierarchical multiple regression for the continuous predictor/ moderator/ moderated mediator variables – quality of life

Predictor/ Moderator/moderated mediator		*B*	SE *B*	β	*t*	*p*
Partner intrusive thoughts	Patients	-.43	.22	.24	-1.97	.052
	Partners	.17	.10	.17	1.69	.10
Partner intrusive thoughts*Group	Patients	.63	.28	.24	2.28	.03*
	Partners	-.08	.14	-.06	-.61	.55
Change in intrusive thoughts	Patients	-.27	.19	-.13	-1.40	.16
	Partners	-.43	.15	-.27	-2.91	.005**
Change in intrusive thoughts*Group	Patients	-.32	.29	-.10	-1.10	.28
	Partners	-.08	.21	-.03	-.36	.72
Change in illness-related communication	Patients	.09	.32	.03	.29	.77
	Partners	-.13	.30	-.05	-.45	.66
Change in illness-related communication*Group	Patients	1.17	.52	.20	2.27	.03*
	Partners	.25	.41	.06	.61	.55

*p<.05, **p<.001

The interaction effect of change in illness-related communication by group was significant in predicting quality of life at three month follow-up. The interaction explained an additional 2.3% of the variance in quality of life (*F* (1, 85) = 5.16, p=.03). To explore this relationship further, quality of life was plotted against change in illness-related communication for each group (see Figure 17). Predicted values for quality of life were obtained by using the following equation (Aiken & West, 1991):

“$\hat{Y} = (b_1 + b_3Z) X + (b_2Z + b_0)$”

$\hat{Y}$ stands for the predicted value of quality of life at three month follow-up. X stands for group (coded as 0 (control) and 1 (GDP)), and Z stands for the z score for change in illness-related communication for the mean, one standard deviation above and one standard deviation below the mean. The unstandardized regression coefficients (B) for the constant, group, change in illness-related communication and the interaction are represented by b_0, b_1, b_2 and b_3 respectively. The equation was summed with the unstandardized regression coefficient for quality of life at baseline. The total product was converted from a z score to give the actual quality of life score.

Table 30: Hierarchical multiple regression for the continuous predictor/moderator variables – perceived stress

Predictor/Moderator/moderated mediator		*B*	SE *B*	β	*t*	*p*
Partner intrusive thoughts	Patients	.15	.13	.14	1.17	.24
	Partners	-.03	.12	-.03	-.25	.80
Partner intrusive thoughts*Group	Patients	-.30	.17	-.19	-1.75	.08
	Partners	-.002	.16	-.002	-.01	.99
Change in intrusive thoughts	Patients	.47	.11	.39	4.31	<.001**
	Partners	.43	.18	.30	2.44	.02*
Change in intrusive thoughts*Group	Patients	-.43	.16	-.24	-2.66	.009**
	Partners	-.16	.25	-.08	-.66	.51
Change in illness-related communication	Patients	.14	.20	.07	.71	.48
	Partners	.28	.33	.12	.86	.39
Change in illness-related communication*Group	Patients	-.28	.32	-.08	-.87	.39
	Partners	-.49	.45	-.15	-1.09	.28

*p<.05, **p<.01

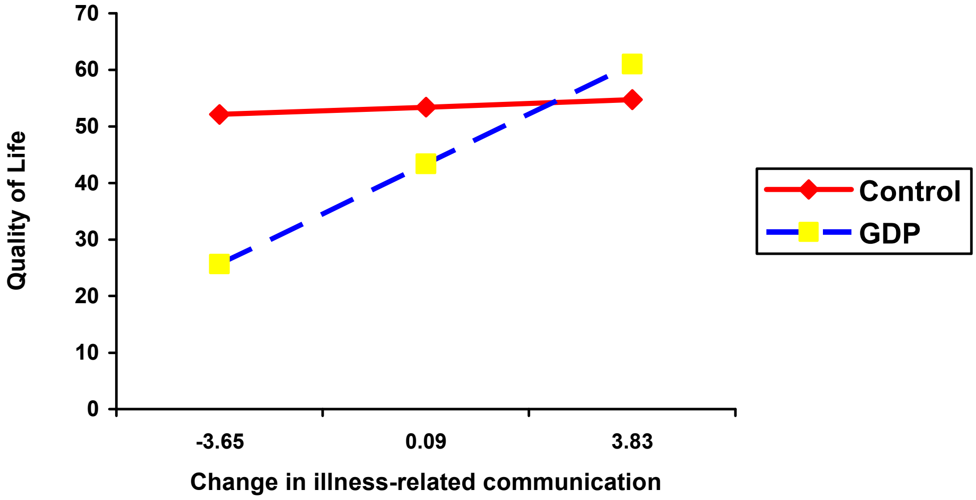

Figure 17: Change in illness-related communication as a moderator of the effects of group on quality of life – patients

For the control group, there was no impact of change in illness-related communication on quality of life at three month follow-up, whereas for the GDP group, quality of life was better if illness-related communication improved, and worse if illness-related communication worsened. Thus, improvements in illness-related communication mediated the effect of group of quality of life in some of the patients in the GDP group.

Partner intrusive thoughts at baseline moderated the effects of group on patients' quality of life at three month follow-up. This interaction explained an additional 2.5% of the variance in quality of life (*F* (1, 84) = 5.19, p=.03). To explore this relationship further, quality of life was plotted against partner intrusive thoughts at baseline for each group, following the equation, and summing it with the unstandardized regression coefficient for quality of life at baseline. These results are depicted in Figure 18.

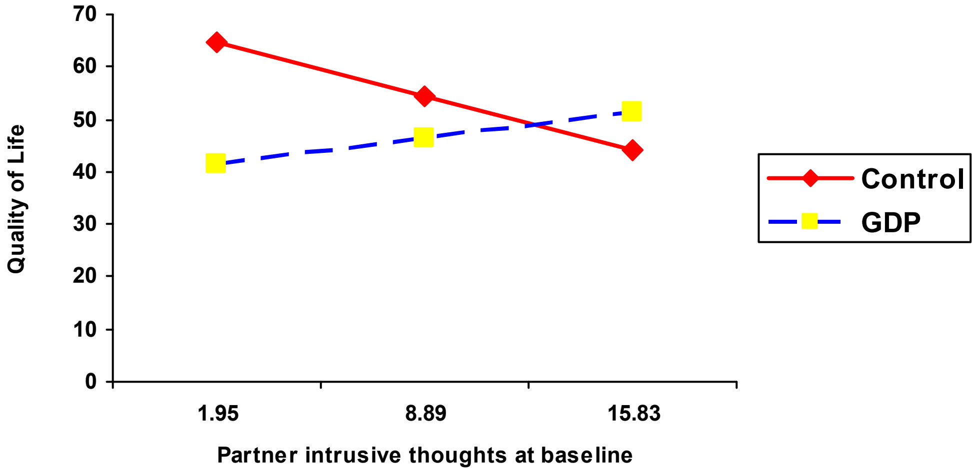

Figure 18: Partners' intrusive thoughts as a moderator of the effects of group on quality of life-patients

For the control group, quality of life at three month follow-up worsened considerably as partner intrusive thoughts increased. However, for the GDP group, quality of life improved as partner intrusive thoughts increased. Finally, in partners, change in intrusive thoughts predicted quality of life at three month follow-up, such that if intrusive thoughts decreased, quality of life also improved.

Change in intrusive thoughts predicted levels of perceived stress at three month follow-up in patients, such that if there was a decrease in intrusive thoughts, perceived stress stayed the same, whereas if levels of intrusive thoughts increased, levels of perceived stress also increased. However, the interaction between change in intrusive and group was significant in predicting quality of life at three month follow-up. This interaction explained 3% of the variance in perceived stress (*F* (1, 84) = 7.07, p=.009). To explore this relationship further, perceived stress was plotted against change in intrusive thoughts for each group, using the equation described earlier. The equation was summed with the unstandardized regression coefficient for perceived stress at baseline (see Figure 19).

For the control group, an increase in intrusive thoughts was associated with higher levels of perceived stress at three month follow-up, whereas for the GDP group, although perceived stress was marginally lower if intrusive thoughts decreased, there was no effect on perceived stress if levels of intrusive thoughts remained constant or increased. Thus, for some of the patients in the control group, an increase in intrusive thoughts mediated an increase in perceived stress. Finally, for partners, change in intrusive thoughts predicted levels of perceived stress at three month follow-up. Results were similar to those for patients: a decrease in levels of intrusive thoughts was associated with perceived stress remaining constant, whereas if levels of intrusive thoughts increased, levels of perceived stress also increased.

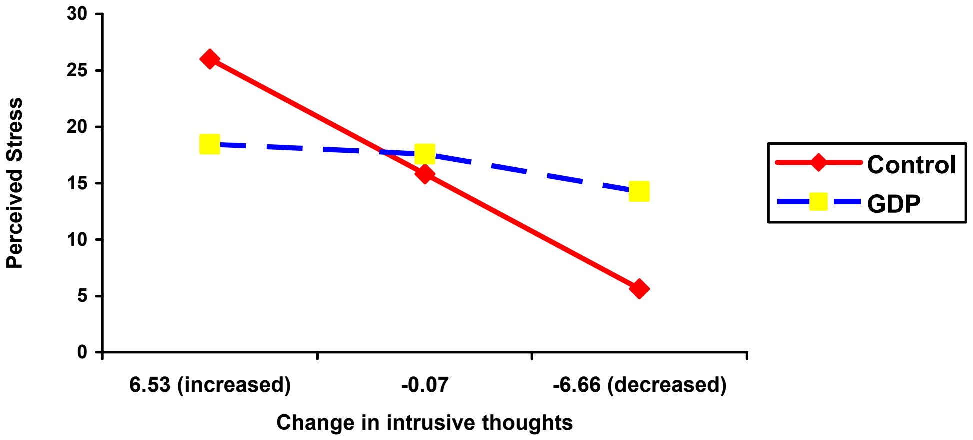

Figure 19: Change in intrusive thoughts as a moderator of the effects of group on perceived stress – patients

7.13 Correlations between word usage and improvements on the primary and secondary outcomes

Previous studies have found that word usage is related to improvements in the GDP group. This was therefore assessed in the current study. It was hypothesized that greater use of positive and negative emotion, insight and causality words (indicative of reflection and emotional processing) would be related to improvements in the GDP group from baseline to three month follow-up, for both patients and partners.

In order to assess this, partial correlations were carried out between change in the primary and secondary outcomes of quality of life, perceived stress, marital communication, illness-related couple communication, intrusive thoughts and emotional representations of the illness from baseline to three month follow-up and the word usage categories of positive emotion, negative emotion, insight and causality words on days 2 and 3, controlling for baseline score on the outcome in question. In order to reduce the possibility of Type 1 error, the percentages of words used on days 2 and 3 were combined.

The results for patients are presented in Table 31. Increased use of positive emotion words on days 2 and 3 were associated with reductions in perceived stress and improvements in illness-related couple communication from baseline to three month follow-up. In addition, reduced use of negative emotion words was associated with reductions in perceived stress from baseline to three month follow-up. The results for partners are presented in Table 32. Increased use of positive emotion words was associated with improvements in illness-related couple communication from baseline to three month follow-up. In summary, these results indicate that word usage had a significant influence on outcomes within the GDP group.

Table 31: Correlations between word usage on days 2 and 3 and change in the primary and secondary outcomes from baseline to three months - patients

Change in outcome variable (baseline to three months)	Positive emotion	Negative emotion	Insight	Causality
Quality of Life (FACT-O)	.03	.02	.10	.003
Perceived Stress	-.31*	.32*	.14	-.27
Intrusive thoughts	.03	.06	-.11	.06
Emotional representations	-.16	.07	-.15	-.15
Marital communication	.22	-.08	.24	.03
Illness-related communication	.32*	-.15	.12	.14

* p<.05

Table 32: Correlations between word usage on days 2 and 3 and change in the primary and secondary outcomes from baseline to three months – partners

Change in outcome variable (baseline to three months)	Positive emotion	Negative emotion	Insight	Causality
Quality of Life (FACT-O)	-.03	.14	-.02	-.06
Perceived Stress	.20	.10	-.003	-.07
Intrusive thoughts	-.06	.03	-.13	.07
Emotional representations	.02	.03	-.08	.12
Marital communication	-.01	.08	.02	-.07
Illness-related communication	.33*	.01	-.12	-.08

*p<.05

7.14 Thinking and talking about the writing at follow-up

At each follow-up, participants were asked to evaluate how much they had thought about what they had written and talked with others about what they had written since participation in the intervention, on a scale from 1 to 7. These results are reported in Tables 33 and 34. Overall, levels of thinking and talking about the writing post-intervention were very low for both groups. Patients in the GDP group were significantly more likely to report thinking more about what they had written at three months, and significantly more likely to report talking about what they had written at six months. For partners, those in the GDP group reported thinking and talking about the intervention more at three months, but there were no group differences at six months. However, even the significant differences were very small.

Table 33: Group differences with regard to thinking and talking about the writing at follow-up – patients (means are presented with standard deviations in brackets)

	GDP	Control	Statistical comparison
Three month follow-up:			
Think	2.54 (1.29)	1.90 (1.03)	t = -2.57 (p=.012)*
Talk	1.56 (1.05)	1.33 (0.53)	t = -1.33 (p=.19)
Six month follow-up:			
Think	2.59 (1.41)	2.12 (1.47)	t = -1.51 (p=.14)
Talk	1.65 (1.04)	1.27 (0.63)	t = -2.05 (p=.04)*

*p<.05

Table 34: Group differences with regard to thinking and talking about the writing at follow-up – partners (means are presented with standard deviations in brackets)

	GDP	Control	Statistical comparison
Three month follow-up:			
Think	2.48 (1.45)	1.60 (0.98)	t = -3.16 (p=.002)**
Talk	1.68 (1.12)	1.25 (0.49)	t = -2.20 (p=.03)*
Six month follow-up:			
Think	2.28 (1.34)	2.08 (1.20)	t = -0.67 (p=.50)
Talk	1.41 (0.68)	1.31 (0.82)	t = -0.60 (p=.55)

*p<.05, **p<.01

7.15 Couple-related outcomes

7.15.1 Correlations between patient and partner improvement

It was hypothesised that when couples participated in the intervention together, their improvements would be correlated. Intraclass correlations were used in order to assess correlations between patient and partner change on the primary and secondary outcomes from baseline to three month follow-up, as this was the period when most improvements were expected to occur. Intraclass correlations were considered to be more appropriate than Pearson correlations as they measure dependence among observations and are sensitive to mean difference. Following this, Fischer's z test was used to test whether the correlations were significantly different. These results are reported in Table 35.

In the control group, correlations between patient and partner change from baseline to three months were significant for the variables for perceived stress, intrusive thoughts, emotional representations of the illness and quality of life, supporting the idea that patient and partner distress are correlated. However, comparison of these correlations between the GDP and control groups revealed that they were significantly different only for quality of life and emotional representations of the illness. Further, there was a highly significant correlation between patient and partner change in illness-related couple communication in the GDP group. Although this was not significantly different to the control group, it suggested that the GDP may have influenced the way in which couples discussed the patient's illness.

Table 35: Intraclass correlations between patient and partner change from baseline to three month follow-up for the primary and secondary outcomes and comparison of group differences

Variable	GDP	Control	Difference
Perceived stress	r=.50 (p=.02)*	r=.45 (p=.04)*	χ^2 =.08 (p=.78)
Intrusive thoughts	r=.33 (p=.11)	r=.52 (p=.01)*	χ^2 =.96 (p=.33)
Emotional representations	r=-.61 (p=.93)	r=.49 (p=.02)*	χ^2 =28.67 (p<.001)**
Quality of life	r=-.45 (p=.87)	r=.44 (p=.04)*	χ^2 =16.93 (p<.001)**
Communication	r=.24 (p=.20)	r=.12 (p=.35)	χ^2 = .29 (p=.59)
Illness-related communication	r=.60 (p=.003)**	r=.26 (p=.17)	χ^2 =3.19 (p=.07)

*p<.05, **p<.01

7.15.2 Discrepancy between couples

7.15.2.1 Absolute discrepancy at baseline

It was hypothesised that discrepancy between couples regarding general and illness-related communication would be related to levels of distress and quality of life. In order to test this, the partner's score at baseline was subtracted from the patient's score at baseline, and the absolute value of the discrepancy was calculated. Pearson product-moment correlations were then used to calculate the linear relation between absolute discrepancy in marital communication and illness-related communication and the primary outcomes of perceived stress and quality of life. These results are reported in Table 36.

Table 36: Correlations at baseline between absolute communication discrepancy and the primary outcomes

Absolute discrepancy variable	QoL - patients	QoL-partners	PSS-patients	PSS-partners
Marital communication	-.15	-.14	.12	.15
Illness-related communication	-.09	.01	.18	.15

There was no relation between discrepancy in either marital communication in general or illness-related communication and the primary outcomes of perceived stress and quality of life in either patients or partners. This indicated that the other partner's levels of satisfaction with communication did not influence quality of life or levels of distress.

Chapter Eight: Discussion of the main study

8.1 Introduction

This thesis investigated the effects of guided written disclosure on perceived stress and quality of life in women with ovarian cancer and their partners. To date there are no known studies of written disclosure for couples with chronic illness, and very few studies assessing the effectiveness of guided written disclosure. Furthermore, most studies have had very short follow-ups. The pilot study indicated that written disclosure was acceptable to women with ovarian cancer, and together with brief stress management it may have led to significant reductions in perceived stress and intrusive thoughts at one month follow-up. The main study followed CONSORT guidelines as far as possible, and included a six month follow-up to determine if any benefits were maintained over time. Inclusion of secondary outcomes relevant to the population in question enabled investigation as to whether the GDP had any effect on tumour marker levels and visits to alternative therapists. In addition, this study aimed to facilitate understanding of the mechanisms responsible for benefit following written emotional disclosure, by comparing two theories: the cognitive processing hypothesis and the social interaction hypothesis.

The previous chapter described the results of the main study with regard to baseline characteristics of the couples, inter-relationships between baseline factors, impressions of the intervention and the effectiveness of blinding, the outcome data for the primary and secondary outcomes, predictors and moderators/ moderated mediators of the primary outcomes, the relation between word usage and outcomes in the GDP group, the post-writing questions and thinking and talking about the writing, correlations between patient and partner improvement, and communication discrepancy as a moderator of outcome. In this chapter, the results relating to each of these categories are discussed in the context of the literature described in the introductory chapters of this thesis. The final chapter attempts to account for differences between the pilot study and the main study, addresses the theoretical and clinical implications of these findings, examines the limitations of the research, and suggests future directions for research.

8.2 Baseline characteristics of the couples

Approximately two thirds of the participants were diagnosed with advanced stage disease. This is consistent with the demographics of ovarian cancer in the general population (Pan et al., 2004). The mean age of participants in this study was 55, which is slightly younger than that of 59 for the general population of ovarian cancer patients (Barber, 1993). However, given that younger people are generally more likely to participate in psychological intervention studies (Manne et al., 2007; Scott et al., 2004), this was expected. Almost all participants had had chemotherapy, and all but eight had had surgery, whereas very few had had radiotherapy, reflecting the NICE recommendations (National Institute of Clinical Excellence, 2003) of cytoreductive surgery where feasible followed by six cycles of chemotherapy. Thus, the majority of participants had experienced the same stressors regarding treatment, although they may have differed with regard to the magnitude of these stressors. Half the sample had recurrent ovarian cancer. Although this is lower than the percentage of patients with ovarian cancer who will eventually develop a recurrence (Pan et al., 2004), some of the participants had only just finished their initial chemotherapy. In fact, ten of the participants had their first recurrence during the study, which was expected as they had been diagnosed with advanced stage disease. The participants had been married for 27 years on average, indicating that the majority were in fairly stable relationships. Approximately one third of the patients were employed. Some had passed the retirement age, which until recently was 60 years of age for women, and some took early retirement due to having had multiple recurrences. On the whole, the participants reported high levels of health behaviours. Only seven participants smoked, and the mean consumption of alcohol was 5 units per week, which is well below the upper recommended limit of 14 units for women.

The GDP and control groups were not significantly different in terms of any of the demographic factors assessed except age and time since diagnosis, with GDP participants being younger and having had longer time since diagnosis. Because of this, age and time since diagnosis were controlled for in all analyses.

8.3 Baseline outcome measures

For the patients, there were no differences between the GDP and control groups with regard to any of the primary outcomes except for perceived stress (the GDP group reported higher levels of stress than the control group) and no differences with regard to any of the secondary outcomes. However, partners in the GDP group reported worse quality of life and less satisfaction with marital communication and illness-related couple communication than those in the control group. Because of this, all findings related to these factors were interpreted with caution. Levels of perceived stress were higher than those in the general population (Cohen & Williamson, 1988). As outlined in Chapter 1, ovarian cancer patients have to cope with a number of stressors including misdiagnoses prior to treatment, surgery, combination chemotherapy and the risk of recurrence. Consequently, living with ovarian cancer, particularly if recurrent, can be highly stressful for patients and their significant others. Quality of life for patients was lower than in the validation study for the FACT-O (Basen-Engquist et al., 2001). Patients undergoing active treatment and those with advanced stage disease were underrepresented in that study, unlike in the present study. However, quality of life in partners was similar to that of the general population (Cella et al., 2003).

Secondary outcome measures indicated that intrusive thoughts were lower than in the general population for both patients and partners (Creamer et al., 2003), and therefore not a problem for most participants. However, approximately one third of the sample experienced high levels of intrusive thoughts. This finding is concurrent with previous research indicating that high levels of distress are present only in a subset of ovarian cancer patients (Kornblith et al., 1995; Norton et al., 2004). The mean score for emotional representations of the illness was higher than that reported for chronic pain patients (Moss-Morris et al., 2002). Ovarian cancer often has a poor prognosis, and fear of a recurrence is one of the main concerns affecting patients (Ferrell et al., 2003), possibly manifested here by high levels of distress about the illness. Chronic pain, while disabling, is unlikely to be terminal. Satisfaction with marital communication was higher than for a general population sample (Fowers & Olson, 1989) – less than 20% of the participants could be classified as maritally distressed with regard to communication. Similar findings have been reported in other studies of couples (Manne, 1999, Baider, 2003) as maritally distressed couples are less likely to agree to participate in such research. It is also possible that a cancer diagnosis may improve marital communication in some cases (Schover, 2004).

Approximately one third of the sample had visited an alternative therapist in the three months prior to participating in the intervention. This reflects the high usage of alternative therapies among ovarian cancer patients following diagnosis, as diagnostic delays tend to impair their relationships with their GPs (Evans et al., 2006). This could also reflect fear or mistrust in the mainstream medical system among some patients.

8.4 Inter-relationships between baseline factors

8.4.1 Relation between baseline demographics and primary outcomes

None of the baseline demographic factors and illness severity factors were significantly correlated with quality of life or perceived stress. With regard to perceived stress, this agrees with previous research with regard to recurrence status (Donovan et al., 2002) and being on active treatment (Boscaglia et al., 2005), but is in contrast to previous studies on ovarian cancer and other cancers, which have found a link between age, disease stage and time since diagnosis and psychological distress (see Arden-Close, Gidron & Moss-Morris, in press for a review). However, it is important to note that the Perceived Stress Scale used here assesses levels of stress in everyday life, which may be less likely to differ across age groups than clinical levels of distress. The relation between disease stage and quality of life would probably be stronger if it was categorized as early or advanced, rather than broken down into four stages. However, too few cases in the current study had early stage cancer. The relation between a longer time since diagnosis and reduced distress is likely to be stronger in individuals who have not experienced a recurrence (Arden-Close, Gidron, & Moss-Morris, in press) but half the sample in the current study had had a recurrence. The relation between having radiotherapy, length of time married, employment status, levels of exercise, smoking and units of alcohol consumed per week and levels of distress has not been addressed in previous studies of ovarian cancer patients. Thus, my null findings cannot be compared to the findings of others.

With regard to quality of life, the lack of any relation with demographic factors is in conflict with the finding reported in Chapter 2 that evidence from previous studies found a strong association between older age and better quality of life and between being on active treatment and worse quality of life. However, previous findings of a relation between age and quality of life did not hold for social well-being (Guo et al., 2004; Miller et al., 2002), and the scale used in the current study consisted of only physical, social and functional well-being subscales. Furthermore, the relation between age and quality of life was in the expected direction, but of very small magnitude. The relationship between length of time married, smoking, alcohol intake and quality of life has not previously been addressed in ovarian cancer patients. Thus, my null findings cannot be compared to the findings of others.

However, in partners, longer time since diagnosis was associated with worse quality of life, the patient having had a recurrence was associated with better quality of life and less perceived stress, more courses of chemotherapy were associated with worse quality of life and more perceived stress, the patient being on treatment was associated with more perceived stress, and more advanced stage disease was associated with more perceived stress. These correlations were small in magnitude. As mentioned above, the relation between time since diagnosis and psychological factors can only be assessed after recurrence status has been taken into account. The findings regarding recurrence status and partners' well-being are surprising. It may be that a worse prognosis draws couples closer together (cf. Schover, 2004), or that patients with a poorer prognosis are less likely to explain the details of their diagnosis and treatment to their partners. Another possible explanation for these findings is that patients who had not experienced a recurrence had finished treatment more recently, and were still recovering from the side-effects of their treatment, which affected their partners. However, the findings regarding numbers of courses of chemotherapy was expected as it is a stressor that is likely to impact on partners' social and functional quality of life. Similarly, the patient being on active treatment increases the number of stressors the partner has to deal with in his daily life. Finally, more advanced stage disease is associated with a worse prognosis, and partners are well aware of this relation, which may cause them more stress.

8.4.2 Relationships between primary and secondary outcomes

The secondary outcomes of intrusive thoughts, emotional representations of the illness, marital communication and illness-related couple communication were significantly correlated with perceived stress and quality of life in both patients and partners. The correlations of intrusive thoughts and emotional representations of the illness with worse quality of life and more perceived stress were particularly strong for patients, which is constant with previous literature (Epping-Jordan et al., 1994; Hipkins et al., 2004). Patients often experience high levels of distress with regard to their illness, which impacts negatively on their ability to enjoy life and the levels of stress they experience in everyday life. The correlations were less strong for partners, but nevertheless indicated that distress about the illness is a significant factor affecting partner quality of life and distress. These correlations indicate that the hypothesis that improvements in these outcomes would mediate improvements in the primary outcomes is plausible. The relations of marital communication and illness-related communication with perceived stress and quality of life were stronger for partners than patients. This may be because women are more likely to have additional sources of support, whereas the spouse tends to be the main confidant for men (Harrison et al., 1995). This is particularly true with regard to illness-related communication. These correlations indicate that the hypothesis that improvements in communication would mediate improvements in the primary outcomes is plausible, particularly for men.

Visits to GPs and consultants were associated with increased perceived stress and worse quality of life in patients. Such visits may cause a disruption to everyday life or could result from increased stress. Further, people are more likely to visit health professionals when they are feeling ill, and their quality of life is therefore low. However, visits to alternative therapists and CA 125 levels were not associated with perceived stress and quality of life in patients. Many ovarian cancer patients are interested in alternative therapies, regardless of prognosis, and view them as a means towards maintaining a healthy lifestyle (Bishop, Yardley, & Lewith, 2006). A higher CA 125 level is a strong indication of a recurrence. However, many of the participants were leading active lives and felt no symptoms even if their cancer had recurred.

8.5 Effectiveness of blinding and acceptability of the intervention

The results indicated that only one third of participants were able to accurately classify whether they were assigned to treatment or control. This difference was particularly pronounced for patients – only 10% of the GDP group thought they were assigned to the intervention. Many participants had thought that they would receive feedback on their writing, even though the consent form had explicitly outlined the study. This is important as expectations of benefit have been associated with improvement in randomized trials (Turner et al., 2002). Thus, any negative effects of the GDP may have been because many in the GDP group did not expect an effect of the condition to which they were assigned, or since they did not receive their expected feedback.

Overall, written disclosure was considered acceptable – there were no complaints about the writing among those who completed it. Some of the partners did not wish to do the writing upon seeing the first question, so withdrew without completing it. This indicates that it would be safe to implement written disclosure as an intervention to be completed at home.

Approximately two thirds of the patients and over half the partners in the GDP group said they would recommend the intervention, indicating that the GDP was viewed positively by a significant number of participants. Previous research has revealed individual differences in who benefits from written disclosure (Frattaroli, 2006; Norman et al., 2004). However, the question about recommendation was answered on a yes/ no basis. Asking this question on a scale from 1 to 7 would have provided more sensitivity into impressions of the intervention. In addition, requiring comments from all participants would have provided more insight into the acceptability and perceived benefit of written disclosure.

8.6 Word usage across the three days

Usage of positive emotion, negative emotion, insight and causality words were compared across the groups. This served as a manipulation check on whether the GDP group had adhered to the instructions and engaged with the task as presented. As expected, both patients and partners in the GDP group had used significantly more positive emotion, negative emotion, insight and causality words than the control group on days 2 and 3, indicating that they had adhered to the instructions. However, patients and partners in the GDP group had also used more negative emotion words than the control group on day 1, when they were required to describe the event without reference to emotions. This is extremely difficult to do when describing a traumatic event. The GDP group had been partially successful in following the instructions, though - the percentage of negative emotion words used on day 1 was considerably lower than on days 2 and 3. The GDP group used more negative emotion words on day 2, when they were required to write about how they thought and felt at the time of the event, how it had changed their lives, and the meaning it had had for them, and more positive emotion words on day 3, when they were required to write about how they think and feel now, and whether they would be able to cope with similar events better. Usage of insight and causality words was high across both days.

8.7 Post-writing questions

After each day of writing, the participants were required to answer several questions. These questions were used as a manipulation check on the degree to which participants had engaged with their essays. With regard to days 1 and 2 and overall, both patients and partners in the GDP group considered their essays to be more personal and more revealing of emotions than those in the control group. This indicated that the GDP group had experienced difficulty in following the instructions on day 1, when they were required to describe the diagnosis and treatment without reference to emotions. However, the GDP group considered their essays to have been more revealing of emotions on day 2 than on day 1, which indicated that they had attempted to follow the instructions on day 1.

The GDP group were more likely than the control group to have told others and to have wanted to tell others about what they had written. Also, with regard to day 2, the GDP group were more likely than the control group to have held back from telling others about what they had written about. However, this difference was not present on Day 1. This was probably because on day 1 the GDP group were required to describe the patient's diagnosis and treatment of ovarian cancer, which consisted mainly of medical facts that the participants had probably told others previously. Overall, the difference between groups was significant for patients and approached significance for partners. This difference may have been because patients were more likely to have been asked questions about their illness than their partners were, or because partners may have been less likely to wish to discuss the cancer. It is possible that participants may have talked about the illness in a more factual manner prior to undergoing the GDP, while this may have shifted to a more emotional and cognitive manner after the GDP.

In addition, the GDP group reported having thought more about the writing topics than the control group both since the study began and before the study began, which indicated that they were dealing with personally meaningful topics and had engaged with their essays. Finally, the partners in the GDP group reported having thought more about the study since it began, compared to the control group, whereas the patients did not. Examination of the scores revealed that this was due to patients engaging more in the study than partners, regardless of the group to which they were assigned. Overall, these results indicated that the GDP group had adhered to the instructions and engaged with the study while participating in it. Thus, any failure to find significant differences at follow-up was unlikely to have been due to lack of involvement in the study or misunderstanding the instructions.

8.8 Aim one: Evaluate the effectiveness of the GDP compared to control writing in reducing distress and improving quality of life

The primary aim of this study was to see whether the GDP would lead to improvements in perceived stress and quality of life in ovarian cancer patients and their partners at three month follow-up, relative to the control group and whether these results were maintained at six month follow-up. However, the results indicated that there was no effect of the GDP on quality of life or perceived stress in patients or partners. Similar results were found when intention-to-treat analyses were carried out, and when sensitivity analyses excluding couples who had completed the intervention separately were carried out. These results indicated that the findings were robust. The GDP therefore had no effect on any of the primary outcomes. These findings agree with a meta-analysis by Frisina et al. (2004), which found a non-significant effect size for the efficacy of written disclosure in improving psychological outcomes in patients with chronic illness. Similarly, four of the five previous studies on written disclosure in cancer patients, three of which involved unsupervised writing at home (Rosenberg et al., 2002; Walker et al., 1999; Zakowksi et al., 2004) have found no effects on psychological outcomes for the overall sample, and limited effects for physical outcomes. It may be that written disclosure, which can be viewed as a type of problem-focused coping, is ineffective for dealing with uncontrollable stressors (Folkman & Lazarus, 1984). The patients in Stanton et al.'s (2002) study, which found positive effects of writing about the cancer on physical symptoms and medical appointments, had just completed treatment for early stage breast cancer, and were at low risk of recurrence. Ten participants had their first recurrence during the study, which is likely to have increased their stress levels and worsened their quality of life. In addition, the participants were supervised while writing, which may have meant they were less likely to be distracted. Alternatively, the cancer may not have been a prominent stressor in the lives of the 44 patients who had not experienced a recurrence and remained disease free throughout the study. For these patients, choosing their own topics to write about may have brought about greater improvements. Although it is not possible to compare the current study directly with previous studies, as it used guided rather than standard writing, the evidence to date suggests that writing about their illness may not be effective for the majority of cancer patients. Written emotional disclosure has not previously been tested in partners of patients with chronic illness. However, the results from the current study echo those of Schwartz and Drotar (2004), who found no benefit of written disclosure for parents of children with chronic illness. As in that study, the partners in the present study may have experienced too many cognitive and emotional demands to fully engage in the writing – greater involvement has been associated with positive outcomes (Lutgendorf & Antoni, 1999). Although the partners wrote at home and were not therefore distracted by unfamiliar surroundings, they may still have been unable to concentrate, particularly since the GDP and completing the questionnaires would have increased the prominence of the illness in their thoughts, at the expense of engaging in the writing. Alternatively, the partners may have benefited more from choosing their own topics to write about.

8.9 Aim two: Evaluate the effectiveness of the GDP compared to control writing in improving the secondary outcomes

8.9.1 Social interaction hypothesis outcomes

There was no effect of the GDP on marital communication or illness-related couple communication for patients or partners. These results do not provide support for the social interaction hypothesis. There could be several reasons for these results. First, communication may have been close to ceiling level at baseline. This idea is supported by the fact that less than 20% of the full sample were found to be maritally distressed with regard to communication – the GDP may lead to improved communication in couples who are less satisfied with their communication, provided partners agree to participate in such studies. In this context, the effect of moderators will be addressed later. Second, in order for illness-related communication to improve, couples need to discuss the illness. Informal discussions revealed that some of the couples did not discuss the writing tasks. Finally, although the couples were implicitly provided with a context to discuss the illness, they were not given training in communication skills. This may be necessary for improvements in illness-related communication.

8.9.2 Cognitive processing hypothesis outcomes

There was no effect of the GDP on intrusive thoughts or emotional representations of the illness in patients. For partners, there was no effect of the GDP on emotional representations of the illness, but intrusive thoughts increased in the GDP group from baseline to three month follow-up relative to the control group. These results do not provide support for the cognitive processing hypothesis. Among couples where the woman has breast cancer, very few have reported discussing the illness regularly (Boehmer & Clark, 2001). Writing about the illness may therefore have forced the partners to reflect in depth about an issue they might avoid examining in detail, and may rarely discuss with their partners, and thus may have increased their awareness of the vulnerability of their partners, leading to an increase in intrusive thoughts. Previous written disclosure studies have not assessed emotional representations of the illness, but effect sizes for written disclosure in chronic illness tend to be small for psychological outcomes (Frisina et al., 2004). Previous written disclosure studies have found reductions in intrusive thoughts in members of couples who have experienced a relationship breakup (Lepore & Greenberg, 2002), individuals with PTSD symptoms (Schoutrop et al., 2002), and healthy students (Lutgendorf & Antoni, 1999). However, there have been no effects on intrusive thoughts in patients with chronic illness (Frisina et al., 2004). This may be because chronic illness is a concurrent stressor that cannot be forgotten about, particularly for individuals who experience a recurrence.

8.9.3 Visits to healthcare professionals

There was no effect of the GDP on visits to alternative therapists or visits to GPs/ consultants. Visits to GPs were unlikely to change for two reasons. First, as ovarian cancer can be asymptomatic in the early stages, patients are highly vigilant for symptoms, and will visit health professionals even for minor ailments. Second, many ovarian cancer patients have lost confidence in their GPs following numerous misdiagnoses, and have become more involved in alternative therapies, which they view as an active means of maintaining a healthy lifestyle (Bishop et al., 2006). These outcomes may be more affected by personality factors such as neuroticism or by stable coping styles such as information seeking.

8.9.4 CA 125

Finally, there was no effect of the GDP on CA 125 levels at follow-up. For this result to be put in context, it must be noted that a number of the participants did not report their CA 125 level at each time point, meaning that there were very small numbers for these analyses. Furthermore, CA 125 was not tested at the time point of each assessment, as patients reported this data with regard to their last visit to their consultant, which may have been any time within the previous three months. This meant that these results could not be accurately mapped on to each time point. Also, the 44 patients who had not had a recurrence and remained disease free reported low CA 125 levels at each time point. This meant that there were a limited number of patients whose CA 125 levels could potentially be influenced by the intervention. However, these findings were viewed as exploratory, since longitudinal relations between dispositional optimism and CA 125 have previously been found (de Moor et al., 2006). CA 125 levels would need to be assessed at the time of each assessment for firmer conclusions to be drawn. Alternatively, written disclosure may be insufficient to change stable traits, which previous research has shown to be more strongly related to CA 125 levels than current psychological well-being (de Moor et al., 2006).

8.10 Aim three: Examine the efficacy of potential mechanisms or mediators of the efficacy of the GDP

Since there were no effects of the GDP on quality of life or perceived stress, and calculation of effect sizes revealed minimal change, it was decided not to test for mediators. However, a number of potential predictors, moderators and moderated mediators of possible benefits from emotional writing were examined. The results regarding these variables are discussed below.

For patients, views about the intervention moderated the effects of the GDP on quality of life, such that in the GDP group, there was no effect of views of the intervention on quality of life, whereas in the control group, those who said they would not recommend the writing reported better quality of life at three month follow-up than those who said they would. This result indicates that viewing the GDP positively does not influence effectiveness. Similarly, there was no moderating effect of views of the intervention on quality of life in partners. Also, marital communication at baseline did not moderate the effects of group on quality of life or perceived stress at follow-up in patients or partners. This may have been due to the low percentage of couples reporting dissatisfaction with marital communication at baseline. Similarly, the presence of a recurrence at baseline did not moderate the effects of group on quality of life or perceived stress at follow-up in patients or partners. This indicates that having recurrent ovarian cancer did not affect outcomes. However, patients who had recurrent ovarian cancer reported lower levels of perceived stress. Although counter-intuitive, this may be because some of the participants who did not have recurrent ovarian cancer at baseline experienced a recurrence between baseline and three month follow-up, whereas many of those with recurrent ovarian cancer had been living with their condition for several years, and had therefore developed strategies for dealing with general and illness-related stressors.

In patients, the partner’s levels of intrusive thoughts at baseline moderated the effects of group on quality of life such that in the control group, patients reported worse quality of life at three month follow-up if their partner experienced higher levels of intrusive thoughts at baseline, whereas in the GDP group, patients reported better quality of life at three month follow-up if their partners experienced higher levels of intrusive thoughts at baseline. Thus, the GDP may have buffered the longitudinal effect of partner intrusive thoughts on patient quality of life. The finding from the control group is in line with previous research on ovarian cancer patients (Jalal, 2004). The GDP may have increased patients’ awareness of the distress the illness has caused their partner (possibly due to discussing their reflections on it as a couple) and enabled them to reframe partner distress as concern, thus reducing its impact on patients' quality of life. It is also possible that the GDP reduced the negative effects of partners' intrusive thoughts on the couple, which then manifested in improved quality of life in patients. Also, there was an interaction effect between change in illness-related communication and group in predicting quality of life, such that in the GDP group, if illness-related communication improved, this improvement mediated the relation between group and improved quality of life at three month follow-up, whereas in the control group there was no effect of change in illness-related communication on quality of life. Thus, if the GDP enhanced illness-related communication, it was beneficial for quality of life. This evidence provides support for the social interaction hypothesis in some individuals. This means that further research needs to be carried out to understand demographic and psychological factors associated with change in illness-related communication following the GDP. In partners, change in intrusive thoughts predicted quality of life at three month follow-up, such that if they decreased, quality of life also improved. These findings add to the evidence base suggesting a negative correlation between intrusive thoughts and quality of life (Lewis et al., 2001; Manne et al., 2004).

In patients, there was an interaction between change in intrusive thoughts and group in predicting perceived stress, such that in the control group, if intrusive thoughts increased, this increase mediated the relation between group and perceived stress at three month follow-up, whereas in the GDP group there was no effect of an increase in intrusive thoughts on levels of perceived stress. Thus, the GDP may have buffered the effect of increased intrusive thoughts on levels of perceived stress. The GDP may have helped participants to put their cancer into perspective, and deal with intrusive thoughts more effectively, by providing a strategy for addressing them. This finding can be related to the instructions of the GDP. The precise verbal labelling and processing of unpleasant emotions may reduce amygdala activity and increase prefrontal cortex activity, thus enabling individuals to think about the event more explicitly (Hariri et al., 2000). Experience from participating in the GDP may thus provide individuals with a strategy to think about intrusive thoughts more explicitly, and reflect on them. Interviews with participants in written disclosure studies are required to explore this idea further (cf. Byrne-Davis et al., 2006). Change in intrusive thoughts also predicted levels of perceived stress at three month follow-up, such that if they decreased, levels of perceived stress also decreased. In partners, change in intrusive thoughts predicted levels of perceived stress at three month follow-up, such that if they decreased, levels of perceived stress also decreased.

8.11 Correlations between word usage and improvements in the primary and secondary outcomes

For the GDP group, correlations between percentage of positive emotion, negative emotion, insight and causality words used across days 2 and 3 of the writing and improvements in the primary and secondary outcomes from baseline to three month follow-up were tested. For patients, reductions in levels of perceived stress were associated with use of fewer negative emotion words and more positive emotion words. To recap, on day 2 there are two parts to the writing. In the first part, participants are required to describe how they felt and what they thought at the time of the event. In the second part, they are required to describe the meaning the event had for them and whether it has caused them to change priorities. On day 3, participants are required to write how they think and feel about the event now, whether their thoughts and feelings differ from those they had at the time of the event, and whether they think they would be able to cope with similar situations better because they experienced that event. It is likely that the results related to word usage relate mainly to the second part of day 2, and the whole of day 3. Thinking of any benefits brought about by the cancer (as indicated by increased use of positive emotion words), may have helped the patients to accept it, and thus view cancer-related difficulties as more manageable, or even as an opportunity rather than a threat. In addition, a positive view of how they coped with the illness may have increased their ability to deal with stressors. However, those who viewed the illness with anger may have been less able to deal with difficulties in their everyday life, due to concentrating more on the anger.

Improvements in illness-related couple communication were also associated with greater use of positive emotion words for both patients and partners. In this case, use of positive emotion words may also have been indicative of benefit finding. The opportunity to reflect on how they currently thought and felt about the event could have provided the participants with more insight into the context surrounding their illness, which may have influenced the way in which they disclosed it to their partners (Pennebaker et al., 1989; Schoutrop et al., 2002). In support of these ideas regarding mechanisms by which word usage led to improvement, Antoni et al. (2001), found that cognitive-behavioural stress management led to increases in benefit finding for early stage breast cancer patients. Similarly, Stanton et al. (2002) found that writing about positive thoughts and feelings regarding the cancer led to health benefits for women with early stage breast cancer. Editing the instructions to require reference to positive emotions on days 2 and 3 may lead to greater improvements at follow-up. Alternatively, there may be individual differences with regard to use of positive emotion words that are responsible for these improvements. For example, individuals higher in dispositional optimism may be more likely to use positive emotion words. Controlling for dispositional optimism is required to test the relation between use of positive emotion words and improvements following writing.

Finally, for partners, improvements in quality of life were associated with increased use of words indicating sadness. Use of such words may have been indicative of greater insight regarding the stresses and problems their partner had suffered, which may have enabled them empathize with their partners more, or to view their own quality of life as better in comparison. The latter explanation is similar to the phenomenon of response shift, whereby people modify their expectations of what is necessary to achieve good quality of life as their health worsens (Lutgendorf et al., 2002).

8.12 Thinking and talking about the event

Levels of thinking and talking about the writing post-intervention were very low for both groups. The majority of participants reported talking about what they had written about ‘not at all’ or ‘not very much’ in the six months post-intervention. Levels of thinking about the event were slightly higher, but still low. Patients in the GDP group reported thinking about the event more at three months and talking about it more at six months, relative to the control group. Partners in the GDP group reported thinking and talking about the event more at six months, relative to the control group. However, these differences mainly reached significance because of the small standard deviations. Research has shown that higher levels of disclosure are longitudinally associated with better health (Pennebaker et al., 1989). However, disclosing about an event is not simply a function of desire to talk, but depends also on the individual’s social network (Pennebaker & Harber, 1993). However, the questions regarding talking about the writing may not have effectively targeted the desired outcome or been sufficiently specific. Since couples participated in the intervention, it may have been more appropriate to ask the participants how much they had talked about the writing with their spouse or partner.

8.13 Correlations between patient and partner improvement

Intraclass correlations were carried out to examine correlations between improvement in patients and partners from baseline to three month follow-up for the GDP and control groups. For the control group, these correlations were significant for perceived stress, cancer-related intrusive thoughts, emotional representations of the illness and quality of life. These results indicated that patient and partner distress tend to be related over time, in agreement with previous research (Hagedoorn et al., 2008). However, these findings do not provide information into the way distress is transmitted between couples. Although for the GDP group, this correlation remained only for perceived stress, further analyses revealed that the correlations differed significantly between the groups only for quality of life and emotional representations of the illness. For these variables, the correlations within the GDP group were negative, suggesting that patients and partners in the GDP group were influenced differently by the intervention with regard to these factors. However, the correlation for illness-related couple communication tended to be significantly different between the GDP and control groups, indicating that the GDP had influenced illness-related communication in both members of the couple, possibly by triggering more discussion of the patient's illness between the couple. Informal discussions with some of the patients post-writing revealed that they had talked about the diagnosis and treatment with their husbands after the first writing day, which they considered had enabled them to understand each other's side of the story. However, this information was anecdotal. Asking each participant whether they had discussed the illness with their partners post-writing would have enabled objective testing of these ideas.

8.14 Discrepancy between couples

Correlations between discrepancy in marital communication and illness-related couple communication and levels of the primary outcomes of quality of life and perceived stress at baseline were carried out. These results revealed no relation between these factors, indicating that concordance with partners with regard to levels of satisfaction with communication was not important for well-being – the individual's level of satisfaction with communication was more important. Thus, if the individual was satisfied with communication with his/ her partner, he/ she experienced better well-being.

Overall, there was no main effect of the GDP on quality of life or perceived stress. However, a number of moderators and moderated mediators of the effects of the GDP on the primary outcomes were identified in patients. These included views of the intervention, change in illness-related communication, change in intrusive thoughts and the partners' levels of intrusive thoughts at baseline. For the GDP group, improvements appeared to be related to use of positive emotion words. General theoretical and clinical implications of the research are discussed in Chapter 9.

Chapter Nine: General Discussion

The current research was designed to test the efficacy of the GDP compared to control writing in reducing distress and improving quality of life in women with ovarian cancer and their partners. There were no main effects of the GDP on these outcomes or the secondary outcomes. However, several moderators and moderated mediators were identified. Following a comparison of the pilot study and the main study, this chapter focuses on general clinical and theoretical implications. Limitations and implications for future research are addressed, and final conclusions are drawn.

9.1 Comparison of the pilot study and the main study

The pilot study found large positive effect sizes with regard to perceived stress and intrusive thoughts, particularly for the group that wrote emotionally first. However, there was no effect of the GDP on perceived stress or intrusive thoughts in the main study. The effects in the pilot study may have reflected a general tendency to improve over time, since there was no control group. However, an AAB design was used, and the effect sizes were considerably larger for the 'writing first' group than for the 'stress management first' group, suggesting that there was at least some effect of the intervention order. Further, as the tendency in the main study, which had a control group, was for the patients to remain the same or get worse over time, this is unlikely.

An alternative explanation for the findings from the pilot study is that it also included thirty minutes of stress management over the telephone. Originally, it was concluded that the improvements were due to the writing, since there were significant correlations between word usage on days 2 and 3 and improvement in the GDP group, and the 'writing first' group improved more than the 'stress management first' group, whereas increased relaxation at follow-up was not related to improvement. However, the process of writing followed by talking (even if not necessarily about the writing topic) may have been partly responsible for the improvements. The value of writing prior to talking in therapy has been previously demonstrated (Snyder et al., 2004). Since participants were not assessed following each component of the intervention, it was not possible to test the effects of each component. Alternatively, the participants in the pilot study may have benefited from being able to do the writing at any time they pleased, and for as long as they needed. In the main study, I telephoned the participants to tell them to start writing, and again after 15 minutes to ask them to stop writing. Although this was necessary to ensure that the participants followed instructions, it did constrain them – many said 15 minutes was not long enough to describe their diagnosis and treatment. Alternatively, the stronger effects found in the pilot study compared to the main study may have been due to non-specific factors such as increased attention paid to the participants. However, since the effect sizes were much larger for the 'writing first' group than the 'stress management first' group, increased contact time is unlikely to have been the only reason for the differential outcomes.

9.2 Theoretical implications

The findings of this study have contributed to the theoretical understanding of reasons and revealed some circumstances when written disclosure may be beneficial. A number of issues were raised in the introductory chapters on the role of demographic, psychosocial and communication-related factors as correlates of distress and quality of life in ovarian cancer patients and their partners, and on the lack of knowledge of mechanisms of improvement in written disclosure. These areas are reviewed here.

9.2.1 Demographic correlates of distress and quality of life

The evidence from this research suggests that demographic and illness-related factors are not significant correlates of distress and quality of life in women with ovarian cancer. However, a number of illness-related factors were related to increased levels of perceived stress and worse quality of life in partners. These findings suggest that partners may be in greater need of support or psychosocial interventions if their wives are diagnosed with advanced stage disease, and while their wives are on treatment.

9.2.2 Psychosocial correlates of distress and quality of life

The systematic review on correlates of psychosocial distress in ovarian cancer suggested that intrusive thoughts regarding the cancer were associated with increased levels of distress, and the excluded studies provided support for this relation. The findings from this study support the evidence for a relation between increased levels of intrusive thoughts and both higher levels of perceived stress and worse quality of life in ovarian cancer patients. Such correlations were found at baseline. In addition, longitudinal relations between an increase in levels of intrusive thoughts from baseline to three month follow-up and higher levels of perceived stress at three month follow-up were demonstrated for the control group only. Similarly, emotional representations of the illness that were indicative of increased distress were associated with increased perceived stress and worse quality of life at baseline. Findings for partners were similar. These findings suggest that increases in levels of intrusive thoughts may be one mechanism by which a cancer diagnosis leads to worsening in quality of life and increased distress. Intrusive thoughts are one of the symptoms present in post-traumatic stress disorder. They reflect an inability to control thoughts about a stressor and process it, thus increasing the presence of the stressor in individuals' lives.

The relation between couple communication and quality of life has been assessed in very few studies (Manne et al., 2006). The research here supports evidence suggesting the importance of couple communication for quality of life. Better marital communication and illness-related couple communication were associated with less distress and better quality of life at baseline in both patients and partners, though, interestingly, the correlations were stronger for partners. This is in line with previous research that men are more likely to name their partner as their sole confidant (Harrison et al., 1995). In addition, improvements in illness-related communication were associated with better quality of life at follow-up for patients in the GDP group. Further research is needed to clarify the direction of this relation for partners and for general communication in patients – the evidence suggests that in women, poor marital satisfaction causes increased depression, whereas in men, depression leads to worse marital satisfaction (Fincham, Beach, Harold, & Osborne, 1997). Finally, discrepancy in communication was not significantly associated with distress or quality of life, suggesting that the individual's own perceptions of communication are more important in predicting well-being than levels of concordance with their partners regarding communication. Similarly, Sagy and Antonovksy (1992) found that consensus as defined by absolute discrepancy with regard to sense of coherence was not associated with couple adjustment to retirement – among incongruent couples, the higher score was a better predictor of retiree adaptation. Thus, preliminary evidence suggests that couple concordance is not a significant predictor of well-being in either partner.

9.2.3 Cognitive processing hypothesis

This study did not provide support for the cognitive processing hypothesis. There was no effect of the GDP on intrusive thoughts and emotional representations of the illness in patients or partners in the main study. Also, there was no relation between use of insight and causality words on days 2 and 3 of the writing and improvements in any of the outcomes. This may be because a number of the participants had already processed and come to terms with the event. In support of this idea, very few participants experienced high levels of intrusive thoughts. Alternatively, confronting emotions relevant to the event may be more important than reflection – Sloan et al. (2007) demonstrated that emotional expression was more effective than insight and cognitive assimilation in reducing depressive symptoms, PTSD symptoms and physical health complaints. Alternatively, written disclosure interventions may be too brief to enable adequate processing of a traumatic event, as such events may affect core beliefs and therefore require cognitive-behavioural therapy to be addressed fully (Westbrook, Kennerly, & Kirk, 2007). Another explanation is that the measures used in the current study were not sensitive to changes in cognitive processing in the study population, as the majority of participants would not have been classified as having clinical levels of PTSD with regard to the intrusive thoughts criterion, and were too close to 'floor' level with regard to intrusive thoughts. Although there were improvements in levels of intrusive thoughts in the pilot study, these may have partly been due to the opportunity to discuss a problem with a nonjudgmental outsider (in the stress management session), or the knowledge of appropriate situations to do relaxation (i.e., when seeing the consultant for checkups). Any improvements in cognitive processing may not necessarily have been due to the writing. In support of this idea, a major reason for the efficacy of cognitive behavioural therapy is that it provides patients with skills to deal with specific situations (Westbrook et al., 2007). Overall, these findings indicate that changes in cognitive processing were not the main reason for any beneficial effects of written disclosure in the current study. However, studies comparing guided and standard disclosure are required to test this issue further.

9.2.4 Social interaction hypothesis

This study provided tentative support for the social interaction hypothesis. Although there was no effect of the GDP on couple communication, improvements in illness-related communication in patients were associated with better quality of life at three month follow-up in the GDP group. These findings suggested that the GDP had changed the way in which some patients discussed their illness with their partners, possibly by providing a covert method to enable them to discuss it with their partners. However, this was not the case for all patients, suggesting that changes in illness-related communication may have been moderated by an unexplained third variable, such as emotional expressiveness. In support of this idea, Manne et al. (2007) found that emotional expression and emotional processing moderated the effects of a couple-focused group intervention on depression. Participants in the GDP group did not report talking more about what they wrote at three month follow-up than those in the control group. However, this question did not address how often patients discussed the topic with their partners in the period immediately post-intervention. Also, it may have been more effective to ask both the GDP and control group to rate how often they had discussed the illness with others at follow-up and how it was discussed. As further evidence in support of the social interaction hypothesis, the correlation between patient and partner change with regard to illness-related couple communication was significant only in the GDP group, and tended to be significantly different to the correlations in the control group. These results suggest that the GDP may have led to similar changes in illness-related couple communication in patients and partners, and made couples more concordant, possibly because it provided a context for them to discuss the illness and its impact on their lives. However, couple communication was not assessed in the best way possible. It could have been assessed directly by requiring participants to wear the electronically activated recorder (EAR) (Kim, 2008), or to have participated in lab discussions of illness-related issues before and after the intervention. Such methods, although beyond the budget of the current study, would be recommended for future research. Also, asking participants about the extent to which they had held back about discussing the illness at each follow-up might have provided more information on the extent to which they had disclosed the topic post-intervention.

9.2.5 Alternative explanations for the benefits

In patients, increased use of positive emotion words and reduced use of negative emotion words on day 2 were associated with reductions in perceived stress at three month follow-up. Also, in both patients and partners, increased use of positive emotion words was associated with improvements in illness-related communication at three month follow-up. Although preliminary, these findings suggest that reflecting on benefits brought about by the illness may be beneficial. Certainly, there are a number of studies suggesting that benefit finding is associated with lower distress, more positive mood, and greater well-being (Lechner, Carver, Antoni, Weaver, & Phillips, 2006), and improved family relationships and greater love for partners (Andrykowski, Brady, & Hunt, 1993). Expressive writing may increase emotion processing and subsequent benefit finding, and cognitive restructuring may increase positive reframing and decrease pessimistic appraisals, as demonstrated by increased use of positive emotion words. Certainly, cognitive behavioural stress management has led to increases in benefit finding in cancer patients (Antoni et al., 2001; McGregor et al., 2004). Particularly on Day 2 of the writing, participants are required to describe how they felt and what they thought at the time of the event, which facilitates emotion processing, and to reflect on the meaning of the event and whether it caused them to change priorities, which may facilitate cognitive restructuring. Thus, greater use of positive emotion words may have indicated enhanced restructuring of the event.

However, demographic and/or personality characteristics may have influenced use of positive emotion words – more optimistic people are more likely to see positive effects of negative events. Higher levels of optimism at baseline have been longitudinally associated with more benefit finding in breast cancer patients (Lechner et al., 2006), and Cameron and Nicholls (1998) found that in healthy students, standard emotional writing led to a reduction in clinic visits only among optimists. However, this would need to be tested further by altering the instructions on days 2 and 3 to require use of positive emotion words and comparing the effects of the altered instructions with the standard GDP instructions, or by assessing e.g.., dispositional optimism at baseline in order to examine the relation between word usage and those factors and the moderating role of optimism. Although a few studies have demonstrated benefits of writing about positive thoughts and feelings (i.e., Stanton et al., 2002), this area requires further exploration.

The GDP buffered the effect of increased intrusive thoughts on perceived stress in patients. Thus, although it did not reduce intrusive thoughts, it reduced the impact of intrusive thoughts on levels of distress. Writing about their diagnosis and treatment may have enabled the patients to reflect on how they coped successfully with their diagnosis and treatment, and therefore enhanced their self-efficacy for dealing with distressing thoughts about the cancer. Assessing self-efficacy for addressing cancer-related distress would provide an objective test of this relation. Also, the GDP changed the relation between partners' intrusive thoughts and quality of life in patients, such that increased partner intrusive thoughts were associated with better quality of life in patients in the GDP group. The GDP may have led to cognitive restructuring of the diagnosis and treatment in partners so as to increase the controllability of their intrusive thoughts, thus reducing patients' distress. Alternatively, it may have provided patients with insight into their partners' strategies for dealing with cancer-related distress, thus enabling them to interpret partner responses such as withdrawal as indicative of increased distress rather than lack of concern. Assessing the impact of partners' unsupportive responses (Manne & Schnoll, 2001) on quality of life both at baseline and follow-up would enable testing of this hypothesis.

9.3 Clinical implications

The findings of this thesis have important clinical implications. The main study has demonstrated that guided written disclosure is not effective at reducing perceived stress and improving quality of life in women with ovarian cancer and their partners, and in fact led to an increase in levels of intrusive thoughts in partners at three month follow-up. This suggests that written disclosure is not an effective intervention for ovarian cancer patients and their partners. However, posthoc several moderators were identified, suggesting that it may be effective for some patients. Importantly, the evidence suggests that the GDP can be carried out safely at home – no participants in the GDP group reported any adverse effects as a result of the intervention. Previous home-based studies of written disclosure for chronic illness have reported similar results (i.e., Broderick et al., 2004). Thus, if further research identifies patients for whom it is effective, it would be possible to offer the GDP as an optional intervention for patients to complete in their free time.

With regard to patients, several moderators were identified. These are discussed in the context of clinical implications of the results. One interesting moderator was partners' intrusive thoughts at baseline. Higher levels of intrusive thoughts in partners were associated with worse patient quality of life at follow-up in the control group, but better patient quality of life in the GDP group. This result indicates that partners' distress can impact on patient quality of life, and suggests that the GDP may buffer the impact of partner distress on patient quality of life, by enabling patients to reframe partner distress as indicative of concern. Further research needs to be carried out to explore this in more depth and understand whether partner participation in written disclosure studies is necessary for patients to experience this buffering effect – distressed partners may be less likely to agree to participate in the GDP. Within the GDP group, improvements in illness-related communication were associated with better quality of life at three month follow-up in patients. Further research is needed to determine demographic and personality-related predictors of change in illness-related communication, in order to understand who may benefit from the GDP, so that providers can offer it to the patients for whom it would be most appropriate. Either way, these results suggest that finding ways of improving couple communication may improve quality of life in ovarian cancer patients. Finally, the GDP buffered the effects of intrusive thoughts on perceived stress, suggesting that it may provide a method for reducing perceived stress in individuals experiencing high levels of intrusive thoughts. A possible explanation for this result is that describing the event chronologically and expressing emotions in words helped patients to process the event and deal with intrusive thoughts more effectively, in line with the cognitive processing basis on which the GDP was developed. Further research is required to examine whether the GDP is effective in a sample of individuals experiencing high levels of intrusive thoughts combined with high levels of perceived stress.

The fact that the GDP increased levels of intrusive thoughts in partners suggests that it was not beneficial for them. Writing about the illness may therefore have forced the partners to reflect in depth about an issue they rarely examined in detail or dealt with differently. While intrusive thoughts have been viewed as a step in cognitive processing of a traumatic event, such in-depth examination of the diagnosis and treatment may not have been necessary for all the partners. This evidence suggests that the GDP cannot be recommended for all partners of patients with cancer. However, across the full sample, if intrusive thoughts decreased, quality of life improved and levels of perceived stress decreased. Therefore, further research is required to examine moderators of change in levels of intrusive thoughts following the GDP in partners, in order to identify those who may benefit from it, and to determine ways to reduce intrusive thoughts in male partners of cancer patients. This is particularly important, as no moderators were identified for partners.

The current research assumed that writing about the diagnosis and treatment of the patient's cancer would provide an opportunity for the couples to discuss it in a non-threatening context. Discussion with the patients post-intervention revealed that some had talked about their diagnosis and treatment with their partners, which may have enabled them to come to a joint understanding of the impact of cancer on their lives. While not obtained in a standardized manner, this evidence suggests that further research to examine whether the GDP is effective in the context of therapy for couples coping with chronic illness (cf. Skerrett, 2003) is warranted, as writing prior to discussing the illness may help break down social constraints and enhance disclosure of the event (Pennebaker et al., 1989; Schoutrop et al., 2002; Zakowski et al., 2004). The results of the pilot study tend to suggest that introducing writing prior to verbal meetings may be helpful.

A number of the participants in the main study reported that fifteen minutes was not long enough for them to describe the details of their diagnosis and treatment. To solve this problem, if the GDP was implemented in practice, patients could be recommended to write until they had completed the details of their diagnosis and treatment, on day 1. Importantly, there were no differences between couples who completed the writing at the same time and at different times. This finding suggests that there is no need to recommend couples to complete the writing at the same time.

9.4 Limitations and future directions

9.4.1 Methodological limitations

When interpreting the findings of this research, there are a number of limitations that need to be considered. First, for ethical reasons, no demographic information was collected about those who refused to participate, which meant it was not possible to compare characteristics of responders and non-responders. Although those invited to participate in the study were provided with the opportunity to tick a box indicating reasons for refusal to participate, not all did so. Therefore, it was not possible to accurately gauge the recruitment rate – a number of the non-responders may not have been eligible to participate, or may have died, as the only means of updating the charity database is notifications from patients and their families. However, this study was a first of its kind, and research on the effectiveness of written disclosure for the general population of ovarian cancer patients would need to be carried out before the GDP could be implemented in practice. Therefore, this does not seriously affect the conclusions that can be drawn from this study, it only questions its generalisability.

The sample for the main study may have been underpowered to detect small to medium effects. The power analysis was based on an anticipated large effect size, following previous studies using the GDP (i.e., Gidron et al., 2002; Duncan et al., 2007). Previous research has found smaller effect sizes for written disclosure in cancer patients (Stanton et al., 2002), suggesting that a larger sample may have been required to demonstrate significant effects. However, the effect sizes for the majority of the measures were extremely small, suggesting that lack of power was not the reason for the non-significant results. Nevertheless, the study was powered for outcome rather than moderation, and these findings should therefore be viewed as exploratory. Related to this, a number of moderation and moderated mediation analyses were carried out, thus increasing the risk of Type I error. Also, the participants were a heterogeneous group with regard to time since diagnosis. This variability limited the conclusions that could be drawn from the research. In particular, regarding participants with advanced stage disease, it was difficult to determine whether improvements were independent of disease progression. Further large-scale studies focusing only on patients with early stage or only on those with recurrent disease are required in order to determine the influence of disease progression on outcomes or partly rule out its effects.

According to CONSORT guidelines, generation of the allocation sequence, enrolment of participants and assignment to groups should ideally be carried out by different researchers. In the main study, these tasks were carried out by a single researcher. However, the allocation sequence was destroyed once opaque sealed envelopes had been created, and these envelopes were kept in a locked cabinet to which the principal researcher did not have access. Once a participant had been enrolled into the trial, another researcher opened an envelope and informed the principal researcher the condition to which they were assigned. Thus, the risk of bias was considered to be minimal. Since the main study was carried out by a single researcher, blinding of the researcher during assessment was not possible, which increased the risk of performance and observer bias. However, all items were self-reported and participants returned questionnaires to the researcher's supervisor, with whom they had not had contact, which minimized the risk of observer bias. The one measure that was later confirmed by doctor records, CA 125, was measured by consultants who were unaware of the study. With regard to performance bias, the instructions were standard and provided in a booklet, and each writing session was timed.

The outcome measures were assessed by self-report. This included outcomes such as CA 125 level, visits to GPs/consultants and visits to alternative therapists, which are subject to recall, awareness and presentation biases. This is a significant limitation with regard to visits to GPs/ consultants, which can be obtained from medical records. However, the significant and very strong correlation between patient-reported and consultant-reported CA 125 levels validated the self-reports of CA 125. Nevertheless, assessing CA 125 levels at the time of each questionnaire would have provided a better understanding of the impact of the GDP on CA 125 levels. Further research on this topic is required in order to explore the relation between psychological factors and tumour progression, as this has been assessed in very few studies (de Moor et al., 2006, von Georgi et al., 2002). Related to this, medical factors such as disease stage and type of treatment were obtained by self-report. Although the CA 125 results suggest that these self-reports are likely to be highly accurate, it would have been better to validate this data against medical records.

In the main study, the participants were followed up after three and six months, whereas in the pilot study they were followed up at one month. A follow-up at one month in the main study would have provided more accurate comparison between the studies. However, it was felt that it would increase response burden, which could negatively impact response rate. Future research would benefit from more follow-ups, in order to chart the course of change following interventions. Related to this, one major limitation of the pilot study was that participants were not assessed in between the writing and stress management, and it was not therefore possible to determine which part of the intervention was responsible for improvements. Another limitation was that many statistical tests were performed, thus increasing the risk of Type I error.

9.4.2 Issues to consider in future research

9.4.2.1 Participant-related issues

The participants were members of an ovarian cancer charity, which may have influenced the results. According to Grande et al. (2006) members of support groups use more active, adaptive coping strategies and report more control over their cancer than patients who are not members of support groups. Thus, the participants in this study may have been more motivated to engage in the study than the general population with ovarian cancer. However, they may also have been less in need of an intervention. This highlights a paradox – those most in need of interventions are less likely to be receptive to them. Further research needs to examine reasons for non-participation in interventions, in order to determine the most appropriate methods of enhancing adjustment in women with ovarian cancer and their partners, in couples not seeking such participation.

The participants in this research reported high levels of satisfaction with marital communication at baseline – fewer than 20% of the sample would be considered to be maritally distressed. Thus, lack of improvements in communication may have been due to a ceiling effect. It is possible that greater improvements would have been demonstrated with couples who had experienced higher levels of distress at baseline. However, it is very difficult to convince partners who are not maritally satisfied to participate in research studies. Related to this, seven of the partners in the GDP group withdrew from the study prior to completing the intervention. In addition, in some couples the partners declined to participate in the study. This raises issues about the acceptability of the intervention for partners. However, the wives of the partners who withdrew from the study either had been living with recurrent cancer for several years or were almost five years post-treatment. The evidence suggests that the GDP would be acceptable to most partners of ovarian cancer patients soon after diagnosis.

These results were based on a cancer that affects only women. Although this meant that there was no confounding effect of gender on outcome, it limits the extent to which the results can be generalised. This is important, as a meta-analysis of written disclosure studies demonstrated larger effects for men (Smyth, 1998). Further research is therefore required to determine the effects of writing about cancer and/ or other chronic illnesses in couples where the man is the patient.

9.4.2.2 Areas for further investigation

There were no effects of the intervention on the cognitive processing measures. However, it is difficult to capture changes in cognitive processing. As an alternative to questionnaires, implicit measures of cognitive processing could be used, such as the Implicit Association Test (Greenwald et al., 2003). Such measures may provide a more accurate estimate of the degree to which people are experiencing illness-related distress or hold implicit biases with possible health consequences (Nausheen, Gidron, Gregg, Tissarchondou, & Peveler, 2007). Also with regard to mechanisms of change, the current research used the computer program Linguistic Inquiry and Word Count 2007 (Pennebaker et al., 2007). However, previous studies have examined the essays in detail, in order to understand additional factors influencing outcome (Suedfeld & Pennebaker, 1997; Creswell et al., 2007). Qualitative analysis of the essays could provide insights into patient and partner differences, or differences between those who improved on the primary and secondary outcomes and those who did not.

In the main study, the participants answered questions at each follow-up about how much they had talked to others about what they wrote. However, given that they completed the study with their partners, it may have been more effective to ask them about how much they had talked to their partner about what they wrote, and how that compared to how much they talked to their partner about it prior to the intervention. Since the intervention was completed by the couple, it was expected that it would influence their communication with each other. Couples were assessed for marital communication and illness-related couple communication. These measures were chosen as it was expected that the intervention would influence communication rather than marital satisfaction in general. However, a measure of marital satisfaction would have enabled direct testing of changes in this variable. Related to this, the measure of illness-related couple communication was developed for this study. Although internal consistency was acceptable and good levels of concurrent, convergent, divergent and predictive validity were demonstrated, it has not been validated previously. Further research is therefore required to validate this measure.

Participants were asked a yes/ no question about whether they would recommend the intervention. However, providing a space for them to describe their responses in more detail would have enabled greater insight into patients' and partners' impressions of the intervention. In general, more qualitative studies, such as that of Byrne-Davis et al. (2006) are needed to explore the experiences of participants in written disclosure studies.

The current research used a guided written disclosure paradigm, which may not be the most effective writing paradigm – some participants may have found it too structured (although some may have benefited from the guidance provided). A comparison of the GDP and standard writing is needed, to see which type of writing is more effective, and/or moderators of the efficacy of each paradigm. Also, it is important to note that the GDP participants were required to write about the patient's illness. While this is similar to the other written disclosure studies on cancer patients, it may not be the most prominent stressor for all participants', particularly those who were diagnosed less recently. Allowing participants to write about a stressor of their choice may have led to greater improvements. In particular, partners did not experience the threat to their lives caused by the diagnosis and treatment, and may have benefited more from writing about a stressor they experienced directly. Although the current research aimed to stimulate couple communication, this could be achieved by allowing couples to write about a predetermined stressor of their choice. Further research comparing writing about the illness to writing about a stressor of each partner's choice and a stressor of the couple's choice is required to test this idea.

9.5 Conclusions

Many ovarian cancer patients experience significant levels of distress. Partners of cancer patients also experience significant levels of distress. However, very few interventions have been tested on ovarian cancer patients, and the majority of interventions for cancer patients do not involve their partners. This thesis systematically reviewed the literature on correlates of distress and quality of life in ovarian cancer patients, and also reviewed correlates of distress in partners of cancer patients to identify correlates of couple communication that lead to increased distress. Based on these results, the GDP, which involved writing for fifteen minutes a day over three days about the patient's diagnosis and treatment of ovarian cancer, according to standardized instructions, was offered to patients with ovarian cancer and their partners

To our knowledge the main study was the first to assess the effectiveness of written emotional disclosure as a stand-alone intervention for couples. It was also the first study to assess the effectiveness of guided written disclosure in patients with a specific chronic illness. It was the first study to show that guided written disclosure is not an effective intervention for all couples with chronic illness. There were no main effects of the intervention on any of the outcomes. In addition, levels of intrusive thoughts increased at three month follow-up in partners in the GDP group.

This study was also the first to examine two alternative theories of the mechanism of improvement following written disclosure: the cognitive processing hypothesis and the social interaction hypothesis. Although there were no positive effects overall, change in illness-related couple communication and increased use of positive emotion words were associated with improvements in quality of life. Further studies are required to understand the factors contributing to these improvements. In addition, the GDP buffered the effects of partners' intrusive thoughts on patient quality of life, such that increased partner intrusive thoughts were associated with better patient quality of life, and buffered the effects of intrusive thoughts on perceived stress in patients at three month follow-up. Further research is needed to understand the mechanisms by which these protective effects of the GDP might occur.

The findings from this study are of theoretical and clinical importance. The results have contributed to the knowledge base and understanding of correlates of distress and quality of life in ovarian cancer patients and their partners, as well as understanding of mechanisms by which written disclosure may lead to benefits in physical and psychological health. Further research is needed to identify those who may benefit from written disclosure, in order to increase our understanding of this type of intervention and so that it can be offered to people for whom it is likely to be effective.

Appendices

Appendix A: Inclusion/ exclusion decision table for full text articles obtained for the systematic review

Ref	Article	Included/ Excluded	If excluded, why?
1	Andersen, B., L. (1995). Quality of life for women with gynecologic cancer. Current Opinion in Obstetrics and Gynecology, 7, 69-76.	Excluded	Review article
2	Anderson, B. (1994). Quality of life in progressive ovarian cancer. Gynecologic Oncology, 55, S151-S155.	Excluded	Review article
3	Anderson, B., & Lutgendorf, S. (1997). Quality of life in gynecologic cancer survivors. CA: A Cancer Journal for Clinicians, 47, 218-225.	Excluded	Review article
4	Auchincloss, S.S. (1995). After treatment: Psychosocial issues in gynecologic cancer survivorship. Cancer, 76, 2117-2224.	Excluded	Review article
5	Awadalla, A.W., Ohaeri, J.U., Gholoum, A., Khalid, A.O.A., Hamad, H.M.A., & Jacob, A. (2007). Factors associated with quality of life of outpatients with breast cancer and gynecologic cancers and the family caregivers: A controlled study. BMC Cancer, 7 (Article no. 102).	Included	
6	Bodurka-Bevers, D., Basen-Engquist, K., Carmack, C.L., Fitzgerald, M.A., Wolf, J.K., de Moor, C. & Gershenson, D.M. (2000). Depression, anxiety and quality of life in patients with epithelial ovarian cancer. Gynecologic Oncology, 78, 302-308.	Included	
7	Booth, K., Beaver, K., Kitchener, H., O'Neill, J., & Farrell, C. (2005). Women's experiences of information, psychological distress and worry after treatment for gynaecological cancer. Patient Education and Counseling, 56, 225-232.	Excluded	Only 6/70 participants had ovarian cancer; results not presented separately
8	Boscaglia, N., & Clarke, D.M. (2007). Sense of coherence as a protective factors for demoralisation in women with a recent diagnosis of gynaecological cancer. Psycho-Oncology, 16, 189-195.	Excluded	Ovarian cancer results not presented separately
9	Boscaglia, N., Clarke, D.M., Jobling, T.W., & Quinn, M.A. (2005). The contribution of spirituality and spiritual coping to anxiety and depression in women with a recent diagnosis of gynecological cancer. International Journal of Gynecological Cancer, 15, 755-761.	Included	
10	Canada, A.L., Parker, P.A., de Moor, J.S., Basen-Engquist, K., Ramondetta, L.M. & Cohen,L. (2006). Active coping mediates the relation between religion/spirituality and quality of life in ovarian cancer. Gynecologic Oncology, 101, 102-107.	Included	
11	Capelli, G., De Vincenzo, R.I., Addamo, A., Bartolozzi, F., Braggio, N. & Scambia, G. (2002). Which dimensions of quality of life are altered in patients attending the different gynecologic oncology health care settings? Cancer, 95, 2500-2507.	Included	

12	Carlsson, M., Strang, P., & Bjurstrom, C. (2000). Treatment modality affects long-term quality of life in gynaecological cancer. Anticancer Research, 20, 563-568.	Excluded	Ovarian cancer results not presented separately
13	Carter, J.R. Chen, M.D., Fowler, J.M., Carson, L.F., & Twiggs, L.B. (1997). The effect of prolonged cycles of chemotherapy on quality of life in gynaecologic cancer patients. Journal of Obstetrics and Gynaecology Research, 23, 197-203.	Excluded	Ovarian cancer results not presented separately
14	Chan, Y.M., Lee, P.W.U., Fong, D.Y.T., Fung, A.S.M., Wu, L.Y.F., Choi, A.Y.Y., Ng, T.Y., Ngan, H.Y.S., & Wong, L.C. (2005). Effect of individual psychological intervention in Chinese women with gynecologic malignancy: A randomized controlled trial. Journal of Clinical Oncology, 23, 4913-4924.	Included	
15	Chan, Y.M., Ng, T.Y., Ngan, H.Y.S., & Wong, L.C. (2003). Quality of life in women treated with neoadjuvant chemotherapy for advanced ovarian cancer; A prospective longitudinal study. Gynecologic Oncology, 88, 9-16.	Included	
16	Chan, Y.M., Ngan, H.Y., Li, B.Y., Yip, A.M., Ng, T.Y., Lee, P.W., Yip, P.S., Wong, L.C. (2001). A longitudinal study on quality of life after gynecologic cancer treatment. Gynecologic Oncology, 83, 10-19.	Excluded	Ovarian cancer results not presented separately
17	Chan, Y.M., Ngan, H.Y.S Yip, P.S.F., Li, B.Y.G., Lau, O.W.K., & Tang, G.W.K. (2001). Psychosocial adjustment in gynecologic cancer survivors: A longitudinal study on risk factors for maladjustment. Gynecologic Oncology, 80, 387-394.	Excluded	Ovarian cancer results not presented separately
18	Coleman, R.L. (2005). Depression, correlates of depression, and receipt of depression care among low-income women with breast or gynecologic cancer. Women's Oncology Review, 5, 227-228.	Excluded	Ovarian cancer results not presented separately
19	Costanzo, E.S., Lutgendorf, S.K., Bradley, S.L., Rose, S.L., & Anderson, B. (2005). Cancer attributions, distress and health practices among gynecologic cancer survivors. Psychosomatic Medicine, 67, 972-980.	Excluded	Participants had endometrial and cervical cancer, not ovarian
20	Costanzo, E.S., Lutgendorf, S.K., Rothrock, N.E., & Anderson, B. (2006). Coping and quality of life among women extensively treated for gynecologic cancer. Psycho-Oncology, 2, 132-142.	Excluded	Ovarian cancer results not presented separately
21	Costanzo, E.S., Lutgendorf, S.K., Sood, A.K., Anderson, B., Sorosky, J.I. & Lubaroff, D.M. (2005). Psychosocial factors and interleukin-6 among women with advanced ovarian cancer. Cancer, 104, 305-313.	Included	
22	de Groot, J.M., Mah, K., Fyles, A., Winton, S., Greenwood, S., DePetrillo, D., Devins, G.M. (2007). Do single and partnered women differ in types and intensities of illness- and treatment-related psychosocial concerns? A pilot study. Journal of Psychosomatic Research, 63, 241-245.	Excluded	Ovarian cancer results not presented separately
23	de Moor, J.S., de Moor, C.A., Basen-Engquist, K., Kudelka, A., Bevers, M.W., & Cohen, L. (2006). Optimism, distress, health-related quality of life, and change in cancer antigen 125 among patients with ovarian cancer undergoing chemotherapy. Psychosomatic Medicine, 68, 555-562.	Included	

24	Ding, Y., Zhu, Y.L., & Zhang, M.F. (2007). Quality of life of Chinese patients with ovarian malignancies during chemotherapy under conditions of no recurrence. Cancer Nursing, 30, 243-251.	Included	
25	Donovan, K.A., Greene, P.G., Shuster, J.L., Partridge, E.E., & Tucker, D.C. (2002). Psychosocial well-being of women with ovarian cancer. Unpublished manuscript.	Included	
26	Eisemann, M., & Lalos, A. (1999). Psychosocial determinants of well-being in gynecologic cancer patients. Cancer Nursing, 22, 303-306.	Excluded	Participants had cervical and endometrial cancer, not ovarian
27	Ell, K., Sanchez, K., Vourlekis, B., Lee, P.J., Dwight-Johnson, M., Lagomasino, I., & Russell, C. (2005). Depression, correlates of depression and receipt of depression care among low-income women with breast or gynecologic cancer. Journal of Clinical Oncology, 23, 3052-3060.	Excluded	Ovarian cancer results not presented separately
28	Ersek, M., Ferrell, B.R., Dow, K.H., & Melancon, C.H. (1997). Quality of life in women with ovarian cancer. Western Journal of Nursing Research, 19, 334-350.	Included	
29	Fasching, P.A., Thiel, F., Nicolaisen-Murmann, K., Rauh, C., Engel, J., Lux, M.P., Beckmann, M.W., & Bani, R. (2007). Association of complementary methods with quality of life and life satisfaction in patients with gynecologic and breast malignancies. Supportive Care in Cancer, 15, 1277-1284.	Excluded	Ovarian cancer results not presented separately
30	Ferrell, B., Cullinane, C.A., Ervine, K., Melancon, C., Uman, G.C., & Juarez, G. (2005). Perspectives on the impact of ovarian cancer; women's views of quality of life. Oncology Nursing Forum, 6, 1143-1149.	Included	
31	Ferrell, B., Smith, S.L., Cullinane, C.A., & Melancon, C. (2003). Psychological well-being and quality of life in ovarian cancer survivors. Cancer, 98, 1061-1071.	Excluded	Qualitative study
32	Fitch, M. (2006). Living with ovarian cancer; Perspectives of older women. Geriatrics and Aging, 9, 607-612.	Excluded	Qualitative study
33	22. Fitch, M., Gray, R.E., DePetrillo, D., Franssen, E., & Howell, D. (1999). Canadian women's perspectives on ovarian cancer. Cancer Prevention & Control, 3, 52-60.	Excluded	Qualitative study
34	24. Fitch, M., Gray, R.E., & Franssen, E. (2001). Perspectives on living with ovarian cancer: older women's views. Oncology Nursing Forum, 28, 1433-1442.	Excluded	Qualitative study
35	23. Fitch, M., Gray, R.E., & Franssen, E. (2000). Women's perspectives regarding the impact of ovarian cancer: implications for nursing. Cancer Nursing, 23, 359-366.	Excluded	Qualitative study
36	Fitch, M., Gray, R.E., & Franssen, E. (2000). Perspectives on living with ovarian cancer: young women's views. Canadian Oncology Nursing Journal, 10, 101-108.	Excluded	Qualitative study
37	Gil, K.M., Gibbons, H.E., Jenison, E.L., Hopkins, M.P., von Gruenigen, V.E. (2007). Baseline characteristics influencing quality of life in women undergoing gynecologic oncology surgery. Health and Quality of Life Outcomes, 5, article no. 25.	Included	

38	26. Gioiella, M.E., Berkman, B., & Robinson, M. (1998). Spirituality and quality of life in gynecologic oncology patients. Cancer Practice, 6, 333-338.	Included	
39	Gotheridge, S.M., & Dresner, N. (2002). Psychological adjustment to gynecologic cancer. Primary Care Update for Ob/Gyns, 9, 80-84.	Excluded	Review article
40	Greimel, E.R. & Friedl, W. (2000). Functioning in daily living and psychological well-being of female cancer patients. Journal of Psychosomatic Obstetrics and Gynecology, 21, 25-30.	Included	
41	Greimel, E., Thiel, I., Peitinger, F., Cegnar, I., & Pongratz, E. (2002). Prospective assessment of quality of life of female cancer patients. Gynecologic Oncology, 85, 140-147.	Included	
42	Guo, Y., Sheng, X-J., Liu, Y., & Hua, X-F. (2004) Evaluation on quality of life for gynecologic cancer patients. Chinese Journal of Cancer Research, 16, 292-296.	Included	
43	Hamilton, A.B. (1999). Psychological aspects of ovarian cancer. Cancer Investigation, 17, 335-341.	Excluded	Review article
44	Hipkins, J., Whitworth, M., Tarrier, N., & Jayson, G. (2004). Social support, anxiety and depression after chemotherapy for ovarian cancer: A prospective study. British Journal of Health Psychology, 9, 569-581.	Included	
45	Hodgkinson, K., Butow, P., Fuchs, A., Hunt, G.E., Stenlake, A., Hobbs, K.M., Brand, A., & Wain, G. (2007). Long-term survival from gynecologic cancer: Psychosocial outcomes, supportive care needs and positive outcomes. Gynecologic Oncology, 104, 381-389.	Included	
46	Hopkins, M.L., McDowell, I., Le, T., & Fung, M.F.K. (2005). Coping with ovarian cancer; do coping styles affect outcomes? Obstetrical and Gynecological Survey, 60, 321-325.	Excluded	Review article
47	Houck, K., Avis, N.E., Gallant, J.M., Fuller, A.F., & Goodman, A. (1999). Quality of life in advanced ovarian cancer: Identifying specific concerns. Journal of Palliative Medicine, 2, 397-402.	Excluded	Qualitative study
48	Howell, D., Fitch, M.I., Deane, K.A. (2003). Impact of ovarian cancer perceived by women. Cancer Nursing, 26, 1-9.	Excluded	Qualitative study
49	Kamer, S., Ozsaran, Z., Celik, O., Bildik, O., Yalman, D., Bolukbasi, Y., Haydaroglu, A. (2007). Evaluation of anxiety levels during intracavity brachytherapy applications in women with gynaecological malignancies. European Journal of Gynaecological Oncology, 28, 121-124.	Excluded	Participants had cervical and endometrial cancer, not ovarian
50	Kornblith, A., Thaler, H.T., Wong, G., Vlamis, V., Lepore, J.M., Loseth, D.B., Hakes, T., Hoskins, W.J. & Portenoy, R.K. (1995). Quality of life of women with ovarian cancer. Gynecologic Oncology, 59, 231-242.	Included	

51	Lakusta, C.M., Atkinson, M.J., Robinson, J.W., Nation, J., Taenzer, P.A., & Campo, M.G. (2001). Quality of life in ovarian cancer patients receiving chemotherapy. Gynecologic Oncology, 81, 490-495.	Included	
52	Le, T., Hopkins, L., & Fung Kee Fung, M. (2005). Quality of life assessment during adjuvant and salvage chemotherapy for advance stage epithelial ovarian cancer. Gynecologic Oncology, 98, 39-44.	Included	
53	Le, T., Leis, A., Pahwa, P., Wright, K., Ali, K., Reeder, B., Hopkins, L., & Fung Kee Fung, M. (2004). Quality of life evaluations in patients with ovarian cancer during chemotherapy treatment. Gynecologic Oncology, 92, 839-844.	Included	
54	Leake, R.L., Gurrin, L.C., & Hammond, I.G. (2001). Quality of life in patients attending a low risk gynaecological oncology follow-up clinic. Psycho-Oncology, 10, 428-435.	Excluded	Ovarian cancer results not presented separately
55	Leon-Pizarro, C., Gich, I., Barthe, E., Rovirosa, A., Farrus, B., Casas, F., Verger, E., Biete, A., Craven-Bartle, J., Sierra, J., Arcusa, A. A randomized trial of the effect of training in relaxation and guided imagery techniques in improving psychological and quality-of-life indices for gynaecologic and breast brachytherapy patients. Psycho-Oncology, 16, 971-979.	Excluded	Participants had cervical and endometrial cancer, not ovarian
56	Levine, E.G., & Silver, B. (2007). A pilot study: Evaluation of a psychosocial program for women with gynecological cancers. Journal of Psychosocial Oncology, 25, 75-98.	Excluded	Qualitative survey
57	Liavaag, A.H., Dorum, A., Fossa, S.D., Trope, C., & Dahl, A.A. (2007). Controlled study of fatigue, quality of life, and somatic and mental morbidity in epithelial ovarian cancer survivors: How lucky are the lucky ones? Journal of Clinical Oncology, 25, 2049-2056.	Included	
58	Lutgendorf, S.K., Anderson, B., Larsen, K., Buller, R.E., & Sorosky, J. L. (1999).	Excluded	Ovarian cancer results not presented separately
59	Lutgendorf, S.K., Anderson, B., Rothrock, N., Buller, R.E., Sood, A.K., & Sorosky, J.I. (2000). Quality of life and mood in women receiving extensive chemotherapy for gynecologic cancer. Cancer, 89, 1402-1411.	Excluded	Ovarian cancer results not presented separately
60	Lutgendorf, S.K., Anderson, B., Sorosky, J.I., Buller, R.E., & Lubaroff, D.M. (2000). Interleukin-6 and use of social support in gynecologic cancer patients. International Journal of Behavioral Medicine, 7, 127-142.	Excluded	Ovarian cancer results not presented separately
61	Lutgendorf, S.K., Anderson, B., Ullrich, P., Johnsen, E.L., Buller, R.E., Sood, A.K., Sorosky, J.I., & Ritchie, J. (2002). Quality of life and mood in women with gynecologic cancer: A one year prospective study. Cancer, 94, 131-140.	Excluded	Ovarian cancer results not presented separately
62	Lutgendorf, S.K., Johnsen, E.L., Cooper, B., Anderson, B., Sorosky, J.I., Buller, R.E. & Sood, A.K. (2002). Vascular endothelial growth factor and social support in patients with ovarian cancer. Cancer, 95, 808-815.	Included	

63	Lutgendorf, S.K., Sood, A.K., Anderson, B., McGinn, S., Maiseri, H., Dao, M., Sorosky, J.I., De Geest, K., Ritchie, J. & Lubaroff, D.M. (2005). Social support, psychological distress, and natural killer cell activity in ovarian cancer. Journal of Clinical Oncology, 23, 7105-7113.	Included	
64	Manne, S., Rubin, S., Edelson, M., Rosenblum, N., Bergman, C., Hernandez, E., Carlson, J., Rocereto, T. & Winkel, G. (2007). Coping and communication-enhancing intervention versus supportive counselling for women diagnosed with gynecological cancers. Journal of Consulting and Clinical Psychology, 75, 615-628.	Excluded	Ovarian cancer results not presented separately
65	McCorkle, R., Pasacreta, J., Tang, S.T. (2003). The silent killer; Psychological issues in ovarian cancer. Holistic Nursing Practice, 17, 300-308.	Excluded	Review article
66	Meden, H., Metz, A., & Monkeberg-Tun, E. (1994). Quality of life of patients with ovarian cancer after surgery and chemotherapy. Onkologie, 17, 50-56.	Included	
67	Miller, B.E., Pittman, B., Case, D., & McQuellon, R.P. (2002). Quality of life after treatment for gynecologic malignancies: A pilot study in an outpatient clinic. Gynecologic Oncology, 87, 178-184.	Included	
68	Miller, B.E., Pittman, B., & Strong, C. (2003). Gynecologic cancer patients' psychosocial needs and their views on the physician's role in meeting those needs. International Journal of Gynecological Cancer, 13, 111-119.	Excluded	Ovarian cancer results not presented separately
69	Molassiotis, A., Chan, C.W.H., Yam, B.M.C. & Chan, S.J. (2000). Quality of life in Chinese women with gynaecological cancers. Supportive Care in Cancer, 8, 414-422.	Included	
70	Molassiotis, A., Chan, C.W.H., Yam, B.M.C., Chan, S.J., & Lam, C.S.W. (2002). Life after cancer; Adaptation issues faced by Chinese gynaecological cancer survivors in Hong Kong. Psycho-Oncology, 11, 114-123.	Excluded	Qualitative study
71	Ngan, H.Y.S., Tang, G.W.K., & Lau, O.W.K. (1994). Psychosocial study on Hong Kong Chinese women with gynecological cancer. Journal of Psychosomatic Obstetrics and Gynaecology, 15, 111-117.	Excluded	Ovarian cancer results not presented separately
72	51. Norton, T.R., Manne, S.L., Rubin, S., Carlson, J., Hernandez, E., Edelson, M.I., Rosenblum, N., Warshal, D. & Bergman, C. (2004). Prevalence and predictors of psychological distress among women with ovarian cancer. Journal of Clinical Oncology, 22, 919-926.	Included	
73	Norton, T.R., Manne, S.L., Rubin, S., Hernandez, E., Carlson, J., Bergman, C. & Rosenblum, N. 92005). Ovarian cancer patients' psychological distress: the role of physical impairment, perceived unsupportive family and friend behaviours, perceived control, and self-esteem. Health Psychology, 24, 143-152.	Included	
74	Parker, P.A., Kudelka, A., Basen-Engquist, K., Kavanagh, J., de Moor, J., & Cohen, L. (2006). The associations between knowledge, CA 125 preoccupation , and distress in women with epithelial ovarian cancer. Gynecologic Oncology, 100, 495-500.	Included	

75	Patnaik, A., Doyle, C., & Oza, A.M. (1998). Palliative therapy in advanced ovarian cancer; balancing patient expectations, quality of life and cost. Anticancer Drugs, 9, 869-878.	Excluded	Review article
76	Penson, R.T., Cella, D., Wenzel, L. (2005). Quality of life in ovarian cancer. Journal of Reproductive Medicine, 50, 407-416.	Excluded	Review article
77	Penson, R.T., Wenzel, L.B., Vergote, I., & Cella, D. (2006). Quality of life considerations in gynecologic cancer. International Journal of Gynecology and Obstetrics, 95, S1, S247-S257.	Excluded	Review article
78	Petersen, R.W., Graham, G. & Quinlivan, J.A. (2005). Psychologic changes after a gynecologic cancer. Journal of Obstetrics and Gynaecology Research, 31, 152-157.	Included	
79	Petersen, R.W., & Quinlivan, J.A. (2002). Preventing anxiety and depression in gynaecological cancer: A randomized controlled trial. BJOG; An International Journal of Obstetrics and Gynaecology, 109, 386-394.	Excluded	Ovarian cancer results not presented separately
80	Pignata, S., Ballatori, E., Favalli, G., Scambia, G. (2001). Quality of life: Gynaecological cancers. Annals of Oncology, 12, S3, S37-S42.	Excluded	Review article
81	Pistrang, N. & Winchurst, C. (1997). Gynaecological cancer patients' attitudes towards psychological services. Psychology, Health and Medicine, 2, 135-147.	Excluded	Ovarian cancer results not presented separately
82	Poszluszny, D. (2001). Psychological trauma and adjustment in women newly diagnosed with gynecologic cancer. Unpublished doctoral dissertation: University of Pittsburgh	Excluded	Ovarian cancer results not presented separately
83	Rannestad, T., Skjeldestad, F.E. (2007) Pain and quality of life among long-term gynaecological cancer survivors: A population-based case-control study. Acta Obstetrica et Gynecologica Scandinavica, 86, 1510-1516.	Excluded	Ovarian cancer results not presented separately
84	Rummans, T.A., Frost, M., Suman, V.J., Taylor, M., Novotny, P., Gendron,T., Johnson, R., Hartmann, L., Dose, A.M., & Evans, R.W. (1998). Quality of life and pain in patients with recurrent breast and gynecologic cancer. Psychosomatics, 39, 437-445.	Excluded	Ovarian cancer results not presented separately
85	Scott, J.L., Halford, W.K., & Ward, B.G. (2004). United we stand? The effects of a couple-coping intervention on adjustment to early stage breast or gynecological cancer. Journal of Consulting and Clinical Psychology, 72, 1122-1135.	Excluded	Only 1 participant had ovarian cancer
86	Steginga, S.K., & Dunn, J. (1997). Women's experiences following treatment for gynecologic cancer. Oncology Nursing Forum, 24, 1403-1408.	Excluded	Qualitative study
87	Stevinson, C., Faught, W., Steed, H., Tonkin, K., Ladha, A.B., Vallance, J.K., Capstick, V., Schepansky, A., Courneya, K.S. (2007). Associations between physical activity and quality of life in ovarian cancer survivors. Gynecologic Oncology, 106, 244-250.	Included	

88	Sun, C.C., Frumovitz, M., Bodurka, D.C. (2005). Quality of life and gynecologic malignancies. Current Oncology Reports, 7, 459-465.	Excluded	Review article
89	Sun, C.C., Ramirez, P.T., Bodurka, D.C. (2007). Quality of life for patients with epithelial ovarian cancer. Nature Clinical Practice Oncology, 4, 18-29.	Excluded	Review article
90	Stewart, D.E., Wong, F., Duff, S., Melancon, C.H. & Cheung, A.M. "What doesn't kill you makes you stronger": An ovarian cancer survivor survey. Gynecologic Oncology, 83, 537-542.	Included	
91	Tabano, M., Condosta, D., Coons, M. (2002). Symptoms affecting quality of life in women with gynecologic cancer. Seminars in Oncology Nursing, 18, 223-230.	Excluded	Review article
92	Van Wilgen, C.P., Dijkstra, P.U., Stewart, R.E., Ranchor, A.V., & Roodenburg, J.L.N. (2006). Measuring somatic symptoms with the CES-D to assess depression in cancer patients after treatment; Comparison among patients with oral/ oropharyngeal, gynaecological, colorectal, and breast cancer. Psychosomatics, 47, 465-470.	Excluded	Ovarian cancer results not presented separately
93	Vaz, A.F., Pinto-Neto, A.M., Conde, D.m., Costa-Paiva, L., Morais, S.S., & Esteves, S.B. (2007). Quality of life of women with gynecologic cancer: Associated factors. Archives of Gynecology and Obstetrics, 276, 583-589.	Excluded	Participants had cervical and endometrial cancer, not ovarian
94	Virtej, P., Badea, I., Constantinescu, G., Boldea, G., Tudose, F. (1998). Female genitor-mammarian cancer in young women: Approach and quality of life. European Journal of Gynaecological Oncology, 19, 87-89.	Excluded	Ovarian cancer results not presented separately
95	von Gruenigen, V.E., Frasure, H.E., Jenison, E.L., Hopkins, M.P., Gil, K.M. (2006). Longitudinal assessment of quality of life and lifestyle in newly diagnosed ovarian cancer patients: The roles of surgery and chemotherapy. Gynecologic Oncology, 103, 120-126.	Included	
96	Weidner, K., Einsle, F., Siedentopf, F., Stobel-Richter, Y., Distler, W., & Joraschky, P. (2006). Psychological and physical factors influencing the health-related quality of life of patients of a department of gynecology in a university hospital. Journal of Psychosomatic Obstetrics and Gynecology, 27, 257-265.	Excluded	Ovarian cancer results not presented separately
97	Wenzel, L.B., Donnelly, J.P., Fowler, J.M., Habbal, R., Taylor, T.H., Aziz, N., & Cella, D. (2002). Resilience, reflection, and residual stress in ovarian cancer survivorship: A gynecologic oncology group study. Psycho-Oncology, 11,142-153.	Included	
98	Wenzel, L.B.; Robinson, S.E.; Blake, D.D. (1995). The effects of problem-focused group counselling for early-stage gynecologic cancer patients. Journal of Mental Health Counseling, 17, 81-93.	Excluded	Only 3/ 37 participants had ovarian cancer
99	Wenzel, l., Vergote, I., Cella, D. (2003). Quality of life in patients receiving treatment for gynecologic malignancies: special considerations for patient care. International Journal of Gynaecology and Obstetrics, 83, S1, 211-229.	Excluded	Review article

100	Zabora, J., Brintzenhofeszoc, K., Currow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. Psycho-Oncology, 10, 19-28.	Excluded	Ovarian cancer results not presented separately
101	Zacharias, D.R., Gilg, C.A., & Foxall, M.J. (1994). Quality of life and coping in patients with gynecologic cancer and their spouses. Oncology Nursing Forum, 21, 1699-1706.	Excluded	Ovarian cancer results not presented separately
102	Zhao, H., Kanda, K., Liu, S.J., & Mao, X.Y. (2003). Evaluation of quality of life in Chinese patients with gynaecological cancer: Assessments by patients and nurses. International Journal of Nursing Practice, 9, 40-48.	Excluded	Ovarian cancer results not presented separately

Appendix B: Sources where studies included in systematic review were identified

Included Articles	**Source where article was identified**
1. Awadalla et al. (2007)	Medline; Embase;
2. Bodurka-Bevers et al. (2000)	Medline; Embase
3. Boscaglia et al. (2005)	Medline; Embase
4. Canada et al. (2006)	Medline; Embase
5. Capelli et al. (2002)	In reference list of Pearman (2003)
6. Chan et al. (2003)	Medline
7. Chan et al. (2005)	Medline;
8. Costanzo et al. (2005)	Medline; Embase
9. de Moor et al. (2006)	Medline; Embase; PsycInfo
10. Ding et al. (2007)	Medline; Embase; PsycInfo
11. Donovan et al. (2002)	Dissertation abstract from PsycInfo, then personal communication with the author
12. Ersek et al. (1997)	Medline
13. Ferrell et al. (2005)	Medline
14. Gil et al. (2007)	Medline
15. Gioiella et al. (1998)	Medline; Embase
16. Greimel & Friedl (2000)	Medline; Embase
17. Greimel et al. (2002)	Medline; Embase
18. Guo et al. (2004)	Embase
19. Hipkins et al. (2004)	Medline; Embase; PsycInfo
20. Hodgkinson et al. (2007)	Medline; Embase
21. Kornblith et al. (1995)	Medline; Embase
22. Lakusta et al. (2001)	Medline; Embase
23. Le et al. (2005)	Medline; Embase
24. Le et al. (2004)	Medline; Embase
25. Liavaag et al. (2007)	Medline; Embase
26. Lutgendorf et al. (2002)	Medline; Embase
27. Lutgendorf et al. (2005)	Medline
28. Meden et al. (1994)	Embase

29. Miller et al. (2002)	Medline; Embase
30. Molassiotis et al. (2000)	Medline; Embase
31. Norton et al. (2004)	Medline; Embase
32. Norton et al. (2005)	Medline; Embase; PsycInfo
33. Parker et al. (2006)	Medline; Embase
34. Petersen et al. (2005)	Medline; Embase
35. Stevinson et al. (2007)	Medline; Embase
36. Stewart et al. (2001)	Medline; Embase
37. von Gruenigen et al. (2006)	Medline; Embase
38. Wenzel et al. (2002)	Medline; Embase; PsycInfo

Appendix C: Introductory letter for pilot study (Chapter 5)

University
of Southampton

Dear

My name is Emily Arden-Close, and I am a PhD student at the Department of Psychology, University of Southampton, working with Dr Yori Gidron. I am writing to request your participation in a study on the effects of writing about significant events and stress management over the telephone on well-being. The study is currently advertised in the Ovacome newsletter.

Participation will involve completing questionnaires, writing about significant events for 15 minutes a day over three days, and taking part in a stress management programme over the telephone (30 minutes). Previous research has shown positive benefits of both this type of structured writing and stress management training. It is hoped that the results of this research will both benefit other women with cancer and further scientific knowledge. All information you provide will remain strictly confidential.

If you are interested in participating, or have any questions, please contact me on ejac103@soton.ac.uk / School of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ/ 02380 462 887.

Yours Sincerely,

Emily Arden-Close

Appendix D: Consent form for pilot study (Chapter 5)

The effects of written disclosure and stress management on well-being
Consent form for research participants

Information sheet

I am Emily Arden-Close, a PhD student at the Department of Psychology, University of Southampton. I am requesting your participation in a study regarding the effects of writing about significant events and being given advice on managing stress over the telephone on well-being. You will be asked to take part in one of the following procedures depending on which condition you are assigned to:

Condition A

1) Complete several questionnaires

2) (after 1 month) Complete several questionnaires and write about significant events for 15 minutes per day over 3 days

3) (2 weeks later) Take part in a stress management programme over the telephone (30 minutes).

4) (1 month later) Complete several questionnaires

Condition B

1) Complete several questionnaires

2) (after 1 month) Complete several questionnaires and Take part in a stress management programme over the telephone (30 minutes).

3) (2 weeks later) Write about significant events for 15 minutes per day over 3 days

4) (1 month later) Complete several questionnaires

Personal information will not be released to or viewed by anyone other than researchers involved in this project. Results of this study will not include your name or any other identifying characteristics.

Your participation is voluntary and you may withdraw your participation at any time. If you have any questions please ask them now, or contact me, Emily Arden-Close, at ejac103@soton.ac.uk / Department of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ.

Statement of Consent

I ________________________ have read the above consent form.

[participants name]

I understand that I may withdraw my consent and discontinue participation at any time without penalty or loss of benefit to myself. I understand that data collected as part of this research project will be treated confidentially, and that published results of this research project will maintain my confidentially. In signing this consent letter, I am not waiving my legal claims, rights, or remedies. A copy of this consent letter will be offered to me.

(Circle Yes or No)

I give consent to participate in the above study. Yes/ No

Signature Date

Name

I understand that if I have questions about my rights as a participant in this research, or if I feel that I have been placed at risk, I can contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: (023) 8059 3995. Further, in the unlikely event that I experience any distress as a result of participation in this study, I am aware that the Ovacome helpline can be contacted on 02073809589.

Appendix E: Letter sent with consent form for pilot study (Chapter 5)

School of Psychology
University of Southampton
Highfield
Southampton
SO17 1BJ

Dear

My name is Emily Arden-Close, and I am a PhD student at the Department of Psychology, University of Southampton. Thank you for agreeing to participate in my study, which was advertised in the Ovacome newsletter.

As I mentioned previously, you will be required to complete questionnaires, write about significant events (15 minutes per day over 3 days), and take part in a stress management programme over the telephone (30 minutes), over a period of three months. Previous research has shown positive benefits of both this type of structured writing and stress management training. It is hoped that the results of this research will both benefit other women with cancer and further scientific knowledge. All information you provide will remain strictly confidential.

Please could you now fill in the informed consent form and attached questionnaires, and return them to me in the envelope provided as soon as possible. I will then contact you after a month to carry out the intervention. Your help is greatly appreciated.

As mentioned previously, I can be contacted on ejac103@soton.ac.uk / School of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ/ 02380 462 887.

Yours Sincerely,

Emily Arden-Close

Appendix F: Questionnaire for first baseline for pilot study

Background Information

Date:

Age:

Occupation:

Highest level of education completed:

Marital status:

Cancer stage at diagnosis:

Time since diagnosis:

Time since treatment:

Types of treatment (i.e., chemotherapy – mention drugs received if known, radiotherapy, etc.):

Do you smoke: Yes/No

If yes, on average how many per day?

Do you drink alcohol? Yes/ No

If yes, on average how many units per week?

On average, how often do you exercise?

5 times a week or more	3-4 times a week	1-2 times a week	Less than once a week	Never

What type of exercise do you do?

On average, how often do you do relaxation (i.e., deep breathing exercises, progressive muscle relaxation)?

5 times a week or more	3-4 times a week	1-2 times a week	Less than once a week	Never

These items deal with ways you've been coping with the stress in your life since you were diagnosed with ovarian cancer. These items ask what you've been doing to cope with the disease and treatment. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been concentrating my efforts on doing something about the situation I'm in.

1 2 3 4

2. I've been getting emotional support from others.

1 2 3 4

3. I've been giving up trying to deal with it.

1 2 3 4

4. I've been taking action to try to make the situation better.

1 2 3 4

5. I've been trying to see it in a different light, to make it seem more positive. 1

2 3 4

6. I've been getting comfort and understanding from someone.

1 2 3 4

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

7. I've been giving up the attempt to cope.

1 2 3 4

8. I've been looking for something good in what is happening.

1 2 3 4

9. I’ve been accepting the reality of the fact that it has happened.

1 2 3 4

10. I’ve been learning to live with it.

1 2 3 4

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.
0 = Never, 1 = Almost Never, 2 = Sometimes, 3 = Fairly Often, 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?

   0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

   0 1 2 3 4

3. In the last month, how often have you felt nervous and “stressed”?

   0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

   0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

   0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

   0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

   0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

   0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control?

   0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

    0 1 2 3 4

Below is a list of difficulties people sometimes have after stressful life events. **Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to your cancer**, i.e., how much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I thought about it when I didn't mean to	0	1	2	3	4
5. Pictures about it popped into my mind	0	1	2	3	4
6. I found myself acting or feeling as though I was back at that time	0	1	2	3	4
7. I had waves of strong feelings about it	0	1	2	3	4
8. I had dreams about it	0	1	2	3	4

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>**

	PHYSICAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	EMOTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>

ADDITIONAL CONCERNS

		Not at all	A little bit	Some-what	Quite a bit	Very much
O1	I have swelling in my stomach area	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
C3	I have control of my bowels	0	1	2	3	4
O2	I have been vomiting	0	1	2	3	4
B5	I am bothered by hair loss	0	1	2	3	4
C6	I have a good appetite	0	1	2	3	4
C7	I like the appearance of my body	0	1	2	3	4
BMT5	I am able to get around by myself	0	1	2	3	4
B9	I am able to feel like a woman	0	1	2	3	4
O3	I have cramps in my stomach area	0	1	2	3	4
BL4	I am interested in sex	0	1	2	3	4
BMT7	I have concerns about my ability to have children	0	1	2	3	4

Appendix G: Second baseline for pilot study

Date:

CA 125 level:

These items deal with ways you've been coping with the stress in your life since you were diagnosed with ovarian cancer. These items ask what you've been doing to cope with the disease and treatment. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been concentrating my efforts on doing something about the situation I'm in.

1 2 3 4

2. I've been getting emotional support from others.

1 2 3 4

3. I've been giving up trying to deal with it.

1 2 3 4

4. I've been taking action to try to make the situation better.

1 2 3 4

5. I've been trying to see it in a different light, to make it seem more positive. 1

2 3 4

6. I've been getting comfort and understanding from someone.

1 2 3 4

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

7. I've been giving up the attempt to cope.

1 2 3 4

8. I've been looking for something good in what is happening.

1 2 3 4

9. I’ve been accepting the reality of the fact that it has happened.

1 2 3 4

10. I’ve been learning to live with it.

1 2 3 4

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.
0 = Never, 1 = Almost Never, 2 = Sometimes, 3 = Fairly Often, 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?

   0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

   0 1 2 3 4

3. In the last month, how often have you felt nervous and "stressed"?

   0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

   0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

   0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

   0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

   0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

   0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control?

   0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

    0 1 2 3 4

Below is a list of difficulties people sometimes have after stressful life events. **Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to your cancer**, i.e., how much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I thought about it when I didn't mean to	0	1	2	3	4
5. Pictures about it popped into my mind	0	1	2	3	4
6. I found myself acting or feeling as though I was back at that time	0	1	2	3	4
7. I had waves of strong feelings about it	0	1	2	3	4
8. I had dreams about it	0	1	2	3	4

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you __during the past 7 days.__**

PHYSICAL WELL-BEING

		Not at all	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING

		Not at all	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	EMOTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you __during the past 7 days.__

ADDITIONAL CONCERNS

		Not at all	A little bit	Some-what	Quite a bit	Very much
O1	I have swelling in my stomach area	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
C3	I have control of my bowels...	0	1	2	3	4
O2	I have been vomiting	0	1	2	3	4
B5	I am bothered by hair loss	0	1	2	3	4
C6	I have a good appetite	0	1	2	3	4
C7	I like the appearance of my body	0	1	2	3	4
BMT5	I am able to get around by myself....................................	0	1	2	3	4
B9	I am able to feel like a woman	0	1	2	3	4
O3	I have cramps in my stomach area	0	1	2	3	4
BL4	I am interested in sex	0	1	2	3	4
BMT7	I have concerns about my ability to have children............	0	1	2	3	4

Appendix H: Stress Management Protocol for pilot study (Chapter 5)

Introduction (5 minutes)

Hello. My name is Emily Arden-Close, and I'm a student at the University of Southampton. I'm calling about the stress management programme you agree to take part in. I first want to thank you for that.
How are you feeling today?
Before we start, you should know that this will take about half an hour. If there's anything you don't understand, please tell me because it's my fault, not yours.

My aim today is to give you some coping strategies to help you deal with difficulties you may have in your everyday life.

[if they go on too long =>] I'm willing to listen to what you're saying, but with your permission, we have a lot to cover.

I imagine that it has been very difficult to go through this experience, hasn't it?

[Give empathy, listen well, and then move on]

Brief explanation about types of coping (2-3 minutes)

Every time you experience a stressful situation, there are many ways to react to it. There is not one correct coping style to deal with every stressor - what to do depends on the situation, and the person. However, research has shown that certain coping strategies may be more effective in certain situations. Broadly speaking, the main strategies of coping are problem-focused coping (this is trying to do something to resolve the situation), and emotion-focused coping (regulating your emotions, when the situation can't be resolved — by using relaxation, humour, etc.).

I shall clarify these different types of coping strategies right now. In order to know which type of coping strategy you need to use, the first question you need to ask yourself is: 'Can I do anything about the situation?'. Can you please give me a few situations in your daily life that you think are under your control? (For example, what you decide to eat).

Very good! Now give me a few situations in your daily life that are not under your control (for example, the weather).

Great – I would recommend that you consider the following wise sentence: 'Grant me the serenity to accept the things I cannot change, the courage to change the things I can, and the wisdom to know the difference.'

We will now learn how to apply the two types of coping styles in daily life situations

Problem-focused coping (10 minutes)

It's generally best to do something to solve a problem if you can. If it's unpleasant, it may be tempting to forget about it and hope it will go away, but often it won't. Research has shown that people who ignore problems that are under their control, tend to be more worried and unhappy in their everyday life, and it will give you more stress in the end. Remember your diagnosis of cancer. You experienced some symptoms, and they didn't go away, so you decided to go to a doctor. That was problem-focused coping - you had a problem, and you did something about it.

Now I'm going to teach you some structured problem solving techniques. Look at the leaflet. I'm going to go through those steps with you. First, I'm going to tell you what the steps are.
1. Choose a problem from your daily life you wish to work on
2, Think of ideas to solve it
3. Evaluate each idea
4. Decide which one is best
5. Plan how to carry it out
6. Review the solution

Ok, I'd like you to think of a problem you've been experiencing since you were diagnosed with cancer, and when you're ready, you can tell me about it. Choose something that you think you have control over.

–Ok, so the problem is .... *Very* good! Now I'd like you to think of some ideas to solve the problem - make a note of them. Often problems can be solved in several different ways.

Ok, very good! Now, which solution do you think would work best for you? It's up to you – there's no right or wrong answers. This might not be your favourite solution, it might just be the most practical one - that's fine.

Yes, that's very good! I'd like you to try this solution out next time you experience this problem. Make a note of it, evaluate its success, and practice it a couple of times, so you're confident about what you're going to do. Many people find this approach to problem-solving helpful, but it is necessary to think it through thoroughly. This is not an easy way out - many problems are only sorted out with a lot of effort. Problem solving is a continuous process. However, this might help you to deal with some problems in your everyday life which are under your control, just like we did together now.

Do you have any questions about what we just did?

Emotion-focused coping (5 minutes)

OK, now, we're going to talk about something different. Can you think of any situation where there's nothing or little you can do to change the situation?

Yes, very good! (if said nothing: for example, going for chemotherapy, going for a checkup). This may make you feel very worried/nervous. Emotion-focused coping is most suitable when cannot change the situation, and all what you can do it to reduce your levels of distress. One of the things you can do is "deep breathing", which I'm going to teach you now. Research has shown that breathing and relaxation exercises have benefits on QOL and immune responses in cancer patients. You do need to practice this regularly, to get the benefits. The instructions are in the booklet. I'll go through this with you, to teach you how to do it. It can be learned quickly. It's helpful if you do it every day, so you know how to do it whenever you want to. There are three stages to it.

1. Take 3 deep breaths. For each breath, inhale from your nose (count 1, 2, 3, 4/5 ....), hold your breath (count 1, 2,3, 4, 5/6 ....), and then exhale (count 1, 2,3,4,5,6,7 ....)
Repeat that 2 more times.

2. Breath normally for 1 minute - we'll do this for half a minute, because we haven't got that much time. Focus on the air coming in and out of your body.

3. Breath normally - again we'll do half a minute for now. Each time you breath, tell yourself a calming/hopeful word. You do not need to tell me your word!

Now, lets practice [counsellor instructs patient].

You can do this while you're having chemotherapy - it should make you feel better. There are other things you can do to make yourself feel better - can you suggest anything.

Ok, try and set aside some time every day to do things that will help you relax and adjust

Things that are partly under your control (6 minutes)

In everyday life, there are many things that are partly under your control, and partly not. Let's think about the prescription of your medication. Do you find it partly under your control?

(if says no). Well, it is your choice whether or not to take the medication. If your medication makes you feel bad (has too many side effects), you can talk to your doctor, and see if he/she can suggest anything different. Some people find this very difficult to do — do you find it hard to speak to your consultant about your medication? Let's practice this now. Say you were my consultant — I would need to tell you: Dr. Smith, the chemotherapy you prescribed me is really making me feel ill. Can you please help me with that? Now, pretend I'm your doctor. What would you say?

(if says doctor doesn't listen). Well, people who are being assertive are listened to more. This doesn't mean being rude - it means standing up for your rights, while still respecting your doctor! I would recommend you try this next time you meet him/her.

(if says completely under own control). Well, while you indeed decide whether you will eventually take your medication or not, your doctor has up-to-date knowledge about the treatment and your condition, so he/she knows which type of medicine may be best for you - it's really a mutual decision.

Research has shown that taking control over decisions is related to better quality of life in cancer patients, and this is why we want you to take some control over this issue, because it is partly under your control!

Summing up (2 minutes)

Well, that's all I have to say for now. Just to review, in general it's good to use problem-focused coping when the situation is under your control, emotion-focused coping when the situation is not under your control, and a combination of them when the situation is partly under your control. Before this ends, do you have any questions? If you think of anything that's not clear, or any questions you want to ask, you can contact me on ejac103@soton.ac.uk / (Yori's office tel. no) I hope this helped and I wish you all the best!

Appendix I: Stress Management Session –Information Leaflet for pilot study (Chapter 5)

Stress Management Session: Information leaflet

Brief explanation about types of coping

Every person often faces situations which he or she may see as stressful. Every time you experience a stressful situation, there are many ways to react to it. There is not one correct coping style to deal with every stressor - what to do depends on the situation, and the person. However, research has shown that certain coping strategies may be more effective in certain situations. The aim of this brief leaflet is to give you the skills for matching the best type of coping with different types of situations. Broadly speaking, the main strategies of coping are problem-focused coping (trying to do something to resolve the situation), and emotion-focused coping (regulating your emotions, by using relaxation, humour, etc.).

Problem-focused coping:

It's generally best to do something to solve a problem if you can. If it's unpleasant, it may be tempting to forget about it and hope it will go away, but often it won't. Research has shown that people who ignore problems that are under their control, tend to be more worried and unhappy in their everyday life.

1. Choose a problem from your daily life you wish to work on
2, Think of ideas to solve it
3. Evaluate each idea
4. Decide which one is best
5. Plan how to carry it out
6. Review the solution

Emotion focused coping - Relaxation:

In situations in which you do not have control over the event, research has shown that it is best to focus on yourself and on regulating your reactions to the event. One type of emotion-focused coping is relaxation.

1. Take 3 deep breaths. For each breath, inhale from your nose (count 1, 2, 3, 4/5 ....), hold your breath (count 1, 2,3, 4, 5/6 ....), and then exhale (count 1, 2,3,4,5,6,7 .....). Repeat that 2 more times.

2. Breathe normally for 1 minute. Focus on the air coming in and out of your body.

3. Breathe normally for 1 minute. Each time you breathe, tell yourself a calming/hopeful word of your choice.

Remember, you can do this i.e., while you're having chemotherapy - it should make you feel more relaxed.

Assertiveness:

In situations in which we can resolve by asking someone to change their behaviour, we need to be assertive. If your medication makes you feel bad (has too many side effects), you can talk to your doctor, and see if he/she can suggest anything different.

Practise this sentence:

Dr. Smith (or use your doctor's name), the chemotherapy you prescribed me is really making me feel ill. Can you please help me with that?

Remember, assertiveness doesn't mean being rude - it means standing up for your rights, while still respecting your doctor! It's recommended that you try this next time you have an appointment and if you have a problem with your medication. Research has shown that taking control over decisions is related to better quality of life in cancer patients.

We wish you successful coping and well-being!

Appendix J: Guided Disclosure Protocol (GDP) as used in pilot study (Chapter 5)

Introduction:

During the following minutes, we will ask you to think about your diagnosis and treatment of ovarian cancer. You will be asked to write about it for 15 minutes per day over 3 days, according to the instructions given below. We wish to remind you that all the information you provide will remain strictly confidential.

One thing that is important for the research is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write.

DAY 1:

Please take a moment to remember all the details of your diagnosis and treatment. Please describe these details in their chronological order of occurrence.

For example:
It was Friday, morning, three years ago…
I woke up and ate…
I spoke with friends…
Later, in the afternoon, the phone rang, and I was told that…
I immediately went to tell…etc.

The important thing is that you describe the event in sections organized according to their order of occurrence, that you write what caused what, in a "journalistic" and objective language, without mentioning your feelings.

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DAY 2:

As before, it is important for the research that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write. Please note that there are two parts to the writing today – part 2 is on the next page.

a. Please describe in detail how you felt and what you thought at the time of your diagnosis. What is important is that you identify and describe in your own words your deepest thoughts and feelings.

b. What meaning did the diagnosis/ treatment have for you, and has it changed your attitude towards life (for example – has it caused you to change priorities)?

DAY 3:

As before, it is important for the research that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don’t worry about grammar, spelling, or sentence structure. Just write.

Now, we are asking you please to describe your thoughts and feelings about the diagnosis and treatment as they are today. Are your current thoughts and feelings different from those you had at the time? Are you able to cope with similar situations better because you experienced this diagnosis/ treatment?

THANK YOU FOR YOUR PARTICIPATION

Appendix K: Follow-up questionnaire for pilot study (Chapter 5)

Background Information

Today’s date:
On average, how often do you do relaxation (i.e., deep breathing exercises, progressive muscle relaxation)?

5 times a week or more	3-4 times a week	1-2 times a week	Less than once a week	Never

CA 125 level:

If you had to choose one, which intervention would you recommend to others?

Stress Management Written disclosure

These items deal with ways you've been coping with the stress in your life since you were diagnosed with ovarian cancer. These items ask what you've been doing to cope with the disease and treatment. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

1. I've been concentrating my efforts on doing something about the situation I'm in.

1 2 3 4

2. I've been getting emotional support from others.

1 2 3 4

3. I've been giving up trying to deal with it.

1 2 3 4

4. I've been taking action to try to make the situation better.

1 2 3 4

5. I've been trying to see it in a different light, to make it seem more positive. 1

2 3 4

6. I've been getting comfort and understanding from someone.

1 2 3 4

1 = I haven't been doing this at all
2 = I've been doing this a little bit
3 = I've been doing this a medium amount
4 = I've been doing this a lot

7. I've been giving up the attempt to cope.

1 2 3 4

8. I've been looking for something good in what is happening.

1 2 3 4

9. I’ve been accepting the reality of the fact that it has happened.

1 2 3 4

10. I’ve been learning to live with it.

1 2 3 4

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.
0 = Never, 1 = Almost Never, 2 = Sometimes, 3 = Fairly Often, 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?

   0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

   0 1 2 3 4

3. In the last month, how often have you felt nervous and "stressed"?

   0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

   0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

   0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

   0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

   0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

   0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control?

   0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

    0 1 2 3 4

Below is a list of difficulties people sometimes have after stressful life events. **Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to your cancer**, i.e., how much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I thought about it when I didn't mean to	0	1	2	3	4
5. Pictures about it popped into my mind	0	1	2	3	4
6. I found myself acting or feeling as though I was back at that time	0	1	2	3	4
7. I had waves of strong feelings about it	0	1	2	3	4
8. I had dreams about it	0	1	2	3	4

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.**

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>

	<u>EMOTIONAL WELL-BEING</u>	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>

	ADDITIONAL CONCERNS	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
O1	I have swelling in my stomach area	0	1	2	3	4
C2	I am losing weight	0	1	2	3	4
C3	I have control of my bowels	0	1	2	3	4
O2	I have been vomiting	0	1	2	3	4
B5	I am bothered by hair loss	0	1	2	3	4
C6	I have a good appetite	0	1	2	3	4
C7	I like the appearance of my body	0	1	2	3	4
BMT5	I am able to get around by myself	0	1	2	3	4
B9	I am able to feel like a woman	0	1	2	3	4
O3	I have cramps in my stomach area	0	1	2	3	4
BL4	I am interested in sex	0	1	2	3	4
BMT7	I have concerns about my ability to have children	0	1	2	3	4

Appendix L: Debriefing Statement for pilot study (Chapter 5)

The effects of written disclosure and stress management on well being
Debriefing statement

The aim of this research was to see the effects of guided written disclosure and stress management on distress, coping and quality of life. It is expected that distress, coping and quality of life will improve as a result of these interventions. Further, it is expected that there will be no differences between groups (one group had written disclosure, then stress management; the other stress management, then written disclosure). Your data will help our understanding of the efficacy of these interventions for people with ovarian cancer, and will provide background information for a larger study to be carried out on members of Ovacome and their partners. Once again results of this study will not include your name or any other identifying characteristics. This research did not use deception. Following completion of the project, I will also send you a summary of the research findings. If you have any further questions please contact me, Emily Arden-Close, at ejac103@soton.ac.uk. Thank you for your participation in this research.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: (023) 8059 3995

Appendix M: Covering letter from Ovacome for main study (Chapters 6-8)

ovacome..

18th June 2007

Dear Member,

I am writing to draw your attention to a new study looking at ways to reduce stress and anxiety in those affected by ovarian cancer. This study is being carried out by Emily Arden-Close, who is a PhD student at the University of Southampton.

Ovacome members have previously participated in studies run by Emily's research team. We have been very impressed with Emily and her colleagues' work. We have received very positive feedback from those who have participated in her previous research.

There is far too little research which is aimed at improving quality of life for those living with the disease, and we therefore encourage you to give serious consideration to taking part. Emily needs over 100 ovarian cancer patients to take part. I enclose a letter from Emily explaining more about this study. Emily will be contactable via the office for anyone who wishes to receive more information about the trial.

I do hope that it is acceptable to write to you. If you do not wish to receive further letters from us regarding participation in similar studies, please let us know and we will amend your notes accordingly. Thank you.

Yours Sincerely,

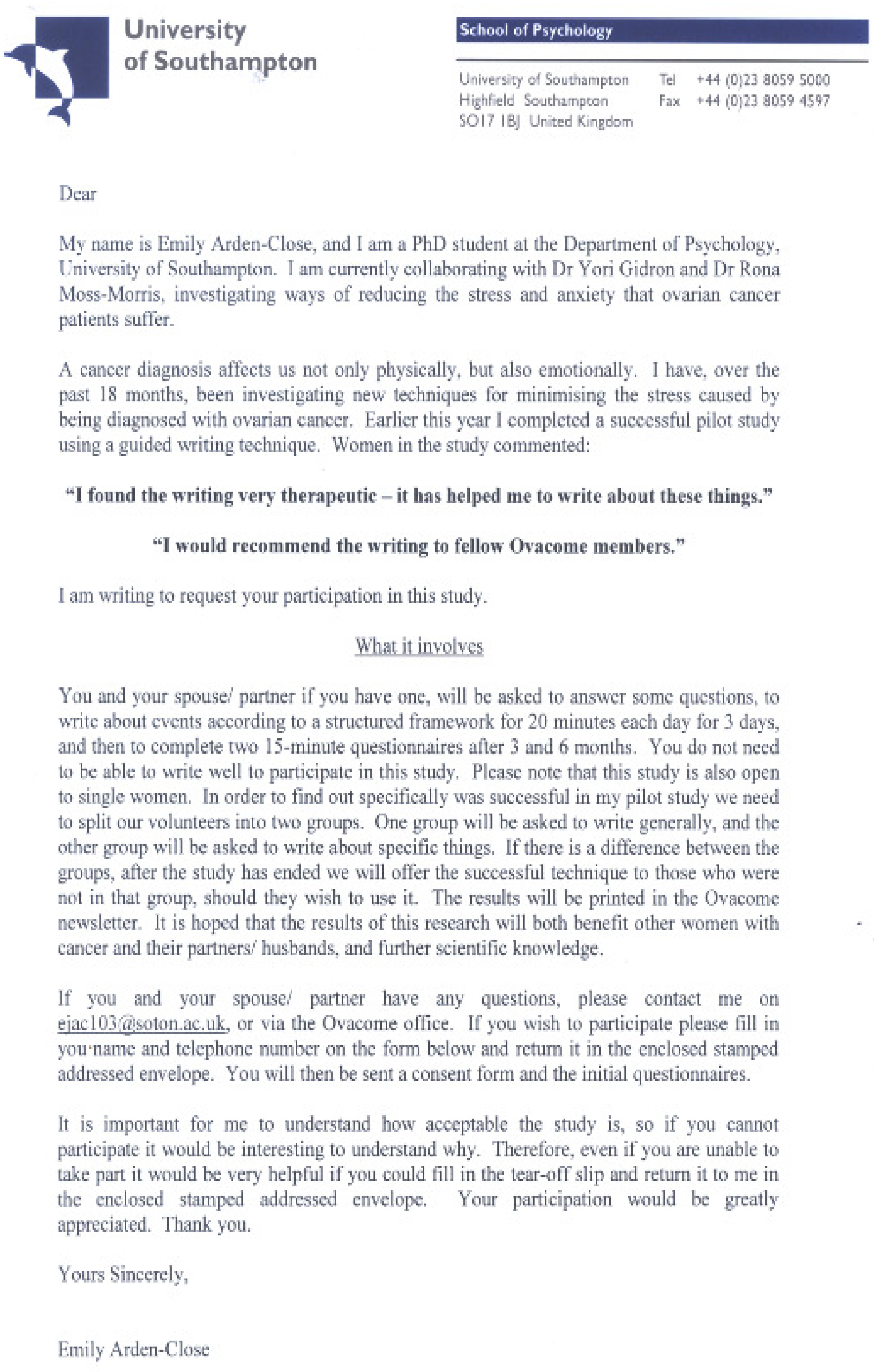
L Bayne

Charity Director,
Ovacome

the ovarian cancer support network
Elizabeth Garrett Anderson Hospital
Huntley Street, London WC1E 6DH
please call us 020 7380 9589
please contact us www.ovacome.org.uk
registered charity number 1058026

..it with us

Appendix N: Information letter for main study (Chapters 6-8)



University
of Southampton

School of Psychology

University of Southampton
Highfield Southampton
SO17 1BJ United Kingdom

Tel +44 (0)23 8059 5000
Fax +44 (0)23 8059 4597

Dear

My name is Emily Arden-Close, and I am a PhD student at the Department of Psychology, University of Southampton. I am currently collaborating with Dr Yori Gidron and Dr Rona Moss-Morris, investigating ways of reducing the stress and anxiety that ovarian cancer patients suffer.

A cancer diagnosis affects us not only physically, but also emotionally. I have, over the past 18 months, been investigating new techniques for minimising the stress caused by being diagnosed with ovarian cancer. Earlier this year I completed a successful pilot study using a guided writing technique. Women in the study commented:

"I found the writing very therapeutic – it has helped me to write about these things."

"I would recommend the writing to fellow Ovacome members."

I am writing to request your participation in this study.

What it involves

You and your spouse/ partner if you have one, will be asked to answer some questions, to write about events according to a structured framework for 20 minutes each day for 3 days, and then to complete two 15-minute questionnaires after 3 and 6 months. You do not need to be able to write well to participate in this study. Please note that this study is also open to single women. In order to find out specifically was successful in my pilot study we need to split our volunteers into two groups. One group will be asked to write generally, and the other group will be asked to write about specific things. If there is a difference between the groups, after the study has ended we will offer the successful technique to those who were not in that group, should they wish to use it. The results will be printed in the Ovacome newsletter. It is hoped that the results of this research will both benefit other women with cancer and their partners/ husbands, and further scientific knowledge.

If you and your spouse/ partner have any questions, please contact me on ejac103@soton.ac.uk, or via the Ovacome office. If you wish to participate please fill in your name and telephone number on the form below and return it in the enclosed stamped addressed envelope. You will then be sent a consent form and the initial questionnaires.

It is important for me to understand how acceptable the study is, so if you cannot participate it would be interesting to understand why. Therefore, even if you are unable to take part it would be very helpful if you could fill in the tear-off slip and return it to me in the enclosed stamped addressed envelope. Your participation would be greatly appreciated. Thank you.

Yours Sincerely,

Emily Arden-Close

____

Please complete one of the following options.

1. I wish to participate in the writing study.

Name: _____________________________ Contact telephone number: ______________

2. I do not wish to participate in the writing study[*].

[*] Please check the box that best explains the reason why

I am not interested.

I am too busy.

I am not feeling well.

Other (please specify where possible): ____

____

Appendix O: Consent form for main study

The effects of guided writing on well-being
Consent Form for Research Participants

Information sheet

I am Emily Arden-Close, a PhD student at the Department of Psychology, University of Southampton. I am requesting your participation in a study regarding the effects of writing about significant events on well-being in people with ovarian cancer and their partners if applicable. You will be asked to complete a series of questions, to write about significant events either in an emotional way or a non-emotional way, for 15 minutes once a day for 3 days, and to complete follow-up questionnaires after 3 and 6 months.

Personal information will not be released to or viewed by anyone other than researchers involved in this project. Results of this study will not include your name or any other identifying characteristics.

Your participation is voluntary and you may withdraw your participation at any time. If you have any questions please ask them now, or contact me, Emily Arden-Close, at ejac103@soton.ac.uk / Department of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ.

Statement of Consent

I ____________________________ have read the above consent form.

[participants name]

I understand that I may withdraw my consent and discontinue participation at any time without penalty or loss of benefit to myself. I understand that data collected as part of this research project will be treated confidentially, and that published results of this research project will maintain my confidentially. In signing this consent letter, I am not waiving my legal claims, rights, or remedies. A copy of this consent letter will be offered to me.

(Circle Yes or No)

I give consent to participate in the above study. Yes/ No

Signature Date

Name

I understand that if I have questions about my rights as a participant in this research, or if I feel that I have been placed at risk, I can contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: (023) 8059 3995. Further, in the unlikely event that I experience any distress as a result of participation in this study, I am aware that the Ovacome helpline can be contacted on 02073809589.

Appendix P: Baseline questionnaires for main study – patients

Code
Date

The effect of guided writing on stress and anxiety in ovarian cancer patients and their partners

Initial questionnaire

Thank you for agreeing to participate in this study. We are very interested in finding out more about any stress and anxiety you may be experiencing as a result of your illness. This will help us to find ways to reduce it.

This booklet contains a number of questions about any stress and anxiety you may be experiencing, and the impact of your illness on your physical health and psychological well-being.

There are no **right** or **wrong** answers to these questions. We are interested in your own personal views.

- **We ask you to answer the questions as honestly as possible.**

This questionnaire is completely CONFIDENTIAL.

It will only be seen by the researchers involved in this study.

Please return your completed questionnaire in the attached stamped addressed envelope. Please note that this questionnaire booklet consists of 8 pages.

Thank you very much for your time

Background Information:

Personal Information:

1. Age: _______________

2. Occupation: ___________________

3. Highest level of education completed: ______________________

4. Marital status: ____________________

5. How long have you been married/ living with your partner? ___________

Illness-related information:

1. Cancer stage at diagnosis: ____________

2. Time since diagnosis: _________________

3. Time since last treatment: _______________

4. Have you had the following treatments?

Surgery: Yes/ No

Chemotherapy (mention drugs received if known): _________________________

Radiotherapy: Yes/ No

5. How many cycles of chemotherapy have you had? _________________________

6. Please give the dates you had these cycles. _________________________________

____

7. Are you currently undergoing treatment? Yes/ No

8. If yes, what? ________________________

9. CA 125 level: __________________

10. Date of last CA 125 test: _____________

Information about health behaviours:

1. Do you smoke? Yes/ No

2. If yes, on average how many per day? _______________

3. Do you drink alcohol? Yes/ No

4. If yes, on average how many units per week? _____________

5. On average, how often do you exercise?

5 times a week or more	3-4 times a week	1-2 times a week	less than once a week	Never

6. What type of exercise do you do? _________________________________

Information about checkups/ medication:

1. Over the past 3 months, how many times have you gone to your GP or a consultant for:

   Illness_____ Injury_____ Checkup_____

2. Over the past 3 months, how many times have you visited an alternative therapist (i.e., reflexologist, aromatherapist, acupuncturist) for:

   Illness _____ Injury _____ Regular treatment _____

3. Over the past 3 months, how many times have you self-treated with over-the – counter medication / alternative medicine (i.e., herbal remedies, traditional Chinese medicine)?

   Over-the-counter remedies _________ Alternative Medicine __________

Stress Questionnaire

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you have felt or thought a certain way.

0 = Never, 1 = Almost Never, 2 = Sometimes, 3 = Fairly Often, 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?

   0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

   0 1 2 3 4

3. In the last month, how often have you felt nervous and “stressed”?

   0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

   0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

   0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

   0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

   0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

   0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control?

   0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

    0 1 2 3 4

Distress experienced

Below is a list of difficulties people sometimes have after stressful life events. **Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to your cancer**, i.e., how much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I thought about it when I didn't mean to	0	1	2	3	4
5. Pictures about it popped into my mind	0	1	2	3	4
6. I found myself acting or feeling as though I was back at that time	0	1	2	3	4
7. I had waves of strong feelings about it	0	1	2	3	4
8. I had dreams about it	0	1	2	3	4

Feelings about your cancer

Please answer the following questions with regard to your feelings about your cancer in general.

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. I get depressed when I think about my cancer					
2. When I think about my cancer I get upset					
3. My cancer makes me feel angry					
4. My cancer does not worry me					
5. Having cancer makes me feel anxious					
6. My cancer makes me feel afraid					

Living with your illness

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.**

PHYSICAL WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)........................	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun...................	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Communication with your partner

The following questions ask about your relationship with your partner. Each question should be answered on the scale shown below.

1	**2**	**3**	**4**	**5**
Disagree Strongly	**Disagree**	**Undecided**	**Agree**	**Agree Strongly**

1. I can express my true feelings to my partner. _____

2. When we are having a problem, my partner often refuses to talk about it. ____

3. My partner sometimes makes comments that put me down. _____

4. I wish my partner were more willing to share his/her feelings with me. ____

5. At times it is hard to ask my partner for what I want. _____

6. Sometimes I have trouble believing everything my partner tells me. ____

7. My partner is a very good listener. ______

8. My partner often doesn’t understand how I feel. _______

9. I am very satisfied with how my partner and I talk with each other. _____

10. It is difficult for me to share negative feelings with my partner. _____

11. It is hard for me to express feelings about my illness to my partner. ______

12. I feel comfortable discussing issues related to my illness with my partner. ____

13. My partner is reluctant to talk about my illness. ______

14. My partner is willing to share his feelings about my illness with me. ______

Appendix Q: Baseline questionnaires for main study – partners

Code
Date

The effect of guided writing on stress and anxiety in ovarian cancer patients and their partners

Initial questionnaire

Thank you for agreeing to participate in this study. We are very interested in finding out more about any stress and anxiety that both you and your partner may be experiencing as a result of her illness. This will help us to find ways to reduce it.

This booklet contains a number of questions about the stress and anxiety you may be experiencing, and the impact of your partner's illness on your physical health and psychological well-being.

There are no **right** or **wrong** answers to these questions. We are interested in your own personal views.

- **We ask you to answer the questions as honestly as possible.**

This questionnaire is completely CONFIDENTIAL.

It will only be seen by the researchers involved in this study.

Please return your completed questionnaire in the attached stamped addressed envelope. Please note that this questionnaire booklet consists of 6 pages.

Thank you very much for your time

Stress Questionnaire

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you have felt or thought a certain way.

0 = Never, 1 = Almost Never, 2 = Sometimes, 3 = Fairly Often, 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?

   0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

   0 1 2 3 4

3. In the last month, how often have you felt nervous and "stressed"?

   0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

   0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

   0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

   0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

   0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

   0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control?

   0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

    0 1 2 3 4

Distress experienced

Below is a list of difficulties people sometimes have after stressful life events. **Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to your wife/ partner's cancer**, i.e., how much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I thought about it when I didn't mean to	0	1	2	3	4
5. Pictures about it popped into my mind	0	1	2	3	4
6. I found myself acting or feeling as though I was back at that time	0	1	2	3	4
7. I had waves of strong feelings about it	0	1	2	3	4
8. I had dreams about it	0	1	2	3	4

Feelings about your wife/ partner's cancer

Please answer the following questions with regard to your feelings about your wife/ partner's cancer in general.

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. I get depressed when I think about my partner's cancer					
2. When I think about my partner's cancer I get upset					
3. My partner's cancer makes me feel angry					
4. My partner's cancer does not worry me					
5. My partner having cancer makes me feel anxious					
6. My partner's cancer makes me feel afraid					

Below is a list of statements relating to your health and everyday life which other people have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>**

<u>PHYSICAL WELL-BEING</u>

		Not at all	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

<u>SOCIAL/FAMILY WELL-BEING</u>

		Not at all	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Communication with your partner

The following questions ask about your relationship with your partner. Each question should be answered on the scale shown below.

1	**2**	**3**	**4**	**5**
Disagree Strongly	**Disagree**	**Undecided**	**Agree**	**Agree Strongly**

1. I can express my true feelings to my partner. _____
2. When we are having a problem, my partner often refuses to talk about it. ____
3. My partner sometimes makes comments that put me down. _____
4. I wish my partner were more willing to share his/her feelings with me. ____
5. At times it is hard to ask my partner for what I want. _____
6. Sometimes I have trouble believing everything my partner tells me. ____
7. My partner is a very good listener. ______
8. My partner often doesn't understand how I feel. _______
9. I am very satisfied with how my partner and I talk with each other. _____
10. It is difficult for me to share negative feelings with my partner. _____
11. It is hard for me to express feelings about her illness to my partner. ______
12. I feel comfortable discussing issues related to her illness with my partner. ____
13. My partner is reluctant to talk about her illness. ______
14. My partner is willing to share her feelings about her illness with me. ______

Appendix R: Guided Disclosure Protocol (GDP) booklets for main study – patients' booklet followed by partners' booklet

The effect of guided writing on stress and anxiety in ovarian cancer patients and their partners

Writing task

Thank you for agreeing to participate in this study on the effects of writing on well-being in ovarian cancer patients and their partners.

This booklet contains the writing task. It is important that you follow the instructions given below. I will telephone you before the writing task to arrange a convenient time for you to do it, and to go through the instructions with you.

PLEASE DO NOT LOOK AT THE WRITING TASK BEFORE STARTING IT.

The writing should be carried out for 15 minutes each day over 3 days, in a quiet room free from distractions. If you prefer to type rather than write, that is also fine. On each day, I will telephone you at a previously agreed time, to remind you to start writing, and again after 15 minutes, to remind you to stop writing.

The writing is completely CONFIDENTIAL.

It will only be seen by the researchers involved in this study.

Please return your completed writing task in the attached stamped addressed envelope. Please note that this booklet consists of 10 pages.

Thank you very much for your time

Code
Date

Introduction:

During the following minutes, we will ask you to think about your diagnosis and treatment of ovarian cancer. You will be asked to write about it for 15 minutes per day over 3 days, according to the instructions given below. We wish to remind you that all the information you provide will remain strictly confidential.

One thing that is important for the research is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write.

DAY 1:

Please take a moment to remember all the details of your diagnosis and treatment. Please describe these details in their chronological order of occurrence.

For example:
It was Friday, morning, three years ago…
I woke up and ate…
I spoke with friends…
Later, in the afternoon, the phone rang, and I was told that…
I immediately went to tell…etc.

The important thing is that you describe the event in sections organized according to their order of occurrence, that you write what caused what, in a "journalistic" and objective language, without mentioning your feelings.

PTO

Post- writing questions

Please answer the following questions at the conclusion of your writing period. Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal":

1. Overall, how personal was the essay that you wrote today ____

2. Overall, how much have you told other people about what you wrote today ____

3. Overall, how much did you reveal your emotions in what you wrote today ____

4. How much have you wanted to tell another person about what you wrote today ____

5. How much have you actively held back from telling others about what you wrote today ____

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

DAY 2:

As before, it is important for the research that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don’t worry about grammar, spelling, or sentence structure. Just write. Please note that there are two parts to the writing today – part 2 is on the next page.

a. Please describe in detail how you felt and what you thought at the time of your diagnosis. What is important is that you identify and describe in your own words your deepest thoughts and feelings.

b. What meaning did the diagnosis/ treatment have for you, and has it changed your attitude towards life (for example – has it caused you to change priorities)?

PTO

Post- writing questions

Please answer the following questions at the conclusion of your writing period. Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal":

1. Overall, how personal was the essay that you wrote today ____

2. Overall, how much have you told other people about what you wrote today ____

3. Overall, how much did you reveal your emotions in what you wrote today ____

4. How much have you wanted to tell another person about what you wrote today ____

5. How much have you actively held back from telling others about what you wrote today ____

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

DAY 3:

As before, it is important for the research that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write.

Now, we are asking you please to describe your thoughts and feelings about the diagnosis and treatment as they are today. Are your current thoughts and feelings different from those you had at the time? Are you able to cope with similar situations better because you experienced this diagnosis/ treatment?

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PTO

Please answer the following questions at the conclusion of your writing period.
Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal".
In answering these questions, consider all three days of your writing.

1. Overall, how personal were the essays that you wrote: _______

2. Prior to the experiment, how much had you told other people about what you wrote? _________

3. Overall, how much did you reveal your emotions in what you wrote on Day 2 and Day 3? _______

4. How much have you actively held back from telling others about what you wrote? _________

5. During your normal day, to what degree have you thought about this study since it began? _______

6. Since the beginning of the experiment, to what degree have you thought about the topics that you wrote about? ________

7. Before the experiment ever began, to what degree did you think about the topics you wrote about? ______

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

The effect of guided writing on stress and anxiety in ovarian cancer patients and their partners

Writing task

Thank you for agreeing to participate in this study on the effects of writing on well-being in ovarian cancer patients and their partners.

This booklet contains the writing task. It is important that you follow the instructions given below. I will telephone you before the writing task to arrange a convenient time for you to do it, and to go through the instructions with you.

PLEASE DO NOT LOOK AT THE WRITING TASK BEFORE STARTING IT.

The writing should be carried out for 15 minutes each day over 3 days, in a quiet room free from distractions. If you prefer to type rather than write, that is also fine. On each day, I will telephone you at a previously agreed time, to remind you to start writing, and again after 15 minutes, to remind you to stop writing.

The writing is completely CONFIDENTIAL.

It will only be seen by the researchers involved in this study.

Please return your completed writing task in the attached stamped addressed envelope. Please note that this booklet consists of 10 pages.

Thank you very much for your time

Code
Date

Introduction:

During the following minutes, we will ask you to think about your spouse/ partner's diagnosis and treatment of ovarian cancer. You will be asked to write about it for 15 minutes per day over 3 days, according to the instructions given below. We wish to remind you that all the information you provide will remain strictly confidential.

One thing that is important for the research is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write.

DAY 1:

Please take a moment to remember as much as you can of your spouse/ partner's diagnosis and treatment. Please describe these details in their chronological order of occurrence.

For example:
It was Friday, morning, three years ago…
I woke up and ate…
I spoke with friends…
Later, in the afternoon, the phone rang, and I was told that…
I immediately went to tell…etc.

The important thing is that you describe the event in sections organized according to their order of occurrence, that you write what caused what, in a "journalistic" and objective language, without mentioning your feelings.

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PTO

Post- writing questions

Please answer the following questions at the conclusion of your writing period. Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal":

1. Overall, how personal was the essay that you wrote today ____

2. Overall, how much have you told other people about what you wrote today ____

3. Overall, how much did you reveal your emotions in what you wrote today ____

4. How much have you wanted to tell another person about what you wrote today ____

5. How much have you actively held back from telling others about what you wrote today ____

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

DAY 2:

As before, it is important for the research that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write. Please note that there are two parts to the writing today – part 2 is on the next page.

a. Please describe in detail how you felt and what you thought at the time of your spouse/ partner's cancer diagnosis. What is important is that you identify and describe in your own words your deepest thoughts and feelings.

b. What meaning did your spouse/ partner’s diagnosis/ treatment have for you, and has it changed your attitude towards life (for example – has it caused you to change priorities)?

PTO

Post- writing questions

Please answer the following questions at the conclusion of your writing period. Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal":

1. Overall, how personal was the essay that you wrote today ____

2. Overall, how much have you told other people about what you wrote today ____

3. Overall, how much did you reveal your emotions in what you wrote today ____

4. How much have you wanted to tell another person about what you wrote today ____

5. How much have you actively held back from telling others about what you wrote today ____

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

DAY 3:

As before, it is important for the research that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write.

Now, we are asking you please to describe your thoughts and feelings about your spouse/ partner's diagnosis and treatment as they are today. Are your current thoughts and feelings different from those you had at the time? Are you able to cope with similar situations better because of the experience of your spouse/ partner's diagnosis/ treatment?

PTO

Please answer the following questions at the conclusion of your writing period.
Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal".
In answering these questions, consider all three days of your writing.

1. Overall, how personal were the essays that you wrote: _______

2. Prior to the experiment, how much had you told other people about what you wrote? _________

3. Overall, how much did you reveal your emotions in what you wrote on Day 2 and Day 3? _______

4. How much have you actively held back from telling others about what you wrote? _________

5. During your normal day, to what degree have you thought about this study since it began? _______

6. Since the beginning of the experiment, to what degree have you thought about the topics that you wrote about? ________

7. Before the experiment ever began, to what degree did you think about the topics you wrote about? ______

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

Appendix S: Control writing booklet for main study – patients' booklet followed by partners' booklet

The effect of guided writing on stress and anxiety in ovarian cancer patients and their partners

Writing task

Thank you for agreeing to participate in this study on the effects of writing on well-being in ovarian cancer patients and their partners.

This booklet contains the writing task. It is important that you follow the instructions given below. I will telephone you before the writing task to arrange a convenient time for you to do it, and to go through the instructions with you.

PLEASE DO NOT LOOK AT THE WRITING TASK BEFORE STARTING IT.

The writing should be carried out for 15 minutes each day over 3 days, in a quiet room free from distractions. If you prefer to type rather than write, that is also fine. On each day, I will telephone you at a previously agreed time, to remind you to start writing, and again after 15 minutes, to remind you to stop writing.

The writing is completely CONFIDENTIAL.

It will only be seen by the researchers involved in this study.

Please return your completed writing task in the attached stamped addressed envelope. Please note that this booklet consists of 10 pages.

Thank you very much for your time

Code
Date

Introduction:

During the following minutes, we will ask you to think about a few things in your daily life, and to write about them. You will be asked to write for 15 minutes per day over 3 days according to instructions you shall receive. We wish to remind you that all the information you provide will remain strictly confidential.

One thing that is important for the research is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write.

DAY 1:

Please describe in an unemotional manner what you did yesterday.

PTO

Post-writing questions

Please answer the following questions at the conclusion of your writing period. Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal":

1. Overall, how personal was the essay that you wrote today ____

2. Overall, how much have you told other people about what you wrote today ____

3. Overall, how much did you reveal your emotions in what you wrote today ____

4. How much have you wanted to tell another person about what you wrote today ____

5. How much have you actively held back from telling others about what you wrote today ____

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

DAY 2:

Please describe in an unemotional manner what you did yesterday.

As before, it is important for the research that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write.

PTO

Post- writing questions

Please answer the following questions at the conclusion of your writing period. Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal":

1. Overall, how personal was the essay that you wrote today ____

2. Overall, how much have you told other people about what you wrote today ____

3. Overall, how much did you reveal your emotions in what you wrote today ____

4. How much have you wanted to tell another person about what you wrote today ____

5. How much have you actively held back from telling others about what you wrote today ____

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

DAY 3:

Please describe in an unemotional manner what you did yesterday.

As before, it is important for the research that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write.

PTO

Please answer the following questions at the conclusion of your writing period.
Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal".
In answering these questions, consider all three days of your writing.

1. Overall, how personal were the essays that you wrote: _______

2. Prior to the experiment, how much had you told other people about what you wrote? _________

3. Overall, how much did you reveal your emotions in what you wrote on Day 2 and Day 3? _______

4. How much have you actively held back from telling others about what you wrote? _________

5. During your normal day, to what degree have you thought about this study since it began? _______

6. Since the beginning of the experiment, to what degree have you thought about the topics that you wrote about? ________

7. Before the experiment ever began, to what degree did you think about the topics you wrote about? ______

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

The effect of guided writing on stress and anxiety in ovarian cancer patients and their partners

Writing task

Thank you for agreeing to participate in this study on the effects of writing on well-being in ovarian cancer patients and their partners.

This booklet contains the writing task. It is important that you follow the instructions given below. I will telephone you before the writing task to arrange a convenient time for you to do it, and to go through the instructions with you.

PLEASE DO NOT LOOK AT THE WRITING TASK BEFORE STARTING IT.

The writing should be carried out for 15 minutes each day over 3 days, in a quiet room free from distractions. If you prefer to type rather than write, that is also fine. On each day, I will telephone you at a previously agreed time, to remind you to start writing, and again after 15 minutes, to remind you to stop writing.

The writing is completely CONFIDENTIAL.

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Please return your completed writing task in the attached stamped addressed envelope. Please note that this booklet consists of 10 pages.

Thank you very much for your time

Code
Date

Introduction:

During the following minutes, we will ask you to think about a few things in your daily life, and to write about them. You will be asked to write for 15 minutes per day over 3 days according to instructions you shall receive. We wish to remind you that all the information you provide will remain strictly confidential.

One thing that is important for the research is that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write.

DAY 1:

To the best of your ability, please describe in an unemotional manner what your spouse/ partner did yesterday.

PTO

Post-writing questions

Please answer the following questions at the conclusion of your writing period. Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal":

1. Overall, how personal was the essay that you wrote today ____

2. Overall, how much have you told other people about what you wrote today ____

3. Overall, how much did you reveal your emotions in what you wrote today ____

4. How much have you wanted to tell another person about what you wrote today ____

5. How much have you actively held back from telling others about what you wrote today ____

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

DAY 2:

To the best of your ability, please describe in an unemotional manner what your spouse/ partner did yesterday.

As before, it is important for the research that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write.

PTO

Post- writing questions

Please answer the following questions at the conclusion of your writing period. Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal":

1. Overall, how personal was the essay that you wrote today ____

2. Overall, how much have you told other people about what you wrote today ____

3. Overall, how much did you reveal your emotions in what you wrote today ____

4. How much have you wanted to tell another person about what you wrote today ____

5. How much have you actively held back from telling others about what you wrote today ____

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

DAY 3:

To the best of your ability, please describe in an unemotional manner what your spouse/ partner did yesterday.

As before, it is important for the research that you write continuously for the entire time. If you run out of things to say, just repeat what you have already written. In your writing, don't worry about grammar, spelling, or sentence structure. Just write.

PTO

Please answer the following questions at the conclusion of your writing period.
Answer them on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal".
In answering these questions, consider all three days of your writing.

1. Overall, how personal were the essays that you wrote: _______

2. Prior to the experiment, how much had you told other people about what you wrote? _________

3. Overall, how much did you reveal your emotions in what you wrote on Day 2 and Day 3? _______

4. How much have you actively held back from telling others about what you wrote? _________

5. During your normal day, to what degree have you thought about this study since it began? _______

6. Since the beginning of the experiment, to what degree have you thought about the topics that you wrote about? ________

7. Before the experiment ever began, to what degree did you think about the topics you wrote about? ______

THANK YOU FOR COMPLETING THE WRITING SESSION AND THE QUESTIONS.

Appendix T: Three month follow-up questionnaire for main study – patients

Code
Date

The effect of guided writing on stress and anxiety in ovarian cancer patients and their partners

Three month follow-up

Thank you for agreeing to participate in this study. We are very interested in finding out more about any stress and anxiety you may be experiencing as a result of your illness, and how it changes over time. This will help us to find ways to reduce it.

This booklet contains a number of questions about any stress and anxiety you may be experiencing, and the impact of your illness on your physical health and psychological well-being.

There are no **right** or **wrong** answers to these questions. We are interested in your own personal views.

- **We ask you to answer the questions as honestly as possible.**

This questionnaire is completely CONFIDENTIAL.

It will only be seen by the researchers involved in this study.

Please return your completed questionnaire in the attached stamped addressed envelope. Please note that this questionnaire booklet consists of 7 pages.

Thank you very much for your time

Background Information:

Illness-related information:

1. Are you currently undergoing treatment? Yes/ No
2. If yes, what? ________________________
3. CA 125 level: __________________
4. Date of last CA 125 test: _____________

Information about checkups/ medication

1. Over the past 3 months, how many times have you gone to your GP or a consultant for:

   Illness_____ Injury_____ Checkup_____

2. Over the past 3 months, how many times have you visited an alternative therapist (i.e., reflexologist, aromatherapist, acupuncturist) for:

   Illness _____ Injury _____ Regular treatment _____

3. Over the past 3 months, how many times have you self-treated with over-the – counter medication / alternative medicine (i.e., herbal remedies, traditional Chinese medicine)?

   Over-the-counter remedies _________ Alternative Medicine __________

Questions about the writing study

Answer the following questions on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal."

1. Since your participation in the writing experiment, how much have you thought about what you wrote? ______________
2. Since the writing experiment, how much have you talked to other people about what you wrote? ________________

Stress Questionnaire

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you have felt or thought a certain way.

0 = Never, 1 = Almost Never, 2 = Sometimes, 3 = Fairly Often, 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?

0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

0 1 2 3 4

3. In the last month, how often have you felt nervous and “stressed”?

0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control?

0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

0 1 2 3 4

Distress experienced

Below is a list of difficulties people sometimes have after stressful life events. **Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to your cancer**, i.e., how much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I thought about it when I didn’t mean to	0	1	2	3	4
5. Pictures about it popped into my mind	0	1	2	3	4
6. I found myself acting or feeling as though I was back at that time	0	1	2	3	4
7. I had waves of strong feelings about it	0	1	2	3	4
8. I had dreams about it	0	1	2	3	4

Feelings about your cancer

Please answer the following questions with regard to your feelings about your cancer in general.

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. I get depressed when I think about my cancer					
2. When I think about my cancer I get upset					
3. My cancer makes me feel angry					
4. My cancer does not worry me					
5. Having cancer makes me feel anxious					
6. My cancer makes me feel afraid					

Living with your illness

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.**

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days</u>

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Communication with your partner

The following questions ask about your relationship with your partner. Each question should be answered on the scale shown below.

1	**2**	**3**	**4**	**5**
Disagree Strongly	**Disagree**	**Undecided**	**Agree**	**Agree Strongly**

1. I can express my true feelings to my partner. _____
2. When we are having a problem, my partner often refuses to talk about it. ____
3. My partner sometimes makes comments that put me down. _____
4. I wish my partner were more willing to share his/her feelings with me. ____
5. At times it is hard to ask my partner for what I want. _____
6. Sometimes I have trouble believing everything my partner tells me. ____
7. My partner is a very good listener. ______
8. My partner often doesn't understand how I feel. _______
9. I am very satisfied with how my partner and I talk with each other. _____
10. It is difficult for me to share negative feelings with my partner. _____
11. It is hard for me to express feelings about my illness to my partner. ______
12. I feel comfortable discussing issues related to my illness with my partner. ____
13. My partner is reluctant to talk about my illness. ______
14. My partner is willing to share his feelings about my illness with me. ______

Appendix U: Three month follow-up questionnaire for main study – partners

Code
Date

The effect of guided writing on stress and anxiety in ovarian cancer patients and their partners

Three month follow-up

Thank you for agreeing to participate in this study. We are very interested in finding out more about any stress and anxiety that both you and your partner may be experiencing as a result of her illness, and how it changes over time. This will help us to find ways to reduce it.

This booklet contains a number of questions about the stress and anxiety you may be experiencing, and the impact of your partner's illness on your physical health and psychological well-being.

There are no **right** or **wrong** answers to these questions. We are interested in your own personal views.

- **We ask you to answer the questions as honestly as possible.**

This questionnaire is completely CONFIDENTIAL.

It will only be seen by the researchers involved in this study.

Please return your completed questionnaire in the attached stamped addressed envelope. Please note that this questionnaire booklet consists of 7 pages.

Thank you very much for your time

Questions about the writing study

Answer the following questions on a scale from 1 to 7 with 1 being “not at all” and 7 “a great deal.”

1. Since your participation in the writing experiment, how much have you thought about what you wrote? ______________

2. Since the writing experiment, how much have you talked to other people about what you wrote? ________________

Stress Questionnaire

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you have felt or thought a certain way.

0 = Never, 1 = Almost Never, 2 = Sometimes, 3 = Fairly Often, 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?

   0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

   0 1 2 3 4

3. In the last month, how often have you felt nervous and “stressed”?

   0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

   0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

   0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

   0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

   0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

   0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control?

   0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

    0 1 2 3 4

Distress experienced

Below is a list of difficulties people sometimes have after stressful life events. **Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to your wife/ partner's cancer**, i.e., how much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I thought about it when I didn't mean to	0	1	2	3	4
5. Pictures about it popped into my mind	0	1	2	3	4
6. I found myself acting or feeling as though I was back at that time	0	1	2	3	4
7. I had waves of strong feelings about it	0	1	2	3	4
8. I had dreams about it	0	1	2	3	4

Feelings about your wife/ partner's cancer

Please answer the following questions with regard to your feelings about your wife/ partner's cancer in general.

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. I get depressed when I think about my partner's cancer					
2. When I think about my partner's cancer I get upset					
3. My partner's cancer makes me feel angry					
4. My partner's cancer does not worry me					
5. My partner having cancer makes me feel anxious					
6. My partner's cancer makes me feel afraid					

Below is a list of statements relating to your health and everyday life which other people have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>**

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Communication with your partner

The following questions ask about your relationship with your partner. Each question should be answered on the scale shown below.

1	**2**	**3**	**4**	**5**
Disagree Strongly	**Disagree**	**Undecided**	**Agree**	**Agree Strongly**

1. I can express my true feelings to my partner. _____
2. When we are having a problem, my partner often refuses to talk about it. ____
3. My partner sometimes makes comments that put me down. _____
4. I wish my partner were more willing to share his/her feelings with me. ____
5. At times it is hard to ask my partner for what I want. _____
6. Sometimes I have trouble believing everything my partner tells me. ____
7. My partner is a very good listener. ______
8. My partner often doesn't understand how I feel. _______
9. I am very satisfied with how my partner and I talk with each other. _____
10. It is difficult for me to share negative feelings with my partner. _____
11. It is hard for me to express feelings about her illness to my partner. ______
12. I feel comfortable discussing issues related to her illness with my partner. ____
13. My partner is reluctant to talk about her illness. ______
14. My partner is willing to share her feelings about her illness with me. ______

Appendix V: Six month follow-up questionnaire for main study – patients

Code
Date

The effect of guided writing on stress and anxiety in ovarian cancer patients and their partners

Six month follow-up

Thank you for agreeing to participate in this study. We are very interested in finding out more about any stress and anxiety you may be experiencing as a result of your illness, and how it changes over time. This will help us to find ways to reduce it.

This booklet contains a number of questions about any stress and anxiety you may be experiencing, and the impact of your illness on your physical health and psychological well-being.

There are no **right** or **wrong** answers to these questions. We are interested in your own personal views.

- **We ask you to answer the questions as honestly as possible.**

This questionnaire is completely CONFIDENTIAL.

It will only be seen by the researchers involved in this study.

Please return your completed questionnaire in the attached stamped addressed envelope. Please note that this questionnaire booklet consists of 7 pages.

Thank you very much for your time

Background Information:

Illness-related information:

1. Are you currently undergoing treatment? Yes/ No
2. If yes, what? ________________________
3. CA 125 level: __________________
4. Date of last CA 125 test: _____________

Information about checkups/ medication

1. Over the past 3 months, how many times have you gone to your GP or a consultant for:

   Illness_____ Injury_____ Checkup_____

2. Over the past 3 months, how many times have you visited an alternative therapist (i.e., reflexologist, aromatherapist, acupuncturist) for:

   Illness _____ Injury _____ Regular treatment _____

3. Over the past 3 months, how many times have you self-treated with over-the – counter medication / alternative medicine (i.e., herbal remedies, traditional Chinese medicine)?

   Over-the-counter remedies _________ Alternative Medicine __________

Questions about the writing study

Answer the following questions on a scale from 1 to 7 with 1 being “not at all” and 7 “a great deal.”

1. Since your participation in the writing experiment, how much have you thought about what you wrote? ______________

2. Since the writing experiment, how much have you talked to other people about what you wrote? ________________

General questions about the research

1. Would you recommend the writing to other people?
   ____

2. Do you think you were in the intervention or control group?
Intervention Control

Stress Questionnaire

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you have felt or thought a certain way.

0 = Never, 1 = Almost Never, 2 = Sometimes, 3 = Fairly Often, 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?

   0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

   0 1 2 3 4

3. In the last month, how often have you felt nervous and “stressed”?

   0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

   0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

   0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

   0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

   0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

   0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control?

   0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

    0 1 2 3 4

Distress experienced

Below is a list of difficulties people sometimes have after stressful life events. **Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to your cancer**, i.e., how much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I thought about it when I didn't mean to	0	1	2	3	4
5. Pictures about it popped into my mind	0	1	2	3	4
6. I found myself acting or feeling as though I was back at that time	0	1	2	3	4
7. I had waves of strong feelings about it	0	1	2	3	4
8. I had dreams about it	0	1	2	3	4

Feelings about your cancer

Please answer the following questions with regard to your feelings about your cancer in general.

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. I get depressed when I think about my cancer					
2. When I think about my cancer I get upset					
3. My cancer makes me feel angry					
4. My cancer does not worry me					
5. Having cancer makes me feel anxious					
6. My cancer makes me feel afraid					

Living with your illness

Below is a list of statements that other people with your illness have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.**

PHYSICAL WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING

		Not at all	A little bit	Some-what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days

	FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home)........................	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun...................	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Communication with your partner

The following questions ask about your relationship with your partner. Each question should be answered on the scale shown below.

1	**2**	**3**	**4**	**5**
Disagree Strongly	**Disagree**	**Undecided**	**Agree**	**Agree Strongly**

1. I can express my true feelings to my partner. _____
2. When we are having a problem, my partner often refuses to talk about it. ____
3. My partner sometimes makes comments that put me down. _____
4. I wish my partner were more willing to share his/her feelings with me. ____
5. At times it is hard to ask my partner for what I want. _____
6. Sometimes I have trouble believing everything my partner tells me. ____
7. My partner is a very good listener. ______
8. My partner often doesn't understand how I feel. _______
9. I am very satisfied with how my partner and I talk with each other. _____
10. It is difficult for me to share negative feelings with my partner. _____
11. It is hard for me to express feelings about my illness to my partner. ______
12. I feel comfortable discussing issues related to my illness with my partner. ____
13. My partner is reluctant to talk about my illness. ______
14. My partner is willing to share his feelings about my illness with me. ______

Appendix W: Six month follow-up questionnaire for main study – partners

Code
Date

The effect of guided writing on stress and anxiety in ovarian cancer patients and their partners

Six month follow-up

Thank you for agreeing to participate in this study. We are very interested in finding out more about any stress and anxiety that both you and your partner may be experiencing as a result of her illness, and how it changes over time. This will help us to find ways to reduce it.

This booklet contains a number of questions about the stress and anxiety you may be experiencing, and the impact of your partner's illness on your physical health and psychological well-being.

There are no **right** or **wrong** answers to these questions. We are interested in your own personal views.

- **We ask you to answer the questions as honestly as possible.**

This questionnaire is completely CONFIDENTIAL.

It will only be seen by the researchers involved in this study.

Please return your completed questionnaire in the attached stamped addressed envelope. Please note that this questionnaire booklet consists of 7 pages.

Thank you very much for your time

Questions about the writing study

Answer the following questions on a scale from 1 to 7 with 1 being "not at all" and 7 "a great deal."

1. Since your participation in the writing experiment, how much have you thought about what you wrote? ______________

2. Since the writing experiment, how much have you talked to other people about what you wrote? ________________

General questions about the research

1. Would you recommend the writing to other people?
____

2. Do you think you were in the intervention or control group?
Intervention Control

Stress Questionnaire

The questions in this scale ask you about your feelings and thoughts **during the last month**. In each case, you will be asked to indicate by circling *how often* you have felt or thought a certain way.

0 = Never, 1 = Almost Never, 2 = Sometimes, 3 = Fairly Often, 4 = Very Often

1. In the last month, how often have you been upset because of something that happened unexpectedly?

   0 1 2 3 4

2. In the last month, how often have you felt that you were unable to control the important things in your life?

   0 1 2 3 4

3. In the last month, how often have you felt nervous and "stressed"?

   0 1 2 3 4

4. In the last month, how often have you felt confident about your ability to handle your personal problems?

   0 1 2 3 4

5. In the last month, how often have you felt that things were going your way?

   0 1 2 3 4

6. In the last month, how often have you found that you could not cope with all the things that you had to do?

   0 1 2 3 4

7. In the last month, how often have you been able to control irritations in your life?

   0 1 2 3 4

8. In the last month, how often have you felt that you were on top of things?

   0 1 2 3 4

9. In the last month, how often have you been angered because of things that were outside of your control?

   0 1 2 3 4

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

    0 1 2 3 4

Distress experienced

Below is a list of difficulties people sometimes have after stressful life events. **Please read each item, and then indicate how distressing each difficulty has been for you DURING THE PAST SEVEN DAYS with respect to your wife/ partner's cancer**, i.e., how much were you distressed or bothered by these difficulties?

	Not at all	**A little bit**	**Moderately**	**Quite a bit**	**Extremely**
1. Any reminder brought back feelings about it	0	1	2	3	4
2. I had trouble staying asleep	0	1	2	3	4
3. Other things kept making me think about it	0	1	2	3	4
4. I thought about it when I didn't mean to	0	1	2	3	4
5. Pictures about it popped into my mind	0	1	2	3	4
6. I found myself acting or feeling as though I was back at that time	0	1	2	3	4
7. I had waves of strong feelings about it	0	1	2	3	4
8. I had dreams about it	0	1	2	3	4

Feelings about your wife/ partner's cancer

Please answer the following questions with regard to your feelings about your wife/ partner's cancer in general.

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. I get depressed when I think about my partner's cancer					
2. When I think about my partner's cancer I get upset					
3. My partner's cancer makes me feel angry					
4. My partner's cancer does not worry me					
5. My partner having cancer makes me feel anxious					
6. My partner's cancer makes me feel afraid					

Below is a list of statements relating to your health and everyday life which other people have said are important. **By circling one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days.</u>**

	PHYSICAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

By circling one (1) number per line, please indicate how true each statement has been for you during the past 7 days.

	FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Communication with your partner

The following questions ask about your relationship with your partner. Each question should be answered on the scale shown below.

1	**2**	**3**	**4**	**5**
Disagree Strongly	**Disagree**	**Undecided**	**Agree**	**Agree Strongly**

1. I can express my true feelings to my partner. _____
2. When we are having a problem, my partner often refuses to talk about it. ____
3. My partner sometimes makes comments that put me down. _____
4. I wish my partner were more willing to share his/her feelings with me. ____
5. At times it is hard to ask my partner for what I want. _____
6. Sometimes I have trouble believing everything my partner tells me. ____
7. My partner is a very good listener. ______
8. My partner often doesn't understand how I feel. _______
9. I am very satisfied with how my partner and I talk with each other. _____
10. It is difficult for me to share negative feelings with my partner. _____
11. It is hard for me to express feelings about her illness to my partner. ______
12. I feel comfortable discussing issues related to her illness with my partner. ____
13. My partner is reluctant to talk about her illness. ______
14. My partner is willing to share her feelings about her illness with me. ______

Appendix X: Debriefing form for main study

The effect of written disclosure on well-being
Debriefing Statement

The aim of this research was to test the effects of you (and your partner where applicable) writing about your cancer diagnosis and treatment in an emotional way on distress, and quality of life (particularly social well-being). It is expected that writing about the diagnosis and treatment will lead to reduced distress, both in general and in relation to the illness, and improved quality of life and social interaction, particularly with your partner, compared to you (and your partner where applicable) writing about what you did the previous day. It is further expected that any improvement you make will be related to the improvement made by your partner/ husband. Your data will help our understanding of ways to reduce distress and improve well-being in ovarian cancer patients and their partners, as well as improving our understanding of the reasons behind the beneficial effects of guided written disclosure.

Once again results of this study will not include your name or any other identifying characteristics. I can let you know the results of the study once I have completed it if you are interested. I also expect to publish them in the Ovacome newsletter in summer 2008. If you were in the control group (writing about what you did the previous day) and would like to take part in the intervention in your own time, or have any further questions, please contact me, Emily Arden-Close at ejac103@soton.ac.uk or 02380595785. Thank you for your participation in this research.

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the Chair of the Ethics Committee, Department of Psychology, University of Southampton, Southampton, SO17 1BJ. Phone: (023) 8059 3995.

Appendix Y: Letter requesting permission to contact consultant for CA 125 levels

University of Southampton

Dear

Thank you very much for your participation in my study on ‘The effect of writing on distress and quality of life in women with ovarian cancer and their partners’– it was greatly appreciated.

We have now started analysing our data, and are finding very interesting results. In order to enable dissemination of our results to the wider research community, we now need to check your reported CA 125 levels against medical records in order to validate them. It would therefore be very helpful if you could provide us permission to confirm these levels with your consultant.

If you are willing to give this permission, then please complete the tear off slip below and return it in the attached stamped addressed envelope. Thank you very much for your cooperation and extra help.

Yours Sincerely,

Emily Arden-Close

I am willing to give permission for the researchers to contact my consultant to confirm my CA 125 levels for the study on ‘The effect of guided writing on well-being.’

Name: _________________________

Address: ______________________________

Name of Consultant: _______________________

Hospital: ________________________________

Appendix Z: Letter to consultant requesting CA 125 levels (patient consent was always enclosed with this letter)

University of Southampton

Dear Dr

Your patient (name) is participating in a research study I am carrying out at the School of Psychology, University of Southampton, in conjunction with Ovacome on 'The effect of writing on well-being.' This study received approval from the School of Psychology ethics committee.

We have found very novel, interesting results relating to predictors of CA 125 levels. Your patient provided us with details of her CA 125 levels for the dates (date) (CA 125 level) and (date) (CA 125 level) by self-report, and has given me permission to contact you to validate this data. I am therefore writing to request confirmation of these self-reports. I confirm that any data provided will only be used for the purposes of this study, and will remain strictly confidential.

If you are willing to provide this information, please could you fill in the tear-off slip below and return it to me in the attached stamped addressed envelope. Thank you.

Yours Sincerely,

Emily Arden-Close, PhD Candidate

Name:

CA 125 level Date 1: ________________

CA 125 level Date 2: ________________

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