**Written emotional disclosure for women with ovarian cancer and their partners: Randomized controlled trial**

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**Abstract**

Objective: Written emotional disclosure for 15-20 minutes a day over 3-4 days improves physical and psychological health, and may benefit cancer patients. However, no studies have tested the effectiveness of guided writing in cancer patients and their partners. A randomized controlled trial tested whether writing about the patient’s diagnosis and treatment of ovarian cancer using the Guided Disclosure Protocol (GDP) is effective in reducing perceived stress and improving quality of life (QoL) in ovarian cancer couples. The study also tested two theories that may account for beneficial effects of written emotional disclosure, the cognitive processing hypothesis and the social interaction hypothesis.

Methods: Patients and their partners (N=102 couples) were randomised to write at homefor 15 minutes a day over three days about the patient’s diagnosis and treatment using the GDP or what the patient did the previous day (control). Couples were assessed at baseline, three and six month follow-ups on the primary outcomes ofperceived stress and QoL, and secondary outcomes ofintrusive thoughts (testing the cognitive processing hypothesis), and illness-related couple communication (testing the social interaction hypothesis).

Results: There were no main effects for any outcomes. However, in patients, the GDP improved QoL if illness-related couple communication improved, and buffered the effect of intrusive thoughts on perceived stress.

Conclusions: The GDP might benefit patients in certain circumstances, through changes in communication (in line with the social interaction hypothesis). Further research is needed to determine whether patients benefit from interventions to improve illness-related couple communication, and under which conditions.

**Keywords**: written emotional disclosure, ovarian cancer, randomized controlled trial; partners

Ovarian cancer is the leading cause of death from gynaecological malignancies. Five-year survival in the UK is 41% [1]. It is often diagnosed at an advanced stage due to lack of or non-specific symptoms [2]. Consequently, despite aggressive treatment, most patients relapse within two years. Patients often experience elevated levels of distress [3] and poor quality of life (QoL) [4-5], suggesting that psychological interventions should be well received. However, in a systematic review of 18 interventions for patients with gynaecological cancers, only one reduced distress, and there were no effects on physical symptoms or functioning [6]. Furthermore, due to multiple methodological limitations including small sample sizes, low consent rates, floor effects and high loss to follow-up, generalizability of these studies to the clinic is questionable. Finally, such interventions are costly and time-consuming.

An inexpensive, adjunct alternative may be written emotional disclosure of traumatic events for as little as 15 minutes a day over three days, which has led to improved mental and physical health across 146 studies [7], and physical health in clinical populations [8]. Fourteen studies have tested written disclosure in cancer patients [9-22]. Although some small, possibly underpowered studies [9-11, 14, 16] demonstrated negative findings, improvements have been demonstrated in physical symptoms [12, 18, 22], psychological distress [18], and QoL [22] in breast cancer, particularly when participants are required to write about their cancer [12, 18, 22]. One large study with negative findings [20] demonstrated reductions in depressive symptoms in women who wrote about their cancer. Written disclosure has also improved couple-related outcomes in other populations [23-25]. By inducing self-reflection, couple-related writing may act as a springboard for discussing the illness, and thus reduce distress and improve QoL in both partners.

Several theories may explain the effectiveness of written disclosure. The cognitive processing hypothesis holds that written disclosure may enable coherent restructuring of traumatic memories into existing schemas [26-27], leading to resolution of the trauma and improved physical health [28]. Based on this theory, improved mood following writing should be mediated through reductions in intrusive thoughts, reflecting more cognitive control over traumatic information. Also, structured writing should facilitate cognitive restructuring of traumatic memories. Duncan and Gidron [29] therefore developed the Guided Disclosure Protocol (GDP). In addition to describing their thoughts and feelings at the time of the event (Day 2), participants describe the event chronologically, with causal links between the event’s segments (Day 1), reflect on how the event affected their life (Day 2) and write how they currently think and feel about the event, and reflect on future coping with a similar event (Day 3) (see [29-30]).The GDP has reduced visits to general practitioners in frequent attendees [30], and reduced PTSD symptoms in parents of children with cancer [31]. Also, similar structured writing has reduced disease activity in rheumatoid arthritis [32] and improved psychological wellbeing in fibromyalgia [33]. However, the GDPhas not been tested in cancer.

The social interaction hypothesis [34] holds that people may be able to interact with others more positively following written disclosure, due to reduced distress and greater self-control. Subsequent increased social sharing following written disclosure (see [35-36]) alerts others to the person’s psychological state, and may increase social support and problem-solving, leading to improved psychological well-being

This study tested the effectiveness of writing about the patient’s diagnosis and treatment for 15 minutes a day over 3 days, using the GDP, on reducing perceived stress and improving QoL in ovarian cancer couples, relative to writing about what the patient did the previous day. GDP participants were expected to demonstrate significantly greater improvements in QoL and reductions in perceived stress three months post intervention, maintained at six months. A secondary aim was to test whether improvements were mediated through reductions in intrusive thoughts, based on the cognitive processing hypothesis, or via improved illness-related couple communication, based on the social interaction hypothesis.

### Method

The GDP [25] for written emotional disclosure was compared to control writing in a randomized controlled trial (RCT). The study was approved by the relevant departmental ethics committee. It followed CONSORT guidelines for designing and reporting RCTs [37].

*Participants*

Participants were members of a UK charity for patients with ovarian cancer who had consented to be contacted by third parties, and their spouses/partners. Invitation letters were sent out to 530 patients with the title ‘Mrs’ (to maximize recruitment of couples), at four time points over 13 months. Interested individuals returned their details in a stamped addressed envelope, and were screened by telephone to determine eligibility and stratify accurately. Uninterested individuals were requested to fill in a slip indicating why from ‘I am not interested’, ‘I am too busy,’ ‘I am not feeling well’ or ‘Other’. Eligible participants had been diagnosed with ovarian cancer, were no more than five years post-treatment, able to read and write in English, and age 18 years or above. Spouses lived with a partner with ovarian cancer.

Of 336 respondents who returned a slip or contacted the researcher indicating receipt of the letter[[1]](#footnote-1), 203 (60%) expressed interest in the study, and 141 couples were eligible. The other 133 were not interested (felt too ill, too busy, or thought the study was not relevant, often due to length of time since their last treatment).Reasons for ineligibility included being single (n=28), and more than five years since their last treatment (n=34). Of these 141 couples, 102 completed baseline measures and were randomized.

*Procedure*

As participants lived all over the UK, assessments and experimental procedures were carried out by mail and telephone,and the writing completed at home. Eligible participants were sent the initial questionnaire (including all measures described below) and a consent form. Following consent, the writing booklet was sent out, and the writing scheduled for three days within the same week (ideally consecutive). Patients and their partners could choose to write at the same time or different times.

Each day, the participant was telephoned at a designated time, and asked to go to a quiet place, and write continuously for 15 minutes, after which the researcher telephoned again, to tell them to stop. After the last session, participants returned the writing by post, to be typed up and content analyzed. At three and six months, follow-up questionnaires were mailed out. Mail was returned to a researcher who had no contact with the participants. Recruitment took place over 13 months. Flow of participants through the trial and follow-up rates at each time point are reported in Figure 1.

*Design*

In an RCT, couples were randomly assigned to written emotional disclosure about the patient’s diagnosis and treatment (GDP; n=53) or writing about what the patient did the previous day, (control; n=49), for 15 minutes a day over three days. This controlled for experimenter contact (participants were telephoned before and after writing), and the partner thinking about the patient (partners wrote about the patient’s activities) [33]. Randomization was conducted before study commencement, in blocks of 10, using [www.randomization.com](http://www.randomization.com), matching for recurrence since initial diagnosis, to increase the probability of obtaining equivalent groups regarding prognosis. Opaque envelopes were numbered and the appropriate condition written inside each envelope according to the randomization table, which was then destroyed. The envelopes were locked in a cabinet and inaccessible to anyone involved in the project. Each participant was allocated a number based on the order in which they entered the trial, which corresponded with a numbered envelope. An independent administrator opened the cabinet and appropriate envelope, and informed the first author of group assignment, after which the appropriate task was posted out.

As a single researcher carried out this study, double blinding was not possible. To reduce risk of measurement bias, questionnaires were returned to a researcher who had no contact with the participants and was unaware of group allocation. Also, all outcomes were assessed by self-report questionnaires, which participants filled in at home. To reduce risk of performance variability, the writing instructions were stated clearly on the booklet, and the writing tasks timed. Participants were informed that writing had improved health across a variety of illnesses, and they would be asked to write about events in either an emotional or a non-emotional way, to ensure expectations did not differ by group.

*Written emotional disclosure*

The GDP protocol was as follows:

*Day 1*: Describe the diagnosis and treatment chronologically, and what led to what, without mentioning emotions.

*Day 2:* Part 1: Describe how you felt and what you thought at the time of the diagnosis; Part 2: What impact has your diagnosis and treatment had on your life, and has it caused you to change priorities?

*Day 3:* How do you currently feel and think about the diagnosis and treatment. Are your current thoughts and feelings the same as at diagnosis? Would you be able to cope with similar situations better because you have experienced it.

Spouses received similar instructions regarding their partner’s cancer and their own responses/reflections.

*Neutral writing*

Both members of the couple wrote about what the patient did the previous day.

*Measures*

*Demographic and medical information*

This included age, occupation, educational level, marital status and time married. For patients, medical information about disease stage, time since diagnosis, time since last treatment, treatment (surgery, chemotherapy and radiotherapy), number of courses of chemotherapy, whether currently undergoing treatment (question repeated at each follow-up), and CA 125 level (a tumour marker with high prognostic value in ovarian cancer) were self-reported. Thirty oneof the CA 125 results were later checked with the patients’ oncologists, with patient consent (correlation r=.99). CA 125 scores were then categorized as above or below 35 U/ml [38], and inter-rater reliability was Kappa=**.**995 (p <.0.001).

*Primary Outcomes*

*Quality of Life (QoL)*

The Functional Assessment of Cancer Therapy- General (FACT-G; [39]) assesses QoL in patients with cancer. Patients completed the physical (7 items), social/family (6 items), and functional wellbeing (7 items) subscales[[2]](#footnote-2). Cronbach’s Alpha ranged from .88 to .91, indicating good reliability. Partners completed the physical (6 items), social/family (5 items), and functional wellbeing (6 items) subscales of the FACT-GP [40], an equivalent scale for assessing QoL in the general population. Cronbach’s alpha ranged from .81 to .84. In both scales, higher scores indicate better QoL.

*Perceived Stress*

The Perceived Stress Scale (PSS; [41]) is a 10-item scale measuring the extent to which individuals perceivedthey were unable to cope with stress during the past month. Higher scores indicate higher levels of perceived stress. Cronbach’s alpha ranged from .90 to .91 for patients, and from .87 to .89 for partners, indicating excellent reliability.

*Secondary Outcomes*

*Intrusive thoughts*

The intrusions subscale (8 items, higher scores indicate higher levels of intrusive thoughts) of the Impact of Event Scale-Revised (IES-R; [42]) assesses intensity of intrusive thoughts ‘during the past seven days’. It was completed with regard to the patient’s cancer. Cronbach’s alpha ranged from .91 to .92 for patients, and from .90 to .92 for partners, indicating excellent reliability.

*Couple communication*

The Couples’ Illness Communication Scale (CICS) is a 4 item scale assessing illness-related couple communication [43]. Higher scores indicate better communication. Items cover the individual’s ability to discuss the illness with their partner and their impression of their partner’s willingness to discuss the illness with them. Cronbach’s alpha ranged from .80 to .85 for patients, and from .72 to .80 for partners, indicating good reliability.

*Word counts and Manipulation Checks*

Percentages of positive emotion, negative emotion, and insight (e.g., understood, realised) words were computed for each writing day, using the programme Linguistic Inquiry and Word Count (LIWC; [44]). Also, after each writing session, participants rated how personal and revealing of emotions they felt their essays were (Pennebaker, 1994, unpublished manuscript).

*Sample size calculation*

This was based on the results for the PSS (one of the primary outcomes) from an unpublished pilot study on written emotional disclosure and telephone-based stress management in 27 women with ovarian cancer. A calculation based on the difference between the means at first baseline and one month following written disclosure revealed an effect size of 0.70. With 80% power and p < .05 statistical significance, using two-tailed tests, 32 participants per group were required to obtain statistical significance. However, as it included two primary outcomes and a longer follow-up period, we aimed to recruit 50 participants per group.

*Statistical analysis*

To determine equivalence between groups on demographic and biomedical characteristics, independent samples T-tests were used for continuous data, and chi-square analysis for categorical data. To test the research questions, 2 x 3 mixed-design repeated measures analyses of covariances (ANCOVA) were performed, with group (GDP, control) as the between-subjects factor, and time (baseline, 3 and 6 months follow-up) as the within-subjects factor. The main test was a time x group interaction, followed by tests to determine the source of any observed interaction. Effect sizes (Cohen’s d) were calculated from η2.Analyses controlled for baseline demographic and illness differences between groups and were intention-to-treat, by carrying the last observation forward [45].

Results

Baseline demographic and disease-related characteristics of patients and partners by group are reported in Table 1. GDP participants were significantly younger than controls, and more time had passed since their diagnosis. Therefore, patient age and time since diagnosis were added as covariates. Also, having treatment at retest was included as a covariate, to partly rule out effects of disease progression and new treatments on outcomes.

*Manipulation checks*

GDP participants used more positive and negative emotion and insight words on days 2 and 3 than controls. They also rated their essays as more personal and revealing of emotions across all three days (all *p* values <.01).

*Primary Outcomes: Effects of Written Emotional Disclosure on Perceived Stress and Quality of Life (QoL)*

The general linear models showed that for perceived stress, there was no group by time interaction for patients (*F* (2, 168) = .30, p=.74; Cohen’s d = 0.11) or partners (*F* (2, 168) = 2.18, p=.12; Cohen’s d = 0.35). Similarly, for QoL, there was no group by time interaction for patients (*F* (2, 168) = 2.56, p=.08; Cohen’s d = 0.35) or partners (*F* (1.75, 145.45) = 1.30, p = .28; Cohen’s d = 0.29). The descriptive data are presented in Table 2.

*Secondary Outcomes: Cognitive processing hypothesis and social interaction hypothesis*

There was no group by time interaction for intrusive thoughts in patients (*F* (2, 168) = 0.46, p=.63; Cohen’s d = 0.14), but a significant interaction for partners (*F* (2, 168) = 3.76, p=.03; Cohen’s d = 0.4). Planned contrasts revealed the change occurred between baseline and three months (*F* (1, 83) = 6.87, p=.01) but not between three and six months (*F* (1, 78) = 0.007, p=.94). The effect was linear, indicating this was due to an increase in intrusive thoughts from baseline to three months in the GDP group only. There was no group by time interaction for illness-related couple communication in patients (*F* (1.72, 144.53) = .77, p=.45; Cohen’s d = 0.19) or partners (*F* (2, 168) = 2.44, p=.09; Cohen’s d = 0.35).

*Mediators and Moderators*

As there was no effect of the GDP on the primary outcomes, no tests for mediators were carried out. Nevertheless, the intervention was hypothesised to have benefited participants who improved on the secondary outcomes (intrusive thoughts and illness-related communication). To test this, change in intrusive thoughts and change in illness-related communication were hypothesised to be moderated mediators (moderator variables whose values influence the process by which treatment leads to the outcome: [46]) of the relation between group and the primary outcomes. These change scores were centred to reduce multicollinearity.Analyses covered only the period from baseline to three months, when most change was expected to take place, to reduce chance of type-I errors.

As both hypothesized moderated mediators were continuous variables, hierarchical multiple linear regressions were utilised. The primary outcome at three months (i.e., QoL) was entered as the DV. The primary outcome at baseline was entered as a predictor on the first step, followed by group, the z-score of the moderated mediator and the interaction term of group by the z-score of the moderated mediator on the second step.

Change in illness-related communication moderated the effect of group on QoL in patients. The interaction explained 2.3% of the variance in QoL at three month follow-up: (B = 1.17, SE = .52, β = .20; *F* (1, 85) = 5.16, p=.03). Plotting QoL against change in illness-related communication for each group following [47] (see Figure **2**) showed that for the control group, QoL was high regardless of change in illness-related communication, whereas for the GDP group, QoL was better if illness-related communication improved, and worse if it worsened. Change in intrusive thoughts moderated the effect of group on perceived stress in patients. This interaction explained 3% of the variance in perceived stress at three month follow-up (B = -.43, SE = .16, β = -2.66; *F* (1, 84) = 7.07, p=.009). Plotting perceived stress against change in intrusive thoughts for each group (see Figure **3**) showed that for the control group, an increase in intrusive thoughts was associated with more perceived stress at three months, whereas for the GDP group, change in intrusive thoughts did not influence perceived stress. No moderated mediators were identified for partners.

Discussion

This study aimed to determine the effect of the GDP on perceived stress and QoL in ovarian cancer couples. However, contrary to expectations, despite including partners, there was no effect of the GDP on the primary outcomes. Approximately half the participants experienced a recurrence during the study. Written disclosure may be ineffective for dealing with recurrent stressors, as it does not teach strategies for dealing with possible recurrences. Studies with positive effects of writing on outcomes [12, 18, 22] have been carried out in patients with breast cancer, which has a much better prognosis than ovarian cancer, and have used standard non-guided writing, which may account for the differences in outcome.

Similarly, the cognitive processing hypothesis was not supported. Intrusive thoughts even increased in partners in the GDP group. Many patients may have already come to terms with the event (few reported high levels of intrusive thoughts). Alternatively, reductions in intrusive thoughts after writing have not been demonstrated in patients with chronic illness [8], which may be considered a concurrent stressor. Although it can be methodologically difficult to capture changes in cognitive processing, this finding means the GDP cannot be recommended for partners of patients with cancer.

Similarly, the social interaction hypothesis was not supported. There was no effect of the GDP on communication. Distressed couples are less likely to agree to participate in such studies [48], and CICS scores at baseline were high, suggesting communication was close to ceiling level. The GDP may be more effective in improving communication in couples experiencing communication problems. Alternatively, for illness-related communication to improve, couples may require training in communication skills.

In patients, enhanced illness-related communication was associated with better QoL in the GDP group only. Writing about emotional aspects of the cancer may have led some couples to share feelings and thoughts not previously revealed, leading to improved illness-related communication and coping with the disease, and thus improved QoL. This relationship fits in with the moderated mediation model outlined by Preacher where a fourth variable affects the path between the independent variable and the moderator [49] (see Figure 4).Writing prior to discussing the illness may help break down social constraints, organize thoughts and enhance disclosure [13, 31]. Conversely, writing and not talking may resurface issues that are not addressed, leading to increased social constraint. To test this hypothesis**,** direct assessment of communication by asking participants about how much they discussed the illness with their partner after writing is required**.**

In patients, the GDP buffered the effect of increased intrusive thoughts. An increase in intrusive thoughts was not associated with increased perceived stress at three months, in the GDP group only. The GDP may have enhanced self-efficacy for dealing with distressing cancer-related thoughts, by enabling reflection on coping with the illness. Precise verbal labelling of unpleasant emotions and causally linking aspects of their memories in the GDP may enable individuals to process such contents in more controlled prefrontal regions, and regulate unpleasant intrusions possibly emanating from limbic-level processing [50]. Further research is needed to test whether the GDP is effective in preventing distress in individuals experiencing high levels of intrusive thoughts.

Several issues need to be addressed in future research. Fifteen minutes was often insufficient for participants to describe their diagnosis and treatment. On Day 1, participants should be invited to write until they feel they have completed all necessary details or be provided with e.g., 30 minutes. Also, the results were based on a cancer that affects only women. The effects of structured writing about cancer/other chronic illnesses where the man is the patient need to be determined.

This study had several limitations. First, for ethical reasons, no demographic information was collected about non-responders, preventing comparisons with responders. Second, the power analysis was based on an anticipated large effect size. Basing it on effects of written disclosure in cancer from previous studies (with smaller effects) might have been more appropriate. Third, medical data was self-reported. Although the high correlation between patient- and consultant-reported CA 125 levels suggested it was accurate, medical information would ideally have been validated against records. Fourth, the participants were members of a support charity, thus possibly more motivated to engage in the study than the general population with ovarian cancer due to use of more active coping strategies [51]. Finally, the PSS may not have captured cancer-related distress sufficiently. The full IES might have been a more appropriate measure of cancer-related distress. Avoidant coping as measured by the IES avoidance subscale could also have mediated the results.

Overall, the findings suggest guided written emotional disclosure is not effective for all ovarian cancer couples, and may even cause negative effects in partners. However, in patients, change in illness-related communication moderated improvements in QoL**,** suggesting that further research is required to determine whetherthe GDP benefits patients if the instructions promote communication.Testing whetherthe GDP reduces intrusive thoughts in individuals high in perceived stress is also recommended. If these protective effects can be replicated, it is importantto understand the mechanisms by which they may occur and whom the GDP may benefit.

References

1. Office for National Statistics, Statistical Bulletin:[Cancer survival in England: one-year and five-year survival for 21 common cancers, by sex and age,](http://www.statistics.gov.uk/pdfdir/can0410.pdf)April 2011. Retrieved 14th March 2012 from [www.statistics.gov.uk](http://www.statistics.gov.uk).

2. Pan SY, Ugnat A-M, Mao Y, Wen SW, & Johnson, KC. Association of cigarette smoking with ovarian cancer. Int J Cancer 2004*;* **111**: 124-130.

3. Norton TR, Manne SL, Rubin S, Carlson J, Hernandez E, Edelson MI et al. (2004). Prevalence and predictors of psychological distress among women with ovarian cancer. J Clin Oncol 2004; **22**: 919-926.

4. Hodgkinson K, Butow P, Fuchs A, Hunt GE, Stenlake A, Hobbs KM, et al. Long-term survival from gynecologic cancer: Psychosocial outcomes, supportive care needs and positive outcomes. Gynecol Oncol 2007; **104**: 381-389.

5. Molassiotis A, Chan CWH, Yam BMC, Chan SJ. Quality of life in Chinese women with gynaecological cancers. Support Care Cancer 2000; **8**: 414-422.

6. Hersch J, Juraskova I, Price M, Mullan B. Psychosocial interventions and quality of life in gynaecological cancer patients: a systematic review. Psycho-Oncol 2009*;* **18***:* 795-810.

7. Frattaroli J. Experimental disclosure and its moderators: a meta-analysis. Psychol Bull 2006;**132**: 823-865.

8. Frisina PG, Borod JC Lepore SJ. A meta-analysis of the effects of written emotional disclosure on the health outcomes of clinical populations. J Nerv Ment Dis 2004; **192**: 629-634.

9. Walker BL, Nail LM, Croyle RT. (1999). Does emotional expression make a difference in reactions to breast cancer? Oncol Nurs Forum 1999;**26**: 1025-1032.

10. Rosenberg HJ, Rosenberg SD, Ernstoff MS, Wolford GL, Amdur RJ, Elshamy RN et al. (2002). The impact of an expressive disclosure intervention on the health of prostate cancer patients. *Int J Psychiatry Med 2002;* ***32***: 37-53.

11. de Moor C, Sterner J, Hall M, Warneke C, Gilani Z, Amato R, et al. A pilot study of the effects of expressive writing on psychological and behavioral adjustment in patients enrolled in a Phase II trial of vaccine therapy for metastatic renal cancer. Health Psychol 2002;**21**: 615-619.

12. Stanton AL, Danoff-Burg S, Sworowski L, Collins CA, Branstetter AD, Rodriguez-Hanley A, et al. Randomized controlled trial of written emotional expression and benefit finding in breast cancer patients. J Clin Oncol 2002; **20**: 4160-4168.

13. Zakowski SG, Ramati A, Morton C, Johnson P, Flanigan R. Written emotional disclosure buffers the effects of social constraints on distress among cancer patients. Health Psychol 2004; **23**: 555-563.

14. Bruera E, Willey J, Cohen M, et al. Expressive writing in patients receiving palliative care: a feasibility study. J Palliat Med 2008; **11**: 15-19.

15. Cepeda MS, Chapman R, Miranda N, et al. Emotional disclosure through patient narrative may improve pain and well-being: results of a randomized controlled trial in patients with cancer pain. J Pain Sympt Manag 2008; **35**: 623-31.

16. de Moor J, Moye L, Low MD, et al. Expressive writing as a presurgical stress management intervention for breast cancer patients. J Soc Integrative Oncol 2008; **6:** 59-66.

17. Gellaitry G, Peters K, Bloomfield D, Horne R. Narrowing the gap: the effects of an expressive writing intervention on perceptions of actual and ideal emotional support in women who have completed treatment for early stage breast cancer. Psycho-Oncol 2010; **19**: 77-84.

18. Henry EA, Schlegel RJ, Talley AE, Molix LA, Bettencourt BA. The feasibility and effectiveness of expressive writing for rural and urban breast cancer survivors. Oncol Nurs Forum 2010; **37:** 749-57.

19. Low CA, Stanton AL, Bower JE, Gyllenhammer L. A randomized controlled trial of emotionally expressive writing for women with metastatic breast cancer. Health Psychol 2010; **29:** 460-66.

20. Jensen-Johansen MB, Christensen S, Valdimarsdottir H, et al. Effects of an expressive writing intervention on cancer-related distress in Danish breast cancer survivors – results from a nationwide randomized clinical trial. Psycho-Oncol 2012. DOI: 10.1002/pon.3193.

21. Mosher CE, DuHamel KN, Lam J, et al. Randomised trial of expressive writing for distressed metastatic breast cancer patients. Psychol Health 2012; **27:** 88-100.

22. Park EY, Yi M. Development and effectiveness of expressive writing program for women with breast cancer in Korea. J Korean Acad Nurs 2012; **42:** 269-79.

23. Snyder DK, Gordon KC, Baucom DH. Treating affair couples: Extending the written disclosure paradigm to relationship trauma. Clin Psychol: Sci Pr 2004*;* **11**: 155-159.

24. Slatcher RB, Pennebaker JW (2006). How do I love thee? Let me count the words: The social effects of expressive writing. Psychol Sci 2006; **17**: 260-264.

25. Lepore SJ, Greenberg MA. Mending broken hearts: Effects of expressive writing on mood, cognitive processing, social adjustment and health following a relationship breakup. Psychol Health 2002; **17**: 547-560.

26. Pennebaker JW. Writing about emotional experiences as a therapeutic process. *Psychol Sci 1997;* **8**: 162-166.

27. Smyth J, True N, Souto J. Effects of writing about traumatic experiences: The necessity for narrative structuring. *J Soc Clin Psychol 2001;* **20**: 161-172.

28. Lutgendorf SK, Antoni MH (1999). Emotional and cognitive processing in a trauma disclosure paradigm. *Cognitive Ther Res 1999;* **23**: 423-440.

29. Duncan E Gidron Y. Written emotional expression and health: Evidence for a new Guided Disclosure technique. *Proc Brit Psychol Society 1999;* **7**: 29.

30. Gidron Y, Duncan E, Lazar A, Biderman A, Tandeter H, Shvartzman P. Effects of written disclosure of stressful experiences on clinic visits and symptoms in frequent clinic attenders. *Fam Pract 2002;* **19**: 161-166.

31. Duncan E, Gidron Y, Rabin E, Gouchberg L, Moser AM, Kapelushnik J. The effects of guided written disclosure on psychological symptoms among parents of children with cancer. *J Fam Nurs 2007;* **13**: 370-384.

32. Broderick JE, Stone AA, Smyth JM, Kaell AT. The feasibility and effectiveness of an expressive writing intervention for rheumatoid arthritis via home-based videotaped instructions. Annals Behav Med 2004: **27**: 50-59.

33. Broderick JE, Junghaenel DU, Schwartz JE. Written emotional expression produces health benefits in fibromyalgia patients. Psychosom Med 2005; **67:** 326-34.

34. Pennebaker JW, Graybeal A. Patterns of natural language use: Disclosure, personality and social integration. *Curr Dir Psychol Sci 2001;* **10**: 90-93.

35. Kovac SH, Range LM. Writing projects: lessening undergraduates' unique suicidal bereavement. *Suicide and Life-Threatening Behavior 2000;* **30**: 50-60.

36. Schoutrop MJA, Lange A, Hanewald G, Davidovich U, Salomon H. Structured writing and processing major stressful events: A controlled trial. *Psychother Psychosom 2002;* **71**: 151-157.

37. Moher D, Schulz KF, Altman DG. The CONSORT statement: revised recommendations for improving the quality of reports of parallel-group randomised trials. Lancet 2001; **357***:* 1191-1194.

38. Bast RC, Klug TL, St John E, Jenison E, Niloff JM, Lazarus H, et al. A radioimmunoassay using a monoclonal-antibody to monitor the course of epithelial ovarian cancer. New Eng J Med 1983; **309**: 883-887.

39. Basen-Engquist K, Bodurka-Bevers D, Fitzgerald MA, Webster K, Cella D, Hu S, et al. Reliability and validity of the Functional Assessment of Cancer Therapy - Ovarian. *J Clin Oncol;* **19**: 1809-1817.

40. Cella D, Zagari MJ, Vandoros C, Gagnon DD, Hurtz HJ, Nortier JWR. Epoetin alfa treatment results in clinically significant improvements in quality of life in anemic cancer patients when referenced to the general population. *J Clin Oncol 2003;* **21:** 366-373.

41. Cohen S, Williamson G. Perceived stress in a probability sample of the United States. In *The social psychology of health: Claremont Symposium on applied social psychology,* S. Spacapan S, Oskamp S (eds.). Sage Publications: Newbury Park, CA, 1988; 31-67.

42. Weiss D, Marmar C. The Impact of Event Scale - Revised. In *Assessing Psychological Trauma and PTSD*, Wilson J, Keane T (eds.). Guildford, New York, 1997

43. Arden-Close E, Moss-Morris R, Dennison L, Bayne L, Gidron Y. The Couples’ Illness Communication Scale (CICS): Development and validation of a measure assessing illness-related couple communication. *Brit J Health Psych 2010;* **15***: 543- 559.*

44. Pennebaker JW, Booth RJ, Francis ME. Linguistic Inquiry and Word Count: LIWC 2007 (Version 2007). LIWC, Austin, TX, 1997. [Computer software].

45. Hollis S, Campbell F. What is meant by intention to treat analysis? Survey of published randomised controlled trials. *Brit Med J 1999;* **319**: 670-674.

46. Muller D, Judd CM, Yzerbyt VY. (2005). When moderation is mediated and mediation is moderated. *J Pers Soc Psychol 2005;* **89**: 852-863.

47. Aiken LS, West SG. *Multiple regression: Testing and interpreting interactions*. Sage Publications, California, 1991.

48. Manne S, Ostroff J, Winkel G, Fox K, Grana G, Miller E. Couple-focused group intervention for women with early stage breast cancer. *J Consult Clin Psych 2005;* **73**: 646.

49. Preacher KJ, Rucker DD, Hayes AF. Assessing moderated mediation hypotheses: Theory, methods and prescriptions. Multivar Behav Res 2007; **42:** 185-227.

50. Hariri AR, Bookheimer SY, Mazziotta C. Modulating emotional responses: Effects of a neocortical network on the limbic system. Neuroreport 2000; **11**: 43-48.

51. Grande GE, Myers LB, Sutton SR. How do patients who participate in cancer support groups differ from those who do not? *Psycho-Oncol 2006;* **15**: 321-334.

Table 1: Baseline demographic and illness characteristics of patients and partners

|  |  |  |  |
| --- | --- | --- | --- |
|  | **GDP****(n=53)** | **Control (n=49)** | **Statistical comparison** |
| Patients’ Age (Mean, SD) | 53.02 (10.30) | 57.39 (8.09) | t = 2.32 (p=.02)\* |
| Disease stage: |  |  |  |
| I | 12 (22.6%) | 11 (22.4%) | χ2 = 3.89 (p=.27) |
| II | 4 (7.55%) | 10 (20.4%) |  |
| III | 30 (56.6%) | 24 (49.0%) |  |
| IV | 7 (13.2%) | 4 (8.16%) |  |
| Months since diagnosis (Mean, SD) | 43.29 (34.05) | 31.54 (21.22) | t = -2.09 (p=.04)\* |
| Months since treatment (Mean, SD) | 16.40 (19.44) | 13.65 (15.34) | t = -.78 (p=.44) |
| Having treatment | 7 (13.2%) | 6 (12.2%) | χ2 = .02 (p=1) |
| Had recurrence | 30 (56.6%) | 24 (49.0%) | χ2 = .59 (p=.55) |
| Number of chemotherapy courses (Mean, SD) | 1.85 (1.35) | 1.53 (0.96) | t = -1.36 (p=.18) |
| Had surgery | 51 (96.2%) | 43 (87.8%) | χ2 = 2.52 (p=.15) |
| Had radiotherapy | 6 (11.3%) | 5 (10.2%) | χ2 = .03 (p=1) |
| Years married/ living with partner (Mean, SD) | 25.67 (13.66) | 28.62 (10.98) | t = 1.11 (p=.27) |
| Education: |  |  | χ2 = 1.92 (p=.38) |
| GCSEs | 16 (30.2%) | 21 (42.9%) |  |
| A-levels/ equivalent | 18 (34.0%) | 15 (30.6%) |  |
| Degree | 19 (35.8%) | 13 (26.5%) |  |
| Employed | 23 (43.4%) | 14 (28.6%) | χ2 =2.42 (p=.15) |
| Partners’ age (Mean, SD) | 55.34 (10.92) | 60.43 (9.22) | t = 2.33 (p=.02) |
| Partners’ education: |  |  | χ2 = .15 (p=.93) |
| GCSEs | 14 (26.4%) | 11 (22.4%) |  |
| A-levels/ equivalent | 18 (34.0%) | 16 (32.7%) |  |
| Degree | 21 (39.6%) | 22 (44.9%) |  |
| Partner employed | 24 (45.2%) | 35 (71.4%) | χ2 = 3.04 (p=.11) |
| CA 125 level (Mean, SD) | 60.43 (165.64) | 65.64 (105.25) | t = .21 (p=.83) |

\*p<.05

Table 2: Scores for the primary and secondary outcomes by group: patients and partners (means presented with standard deviations in brackets)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Outcome** |  | **Group** | **Baseline** | **3 month follow-up** | **6 month follow-up** |
| Quality of Life | Patients | GDP | 58.87 (12.53) | 56.00 (15.30) | 56.30 (14.96) |
|  |  | Control | 60.13 (11.06) | 60.26 (11.77) | 60.26 (12.58) |
|  | Partners | GDP | 45.75 (7.40) | 46.86 (7.61) | 45.50 (7.63) |
|  |  | Control | 50.94 (8.99) | 49.57 (8.53) | 49.11 (8.90) |
| Perceived Stress | Patients | GDP | 18.10 (7.70) | 18.95 (7.68) | 18.85 (7.74) |
|  |  | Control | 14.17 (7.67) | 15.09 (6.92) | 16.23 (7.82) |
|  | Partners | GDP | 15.13 (6.69) | 17.13 (6.52) | 16.45 (6.19) |
|  |  | Control | 12.29 (6.92) | 12.40 (6.36) | 13.29 (7.68) |
| 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) |
| 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) |

**Invitation sent out (530)**

**Replied to invitation (336)**

**Assessed for eligibility (203)**

**Excluded (n= 62)**

* Not meeting inclusion criteria (62)
* Patient refused to participate (0)

## Enrolment

**Returned initial questionnaire (102)**

* Couple not interested (12)
* Partner ill/ not interested (21)
* Woman died: (2)
* Woman too ill (4)

Randomized

**Control** **(n= 49)**

Couple received intervention (n= 44)

Patient did not complete intervention (n=2)

* Not interested (1)
* Died (1)

Partner did not receive intervention (n=3)

* Not interested (3)

**GDP (n= 53)**

Couple received intervention (n=44)

Patient did not complete intervention (n=2)

* Too ill (1)
* Not interested (1)

Partner did not receive intervention (n=7)

* Not interested (7)

## Allocation

**Questionnaires returned (n=39)**

**Lost to follow-up (n= 5)**

* Patient died (3)
* Partner failed to return questionnaire (1)
* Couple dropped out (1)

**Questionnaires returned (n=41)**

**Lost to follow-up (n= 3)**

* Patient died (2)
* Partner dropped out (1)

## 3 month follow-up questionnaire

## (3 month)

**Questionnaires returned (n=39)**

**Lost to follow-up (n= 2)**

* Patient too ill (1)
* Questionnaire not returned (1)

**Questionnaires returned (n=37)**

**Lost to follow-up (n=2)**

* Patient died (1)
* Questionnaire not returned (1)

## 6 month follow-up questionnaire

## (6 month)

Analyzed (intention-to-treat) (n=49)

Analyzed (intention-to-treat) (n=53)

## Analysis

Figure : Flow of participants through the trial

Figure **2**: Change in illness-related communication as a moderator of the effects of group on quality of life – patients

Figure **3**: Change in intrusive thoughts as a moderator of the effects of group on perceived stress – patients

1. The Ovacome database is not based on hospital records, but updated by members and their families. Many of those who did not respond to the initial letter may have been in hospital, died, moved away or been ineligible to participate. [↑](#footnote-ref-1)
2. The emotional well-being subscale had low reliability in a pilot study, hence was not utilized. [↑](#footnote-ref-2)