Using narratives to understand the psychosocial impact and meaning making of those diagnosed with a secondary cancer diagnosis

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Thesis submitted in partial fulfilment of the requirements of Staffordshire and Keele Universities for the jointly awarded degree of Doctorate in Clinical Psychology

November~~July~~ 2014

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I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.

I confirm that the decision to submit this thesis is my own.

I confirm that except where explicitly stated, the work has not been submitted for another academic award.

I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.

Signed:

Date:

Acknowledgements

A special thanks to Alison Tweed and Marilyn Owens for the help and support with this project beyond the call of duty. I would like to thank the amazing participants who took part in this study.

I would like to thank Emma and Erik, Clare, ~~and~~ Amy and Zoe ~~Amy~~ for your continued support and motivation and of course thanks to Mum, Dad, Phil, Sarah and Freya.

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Note to reader

This thesis comprises three papers: a literature review, a research paper and a reflective paper. The proposed journals for publication of these papers are: Psycho-Oncology (paper 1), Qualitative Health R~~r~~esearch~~Methods in Health~~ (Paper 2) and the Clinical Psychology Forum (Paper 3). All three journals are peer reviewed and known to publish papers on subjects relating to this thesis.

Paper 1 has a word limit of 6000 words, with an abstract of 250 words. Paper 2 has no specified word limit or conventions regarding abstract length. Paper 3 has a word limit of 2500 with a 40 word summary. The proposed journals provide slightly different style guidance, but are largely based on American Psychological Association guidance (APA 6th Edition). Therefore the thesis is presented adhering to that guidance and the required alterations will be made prior to submission for publication.

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Consistent with academic requirements, the papers are typed in Arial 12 font, with double line spacing. All identifiable information is omitted or altered to protect the anonymity of the participants. The overall word count for the thesis is 19914 excluding the contents page, references and appendices.

Thesis Abstract

As the number of cancer survivors and the duration of survival increases in the UK, there is an increasing interest in psychosocial care, to improve outcomes for cancer patients.

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The aim of the literature review was to investigate the evidence for the impact of psychosocial interventions on the mental health and well-being of cancer patients in the UK since the C~~c~~ancer R~~r~~eform S~~s~~trategy was published in 2007. The review focused on thirteen studies. Support was found for the use of Cognitive Behavioural Therapy (CBT) techniques, psycho-education and bibliotherapy. There is also some support for lower level interventions such as self-help, ~~-~~self administered interventions and complementary therapies.

Insufficient research exists regarding the impact and the lived experience of secondary cancer (i.e. cancer that has spread to another site). The aims of the research study were to examine psychosocial impact and meaning-making of five participants who experienced a secondary cancer diagnosis. The findings highlight some of the nuances of unique cancer journeys. Very few of the participants' overall narratives were concerned with the impact of the diagnosis. Concerns were more focussed on everyday life issues, for example, maintaining important aspects of life before the diagnosis such as 'date-night' (nights out with partners), family, holidays, money, and appointments to attend. Common elements of the group narrative included: the high costs of treatment, negotiating treating teams, striving for normality, continuous biographical disruption, comparison with others, and feedback from others. Recommendations include~~d~~ examining ways to streamline appointments between teams, to increase participants' time to live and maintain normal lives and roles.

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Paper One: Literature Review

What is the evidence for psychosocial interventions developed for adults in the UK with cancer following the publication of the 2007 cancer reform strategy?

Abstract

As the number of cancer survivors and the duration of survival increases in the UK, there is an increasing interest in psychosocial care, to improve outcomes for cancer patients. Previous literature reviews have focussed on research from around the world. The aim of this review was to look at the evidence for the impact of psychosocial interventions on the mental health and well-being of cancer patients, since the publication of the ~~c~~Cancer R~~r~~eform ~~s~~Strategy in the UK in 2007. The review focused on thirteen studies of interventions, which addressed mental health and well-being in cancer patients. There was no agreement on the best method of intervention, but the studies reported give some support to the use of Cognitive Behavioural Therapy (CBT) techniques, psycho-education and bibliotherapy. There is also ~~also~~ some support for lower level interventions (e.g. self-help interventions~~,~~), exercise, ~~less labour intensive interventions,~~ and complementary therapies~~interventions~~. The quality of the reviewed studies was limited and more research in this area needs to be generated to establish an evidence base within the UK. Limitations are identified with the variety of measures used to assess mental health, well-being

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and quality of life in these studies, and the use of more standardised measures is recommended to allow easier comparisons between studies for future research. ~~(203)~~

Introduction

Survival rates in cancer have significantly improved over the last 30 years and those improvements are set to continue. Macmillan (2007) estimated that there were two million cancer survivors living in the UK with a cancer diagnosis, which was set to increase by three percent year on year. Improvements in survival are a result of improved or newer treatments, earlier diagnosis and screening, and public health campaigns. Macmillan (2007) defines a cancer survivor~~s~~ as:

> “Someone who has competed initial cancer treatment and has no evidence of active disease, is living with progressive disease and maybe receiving active treatment, but is not in the terminal phase of the illness, or has had cancer in the past.” (p.6)

Feuerstein (2007) offers a more inclusive description of cancer survivors as:

> “Adults with a cancer diagnosis, following primary treatment, through until the end of life”~~.(~~. (p.7)

Historically, measures of successful interventions with people with cancer were assessed by length of time of survival from diagnosis. However, there has been a move over more recent years to evaluate oncological interventions based on quality of life as well as the quantity of life (Jacobsen, Davis & ~~and~~ Cella, 2002). The improvement in survival rates have led to many people to consider cancer as a chronic illness (Tritter ~~an~~& C~~d C~~alnan, 2002). In an attempt to address the

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non-medical implications of cancer, emphasis has been placed on helping people to come to terms with the psychosocial impact of the disease as well as managing the disease itself.

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The UK Context

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National Institute of Clinical Excellence (NICE, 2004) guidance on cancer and palliative care recommends that cancer services need to improve assessments to include physical, social, psychological and spiritual needs. This document also suggests that cancer patients should have better access to high quality information, and better signposting to voluntary and statutory support services. The C~~c~~ancer R~~r~~eform S~~s~~trategy (Department of Health, 2007) issued guidance on the provision of supportive and palliative care, which focuses on, amongst other issues, the provision of psychological support. This stepped care model advocates increasing levels of psychological care based on needs. The lowest level advocates general levels of psychological support up to specialist psychological or psychiatric interventions at level four.

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The C~~c~~ancer R~~r~~eform S~~s~~trategy (DoH, 2007) is also committed to the development of the National Cancer Survivorship Initiative (NCSI), set up in the UK to specifically look at survivorship. The NCSI set out to understand the needs of those living with cancer and to develop models of care that meet their needs. Their goal is to support cancer survivors to live a healthy and active life, for as long as possible. The NCSI identified gaps in data and evidence from the UK relating to health outcomes for individuals following cancer treatment (Richards, Corner &~~and~~ Maher, 2011). The NCSI developed research priorities, which include developing interventions to address the consequences of cancer

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and its treatment: including the management of symptoms, long term and late effects and sexual issues. Another priority identified was the development and testing of psychological interventions.

The National Cancer Research Institute identify a number of areas as opportunities for research with a high probability of generating impact in the short and long term. These include emotional distress, depression, anxiety and social needs. In improving outcome strategies for cancer (DoH, ~~epartment of Health, ~~2011) there is a recognition that not enough attention has been given to the long term consequences of cancer diagnosis for the ever increasing number of individuals surviving the disease or how to enable individuals to return to active lives following the completion of initial cancer treatment. Interest in cancer survivorship programmes has gathered pace in the UK since the publishing of the C~~c~~ancer R~~r~~eform S~~s~~trategy (DoH, 2007). These programmes assume that some people require further psycho-social input following cancer treatment subsequent to their diagnosis and treatment, to support them to return to their life following or with cancer.

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Wider context of the literature: psychosocial interventions

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~~There has been some discussion around what constitutes a psychosocial intervention. ~~In the literature the term ‘psycho-social’ and ‘psychological’ have been used interchangeably when defining non-medical interventions in cancer care. Hodges et al. (2011) were unable to find any clear definitions on what constitutes a psychosocial intervention. They propose that studies should focus on specified domains of interventions to constitute content, proposed mechanism, target outcomes and method of delivery rather than grouping all interventions together as psychosocial where there is a non-medical component. In response to this, they published the ‘COMPASS checklist’ to encourage reviewers and researchers to consider how to clearly define the interventions and mode of action.

There are a wide range of studies looking at individual psychosocial interventions for people who have experienced a diagnosis of cancer worldwide. The main body of *original* research papers and studies have been focussed outside of the UK, predominantly in North America, mainland Europe and Australia. Interestingly the UK has been responsible for producing 19.7% of the worldwide-published *reviews* of psychosocial cancer care, suggesting a focus and reliance on findings from studies from overseas rather than the publishing of original research. This might suggest that the UK looks at developing models of care based largely on work done overseas. The papers mentioned previously suggest that there should be more of a focus to develop UK research for models of care that meet the needs of the UK population.

Specific psychosocial intervention studies have been published describing a wide variety of interventions internationally since the C~~c~~ancer R~~r~~eform S~~s~~trategy was published, with reported positive effects. The literature demonstrates a wide variety of psychosocial interventions and suggests that there is little agreement on what may constitute an ‘ideal’ form of support for people living with and beyond a cancer diagnosis.

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Previous meta-analyses and systematic reviews

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Several meta-analyses and systematic reviews have been carried out investigating psychosocial interventions developed for cancer survivors worldwide. The current paper will focus on reviews~~,~~ which describe generic outcomes in terms of mental health, well-being and quality of life rather than focussing on specific reviews of individual interventions or cancer sites. No previous reviews have concentrated on UK only studies. Rather than to describe in detail all of the published reviews here, the focus will be on two meta-reviews which encompass many of the previous reviews.

Jacobsen and Jim (2008) carried out a meta-review looking specifically at psychosocial interventions, which addressed outcomes in terms of symptoms of anxiety and depression. They meta-analysed 14 reviews and based on their findings, proposed the use of the following psycho-social interventions that had a basis in the evidence: Psycho-education for new cancer patients;~~,~~ problem solving therapy for distressed cancer patients;~~,~~ stress management training for chemotherapy patients;~~,~~ cognitive behaviour therapy for depression in patients with metastatic cancer; and group cognitive behaviour therapy for cancer survivors.

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Raingruber (2011) analysed 19 randomised controlled trials (RCTs), which focussed on therapeutic communication and supportive interventions. Of the 19 studies reviewed, 11 demonstrated positive findings, and a further four more studies demonstrated positive findings after post-hoc analysis. Studies were grouped into four main categories: Cognitive behavioural interventions~~,~~; supportive interventions~~,~~; group interventions; and telephone-assisted

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interventions. Consistent outcomes, which were reported by ~~affected by~~ more than one study, included decreased depression, decreased anxiety, ~~improved~~and improved quality of life and enhanced functional status / well-being.

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Many other meta-analyses and systematic reviews have been carried out particularly over the last decade (e.g. Edwards, Hulbert-Williams & Neal (2008), Newell, Sanson-Fisher &~~and~~ Savolainen (2002), ~~Rehse and Pukrop (2003),~~ Osborn, Demoncada &~~and~~ Feuerstein (2006), Rehse & Pukrop (2003), Williams &~~and~~ Dale (2006)~~, Edwards, Hulbert-Williams and Neal (2008)).~~)

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There seem~~s~~ to be some contrasting conclusions made by different reviews, which focus on slightly different combinations of original papers. The Cochrane review (Galway et al., 2012), a highly respected source of evidence in the UK, reports no improvements in mental health or quality of life from psychosocial interventions. This contrasts with other reviews. There may be a difference in the level of evidence that is acceptable for inclusion in the Cochrane review, as these only publish gold-standard level research. All other reviews reported here provide some evidence for psychosocial interventions and their positive impact on mental health, quality of life and emotional well-being. There appear to be some ~~re-occurring~~recurring themes in the reviews, particularly for the evidence for cognitive behavioural therapy, ~~or~~ behavioural therapy, problem solving interventions and psycho-education.

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Aims of the literature review

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This review of the literature was carried out to examine whether UK research published since the C~~c~~ancer R~~r~~eform S~~s~~trategy (2007) has expanded the evidence base. Several documents published around this time suggested the need for original UK research in the area of survivorship, and generally in cancer care to meet the psychosocial needs of people experiencing a diagnosis of cancer. The focus of this review ~~will be~~is on papers published within Great Britain in response to the publications mentioned. The decision to limit the review to UK papers was made considering the unique combination of healthcare and benefits system, and contextual factors in the cultural make-up and attitude towards the health service. There are some similarities with other healthcare systems in other countries but the UK healthcare systems are driven by specific policies and papers which drive the development of specific systems which are unique to the UK although influenced by developments around the world. The context of cancer in the UK is therefore assumed to be different to other parts of the world.

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The research question:

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What is the evidence for psychosocial interventions developed for adults in the UK following the publication of the cancer reform strategy? This is ~~P~~primarily an investigation of the evidence for the impact of interventions on mental health and emotional well-being (to include anxiety, depression, distress and quality of life).

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Search Strategy

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A review of the literature, which explored psychosocial interventions in cancer care, was carried out using the following databases:

- EBSCO~~bsco~~ All Health
- ~~Ebsco~~ EBSCO Psychology and Sociology
- ISI web of knowledge
- Cochrane L~~l~~ibrary
- Google ~~s~~Scholar

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The searches were based on the following exploded search terms: ‘Cancer’ AND ‘Psycho-social’ OR ‘Psychological’ AND ‘interventions’.

In order to cover a range of literature relevant to this review, studies conducted using any methodology were included. A web search was completed to check for papers not included during the search of the electronic databases. Highlighted papers were cross-referenced by hand to check for relevant papers, which had not been previously identified.

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Inclusion criteria

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- Papers printed in English language
- Any psycho-social intervention
- Any stage following diagnosis
- Any methodology
- Any studies which comment on outcomes in terms of anxiety, distress, depression, quality of life or well-being
- Studies carried out in the UK
- Studies published between 2007 and September 2012

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Exclusion Criteria

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- Studies published before 2007
- Interventions involving under 18’s
- Medical interventions
- Studies involving family/ caregiver/ partner interventions
- Studies reporting outcomes in terms of duration of survival

Search Findings

The exploded search terms Cancer AND Psychological OR Psychosocial AND Intervention AND Adult were entered into the databases and a search conducted for title and keywords. S~~and s~~tudies were limited to those published from 2007-2013~~2~~. This initial search yielded 203 individual studies. Abstracts were read on these papers and studies were excluded for those that involved family or caregiver interventions (12), no interventions (75), systematic reviews (17), children (3), health behaviour outcomes (4), not cancer specific (6) and impact on physical symptoms (2). This yielded 84 studies for further investigations. Removing the remaining international studies (77), left 7 studies. These papers were read and a further six studies were discovered by hand searching the references. This left a final total of 13 papers for detailed review (see figure 1~~diagram 2~~.)

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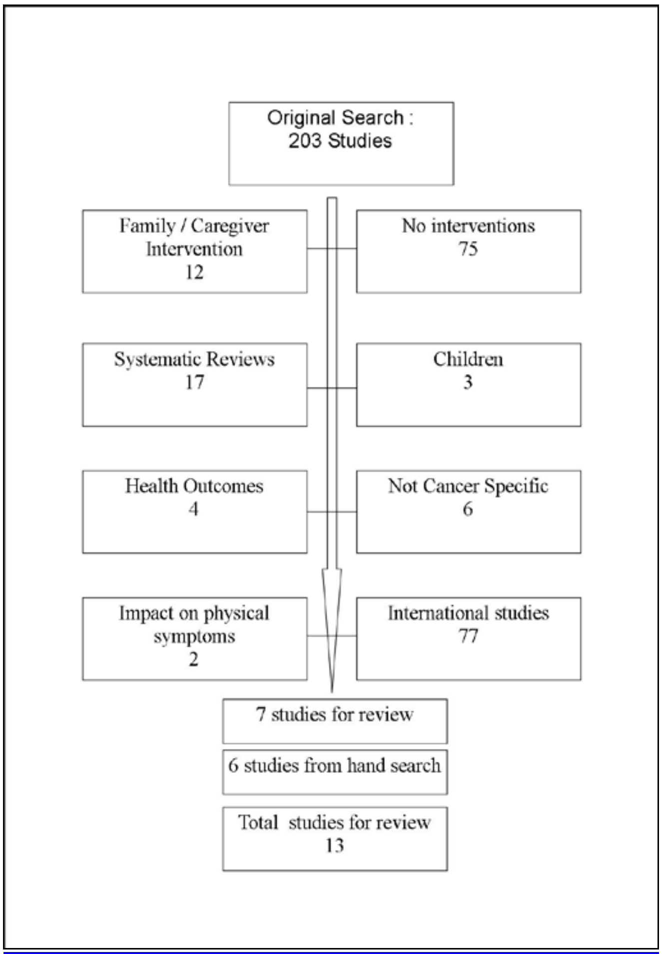

Figure 1: Flow chart of literature search

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The studies for review were summarised using the 'COMPASS' checklist (Hodges et al., 2011) based on recommendations for describing psychosocial interventions. This tool was developed in response to their findings that the description of psychosocial and or psychological interventions was an umbrella term, which was used interchangeably to incorporate any non-medical intervention in cancer care. This tool encourages reviewers to focus on specified domains of interventions to separate and describe intervention studies in the domains of content, mechanism, outcomes and method of delivery (See A~~a~~ppendix A1).

The methodological quality of the studies was reviewed using the Critical Appraisal Skills P~~p~~rogramme tool (CASP, 2010). Appropriate questions were drawn from the tools based on individual study design, specifically: randomised control trials (CASP 2010a), cohort studies (CASP, 2010b), case control studies (CASP, 2010d) and qualitative studies (CASP, 2010e) checklists.

Papers for review

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These articles were read and analysed for content. The studies are briefly described below, with supplementary~~ed~~ details found in ~~Appendix A~~Appendix A1~~.~~ (using the COMPASS checklist, Hodges et al.~~,2011~~, 2011), and additionally described in Appendix A2~~table 1~~. Categories were developed that described the aims, content and findings of the articles. The aims of the review were to examine the impact of psychosocial interventions on the mental health and well-being of adults with a diagnosis of cancer. 13 ~~Thirteen~~ articles were identified because they address outcomes in terms of mental health and well-being of the person with cancer based on specific psychosocial interventions.

Results

Overview of studies

Bourke et al. (2012) Developed and tested a lifestyle intervention aimed at patients treated for prostate cancer with androgen suppression therapy. The intervention included a bi-weekly programme of exercise and nutritional advice. The intervention lasted twelve weeks.   Three to six months following the intervention, twelve participants took part in three separate focus groups. Analysis was undertaken of the focus group data using framework analysis. The study reported that the intervention was considered beneficial by the study participants in reducing anxiety around treatment and also disease progression.

Cox et al. (2008) evaluated the use of telephone follow-up to screen for psychological problems following primary treatment for ovarian cancer. The aims were to assess which areas of psychosocial well-being women with ovarian cancer discuss, participant satisfaction with follow-up and the benefits of telephone follow-up from a patient perspective. Fifty-two women were followed up every three months for a total of ten months. Data was also collected from the phone contacts of issues~~,~~ which the participants chose to discuss with the Clinical Nurse Specialist in the telephone follow-up. The findings indicate a significant improvement in emotional well-being. No other significant differences were found in terms of quality of life characteristics. The~~y~~ authors

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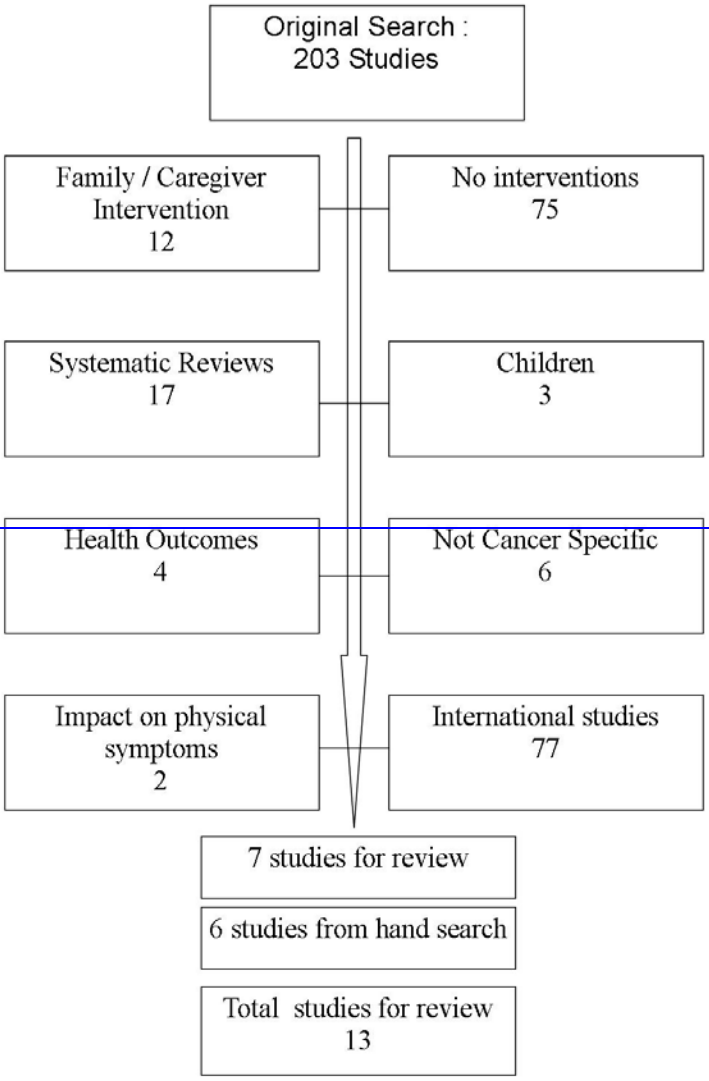

~~*Figure 1: Flow chart of literature search*~~

conclude that ~~the outcomes suggest that~~ this type of follow-up offers an acceptable opportunity for psychosocial support for women with ovarian cancer.

Daley et al. (2007) carried out a 3-arm RCT to compare exercise therapy, exercise placebo, and treatment as usual (TAU). Exercise placebo was described as toning and stretching exercises, exercise therapy was aerobic exercise of moderate intensity. Each of the two intervention groups received individual sessions three times per week. Measures of quality of life and mental health functioning were taken at baseline, 8 weeks and 24 weeks. ~~Their findings suggest that the p~~Participants in the exercise group scored significantly better on quality of life scores over TAU. Additionally both the exercise therapy and exercise placebo group showed a significant improvement in scores of depression at 8 and twenty-four weeks.

Galfin, Watkins and Harlow(2008) carried out an RCT to test the effectiveness of a brief guided ~~self help~~self-help intervention for managing psychological distress. The intervention involved a 30-minute face-to-face session to talk about and train in concreteness training, which is a visualisation exercise that focuses the participant on an episode of autobiographical memory and encourages them to become absorbed in it. Participants in the intervention group were asked to repeat the exercise daily for four weeks. Pre and post measures were taken at baseline and after 4 weeks. Findings indicate that the intervention group showed ~~specific~~ significant improvements in anxiety over the control group on the Generalised ~~a~~Anxiety ~~d~~Disorder 7 item scale (GAD-7, Spitzer et al., 2007).

Gellaitry, Peters, Bloomfield and Home (2010) carried out a study to assess the effects of an expressive writing intervention on perceptions of support in women completing treatment for early stage breast cancer. Eighty participants took part in their study. Participants in the intervention arm were asked to write for a period of 20 minutes on four consecutive days around four guided topics (emotional disclosure, cognitive appraisal, benefit finding and looking to the future). Measures were carried out at baseline, one month, three months and six months. In addition, interviews were carried out with those participating in the intervention arm after six months. The overall findings of the ~~study,~~study indicate that participants in the expressive writing group experienced significantly greater satisfaction with the emotional support which they received. No significant differences were found in terms of quality of life, mood or healthcare utilisation. Post-hoc analysis showed that satisfaction with emotional support was negatively correlated with depression / dejection, anger and hostility; and positively correlated with social and family well-being.

Imrie and Troop (2012) carried out a RCT looking at using compassion focused expressive writing exercises in a day hospice setting and its impact on distress and well-being. Participants were randomised to either take part in 20 minutes of expressive writing, or ten minutes of expressive writing followed by some ~~self compassion~~self-compassion guidance training before being asked to write again for a further 10 minutes on the same topic. These sessions occurred on two occasions. Measures looking at self-esteem, mood and stress were administered at baseline and after three weeks. Additionally computer textual analysis was carried out on the pieces of creative writing. The authors found that there was an increase in self-soothing behaviour and self-esteem in the compassion group. They also found an increase in stress in the compassion group compared to the control group. However because of low numbers of participants, they were unable to apply inferential statistics.

Pitceathly et al. (2009) carried out a study to test a preventative psychological intervention, which aimed to prevent anxiety and depressive disorders in cancer patients.   The intervention consisted of three structured sessions taking place over a six-week period. In addition, participants were offered supporting literature, which was~~ere~~ developed for the study. 311 ~~Three hundred and eleven~~ participants completed measures looking at anxiety and depression (The structured clinical interview from the D~~d~~iagnostic and S~~s~~tatistical M~~m~~anual of M~~m~~ental D~~d~~isorders 3rd edition, DSM-III-R, American Psychiatric association, 2000; and the ~~Hopital~~Hospital A~~a~~nxiety and D~~d~~epression S~~s~~cale, Zigmund &~~and~~ Snaith, 1983). Participants were stratified into low or high-risk groups for developing anxiety or depression. This was achieved by completing a C~~c~~oncerns C~~c~~hecklist (Harrison &~~and~~ Mcguire, 1994). Scores above a cut-off of eight on the C~~c~~oncerns C~~c~~hecklist or previous contact with a health professional led to participants being stratified as high risk for experiencing anxiety or depression.   Data was collected at six months and 12~~twelve~~ months after baseline. Researchers who were blind to the stratification or treatment group conducted assessments. The results indicate that there is no difference between the experimental group and the controls for diagnosis of anxiety or depression at six or 12~~twelve~~ months. Secondary outcomes suggest significantly lower scores on anxiety and depression combined scores at four and six months, in the intervention group over the control, but only in the high risk group.

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Ramachandra, Booth, Pieters, Kalliopi and Huppert (2009) developed a study aimed to evaluate a brief, easy to use intervention that could improve well-being and quality of life in cancer patients. The well-being intervention had three strands: keeping a well-being diary (participants were asked to record three positive experiences each day), using a mindfulness CD (body scan to use twice per day) and planning a pleasurable weekly activity. Thirteen women with metastatic breast cancer and fourteen men with metastatic prostate cancer were recruited to take part in the study. Participants were randomised into the intervention arm or waiting list deferred entry group (control). Participants were followed up at six, 12~~twelve~~ and 18~~eighteen~~ weeks. The study reports a significant improvement in quality of life at six~~6~~ weeks in the intervention group. There were no significant improvements in anxiety, depression or social functioning.

Semple, Dunwoody, Kernohan and McCaughan (2009) developed and tested an intervention for patients following treatment for head and neck cancer. Their study investigated the benefits of *problem focussed sessions*. This intervention looked specifically at eight common problems (anxiety, depression, eating and drinking, fatigue, appearance, speech, smoking cessation and finance). Their time-limited intervention focussed on any three problems from those eight. Between two and six sessions were delivered by one clinician. Interventions were delivered on an individual basis, in the participants' own home. Additional bibliotherapy was produced based on the eight problems, and this was delivered adjuvantly. Participants self-selected into the intervention arm of the study or the control arm. The control arm consisted of treatment as usual which was their usual medical care. Assessments were measured at two points: within one week of completion of the intervention and then at three months. Significant ~~findin~~improvements ~~gs~~ were found in the intervention group over control in the domains of psychological distress, anxiety, depression, improved psychological functioning and quality of life. These were found at completion of the intervention, and were maintained at three-month follow-up.

Comment [HP16]: Improvements?

Serfaty, Wilkinson, Freeman, Mannix and King (2012) carried out an RCT looking at the equivalency of a~~A~~romatherapy massage (AM) and~~to~~ Cognitive ~~b~~Behavioural T~~t~~herapy (CBT). 39 ~~Thirty-nine~~ participants took part who were screened to have a clinically significant score on either anxiety or depression scales. Participants were randomised to receive either CBT or AM. The experimental arms of the study received eight~~8~~ sessions of either CBT or AM. The researchers found significant improvements in mood, depression and anxiety scores from baseline with both interventions. They found no significant differences between CBT or AM on any measure at three months and six months. From this finding, the authors suggest that AM is equivalent to providing CBT for distress in cancer patients at least in the short term.

Sharp et al. (2010) carried out an RCT to test a reflexology intervention for people with newly diagnosed breast cancer. There were three intervention arms: reflexology and TAU, scalp massage and TAU, and TAU. Each person in the intervention groups received eight sessions of scalp massage or reflexology. Pre and post measures of quality of life, mood and mental health were carried out at baseline, 18 and 24 weeks. Findings indicated that at 18 weeks, participants in the scalp massage intervention had significantly improved scores on quality of life ~~than~~ compared with the control group. Massage and reflexology groups scored better than TAU group on mood and relaxation. At 24 weeks, only the reflexology group scored significantly better than TAU and only on quality of life.

Strong et al. (2008) carried out an RCT, which assessed an intervention aimed at those with a diagnosis of cancer and ~~a~~ major depression. Two hundred outpatients were randomised to receive usual care or a depression care for people with cancer intervention. ~~One hundred and one~~101 people took part in the intervention plus usual care. The intervention comprised of education about depression, problem-solving, coping strategies, and communication skills. Participants were offered up to ten~~,~~ 45-minute sessions with a nurse who followed a manualised intervention protocol. Findings indicated that the treatment effect of the intervention was significant, with reductions in depression scores at three~~3~~ months, maintained at 12 months.

Thomson, Ander, Menon, Lanceley and Chatterjee (2012) carried out a study looking at evaluating a heritage focused intervention, for oncology ward inpatients. ~~One hundred~~100 females ~~participants~~ took part in the study: 79 in the experimental group and 21 controls. In the intervention setting, participants were asked to choose, handle and discuss a series of six objects with a facilitator. These were items of significant historical interest. The control condition did the same with photographs of the objects. A single session was conducted at the bedside and lasted around 30 minutes. Pre and post measures were administered. ~~Findings indicate that p~~Participants in the heritage intervention showed increases in positive mood, ~~and increases in~~ wellness and happiness scores.

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~~Table 1. Methodology of review studies~~

~~Author~~	~~Sample~~	~~Research methodology~~	~~Major findings in the context of mental health and well being~~	~~Study Limitations~~
~~*Bourke et al.* *(2012)*~~	~~N=12~~ ~~Men with advanced prostate cancer~~	~~Qualitative analysis~~ ~~Focus groups~~	~~Intervention considered beneficial for:~~ ~~reducing anxiety around treatment~~ ~~reducing fear of reoccurrence~~	~~Low participant numbers~~ ~~Unable to generalise findings~~
~~*Cox et al. (2008)*~~	~~n=56~~ ~~women with~~ ~~ovarian cancer~~	~~Cross-sectional design~~ ~~Pre and post measures FACT-Ovarian, experience and satisfaction with care questionnaire~~	~~Significant improvement in emotional well being. (P<0.05)~~ ~~-No other significant findings~~	~~No power calculations~~ ~~No control group / randomisation~~ ~~No reference for the FACT-O~~ ~~No validity / reliability reported for experience and satisfaction with care questionnaire~~

~~*Daley et al. (2007)*~~	~~N=96~~ ~~Women treated for breast cancer~~	~~Randomised control trial~~ ~~Pre and post measures;~~ ~~FACT-G, FACT-B, revised piper fatigue scale, BDI-II, Physical self perception profile.~~ ~~Baseline, 8 weeks, 24 weeks~~	~~Significant differences reported in~~ ~~Quality of life significantly improved in exercise group over usual care group at 8 weeks (FACT-G p=.004; FACT-B p=.002)~~ ~~Both exercise therapy and exercise placebo showed significant increased in depression of usual care group at 8 and 24 weeks (p<.001)~~	~~Falls short of recruitment for power calculation~~
~~*Galfin, Watkins and Harlow (2012)*~~	~~N=24~~ ~~Palliative care~~ ~~BDI-FS>4~~ ~~GAD-7>5~~	~~Randomised control trial~~ ~~Pre and post measures~~ ~~BDI-FS, GAD-7, WHOQOL-BREF~~	~~Significant improvements on anxiety of intervention group over control p<0.001~~	~~Does not mention power calculation~~
~~*Gellaitry, Peters, Bloomfield and Home (2010)*~~	~~N=80~~ ~~Women with breast cancer~~	~~Mixed methods~~ ~~Primary outcome measures: Social support, quality of life, psychological well-being at healthcare~~	~~Greater satisfaction with received emotional support in intervention group (p<0.05)~~	~~No power calculation~~ ~~No blinding for participants~~ ~~No statement of ethical approval~~

		~~utilisation~~		~~No structured analysis of qualitative data~~ ~~Post-hoc analysis~~
~~Author~~	~~Sample~~	~~Research methodology~~	~~Major findings in the context of mental health and well being~~	~~Study Limitations~~
~~*Imrie and Troop (2012)*~~	~~N=6~~ ~~Day hospice patients~~	~~Mixed methods~~ ~~RCT and textual analysis~~ ~~Pre and post measures:~~ ~~SISE, SDHS, PSS10, LIWC~~ ~~Tested at baseline and 3 weeks~~	~~Increase in self soothing behaviour and self esteem in experimental group~~ ~~5/6 report increase in happiness~~ ~~Increase in stress in the experimental group, and decrease in the control group.~~	~~Does not state randomisation procedures~~ ~~Very low participant numbers~~ ~~No statistical analysis~~
~~*Pitceathly et al. (2009)*~~	~~N=313~~	~~RCT : 3 arm intervention study~~	~~Significant reduction in HADS scores at 4 and 6 months in the 'high risk'~~	~~Under powered~~ ~~Purposive sampling~~

		~~Structured clinical interview from DSM III-R, HADS~~	~~intervention group ($p<0.05$)~~	~~No mention of ethical approval~~
~~*Ramachandra, Booth and Pieters, Kalliopi and Huppert. (2009)*~~	~~n=27~~ ~~13 women with breast cancer, 14 men with prostate cancer~~	~~Mixed methods~~ ~~Quality of life, anxiety and depression, social and occupational functioning and brief semi-structured interview~~ ~~Follow up at 6, 12 and 18 weeks~~	~~Significant improvement in intervention group of quality of life scores at 6 weeks ($p=0.046$)~~	~~No power calculation~~ ~~Does not state randomisation procedure~~ ~~Qualitative data not analysed in any structured way~~ ~~Non-parametric data~~ ~~No medium or long term follow-up~~
~~*Semple, Dunwoody, Kernohan and McCaughan (2009)*~~	~~n=54~~ ~~Head and neck cancer~~	~~Quasi-experimental design~~ ~~Pre and post measures : HADS, WASA, HRQoL, UWQoLv4~~	~~Significant improvements in the intervention group over controls on:~~ ~~Anxiety ($p=0.001$)~~ ~~Depression ($p=0.005$)~~ ~~Social functioning ($p=0.048$)~~ ~~Quality of life ($p=0.042$)~~	~~Not enough detail for replication~~ ~~Bespoke individually tailored interventions~~ ~~No mention of ethical approval~~ ~~Under powered~~ ~~Self selection into the intervention group~~ ~~Therefore no randomisation~~

~~Author~~	~~Sample~~	~~Research methodology~~	~~Major findings in the context of mental health and well being~~	~~Study Limitations~~
~~Serfaty, Wilkinson and Freeman, Mannix and King (2012)~~	~~N=39~~ ~~HADS score above 8~~	~~Randomised control trial~~ ~~CBT Versus Aromatherapy Massage~~ ~~Pre and post measures:~~ ~~Profile of mood states-total mood score, EuroQol 5-D.~~ ~~Test points at baseline, 3months and six months~~	~~No significant differences between Cognitive behavioural therapy and aromatherapy message in Mood or Quality of life at any point.~~ ~~Report that Aromatherapy is equivalent to CBT for treating distress~~	~~Comparison study (no control group)~~ ~~No power calculation~~
~~Sharp et al. (2010)~~	~~N=183~~ ~~Early breast~~	~~Randomised control trial~~ ~~3 arm intervention~~	~~Significant findings at 18 weeks~~ ~~Massage patients significantly better~~	~~Falls short of recruitment for power calculation~~

	~~cancer~~	~~study~~ ~~Pre and post measures~~ ~~FACT-G, FACT-B, TOI, MRS, HADS, SCID~~ ~~Tested at baseline, 18 weeks and 24 weeks~~	~~scores on QOL over treatment as usual~~ ~~Massage and Reflexology significantly better scores of mood and relaxation~~ ~~At 24 weeks~~ ~~Reflexology significantly better QOL scores than treatment as usual~~	
~~*Strong et al. (2008)*~~	~~N=200~~ ~~Cancer and major depression~~	~~Randomised control trial : Longitudinal design~~ ~~Primary outcome measure SCL-20 (depression scale from SCL-90) Measured at 3, 6 and 12 months~~	~~Significant differences of intervention group over control in:~~ ~~Depression (p=0.008)~~ ~~Anxiety (p= *not reported*)~~	~~Medication usage a major confounding variable, not commented on.~~ ~~Medication use in intervention group far above controls (p<0.01) at 4 and 6 months~~
~~*Thomson, Ander and Menon, Lanceley and Chatterjee (2012)*~~	~~N=100~~ ~~Women with cancer~~	~~Mixed methods, quasi-experimental design.~~ ~~Primary outcome measures: PANAS and VAS. Pre-test and post-test measurement~~	~~Significant differences of experimental group over control in:~~ ~~Levels of positive emotion (p<0.001)~~ ~~Well-being (p<0.02)~~ ~~Happiness (p<0.02)~~	~~convenience sample~~ ~~no mention of randomisation procedures~~ ~~no mention of power calculation~~ ~~pre and post measures~~

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Critical appraisal of the literature

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Studies reporting on mental health outcomes

Many of the studies ~~involved in the literature~~ reviewed commented on and tested for changes in anxiety and depression following the interventions. The most commonly utilised measure of anxiety and depression was the Hospital Anxiety and Depression S~~s~~cale (HADS; Zigmond &~~and~~ Snaith, 1983). The HADS was used in three studies (Pitceathly et al., 2009; Semple, et al., 2008; Ramachandra et al, 2009). The S~~s~~ymptom C~~c~~hecklist 10 I~~i~~tem S~~s~~cale (SCL-10) for anxiety and SCL-20 scale for depression, (both subscales from the SCL-90: Derogatis, Lipman~~,~~, ~~and~~ Rickels, Uhlenhuth &~~and~~ Covi, 1974) were~~as~~ used in one study; (Strong et al, 2008), and the P~~p~~ositive and N~~n~~egative A~~a~~ffect S~~s~~cale (PANAS, Watson, Clark &~~and~~ Tellegen, 1988) was used in one by Thomson et al~~.(~~. (2012)~~. The~~. The S~~s~~tructured C~~c~~linical I~~i~~nterview from DSM-III-R (American Psychiatric Association ~~(APA~~(APA, 1987)) and DSM-IV (APA, 1994) was used in two studies (Pitceathly et al., 2009; and Strong et al., 2008). Two versions of the Beck depression inventory were used, The BDI-FS (Beck, Depression Inventory- Fast Screen (Beck, Steer & ~~and~~ Brown, 1996) was used by Galfin et al. (2011), and the Beck Depression Inventory 2nd edition, (BDI-II; Beck, Steer &~~and~~ Brown,1996) by Daley et al (2011). The Generalised A~~a~~nxiety D~~d~~isorder-S~~s~~even I~~i~~tem (GAD-7, Spitze, Kroenke, Williams &~~and~~ Lowe, 2007) was used by Galfin et al~~.(~~. (2011).

One fundamental difference between studies was the reliance on either self-report measures or assessment through clinical interview for measuring psychological distress. Self-report measures can be open to manipulation by participants who perhaps would like to show appreciation for the care that they have received. Equally, structured clinical interviews are more open to

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interpretation by those analysing the data, and could be subject to response bias. All measures used in the studies for mental health assessment are reported to be valid and reliable, with previous use in cancer field. Hall, A’Hern and Fallowfield (1999) proposed that the HADS is not a particularly sensitive tool for detecting anxiety and depression, and that clinical interviews improve this. However this is far more labour intensive, and as many of the study designs were within participant designs, they were used for evaluating for difference rather than making diagnoses. Comparison of studies is difficult due to the various ways in which mental health is operationalised by the authors. As such there is no agreement on the best way to assess participants’ mental health functioning. This would be a recommendation for future research in this area. An agreed best practice for assessment would make comparisons and pooling of studies more straight forward.

Studies reporting on Well-being

Three studies reported on well-being. This was operationalised differently by all studies so again comparison across studies is difficult. Two studies used very specific measures designed for use with the specific cancer patient group, whereas the third study used a more generic approach to well-being, but one that has been used in cancer care previously. Cox et al. (2008) used the Functional Assessment of Cancer Treatment-Ovarian (FACT-O; Basen-Engquist et al., 2001) specifically designed for assessment in ovarian cancer. Gellaitry et al. (2010) used the Functional Assessment of Cancer Treatment Breast (FACT-B; Brady et al., 1997), specifically designed for people with breast cancer, and also the P~~ p~~rofile of M~~m~~ood S~~s~~tates (McNair, Lorr &~~, and~~

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Droppelman,1971). Thomson et al. (2012) used the Visual Analogue S~~s~~cale (VAS) W~~w~~ellness and H~~h~~appiness S~~s~~cale (Wewers & ~~and~~ Lowe, 1990). Well-being is a particularly difficult concept to measure and operationalize and appears in the literature to be measuring very similar attributes to quality of life. All of these are self report measures which are open to manipulation by participants who could quite naturally show their appreciation for help by responding more positively.

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Studies reporting on quality of life.

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Several studies reported on changes to quality of life. Overall studies utilised different measures to assess quality of life. Four studies used cancer-specific quality of life tools. The Functional A~~a~~ssessment of C~~c~~ancer T~~t~~herapy – Breast (FACT-B, Brady et al., 1997) was used by Gellaitry et al. (2010) and Daley et al. (2011) , the ovarian version FACT-O (Basen-Engquist et al., 2001) by Cox et al. (2008) and the general version FACT-G (Cella et al.,1993) by Daley et al. (2011).

The remaining studies used more generic measures of quality of life. Semple et al. (2008) used the University of Washington Quality of Life version 4 (UWQoLv4, Rogers et al., 2002), Ramachandra et al. (2009) and Galfin et al. (2011) used the WHO Quality of Life – Brief (WHO-QoL-Bref, WHOQOL Group, 1998~~) ,~~), and Strong et al. (2008) used the European O~~o~~rganisation for R~~r~~esearch and T~~t~~reatment of C~~c~~ancer Q~~q~~uality of L~~l~~ife A~~a~~ssessment in O~~o~~ncology (EORTC QlQ - Aronson, Cull, Kaasa & ~~,~~ Sprangers, 1994). All of these health related quality of life measures are validated to be used in a cancer setting, but the FACT measures were specifically designed for use in cancer settings, which may suggest better validity with this client group. There are again difficulties in comparing study outcomes when the measures used are so very different across studies.

Studies reporting positive findings

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All studies reported positive findings on at least one domain, using this as evidence for supporting the studied intervention. Improvements in anxiety and depression were reported by ~~(~~Semple et al~~.(~~. (~~,~~ 2008), ~~;~~ Pitceathly et al~~.(~~. (~~,~~2009), ~~;~~ Strong et al~~.(~~. (~~,~~2008) ~~;~~ and Thomson et al~~.(~~. (~~,~~2012)~~)~~. Improvements in depression were found by Daley et al. (2007) and ~~,~~ Sharp et al. (2010), while~~and~~ Serfaty et al. (2011) reported no differences in depression scores between the two interventions (CBT and AM) which they used to promote the use of aromatherapy massage. Imrie and Troop (2012) noted improvements in happiness in both the experimental and the control group~~,~~; however due to low numbers they were unable to statistically test for significance. Additionally, Bourke et al. (2012) report positive outcomes in terms of fear and anxiety using qualitative methods.

Galfin et al. (2012) found significant improvements in anxiety in the experimental group over the controls. Imrie and Troop (2012) found that their intervention actually increased the participants' stress over the control group; however because of low numbers of participants this could not be statistically tested. Four studies demonstrated significant improvements in quality of life domains in the experimental groups. These were the self-administered intervention (Ramachandra et al., 2009), problem focussed intervention (Semple et al., 2009), reflexology (Sharp et al., 2010) and exercise intervention

(Daley et al., 2007). Two studies assessing quality of life found no difference following the intervention (Strong et al.~~,2008~~, 2008; Cox et al., 2008). Serfaty et al. (2011) found no difference in quality of life between a CBT intervention and aromatherapy massage, which they use to suggest parity between the two interventions. Two studies reported positive outcomes in terms of general well-being (Thomson et al.~~,2012~~, 2012; Cox et al., 2008).

Range of interventions

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There is a range of types of interventions which are delivered in these studies, similar to the wider literature. Some of the studies carried out interventions along similar themes. Two studies employed a writing intervention; two studies employed a self-help type intervention; two studies incorporated exercise into the intervention, and two studies employed complementary therapies in their intervention.

Four studies utilised ~~a~~ CBT principles in their intervention. Pitceathly et al. (2009), Semple et al. (2008) and Strong et al. (2008) stated that their interventions were based on CBT principles but the actual mechanism of this and how exactly CBT principles were used is unclear in any of the studies except one. Serfaty et al. (2012) used a standardised CBT package for cancer patients (Mannix~~, Blackburn & and Garland~~ et al. 2006) to provide a comparison group. Five studies used psycho-education and / or bibliotherapy for at least part of their interventions (Strong et al., 2008; Bourke et al., 2012; Cox et al., 2008; Semple et al., 2008; Pitceathly et al., 2009). Four of these studies provided information in person and or supported by written information on anxiety and depression.

In delivering the interventions, there were several differences in presentation, as well as content. Many of the interventions were led by cancer nurses/ non-specialists trained and supervised specifically to deliver the interventions (usually by the authors).   The studies that involved complementary therapy and exercise therapy were the studies that also used qualified practitioners to deliver the interventions (Daley et al, 2007; Bourke et al., 2012; Serfaty et al., 2012; Sharp et al., 2012).

Ten studies used face-to-face delivery of the interventions, or direct contact through the telephone (two studies used these methods of communication interchangeably, suggesting that these would be comparable). Three studies used self-guided/ led interventions (Galfin et al, 2012; Ramachandra et al, 2009; Gellaitry et al, 2010).   There are not enough studies reported here to be able to comment on which components of the interventions were most or least helpful. The studies themselves do not comment on how different components contribute to overall change in functioning, and each intervention has numerous confounding variables.

Screening

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Some of the studies' inclusion / exclusion criterion~~,~~ tended to either exclude people with significant psychiatric difficulties (~~eg~~e.g. ~~(~~Semple et al., 2008; Pitceathly et al., 2009;   Gellaitry et al., 2010;   Ramachandra et al., 2009), or seek to only include people with significant difficulties (~~eg.~~e.g. Strong et al., 2008; Galfin et al., 2012; Serfaty et al., 2012). Other studies tended to be open for general inclusion of the population (Cox et al., 2008; Thomson et al., 2012; Bourke et al., 2012). Previous authors have commented on the fact that only those with significant levels of psychological distress benefit significantly from receiving interventions at all (e.g. Fawzy, 1995). The findings of Pitceathly et al. (2009) do support this notion, but support for these claims are not found in any of the other studies, where all groups gained some benefit from the various interventions.

Methodological limitations of the reported studies

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Several of the studies had limitations~~,~~ in their methodology. In terms of the quantitative studies, only one study was adequately powered (Strong et al., 2008). Seven of the studies made no comment of a power calculation (Cox et al., 2008; Gellaitry et al., 2010; Ramachandra et al., 2009; Serfaty et al., 2012; Imrie and Troop, 2012; Thomson et al., 2012; Galfin et al., 2012). Four studies made reference to a power calculation but their study did not achieve the proposed power (Semple et al., 2009; Pitceathly et al., 2009; Sharp et al., 2012; Daley et al., 2007).

In terms of randomisation, two studies had no control group (Cox et al., 2008; Serfaty et al., 2012), and two studies did not state how randomisation took place (Ramachandra et al., 2009; Imrie and Troop, 2012). In one study, participants were told of the two groups, so the randomisation was not blind. Pitceathly et al. (2009) used purposive sampling, and Semple et al. (2009) allowed participants to self-select into the intervention arm of the study or not.

In several studies, ethical approval was also not mentioned (Cox et al., 2008~~;~~ ~~Gellaitry~~; Gellaitry et al., 2010; Pitceathly et al., 2009)

Discussion of findings

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Since the publication of the C~~c~~ancer R~~r~~eform S~~s~~trategy (2007) there has been a paucity of studies carried out in the UK on psycho-social interventions for people with a cancer diagnosis. This is despite numerous recommendations from several papers; e.g. the Cancer R~~r~~eform S~~s~~trategy, (DoH~~, 2007~~, 2007), NICE (2004) and I~~i~~mproving O~~o~~utcome S~~s~~trategies for C~~c~~ancer (DoH, 2011). The general approach to providing psychosocial care appears to be piecemeal in its application with little agreement on what constitutes an 'ideal' intervention. The paucity of studies ~~This~~ may be as a result of services not publishing findings, or particularly not publishing in peer reviewed journals, or that research in this area is not taking place. There is evidence of the publishing of reviews by UK authors based on largely overseas findings, which suggest an interest in developing services in this area. There continues to be an over reliance on overseas studies, which while obviously having some relevance, lacks evidence of validity with a UK population with its unique cultural, contextual make-up.

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All of the intervention studies reviewed here state at least one positive outcome in terms of mental health, emotional well-being, and/ or quality of life. Comparison across studies is difficult as all of the interventions are markedly different in their presentation, delivery, participant selection and measurement of symptoms. However there is generally a support in the literature for cognitive behavioural type interventions, psycho-education and bibliotherapy. This mirrors the findings from the previous systematic reviews, and may suggest that the design of these interventions was understandably based on~~ the~~ previously published data. Overall, the approach to ~~psychsocial~~psychosocial cancer care seems to share some commonalities with a primary care model of mental health intervention; i.e. basic manualised CBT / self-help type interventions delivered by people specifically trained for that intervention only. This may suggest a lack of creativity in attempting to use other models of care that may be more appropriate for a UK population. Generally within these studies, there is no effort to separate out or comment on the mode of action of the interventions.

There is also support found in the literature for lower level interventions such as self-help interventions, exercise therapy and complementary therapies for addressing mental health, quality of life and emotional well-being.

The research reviewed was found to be of limited quality, with at least ~~of~~ one of the following problems in each study: power, randomisation/ control groups, and sampling. This makes the findings less reliable and valid and less able to generalise. Many of the studies advocate further research in this area with better powered studies and increased randomisation strategies; as such they share aspects in common with pilot studies. A large proportion of the reviewed studies look specifically at the early survivorship population (those having received a primary diagnosis and having received primary treatment) which is also reflected in the wider literature ~~also~~. Those people experiencing advanced and terminal cancers have been traditionally of less interest to researchers and services alike, and this seems to suggest a gap in the literature. Overall there appears to be a distinct lack of high quality, UK studies which look at addressing the psychosocial needs of cancer survivors, with people experiencing advanced, secondary or terminal cancers being a largely excluded group. More research needs to be carried out in all areas of the cancer

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survivorship continuum to establish an evidence base within the UK that meets the psychosocial needs of the full range of cancer survivors.

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Paper Two- – Research Paper

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Using narratives to understand psychosocial impact and meaning-making following a secondary cancer diagnosis

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Abstract

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Improvements in early detection and treatment have led to an increase in both survival and quality of life in advanced cancer. Insufficient research exists regarding the impact and the lived experience of secondary cancer. The aims of the current study were to examine psychosocial impact and meaning-making following a secondary cancer diagnosis. Five participants' stories about their cancer journey were collected in a single interview with each participant. Structural narrative analysis was used to analyse participant stories.

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The findings highlight some of the nuances between people on their unique cancer journeys. Very few of the participants' overall narratives were concerned with the impact of the actual diagnosis. Narratives focussed on everyday life issues, for example, 'date night', family, holidays, money, and appointments to attend.

Common elements of the group narrative included: the high costs of treatment, negotiating treating teams, striving for normality, continuous biographical disruption, comparison with others, finding positives and feedback from others. Recommendations include examining ways to streamline appointments between teams, to increase participants' time to live and maintain normal lives and roles.~~ (170)~~

Introduction

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Macmillan (2007) estimated that there were approximately two million people living with cancer in the UK. Historically, measures of successful interventions in cancer focussed on length of survival. Recent developments in the field have focussed on quality of life as well as quantity of life (Jacobsen, Davis & ~~and~~ Cella, 2002). In addition to improvements in curative medicine, there have been significant improvements in stabilization and palliative treatments. Therefore, people are living longer with cancer. This has led to the emergence of a new survivor population: those living *with* advanced cancer (Higginson &~~and~~ Constantini, 2008). Where cancer cells spread from a primary site to another part of the body, this is called a secondary cancer or metastasis (Macmillan, 2007). The number of people currently living with a secondary cancer diagnosis is~~, however ,~~ unknown.

Several papers published recently in the UK have focused on improving the lives of people diagnosed with cancer (e.g. The National Institute of Clinical Excellence (NICE, 2004); The Department of Health (DoH, 2007)). In I~~i~~mproving O~~o~~utcome S~~s~~trategies for C~~c~~ancer (DoH~~epartment of Health~~, 2011), there is a recognition that inadequate attention has been given to the long-term consequences of cancer diagnosis for the ever-increasing number of individuals surviving the disease.

More recently, the focus is shifting towards improving quality of life for people diagnosed with cancer, and how to achieve this. What is less clear from the research are the complexities of living with and beyond cancer care, what the experience of this is like and how this can be improved.   Corner (2008) comments that the complexities of living with cancer are not reflected in the cancer survival statistics.

Limitations of existing research

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Research into secondary cancer tends to be grouped together with primary diagnosis, recurrence and advanced cancer studies (e.g. Morse & ~~and~~ Fife, 1998). This suggests that the diagnosis of a secondary cancer as a unique experience has been largely ignored. Harris et al. (2008) found that there are few papers which focus on end of life issues, some exceptions are clinical trials and quality of life measures. However, these are mainly devoted to discussions of the physical experience of treatments, rather than being concerned with emotional experiences or a person's views. ~~Field and Cassel (1997) propose that much more is assumed than known regarding the desires of people with advanced cancer~~Ryan(2005) proposes that information from a patient's experience of approaching death as a result of advanced cancer is limited and that only by knowing about the experience of living with advanced cancer can meaningful care be developed for patients and carers.

Literature from palliative care does not tend to differentiate between types of cancer and stages of cancer (other than being non-curative). There is however some research considering the experience of cancer. Brennan (2001) proposes a social transition model of cancer to explain the differences of individual responses to the cancer journey over a broad spectrum, from ~~pyschological~~psychological disorders to positive growth. In this model, adjustment is regarded as the transition over time as the individual attempts to learn and adapt to the multitude of changes associated with the illness pathway

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within a number of social contexts. Romanoff and Thompson (2006) suggest that individuals who find positive meanings in their illness and loss, experience less depression, better quality of life and emotional well-being. They also propose that not all people engage in a search for meaning following the diagnosis of illness and not all people who search, find a meaning. Stroebe and Schut (1999) Propose that people oscillate coping styles between expressions of grief and the need to continue with everyday living (restoration-focussed coping).

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Taken together, the lack of evidence around the experience of a diagnosis of secondary cancer, living with secondary cancer and the general lived experience of cancer indicates a shortfall in the evidence base. This would suggest that further studies in this area would be helpful to understand and contribute to the care of this client group.

Qualitative enquiry

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Qualitative enquiry is an~~the~~ appropriate methodology for uncovering or understanding a phenomenon about which little is known (Strauss &~~and~~ Corbin, 1990). Murray (2008) argues that narratives are an everyday means of making sense of the disruption of illness but narrative enquiry has been sparsely utilized in research with cancer patients. Brown and Addington-Hall (2008) propose that narratives serve to make sense of complex difficulties and help patients, families and healthcare professionals to have improved understanding of experience. Therefore, narrative enquiry is a useful tool in understanding people's experiences in response to illness that could be applied within a secondary cancer context.

Few narrative studies have looked at the lived experience of cancer patients as a whole. Several studies analysed narratives, which people create around specific cancers, such as prostate cancer (e.g. Cayless, Forbat, Illingworth, Hubbard &~~and~~ Kearney, 2010), or lung cancer (e.g. Levealahti, Tischelmen &~~and~~ Ohlen, 2007). These tend to focus on a life following initial cancer treatments. Other studies ask specific questions about certain experiences, such as facing death (e.g. Ryan, 2005). Benzein, Norberg and Saveman (2001) looked at narratives of hope in terminal cancer care. Their narrative analysis concludes that support for the experience of living with terminal illness is not living without hope. They propose that having ~~confirmatative~~confirmative relationships and an experience of feeling at home encourages the experience of hope. Although many aspects of the experience of a secondary cancer have been examined individually, t~~T~~he impact and experience of a secondary diagnosis of cancer as a unique experience has been largely neglected.

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Primary aims

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The aims of the current study are to explore the experience of the impact, meaning-~~-~~making, and living with, a diagnosis of secondary cancer, and to gain a better understanding of this group’s needs, within the context of their cancer journey. By exploring people’s narratives about their cancer diagnosis, it could be presumed that a better understanding of people’s unique journey following a diagnosis will be gained, and how these narratives may differ from a primary diagnosis.

Secondary aims

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Emerging themes between participants could highlight met and unmet needs within this population. Through analysis of people’s narratives around a secondary diagnosis, one might identify whether and how people access and use personal and external resources through their cancer journey, and how this may relate to cancer services provision. Findings from the current study could be used by service providers and clinical staff to evaluate service provision for those people who are diagnosed with a secondary cancer, to ensure that their needs are better met.

Method

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Design

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A structural narrative approach was used to undertake in depth analysis of the interview data obtained in a single session. The study was carried out following ethical approval from Staffordshire University and NHS R&D and ethics (See A~~a~~ppendix D and E).

Sample

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Interviews were undertaken with a convenience sample of participants with a secondary cancer diagnosis. The participants were recruited from two day-hospices in England. The inclusion criteria for this study w~~as~~ere Adults (18 or over), who had received a secondary cancer diagnosis and were physically and mentally able to take part in a research interview. People were excluded from taking part in the study if they were considered to be in the end of life phase by health staff, or considered too unwell or too distressed to take part. Six people were approached by hospice staff and five agreed to take part (See Table 1.). The sample size was dictated by sample selection criteria and the research design. Turpin et al. (1997) suggest a minimum of five participants in qualitative studies as an attempt is made to understand a small number of participant~~'~~s' own frames of reference. Baker and Edwards (2012) propose that any number greater than one is sufficient for qualitative studies. They propose that a smaller study, which is creatively and interpretively analysed, can be superior to a study with a larger number, which is not.

Table 1. Participant information

Pseudonym	Gender	Age	Primary diagnosis	Secondary diagnosis
Peter	Male	77	Prostate cancer	Bone metastasis
Angela	Female	54~~43~~	Breast cancer	Bone & liver metastasis
Kate	Female	38	Breast cancer	Bone metastasis
Julia	Female	62	Chest tumour	Pleural tumour

Keith	Male	56~~4~~	Oesophageal cancer	Bone metastasis

Interviews

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Five participants took part in a single semi-structured interview each, where they were asked to talk about their experiences of cancer and about their cancer journey. Interviews took place in a hospice setting or the participants' home. (For the interview topic guide see A~~a~~ppendix B~~A~~.)

Interviews were digitally recorded; field notes and a reflective journal were kept. The researcher completed all interviews, verbatim transcription and analyses of the data.   Interviews lasted between 35 and 50 minutes.

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Data Analysis

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The material was subjected to a process of narrative structural analysis, with attention to units of discourse (Gee, 1991). Gee's approach to oral narratives attends to other linguistic features in addition to structure, particularly how a narrative is spoken. Interpretation of content in terms of topics, themes and prosodic features is used to organise the narrative into hierarchically structured units such as lines, stanzas, strophes and parts.   The processes of Gee's method are briefly described here.

Each recorded interview was listened to on several occasions and transcribed by the researcher. Dysfluencies, false starts and the participation of the interviewer were removed from the transcription as the method dictates. The narrative was structured into idea units, lines, stanzas, strophes and parts. (See Appendix C1~~B~~ for an example excerpt of a coded transcript.)

The fundamental parts of the narrative are idea units. These were identified from the audio recording by a pitch glide on the pronunciation of the word. This idea unit signals the focus of a sentence. A sentence can have more than one idea unit. Idea units were grouped into lines, each was numbered and idea units separated by a slash ("/"). Each line was about one central idea or argument. For example:

> "EARLY IN 2009 just at the end of February beginning of March/ I realized I COULDN'T COPE anymore/ because I'd got NOBODY COMING IN"

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Stanzas are a group of lines about a single topic, and each stanza captures a single vignette or scene. Each involves a shift from the preceding stanza. Stanzas tend to go together in pairs of related content, called strophes. The final part of the structural organisation of the narrative was to identify the larger parts of the story into which the strophes fall. Stanzas, strophes and parts were labelled to reflect content of the story.

Gee describes five levels of textual structure, each of which promotes an interpretation of meaning of the text. Level one: the line and stanza structure is outlined above. In Level two, the syntax and cohesion structure were identified. Syntax refers to the way in which words integrate material within and across lines and that may be used to switch topics or enhance contrasts. Cohesion refers to the ways in which lines and stanzas are linked throughout the narrative. This encourages the researcher to consider what connections the narrator makes.

In level three the mainline plot and off-mainline plot were identified and noted. The main events of the plot are those contained in the main clauses of the narrative. These are specifically verb and noun phrases which stand alone as sentences and are the actions undertaken by the narrator in the expression of the narrative. For example: (mainline underlined)

> "But THEN IN 2008 / I was diagnosed with prostate cancer which had ALSO spread into the bone"

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Offline plots contain aspects of the narrative concerned with states, generic events, repetition and habitual events that make up the rest of the narrative. At level four, the psychological subjects were identified. This represents what the narrator is empathising with. I/We / They indicate this. The fifth level of analysis is the focussing system. This was identified as the central topics or themes contained in and across the lines of text (as indicated by pitch glides). These were the key images or themes out of which the reader / listener is invited to build an overall interpretation of the narrative (See appendix C2 for an example of data analysis).~~.~~

The final interpretation involved the reading of the focussed material within the overall structure of the narrative. Gee calls this thematic interpretation. The five levels of structure and the interpretative questions, which they set, constrain what counts as senseful, appropriate and a fair reading of the narrative. The data was interpreted from a realist-constructionist standpoint. Reflexivity entails the researcher being aware of his effect on the process and outcomes of research based on the premise that 'knowledge cannot be separated from the knower' (Steedman, 1991). A reflexive journal was kept to monitor decisions about what was included in the analysis, and the findings.

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Results

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Each account was analysed using the methodology outlined by ~~Gee(~~Gee (1991). Each narrative is presented as a case study. The group narratives are then considered as a whole.

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Case study One: Peter

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Cancer Journey

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Peter first experienced cancer in the context of caring for his wife, before being diagnosed ~~himself~~ with prostate cancer with secondary bone metastases. Both primary and secondary diagnoses were given at the same time. Peter was given hormone treatment and two prostate operations. He has attended the hospice regularly since his diagnosis and the loss of his wife to cancer. The main themes, which are located within Peter's narrative, are his experiences with his wife, partnerships, coping, treatment dilemmas and competence.

The impact of the diagnosis

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Peter introduced his own cancer diagnosis within the context of caring for his wife, who had advanced breast cancer at the time. His diagnosis appeared to have far less gravitas in the narrative compared with the fact that his wife was in the last year of her life. He spent nine stanzas talking about his wife and only two lines speaking about his own cancer diagnosis. As such, Peter appears to present this as only a minor story line compared to his wife's illness and care.

> "I was diagnosed with PROSTATE CANCER, WHICH HAD ALSO SPREAD to the bone.
> So this was FAMILIAR TERRITORY." (Stanza 5)~~.~~

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The diagnosis is referred to later in the narrative where Peter goes into more detail of the experience of the diagnosis, in a very matter-of-fact style, before going straight on to talk about treatment. The matter-of-fact style might be explained by Peter's story being well rehearsed over time, where Peter has had time and space to organise and make sense of his journey. Alternatively, he may be defending himself from the emotion attached to such a significant health event.

> "So then, I WENT BACK
> The problem was ok you've got PROSTATE CANCER
> But we do the scans and we've found that it's in the BONES AS WELL
> So a bit IN THE BACK AND A BIT IN THE PELVIS." (S~~s~~tanza 34)~~)~~

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Experiences with his wife

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Peter's cancer experiences with his wife accounts for up to a third of the narrative, with several references to his difficulty in being without her further on in his account. His experience with his wife sets the context for his own cancer journey.

Following the death of his wife, she is referred to in several places and continues to act as context for his own cancer journey. Peter appeared to find this memory of shared experiences comforting. She was referred back to over several stanzas for example:

> "WITHOUT MY WIFE, IT IS VERY DIFFICULT." (Stanza 22)~~.~~
> "MY WIFE WENT for her treatment there." (Stanza 32)~~.~~
> "Having been DOWN THE ROAD WITH MY WIFE." (Stanza 45)~~.~~

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Partnerships

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A significant thread in Peter's journey was his attempt to find partnerships with services, friends and relatives to perhaps compensate for the lost support of his wife. Closely related is the journey of negotiating between teams and services. Stanza 30 talks of the frustration of being between teams, predominantly in Peter's case between oncology and urology, which is finally negotiated and leads to a feeling of belonging.

> "There is a point when you are not sure WHOM YOU BELONG TO
> anymore
> At one stage, I was feeling that I was a bit of a PING-PONG BALL."
> (S~~s~~tanza 38)~~.~~

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Treatment dilemma

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Peter was continuously making cost-benefit analyses of further treatment or stopping treatment. This dilemma is evident throughout the narrative:

> "So I don't want to go down a load of treatment, which is ABSOLUTE PURGATORY / FOR THE SAKE OF a few months." (S~~s~~tanza 22)~~.~~

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> "Before the prostate operation, THIS TIME/ I wondered if it was WORTH THE HASSLE
> I know I'M TIME LIMITED but the problem is you don't know how long
> If it wasn't going to be too long then is it WORTH THE HASSLE?"
> (S~~s~~tanza 42)~~.~~

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Peter had always concluded to continue with the treatments offered up until that point, but by exploring this narrative, he was open to discontinuing treatment at some point in the future. This may also suggest that Peter had found a level of acceptance about the prognosis of his cancer, and would be willing to make the choice of quality of life over quantity when he felt that the time was right. By this acceptance, he was maintaining a level of control over his cancer.

Competence

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Peter's level of perceived competence was explored. This is evident in his role as a carer, his ability to understand information and his abilities to be assertive and make decisions. Competence appeared to be an important value for Peter in retaining an element of control over his illness and interactions with services.

> "In terms of OTHER SUPPORT for her / there was VERY LITTLE to report because / I MANAGED TO COPE VERY WELL LOOKING AFTER HER." (Stanza 5)~~.~~

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> "She said you're PERFECTLY CAPABLE of making your own mind up
> And when I looked at it, yes OF COURSE I AM." (S~~s~~tanza 43)~~.~~

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Summary

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Overall Peter's account of his cancer journey appeared to be carefully constructed and considered. He is still coming to terms with the loss of his wife, but appears to have been able to accept his cancer diagnosis and prognosis. His wife is a mainstay throughout the story and is his point of reference and context throughout, both during her life and after her death. Peter maintains an element of control over his cancer by retaining his ability to consider information and make decisions about his own care based on his own needs, thus reinforcing his ideas and values around his own level of competence. Peter attempts to maintain an internal locus of control even within a seemingly out of control disease progress.

Case Study 2: Angela

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Cancer Journey

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Angela was diagnosed with breast cancer with bone metastasis at first diagnosis. She had a lumpectomy, radiotherapy, chemotherapy, and hormone treatment before the cancer metastasized further in her liver, and she became too unwell to have further chemotherapy. Her narrative builds around the following themes: luck, missed opportunities in self and others, the costs of treatment and the family context of cancer, and coping.

Impact of the Cancer Diagnosis

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Angela talked about her initial cancer diagnosis as being a shock particularly as she also received a secondary diagnosis at the same time. However, this was explained in only two lines:

> "So it was a hell of a shock really because I got the DIAGNOSIS OF THE LUMP
> Almost straight away because I had A SCAN BEFORE THAT/ I'd got the diagnosis that it had ALREADY SPREAD." (S~~s~~tanza 8)

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Of greater significance was when she was told about the cancer spreading to her liver. The impact of this was described in five stanzas. This may be because the new prognosis is very recent and has not been assimilated into the whole narrative as yet, or possibly because of the poorer prognosis. This is perhaps an example of repeated biographical disruption where the progress of the cancer has taken an unforeseen route. This may have led Angela to consider her mortality.

Luck and guilt

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Angela makes repeated reference to luck. She describes feeling very lucky in comparison with other people affected by cancer, and questions how other people cope, particularly in reference to pain and finances.

> "But then it [the pain] JUST SETTLED INTO A PATTERN luckily touch wood
> I don't know HOW OTHER PEOPLE COPE." (Stanza 17)

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> "Two KIDS TO SUPPORT AT UNIVERSITY / and just general living expenses is a NIGHTMARE
>
> I just don't know HOW PEOPLE COPE." (S~~s~~tanza 19)

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However, this apparent good fortune contrasts with feelings of guilt when comparing Angela's experience to others.

> "I feel GUILTY SOMETIMES that I feel quite well off." (Stanza 22)

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By focussing on the ideas of good fortune when considering cancer, this may be balancing Angela's negative thoughts about the disease. This also focuses on two very specific aspects: finances and pain, which appear to be the two most important effects of cancer for Angela. Luck is not mentioned in terms of developing cancer. This perhaps suggests an acceptance of the diagnosis.

Missed Opportunities

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Angela worries about missed opportunities. She suggests that there were opportunities that she has missed but also opportunities that services have missed too. When considering her own opportunities it is mainly about the onset in the breast and in the back:

> "It was a HUGE LUMP/ how I'D NOT FOUND it before god only knows." (S~~s~~tanza 4)

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When talking about the back pain, which was subsequently diagnosed as bone metastasis, Angela commented that:

> "So I just think to myself, I SHOULD HAVE SPOTTED SOMETHING YEARS AGO
> IF I'D SPOTTED something years ago / MAYBE I'd be alright."
> (S~~s~~tanza 8)~~.~~

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There are times where she felt let down by the services particularly in light of the progression and detection of her illness. Angela talked about seeing a physiotherapist for back pain, which turns out to be bone metastasis. She also experienced anger towards her clinicians when being given the news that her cancer had progressed to her liver. This was a big shock because she had had a number of negative scans previously.

> "Then I broke my leg at Christmas and SUDDENLY THEY ULTRASOUNDED MY LIVER AND THERE IT WAS AGAIN
> So that week was a week from hell because I WAS SO ANGRY SO ANGRY." (S~~s~~tanza 30)

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After being given the diagnosis of liver metastasis, Angela was given a prognosis of six to nine months and was told to put her affairs in order. Following this at her next appointment, she felt that she was given different news, by another clinician.

> "He explained to me that what he should have said was that WITHOUT ANY TREATMENT AT ALL / then six to nine MONTHS PROBABLY." (S~~s~~tanza 38)~~.~~

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Angela appeared to be searching for answers as to whether anyone was to blame for her cancer. She questioned both herself and services. The regret of missed opportunities and the possible biographical disruption which may have occurred due to missed opportunities appears to weigh heavily on Angela. This would suggest that she was perhaps still trying to make sense of the diagnosis and searching for acceptance.

Costs of treatment

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Angela described that the treatment for cancer was hard work, aside from the physically demanding treatment itself. She presented the costs of treatment in terms of time, transportation to and from various appointments and treatments.

> "It's HARD WORK / you've got ONCOLOGY APPOINTMENTS /you've got BREAST SURGEON appointments / and now I've got ORTHOPAEDIC APPOINTMENTS that I have to go to."~~.~~ (Stanza 54)

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In addition to the cost in terms of time to attend the appointments, there is also the actual financial cost of attending appointments, which involved petrol and parking.

> “That means car parking at hospitals to go to radiotherapy FIFTEEN DAYS CONTINUOUSLY.” (S~~s~~tanza 20)

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Angela talked of the impact on finances of cancer. Similarly, with an incurable cancer diagnosis, time becomes a finite and precious resource too. These resources are both important to Angela and spending them was difficult for her.

Family Context of cancer

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Angela noted the impact of the initial cancer diagnosis on the whole family unit:

> “So it sort of HIT US ALL PRETTY HARD really.” (S~~s~~tanza 14)

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Angela appeared to feel guilt both for the over involvement of her daughter in her illness and her inability to care for her mother.

> “I FEEL GUILTY/ I think that you should be LOOKING AFTER YOUR MOTHER at that time shouldn’t you?” (S~~s~~tanza 51)

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> “WHEREAS MY 22 YEAR OLD DAUGHTER SHOULDN’T have to be looking after me at my age.” (S~~s~~tanza 52)

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Angela went on to consider the life of the family unit when she is gone and her regret at not being able to be a grandmother. Angela talked about pre-existing difficulties within the family that are exacerbated by the impact of the illness. She described individual issues with all family members.

Summary

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In Angela's narrative, there was a balance between positivity and anger (about herself, husband and services). Her cancer narrative is embedded within the context of her family. She paid close attention to both costs and resources when considering her illness, in terms of finances, emotions, time and relationships. There appeared to be specific focus on finances, including worries about income, providing and leaving money. Her newer diagnosis of liver metastasis appeared to be the most raw, perhaps due to the recentness of the diagnosis or because of the dramatic change in prognosis and with that the biographical disruption. She continued to search for answers about her illness, perhaps in an attempt to regain a level of control within ~~it ,~~it, which continued to progress.

Case Study 3: Kate's Story

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The cancer journey

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Kate was first diagnosed with primary breast cancer, which was treated with a lumpectomy and then a mastectomy. She was given hormone treatment for 5 years. After a period of 8 years in remission, she was diagnosed as having secondary bone metastases in her spine. Her primary tumour site was undefined. She has since been treated with chemotherapy and radiotherapy. Some of the themes, which were present in Kate’s narrative, were nursing, impact on others, teams, making changes to cope and the occupation of cancer treatment.

Impact of the cancer diagnosis

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Kate referred to her experience of cancer at times in terms of her ‘battle’ and ‘the fight’. When she discussed the emergence of her secondary cancer she referred to it as ‘It side swiped me’ as it returned somewhere where she could not check: in her spine.

> “I thought I’M A NURSE, WE GET BAD BACKS/ hospitals are FULL OF PEOPLE with bad backs.” (S~~s~~tanza 76)

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Kate talked about the period between her first and second experience of cancer. She described having an increased awareness of cancer and in some sense waiting for the cancer to return:

> “But when you’ve had it , YOU ALWAYS THINK WELL I COULD GET IT AGAIN / I SUPPOSE WAITING for it to come back in a way/ but NOT ALL THE TIME.” (S~~s~~tanza 73)

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Kate talked of her shock at the return of the cancer after 8 years of remission.

> “DIDN’T SEE IT COMING BASICALLY / THE SECOND TIME
> I’d always thought that the second time would be LIKE THE FIRST TIME.” (S~~s~~tanza 15)

> “But to be told that I was STRAIGHT INTO METASTASES
> I think that was more of THE SHOCK.” (S~~s~~tanza 16)

Kate’s vigilance for the possible return, and the cancers return despite this was very difficult for her to accept. She held an idea that it would return in the breast, she would catch it early and receive treatment for a reoccurrence. This biographical disruption was particularly difficult to tolerate.

Nursing

Kate’s experience of nursing was evident in all aspects of her life with cancer. She described the value, which she had found in the support of her colleagues, whom she felt more able to be open and honest around.

> “I can talk to my NURSE FRIENDS IN A LOT MORE DEPTH than I can to family.” (S~~s~~tanza 48)

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> “IM LUCKY that I’ve got more nurses around me than anybody
> Because THEY, WE HAVE A DIFFERENT OUTLOOK.” (S~~s~~tanza 59).

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Kate’s experience of nursing had helped her to make sense of the experience of cancer and cancer services. She talked about her experience of treating others and how this had helped her to accept her own experience:

> “My thing is I’m NOT SCARED OF THE HOSPITAL
> I KNOW what they’ve got to do.” (Stanza 62)

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She felt able to talk to the medical team on a higher level than laypersons. This helped her maintain the idea that she was more than another patient:

> “I think NURSE-WISE AS WELL,
> THEY TALK TO ME as I talk to them
> I UNDERSTAND so if they are talking about drugs/ we KNOW WHAT WE’RE TALKING ABOUT.“ (S~~s~~tanza 42)~~.~~

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The use of ‘We’ suggests that she felt a part of the treating team. This appeared to help her to feel more competent, in control and knowledgeable about her circumstances. Also, this may have helped to feel as though her treatment was co-constructed. She described sometimes finding it difficult to accept her role as a patient.

> “It’s HARDER TO SEE YOURSELF AS A PATIENT~~/ it~~/ it might JUST BE ME.” (Stanza 61)~~.~~

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Teams

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Kate described having a number of consultants in the context of describing how well she felt that she was looked after by cancer services:

> "Well I'VE GOT ABOUT FIVE CONSULTANTS, well I'm back to four." (S~~s~~tanza 36)~~.~~

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Kate made favourable comparisons of cancer services over primary care and general medical care, based on her personal experiences of care.

> "You get used to being LOOKED AFTER REALLY WELL." (S~~s~~tanza 38)~~.~~

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Kate described a number of conflicts between two teams over whether or not she was developing liver metastases, whether or not she had stomach cancer or breast cancer in the primary site and whether to continue with hormone treatment or switch to chemotherapy. Rather than being damaging, she saw this as people striving to give her the best care.

~~Impact~~ Impact of cancer on others

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Kate mentioned several examples of how her cancer had negatively affected others. She talked about a previous close friend:

> “I’ve got one friend who I HAVE KNOWN A LONG TIME / but she told me last year that she’d HAD A TERRIBLE YEAR AND PART OF THAT WAS BECAUSE OF ME BEING ILL.~~ ~~“ (Stanza 50)~~.~~

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She also talked about her sister who took time to adjust to the cancer diagnosis and her husband.

> “My sister took A LITTLE BIT TO GET HER HEAD ROUND IT, which she did
>
> It’s A LOT FOR [MY HUSBAND] TO TAKE ME SOMEWHERE and it’s a lot on him.” (S~~s~~tanza 80)~~.~~

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Kate’s worry about affecting others appeared to be her greatest fear. This may have been driven by her need to protect others from her cancer, and may have been influenced by her career. Kate also talked at length about how others perceive her health and well-being from either the expectation that she should appear to be more poorly or dying, to others commenting that she looks ‘really well’ and wondering whether she is in recovery.

> “My husband’s brother says, ‘OH YOU LOOK REALLY WELL / ARE YOU FEELING BETTER THEN.” (S~~s~~tanza 53)~~.~~

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> “But the main thing everybody says ‘OH YOU LOOK SO WELL.”~~’~~ (S~~s~~tanza 58)~~.~~

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Although this was a point for amusement, Kate found it difficult not being be understood and people not appreciating the true extent of her experiences.

Occupation of cancer treatment.

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Kate described in some detail her level of involvement in her cancer treatment. This was a topic that Kate and her husband had spent time discussing, as it was a well-developed discourse.

> "But then that's life, you're at the HOSPITAL EVERY WEEK / you're BEING SCANNED
>
> You know that is LIFE FOR US NOW you know the hospital, the hospice in between
>
> I've been in EVERY SCANNER in the county." (S~~s~~tanza 94)~~.~~

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Kate described how she and her husband sought time away from the hospital and found difficulty in doing so.

> "Our life now is getting TIME AWAY FROM A HOSPITAL APPOINTMENTS
>
> If you've got a couple of weeks with no hospital appointment YOU'RE DOING WELL

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> And they do try, the hospital will say try and HAVE A FEW WEEKS AWAY FROM US / and then you get a scan in the middle of it so it NEVER QUITE WORKS OUT yeah.” (S~~s~~tanza 95)~~.~~

Kate was aware of the amount of time which she spends undergoing treatment, tests, scans and consultations. She was also aware of how this affected other aspects of her life, particularly the quality aspects of normal life. However, she was resigned to engaging with this to support her life in terms of adding survival time and quality.

Summary

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Kate’s experiences as a nurse appeared to help her deal with her experiences as a patient although she initially found this difficult to accept. At times, she viewed her own experience as a case study, which allowed input of her own knowledge and expertise. She experienced her treatment not a passive recipient, but felt more involved and valued as a result.   She was able to use her understanding of the systems to evaluate the services and treatment received.   Her experiences were framed in the context of nursing.

The support of her nursing colleagues appeared to be an invaluable source of support. This allowed her to protect her husband and sister from some of the more difficult experiences of her treatment.   However, she clearly valued the support of both her husband and sister, who were able to offer her something different from nursing colleagues. Kate and her husband took a problem solving approach to ‘living with cancer’, which appeared to have been effective in helping them both to manage. Kate talked about the all-consuming level of time in engaging with cancer treatment and the associated hassle that this created. She identified the lack of time for anything else, which appeared to be a clear source of frustration and an obstacle to getting on with her life.

Case Study 4: Julia's Story

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Cancer journey

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Julia was diagnosed with secondary cancer during her first contact with services. Her primary tumour was located behind her heart with a secondary tumour in her lung. Julia was given hormone treatment, and two courses of chemotherapy. The themes which were present in her narrative were her relationship with cancer, taking an active part in treatment, beating the numbers, survivor's guilt and making adjustments.

Impact of the diagnosis

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Julia spoke of her diagnosis and the impact of it for five stanzas. She spoke about initial shock when cancer was first mentioned, but did not really remark on her own responses further. She spoke about medical staff not knowing what to say, and about the devastation of her husband.

> "But I WASN'T REALLY AWARE
>
> So it was perhaps GOOD FOR ME but in their eyes

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> I WAS ALREADY when they finally told me / I WAS ALREADY STAGE 4
>
> My cancer was stage 4 so it was a SERIOUS SITUATION." (S~~s~~tanza 9)

> "It was DEVASTATING FOR MY HUSBAND / my husband had been WORKING AWAY." (S~~s~~tanza 10)

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It appeared that Julia was more tuned in to the responses of others around her, or perhaps cut-off from her own emotions at the point of diagnosis perhaps as a defence mechanism. Julia appears more in tune with her emotions in later parts of the narrative so it is possible that her experiences around the diagnosis remain too painful, or less important than other aspects of her narrative.

Relationship with cancer

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Julia talked about her cancer in terms of having a relationship with it. She described it as something that cannot be shared.

> "It is I think it is VERY PERSONAL TO THE INDIVIDUAL
>
> I think it's like, NOT AN AFFECTION, you don't feel affection for it
>
> It's something that YOU CAN'T SHARE really / you can tell people how you feel; you can describe your symptoms or whatever BUT YOU CAN'T SHARE IT WITH ANYBODY
>
> It's VERY MUCH YOURS." (S~~s~~tanza 59)~~.~~

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This could be a mechanism to protect others from her cancer and may account for her unwillingness to share her diagnosis story. Julia also describes the cancer as something, which is always with her.

Julia refers to the fact that none of the treatment has helped in stopping the cancer from moving forward. She felt that each course has held back the progression.

> “I was NEVER IN REMISSION,
> It had never REALLY SHRUNK it / it had just HELD IT.” (S~~s~~tanza 25)~~.~~

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This reflected Julia’s position as a realist, and may be presented to counter the opinions of others who suggest that she ‘looks well’ or ‘seems well’ which she describes as not truly reflecting how she felt.

> “And people say to me [Julia] you’re doing SO WELL AND YOU COPE SO WELL
> But actually sometimes, I DON’T FEEL AS IF I DO INSIDE
> I might on THE OUTSIDE,
> But there have been times when you want to SCREAM AT SOMEBODY WHEN THEY SAY IT because you think well no I’m not coping very well sometimes.” (S~~s~~tanza 65)~~.~~

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This was a source of occasional frustration for Julia, as there was incongruence from what appeared to be from the outside and the lived experience.   This appeared to create a dilemma for Julia as she stated that her cancer cannot be understood by others, but she would like others to understand her lived experience better.

Doing something / regaining power

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Julia spoke about opportunities whereby she can take part in her treatment. For example when her consultant suggests that she can influence recovery from her biopsy surgery by walking to aid her recovery. Julia took an active role:

> "So as SOON AS I'D HAD THE SURGERY
> I WALKED EVERY DAY in the hospital as far as I could walk
> AS THEY'D LET ME to make sure my lung lifted /and stuck in the RIGHT
> POSITION." (Stanza 16)~~.~~

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Julia talked about her decision to stop any further active treatment:

> "I think that his feeling is that he's thrown THREE LOTS OF
> TREATMENT AT IT~~,~~
> And now it's started to IMPACT ON MY WELL-BEING,
> And there has to be a time when you say ENOUGH REALLY
> That's pretty much WHERE I'M AT, at the moment." (S~~s~~tanza 36)

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Julia spoke about maintaining normality in her life, which she saw as very important. She gave the examples of seeing family, going shopping, short trips away and maintaining ‘date night’ with her husband.

> “[my husband] and myself we’ve been married 35 years but we have a DATE NIGHT / FRIDAYS IS OUR DATE NIGHT / we go out for a meal EVERY Friday
>
> EVEN LAST FRIDAY/ I had the chemo and I’ll be honest I DIDN’T FEEL LIKE IT,
>
> [My husband] feels it’s NON-NEGOTIABLE unless I’m really sort of really feeling poorly / because there will come A TIME WHEN I WON’T BE ABLE TO DO IT
>
> And so we do try and PUSH THE BULLET a little bit.” (S~~s~~tanza 43)~~.~~

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These three examples seemed to suggest that it is important for Julia to maintain control over her treatment and her life, as she gave the impression that she is a person who does not readily accept an external locus of control. This taking back of responsibility was an important aspect of Julia’s self-image.

Luck Versus Guilt

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Of significance to Julia appeared to be ‘beating the odds’ and her apparent luck in some aspects of her cancer treatment. This appeared to give her something to measure her progress against, although the progression of the cancer is not something, which she is able to overcome. This appeared to give her some comfort, satisfaction and maintains her morale.

> “I have EXCEEDED THE ODDS that they gave me.” (S~~s~~tanza 16)~~.~~

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> “EVEN NOW it’s only in my lung that I am aware of/ after 26 months
> WHICH IS A LONG TIME.~~-~~“ (S~~s~~tanza 18)~~.~~

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> “When I see him, he [oncologist] always says HOW REMARKABLY I’VE DONE
> How good it is that I’ve seen TWO CHRISTMASES, which he didn’t think I would see.” (S~~s~~tanza 31)~~.~~

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It is important for Julia to ‘do her best’ for her family to be around for as long as possible, with some quality of life. Julia’s better than expected survival in comparison to her peers conversely also creates a level of guilt.

> “I question why OTHER PEOPLE HAVE IT SPREAD THROUGH THEIR BODY AND MINE DOESN’T
> It doesn’t seem LOGICAL THAT IT HASN’T SPREAD / when NORMALLY IT DOES spread in other people.” (S~~s~~tanza 62)

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This dilemma of ‘why me’ seemed to be apparent throughout Julia’s story. She was happy with her progress, appeared sometimes disappointed about the efficacy of the treatment, and felt as though she has somehow had an unfair advantage over her peers in her success at living with cancer. Julia appeared fully aware of the context of her experience within a population of cancer survivors, and within the context of her family and wider society.

Summary

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Julia had clearly spent a good deal of time trying to make sense of her cancer diagnosis and journey. She appeared to display a balanced account of both the difficult experience of a cancer diagnosis and to be able to reflect on some of the positive aspects of her life as a whole and her cancer journey. There appeared to be evidence of several dilemmas in Julia’s account. The dilemma about treatment or no further treatment is considered, as is the dilemma between sharing and protecting others from her experience. Her story highlighted both sadness and some satisfaction with aspects of her journey. Her story appeared to demonstrate a person attempting to retain some aspects of control over her life and treatment whilst attempting to manage both the symptoms of the illness, the side effects of the treatment and the psychological difficulties in coming to terms with a terminal illness. Julia attempted to take an active part in her cancer experience where possible.

Case Study 5: Keith’s Story

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Cancer Journey

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Keith was diagnosed with cancer of the oesophagus with secondary bone metastasis in the shoulder. He was given both diagnoses at the same time. Keith was treated with radiotherapy and chemotherapy. He had experienced the radiotherapy but was only part way through chemotherapy. The themes, which were drawn from the narrative, are partnership working, positive feedback, normality and post-traumatic growth.

Impact of the cancer diagnosis

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Keith~~vin~~’s story focused on the impact of the cancer diagnosis more than the other case studies. This may be due to him being closer to diagnosis in terms of time. Keith referred back to questioning his diagnosis on several occasions, talking about it as an existential crisis. This is evident in Stanza 5, Stanza 19, 20 and 65. This would suggest that he was having difficulty in coming to terms with the diagnosis.

“The FEELINGS still exist / of why should I still go THROUGH ALL OF THIS,
THE SHOCK has worn off
But I DON’T SEE WHY,
I still wonder why, WHY ME.” (Stanza 19).

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The ‘why me’ narrative almost frames every other story in the whole piece. Keith was communicating his difficulty with the experience, acceptance of the diagnosis and his bad luck in comparison to others who have worse lifestyles than he has.

Partnership working

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Keith talked of ‘shutting down’ when diagnosed with cancer. He talked about his wife having to take over managing his care where previously he had been able to look after himself. He refers to this early in his account and refers back to this throughout.

“[My partner] had to take EVERYTHING ON BOARD,
Well I was THERE
But the lights were on but NOBODY WAS IN,
And it WENT ON FROM THERE.” (Stanza 4).

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He mentioned specifically about her having to manage his medication and dietary intake. Keith appears to adopt the patient role, aspects of passivity and going into shock. Keith refers many times to the support of his wife. He refers to his progress often as “we”, particularly when considering solving problems.

> “The second time around WE MANAGED TO GET RID OF A LOT OF THE BOREDOM / —By taking a load of BOOKS IN, A RADIO A MOBILE PHONE

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> And also WE WENT OUT AND BOUGHT a portable DVD player
> On the whole we managed to KILL MOST OF THE TIME.”
> (Stanza 48).

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The care and support his wife was seen as invaluable to Keith. Keith’s passivity should be considered in light of the timing of the interview. Keith was still in the midst of primary treatment. This experience and the experience of the cancer itself appeared to be psychologically challenging.

Happy with progress / positive feedback

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Keith’s focus throughout his story is tinged with positivity and hopefulness. He was still in active treatment and talked about his progress following the treatment in terms of both what he had noticed, and feedback from others. This was stated in Stanzas 29, 33 and 46.

> “I’ve been told SINCE THE TREATMENT STARTED
> The consultant has ALREADY SAID,
> I LOOK A LOT BETTER,

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> I been told by different people, relatives that I LOOK A LOT BETTER AND SOUND A LOT BETTER.” (S~~s~~tanza 29)~~.~~

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> “But I think from what the GP AND THE CONSULTANT have said,
>
> They’re QUITE HAPPY with the results
>
> And WHAT I’VE SAID so far
>
> That it MUST BE WORKING.” (Stanza 46)~~.~~

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In Stanza 33, Keith talks about his own thoughts about his progress too. Following this, he goes on to talk about his improvements around his eating and around his pain levels.

> “So I would say that it’s a GOOD SIGN THAT IM GETTING BETTER.”
>
> (Stanza 33)~~.~~

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Keith was most pleased by the feedback of others in monitoring his progress. He noticed the improvements himself but he valued the opinion of others over and above this. The positivity of others had allowed him to maintain a good level of morale.

Normal

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Keith talked on a number of occasions about the difficulty in his experience, but also the normality of his experience. He appeared to have been seeking reassurance from peers, medics, the clergy and society in general. This appeared to be important to Keith that he retains normality.

> "I mean I've been told that that's what EVERYBODY GOES THROUGH
> When they've been DIAGNOSED WITH CANCER
> And being treated that's HOW THEY FEEL.
> ALL THE WAY THROUGH THE TREATMENT they said they still get days like that." (Stanza 41).

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Retaining normality was very important to Keith. He was keen to express that none of his reactions were abnormal; however, he may have once believed that they were. Keith seemed to find comfort in having shared experiences with other people with cancer.

Post Traumatic Growth

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Keith referred on several occasions to positive personality changes that have occurred. He talked about improvements in being able to express his feelings more, being more patient and less argumentative. He talked about cancer as a life-changing experience, but in contrast to the existential crisis, he notes several positive changes in his life. There are at least five references to this.

> "All this [the claustrophobia] has occurred SINCE THE CANCER HAS KICKED IN,
> I've also found that my ATTITUDE TOWARDS PEOPLE GENERALLY HAS CHANGED
> I can be MORE PATIENT
> And MORE UNDERSTANDING of people's illnesses and disabilities."
> (Stanza 55).

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Keith had been searching for positives to the experience and this part of his narrative contrasts with the existential crisis thread. This leaves the account seemingly balanced. It appeared to be important to Keith for the cancer to have at least some positive impact on his life.

Summary

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Keith remained in the primary treatment phase at the time of the research interview. Keith's narrative was less organised than other participants, in terms of flow and content, but this could be due to his position in terms of time since diagnosis. Keith was perhaps the closest participant from the actual diagnosis, so has had less time to organise and make sense of his story. His tone appeared to have more in common with cancer survival stories, in his description of hope for cure and remission. Keith may always have the 'why me' question in his narrative. It is unclear whether this is due to his stage of his journey or if he will find acceptance. Keith's account overall is very balanced, with almost an equal number of positive and negative statements and he was continuing to try to make sense of the experience of cancer. He was still experiencing biographical disruption and liminality as he is continuing to work out his story. Overall Keith appears unsure of his own skills and abilities, and was at that time reliant on others for feedback and support. He saw his wife and team as essential in helping him to cope. Through much of his account, he appears to be a passive recipient, however he has reflected on his experience and continues to make sense of what has happened to him.

Overall Analysis of Combined narratives: Shared narratives

It was considered equally important to consider the collective narrative. Themes which occur in more than one persons’ narrative were~~as~~ included, even if they did not emerge as a significant part of the individual’s narrative.

Impact of the diagnosis

Most of the participants talked about the shock of diagnosis; however, this was not a narrative that was developed in the majority of peoples’ stories.   For most people it appeared as a marker for the start of their cancer journey. Keith spent much more time than others talking about the diagnosis. Overall, participants only talked about their diagnosis for between two lines and five stanzas.   Of much more interest to participants was telling the story of how they live with

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cancer. Inferences cannot be drawn about the differences between primary and secondary diagnoses as these were only demarcated in one account.

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Costs of treatment

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Four of the participants commented on the high costs associated with their secondary cancer treatment. This incorporates costs in terms of energy attending appointments, difficulty in getting away due to increased travel costs and worries about becoming ill away from their treating team, in addition to the actual costs of transport and parking.   Of most significance appears to be the costs in terms of time. Participants appeared to spend a large proportion of their time attending appointments, blood tests, scans and follow-ups. It appeared that time away from the hospital was difficult to attain.   This may be because participants feel as though they are time-limited in terms of their survival and anything which affects this was seen as problematic.   There was little acknowledgement of the hardships of the treatment itself except in Julia and Angela’s case who were hospitalised by chemotherapy. These narratives were not developed in either case.

Comparison with others

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The comparison of progress with others appeared to be an important way of understanding a person’s cancer journey.   This led to feelings of luck, guilt, normality or a combination of the three. Where people felt lucky in some aspects of their progress they also tended to feel guilt. For Angela and Julia they both experienced some feelings of luck but also some feelings of guilt.

Angela felt guilty when considering her financial position in comparison with others. Julia talked about feeling guilty that her prognosis seemed to be over and above that expected of people around her. Keith looked to others as a marker for the normality of his experience.   Kate compared her experience of cancer with those whom she has nursed. Peter was able to monitor his own journey by comparing it with that of his late wife.

Normality

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The notion of ‘normality’ was present in all of the narrative accounts.   Keith found comfort in finding his reactions to the diagnosis and treatment were normal and common. Julia and Kate spoke about their efforts to maintain some forms of normality in their lives. This involves continuing in things which they have always done, possibly relating to maintaining roles and aspects of their life from before their cancer journey. This comes with extra costs and extra considerations for people on a cancer journey in terms of energy and well-being, but the benefits of the role maintenance appears to be very good for morale. All participants make some comments on finding ways to cope with the disease and the associated sequelae.

Feedback from others / expectations of others

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Contextually, the cancer impacted on a person's systems, and how they react to the cancer can impact on how the person copes. The majority of participants expressed concerns over the impact of cancer of people close to them. All participants described some feedback from others. The reports were basically split into two categories: helpful feedback and unhelpful feedback. Two men in this study only reported on positive feedback. Two female participants both commented on negative feedback that appeared to be well intended. Julia and Kate described the feedback from people suggesting that they look well or are doing well. These are probably innocent comments that are meant to convey a compliment but are construed as the person not understanding the experience.

Treatment dilemmas and approaching the end of treatment

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Both Peter and Julia talk about their dilemmas about continuing treatment; for Peter, this is an ongoing evaluation, whereas for Julia, she has decided that she does not want to have any further treatment. This may be due to Julia's experience of treatment holding progression, rather than having any more beneficial effects. These are both dilemmas that both people have reflected upon at great length. There is no mention in the other participants' accounts, which may be due to timing or personality traits of the individual involved.

Negotiating Teams

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All participants considered their care teams, and the process of negotiating their treatment. All participants are under at least two teams and some up to four. Angela, Julia and Peter express some anger at teams over possible missed opportunities, extended periods of waiting or of experiencing differences of opinion between teams or clinicians. Keith describes simply being unable to relate to one particular clinician. However, throughout their journeys, the participants appear to find the right combination of care, perhaps through negotiation, feeling more familiar and therefore understanding the process more and feeling more contained. Both Kate and Keith comment on the special care that they receive as cancer patients. Conversely, all participants comment on the amount of time spent at hospitals for appointments, scans, reviews and tests. This appears to be due to having cancer in at least two sites. More metastases mean more teams and more appointments. As the cancer progresses, the need for greater input increases too.

Continuous biographical disruption

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There is evidence of the notion of continual biographical disruption. Being diagnosed with cancer causes a very definite disruption itself. The major cause of extra distress is when the journey appears to be disrupted again in light of either progression or the development of new symptoms, or difficulties which the participants must again re-evaluate their perceived journey. Angela, Peter, Kate and Julia all express this. The outcomes of these disruptions always result in further input, treatments and appointments.

Finding positives in the cancer experience

All of the participants in this study report on some positivity within the experience of cancer. As such, the accounts appear to be somewhat balanced and to a certain degree uplifting. This is perhaps in contrast to lay-persons' ideas of what the cancer journey might be like. Peter talked about finding and maintaining competence in many aspects of his life and Angela speaks of her good fortune in comparison with other cancer patients. Kate makes reference to her valued support of her colleagues and family and her collaborative role in her treatment. Julia continually makes reference to her attempts to regain power and control, doing her best, and reflecting on a life well lived. Keith spoke of his management of boredom and positive changes to his personality and coping styles.

Discussion

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There are clearly individual differences both in the cancer journey itself and patients' experience of it. However, there are also some similarities and common features which participants share. These are specifically: costs of treatment, negotiating teams, maintaining or searching for normality, comparison with others, impact on others and treatment dilemmas. A very small percentage of the participants' narrative discusses the impact of the diagnosis on the person with cancer in direct terms. The narratives are much more concerned with the experience of others and attempting to get on with life which cancer and more specifically cancer treatment seems to impact on. Participants find creative ways to carry on as near to normally as possible.

All participants display elements of 'biographical disruption' (Bury, 1982) as would be expected in the development of a life-limiting illness. In secondary cancer, the trajectory of the illness constantly changes in light of further development of the cancer in various sites. Therefore there appears to be continuous biographical disruption which can change over weeks, months or years. Giddens (1994) refers to this as reflexivity. There is evidence of this in at least four of the accounts reported. Similarly, all participants engage in what Corbin and Strauss (1991) term as 'comeback', where the person attempts to reconnect their life prior to diagnosis with the present and future. There are clear examples of this in the current dataset.

Previous findings in the field of terminal illness have indicated that maintaining normality is one of two priorities for individuals, the other being preparing for death (Ekman, Bergbom, Ekman Bertold &~~and~~ Mahsneh, 2004). There is support for maintaining normality, but the preparation for death is a narrative that is not explored by participants here. Winter (2010) suggests that in advanced cancer, maintaining normality in everyday life~~ves~~ maintains at distance a future of illness and annihilation. Similarly, in the field of diabetes, normalisation is seen as a process where the impact of the illness is bracketed off so the effects on the persons' identity remain relatively slight (Kelleher, 1988). Most of the participants attempt to regain or maintain internal locus of control (E.g. Rotter~~,19~~,~~75~~, 1975) throughout the illness progression, and this level of perceived control appears to change over time as the illness progresses. As this occurs people find alternative ways to maintain or regain control. For example, Julia remains in control by having the ability to choose when to stop active treatment.

Many of the participants in this study spoke about the process of negotiating teams to a point where they were happy with the support which they received.

This might be considered to be a normal process which cancer patients engage in but this is difficult to ascertain with this small pool of participants. Mariscotti (2008) spoke about 'negotiating the dance' between clinician and patient. This looked at first person accounts of patients' relationships with GP~~'~~s throughout primary cancer treatment. The findings here suggest~~s~~ that parallel processes go on when working with a number of treating teams, or to use Mariscotti's metaphor a number of simultaneous dances are taking place, which must be negotiated to find an acceptable position for the patient within the context of a number of teams. ~~.~~

Comment [A34]: Expand a little here. What do you mean by parallel process in this context?

Belizzi, Bland and Oakes (2006) discussed social comparison theory with reference to cancer patients. They describe three types: upward, downward and parallel comparisons. They found that people who make downward and parallel comparisons tend to benefit from such comparisons. All narratives in this study did focus on downward comparisons, either feeling lucky or guilty compared to those worse off than them. There was no mention of others' who were coping better than participants.

Research which investigates~~look at~~ costs in cancer, has largely covered the cost of providing treatment. There is emphasis in the UK on the financial hardships which cancer can bring, but this is largely around loss of earnings and accessing benefits. The personal costs of cancer are not examined in the research. Considering the notion of time, the evidence base looks at waiting times, recovery times and survival time (e.g. Block et al., 2009). ~~.~~ These are all important organisational concerns, but the patient experience appears to be lost within this. The findings of this study highlight both the personal financial costs

Comment [A35]: Give example reference here and the impact of cancer treatment on time as important aspects of the narratives of cancer patients.

All participants reflected on aspects of positivity in the cancer experience. One participant talked about positive changes in personality following the diagnosis which suggest some aspects of post-traumatic growth. Calhoun and Tedeschi (1998) report occurrences of posttraumatic growth in illnesses such as cancer, HIV, and heart problems. The evidence base of post traumatic growth in secondary cancer is limited in comparison with the survivor population but has been found along the full trajectory of the cancer spectrum (Sumalla, Ochoa & Blanco, 2009). Arp~~o~~awong, Richeimer, Weinstein, Elghamrawy and Milam (2013) studied people in active treatment. They found that 87% of respondents experienced at least one positive life change through their cancer experience. A review of the post traumatic ~~growth literature~~growth literature in cancer (Heffron, Grealy & Mutrie, 2009) found some positive changes after cancer. They propose that through the process of cancer positive changes can occur in the re-appraisal of relationships, changing of priorities, existential re-evaluation and a new awareness of the body. Similarly Horgan, Holcomb and Salmon (2010) found positive changes following breast cancer: changed priorities in life and increased empathy for others. The findings here give partial support to these findings in the context of secondary cancer. ~~Calhoun and Tedeschi (1998) report occurrences of posttraumatic growth in illnesses such as cancer, HIV, and heart problems. Post-traumatic growthThis is usually more associated with the cancer survivor population, but has been found along the full trajectory of the cancer spectrum (Sumalla, Ochoa and Blanco, 2009). This may be~~

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~~associated with the participant in this study being more hopeful about prognosis, or based on the personality traits of the individual.~~

This study has attempted to begin the address the shortfall in the secondary cancer studies and also the living with cancer evidence base. Harris et al. (2008) previously identified a shortage of studies which address the views of people affected by cancer. The study has reflected some of the complexities of living with cancer which Corner (2008) suggested were not reflected in the survival literature, and also investigated some of the longer term consequences of a cancer diagnosis which was highlighted as a need in the Improving Outcome Strategies for Cancer document (DoH, 2011).

Comment [A36]: Good to see more theory and links with the lit in this section. Can you link any of this main section back to your introduction?

Implications for services

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Due to low participant numbers in this study and because of the nature of the research method, the results are not generalisable. However it is hoped that the ideas expressed within will resonate for strategic planning and front-line care in improving the experience of cancer services. The NHS outcomes framework for 2013/2014 (DoH, 2012), identify two domains which are relevant to the findings in this study: Enhancing quality of life for people with long-term conditions and ensuring that people have a positive ~~expereince~~experience of care.

The findings suggest that people would be well served if services could support them to be able to negotiate treatment more easily. Additionally, the outcomes suggest that finding ways to streamline appointments for cancer patients so they are not forced to spend more time than is necessary attending appointments or scans, would free up more time for them to live their lives.

These findings advocate for services to be more joined up, to share information and to be~~being~~ more collaborative, putting the patient more at the centre of care. This would also support the provision of 'cancer centres' which are perhaps better set up to deliver streamlined, patient centred care.

The findings suggest that there is some value in supporting people to maintain normality, and links with their lives from before cancer. The final recommendation would be around finding ways to support cancer patients, carers and families in a way that supports the whole system. This obviously goes on currently but still appeared to be less than optimal in some cases.

Comment [A37]: Link this to NHS literature. The NHS plan talks about enhancing the patient experience. The Berwick report also highlights this.

Limitations

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As previously mentioned, due to the low number of participants it is difficult to generalise the findings across the population of people experiencing a secondary cancer diagnosis. However, interviewing fewer participants has allowed the study to go into significant depth with the analysis. One of the difficulties with narrative studies is the issue of validity and rigour. Reissman (1993) discussed the concept of rigour in narrative analysis. She proposes four characteristics for ensuring rigour: Persuasiveness of the analysis, correspondence, coherence and pragmatism. Persuasiveness is achieved if the analysis is reasonable and convincing. The method proposed by Gee (1991) has a clear process to follow when analysing data. One would assume that other researchers would report similar findings from their analysis of the data. Based on the audio recordings, the line and stanza structure would be identical as would the five levels of analysis. The sixth level of analysis: A coherent reading of the narrative could potentially vary between researchers and it is entirely possible that researchers might find in the data the information which they are looking for. A reflective diary was maintained to record all decisions about reporting the data and the analysis. The final analysis has been read widely and appears to be acceptable to readers.

Coherence is how the analysis makes use of global, local and themal analysis both within and between participants. Employing the method correctly again addresses most of these concerns as this is level two and six of the analysis. The analysis of coherence within and between participants was limited by the word count where only the most significant narratives could be reported on. These decisions are open to criticism and debate, but appear to be coherent in the overall analysis. Correspondence is whether the analysis and the reporting makes sense to the participants. Due to time constraints this has not been possible before submission. Pragmatism is the extent to which further research is made on the basis of the original work. This can only be evaluated following submission and publication. In terms of rigour, this study has met two of Reissman's four criteria and will potentially meet all four after publication.

~~As previously mentioned due to the low number of participants it is difficult to generalise the findings across the population of people experiencing a secondary cancer diagnosis. However interviewing fewer participants has allowed the study to go into significant depth with the analysis. One of the difficulties with narrative studies is the issue of validity and rigour. The method proposed by Gee (1991) has a clear process to follow when analysing data. One would assume that other researchers would report similar findings from their analysis of what is in the data. However it is entirely possible that researchers might find in the data the information which they are looking for. A~~

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~~reflective diary was kept by the researcher to record all decisions about reporting the data and all parts of the analytic process were carried out to identify participant stories. With a higher word limit, further depth could have been reported, however those reported here appeared to be the priorities for the narrators. Reissman (1993) discussed the concept of rigour in narrative analysis. She proposes four characteristics for ensuring rigour: persuasiveness of the analysis, correspondence, coherence and pragmatism. Persuasiveness is achieved if the analysis is reasonable and convincing. Correspondence is whether the analysis and reporting makes sense to the participants. Coherence is how the analysis makes use of global, local and themal analysis, and pragmatism is the extent to which further research is made on the basis of the original work. Correspondence and pragmatism takes part in the dissemination of the study. The analysis here appears to be both persuasive and coherent.~~

Comment [A38]: I'd be tempted to rework this section a bit to comment on how your work addresses Reissman's 4 factors.

Further research

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The concept of time and time spent in contact with cancer services appears to be an important aspect of the cancer journey. Further research may ~~could be carried out~~ investigate~~ing~~ the actual time spent compared with the perception of time, or how the time in contact with services is used. Data~~This~~ could be used to highlight any repetition or ways in which people's treatment journey could be streamlined to limit the amount of wasted time for people where time is a very precious and perhaps limited commodity. From the findings here people tend to find appropriate care by negotiation with various teams and clinicians. I~~i~~t would be of interest to examine how people do this and if anything can be done to make this process easier. This could be measured by a series of interviews

Comment [A39]: How would you research this? Briefly specify over time specifically about their contact with the treating teams or equally this could be done by asking participants to keep a diary of their contacts with the teams for analysis.

Some of the data collected here suggests that how people make sense of their story may change over time. Two participants with relatively new diagnoses appeared anecdotally to be more distressed than participants with more historical diagnoses. To examine this phenomenon, longitudinal data could be collected and compared within participants, to examine the impact on distance of time from diagnosis.

Comment [A40]: This section is a bit tentative. Try and make more punchy!

Conclusion

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Narrative analysis with attention to units of discourse is an appropriate way to examine the psycho-social impact of people diagnosed with secondary cancer to look at individuals' issues, life experience and the cancer journey. Although cancer and particularly a secondary cancer diagnosis impacts on all aspects of an individual's life, the psycho-social impact on an individual does not form a large portion of the participants' story about themselves. Individuals in this study focussed much more on maintaining the other aspects of their life which does not include cancer, where possible. Of particular interest is how people negotiate an increasing number of treating teams which become apparent in secondary cancer, to find acceptable levels of care.   The notion of time spent engaged in treatment, under treatment surveillance, and attending appointments appears to be significant and interferes with participants taking part in their 'normal' life. These two aspects of a person's cancer journey highlight the importance for services to continue to develop ways to help individuals to negotiate their treatment and also to maximise any opportunities to save time for ‘normal’ activities~~. It was not possible to explore differences between primary and secondary diagnosis in this study as four participants experienced a secondary diagnosis in their first contact with services.~~

Comment [A41]: Nice summary

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Paper Three – Reflective Paper

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My platform ticket and ride-along on the cancer journey

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Introduction

Conducting a thesis is a significant element of completing a doctorate in Clinical Psychology. This commentary offers some personal reflections on the conduct of this thesis: ‘Using narratives to understand the psychosocial impact and meaning making of those diagnosed with a secondary cancer diagnosis’. This paper is largely written in the first person and is focussed on the barriers and challenges to completing a piece of research, and the learning points from this process.

Topic generation

Working in the field of health psychology as an assistant psychologist within both a cardiac setting and also a cancer setting, and also having a trainee placement in a cancer setting brought me into contact with people in distress trying to make sense of illness and recovery. I always found myself drawn to admire the resilience of people and how they found ways to make sense of an illness within the context of their life. As a clinician I have long been interested in people’s stories and how people organise these stories to present them to a listener. I have been shocked at laypersons’ responses to the perceived difficulties of working with people who are ill and the perceptions around how difficult this is. Prior to working with people experiencing illness I would have perhaps shared this perspective. The experience of working with people facing illness, I have always found to be hopeful and positive and I wanted to share these ideas with others, I was of course unsure if my project would highlight this. From personal experience, during my first year of clinical training, my uncle was diagnosed with motor neurone disease and subsequently died. I was very struck by his dignity and how well he faced up to this terminal diagnosis, and how he lived his life well up until his death despite the disabilities and the mental difficulties which this illness brought. The concept of facing up to mortality has been a topic of both interest and fear in my life, which we must all face up to at some point. My trainee placement in particular led me to work with people that were under palliative treatment and attending the hospice. I developed an interest in how people cope and make sense of this type of prognosis, but also in the stories people tell which help them to make sense of the experience. I always found this to be very~~a~~ powerful~~ experience~~. I found that people often talked to me as a clinician about their cancer experiences, but rarely with their peers or family. The idea for my research project came from having some way to allow others to share in stories about their ~~ experience of the ~~cancer journey.

Comment [A43]: Repetitive use of the word ‘experience’ so I have suggested some changes.

The ethics process

Ethically working with a population of people who by their very definition are facing an illness without the traditional concept of cure and recovery, was always going to be a difficult population to access for the purposes of study. I was aware of the need for sensitivity and of working ethically with this group[~~population~~. Communicating this to the relative parties was never going to be easy.

Comment [A44]: Relevant?

Traditionally the focus for~~of~~ Trainee clinical psychologist's in terms of the research thesis is to access people quickly and conveniently, and ~~to~~ not to work with NHS patients due to the difficulty in navigating the NHS ethics minefield. My particular focus was not to do a piece of research for the sake of completing a research task, but for it to be meaningful and worthwhile and to contribute back to the organisation which has funded my training.

My research participants were a hybrid population: people under the care of a hospice. The hospice is a private charity organisation which sees patients who are partly funded by the NHS but are not technically NHS patients. To cover all bases I went for University ethics, and NHS ethics. (Please see appendices D and E for~~for~~ relevant approvals). My University ethics went through on second attempt, and I got through proportionate review on my first attempt. I was particularly surprised by this as this population is usually well protected by ethics committees, who perhaps gate-keep these participants too rigidly leading to less people carrying out research in this area. However my study was delayed in trying to get Research and development a~~&D a~~pprovals.

Comment [A45]: Specify appendices

Comment [A46]: Specify in full, then abbreviate

I had many dilemmas when going for NHS R&D. In the context of the health service at that time, Primary C~~c~~are T~~t~~rusts had just collapsed, Clinical Commissioning Groups (CCG) were very much in their infancy. There was no facility for achieving R&D through CCGs at that time. Conversely through numerous conversations with various research committees and R&D departments, I was given the advice that ~~actually~~ I~~i~~ could have undertaken the project ~~gone~~ without NHS Ethics and R&D approvals. Navigating this part of the research process held up my study for a considerable period, and caused much frustration. I proceeded with both University, NHS and hospice permissions to continue with the study, but without formal NHS R&D approvals.

Reviewing the literature

The available literature for my chosen area of research was so sparse that I was forced to choose a related but different topic area. I chose to look at the psychosocial interventions developed for survivors of cancer. My primary interest for the research paper was the psychosocial experience of a secondary cancer and particularly a secondary cancer diagnosis. I was interested in the UK context, so focussed my review on UK studies which were developed after a significant paper was published: The C~~c~~ancer R~~r~~eform S~~s~~trategy (Department of Health, 2007). This highlighted that there is limited research being carried out in the UK with a reliance on studies from overseas, and ~~also the idea that~~ there exists~~is~~ no recognised ideas about best practice, or even what constitutes a psycho-social / psychological intervention in the field of cancer. There appears to be very little uniformity in either the interventions used or the methods of assessing the interventions which leads me to believe that there is very little communication or the sharing of ideas between research groups in this setting. This is obviously not good for cancer patients and probably reflects the idea that the psychological and mental health impact of cancer is still a relatively new and under researched area of cancer care. For the evidence base to improve in the UK there needs to be a more integrated and collaborative approach to research in this area.

Comment [A47]: You might want to say what this meant to you as a researcher?

The research report

The research report itself was a strenuous and difficult task. The use of narrative analysis seemed very appropriate to look at individuals' experience of a secondary cancer diagnosis. I was drawn to the idea of case studies as I believe in the strength of the stories of individuals ~~which I believe~~ are very powerful and can sometimes be lost when broken down thematically in methods such as IPA or grounded theory. Armed with the knowledge that I~~i~~ wanted to 'do' narrative analysis, I explored many different approaches to this. I opted for perhaps the most structured of these; Gee's method of narrative analysis with attention to units of discourse. This appealed because it gives you a step by step method of how to analyse your data. I also liked how the method broke down the data into poetic stanzas. However this was a very long, labour intensive process. Some studies which use this method report on a single case study. The data gave very satisfying poetic stanzas for each participant, which unfortunately was lost in the final report. I also have a number of notebooks of a reflective diary on decisions about what to include or exclude which is also not part of the final report. These two pieces of personal work are perhaps the most satisfying as they are the evidence for me as a researcher of the work which I have put in to this project.

Reporting on these narratives involves lots of reduction. Decisions on what to include and exclude was perhaps the most difficult of the tasks of this research although guided by the method, the reported narratives needed to be limited.

I really wanted the voices of my participants to be the main focus of my research. This brought real dilemmas. I felt a real pressure to do my participants justice and to try and keep their narratives whole. I think I~~i~~ could have used the word limit five times over. Each manuscript was between 5000-7000 words. To fit into a reasonable word count there was a maximum of 1400 words for each participant which included analysis. I would estimate that approximately 300 words of extracts were~~as~~ used for each participant. I had real dilemmas of what to include and exclude.

Getting the right level of recruitment was difficult. Ideally I~~a~~ was looking to recruit people with demarcated primary and secondary diagnoses, however this proved difficult. Four of the five participants had both primary and secondary diagnoses at the same time. Initially I wanted to recruit upwards of six participants. Perhaps on reflection, even five was too many. Some depth of the reporting of the analysis is lost in the report due to the word limit.

Professional learning

The research experience has been both difficult and enlightening. I found the concept of semi-structured interviewing to be difficult coming from the standpoint of a clinician. To allow people to speak at length without lengthy~~lots of~~ questioning was at first difficult. I was surprised at times in the ways in which narratives developed naturally and how people explored their narratives around experiences without prompting. I think that this has perhaps encouraged me to speak less sometimes in clinical settings to really hear~~re~~ how people understand their experiences and how they make sense of it. I feel that I have developed expertise in this particular research method which I would recommend to the novice researcher as a contained method to analyse narratives. Largely with narrative methods, both its strength and weakness is that there is no prescribed way to carry it out. Since using this method, I have found the way I work with language has changed somewhat. I am more tuned in to hear the focus of sentences and to recognise stanzas, strophes and parts of stories. I hope that this will not diminish over time.

I am not sure that I was prepared for the level of involvement that this piece of work has required. At times this work has felt too big for me to manage alongside other academic and clinical demands and I have sometimes felt as though I have held back because I have wanted so badly for this to be right and fair to my participants. I know my data intimately and I am pleased with the outcomes of this piece of work, but I~~i~~ am still scared whether~~that~~ I have done my participants justice. I have been at times perhaps, too emotionally attached to this piece of work. This has at times led me to be very sympathetic in my analysis. However through the use of the reflective journal and conversations with my supervisors and colleagues, I have been able to recognise this and to limit its impact on the analysis and the reporting to a minimum.

Comment [A48]: How might this have affected your analysis or write up?

Personal learning

I find that the narratives of the participants in this story are very moving and powerful accounts. I am really struck by the resilience and attempts to cope which what I~~i~~ can only imagine are ~~a~~ difficult prognose~~i~~s. I hope that when I am forced to look at my own mortality I am able to do this with similar dignity and optimism~~hope~~. I have enjoyed hearing the stories of participants in a more naturalistic form, without interruption and to see a fully formed story emerge from the interactions.

The research process has been arduous at times and at times I have not wanted to finish it or rush it to get through. However I have felt pressure to get this right for the sake of my participants, whose time I have used, particularly when an important narrative from the study is of not having enough time for normal things. I hope that I have been able to do them justice. I have found this piece of work to be deeply personal and I have struggled to let it go and be happy with any part of it. On reflection, a less meaningful research project would have perhaps been easier~~more easy~~ to complete quickly and to be less involved with. However I am of the belief that all research completed outside of academic work will be around topics which have significance to me as an individual and a clinician. In this respect this project has prepared me for future attempts at research in the workplace and the experience has had a positive impact on my clinical work.~~.~~

Comment [A49]: And clearly wider than that.

This is a nice reflective review and you have talked about the impact of the project and how you have evolved as a researcher.

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~~Appendix A : COMPASS Checklist for review studies~~

Appendix A1: COMPASS checklist for reviewing psychosocial/ psychological interventions (Hodges et al., 2011)

Lifestyle Intervention: Bourke et al. (2012)

Context	Indications	Prostate cancer
	Population	Inclusion: T3-T4 Prostate cancer Receiving Androgen suppression Therapy for >6months Exclusion: Unstable Angina, uncontrolled hypertension, recent heart attack, pacemakers, unstable bony metastases, those already undertaking regular exercise
	Location	Sheffield: outpatient clinics
Domain 1. Intervention content	Components	Supervised tapered exercise programme. Nutritional advice pack and small group healthy eating seminars lasting 15-20; minutes carried out fortnightly.
	Techniques	Not specified
	Treatment Materials	Nutritional advice pack
Domain 2. Proposed Mechanism	Mechanism of action	Not commented upon
Domain 3. Target Outcome	Primary Outcome	Qualitative analysis of focus group
	Secondary Outcome	N/A
Domain 4. Method of delivery	Delivery setting and method	Community setting, facilitated
	Timing of treatment	Fortnightly for 12 weeks
	Therapist	Not commented upon
	Training	Not commented upon

Nurse led follow-up: Cox et al. (2008)		
Context	Indications	Ovarian cancer
	Population	Inclusion: Post cancer treatment Women with stable stage II-IV disease Exclusion: Patients with confusion, unable to speak English, or who did not have a telephone
	Location	Surrey: oncology clinics
Domain 1. Intervention content	Components	20 minute phone call: Focus on providing tailored information, practical advice and coping strategies in physical, psychological and social domains and signposting.
	Techniques	Not specified
	Treatment Materials	None
Domain 2. Proposed Mechanism	Mechanism of action	Not commented on
Domain 3. Target Outcome	Primary Outcome	Functional Assessment of cancer treatment – Ovarian (FACT-O; Basen-Engquist, Bodurka-Bevers and Fitzgerald; 2001) Satisfaction and experience with follow-up questionnaire
	Secondary Outcome	N/A
Domain 4. Method of delivery	Delivery setting and method	Telephone contact
	Timing of treatment	Three monthly for ten months
	Therapist	Nurse led
	Training	N/A

Exercise therapy : Daley et al. (2011)		
Context	Indications	Breast cancer
	Population	N=96 (34:exercise therapy, 36 exercise placebo, 38 usual care) Inclusion: 18-65 years ~~Wonmen~~Women not regularly active Treated for localised breast cancer in previous 12-36 months Exclusion: Women with metastases, inoperable or ~~locoregional~~loco regional disease. Participants randomised into 3 groups
	Location	England
Domain 1. Intervention content	Components	Exercise therapy VS Exercise placebo VS Usual care
	Techniques	Exercise ~~therapy:Individual~~therapy: Individual aerobic exercise sessions of 50 minutes, 3 times per week Exercise placebo : individual weekly body conditioning and toning exercises
	Treatment Materials	
Domain 2. Proposed Mechanism	Mechanism of action	Not commented upon
Domain 3. Target Outcome	Primary Outcome	Functional assessment of cancer therapy-general (FACT-G; Cella et al., 1993) Functional Assessment of Cancer Therapy- Breast(FACT-B; Cella et al., 1993)
	Secondary Outcome	Revised Piper Fatigue Scale (Piper, Dibble, and Dodd et al, 1998) Beck Depression Inventory-version two (BDI-II;Beck, Steer and Brown,1996) Physical self-perception profile(Fox and Corbin, 1989) The Satisfaction with life scale (Diener, Emmons, Larsen et al;1985)
Domain 4. Method of delivery	Delivery setting and method	Individual gym sessions
	Timing of treatment	Baseline, 8 weeks, 24 weeks
	Therapist	Qualifications not commented upon.
	Training	Not commented upon

Brief guided self-help intervention –: Galfin, Watkins and Harlow (2011)		
Context	Indications	Palliative care
	Population	N=34, 15 men,19 women Inclusion: 18+, In receipt of palliative hospice care. BDI-FS>4 and/or GAD7 >4 Ability to generate detailed memory Exclusion: Learning disability or organic brain damage Currently receiving psychotherapy or counselling Unable to engage for physical, practical or other reasons Participants randomised to immediate treatment or waiting list treatment
	Location	Hospices in Devon and Somerset
Domain 1. Intervention content	Components	Delivery of concreteness guided self-help training. 30 minute face to face training and practice of visual imagery exercise. 10 minute daily self-help practice, for four weeks
	Techniques	Visual imagery techniques based on autobiographical memory of events
	Treatment Materials	Additional digital recording of the exercise
Domain 2. Proposed Mechanism	Mechanism of action	Interruption of rumination
Domain 3. Target Outcome	Primary Outcome	Beck Depression Inventory- fast screen (BDI-FS; Beck, Guth and Steew et al,1997) General Anxiety Disorder–seven item(GAD-7; Spitzer, Kroenke and Williams et al, 2007) World Health Organisation Quality of Life – Short Version(WHOQOL-Bref; Skevington, Lofty and O'Connell, 2004)
	Secondary Outcome	
Domain 4. Method of delivery	Delivery setting and method	One face to face training session Daily, self-guided exercises, weekly telephone calls from the author
	Timing of treatment	4 weeks of daily exercise
	Therapist	Qualifications not commented upon, intervention delivered by author
	Training	Not commented upon

Expressive writing intervention: Gellaitry, Peters, Bloomfield and Home(2010)		
Context	Indications	Women who have completed breast cancer treatment
	Population	Inclusion: Women completing breast cancer treatment Exclusion: Unable to write for 20 minutes Unable to speak, write or understand English A defined psychiatric disorder
	Location	Brighton: outpatients clinic
Domain 1. Intervention content	Components	Participant's asked to write at home for 20 minutes on four consecutive days. Day 1: Emotional disclosure, Day 2: Cognitive appraisal, Day 3: Benefit finding, Day 4: Looking to the future
	Techniques	N/A
	Treatment Materials	Writing guidelines for each day
Domain 2. Proposed Mechanism	Mechanism of action	Not commented upon
Domain 3. Target Outcome	Primary Outcome	Significant other scale Functional Assessment of Cancer Therapy (FACT-B; Brady, Cella and Mo et al, 1997) Profile of Mood states (McNair, Lorr and Droppelman, 1971) Follow up at 1,3 and 6 months
	Secondary Outcome	N/A
Domain 4. Method of delivery	Delivery setting and method	At home, not supervised
	Timing of treatment	4 consecutive days, participant led
	Therapist	N/A
	Training	N/A

Compassion Focused expressive Writing – Imrie and Troop (2012)		
Context	Indications	Hospice patients
	Population	N=6, Inclusion: Day hospice attendees Exclusion: Not mentioned Participants randomised to attend either stress only writing exercise (control) or stress plus self-compassion group (intervention).
	Location	Hertfordshire Day hospice
Domain 1. Intervention content	Components	Participants asked to write about something difficult from their week for 20 minutes. Participants in intervention group were stopped after 10 minutes and asked to write about it again and given further instructions of how to write with self-compassion.
	Techniques	Compassion-focussed writing exercise and instruction
	Treatment Materials	None
Domain 2. Proposed Mechanism	Mechanism of action	Not commented upon
Domain 3. Target Outcome	Primary Outcome	Single item Self-esteem Scale (SISE; Robins et al, 2001) Short Depression-Happiness Scale (SDHS; Joseph et al, 2004) Perceived Stress Scale (PSS10; Cohen and Williamson, 2004)
	Secondary Outcome	Computerised text analysis programme (LIWC, Pennebaker et al, 2001) Likert scales to rate: how personal the writing was, how meaningful the writing was and how valuable they had found the experience.
Domain 4. Method of delivery	Delivery setting and method	Work in groups of 2-7 in a day hospice setting
	Timing of treatment	2 session over 3 weeks
	Therapist	Qualifications not commented upon, clinical and academic supervision delivered by authors.
	Training	Not commented upon

Appendix A2 Methodology of review studies

Author	Sample	Research methodology	Major findings in the context of mental health and well being	Study Limitations
Bourke et al. (2012)	N=12 Men with advanced prostate cancer	Qualitative analysis Focus groups	Intervention considered beneficial for: reducing anxiety around treatment reducing fear of reoccurrence	Low participant numbers Unable to generalise findings
Cox et al. (2008)	n=56 women with ovarian cancer	Cross-sectional design Pre and post measures FACT-Ovarian, experience and satisfaction with care questionnaire	Significant improvement in emotional well-being. (P<0.05) No other significant findings	No power calculations No control group / randomisation No reference for the FACT-O No validity / reliability reported for experience and satisfaction with care questionnaire
Daley et al. (2007)	N=96 Women treated for breast cancer	Randomised control trial Pre and post measures; FACT-G, FACT-B, revised piper fatigue scale, BDI-II, Physical self perception profile. Baseline, 8 weeks, 24 weeks	Significant differences reported in Quality of life significantly improved in exercise group over usual care group at 8 weeks (FACT-G p=.004; FACT-B p=.002) Both exercise therapy and exercise placebo showed significant increased in depression of usual care group at 8 and 24 weeks (p<.001)	Falls short of recruitment for power calculation
Galfin, Watkins and Harlow (2012)	N=24 Palliative care BDI-FS>4 GAD-7>5	Randomised control trial Pre and post measures BDI-FS, GAD-7, WHOQOL-BREF	Significant improvements on anxiety of intervention group over control p<0.001	Does not mention power calculation
Gellaitry, Peters, Bloomfield and Home (2010)	N=80 Women with breast cancer	Mixed methods Primary outcome measures: Social support, quality of life, psychological well-being at healthcare utilisation	Greater satisfaction with received emotional support in intervention group (p<0.05)	No power calculation No blinding for participants No statement of ethical approval No structured analysis of qualitative data Post-hoc analysis

Author	Sample	Research methodology	Major findings in the context of mental health and well being	Study Limitations
Imrie and Troop (2012)	N=6 Day hospice patients	Mixed methods RCT and textual analysis Pre and post measures: SISE, SDHS, PSS10, LIWC Tested at baseline and 3 weeks	Increase in self soothing behaviour and self esteem in experimental group 5/6 report increase in happiness Increase in stress in the experimental group, and decrease in the control group.	Does not state randomisation procedures Very low participant numbers No statistical analysis
Pitceathly et al. (2009)	N=313	RCT : 3 arm intervention study Structured clinical interview from DSM III-R, HADS	Significant reduction in HADS scores at 4 and 6 months in the 'high risk' intervention group ($p<0.05$)	Under powered Purposive sampling No mention of ethical approval
Ramachandra, Booth and Pieters, Kalliopi and Huppert. (2009)	n=27 13 women with breast cancer, 14 men with prostate cancer	Mixed methods Quality of life, anxiety and depression, social and occupational functioning and brief semi-structured interview Follow up at 6, 12 and 18 weeks	Significant improvement in intervention group of quality of life scores at 6 weeks ($p=0.046$)	No power calculation Does not state randomisation procedure Qualitative data not analysed in any structured way Non-parametric data No medium or long term follow-up
Semple, Dunwoody, Kernohan and McCaughan (2009)	n=54 Head and neck cancer	Quasi-experimental design Pre and post measures : HADS, WASA, HRQoL, UWQoLv4	Significant improvements in the intervention group over controls on: Anxiety ($p=0.001$) Depression ($p=0.005$) Social functioning ($p=0.048$) Quality of life ($p=0.042$)	Not enough detail for replication Bespoke individually tailored interventions No mention of ethical approval Under powered Self-selection into the intervention group Therefore no randomisation

Author	Sample	Research methodology	Major findings in the context of mental health and well being	Study Limitations
Serfaty, Wilkinson and Freeman, Mannix and King (2012)	N=39 HADS score above 8	Randomised control trial CBT Versus Aromatherapy Massage Pre and post measures: Profile of mood states- total mood score, EuroQol 5-D. Test points at baseline, 3months and six months	No significant differences between Cognitive behavioural therapy and aromatherapy message in Mood or Quality of life at any point. Report that Aromatherapy is equivalent to CBT for treating distress	Comparison study (no control group) No power calculation
Sharp et al. (2010)	N=183 Early breast cancer	Randomised control trial 3 arm intervention study Pre and post measures FACT-G, FACT-B, TOI, MRS, HADS, SCID Tested at baseline, 18 weeks and 24 weeks	Significant findings at 18 weeks Massage patients significantly better scores on QOL over treatment as usual Massage and Reflexology significantly better scores of mood and relaxation At 24 weeks Reflexology significantly better QOL scores than treatment as usual	Falls short of recruitment for power calculation
Strong et al. (2008)	N=200 Cancer and major depression	Randomised control trial : Longitudinal design Primary outcome measure SCL-20 (depression scale from SCL-90) Measured at 3, 6 and 12 months	Significant differences of intervention group over control in: Depression ($p=0.008$) Anxiety (p= *not reported*)	Medication usage a major confounding variable, not commented on. Medication use in intervention group far above controls ($p<0.01$) at 4 and 6 months
Thomson, Ander and Menon, Lanceley and Chatterjee (2012)	N=100 Women with cancer	Mixed methods, quasi-experimental design. Primary outcome measures: PANAS and VAS. Pre-test and post-test measurement	Significant differences of experimental group over control in: Levels of positive emotion ($p<0.001$) Well-being ($p<0.02$) Happiness ($p<0.02$)	convenience sample no mention of randomisation procedures no mention of power calculation pre and post measures within 40 minutes

Appendix B: Topic Guide

Life before cancer diagnosis
Primary Diagnosis
Cancer Treatment
Secondary Diagnosis
Further Treatment

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Appendix C1 : Example line and stanza structure~~Example Full transcript~~

Part One: First appearance of cancer

Strophe One: Normal life context

Stanza One: Lost weight

Comic relief 2009 it all started I think when I DISCOVERED MY LUMP believe it or not

My daughter and I had been going to SLIMMING WORLD / id lost three stone and shed lost THREE STONE

A chap from work PHONED ME UP / on the Thursday which was MY DAY OFF

He was wanting to dress up as something for COMIC RELIEF at work

Stanza two: Trying on bras

He wanted to know if I'd got any BRA'S THAT WERE TOO BIG FOR ME/ cos id lost WEIGHT /as you do

So I said I'll go and have a TRY ON OF A FEW AND SEE what's what

I was actually trying on bras to LEND THEN TO MY FRIEND for his comic relief dress up as Cher I think

AND I JUST FELT A LUMP,

Strophe Two: the lump

Stanza Three: finding the lump

Id NOT NOTICED it before / I just sort of sat there and I thought that just DOESN'T FEEL RIGHT does it

It was lunchtime and I was PANICKING as soon as id found it

I phoned up MY GP / and was crying and panicking on the phone / saying I'VE FOUND A LUMP and I don't know what to do

Cos it's Friday and I thought, oh god IVE GOT TO WAIT UNTIL MONDAY and blah blah blah

Stanza Four: showing the GP

She got me in straight away on the day TO HAVE A LOOK AND HAVE A FEEL

She referred me straight away to the BREAST SURGEONS at Telford

I got a phone call EARLY THE FOLLOWING WEEK to go in to see them

It was a HUGE LUMP / how ID NOT FOUND IT before god only knows,

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I was just AMAZED that id found it

Strophe Three: Cancer stories

Stanza five: Others' cancer stories

You just think OH RIGHT / id heard LOTS OF THESE STORIES

One goes and gets their lump out and EVERYONE'S FINE AREN'T THEY

Cos you hear a lot of the ones that you know HAVE THE CHEMO AND JUST RECOVER straight away

It was a BIG LUMP so obviously because of the size… of it

Stanza Six: My different cancer story

They biopsied it first and it WAS CANCEROUS /

So I was booked in for A LUMPECTOMY

The results were that most of the NODES UNDER THE RIGHT ARM WERE AFFECTED

So because of that they obviously SCANNED THE REST OF YOUR BODY

Strophe 4: Missed warning signs

Stanza 7: back problems

ID BEEN OVERWEIGHT /

I'd had BACK PROBLEMS for the last few years/ and id been seeing the PHYSIOTHERAPIST FOR A BAD BACK and

Sometimes it got as so I could HARDLY WALK cos of the pain in my back

As soon as we'd had the scan and it showed that the CANCER HAD ALREADY SPREAD TO MY BONES

And a large part in my SACRUM/

WHICH EXPLAINS the back ache for the last few years

Stanza 8: I missed something

So I just think to myself / I SHOULD HAVE SPOTTED SOMETHING YEARS,

If ID SPOTTED something years ago/ maybe I'd be alright,

So it was a hell of a shock really cos I got the DIAGNOSIS OF THE LUMP

Almost straight away cos I had A SCAN BEFORE THAT/ id got the diagnosis that it had ALREADY SPREAD

So it was SECONDARY

Strophe 5: cancer treatment related problems

Stanza 9: Lumpectomy

I recovered from the lumpectomy but by the time my SCAR HAD HEALED

My scar DIDN'T HEAL VERY FAST

Everything seemed to GO WRONG,

I had an INFECTION IN MY SCAR and one thing or another

Stanza 10: Back pain

But because of that it sort of DELAYED ME STARTING THE CHEMO

Which was QUITE GOOD IN A WAY because my back had got to be so painful I couldn't even move my legs without screaming

So just sort of went suddenly DOWNHILL THAT QUICK with the back

They said it was because it had GRABBED the sciatic nerve so the bit that was in that sacrum at the back had grabbed the right hand sciatic nerve/ so this leg was UNBEARABLE

Strophe 6: Primary Treatment

Stanza 11: radiotherapy

So I had five days of RADIOTHERAPY before I started the chemo

At that point I was at the lowest because pain was UNBEARABLE IN MY BACK ,

I can stand most things but really BAD PAIN I thought /

I don't know HOW LONG I CAN COPE with this pain

Stanza 12: positive impact on back pain

THANKFULLY within a week or two of having the radiotherapy

It must have just eased it enough to RELEASE THAT NERVE,

And I started to FEEL LESS PAIN

Thank goodness

Part Two: Impact of the diagnosis

Strophe7: Impact on Family members

Stanza 13: Family context

Within a month or so of being diagnosed I was HAVING TO USE A STROLLER TO WALK because of my back and

It seemed to happen all so SUDDENLY SO IT WAS A BIT OF A SHOCK REALLY

MY DAUGHTER WAS DOING HER A-LEVELS / SON WAS DOING HIS AS-LEVELS,

My husband and I haven't really got on well for THE LAST FIFTEEN YEARS/ HES LIKE A LODGER

Stanza 14: son's reaction

So it sort of HIT US ALL PRETTY HARD really

My son decided he would be AN OSTRICH /

He just IGNORED IT, /

If I wasn't feeling very well HE'D LEAVE THE ROOM bury his head in the sand

Strophe 8: improvements through treatment

Stanza 15: improvements in physical symptoms

The first year was ABSOLUTE HELL REALLY,

Going through ALL OF THESE TREATMENTS and then everything

Suddenly I could walk better AND I WAS IN LESS PAIN

We seemed to just MOSY ALONG for the next couple of years

Stanza 16: improvements, impact on daughter

My daughter went off to UNIVERSITY / but was CLOSE ENOUGH TO COME HOME most weekends,

So it's HER THAT BEEN AFFECTED MORE than anybody

She probably DIDN'T WANT TO come home every weekend but felt she ought to,

I TOLD HER NOT TO BUT SHE DID so, while she was away at university

CODA

So er but the first year was absolute hell

Part Three: How do others cope, I'm lucky

Strophe 9: How do others cope with cancer?

Stanza 17: Pain

I don't know how people COPE WITH IT ACTUALLY if they're in constant pain

Because the pain was UNBEARABLE to start with

But then it just seemed to SETTLE INTO A PATTERN

Luckily touch wood, and I DON'T KNOW HOW OTHER PEOPLE COPE

Stanza 18: finances

I had long term HEALTH INSURANCE at work

Because I WAS TOO ILL to go to work obviously / GOT PAID for the first six months

After that six months if I hadn't had long term health insurance I would have GONE DOWN TO SICKPAY

And I just DON'T KNOW how we would have coped

Strophe 10: Cancer costs / impact on finances

Stanza 19: general living costs

TWO KIDS TO SUPPORT at university /And just general living expenses is a NIGHTMARE

I just don't know HOW PEOPLE COPE

I've seen people on the television as well that have said suddenly they've got no money so WHAT DO THEY DO?

Because you're EXPECTED TO GO FOR ALL THESE TREATMENTS

Stanza 20: practical costs of cancer

That means car parking at the hospitals to go to radiotherapy FIFTEEN DAYS CONTINUOUSLY

If I hadn't have had THIS INSURANCE…,

So I carried on GETTING PAID seventy five percent of my salary /

I wouldn't have coped at all, at the stage WE WERE AT

Strophe 11: drawbacks of financial stability

Stanza 21: my husband's responsibilities

But then again it might have been good because my husband might have had to CHUCK IN RUNNING HIS OWN BUSINESS which is down in south wales

COME HOME and things might have been better so you never know

Cos er that must be a HELL OF A SHAKE UP FOR PEOPLE that haven't got any insurance

Suddenly have to stop work, six months have gone and YOU'VE GOT NO SALARY

Stanza 22: Guilt

I feel GUILTY SOMETIMES THAT I FEEL QUITE WELL OFF

I was on a GOOD SALARY any way / 75% of that good salary is PERFECTLY ADEQUATE for us to live on

SO WE'RE VERY LUCKY

So we sort of PUDDLE ON for a bit really and

Strophe 12: maintaining roles

Stanza 23: Daughter - supporting mother

then last year was quite a good year EXCEPT FOR MY MOTHER

MY FATHER DIED TWO YEARS ago into this /

he was a CARER FOR MY MOTHER who lives in [the central midlands]

So it always FALLS ON THE DAUGHTER doesn't it

Stanza24: supporting mother too much

BECAUSE I WASN'T WORKING and I could drive / I used to go over to HER BUNGALOW every two or three weeks

stop for two or three days

SORT HER PENSION OUT AND GET HER A HOME DELIVERY OF SHOPPING and stuff and

ignoring everybody that was telling me I was DOING TOO MUCH myself and I really needed to rest

Strophe 13: Maintaining roles mother

Stanza 25 feeling unwell but stuff to do

Eventually at the end of last year ID STARTED TO FEEL UNWELL AGAIN

But I HAD TO KEEP GOING because my daughter and I were going to Florida for three weeks In June

which coincided with HER GRADUATING AND GETTING A JOB

so we went to visit FAMILY IN FLORIDA FOR THREE WEEKS

Stanza 26: feeling unwell again, but stuff to do

we got BACK FROM THAT OK

my mom had had another fall and been in HOSPITAL AGAIN WHILE I WAS AWAY

SHES ALWAYS BEEN A WORRY since my father died so I've had her to worry about

But gradually towards the end of last year SOMETHING DIDN'T FEEL RIGHT

Strophe 14: further treatment

Stanza: 27 change of meds

In December last year I went TO SEE THE ONCOLOGIST and

WE DECIDED that the next phase was going to be to give me some hormone jabs to push me into the menopause / so I could SWITCH DRUGS

They presumed that it was perhaps the tamoxifen had STOPPED WORKING as efficiently as it should have

Which was perhaps why my bones were being a bit more ACHEY AND GENERALLY FLARING UP AGAIN

Stanza 28: further scans

I also felt a bit angry cos id not had a bone scan since the VERY FIRST YEAR when I was diagnosed

So OTHER THAN ME SAYING that I was having a lot of pain in shoulders and knees and stuff

I WOULD NOT have been given another bone scan

Whether it was just OVERLOOKED I don't know

Strophe 15: further health complications

Stanza29: broken leg

I had the appointment at the BEGINNING OF DECEMBER but

Then two days before Christmas I fell back on a dining chair at home and IT SNAPPED MY LEG

So the top of my FEMUR on the right leg / which is obviously because of a HOT SPOT OF CANCER there

Everything went on hold for a while, while I went in and had MY LEG PINNED BACK TOGETHER

Stanza 30: Liver function

While I was in there my blood showed FLUCTUATING LIVER FUNCTION

So the orthopedic people decided to do an ULTRASOUND ON MY LIVER

I'd been having CT SCANS every six months / the last one id had in November HADN'T SHOWED ANYTHING

But then I broke my leg at Christmas and SUDDENLY THEY ULTRASOUNDED MY LIVER AND THERE IT WAS AGAIN

So that week was a week from hell because I WAS SO ANGRY SO ANGRY

Strophe16: changing the message

Stanza31: change story to supporters

I'd been having ALL THESE TESTS/

and telling everyone that that MEANT THAT I WAS OK /

EVERYTHING WAS STABLE AND FINE AND/

then suddenly it had flared up again IN MY LIVER

Stanza 32: changing story of professionals

Which I still HAVEN'T HAD AN EXPLANATION for really cos

apparently USUALLY CT scans pick things up

but in this case either it hadn't been read properly OR IT DID JUST APPEAR OUT OF THE BLUE

So to FEEL BETTER ABOUT EVERYBODY I have to think that it just appeared between November and Christmas

Cos OTHERWISE I WANT TO PUNCH SOMEBODY so you know

Strophe 17: change in prognosis

Stanza 33: my thoughts about liver mets

for some reason I assumed it [the liver mets] behaved in a SIMILAR WAY TO THE BONES ,

that IT COULD JUST STABILIZE and be there for years or whatever but so

it wasn't until they told me THAT I HAD TO STOP THE CHEMO BECAUSE IT WAS MAKING ME TOO ILL

I told him SO WHAT HAPPENS NOW then / he said well he said well you need to PUT YOUR AFFAIRS IN ORDER basically

Stanza 34: new prognosis

And I said well what's the PROGNOSIS then

and he said 6-9 MONTHS

my daughter was there with me and WE JUST FELL TO PIECES,

no she wasn't there with me that TIME I WAS ON MY

Strophe 18: treatment for liver mets

Stanza 35: too ill for chemotherapy

I'd gone in for CHEMOTHERAPY thinking I was going for chemotherapy

To get there and be told that because I WAS TOO ILL / I COULDN'T HAVE IT

So THEY DIDN'T KNOW WHAT I WAS THERE FOR.

Nobody knew why I had turned up but the ONCOLOGIST FITTED ME IN and explained the situation

Stanza 36: differences in liver mets

Obviously once it's gone into the liver; it can be more AGGRESSIVE than in the bones apparently

im trying to be OPTIMISTIC at the moment

ive had three lots of CHEMO BEFORE

I couldn't have anymore and seemed to have SLOWED THINGS DOWN

Stanza 37: stabilized liver mets

The recent scans have shown that my LIVER DOESN'T SEEM TO BE GETTING ANY WORSE so

I have to be OPTIMISTIC that I can keep it at bay with what I've got

THE WAY HE EXPLAINED IT we went for a month or so thinking that I've only got six months to live

Strophe 19: Prognosis

Stanza 38: another change in prognosis

I WENT BACK for my next appointment and it wasn't my oncologist / it was one of his RESIDENTS

He explained to me that what he should have said was that WITHOUT ANY TREATMENT AT ALL THEN 6-9 MONTHS PROBABLY

But because I'm still able to have the HORMONE TREATMENTS; the Herceptin and the hormone zolodrex,

Because IT'S ALL PART OF THE BREAST CANCER / which is HORMONE RECEPTIVE

Hopefully even in the liver the hormones will HOLD IT BACK AND SLOW IT DOWN

Stanza 39: reject prognosis

So from that point of view I've decided to IGNORE 6-9 MONTHS

And just think well suddenly IF I FEEL WORSE THEN I'LL FEEL WORSE wont I,

At the moment I'm feeling QUITE HEALTHY /

My LEGS MENDING / and I can WALK AGAIN

Strophe 20: Recovery from broken leg

Stanza 40: associated disabilities

Twenty weeks of HOPPING ON ONE LEG

I had to have a BED DOWNSTAIRS which was not very nice

You think god AM I EVER GOING TO GET BACK UPSTAIRS AGAIN

So those few months were A BIT BAD REALLY

Stanza 41: recovering from broken leg

Having to HAVE CARERS AT HOME / having to come and HELP ME WASH/ cos I could only hop on ONE LEG

There's No plaster I've got a 40cm rod up there with another one into the hip

It was JAGGED BREAK on the outside / there's BITS OF BONE / So I've had 20 WEEKS of not being able to put weight on it / but

As soon as I could start putting weight on it so I could get BACK UPSTAIRS / then I FELT A LOT BETTER

Part : The hospice and the future

Strophe 21: The hospice

Stanza 42: choosing the hospice

That sort of coincided with STARTING HERE as well /

Just after I started going back UPSTAIRS

Which I WASN'T SURE ABOUT DOING cos

I thought do I REALLY WANT TO COME

Stanza 43: previous offers of hospice

I was offered the chance four years ago once it had gone into my bones, IT WAS TERMINAL

so they ASKED ME if I wanted to come then but

I think, the first year I was just TOO ILL to want to do anything and

then when I started TO FEEL BETTER then obviously I didn't want to come anyway

Stanza 44: reasons for choosing hospice

But now it has gone into the liver it seems that I might HAVE LESS TIME

I thought I might as well come and have a look around and SEE ABOUT COMING HERE

it is GOOD I DO ENJOY IT,

Strophe 22: The hospice. / The future

Stanza 45: the future

You sort of have to think when they say about PUTTING YOUR AFFAIRS IN ORDER

As to whether you would want to DIE AT HOME OR NOT

So I thought I would probably PREFER NOT TO

From VISITORS AND FAMILY POINT OF VIEW SO

Stanza 46: making things easier in the future

If I got the chance to come in here THEN I WOULD PREFER TO BE IN HERE

So I thought I might as well GET USED TO PEOPLE cos

Then it'll be NICER WHEN IM HERE because I'll know people won't I.

But yeah so coming here HAS CHEERED ME UP a lot really

Strophe 23: recovery from broken leg

Stanza 47: the leg and driving

And obviously my legs getting STRONGER AND STRONGER every week so

I'm hoping that the next time I go to the ORTHOPEDIC PERSON / that he will say that I can DRIVE AGAIN

I was DRIVING ALL THESE FOUR YEARS cos it was my back really

So as long as I'm SITTING DOWN IM QUITE COMFORTABLE

Stanza 48: insurance

But because id broken my leg FROM AN INSURANCE POINT OF VIEW /

The say-so went back to the orthopedic surgeon as OPPOSED TO MY GP

Whereas before my GP had got it in my notes that because I'm on MORPHINE AND STUFF

BUT NOT TOO STRONG,

Strophe 24: arguments to continue driving

Stanza 49: sensible

If I'm TOO DROWSY I don't drive so/ he considers that IM SAFE TO DRIVE SHORT TO MEDIUM DISTANCES so,

But since I broke my leg, now it's up to THE ORTHOPEDIC SURGEON TO SAY MY LEGS STRONG ENOUGH to drive so from and insurance point of view,

so I haven't been able to DRIVE SINCE CHRISTMAS but its driving me mad

Stanza 50: the car / I won't go mad

I've got an automatic car so if it had been MY LEFT LEG IT WOULD HAVE BEEN OK,

It's my RIGHT LEG,

But I'm hoping that when I go back in a couple of weeks that he'll say THAT I CAN DRIVE AGAIN.

I'm not going to GO FAR cos

I'm NOT GOING TO TIRE MYSELF OUT GOING LOOKING AFTER MY MOTHER COS I KNOW I CANT do it but

Strophe 25: caring dilemma

Stanza 51: guilt over mother

I feel SORRY FOR HER from my point of view obviously

She's worried about me

But she's not capable of looking after herself so THERE WILL COME A POINT WHERE SHE'LL HAVE TO GO INTO RESIDENTIAL CARE

I FEEL GUILTY/ I think that you should be LOOKING AFTER YOUR MOTHER at that time shouldn't you

Stanza 52: guilt over daughter

WHEREAS MY 22 YEAR OLD DAUGHTER SHOULDN'T have to be looking after me at my age

It does make THINGS AWKWARDNESS

My husband has IMPROVED we do get on better than we used to but er

From his point of view it's BEEN A SHOCK AS WELL SO

Stanza 53: My son

My 21 year old son is probably the one who TAKES IT ALL BETTER /

By just NOT WANTING TO KNOW all of the details / just doing what he NEEDS TO DO?

He's come back from university and he COOKS THE DINNER AND STUFF

And makes SURE I GET TO BED ON TIME / so he's fine

Strophe 26: the hard work of cancer treatment

Stanza 54: the tasks

Its HARD WORK

You've GOT ONCOLOGY appointments /

You've got BREAST SURGEON appointments /

Now I've got ORTHOPEDIC APPOINTMENTS that I have to go to and

Stanza 55: the travelling

Really in a RURAL AREA like this it's hard work cos to get from [The north of the county] to [the cancer center]

It's a FIFTY MINUTE JOB so if ever I'm in the chemo unit or my bloods not right so I'm in for a few days

It's a LONG WAY for everybody to come.

TO VISIT AND THEY GET TIRED

Strophe 27: The present / future

Stanza 56: coping today

I'm just taking EACH DAY AS IT COMES it

I've decided that's the ONLY WAY I CAN DEAL WITH it these days

I'm sort of RELIANT ON OTHER PEOPLE in some ways/ but I try and DO AS MUCH AS I CAN myself

I'm sort OF RESIGNED to the fact that it's going to get me at some point / but I'm not going TO LET IT GET ME UNTIL I HAVE TO

Stanza 57: how liver mets kills people

Now it's gone to the LIVER AND ITS INOPERABLE /

It'll be a matter of just waiting for it to be JUST TOO MUCH IN THE LIVER /

AND THEN THAT'S IT ISN'T IT apparently

It does worry me that when you ask people about it all they say is that you just get more and more tired suddenly YOU'RE TOO TIRED AND THEN THAT'S IT

Stanza 58: liver Mets and me

Cos I get tired quite a lot and I think oh god AM I GOING TO GO TO SLEEP AND NOT WAKE UP

BUT I'M ASSURED by all the blood tests and everything else that

I'M NOT READY TO POP YET SO

You just have to BELIEVE that you're going to wake up again

Strophe 28: The future without me

Stanza 59: no grand parenting

But it's quite hard; it's obviously HARDER LOOKING AT YOUR CHILDREN

Because my children are 21 AND 22

I'm probably NOT GOING TO SEE ANY GRANDCHILDREN

Not going to see them GET MARRIED AND SETTLE DOWN SO THAT'S QUITE HARD

Stanza 60: my son's ideas

As far as my son is concerned I'LL STILL BE HERE WHEN HES 40 realistically that's probably not the case

But while he carries on believing THAT IT KEEPS HIM HAPPY so that's good

It's either being an ostrich and burying his head in the sand or its HIS WAY OF COPING with it isn't it,

He ONLY COPES WITH BAD THINGS WHEN THEY HAPPEN rather than thinking about them going to happen

Strophe 29: support and non-support

Stanza61: daughter

My daughter tends to be THE OTHER ,

shes BEEN THROUGH IT ALL with me,

been to ALL OF THE APPOINTMENTS and seen me through it all where its

between the ages of 18 to 22 its REALLY NOT SOMETHING THAT SHE SHOULD HAVE HAD TO DO

Stanza 62: husband (positives)

But my husband is NOT THE MOST SUPPORTIVE person

He DID ACTUALLY START TO COME TO CHEMO WITH ME THIS TIME, he didn't last time

He has TRIED TO BE MORE HELPFUL and he knows he has to be and

IT'S NOT FAIR TO RELY ON MY DAUGHTER to do everything so he does do more than he used to

Strophe30: husband

Stanza63: husband regrets

But he still only comes home AT WEEKENDS COS THAT'S HIS JOB,

if he didn't do his job then WE WOULDN'T HAVE ANY OF HIS MONEY COMING IN so it has to be done

But then again IF WE'D HAD A GOOD RELATIONSHIP/ I think he would've STOPPED DOING THAT and he would have come home and packed yoghurts at mullers just to be at home you know so

Stanza 64: husband resentment

Whereas BECAUSE OF MY LIFE INSURANCE he has been able to carry on exactly as before but except for the weekends,

I do feel a bit RESENTFUL FOR HIM, THAT'S HES / ONCE AGAIN HES GOING TO FALL ON HIS FEET

COS MY MONEY IS KEEPING US GOING AND

WHEN I POP MY CLOGS HE'LL BE QUITE RICH there you go so once agin hes landed on his feet

Stanza 65: husband resentment

It's only me going BACK TO WORK AND WORKING which meant he can carry on running his own business

So sort of I TRY NOT TO BE RESENTFUL,

But because it's NOT WORTH THE AGRO, but sometimes it's hard but

I don't know what more I can say really.

Part: finding positivity

Strophe31: good aspects

Stanza 66: children and friends

Not a very nice story but then again ive got TWO REALLY NICE CHILDREN

IVE GOT LOTS OF FRIENDS, my friends from Muller that I work with because its only round the corner

There's some of them that still bring their BUTTIES ROUND AT LUNCHTIME to come and see me

The whole gang of them came and DID MY GARDEN AND BUILT ME A SUMMER HOUSE THIS SUMMER

Stanza 67; the summer house

Once when they heard THAT IT MIGHT BE MY LAST SUMMER they all come and done that for me

IVE GOT SUCH GOOD FRIENDS

I mean I felt AWKWARD Letting them do it,

But when I spoke to the psychologist she said they need to have SOMETHING TO DO because they can't do anything else

Strophe32: such good friends

Stanza 68: friends doing stuff

So they all came and TIDIED UP MY GARDEN AND BUILT ME THIS LOVELY SUMMER HOUSE

Which if it would stop raining I could GO AND SIT IN

It means that I've got SUCH GOOD FRIENDS

A few years ago it got to a point where I think MY HUSBAND WAS RESENTFUL of the fact that I have friends because he doesn't have any cos he travels around

Stanza 69: friends support through treatment

Occasionally in the first year when we were going it was my FRIENDS THAT WERE TAKING IT IN TURNS

When I had to go to RADIOTHERAPY FOR 15 DAYS ,

People I worked with took it IN TURNS TO TAKE ME for radiotherapy

Cos my husband had to carry on working otherwise he wouldn't have had any more MONEY SUPPOSEDLY

Strophe 33: Husband compared with friends

Stanza 70: husband resentment

When I've asked him to do something and HES BEEN A BIT OFF,

He's said you've GOT ALL THESE GOOD FRIENDS, why don't you ask them to do it

Yes I have and I'm glad I have got them cos I don't know WHERE I WOULD HAVE BEEN WITHOUT THEM

Cos he would have had to HAVE PULLED HIS WEIGHT AND DONE SOMETHING

So don't know

Stanza 71: regrets about relationship

When I think about it, I wish id have got RID OF HIM 15 YEARS AGO you see/ I might have MET SOMEBODY NICE

But you just SORT OF DRIFT your children go to school/ you're working / you come home and then he comes home at the weekend

And it doesn't really matter cos he's moved into the back room anyway and

He's just a lodger and it's easier cos I don't have to take the CHILDREN ANYWHERE TO BE ABLE TO SEE HIM

Strophe 34: husband in early days

Stanza 72: let down by husband

In those early days, THE FIRST LOT OF CHEMO I had four years ago,

everytime I have chemo IT DOES SOMETHING TO ME

Apparently id had STOMACH ULCERS BREWING up for years and

The first lot of chemo that I had after a week or so BURST MY STOMACH ULCERS

Stanza 73: husband leaving care to kids

My husband was on HOLIDAY IN GERMANY cos he goes to Germany and rides on trains every year

He used to take the kids until THEY GOT OLD ENOUGH NOT TO WANT TO GO

But he'd still booked his holiday to go EVEN THOUGH I WAS STARTING MY CHEMO ,

We DIDN'T KNOW WHAT WOULD HAPPEN

Stanza 74: kids to sort me out

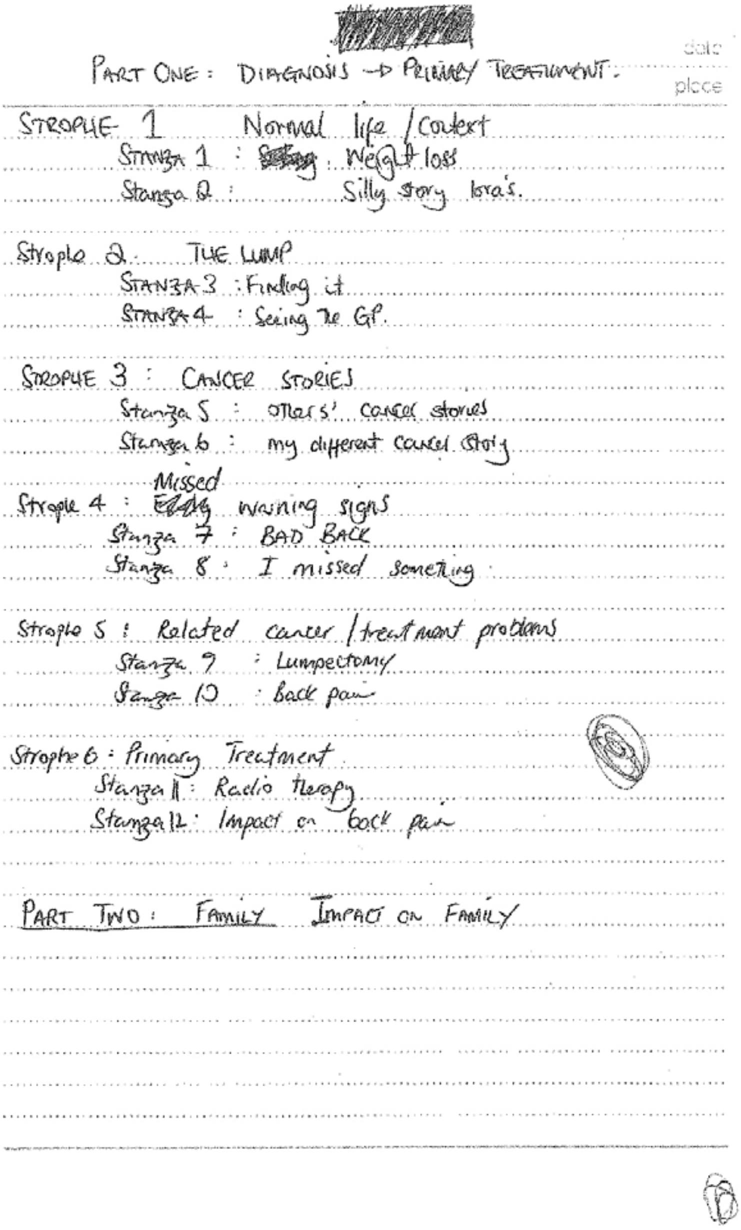
So sort of 10 o clock at night I was sort of CRAWLING ACROSS THE FLOOR IN THE HALLWAY

HAVING LOST SO MUCH BLOOD that I could hardly walk and

IT WAS DOWN TO MY TWO KIDS TO GET ME TO HOSPITAL AND SORT ME OUT

IT SHOULDN'T HAVE BEEN LEFT TO THE KIDS TO HAVE TO CLEAN UP AFTER ME AND DO THAT,

Appendix C2: Stages of Analysis



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date

place

PART ONE : DIAGNOSIS → PRIMARY TREATMENT.

STROPHE 1 Normal life / context
Stanza 1 : ~~[illegible]~~ Weight loss
Stanza 2 : Silly story Iora's.

Strophe 2. THE LUMP
STANZA 3 : Finding it
STANZA 4 : Seeing the GP.

STROPHE 3 : CANCER STORIES
Stanza 5 : others' cancer stories
Stanza 6 : my different cancer story

Strophe 4 : ~~Early~~ Missed warning signs
Stanza 7 : BAD BACK
Stanza 8 : I missed something

Strophe 5 : Related cancer / treatment problems
Stanza 9 : Lumpectomy
Stanza 10 : Back pain

Strophe 6 : Primary Treatment
Stanza 11 : Radio therapy
Stanza 12 : Impact on back pain

PART TWO : FAMILY IMPACT ON FAMILY

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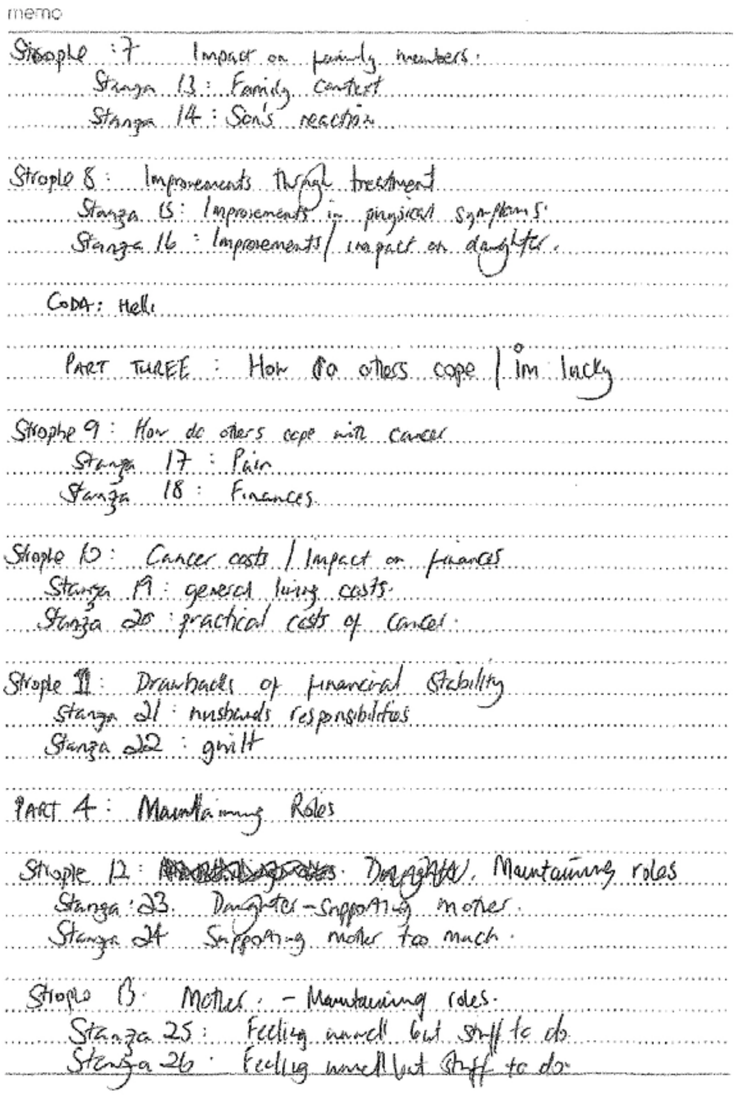


memo

Strophe :7 Impact on family members.
Stanza 13 : Family context
Stanza 14 : Son's reaction

Strophe 8 : Improvements through treatment
Stanza 15 : Improvements in physical symptoms.
Stanza 16 : Improvements / impact on daughter.

CODA: Hell

PART THREE : How do others cope | Im lucky

Strophe 9 : How do others cope with cancer
Stanza 17 : Pain
Stanza 18 : Finances.

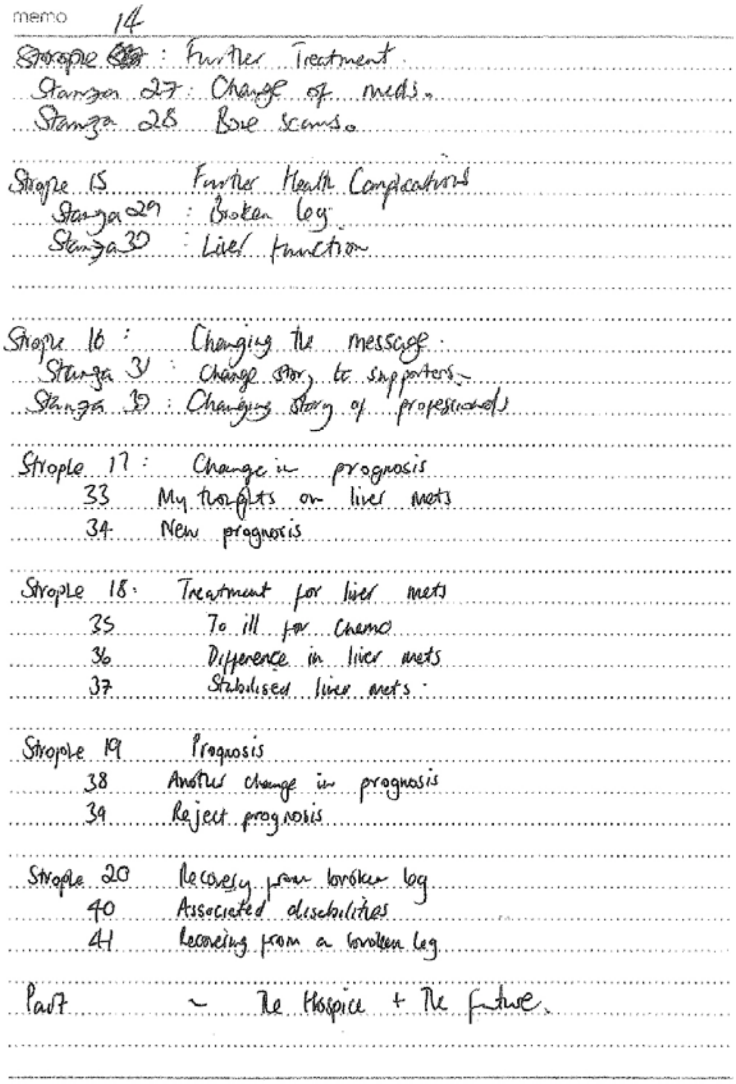
Strophe 10 : Cancer costs / Impact on finances
Stanza 19 : general living costs.
Stanza 20 : practical costs of cancer.

Strophe 11 : Drawbacks of financial stability
Stanza 21 : husbands responsibilities
Stanza 22 : guilt

PART 4 : Maintaining Roles

Strophe 12 : Daughter. Maintaining roles
Stanza : 23. Daughter - supporting mother.
Stanza 24 Supporting mother too much.

Strophe 13 · Mother : - Maintaining roles.
Stanza 25 : Feeling unwell but stuff to do.
Stanza 26 : Feeling unwell but stuff to do.



memo 14

Strope : Further Treatment.
Stanza 27: Change of meds.
Stanza 28 Bone scans.

Strope 15 Further Health Complications
Stanza 29 : Broken leg.
Stanza 30 : Liver function

Strope 16 : Changing the message:
Stanza 31 : Change story to supporters.
Stanza 32 : Changing story of professionals

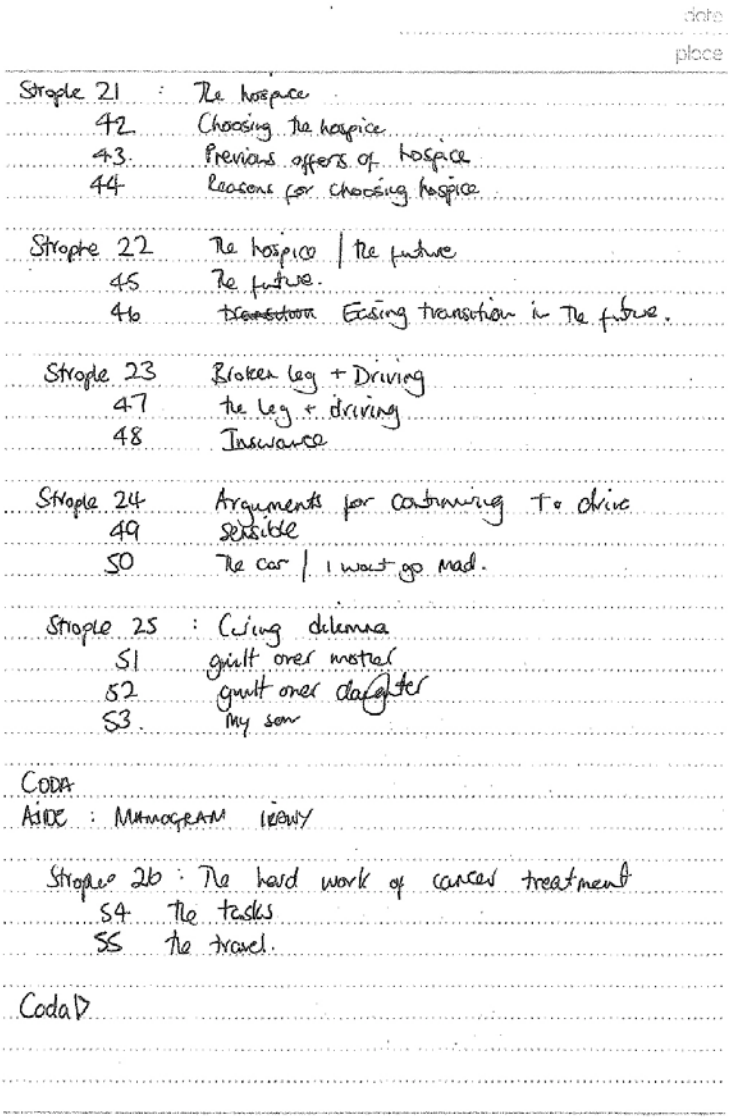
Strople 17 : Change in prognosis
33 My thoughts on liver mets
34 New prognosis

Strople 18: Treatment for liver mets
35 To ill for chemo
36 Difference in liver mets
37 Stabilised liver mets.

Strople 19 Prognosis
38 Another change in prognosis
39 Reject prognosis

Strople 20 Recovery from broken leg
40 Associated disabilities
41 Recovering from a broken leg

Part ~ The Hospice + The future.



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Strophe 21 : The hospice
42 Choosing the hospice
43. Previous offers of hospice
44 Reasons for choosing hospice

Strophe 22 The hospice | the future
45 The future.
46 ~~transition~~ Easing transition in The future.

Strophe 23 Broken leg + Driving
47 the leg + driving
48 Insurance

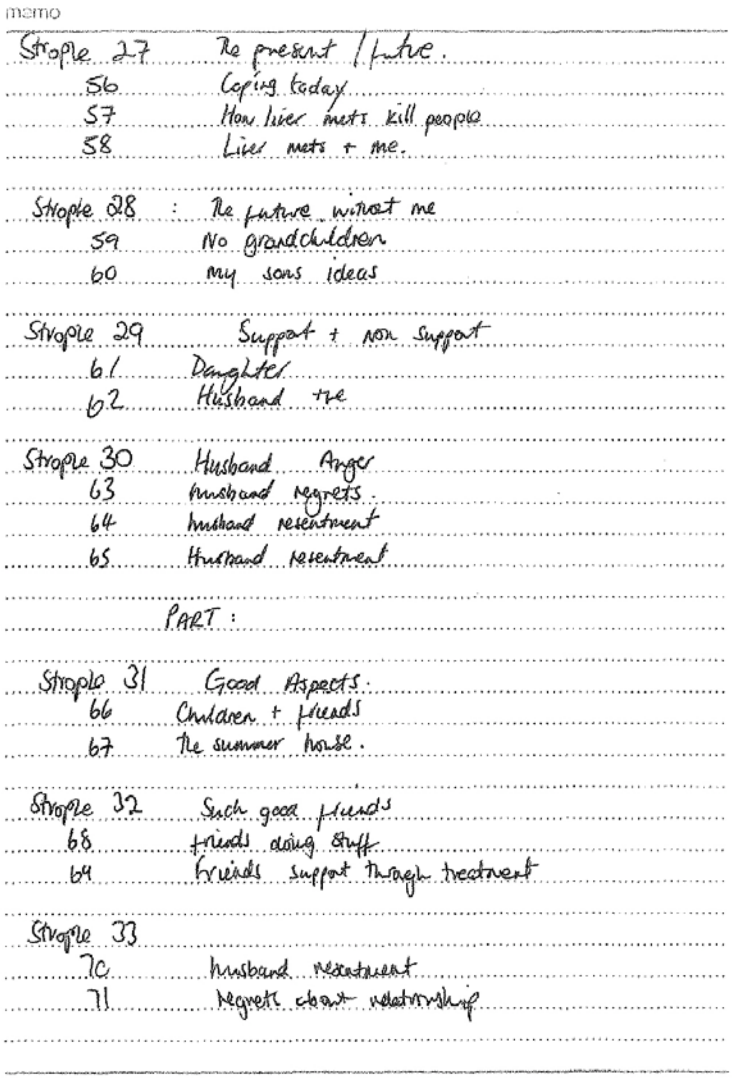
Strophe 24 Arguments for continuing To drive
49 sensible
50 The car | I won't go mad.

Strophe 25 : Caring dilemma
51 guilt over mother
52 guilt over daughter
53. My son

CODA
ASIDE : MAMMOGRAM IRONY

Strophe 26 : The hard work of cancer treatment
54 The tasks
55 The travel.

Coda D

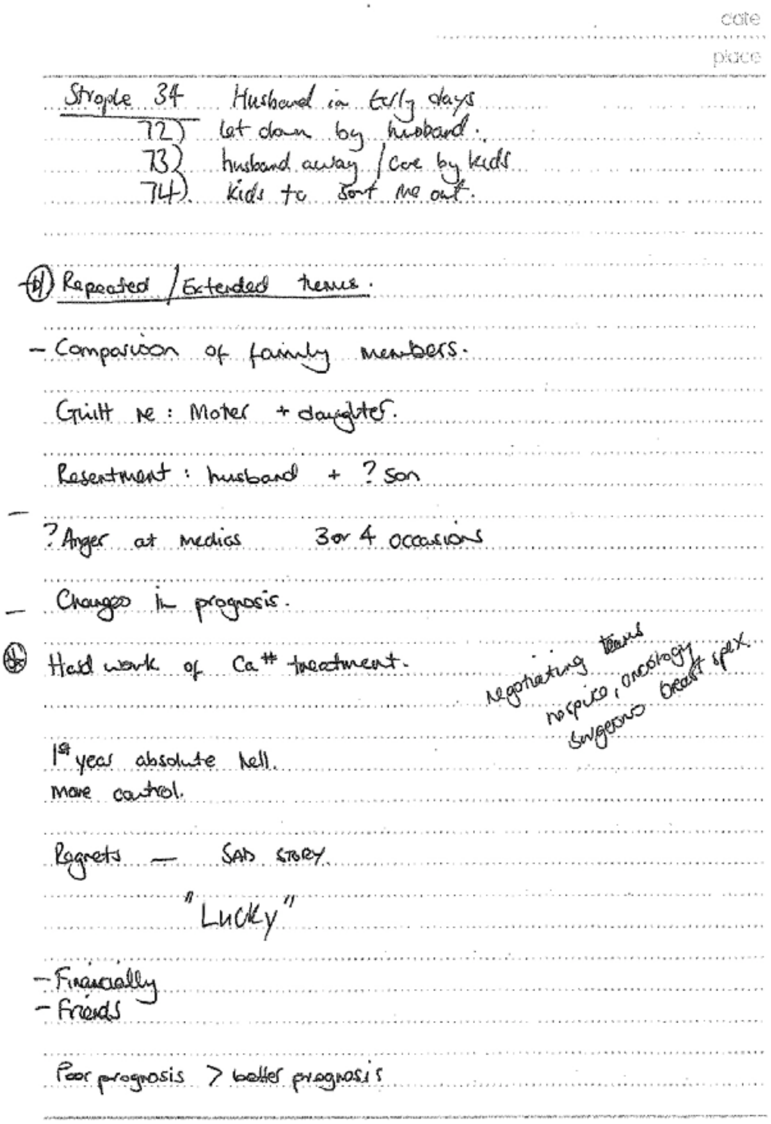


memo

Strophe 27	The present / future.
56	Coping today
57	How liver mets kill people
58	Liver mets + me.
Strophe 28 :	The future without me
59	No grandchildren
60	my sons ideas
Strophe 29	Support + non support
61	Daughter
62	Husband +ve
Strophe 30	Husband Anger
63	husband regrets.
64	husband resentment
65	Husband resentment

PART :

Strophe 31	Good Aspects.
66	Children + friends
67	The summer house.
Strophe 32	Such good friends
68	friends doing stuff
69	friends support through treatment
Strophe 33	
70	husband resentment
71	Regrets about relationship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Strophe 34 Husband in Early days
72) let down by husband.
73) husband away / care by kids
74) Kids to sort me out.

④ Repeated / Extended themes.

- Comparison of family members.

Guilt re: Moter + daughter.

Resentment : husband + ? son

— ? Anger at medics 3 or 4 occasions

— Changes in prognosis.

⑤ Hard work of Ca# treatment.

Negotiating teams
hospice, oncology, breast spex
surgeons

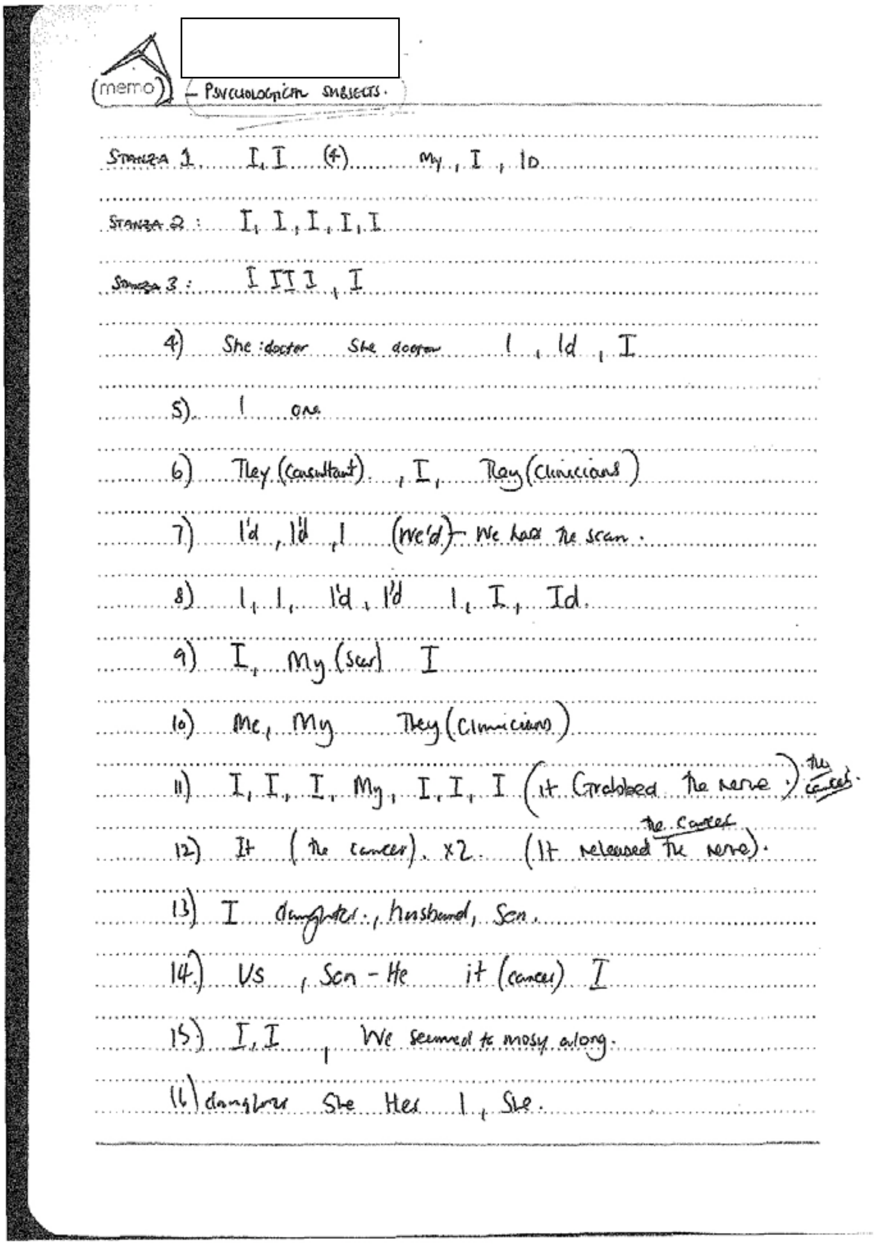
1st year absolute hell.
more control.

Regrets — SAD STORY

"Lucky"

- Financially
- Friends

Poor prognosis > better prognosis



memo [redacted]

– Psychological subjects.

Stanza 1. I, I (4) My, I, ID

Stanza 2: I, I, I, I, I

Stanza 3: I II I, I

4) She: doctor She doctor I, Id, I

5) I one

6) They (consultant), I, They (clinicians)

7) I'd, I'd, I (we'd) – We had the scan.

8) I, I, I'd, I'd I, I, Id.

9) I, My (scar) I

10) Me, My They (clinicians)

11) I, I, I, My, I, I, I (it Grabbed the nerve.) the cancer.

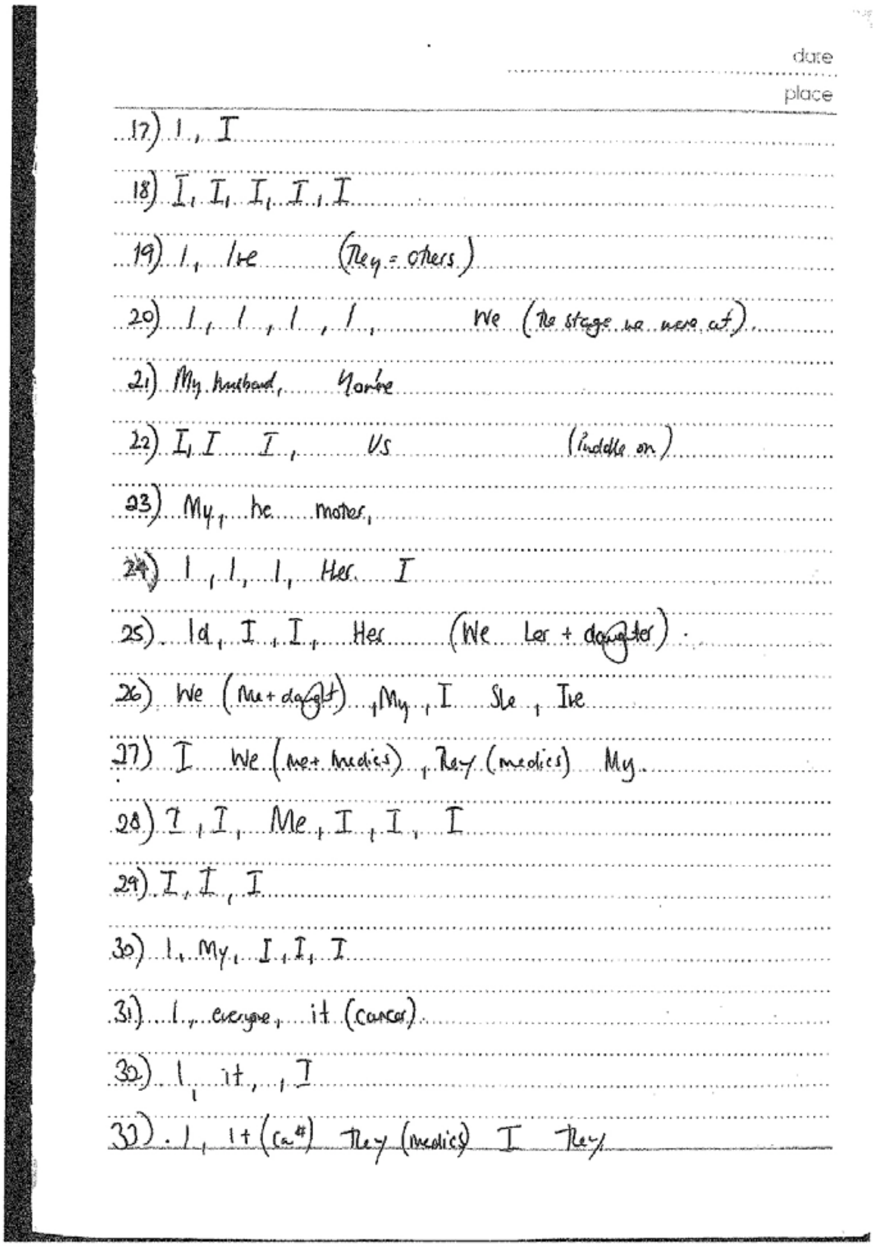
12) It (the cancer). x2. (It released the cancer The nerve).

13) I daughter, husband, Son.

14) Us, Son – He it (cancer) I

15) I, I, We seemed to mosy along.

16) daughter She Her I, She.



date

place

17) I, I

18) I, I, I, I, I

19) I, I've (They = others)

20) I, I, I, I, We (the stage we were at)

21) My husband, Yorke

22) I, I I, Us (Paddle on)

23) My, he mother,

24) I, I, I, Her I

25) Id, I, I, Her (We her + daughter).

26) We (Me + daught), My, I She, I've

27) I We (me + medics), They (medics) My.

28) I, I, Me, I, I, I

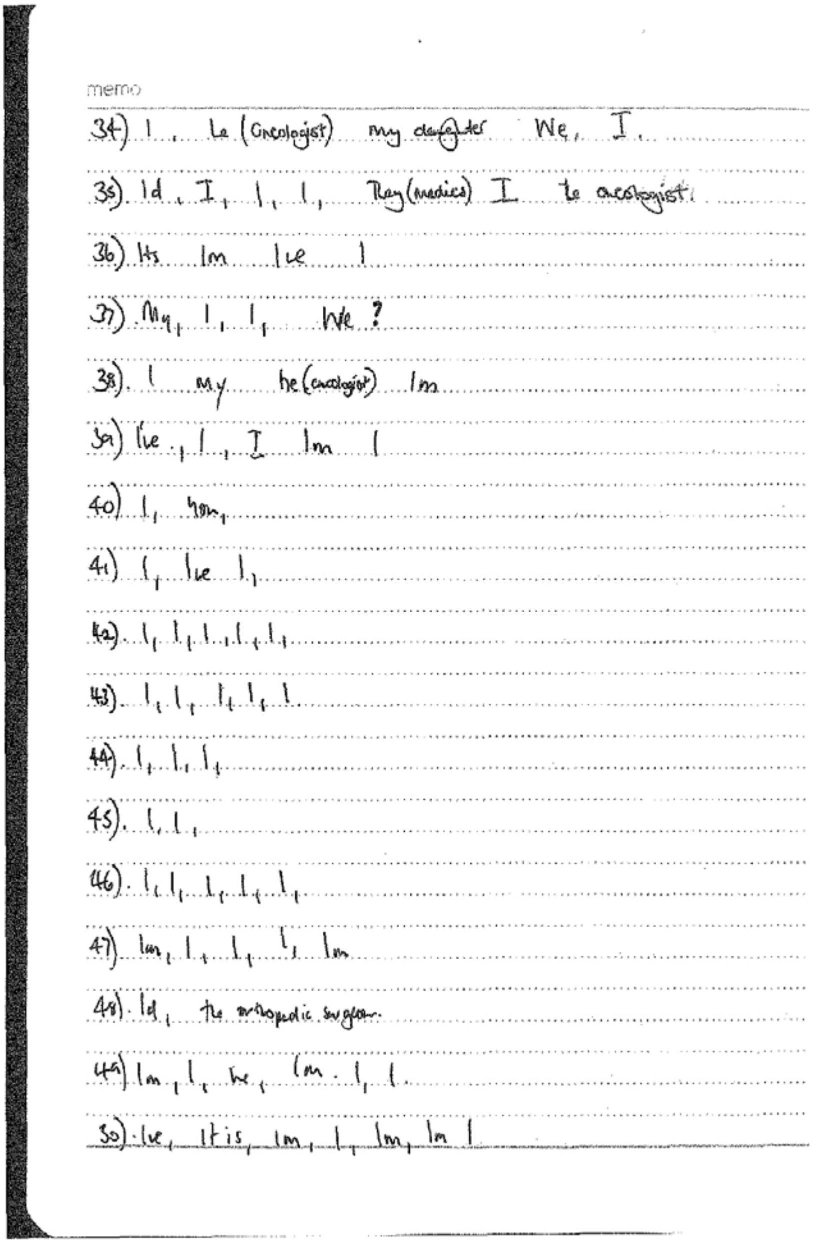
29) I, I, I

30) I, My, I, I, I

31) I, everyone, it (cancer)

32) I, it, , I

33) I, It (ca#) They (medics) I They



memo

34) I, he (Oncologist) my daughter We, I.

35). Id, I, I, I, They (medics) I he oncologist.

36) Its Im Ive I

37) My, I, I, We ?

38). I my he (oncologist) Im

39) Ive, I, I Im I

40) I, you,

41) I, Ive I,

42). I, I, I, I, I,

43). I, I, I, I, I

44). I, I, I,

45). I, I,

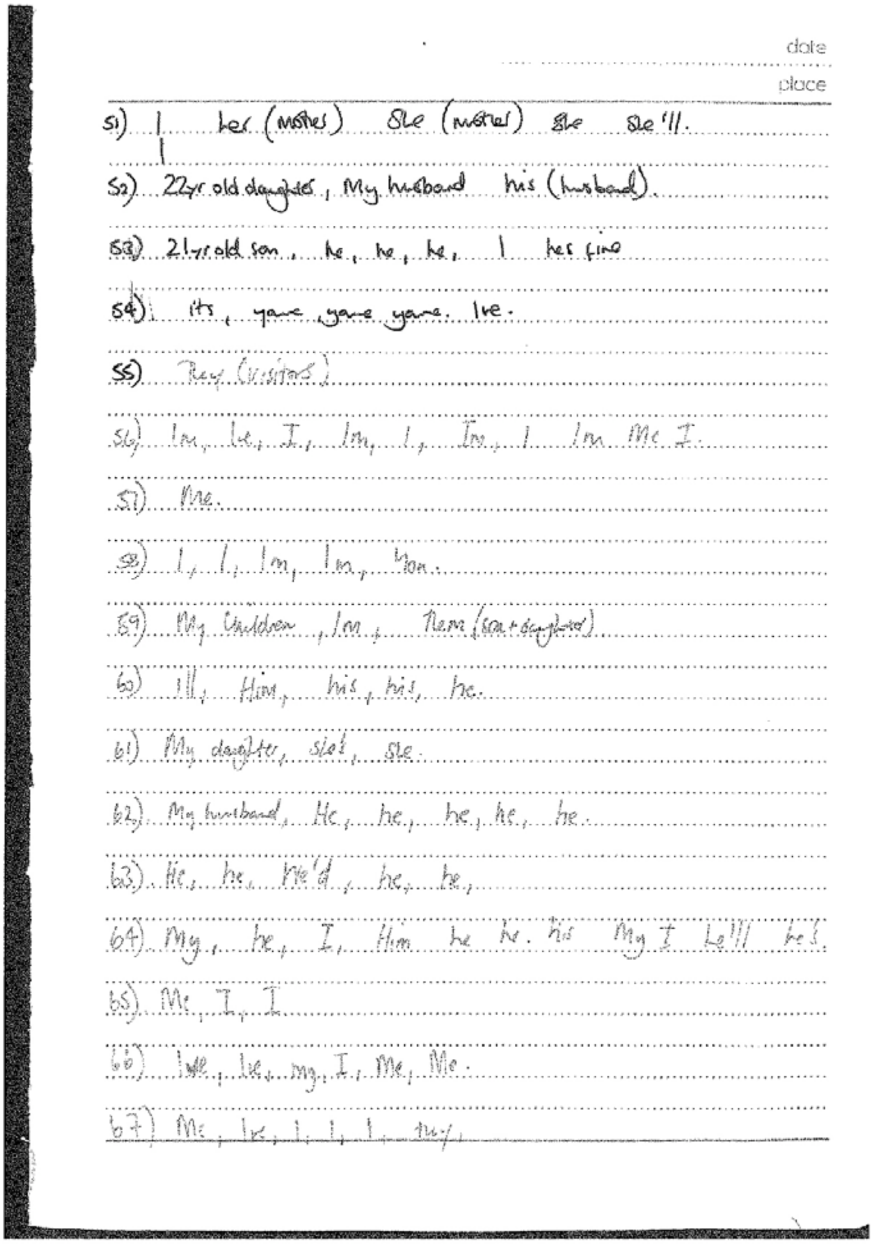
46). I, I, I, I, I,

47) Im, I, I, I, Im

48). Id, the orthopedic surgeon.

49) Im, I, he, Im. I, I.

50)· Ive, It is, Im, I, Im, Im I



date

place

51) I her (mother) She (mother) She She'll.

52) 22yr old daughter, My husband his (husband).

53) 21yr old son, he, he, he, I he's fine

54) its, yours yours yours. Ive.

55) They (visitors)

56) Im, Ive, I, Im, I, Im, I Im Me I.

57) Me.

58) I, I, Im, Im, You.

59) My Children, Im, Them (son+daughter)

60) I'll, Him, his, his, he.

61) My daughter, she's, she.

62) My husband, He, he, he, he, he.

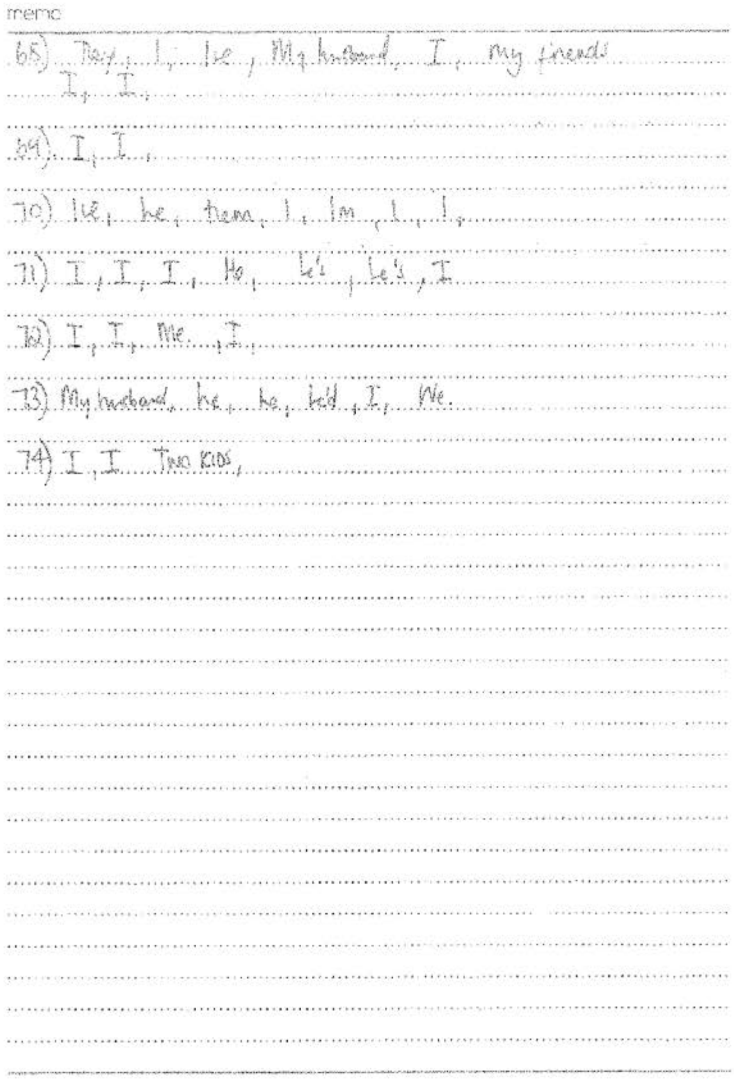
63) He, he, He'd, he, he,

64) My, he, I, Him he he. his My I he'll he's.

65) Me, I, I

66) I've, Ive, my, I, Me, Me.

67) Me, Ive, I, I, I, my,



memo

65) They, I, he, My husband, I, my friends
I, I,

69) I, I,

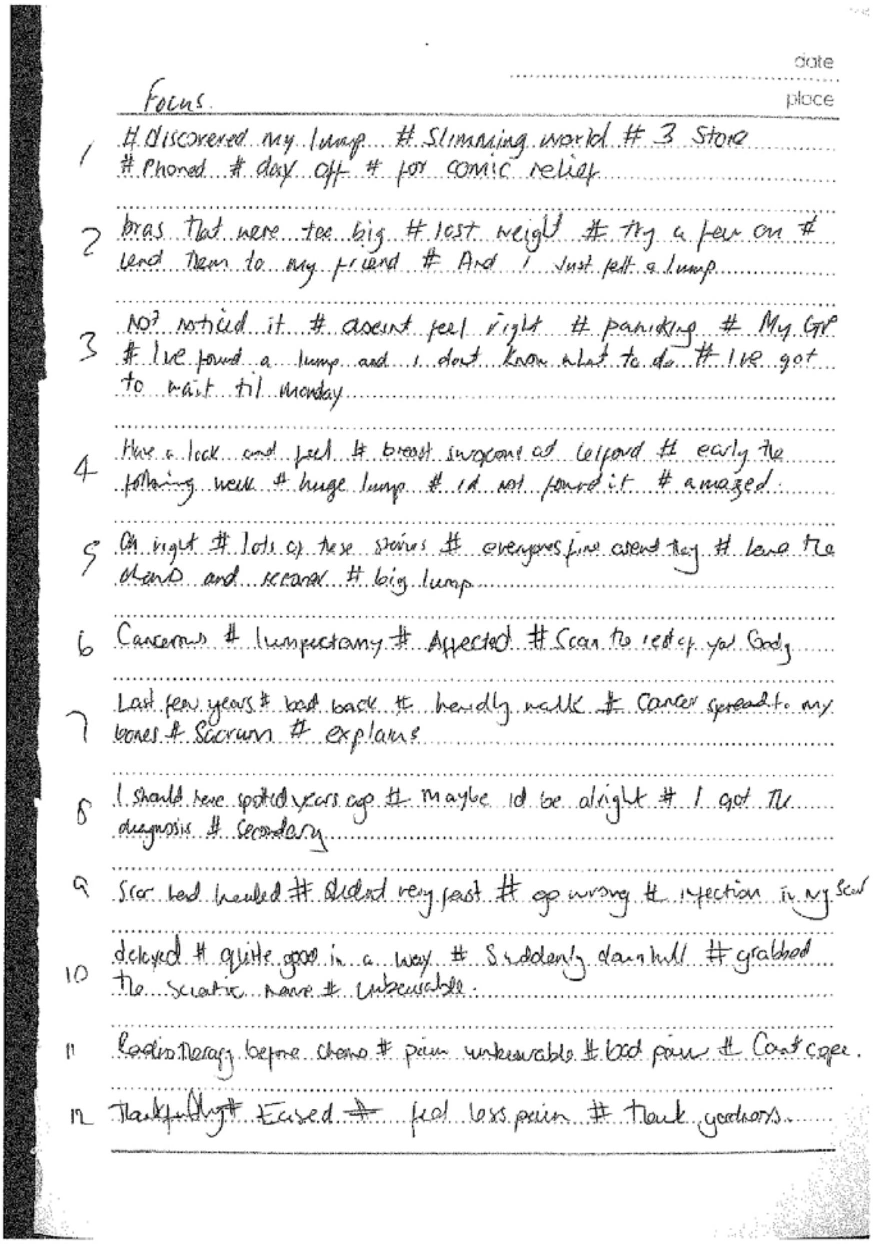
70) He, he, them, I, him, I, I,

71) I, I, I, He, he's, he's, I

72) I, I, Me, I,

73) My husband, he, he, he'd, I, We.

74) I, I Two KIDS,



date

place

Focus.

1 # discovered my lump # Slimming world # 3 Store # Phoned # day off # for comic relief

2 bras that were too big # lost weight # try a few on # lend them to my friend # And I just felt a lump

3 No? noticed it # doesnt feel right # panicking # My GP # Ive found a lump and i dont know what to do # Ive got to wait til Monday

4 Have a look and feel # breast surgeons at Telford # early the following week # huge lump # id not found it # amazed.

5 Oh right # lots of these stories # everyones fine arent they # leave the ward and scream # big lump

6 Cancerous # lumpectomy # Affected # Scan the rest of your body

7 Last few years # bad back # hardly walk # Cancer spread to my bones & Sacrum # explains

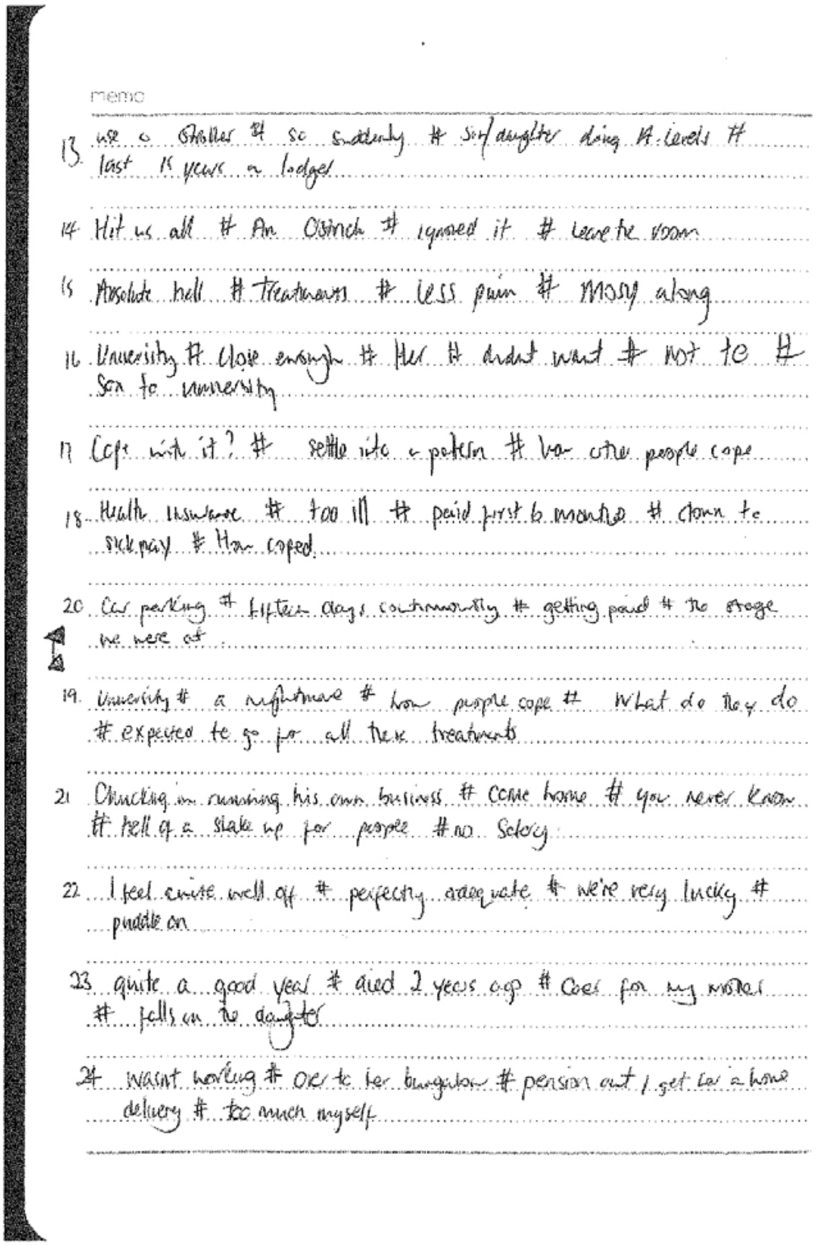
8 I should have spotted years ago # maybe id be alright # I got the diagnosis # Secondary

9 Scar had healed # didnt very fast # op wrong # infection in my scar

10 delayed # quite good in a way # Suddenly downhill # grabbed the sciatic nerve # unbearable.

11 Radiotherapy before chemo # pain unbearable # bad pain # Cant cope.

12 Thankfully # Eased # feel less pain # thank goodness.



memo

13 use a Stroller # so suddenly # Son/daughter doing A-levels #
last 15 years a lodger

14 Hit us all # An Ostrich # ignored it # Leave the room

15 Absolute hell # Treatments # less pain # mosey along

16 University # close enough # Her # didn't want # not to #
Son to university

17 Cope with it? # settle into a pattern # how other people cope

18 Health insurance # too ill # paid first 6 months # down to
sickpay # How coped

20 Car parking # fifteen days continuously # getting paid # the stage
we were at

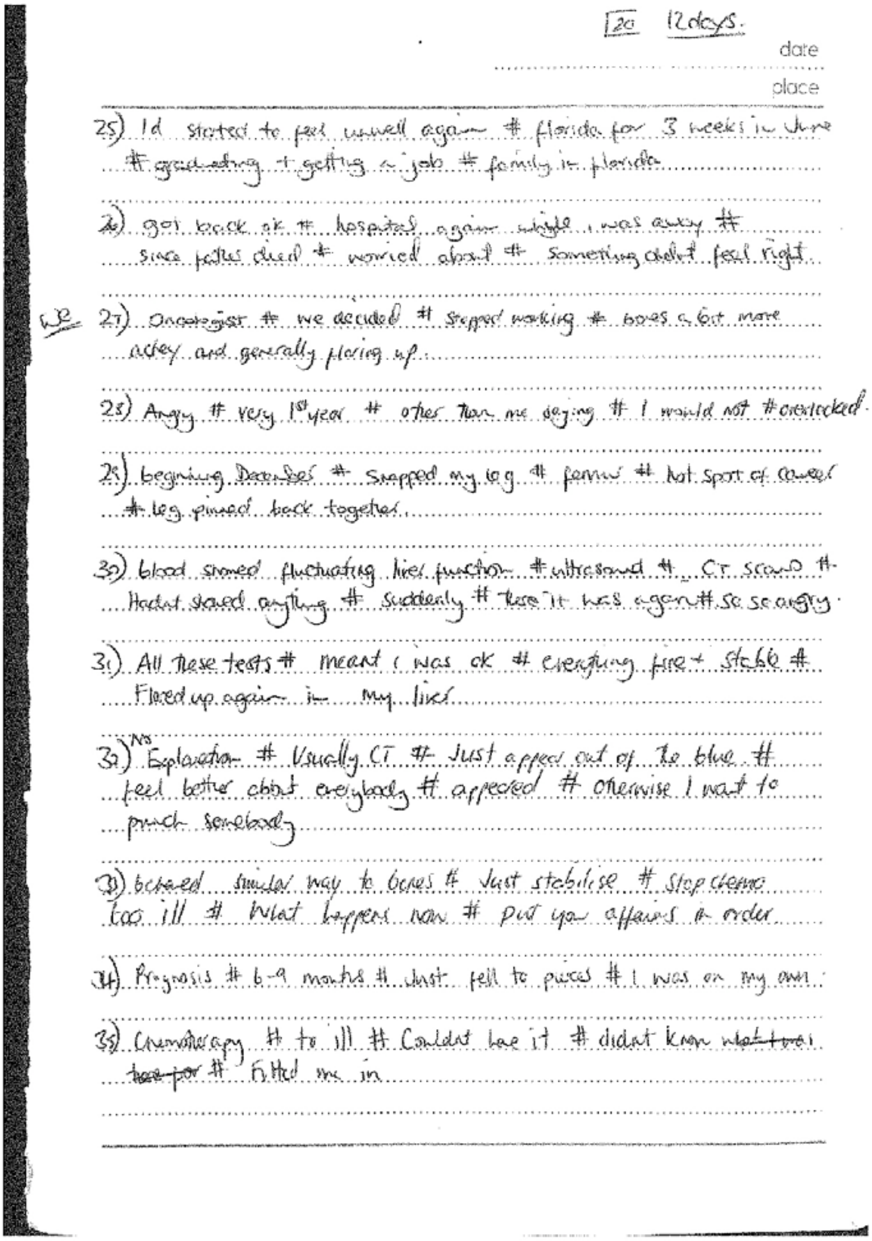
19 University # a nightmare # how people cope # What do they do
expected to go for all their treatments

21 Chucking in running his own business # come home # you never know
hell of a shake up for people # no salary

22 I feel quite well off # perfectly adequate # we're very lucky #
puddle on

23 quite a good year # died 2 years ago # carer for my mother
falls on the daughter

24 wasn't working # over to her bungalow # pension out / get her a home
delivery # too much myself



20 12 days.

date

place

25) I'd started to feel unwell again # florida for 3 weeks in June # graduating + getting a job # family in florida

26) got back ok # hospital again while I was away # since father died # worried about # something didnt feel right.

WE 27) Oncologist # we decided # stopped working # bones a bit more achey and generally flaring up.

28) Angry # very 1st year # other than me dying # I would not # overlooked.

29) begining December # snapped my leg # femur # hot spot of cancer # leg pinned back together.

30) blood showed fluctuating liver function # ultrasound # CT scan # Hadnt showed anything # suddenly # there it was again # so so angry.

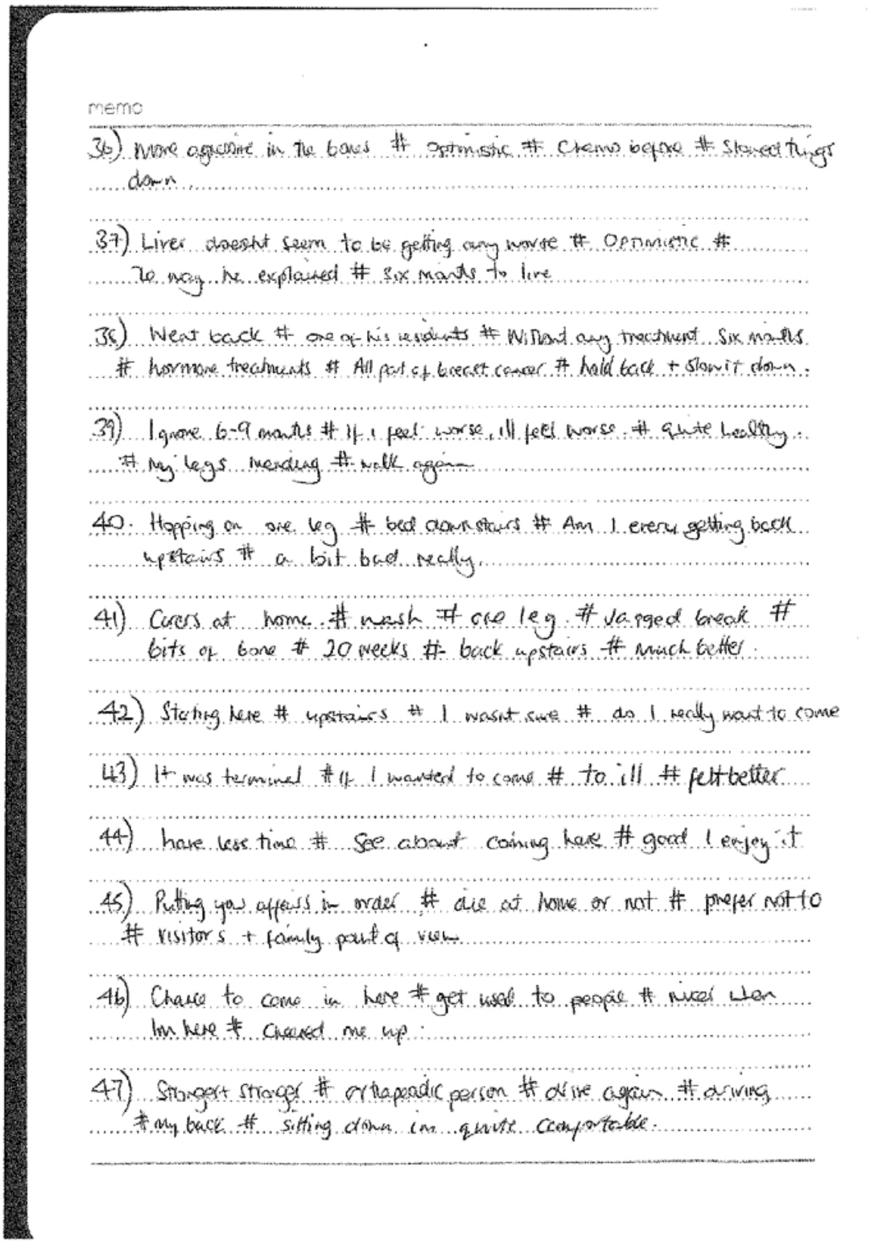
31) All these tests # meant I was ok # everything fine + stable # Flared up again in my liver

32) NS Explanation # Usually CT # Just appear out of the blue # feel better about everybody # affected # otherwise I want to punch somebody

33) behaved similar way to bones # Just stabilise # Stop chemo too ill # What happens now # put you affairs in order

34) Prognosis # 6-9 months # Just fell to pieces # I was on my own.

35) Chemotherapy # to ill # Couldnt take it # didnt know ~~what treat~~ ~~here for~~ # Fitted me in



memo

36) More aggressive in the bones # Optimistic # Chemo before # Slowed things down

37) Liver doesnt seem to be getting any worse # Optimistic # The way he explained # Six months to live

38) Went back # one of his residents # Without any treatment Six months # hormone treatments # All part of breast cancer # hold back + slow it down.

39) Ignore 6-9 months # If i feel worse, ill feel worse. # quite healthy. # My legs mending # walk again

40. Hopping on one leg # bed downstairs # Am I every getting back upstairs # a bit bad really.

41) Carers at home # wash # one leg # Jagged break # bits of bone # 20 weeks # back upstairs # much better.

42) Staying here # upstairs # I wasnt sure # do I really want to come

43) It was terminal # if I wanted to come # to ill # felt better

44) have less time # See about coming here # good I enjoy it

45) Putting you affairs in order # die at home or not # prefer not to # visitors + family point of view

46) Chance to come in here # get used to people # nicer when Im here # Cheered me up

47) Stronger stronger # orthopaedic person # drive again # driving # my back # sitting down im quite comfortable.

Appendix C3 : ~~Amanda :~~ Original transcript (Angela).

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NJ: OK Angela~~manda~~, I just need to check that you've read the information about my study, and I'll answer any questions you might have before we start.

No that's fine.

NJ: I just need to get you to sign this consent form to say you've read and you agree to taking part.

OK

NJ: Also if you want to stop at any point that would be fine.

I understand, it should be fine

NJ: I guess, basically I want to hear about your journey and how your getting on with things

Comic relief 2009 it all started I think when I discovered my lump believe it or not

Because id lost, my daughter and I had been going to slimming world so id lost three stone and shed lost three stone and erm a chap from work phoned me up on the Friday which was my day off, no Thursday was day off and he was wanting to dress up as something for comic relief at work

So he wanted to know if id got any bra's that were too big for me cos id lost weight as you do

So I said il go and have a try on of a few and see ~~whats~~what's what

I was actually trying on bras to lend then to my friend for his comic relief dress up as cher I think

And I just felt a lump, id not noticed it before and er I just sort of sat there and I thought that just doesn't feel right does it so, and it was sort of lunchtime and I was panicking as soon as id found it

So I phoned up my GP unit and er was crying and panicking on the phone saying ~~i~~i've found a lump and I don't know what to do cos its Friday and I thought, oh god ~~i~~i've got to wait until Monday and blah blah blah

So Thursday it was, Thursday

But erm she got me in straight away on the day to have a look and have a feel and she referred me straight away to the breast surgeons at (place name) so I think I got a ~~phonecall~~phone call early the following week to go in to see them and erm it was a huge lump I mean how id not found it before god only knows, I just presume that because id lost so much weight, that maybe my weight was masking it or id just not noticed, I don't have a sexual relationship with my husband anymore for the last 15 years

Cos ~~he~~she's like a lodger

So erm I just I was just amazed that id found it.

But erm I just I suppose you just think oh right you know id heard lots of these stories and then one goes and gets their lump out and ~~everyones~~everyone's fine aren't they

Cos you hear a lot of the ones that you know have the chemo and just recover straight away but erm it was a big lump and er so obviously because of the size of it well they biopsied it first and it was cancerous so I had the , I was booked in for a lumpectomy

Where the results of that were the that er most of the nodes under the right arm were affected

So because of that they obviously scanned the rest of your body don't they and id been also because id been overweight id had back problems for the last few years and id been seeing the physiotherapist and all sorts just for a bad back and sometimes it got as so I could hardly walk cos of the pain in my back but erm as soon as we'd had the scan and it showed erm showed that the cancer had already spread to my erm bones and a large part in my sacrum which explains the back ache for the last few years

So I just think to myself you know I should have spotted something years, if id spotted something years ago maybe you know id be alright , so erm it was a hell of a shock really cos I got the diagnosis of the lump and almost straight away cos I had a scan before that id got the diagnosis that it had already spread so it was secondary not erm so , but I recovered from the lumpectomy but by the time my scar had healed cos my scar didn't heal very fast everything seemed to go wrong, I had an infection in my sca-r and one thing or another but because of that it sort of delayed me starting the chemo

Which was quite good in a way because my back had got to be so painful that I couldn't , I couldn't even move my legs without screaming so just sort of went suddenly downhill that quick with the back

They said it was because it had grabbed the sciatic nerve so the bit that was in that sacrum at the back had grabbed the right hand sciatic nerve so this leg was unbearable

So I had five days of radiotherapy before I started the chemo

At that point I was at the lowest because pain was unbearable in my back , I can stand most things but really bad pain I thought I don't know how long I can cope with this pain

But er but thankfully within a week or two of having the radiotherapy it must have just eased it enough to release that nerve, and I started to feel less pain thank goodness so

So that , and then just from within a month or so of being diagnosed I was having to use a stroller to walk because of my back and it seemed to happen all so suddenly so it was a bit of a shock really and that stage my daughter was doing her a-levels son was doing his as-levels, I say my husband and I haven't really got on well for the last fifteen years even though he lives, he works away all week and he comes home at weekends , so he has his own room and ~~hes~~he's like a lodger

So it sort of hit us all pretty hard really cos erm my son decided he would be an ostrich, so he just ignored it, if I wasn't feeling very well he'd leave the room bury his head in the sand

But erm I don't know, the first year was absolute hell really, going through all of these treatments and then everything seemed to erm, suddenly I could walk better and I was in less pain and er we seemed to just ~~mosy~~mosey along for the next couple of years which erm, my daughter went off to university but er she was close enough to come home most weekends so she used to, so its her that been affected more than anybody cos erm she probably didn't want to come home every weekend but felt she aught to, I told her not to but she did so , while she was away at university and then my son went off to university

So er but the first year was ~~absoloute~~absolute hell

I don't know how people cope with it actually if ~~theyre~~they're in constant pain because the pain was unbearable to start with

But then it just seemed to settle into a pattern

Luckily touch wood, and I don't know how other people cope

I had long term health insurance at work because I was too ill to go to work obviously

Got paid for the first six months but er

After that six months if I hadn't had long term health insurance I would have gone down to ~~sickpay~~sick pay and I just don't know how we would have coped

Two kids to support at university

And just general living expenses anyway is a nightmare plus

(helicopter overhead)…

I just don't know how people cope

I've seen people on the television as well that have said suddenly they've got no money so what do they do?

Because ~~e~~you're expected to go for all these treatments and that means car parking at the hospitals you know to go to radiotherapy fifteen days continuously it means , if I hadn't have had this insurance, so I carried on getting paid seventy five percent of my salary I ~~wouldnt~~wouldn't have coped at all, at the stage we were at but erm

But then again it might have been good because my husband might have had to chuck in running his own business which is down in south ~~wales~~Wales and come home and things might have been better so you never know

But so basically as far as money was concerned we were so lucky that erm we could carry on virtually as we were

Cos er that must be a hell of a shake up for people that haven't got any insurance

Suddenly have to stop work , six months have gone and you've got no ~~no~~ salary

But so I feel guilty some times that I feel quite well off because I carried on

I was on a good salary any way so 75% of that good salary is perfectly adequate for us to live on so we're very lucky

So we sort of puddled on for a bit really and then last year was quite a good year except for my mother , ~~shes~~she's my father died two years ago into this who he was a carer for my mother who lives in (town 80 miles away)

So it sort of as it does it always falls on the daughter doesn't it that because I wasn't working and I could drive I used to go over to her bungalow every two or three weeks and stop for two or three days sort her pension out and get her a home delivery of shopping and stuff and ignoring everybody that was telling me I was doing too much myself and I really needed to rest

So I don't know whether that was why eventually at the end of last year id started to feel unwell again sort of the beginning of the year on and off

But I had to keep going because my daughter and I were going to (~~america~~America) for three weeks

In ~~june~~June ~~whuich~~which coincided with her graduating and getting a job so we went to visit family in (~~america~~America) for three weeks

But so we got back from that ok and my mom had had another fall and been in hospital again while I was away so ~~shes~~she's ~~shes~~ always been a worry since my father died so ~~i~~I've had her to worry about

But gradually towards the end of last year something didn't feel right so I was seeing the oncologist and I think they erm they~~t~~ decided that probably

When I was first diagnosed it was hormone receptive cancer and because I was pre – menopausal you go onto the tamoxifen drug

And id been on it for about three years and it had still not kicked me into post menopause which they hope it does because there are more drugs that they can give you when your post than pre apparently and tamoxifen is the only one for when your pre-menopausal but there quite a few that you can use when ~~youre~~you're after

In December last year I went to see the oncologist and we decided that the next phase was going to be to give me some hormone jabs to push me into the menopause

So I could switch drugs because they presumed that it was perhaps the tamoxifen had stopped working as efficiently as it should have

Which was perhaps why my bones were being a bit more achey and generally flaring up again

I also felt a bit angry cos id not had a bone scan since the very first year when I was diagnosed

So other than me saying that I was having a lot of pain in shoulders and knees and stuff that nobody had, id not been given another bone scan

Whether it was just overlooked I don't know but

So that was going to be the next stage and I had the appointment at the beginning of December but then two days before Christmas I fell back on a dining chair at home and it snapped my leg

So the top of my femur on the right leg which is obviously because of a hot spot of cancer there

So it sort of everything went on hold for a while, while I went in and had my leg pinned back together

And but while I was in there my blood showed fluctuating liver function so

So the ~~orthopedic~~orthopaedic people decided to do an ultrasound on my liver

Whereas id been having ct scans every six months and the last one id had in November hadn't showed anything but then I broke my leg at Christmas and suddenly they ~~ultrasounded~~ultra sounded my liver and there it was again

So that week was a week from hell because I was so angry so angry

That id been having all theses tests and telling everyone that that meant that I was ok and everything was stable and fine and then suddenly it had flared up again in my liver

Which I still haven't had an explanation for really cos apparently usually ct scans pick things up but in this case either it hadn't been read properly or it did just appear out of the blue

So to feel better about everybody I have to think that it just appeared between ~~novemeber~~November and Christmas so

Cos otherwise I want to punch somebody so you know

At that point I dwell really I don't know if its just because my bones sort of settled and I know id lasted three years so I just thought it was something else, they'll give me some chemo and it will settle down

So I started the chemo, but for some reason, I mean he did apologise, my oncologist, but for some reason I assumed it behaved in a similar way to the bones , that it could just stabilize and be there for years or whatever but so it wasn't until they told me that I had to stop the chemo because it was making me too ill that I told him so what happens now then and he said well he said well you need to put your affairs in order basically

And I said well ~~whats~~what's the prognosis then and he said 6-9 months , I I just well my daughter was there with me and we just fell to pieces, no she wasn't there with me that time I was on my own

Cos id gone in for chemotherapy thinking I was going for chemotherapy to get there and be told that because I was too ill and I couldn't have it so they didn't know what I was there for. Nobody knew why I had turned up but the oncologist fitted me in and explained the situation

So er obviously once its gone into the liver, its more, can be more aggressive than in the bones apparently so im trying to be optimistic at the moment ~~i~~i've had three lots of chemo before I couldn't have anymore and seemed to have slowed things down and the erm recent scans have shown that my liver doesn’t seem to be getting any worse so I have to be optimistic that I can keep it at bay with what ~~i~~i’ve got

The way he explained it we went for a month or so thinking that ~~i~~i’ve only got six months to live really

And when I went back for my next appointment and it wasn’t my oncologist , and it was one of his residents he explained to me that what he should have said was that without any treatment at all then 6-9 months probably but because I’~~i~~m still able to have the hormone treatments; the herceptin and the hormone zolodrex, four weekly hormone jabs that because its all part of the breast cancer which is hormone receptive hopefully even in the liver the hormones will hold it back and slow it down

So from that point of view ~~i~~i’ve decided to ignore 6-9 months and just think well suddenly if I feel worse then ill feel worse wont I , but at the moment while I~~i~~m feeling quite healthy and my legs mending and I can walk again that twenty weeks of hopping on one leg , so I had to have a bed downstairs which was not very nice cos you think god am I ever going to get back upstairs again

So those few months were a bit bad really having to have carers at home having to come and help me wash cos I could only hop on one leg

No plaster I’ve got a 40cm rod up there with another one into the hip but it was jagged it was a jagged break on the outside sort of ~~theres~~there’s bits of bone

So I’~~i~~ve had 20 weeks of not being able to put weight on it but as soon as I could start putting weight on it so I could get back upstairs then I felt a lot better

That sort of coincided with starting here as well, just after I started going back upstairs when I started coming here weekly which I wasn’t sure about doing cos I thought do I really want to come

Cos I was offered the chance four years ago obviously cos once it had gone into my bones, it was terminal so they asked me if I wanted to come then but I think, the first year I was just too ill to want to do anything and then when I started to feel better then obviously I didn’t want to come anyway

But now it has gone into the liver im obviously it seems that I might have less time then I erm I though I might as well come and have a look around and see about coming here and it is good I do enjoy it and anyway it sort of gets you , you sort of have to think when they say about putting your affairs in order

As to whether you would want to die at home or not

So I thought I would probably prefer not to from visitors and family point of view so if I got the chance to come in here then I would prefer to be in here

So I thought I might as well get used to people cos then ~~itll~~it’ll be nicer when im here because I’ll know people wont i.

(Phonecall………)

NJ: its ok to answer it if you need to.

But yeah so coming here has cheered me up a lot really

And obviously my legs getting stronger and stronger every week so

Im hoping that the next time I go to the ~~orthopedic~~orthopaedic person that he will say that I can drive again cos I was driving all these four years cos it was my back really so as long as im sitting down im quite comfortable

But because id broken my leg the er the from an insurance point of view, the say-so went back to the erm ~~orthopedic~~orthopaedic surgeon as opposed to my gp whereas before my gp had got it in my notes that because im on morphine and stuff but not too strong, if im too drowsy I don't drive so he considers that im safe to drive short to medium distances so, but since I broke my leg, now its up to the ~~orthopedic~~orthopaedic surgeon to say my legs strong enough to drive so from and insurance point of view, so I haven't been able to drive since Christmas but its driving me mad

I've got an automatic car so if it had been my left leg it would have been ok , its my right leeg, but im hoping that when I go back in a couple of weeks that hell say that I can drive again. Im not going to go far cos im not going to tire myself out going looking after my mother cos I know I cant do it but

I feel sorry for her from my point of view obviously

~~Shes~~She's worried about me but ~~shes~~she's not capable of looking after herself so there will come a point where she'll have to go into residential care

So I feel guilty cos I think that you should be looking after your mother at that time shouldn't you whereas my 22 year old daughter shouldn't have to be looking after me at my age

It does make things awkward… my husband has improved we do get on better than we used to but er

From his point of view its been a shock as well so

My 21 year old son is probably the one who takes it all better by just not wanting to know all of the details just doing what he needs to do, ~~hes~~he's come back from university and he cooks the dinner and stuff and makes sure I get to bed on time

So ~~hes~~he's fine

But for it to hit you when I was 50, I found the lump in the ~~april~~April and I was 50 in the ~~july~~July obviously when you get to have your free ~~mamogrms~~mammograms so it was a bit of a , a bit strange having a letter through suggesting I should go and get a free mammogram when id just had half of my breast removed so erm

Its just the whole thing of the shock of it all

And because you its hard work you've got oncology appointments you've got breast surgeon appointments now ~~i~~i've got ~~orthopedic~~orthopaedic appointments that I have to go to and really in a rural area like this its hard work cos to get from (town) to (town) it's a fifty minute job so if ever im in the chemo unit or my bloods not right so im in for a few days it's a long way for everybody to come.

To visit and they get tired

Like I say the first year was like a year from hell

And er the six months well the first four or five months from Christmas were pretty bad as well

But erm hopefully now im sort of now what the word …

Im sort of im just taking each day as it comes it er ive decided that's the only way I can deal with it these days im sort of reliant on other people in some ways but I try and erm I try and do as much as I can myself so but erm im sort of resigned to the fact that its going to get me at some point but im not going to let it get me until I have to

Now its gone to the liver and its inoperable then ~~itll~~it'll be a matter of just waiting for it to be just too much in the liver and then that's it isn't it apparently

It does worry me that when you ask people about it all they say is that you just get more and more tired suddenly ~~youre~~you're too tired and then that's it cos I get tired quite a lot and I think oh god am I going to go to sleep and not wake up you know what I mean

But im assured by all the blood tests and every thing else that im not ready to pop yet so you just have to believe that ~~youre~~you're gonna wake up again

But its quite hard, its obviously harder looking at your children

Because my children are 21 and 22 im probably not going to see any grandchildren not going to see them get married and settle down so that's quite hard but

As far as my son is concerned I'll still be here when ~~hes~~he's 40 realistically that's probably not the case

But while he carries on believing that it keeps him happy so that's good

Its either being an ostrich and burying his head in the sand or its his way of coping with it isn't it, he only copes with bad things when they happen rather than thinking about them going to happen

My daughter tends to be the other , ~~shes~~she's been through it all with me, been to all of the appointments and seen me through it all where its between the ages of 18 to 22 its really not something that she should have had to do

But my husband is not the most supportive person

He did actually start to come to chemo with me but er this time, he didn't last time

He did make the effort each month to have the day off and come to chemo with me

He has tried to be more helpful and he knows he has to be and ~~its~~it's not fair to rely on my daughter to do everything so he does do more than he used to

But he still only comes home at weekends cos that's his ~~job,~~job; if he didn't do his job then we wouldn't have any of his money coming in so it has to be done

But then again if we'd had a good relationship I think he would've stopped doing that and he would have come home and packed yoghurts at (local factory) just to be at home you know so

Whereas because of my life insurance he has been able to carry on exactly as before but except for the weekends,

I do feel a bit resentful for him, that's ~~hes~~he's

once again ~~hes~~he's going to fall on his feet cos my money is keeping us going and when I pop my clogs he'll be quite rich there you go so once again ~~hes~~he's landed on his feet

~~its~~Its only me going back to work and working which meant he can carry on running his own business

~~so~~So sort of I try not to be resentful, but because its not worth , not worth the agro, but sometimes its hard but I don't know what more I can say really.

Not a very nice story but then again I'~~i~~ve got two really nice children

I've got lots of friends, my friends from (local factory) that I work with because its only round the corner

~~Theres~~There's some of them that still bring their butties round at lunchtime to come and see me

The whole gang of them came and did my garden and built me a summer house this summer once when they heard that it might be my last summer they all come and done that for me

I've got such good friends

I mean I felt awkward letting them do it, but when I spoke to the psychologist she said they need to have something to do because they cant do anything else so they all came and tidied up my garden and built me this lovely summer house

Which if it would stop raining I could go and sit in

It means that I'~~i~~ve got such good friends

A few years ago it got to a point where I think my husband was resentful of the fact that I have friends because he doesn't have any cos he travels around

Occasionally in the first year when we were going it was my friends that were taking it in turns when I had to go to radiotherapy for 15 days , people I worked with took it in turns to take me for radiotherapy

Cos my husband had to carry on working otherwise he wouldn't have had any more money supposedly

When I'~~i~~ve asked him to do something and ~~hes~~he's been a bit off , ~~hes~~he's said you've got all these good friends, why don't you ask them to do it

Yes I have and im glad I have got them cos I don't know where I would have been without them

Cos he would have had to have pulled his weight and done something

So don't know

When I think about it, I wish id have got rid of him 15 years ago you see, I might have met somebody nice

But you just sort of drift your children go to school and you're working and you come home and then he comes home at the weekend and it doesn't really matter cos hes moved into the back room anyway and ~~hes~~he's just a lodger and its easier cos I don't have to take the children anywhere to be able to see him cos he comes home but its not an ideal relationship

In those early days , the first lot of chemo I had four years ago, ~~everytime~~every time I have chemo it does something to me

Apparently id had stomach ulcers brewing up for years and the first lot of chemo that I had after a week or so burst my stomach ulcers

My husband was on holiday in ~~germany~~Germany cos he goes to ~~germany~~Germany and rides on trains every year and he used to take the kids until they got old enough not to want to go

But he'd still booked his holiday to go even though I was starting my chemo , we didn't know what would happen so sort of 10 o clock at night I was sort of crawling across the floor in the hallway having lost so much blood that I could hardly walk and it was down to my two kids to get me to hospital and sort me out

And sort of around that time my son just wanted to kill his dad cos he should have been there shouldn't have been left to the kids to have to clean up after me and do that, it was horrible

So then I was in hospital for a few weeks with those ulcers as well, so that first year was\not very good

When I was in hospital just to give something else to laugh at

When I went in with the stomach ulcers I had an infection, a gnat had bitten me on the chest and while I was in hospital with the ulcers I kept trying to tell the nurses that they really needed to look at this cos it was turning nasty, everyone ignored me for the first five days until it was a hole in my stomach

And then they gave me these anti-~~biotics~~biotic which reacted with the steroids I was on and I went totally doo-lally , how it says these side effect,…complete personality change I was completely off the wall I was running around the ward, locking myself in the toilets saying that my husband was a conspiracy theory that he wanted to put me away so he could get my money

But then as the tablets wore off through the day id go back down again and then id go mad again and then… it was horrible… my husband and daughter figured it out, they went on the internet and looked it up………

And that's basically it really. Do you want anything else.

NJ: No that's fine unless there is anything else which you think is important to tell me.

No I think that's everything really.

NJ: Thanks so much for taking the time to tell me your story.

~~Appendix C: Sample Transcript~~

~~PART ONE: WIFE'S CANCER JOURNEY / CARER~~

~~STROPHE One: WIFE AND CANCER~~

~~STANZA ONE: WIFE'S 1st EXPERIENCE OF CANCER~~

~~Does that include MY WIFE / that's where IT STARTED for me really / SHE HAD CANCER~~

~~In the early 90's/ she had a MASTECTOMY for breast cancer and~~

~~THINGS WENT PRETTY WELL for that~~

~~She just had check-ups / and a BIT OF RADIOTHERAPY~~

~~STANZA TWO: WIFES REOCCURENCE~~

~~The beginning of 2002 she had a REOCCURRENCE on the scar line / and this time they could CARVE that off~~

~~She also had bone cancer which GRADUALLY GOT WORSE~~

~~So she went DOWN THE ROAD of more radiotherapy, chemotherapy, all sorts of medications~~

~~BATTLED ON VERY WELL / but gradually GOT WORSE It spread from the satrim, the thigh, the back and a then bit in the skull~~

~~STROPHE Two: INTRODUCTION TO CANCER SUPPORT AND THE HOSPICE (through wife)~~

~~STANZA THREE: EXPERIENCE OF CANCER SUPPORT~~

~~So I GOT USED to some of the cancer support then / cos I was taking her to the hospital~~

~~She DIDN'T GET INVOLVED WITH THE HOSPICES then~~

~~Except for a problem with LYMPHODEMA in her arm which swelled up,~~

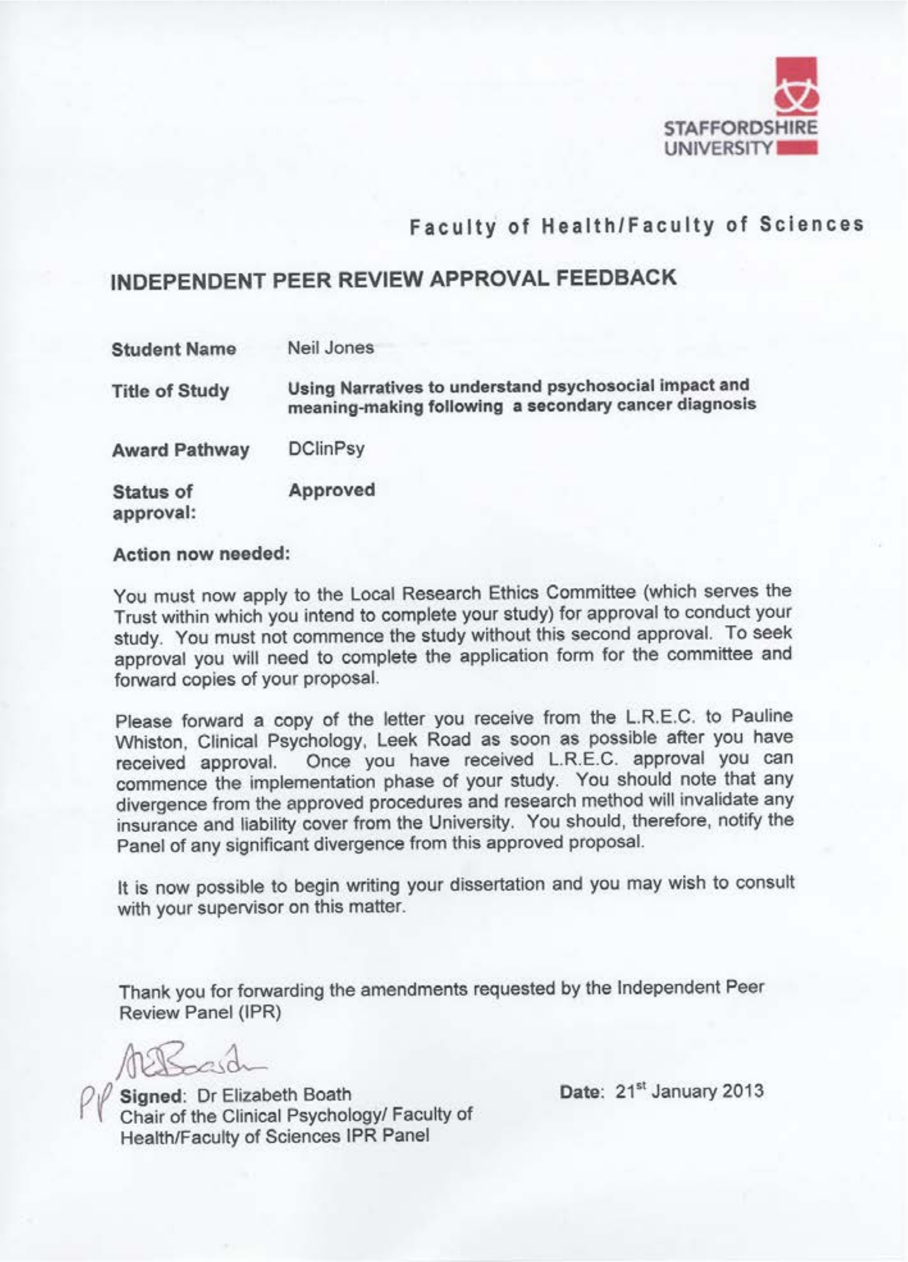
~~She was treated ORIGINALLY for that at the hospice~~

~~STANZA FOUR: INTRODUCTION TO HOSPICE CARE~~

~~Then when we moved [locally] in 2000~~

~~She started COMING HERE for a little bit [the hospice],~~

Appendix D: Peer Review approval letter



STAFFORDSHIRE UNIVERSITY

Faculty of Health/Faculty of Sciences

INDEPENDENT PEER REVIEW APPROVAL FEEDBACK

Student Name	Neil Jones
Title of Study	**Using Narratives to understand psychosocial impact and meaning-making following a secondary cancer diagnosis**
Award Pathway	DClinPsy
Status of approval:	**Approved**

Action now needed:

You must now apply to the Local Research Ethics Committee (which serves the Trust within which you intend to complete your study) for approval to conduct your study. You must not commence the study without this second approval. To seek approval you will need to complete the application form for the committee and forward copies of your proposal.

Please forward a copy of the letter you receive from the L.R.E.C. to Pauline Whiston, Clinical Psychology, Leek Road as soon as possible after you have received approval. Once you have received L.R.E.C. approval you can commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

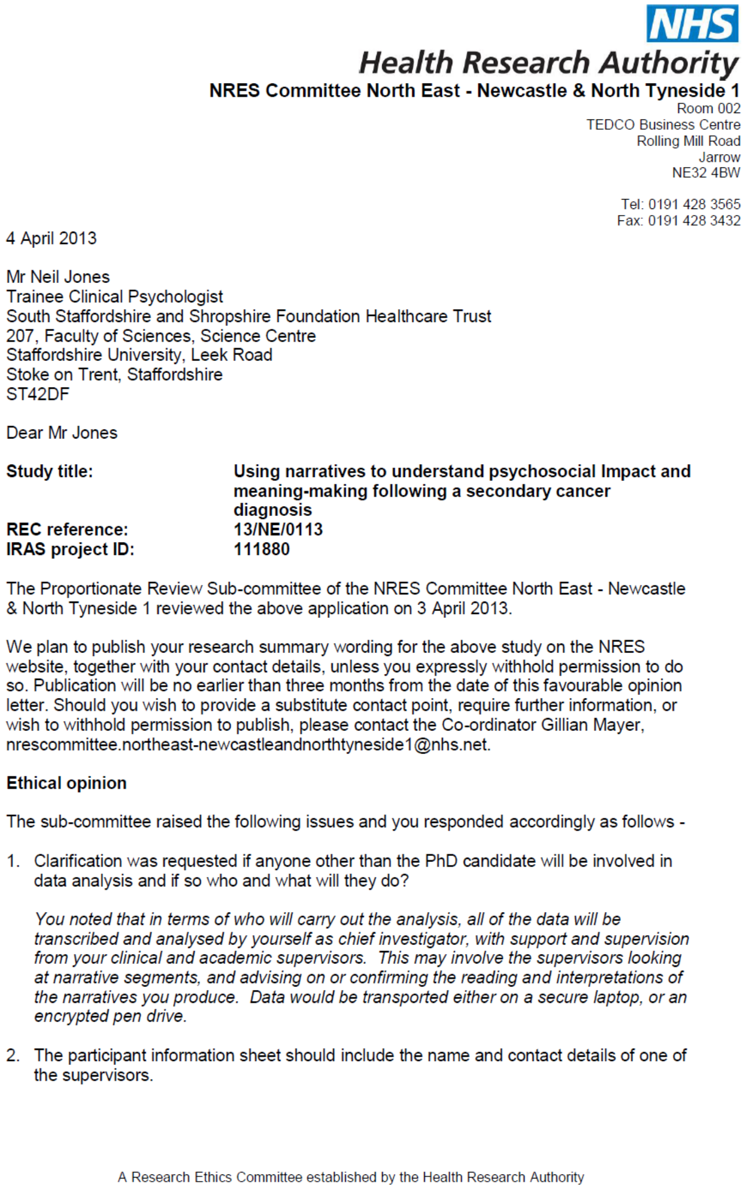
It is now possible to begin writing your dissertation and you may wish to consult with your supervisor on this matter.

Thank you for forwarding the amendments requested by the Independent Peer Review Panel (IPR)

PP **Signed**: Dr Elizabeth Boath
Chair of the Clinical Psychology/ Faculty of Health/Faculty of Sciences IPR Panel

Date: 21st January 2013

Appendix E : National Research Ethics Service Approval Letter



NHS
Health Research Authority
NRES Committee North East - Newcastle & North Tyneside 1
Room 002
TEDCO Business Centre
Rolling Mill Road
Jarrow
NE32 4BW

Tel: 0191 428 3565
Fax: 0191 428 3432

4 April 2013

Mr Neil Jones
Trainee Clinical Psychologist
South Staffordshire and Shropshire Foundation Healthcare Trust
207, Faculty of Sciences, Science Centre
Staffordshire University, Leek Road
Stoke on Trent, Staffordshire
ST42DF

Dear Mr Jones

Study title:	**Using narratives to understand psychosocial Impact and meaning-making following a secondary cancer diagnosis**
REC reference:	**13/NE/0113**
IRAS project ID:	**111880**

The Proportionate Review Sub-committee of the NRES Committee North East - Newcastle & North Tyneside 1 reviewed the above application on 3 April 2013.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Gillian Mayer, nrescommittee.northeast-newcastleandnorthtyneside1@nhs.net.

Ethical opinion

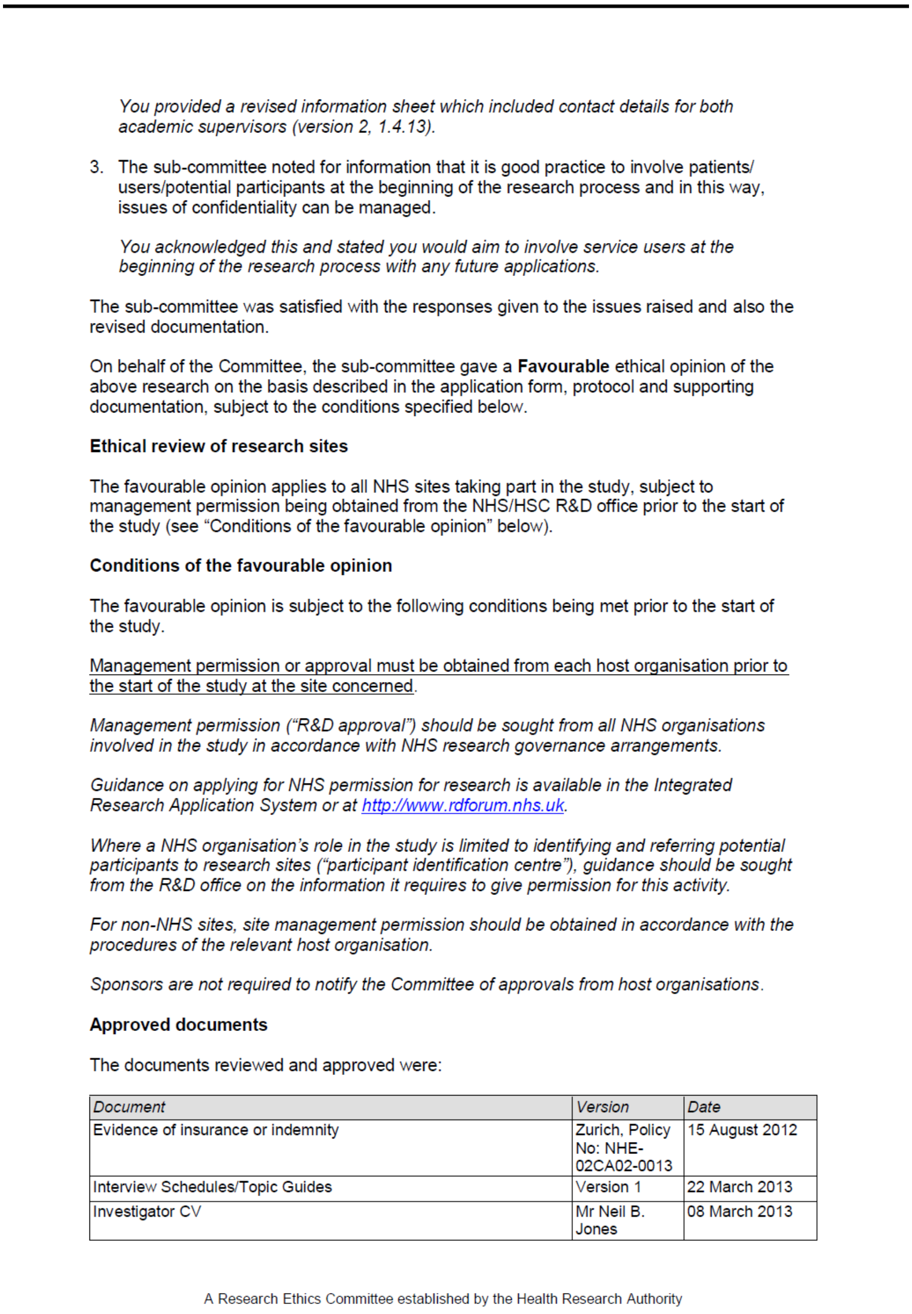
The sub-committee raised the following issues and you responded accordingly as follows -

1. Clarification was requested if anyone other than the PhD candidate will be involved in data analysis and if so who and what will they do?

   You noted that in terms of who will carry out the analysis, all of the data will be transcribed and analysed by yourself as chief investigator, with support and supervision from your clinical and academic supervisors. This may involve the supervisors looking at narrative segments, and advising on or confirming the reading and interpretations of the narratives you produce. Data would be transported either on a secure laptop, or an encrypted pen drive.

2. The participant information sheet should include the name and contact details of one of the supervisors.

A Research Ethics Committee established by the Health Research Authority



You provided a revised information sheet which included contact details for both academic supervisors (version 2, 1.4.13).

3. The sub-committee noted for information that it is good practice to involve patients/ users/potential participants at the beginning of the research process and in this way, issues of confidentiality can be managed.

   You acknowledged this and stated you would aim to involve service users at the beginning of the research process with any future applications.

The sub-committee was satisfied with the responses given to the issues raised and also the revised documentation.

On behalf of the Committee, the sub-committee gave a **Favourable** ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

Approved documents

The documents reviewed and approved were:

Document	*Version*	*Date*
Evidence of insurance or indemnity	Zurich, Policy No: NHE-02CA02-0013	15 August 2012
Interview Schedules/Topic Guides	Version 1	22 March 2013
Investigator CV	Mr Neil B. Jones	08 March 2013

Investigator CV	Dr Alison Elaine Tweed	
Other: Staff Information	Version 1	22 March 2013
Other: Debrief Sheet	Version 1	22 March 2013
Participant Consent Form	Version 1	22 March 2013
Participant Information Sheet	Version 2	01 April 2013
Protocol	Version 1	01 March 2013
REC application	IRAS Version 3.4 111880/428343/1/970	22 March 2013
Referees or other scientific critique report	Dr Elizabeth Boath (Staffordshire University)	21 January 2013
Summary/Synopsis	Version 1	22 March 2013

Membership of the Proportionate Review Sub-Committee

The members of the Sub-Committee who took part in the review are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

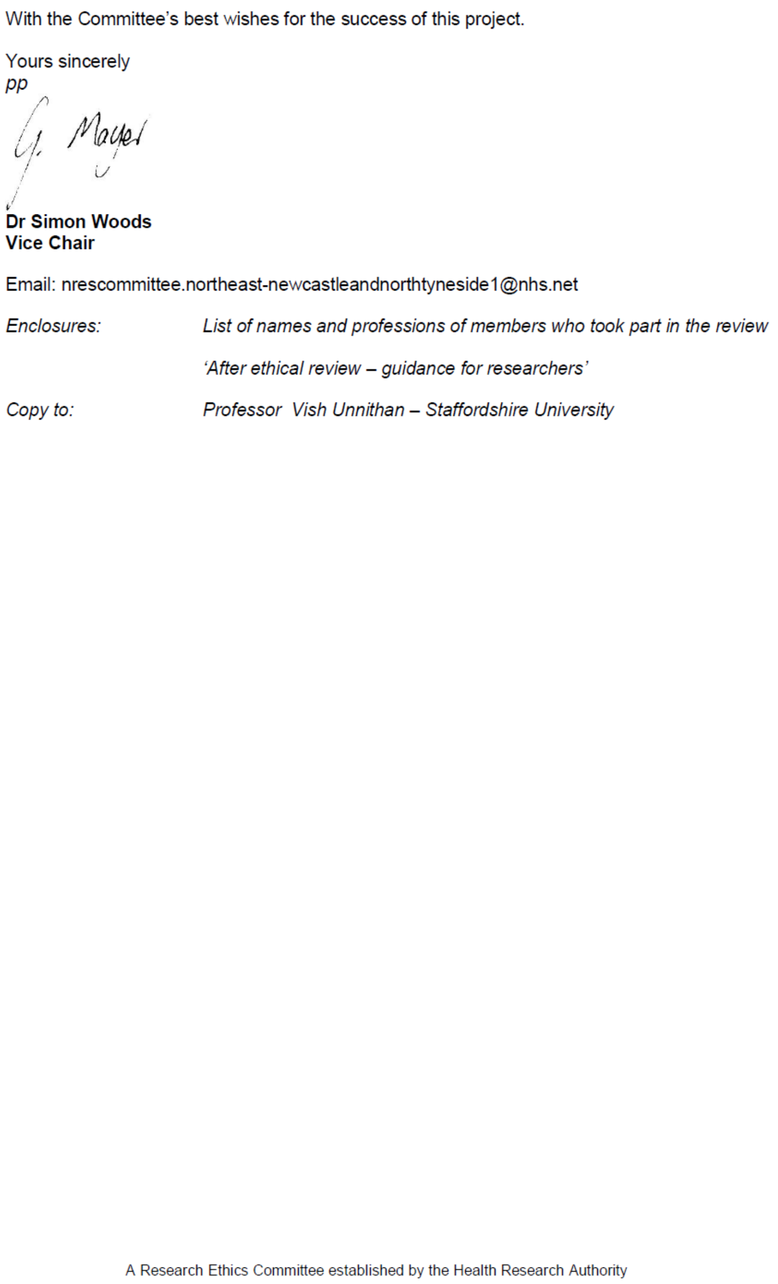
The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.
information is available at National Research Ethics Service website > After Review

13/NE/0113 **Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/



With the Committee's best wishes for the success of this project.

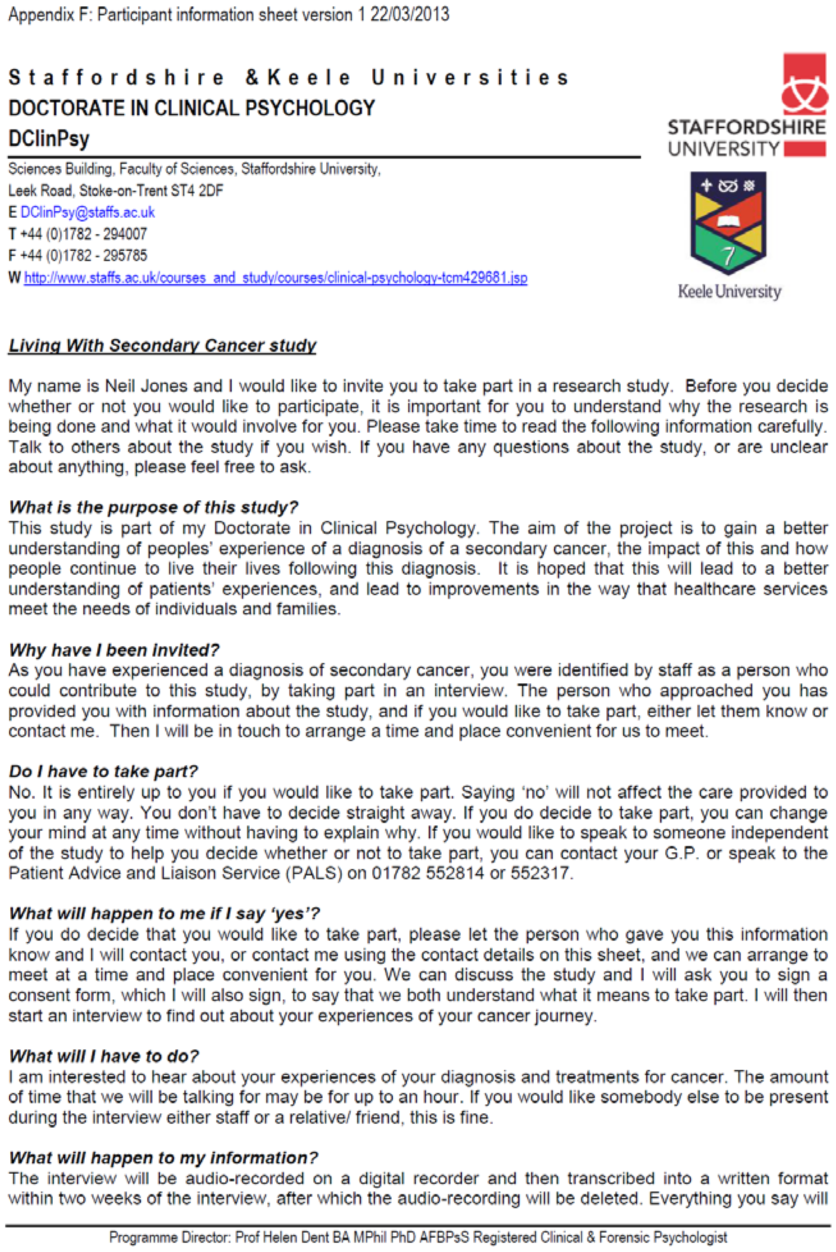
Yours sincerely
pp
G. Mayer
Dr Simon Woods
Vice Chair

Email: nrescommittee.northeast-newcastleandnorthtyneside1@nhs.net

Enclosures:	*List of names and professions of members who took part in the review*
	'After ethical review – guidance for researchers'
Copy to:	*Professor Vish Unnithan – Staffordshire University*

A Research Ethics Committee established by the Health Research Authority

Appendix F: Participant Information



Appendix F: Participant information sheet version 1 22/03/2013

Staffordshire & Keele Universities
DOCTORATE IN CLINICAL PSYCHOLOGY
DClinPsy

STAFFORDSHIRE UNIVERSITY

Keele University

Sciences Building, Faculty of Sciences, Staffordshire University,
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F +44 (0)1782 - 295785
W http://www.staffs.ac.uk/courses_and_study/courses/clinical-psychology-tcm429681.jsp

Living With Secondary Cancer study

My name is Neil Jones and I would like to invite you to take part in a research study. Before you decide whether or not you would like to participate, it is important for you to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. If you have any questions about the study, or are unclear about anything, please feel free to ask.

What is the purpose of this study?
This study is part of my Doctorate in Clinical Psychology. The aim of the project is to gain a better understanding of peoples' experience of a diagnosis of a secondary cancer, the impact of this and how people continue to live their lives following this diagnosis. It is hoped that this will lead to a better understanding of patients' experiences, and lead to improvements in the way that healthcare services meet the needs of individuals and families.

Why have I been invited?
As you have experienced a diagnosis of secondary cancer, you were identified by staff as a person who could contribute to this study, by taking part in an interview. The person who approached you has provided you with information about the study, and if you would like to take part, either let them know or contact me. Then I will be in touch to arrange a time and place convenient for us to meet.

Do I have to take part?
No. It is entirely up to you if you would like to take part. Saying 'no' will not affect the care provided to you in any way. You don't have to decide straight away. If you do decide to take part, you can change your mind at any time without having to explain why. If you would like to speak to someone independent of the study to help you decide whether or not to take part, you can contact your G.P. or speak to the Patient Advice and Liaison Service (PALS) on 01782 552814 or 552317.

What will happen to me if I say 'yes'?
If you do decide that you would like to take part, please let the person who gave you this information know and I will contact you, or contact me using the contact details on this sheet, and we can arrange to meet at a time and place convenient for you. We can discuss the study and I will ask you to sign a consent form, which I will also sign, to say that we both understand what it means to take part. I will then start an interview to find out about your experiences of your cancer journey.

What will I have to do?
I am interested to hear about your experiences of your diagnosis and treatments for cancer. The amount of time that we will be talking for may be for up to an hour. If you would like somebody else to be present during the interview either staff or a relative/ friend, this is fine.

What will happen to my information?
The interview will be audio-recorded on a digital recorder and then transcribed into a written format within two weeks of the interview, after which the audio-recording will be deleted. Everything you say will

Programme Director: Prof Helen Dent BA MPhil PhD AFBPsS Registered Clinical & Forensic Psychologist

remain anonymous, and any information that could identify you will be removed. The transcripts will be locked in a secure place. The recordings will be heard by me, and the transcripts will be seen by me and supervisors overseeing this project. As this project is being conducted as part of my Doctorate in Clinical Psychology, transcripts may be checked by people external to the project, e.g. external examiners. However, they would not be able to identify you.

If you tell me that you, your child or somebody else may be at harm or risk of harm, in accordance with NHS Safeguarding policies and procedures I will have to let other agencies know.

After interviews, researchers like to use quotes in reports or journal articles to highlight individuals' experiences. If I use any quotes from your interview in a written report, these will be anonymised so the quote cannot be traced back to you.

What if I don't want my interview used in the research?

It is absolutely fine to change your mind - we all do from time to time. After I have transcribed your interview, there will be a one month period in which you may choose to withdraw your contribution. If you decide to do this, it will not affect the services you receive in any way.

Are there any risks to taking part?

You may feel upset talking about your experience with me. If you do, and you would not like to continue, the interview can be stopped at any time. I am a trainee clinical psychologist and have previously worked in cancer services, so I will keep an eye on distress levels, in case I feel you need to stop. I will provide you with phone numbers for people you can contact if you would like to talk about anything that has been raised for you during the interview. In addition, Marilyn Owens, Consultant Clinical Psychologist, can offer you a session to meet with her if you would find that helpful.

Are there any benefits from taking part?

It is hoped that you will find it useful to share your experiences of your diagnosis and treatment, but I cannot promise any direct benefits from taking part. This study will contribute to the wider understanding of peoples' experiences of cancer diagnosis and treatment, and how services can improve to meet the needs of cancer patients.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the service you are involved with, or from PALS (01743-277586 Shropshire or 01952-580478 Telford & Wrekin).

Who is funding this study?

This study is being undertaken as part of a Doctorate in Clinical Psychology. The two universities that are supporting and regulating this research are Staffordshire University and Keele University. *All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests.* This study has been reviewed and approved by both the NHS Research Ethics Committee and Staffordshire University Independent Peer Review Panel.

Further information and contact details

If you would like any further information about this study, please contact me:

Neil Jones
Staffordshire University
Clinical Psychology Training Programme
Faculty of Sciences
Leek Road
Stoke-on-Trent, ST4 2DF
Telephone: 01782 294007
Email: n.jones@med.keele.ac.uk

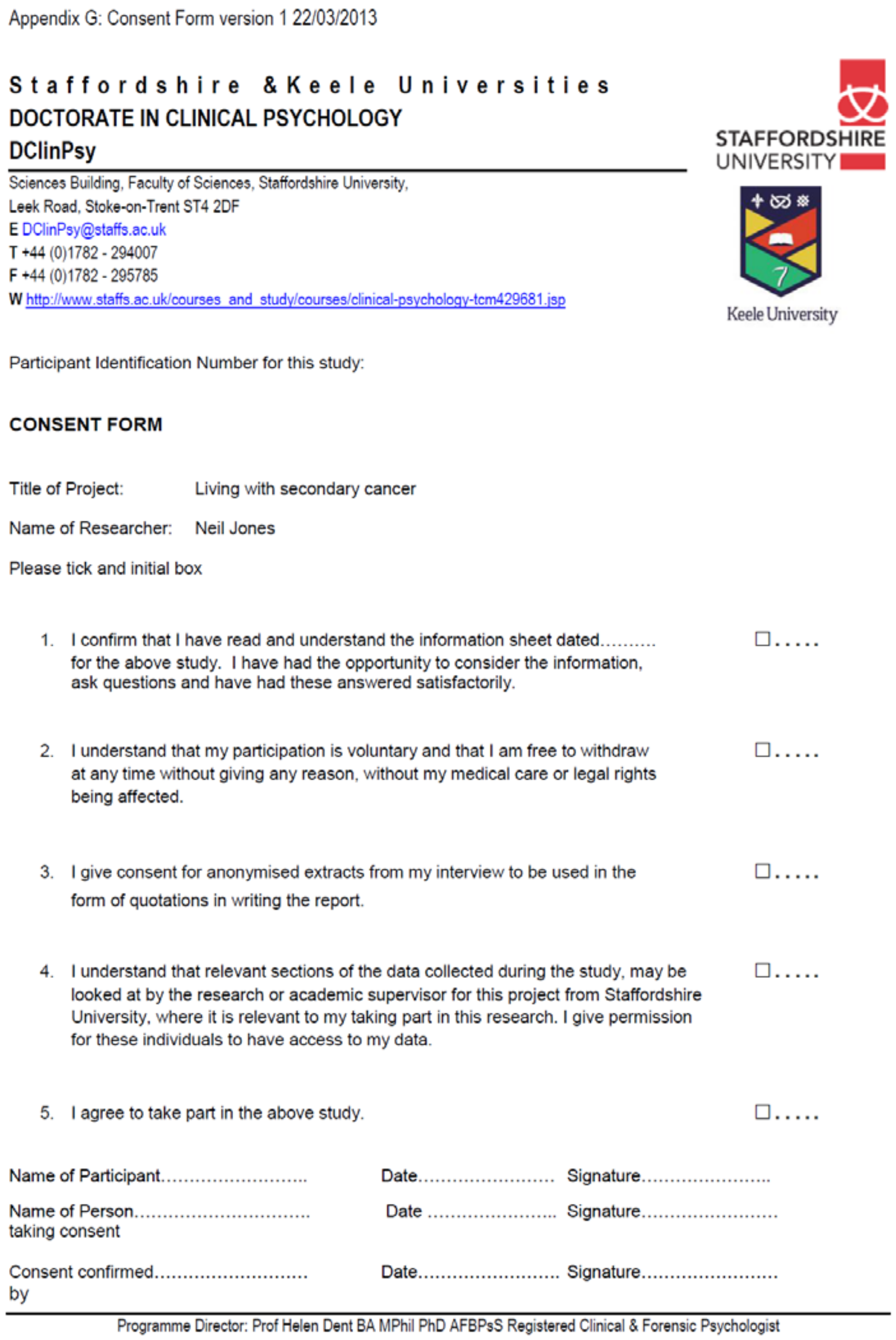
If you would like to speak to someone independent of the study, you can contact:

Patient Advice and Liaison Service (PALS)
William Farr House
Mytton Oak Road
Shrewsbury
SY3 8XL

Telephone: 01743 277586 or 01952-580478
Email:
PALS@telfordpct.nhs.uk
tracy.eggby-jones@shropshirepct.nhs.uk

Thank you for considering this research, and I look forward to seeing you if you decide to take part.

Appendix G : Consent form



Appendix G: Consent Form version 1 22/03/2013

Staffordshire & Keele Universities
DOCTORATE IN CLINICAL PSYCHOLOGY
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F +44 (0)1782 - 295785
W http://www.staffs.ac.uk/courses_and_study/courses/clinical-psychology-tcm429681.jsp

STAFFORDSHIRE UNIVERSITY

Keele University

Participant Identification Number for this study:

CONSENT FORM

Title of Project: Living with secondary cancer

Name of Researcher: Neil Jones

Please tick and initial box

1. I confirm that I have read and understand the information sheet dated.......... for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐.....
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐.....
3. I give consent for anonymised extracts from my interview to be used in the form of quotations in writing the report. ☐.....
4. I understand that relevant sections of the data collected during the study, may be looked at by the research or academic supervisor for this project from Staffordshire University, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐.....
5. I agree to take part in the above study. ☐.....

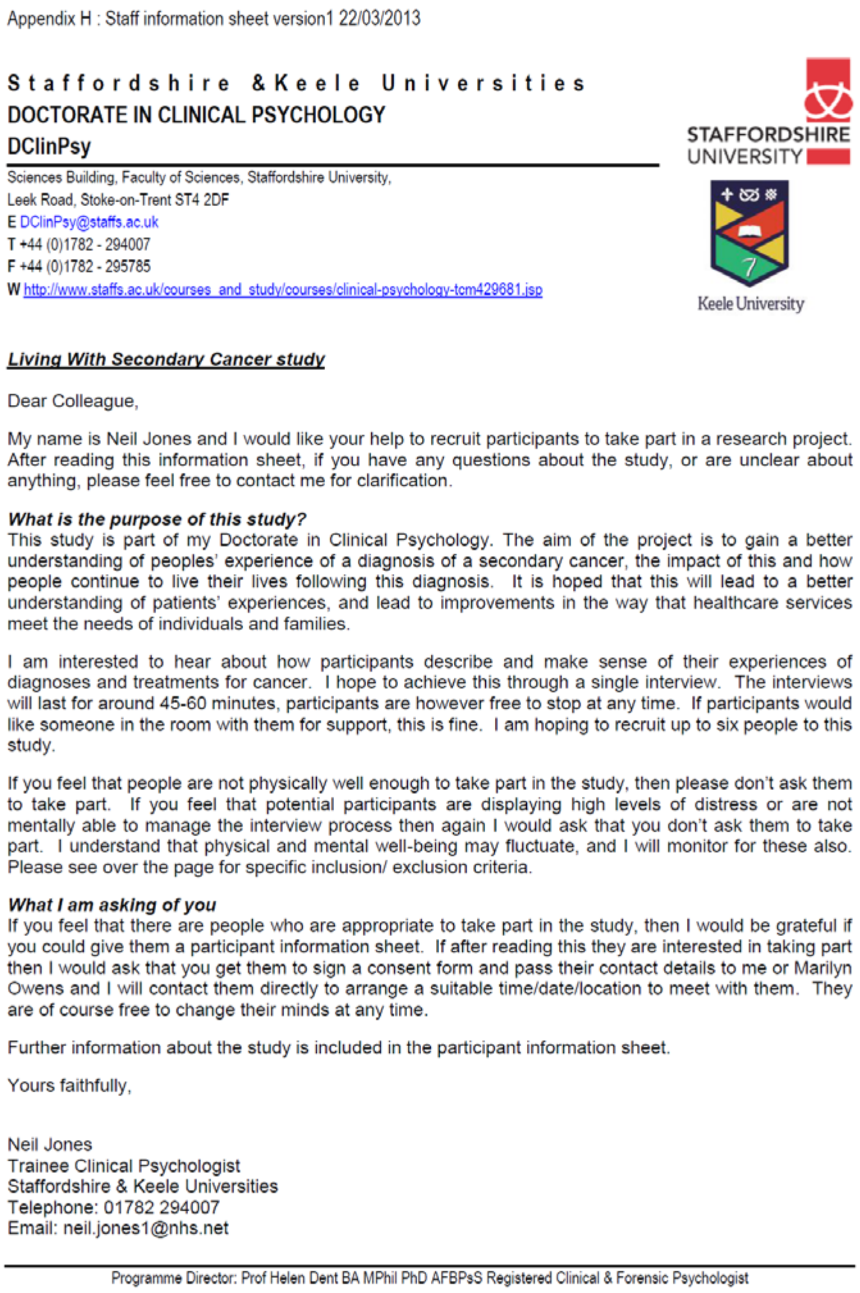
Name of Participant.......................... Date........................ Signature.......................

Name of Person............................... taking consent Date .... Signature........................

Consent confirmed.......................... by Date......................... Signature........................

Programme Director: Prof Helen Dent BA MPhil PhD AFBPsS Registered Clinical & Forensic Psychologist

Appendix H: Staff information



Appendix H : Staff information sheet version1 22/03/2013

Staffordshire & Keele Universities
DOCTORATE IN CLINICAL PSYCHOLOGY
DClinPsy

Sciences Building, Faculty of Sciences, Staffordshire University,
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E DClinPsy@staffs.ac.uk
T +44 (0)1782 - 294007
F +44 (0)1782 - 295785
W http://www.staffs.ac.uk/courses_and_study/courses/clinical-psychology-tcm429681.jsp

STAFFORDSHIRE UNIVERSITY
Keele University

<u>Living With Secondary Cancer study</u>

Dear Colleague,

My name is Neil Jones and I would like your help to recruit participants to take part in a research project. After reading this information sheet, if you have any questions about the study, or are unclear about anything, please feel free to contact me for clarification.

What is the purpose of this study?
This study is part of my Doctorate in Clinical Psychology. The aim of the project is to gain a better understanding of peoples' experience of a diagnosis of a secondary cancer, the impact of this and how people continue to live their lives following this diagnosis. It is hoped that this will lead to a better understanding of patients' experiences, and lead to improvements in the way that healthcare services meet the needs of individuals and families.

I am interested to hear about how participants describe and make sense of their experiences of diagnoses and treatments for cancer. I hope to achieve this through a single interview. The interviews will last for around 45-60 minutes, participants are however free to stop at any time. If participants would like someone in the room with them for support, this is fine. I am hoping to recruit up to six people to this study.

If you feel that people are not physically well enough to take part in the study, then please don't ask them to take part. If you feel that potential participants are displaying high levels of distress or are not mentally able to manage the interview process then again I would ask that you don't ask them to take part. I understand that physical and mental well-being may fluctuate, and I will monitor for these also. Please see over the page for specific inclusion/ exclusion criteria.

What I am asking of you
If you feel that there are people who are appropriate to take part in the study, then I would be grateful if you could give them a participant information sheet. If after reading this they are interested in taking part then I would ask that you get them to sign a consent form and pass their contact details to me or Marilyn Owens and I will contact them directly to arrange a suitable time/date/location to meet with them. They are of course free to change their minds at any time.

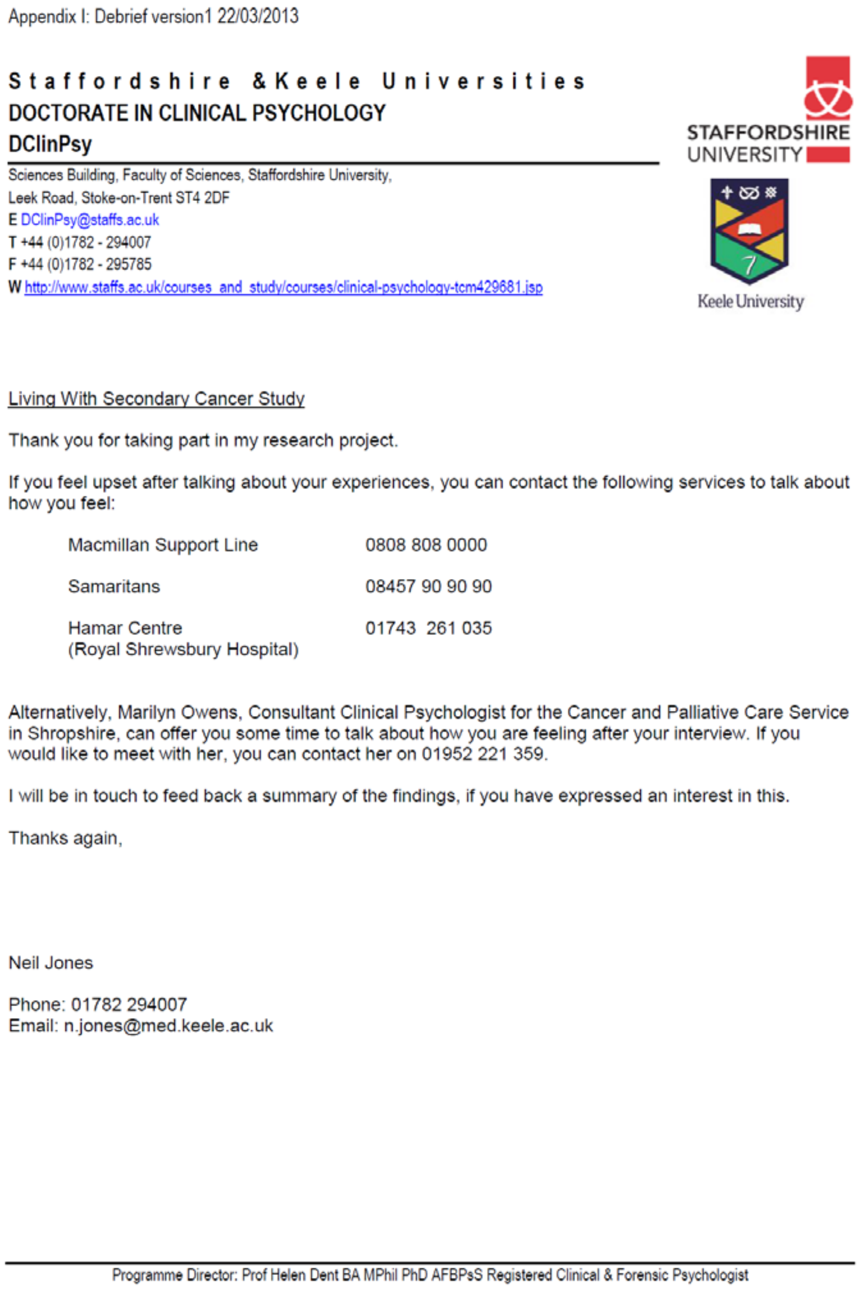
Further information about the study is included in the participant information sheet.

Yours faithfully,

Neil Jones
Trainee Clinical Psychologist
Staffordshire & Keele Universities
Telephone: 01782 294007
Email: neil.jones1@nhs.net

Programme Director: Prof Helen Dent BA MPhil PhD AFBPsS Registered Clinical & Forensic Psychologist

Appendix I: Debrief



Appendix I: Debrief version1 22/03/2013

Staffordshire & Keele Universities
DOCTORATE IN CLINICAL PSYCHOLOGY
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STAFFORDSHIRE UNIVERSITY
Keele University

Living With Secondary Cancer Study

Thank you for taking part in my research project.

If you feel upset after talking about your experiences, you can contact the following services to talk about how you feel:

Macmillan Support Line	0808 808 0000
Samaritans	08457 90 90 90
Hamar Centre (Royal Shrewsbury Hospital)	01743 261 035

Alternatively, Marilyn Owens, Consultant Clinical Psychologist for the Cancer and Palliative Care Service in Shropshire, can offer you some time to talk about how you are feeling after your interview. If you would like to meet with her, you can contact her on 01952 221 359.

I will be in touch to feed back a summary of the findings, if you have expressed an interest in this.

Thanks again,

Neil Jones

Phone: 01782 294007
Email: n.jones@med.keele.ac.uk

Programme Director: Prof Helen Dent BA MPhil PhD AFBPsS Registered Clinical & Forensic Psychologist