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**An Investigation of Personality Factors and Beliefs about
Illness that may Influence the Time Taken to Seek Help for
Cancer Symptoms**

AND CLINICAL RESEARCH PORTFOLIO

Volume 1

(Volume 2 bound separately)

Lynn Steele

Section of Psychological Medicine

University of Glasgow

July 2010

**Submitted in partial fulfilment of the requirements for the degree of Doctorate in
Clinical Psychology**

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CLINICAL RESEARCH PORTFOLIO –TABLE OF CONTENTS

VOLUME ONE

	Page
Chapter 1: Systematic Literature Review	6
Is there an association between psychological factors in response to a diagnosis of breast cancer and recurrence or survival rates in early stage breast cancer?	
Chapter 2: Major Research Project Paper	49
An investigation of personality factors and beliefs about illness that may influence the time taken to seek help for cancer symptoms	
Chapter 3: Advanced Practice I Reflective Critical Account (Abstract)	86
A reflection on providing psychological advice and guidance to others at an organisational level	
Chapter 4: Advanced Practice II reflective Critical Account (Abstract)	88
A reflection on working within complex systems	

CLINICAL RESEARCH PORTFOLIO – APPENDICES

	Page
Appendix 1: Systematic Literature Review	
1.1 Guidelines for Submission to The Breast Journal	90
1.2 Methodological Quality Criteria Checklist	93
1.3 Full Titles of Outcomes Measures Listed in Table 2	95
 Appendix 2: Major Research Project	
2.1 Guidelines for Submission to Psycho-Oncology	96
2.2 Major Research Proposal	100
2.3 Ethics Committee Approval Letters	128
2.4 Research & Development Approval Letter	132
2.5 Participant Information Sheet	133
2.6 Participant Consent Form	135
2.7 Recording Sheet for Estimation of Symptom and Action Appraisal	136

CHAPTER ONE: SYSTEMATIC LITERATURE REVIEW

**Is there an association between psychological factors in response to a
diagnosis of breast cancer and recurrence or survival rates in early
stage breast cancer?**

Running Title: *Psychological Factors & Survival Outcome*

Lynn Steele¹

Prepared in accordance with submission guidelines for The Breast Journal

(See Appendix 2.1)

**Submitted in partial fulfilment for the requirements of the degree of Doctorate in
Clinical Psychology**

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Abstract:

Objective: There is, however, much debate within the research community as to the role of psychological factors in predicting or influencing disease outcome in breast cancer. Previous reviews have investigated the role of psychological factors in studies with extremely heterogeneous samples making it difficult to generalise findings. This present review therefore tried to address this criticism by focusing on studies only including participants with early stage breast cancer. The aim was to summarise the evidence for an association between psychological responses and the risk of recurrence and/or survival outcome in this population.

Method: A systematic search was performed using the Ovid MEDLINE, EMBASE and PsychoINFO databases to identify relevant studies. Sixteen studies were identified which met inclusion criteria. Criteria assessing methodological quality were applied using a specifically designed checklist, which resulted in a methodological quality rating being calculated for each study.

Results: From the sixteen studies identified only three were rated as ‘high’ quality and the majority were of ‘moderate’ quality. The findings of the review indicated that there are contradictory findings in the literature for the main psychological factors investigated. The methodological flaws that are inherent within the literature are highlighted.

Conclusions: As yet there is not sufficient evidence for any psychological factor to conclude that it significantly contributes to the progression of cancer. There are however too many studies with significant findings to conclude that these psychological factors are of no importance at all. There is a need for further and more rigorously designed research and so future research directions are discussed.

Keywords: breast cancer, psychological factors, progression, survival, systematic review.

Introduction

Breast cancer is the most common cancer diagnosed in women in Scotland and a significant cause of morbidity and mortality(1;2). The number of people being diagnosed with breast cancer each year continues to rise, mainly due to the life expectancy increasing and an aging population(1;3). There has, however, been a noted improvement in breast cancer survival, with a 39% decrease in death rates from breast cancer observed between 1989 and 2008 (2). This in the main is due to improvements in screening and treatment(1;2). These improvements have resulted in an interest in the quality of life and psychological wellbeing of survivors of breast cancer. A study by Dean(4) found that one in four women experienced significant psychological symptoms twelve months after mastectomy. The most common difficulties were depression, anxiety and sexual dysfunction(4). In the literature there is evidence and general consensus that psychological interventions do improve psychological wellbeing in cancer survivors(5). In the development of this field the question has been raised as to whether psychological factors can play a role in the progression of disease. A psychological intervention study with individuals with advanced breast cancer initially gave weight to this claim(6). It demonstrated that after 10 years' follow up participants who received therapy had lived twice as long as those patients in the control group (37 months compared with 19 months)(6). The study, however, had some methodological problems and these findings have not been consistently replicated in other similar studies(7).

There are opposing views in the literature regarding the influence of psychological factors on the progression of cancer and long-term survival for breast cancer patients. The claim that psychological factors may influence disease progression is of great interest

to cancer patients. Some researchers have expressed their concern regarding the potential harm for patients, who may put themselves under undue pressure to employ a particular coping style or response, which is not their normal coping style, to improve the outcome of their disease(8). There is evidence that those individuals who attribute the diagnosis of cancer to psychological factors are more distressed and less hopeful than other patients(8). There has been a large body of research investigating the role of various psychological factors across cancer types but there is no consensus. There are a number of mechanisms that have been postulated. Previous research has investigated the possible mechanisms that may influence the relationship between psychological factors and cancer progression. It has been suggested that this relationship could be mediated through behavioural factors such as poor adherence regarding medical advice or more directly through biological correlates of certain emotional states. For example, Levy and colleagues found that the level of NK cell activity appeared to predict the chance of later recurrence in successfully treated breast cancer patients(9).

Whether psychological factors affect the course of cancer has important implications, both for the role of psychological screening and treatment of cancer patients, and for the progression of research. If an individual's psychological response to their breast cancer diagnosis did affect their prognosis then appropriate psychosocial interventions could be developed which might improve survival after breast cancer. Conversely, if no such effect exists, women's concerns could be allayed and this burden of responsibility lifted. Several methodological problems have contributed to the uncertainty surrounding the role of psychological factors and survival outcomes in cancer. One problem is that some studies include participants with advanced stage cancer. It is likely that the role of

psychological factors may be extremely difficult to detect in these individuals and it also results in heterogeneous groups, which makes it difficult to draw firm conclusions and generalise findings. Therefore this systematic review will focus on breast cancer patients with early stage disease and no evidence of metastasis. It seeks to determine whether methodological factors contribute to the variance in the findings regarding the association between psychological factors and recurrence or survival in this population group.

Objective

The present systematic review will summarise the literature, bearing in mind the methodological rigour of the studies retrieved when considering their findings. It will aim to answer the following question:

- What is the evidence for an association between psychological factors in response to a diagnosis of cancer and recurrence or survival rates in primary early stage breast cancer?

Method

Search Strategy

A systematic literature search was carried out using the OVID online interface to access the PsychINFO (1967-2010), MEDLINE (1950 – 2010) and EMBASE (1980-2010) databases (See Figure 1). Limits were set on search terms to include ‘English language’ and ‘human’.

The following search terms were used:

1. [breast cancer] OR [breast neoplasm] OR [breast tumour] OR [breast tumor]
2. [survival] OR [mortality] OR [death] OR [recurrence] OR [progression]
3. [depression] OR [anxiety] OR [psychological factors] OR [psychosocial factors] OR [psychological coping] OR [coping behaviour] OR [emotional responses]

The results of these searches were then combined using the Boolean operator 'AND'.

Table 1 provides a flow diagram of the search strategy. The search identified one hundred and sixty-four journal articles potentially suitable for inclusion. The following inclusion and exclusion criterion was then applied:

Inclusion Criteria

1. Studies that include a breast cancer population.
2. Design is prospective.
3. Studies which include the measurement of psychological variables as predictive variables of disease recurrence or survival outcome.
4. Studies published in a peer-reviewed journal article.

Exclusion Criteria

1. Studies including heterogeneous cancer sites, without separate analysis for breast cancer.
2. Studies in which the stage of cancer at diagnosis or at the commencement of the study was identified as metastatic for participants within the sample.

3. Studies only investigating psychosocial factors, such as social support as a predictor of survival or recurrence.
4. Studies which include psychological variables but not as predictive variables of disease recurrence or survival outcome.
5. Studies only focusing on the association between psychological factors and the development of breast cancer.
6. Studies evaluating psychological interventions for psychological variables, which may impact on disease progression or survival outcome.
7. Studies using a retrospective design.
8. Review articles, single case studies, dissertations or qualitative studies.
9. Articles summarizing findings about the association between psychological variables and survival as part of their study but which have been reported in other articles in more detail.

Given the above criterion, fifty-five articles were excluded on title alone, mainly due to being surgical or pharmacological studies. Of the remaining one hundred and nine, a further ninety-one articles were excluded based on their abstract as they did not fulfil the specified inclusion and exclusion criteria. This left a full article search of the remaining eighteen studies, which were read in their entirety, of which eight were excluded for the reasons specified in Table 1.

Further to this the reference sections of the articles included and the reference section of review articles identified from the literature search were reviewed to identify additional articles. An additional six articles were identified, which met review inclusion criteria

and had not been generated by the electronic search. This resulted in a total of 16 articles for review.

[Insert Table 1 around here]

Methodological Appraisal of Included Studies

A methodological appraisal of the articles was applied to all 16 studies according to the criteria in Appendix 1.2. The scoring system was based on the Scottish Intercollegiate Guidelines Network guidelines for assessing the quality of cohort studies with additional items that were specific to outcome studies in this area. There was a total of 13 items and studies were awarded a score 2 if the criterion was met, 1 if it was partly met and 0 if the criterion was not met or it was not possible to determine from the information given. Therefore, each paper was given a rating out of 26, with higher scores indicating superior methods. Papers that met 75% of the methodological criterion specified were considered to be of 'high' quality. Papers that rated between 50% and 75% were deemed to have a 'moderate' quality rating and those studies that achieved less the 50% quality rating were considered to be of 'lower' quality.

Reliability of quality rating

To assess the reliability of this tool, a second reviewer using the same tool rated 7 of the final 16 papers. These included papers of high, medium and low methodological quality. Overall percentage agreement was high (>95%). Discrepancies in ratings were resolved by the author and independent rater meeting to discuss and review disagreements.

Results

Review of Findings

The sixteen studies included in the review ranged in sample size from 40 to 708 participants. No studies included male participants. Nine of the sixteen studies investigate depression, seven examine anxiety, eleven explore psychological response or coping and five examine emotional control. A further six studies also investigate general psychological distress. Table 2 provides details of study design, sample characteristics, psychological variables measured, disease outcome and main findings. Studies will be reviewed in order of quality rating. Overall three studies were of 'high' quality, eleven were 'moderate' quality and two were of 'low' methodological quality.

[Insert Table 2 around here]

High Quality

These three studies investigated different psychological factors.

Barracough and colleagues(10) was rated as the highest methodological quality study and examined the effect of psychosocial stress on cancer recurrence. The experience of a depressive illness was assessed as an adverse life event and findings indicated that it was associated with a shorter time to disease recurrence. Despite being of particularly high methodological quality, the relationship between depression and recurrence was not the main focus of the study. Symptoms of major depression were assessed in interview, using American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders – 3rd Edition (DSM-III). Only 45 of 204 participants met criteria. It is also important to note that the follow up period was only three and half years.

Watson and colleagues(11) examined the association between breast cancer survival and recurrence with a number of psychological factors measured at two time points (see Table 2). Although this was one of the three highly rated methodological studies there were a number of limitations noted. Survival was recorded as death from all causes rather than as a result of cancer recurrence and there were a significant number of statistical tests completed so increasing the risk of a Type 1 error. A high score on the depression scale of the Hospital Anxiety and Depression Scale (HADS) was associated with increased risk of death but not recurrence; however, only 2% of the sample met 'caseness' for depression. Response to cancer was analysed in two forms; firstly by recording one 'predominant response' as assessed by the Mental Adjustment to Cancer Scale (MAC), which did not result in any significant associations being found. The second form of analysis dichotomised each scale at the standard cut-off score so an

individual was categorised as being high or low on each type of response. This indicated a significant association between the helplessness and hopelessness category and event free survival only (see Table 2).

Goodwin and colleagues(12) examined the effects of reduced health-related quality of life and psychologic factors on breast cancer survival and recurrence (see Table 2). Although categorised as a high quality study there were a number of limitations identified. Approximately half of the sample was followed up for less than five years and they only classified distant metastatic cancer as recurrence. Baseline measures were returned by post so the range of time from diagnosis to return of questionnaires was 0.5 week to 36 weeks, which resulted in individuals being assessed at significantly different stages in treatment. Some of the participants assessed immediately after diagnosis would have been going through normal adjustment and may not have experienced significant psychological distress. They did however complete a follow up assessment a year later but which again were returned over a protracted period (42-76 weeks). A strength of the study was that it considered the issue of power, however the variables which had 80% power to detect hazard ratios were in the main for total scores of measures used rather than individual subscales.

Moderate Quality

The 11 studies rated as 'moderate' quality investigated a range of psychological variables. The most frequently investigated psychological factor was coping or psychological response to a diagnosis of cancer, although a range of measures were used to examine the type of response. Studies are therefore critiqued by summarising the

studies which did not find a significant association and then those that did for recurrence and/or survival. In each section the study rated with the highest score for methodological criteria is reported first. The results for the other psychological factors assessed in each study are also discussed. Four studies did not find a significant association between coping response and outcome as defined by survival or recurrence.

Buddeberg and colleagues(13) investigated the effect of different coping strategies on breast cancer survival using two questionnaires as can be seen in Table 2. It did not find a significant relationship between coping response and survival. The measures employed in this study were not used in any of the other included studies. This article has a number of strengths in terms of its design, particularly including multiple assessments of coping over the follow-up period. This indicated firstly that the form of coping employed changed over time and secondly that numerous coping strategies could be employed at any one time point. A significant methodological flaw, however, was that as a result of a reduced sample size over time there was only adequate power to detect large effect sizes.

Cousson-Gélie and colleagues(14) investigated the role of anxiety and coping strategies (see Table 2). They did not find a significant association between the type of coping strategy employed and outcome. The tool used to assess coping was not used in other studies apart from one, which used a different version of the scale and included different categories. They did however find a significant association between survival and anxiety; low anxiety scores being associated with shorter survival times. The authors postulated that low anxiety scores indicated the absence or controlled expression of negative effect and questioned if there was a role for the restriction of emotions but this

was not assessed. Although this study has a number of strengths it did not include repeated measures of coping and anxiety and the psychological variables were assessed three weeks after diagnosis. Psychological factors assessed during the first month, may be capturing a normal reaction to being informed of a diagnosis of a life-threatening illness, rather than the onset of a clinically significant problem that may affect outcome.

A study by Phillips and colleagues(15) assessing social support and psychological factors (see Table 2) found a significant association between the coping response ‘anxious preoccupation’ and disease recurrence and overall survival. This effect however, was only found in the analysis which was not adjusted for biological and treatment factors. The authors postulated that the association between ‘anxious preoccupation’ and outcome was due to anxious preoccupation being correlated with poor prognostic factors such as age and grade of tumour, rather than being directly associated with a poorer prognosis. This study had a number of limitations such as there being a wide range in the time from diagnosis until assessment of psychological factors. The authors however tried to address this by taking it into consideration during the analysis of the results. The other significant drawbacks are that assessment of psychological measures only happened at one time point and it was not clear if survival rates were all cause or cancer specific. The study did not find an association with depression or anxiety as measured by the HADS. The variation in time at assessment may impact on these findings but probably more significant is the low level of symptomatology reported by the sample, particularly for depression (only 3% scoring above the cut-off point of 10 for ‘caseness’).

A study by Butow and colleagues(16) assessed psychological factors in relation to survival time. It did not find a significant association for coping response or psychological adjustment but used assessment tools not used by other studies. It did find a significant association between two aspects of cognitive appraisal of threat (see Table 2). This was a sub-scale selected from a validated tool and had not been used by any of the other studies. The main limitations were that psychological responses were only assessed at one time point and the follow up period would have benefitted from being longer.

Five studies did find a significant association between coping response and outcome.

The study by Osborne and colleagues(17) was rated as medium quality and assessed the role of immune factors and psychosocial factors in survival from early breast cancer (see Table 2). It was one of two studies which tried to examine a possible biological mediating role, which meant as a result psychological measurements were assessed only at one time point. There was a significant association found for a fighting spirit – minimising the illness but no significant association found for anxiety or depression. Unfortunately, there are limitations to this study, as the time of assessment from diagnosis varied considerably between participants ranging from five to seventeen months. Also a small sample size and multiple comparisons meant that the study only had sufficient power to detect large hazard ratios.

Lehto and colleagues(18) examined a large number of psychological and psychosocial variables (see Table 2). The study found a significant effect for individuals using a distancing response and behavioural escape avoidance, using a standardised measure.

They also found a significant association for emotional defensiveness and depression (see Table 2). Depression was assessed using a screening tool assessing feelings and symptoms experienced during the previous month. This was not used by any of the other included studies. Overall, although there were a number of methodological strengths to this article a significant limitation was that assessment of psychological factors was made at only one time point. There were also a large number of variables included in the analysis and the issue of power was not addressed.

An early study by Greer and colleagues(19) investigated the association of a number of psychological responses to breast cancer and outcome. As a result of being an earlier study response to cancer was assessed by interview and the predominant response was rated independently by two observers rather than by a standardised tool, which is an obvious limitation. Although there was a number of time points, analysis only included variables measured at baseline and at 3 months and coping response was only assessed at one time point. Analysis did not include the Cox proportional hazards regression model which allows analysis of time to event. Analysis found recurrence free survival significantly more common among individuals with denial or fighting spirit responses than stoic acceptance as assessed at three months. There were no significant associations for the other variables assessed. Depression which is commonly investigated in other studies was assessed using the Hamilton Rating Scale (HRS). The range of scores for the depression measure is not reported so it is unclear if the scores were skewed. Another obvious limitation is the small sample size particularly due to the reduction in the sample size at three months.

Dean and colleagues(20) examined the relationship between general health and a number of psychological factors assessed at two time points (see Table 2) and survival and cancer recurrence. Although this study found an association for particular coping responses (see Table 2) a major limitation is that individuals were categorised at each time point as exhibiting a predominant response as assessed by interview and rated by the interviewer, rather than using a standardised measure. Depression and anxiety was assessed using research diagnostic criteria, which may result in significantly different results compared to the use of self-report measures. The results showed that meeting diagnostic criteria pre-operatively resulted in an association with recurrence but this was not evident when measured post-operatively. For neither time point was there an association with survival. These findings are in opposition to those reported by Barraclough and colleagues(10).

Morris and colleagues(21) examined the effect of psychological response on survival and recurrence at 3 years after diagnosis and 5 years later. Fighting spirit or denial responses tend to have better prognosis than stoic acceptance or a helpless/hopeless response (see Table 2). Depression scores did not distinguish between those who died or not at five year follow up. Although this study found a significant association between psychological response and outcome, psychological response was elicited by interview. Although the authors made efforts to rate the predominant psychological response only 88 of the 107 participants could be categorized. The five categories had to be collapsed as a result of small numbers within each category, for example only four participants were characterized as using the hopeless/helpless response. A strength however was that it did assess psychological responses at a number of time points.

Two of the eleven studies did not investigate the role of coping:

The study by Tross and colleagues (22) specifically investigated if the degree of psychological symptoms present in response to a diagnosis of breast cancer was associated with recurrence and/or overall survival. The use of a general measure of psychological distress versus a more specific psychological construct is unlikely to be significantly associated with outcome data. Further to this the data was trichotomized and only 12.5% of the sample was included in the top category with symptom levels at or above the cut-off for psychiatric casesness. Other limitations to the study are that it only measured psychological responses at one time point, only all cause mortality was reported and the analysis did not include the use of the Cox proportional hazards regression model.

The study by Kreitler and colleagues(23) used a general measure of psychological distress and did find a significant association but this was not as strong as other psychosocial factors assessed. Using a validated tool to assess anxiety it did find lower anxiety scores were associated with better health at three years but not five years. Unlike the study by Cousson-Gélie and colleagues(14) anxiety was not associated with survival. The studies used the same measure to assess anxiety so this difference may have been due to the timing of assessment or the length of follow-up. There was a significant amount of variance in the timing of assessment for this study.

Low Quality

The two studies rated as low quality only investigated general distress levels and psychological adjustment in association with outcome data. While the study by Levy and

colleagues(9) found an association between lower Profile of Mood States (POMS) scores at follow-up and longer disease-free survival there were several limitations. These included assessment of psychological factors at baseline occurring five days after surgery. Strengths of the study however, were that assessment was carried out at three time points and that although a general measure of distress was selected; this was assessed using a standardised tool. The last article reported by Gilbar(24) was rated as being of the lowest methodological quality. Stepwise backward logistic regression analysis found evidence for high anxiety being associated with the development of metastasis and anxiety and somatisation predicting length of survival. The most significant limitations of this study were the small sample size, assessment of psychological factors only two weeks after surgery and only at this time point. Also well established medical and biological predictive variables were not recorded. A strength of the paper was that it followed participants up for a significant length of time.

Discussion

This literature review focused on studies investigating early stage breast cancer so as to provide a more homogenous sample. It was hoped that it would illuminate further the role of psychological factors in this particular group. It is difficult however to draw firm conclusions about the association between psychological factors in general or even specific psychological constructs and long term outcomes regarding cancer recurrence and survival. The reason for this is that a relationship identified in one study is not systemically confirmed in other studies and in fact there are often contradictory findings as evidenced in this review.

There were eleven studies investigating psychological response or coping. There was no association found in four of the studies, which often employed less commonly used assessment measures. One of these studies however did use the MAC, which is frequently used. Three found a significant association and another observed a trend for positive coping responses to increase survival and/or time to recurrence. These responses included denial, fighting spirit and distancing post-operatively and stoic or hopeless/helpless responses pre-operatively. The remaining four studies found responses categorised as hopeless/helpless, behavioural-escape avoidance and anxious preoccupation were associated with poorer outcomes.

There were nine studies in this review investigating depression. Five found no association with cancer recurrence or survival; two found an association which indicated a positive effect on recurrence only; one study was associated with poorer survival only and in the final study depression was associated with poorer survival outcomes and increased risk of recurrence. For anxiety four of the seven studies found no association. One study found a positive effect of anxiety assessed pre-operatively on disease recurrence. The remaining two found a negative effect of anxiety on outcome. Six studies explored the relationship between general psychological distress and outcome measures. Three found no association and the other three found higher distress resulted in poorer outcomes. Lastly emotional control was assessed by five studies; four did not find an association and one using a different assessment tool found emotional defensiveness was associated with shorter overall survival.

The findings of this review highlight the many methodological flaws that are inherent within the literature investigating the association between psychological factors and disease progression for early stage breast cancer. As yet there is not sufficient evidence for any psychological factor to conclude that it significantly contribute to the progression of cancer. There are however too many studies with significant findings to conclude that these psychological factors are of no importance at all. The main methodological flaws that were highlighted in numerous studies were the timing and frequency of psychological assessments and studies being too small and under-powered to calculate anything other than large effect sizes. In earlier papers there were many studies using interviews to assess psychological factors rather than reliable and validated tools. This has been less of a problem in more recent papers, reflecting the development of psychological assessment tools in this area.

Implications for Future Research

These methodological difficulties limit the generalizability of findings and their ability to influence clinical practice. If particular psychological factors were identified as important for disease progression in early stage breast cancer then these could be screened for in clinical practice and appropriate interventions could be developed. The following recommendations based on this review may be helpful to consider when designing future studies in this area:

- Psychological factors should be measured and analyzed at multiple time-points. If the limits of the study do not allow multiple time-points then assessment should not

occur with the first month. Assessments completed at this time may only assess a normal reaction to being informed about a diagnosis of cancer rather than the onset of a clinically significant problem that may affect health behaviours and outcomes.

- Whenever possible, cancer-specific mortality should be reported separately from all-cause mortality to draw conclusions about the direct impact of psychological factors on the progression of cancer specifically.
- If there is an association between psychological factors and outcome it would be beneficial to investigate possible mediating links. Although a biological mediating link is plausible, there is little evidence in breast cancer populations currently (9;17).
- The literature however would benefit from a refinement of the range of tools being used to assess a particular psychological factor. This would allow findings to be compared and generalised as a variety of instruments of different levels of validity and reliability have been employed.

Strengths & limitations of the present review

The systematic literature search indicated that this was the first systematic review to focus on the association between psychological variables and survival or recurrence outcome for first occurrence early breast-stage cancer. This resulted in the exclusion of heterogeneous samples and studies' investigating psychological responses after recurrence has occurred. Other reviews have focused on studies assessing psychological responses with mixed cancer types making it difficult to draw conclusions about psychological factors because of the variance in biological and medical predictive variables across cancer sites which influence outcome.

The present review however has a number of limitations. Firstly, the review was limited to the evaluation of results in published articles, which may result in a publication bias. Secondly, the methodological quality of studies was assessed using a structured rating scale designed especially for this review. No previously published checklist was found to meet the requirements of the review. Whilst quality ratings were completed by an independent rater and a high level of agreement was reached, there may be limitations in the design of the checklist which could have introduced bias into the ratings. Further to this the methodological quality was not rated for all the studies by an independent rater. It is also worth noting that the review has included studies that vary in the number and type of variables being included for investigation. Between and within studies continual and dichotomised data were utilised. The methodological criteria did not address this. Another possible limitation of the study that has to be considered is that the methodological criteria awarded higher scores to studies that made adjustments for biomedical variables that are known to be predictive for disease outcome. It however may be possible that psychological factors interact with biomedical factors. For example, life events were related to recurrence in females with breast cancer, in the presence of receptors for oestrogen and/or progesterone but this relationship was not evident in participants with receptor negative breast cancer(25).

Conclusion

The aim of the present review was to summarise the evidence for an association between psychological responses to early stage breast cancer and the risk of recurrence and/or

survival outcome. Some tentative evidence has been found for there being a possible association between psychological responses but there is also research that refutes these claims. The varied methodologies undertaken in the studies make it difficult to draw comparisons between studies. Better controlled studies with larger sample sizes are needed before recommendations can be made with confidence. If associations between psychological factors and survival are evident after utilising more rigorous methodology this will allow clinicians to identify individuals at risk and focus interventions on the possible mechanisms identified.

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Table 1 – Flow diagram of papers included and excluded at each search stage

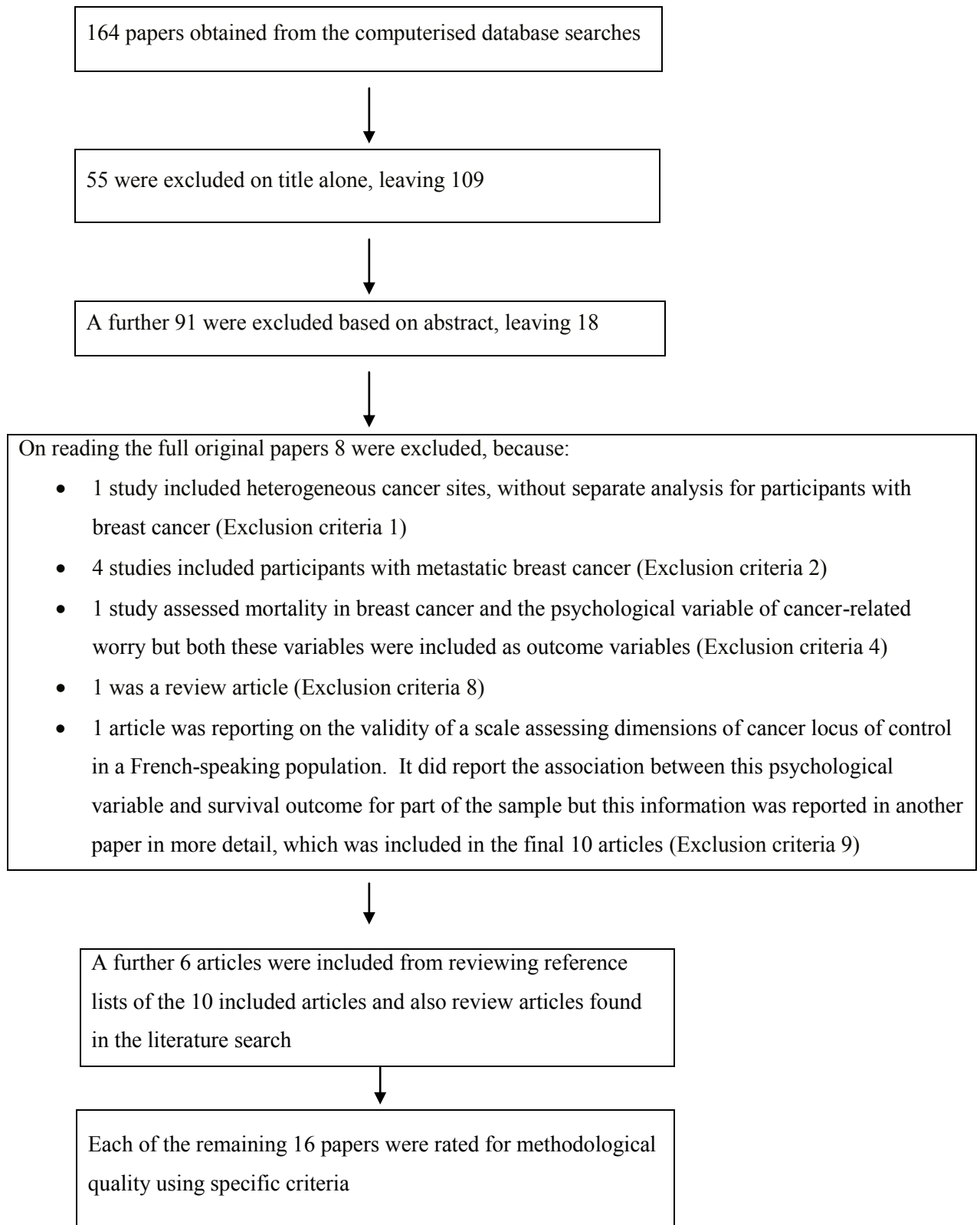


Table Two: Summary Table of Identified Studies including Methods, Sample Characteristics, Psychological Variables, Disease Outcome and Main Findings

Study & Quality Rating	Methods 1. Sampling of Participants 2. When Psychological Factors Assessed	Sample 1. N 2. Mean Age (years) 3. Stage of Cancer	Psychological Variables Examined	Outcome 1. Length of Follow 2. Recurrence or survival outcome	Main Findings
Greer et al., 1979 (19) (65%)	1. Consecutive sample of convenience 2. Preoperatively & 3 & 12 months post-operatively and then annually for 4 years. - At follow up only ratings of depression & psychological response to cancer were repeated	1. 69 (at 3 months n=57) 2. not reported (< 70) 3. T 0–1 N 0–1 M 0	1. Depression (HRS) 2. Hostility (HDHQ) 3. Extraversion and Neuroticism (EPI) 4. Psychological response: - denial - fighting spirit - stoic acceptance - helplessness/hopelessness	1. 5 years 2. - 33 (49%) alive & no recurrence - 16 (24%) alive with metastases - 18 (27%) had died of breast cancer - 2 died of other disorders	<ul style="list-style-type: none"> Recurrence-free survival was significantly more common among patients who reacted to cancer with denial or fighting spirit than among patients who responded with stoic acceptance and helplessness /hopelessness
Dean & Surtees, 1989 (20)	1. Consecutive sample of convenience 2. Before operation & three	1. 121 2. 48.7 (20-60)	1. Depression (RDC) 2. Anxiety (RDC)	1. Mean 6.7 (0.77) years (range 6-8)	<ul style="list-style-type: none"> Participants assessed as an RDC case pre-operatively were less likely to have a

(65%)	months after operation.	3. T0-2, N0-1, M0	3. Coping response (assessed in interview and predominant coping response categorised by interviewer) 4. Personality (EPI)	2. - 37 recurrences - 22 died (21 of breast cancer)	recurrence. The association with survival did not reach significance <ul style="list-style-type: none"> • RDC assessed post operatively was not associated with recurrence or survival • Coping response employed post- operatively was not significantly related to recurrence or survival, although survival for individuals employing a denial response was better than other responses. • Personality variables were not associated with cancer recurrence or survival outcome. • When demographic tumour and treatment variables were accounted for: - RDC cases ($p < 0.01$), and individuals with a coping strategy
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					<p>categorised as either hopeless/helpless or stoic ($p<0.05$) pre-operatively were more likely to have been recurrence free</p> <ul style="list-style-type: none"> - individuals employing a strategy categorised as denial ($p<0.05$) post-operatively had a better chance of remaining recurrence free than all other coping strategies - these variables did not reach significance when performed in relation to survival
Levy et al., 1991 (9) (46%)	<p>1. Consecutive sample from a highly selective population</p> <p>2. Assessed approximately 5 days after surgery & before they received any other adjuvant treatment</p>	<p>1. 81</p> <p>2. 50 (28-74)</p> <p>3. Stage 1 or 2</p>	<p>1. Measure of Mood State (POMS)</p> <ul style="list-style-type: none"> - overall distress only assessed 	<p>1. Minimum of 5 years (range: 5-8; 60% followed up for 7 years or longer)</p> <p>2. 29 – disease recurrence</p>	<ul style="list-style-type: none"> • POMS score not predict if recurrence occur or not • Time to recurrence for those who relapsed (causal path modelling technique): <ul style="list-style-type: none"> - Lower POMS score at follow up associated with longer disease-free survival

				(excluded local recurrences, of which there were 9)	- Indirectly a higher POMS score at baseline predicted a shorter time to recurrence via the path linked to the follow up POMS score.
Barracclough et al., 1992 (10) (85%)	<p>1. Consecutive sample of convenience</p> <p>2. Three interviews post-operatively at 4, 24 & 42 months</p>	<p>1. 204</p> <p>2. 54.3 (11.1)</p> <p>3. Breast cancer with no spread beyond the axilla</p>	1. Depressive symptomatology (DSM III criteria)	<p>1. 4 - 42 months after operation</p> <p>2. Relapse of breast cancer in 47 (23%)</p> <p>- 26 of these died</p> <p>- 1 death unrelated to cancer</p>	<ul style="list-style-type: none"> • Prolonged major depression during follow up associated with a longer time to event (HR 0.85; CI 0.41 to 1.79)

Morris et al., 1992 (21) (58%)	1. Consecutive sample of convenience 2. Interviewed at 3 months post diagnosis & further tests completed at 6 to 9 months post diagnosis and another interview at 12 months.	1. 88 2. No mean reported (Range: 18-70) 3. T 0–2, N 0–1, M 0	1. Anxiety (STAI) 2. Depression (Wakefield Self Assessment Depression Inventory) 3. Emotional Control (CECS) 4. Patient's Responses to Diagnosis (PRD): - Fighting spirit (PRD 1) - Denial (PRD 2) - Anxious preoccupation (PRD 3) - Stoic acceptance (PRD 4) - Helplessness/hopelessness (PRD 5)	1. 5 year 2. - 20 died - 8 alive with recurrence - 79 alive without recurrence	<ul style="list-style-type: none"> Psychological factors other than response to diagnosis were not associated with outcome PRD code was associated with poorer survival ($p = 0.06$) Association of PRD code with recurrence was not clear ($p = 0.15$) Patients with PRD 1 and 2 had a better prognosis than patients with PRD 3–5 although not statistically significant ($p = 0.07$ for overall survival & $p = 0.19$ for recurrence)
Tross et al., 1996 (22) (62%)	1. Consecutive sample from a highly selective population 2. Assessment of psychological symptoms following surgery & prior to chemotherapy commencing	1. 280 2. Mean not reported- < 40: 19% - 40-49: 27%	1. Symptom scores (SCL-90-R) - Assesses: somatization, obsessive-compulsive symptoms, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation,	1. 15 years 2a. Disease free survival by GSI rating (years): - low: 7.48 - med.: 7.04	<ul style="list-style-type: none"> No evidence that psychological factors as measured by the GSI contributed to length of disease-free or overall survival

		- 50-59: 29% - 60-69: 23% - ≥ 70 : 3% 3. Stage II	psychoticism - Only Global Severity Index (GSI) used in analysis divided into 3 subgroups: low, medium & high	- high: 4.90 2b. Overall survival by GSI rating (years): - low: 11.62 - med.: 10.21 - high: 9.58	
Gilbar, 1996 (24) (42%)	1. Selected at random from a convenience sample of 102 patients who were receiving chemotherapy treatment 2. Assessed approximately 2 weeks post surgery	1. 40 2. 50.06 3. Stage 1 or 2	1. Psychosocial adjustment to illness (PAIS) - 1 of 7 dimensions assesses psychological distress 2. Psychological Distress (BSI) - 9 symptom areas & overall distress score (GSI)	1. 8 years 2. - 8 died - 7 developed bone metastases - 25 remained disease free	<ul style="list-style-type: none"> Participants who died had higher levels of psychological distress as measured by the PAIS & the following scales in the BSI: anxiety, hostility, paranoid ideation and GSI Participants who developed metastasis had higher levels of anxiety Length of survival was predicted by higher levels of anxiety and somatisation
Buddeberg et al, 1996 (13)	1. Consecutive sample of convenience	1. 107 2. 52.6	1. Coping strategies - ZQCI	1. 5 to 6 years after the primary	<ul style="list-style-type: none"> There is no steady significant relationship between

(73%)	2. Assessed 6 months after surgery	(29-70) 3. T1-4, N0-1, M0	Every 3 months in 1st year (assessments 1 - 5) & every 6 months during the 2nd and 3rd year (assessments 6 - 9) - FQCI Every 12 months (assessments 1, 5, 7, 9).	surgical treatment 2 - 66.4% recurrence-free - 1.9% local-regional recurrence-5.6% distant metastases - 23.4% died from breast cancer - 1.9% developed a 2nd carcinoma - 0.9% died from cardiac disease	the different coping strategies and disease outcome
Kreitler et al., 1997 (23) (58%)	1. Sampled from five hospitals participating in the study 2. The mean time from assessment was 13.34 months after surgery or 9.89 months after the end of treatment.	1. 96 2. 53.13 (10.04) 3. Stage I&II	1. Adjustment (PAIS) - one scale assess psychological distress 2. Locus of control (Locus of Control Questionnaire) 3. Anxiety (STAI)	1. The health state of patients was examined at 3 and 5 years after surgery - Follow-up was up to	<ul style="list-style-type: none"> Both medical and psychological variables are significant predictors for good health state on 3 years and survival on 5 years. Higher levels of

				<p>five years</p> <p>2a. After 3 years: - 73.96% good state of health - 1.04% died</p> <p>2b. After 5 years: - 70.83% good state of health - 14.58% died</p>	<p>psychological distress predict better health at 3 years and overall survival</p> <ul style="list-style-type: none"> • There was no significant association found for locus of control • Lower levels of anxiety were associated with better health at 3 years but not 5 years. Level of anxiety was not associated with survival.
<p>Watson et al., 1999 (11)</p> <p>(85%)</p>	<p>1. Consecutive sample of convenience</p> <p>2. Psychological response measured 4 to 12 weeks and 12 months after diagnosis</p>	<p>1. 578</p> <p>2. 55 (10.6)</p> <p>3. Stage I & II</p>	<p>1. Patients' reactions to having cancer (MAC)</p> <ul style="list-style-type: none"> - fighting spirit - helplessness or hopelessness - anxious preoccupation - fatalism - avoidance <p>2. Extent suppress negative emotions (CECS)</p> <ul style="list-style-type: none"> - anger - anxiety - sadness 	<p>At 5 years, - 395 (68.3%) women alive with no relapse - 50 (8.65%) alive with relapse - 133 (23%) had died (122 (21.1%) of breast cancer)</p>	<ul style="list-style-type: none"> • Assessment at baseline: - a high score on the depression scale associated with a significant increased risk of death from all causes by 5 years (HR 3.59, 95% CI 1.39 to 9.24). - High scores on the helplessness and hopelessness category significantly

			3. Presence of depression or anxiety symptoms (HADS)		<p>associated with increased risk of relapse at 5 years, compared with women with a low score in this category (HR 1.55, 95% CI 1.07 to 2.25).</p> <ul style="list-style-type: none"> • Assessment at 1 year follow-up: <ul style="list-style-type: none"> - increased risk of death during follow up for the HAD scale category of depression remained significant (adjusted HR 4.04, 95% CI 1.54 to 10.64) for a score >11 on depression scale. - The association between a high helplessness or hopelessness score & event-free survival was reduced from baseline and no longer significant • No associations found for other reactions,
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					anxiety or suppression of emotions
Butow et al., 2001 (16) (69%)	1 Consecutive sample of convenience 2. Assessment completed at a median of 90 days from diagnosis (mean 3.8 (2.3) months)	1. 211 2. 51 (11) 3. Early stage breast cancer (Mean tumour size 1.3 (1.6))	1. Cognitive appraisal of threat (13-item cognitive appraisal subscale of the Stress Questionnaire) - independence - family - disease 2. Coping response (COPE) - active - distraction - avoidant 3. Psychological adjustment (PAC)	1. Up to 2 years 2. - 30 (14%) died - 36 (17%) relapsed	<ul style="list-style-type: none"> Two psychological factors independently predicted both longer overall survival and a longer time to relapse while controlling for tumour size, number of nodes involved and treatment: <ul style="list-style-type: none"> - Low levels of concern about disease - High levels of concern about dependence Coping response & psychological adjustment were not significantly associated with either outcome
Goodwin et al, 2004 (12) (77%)	1. Consecutive sample during final 5 years of a larger prospective cohort study examining prognostic effects of a number of lifestyle-related factors 2. Assessed 2 months after	1. 397 2. 52.0 (9.9) 3. T1 - T3, N0/N1 and M0	1. Measure of Mood state (POMS) 2. Stress response syndrome (IES) 3. Coping Response (MAC)	1. 50% of the patients were followed ≥ 6 years & 0.75% (3) followed up for less than 1 year	<ul style="list-style-type: none"> No consistency of associations across outcomes or questionnaires No baseline measures were significantly associated with

	diagnosis and 1 year later		<p>4. Emotional control (CECS)</p> <p>5. Psychosocial adjustment to illness (PAIS-SR) -includes a scale assessing psychologic distress</p>	<p>2.</p> <p>- 55 (13.85%) distant recurrences</p> <p>- 34 (8.56%) died of breast cancer</p> <p>- 2 (0.5%) experienced non-breast cancer-related deaths</p>	<p>outcome</p> <ul style="list-style-type: none"> At 1 year the avoidance subscale on the IES was associated with OS ($p = 0.014$), suggesting higher scores on this subscale was significantly associated with a lower risk of death Out of 140 investigated prognostic associations, only 4 were statistically significant which was less than expected by chance
Osborne et al., 2004 (17) (73%)	<p>1. Consecutive sample of convenience</p> <p>2. Approximately two-thirds of the sample were interviewed between 5 and 9 months following diagnosis, the remaining one-third was interviewed 9 to 17 months following diagnosis</p>	<p>1. F - 61</p> <p>2. 56 (27-75)</p> <p>3. T1-3, N0-1, M0</p>	<p>1. Anxiety (HADS)</p> <p>2. Depression (HADS)</p> <p>3. Mental adjustment to cancer (MAC - Australian form) - Fighting spirit - minimising the illness - Fighting spirit – positive orientation to the illness</p>	<p>1. Follow up time ranged from 6.1 to 7.9 years</p> <p>2a. Overall survival: - 18 (29%) died - 14 (23%) from breast</p>	<ul style="list-style-type: none"> No statistically significant effects of anxiety or depression on survival were found High score on subscale assessing fighting spirit - minimizing the illness was associated with longer survival (HR

			<ul style="list-style-type: none"> - Helplessness/hopelessness - Fatalism - Loss of control - Angst (strong negative affect) 	<p>cancer</p> <ul style="list-style-type: none"> - 3 from other causes & 1 case the cause of death could not be verified <p>2b. 5 years after diagnosis there were 11 deaths (18%)</p>	<p>0.77, $p = 0.008$).</p> <ul style="list-style-type: none"> • No substantial evidence for a link between psychosocial factors and biological factors.
<p>Lehto et al., 2006 (18)</p> <p>(73%)</p>	<p>1. Consecutive sample of convenience</p> <p>2. Interviewed 3 to 4 months after diagnosis</p>	<p>1. 101</p> <p>2. 54.2 (8.45)</p> <p>3. Stage 1-3</p>	<p>1. Coping Response (WOC-CA)</p> <ul style="list-style-type: none"> - Focusing on positive - Distancing - Seeking & using social support - Cognitive escape-avoidance - Behavioural escape avoidance <p>2. Anger Expression (AX/Scale)</p> <p>3. Emotional Expression (R/ED)</p>	<p>1. From 8 to 9 years (Jan 1996-15th February 2005)</p> <ul style="list-style-type: none"> - Event-free survival - Overall survival <p>2. By 15 February:</p> <ul style="list-style-type: none"> - 31(30.7%) relapsed - 20 (19.8%) died 	<ul style="list-style-type: none"> • In univariate analysis: <ul style="list-style-type: none"> - Emotional defensiveness ($p = 0.007$) and behavioural escape-avoidance ($p = 0.057$) were significantly associated with shorter survival. • In multivariate analysis: <ul style="list-style-type: none"> - Distancing (minimising) coping was associated with longer overall survival ($p = 0.034$).

			4. Depression Scale (DEPS)		<p>- Emotional defensiveness (anti-emotionality; $p = 0.021$), behavioural escape-avoidance coping ($p = 0.008$), and high level of perceived support ($p = 0.009$) were associated with shorter overall survival.</p> <p>- Depressive symptoms had a survival-decreasing effect before the coping patterns were added into the final models ($p < 0.05$).</p> <p>- Depressive symptoms tended to predict a shorter event-free time survival ($p = 0.066$)</p>
Cousson-Gelie et al., 2007 (14) (73%)	1 Consecutive sample of convenience 2. 3 weeks after diagnosis & treatment plan confirmed	1. 75 2. 48 (9.8) 3. Stage II-III (T2-4)	1. Coping (WCC-R) - Problem-focused coping - Emotion-focused coping - Seeking social support 2. Anxiety (STAI)	1. 10 years 2. 43 (57.3%) died - 37 of breast cancer	<ul style="list-style-type: none"> • No significant association between the type of coping strategy employed and outcome • After adjustment low

				- 6 cause not specified - survival analysis based on 69 - 32 (46.4%) alive - 37 (53.6%) dead	anxiety scores were significantly associated with an increased risk of death
Phillips et al., 2008 (15) (69%)	1. Highly selective sample – recruited incident cases of breast cancer with younger age groups being oversampled. 2. the median time between diagnosis and interview was 11 months (range: 2-42 months)	1. 708 for overall survival & 638 for distant disease free survival 2. 40 (8.2) 3. Non-metastatic breast cancer (size <20- >50 mm)	1. Anxiety (HADS) 2. Depression (HADS) 3. Adjustment or response to cancer (MAC) - fighting spirit - helplessness/hopelessness - anxious preoccupation - fatalism - avoidance 4. Emotional control (CECS)	1. Median follow up 8.2 (range: 0.8-14.4) years 2. - Overall Survival: 170 (24%) died - Distant Recurrence: 209 (33%)	<ul style="list-style-type: none"> Adjusted analysis: no significant association between any psychological factors and either outcome Unadjusted analysis: Higher scores on anxious preoccupation scale associated with poorer outcomes when analysed as a continuous variable (p=0.02) Allowing this association to depend on the time delay between diagnosis & assessment showed there was no association of delay

					with death ($p=0.7$); but there was a tendency for the association with recurrence to be weaker if the data were collected further from diagnosis ($p=0.08$)
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*See Appendix 1.3 for full titles of psychological measures.

CHAPTER TWO: MAJOR RESEARCH PROJECT

An Investigation of Personality Factors and Beliefs about Illness that may Influence the Time Taken to Seek Help for Cancer Symptoms

Short Title: *Factors that Influence the Time Taken to Seek Help for Cancer Symptoms*

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Prepared in accordance with submission guidelines for Psycho-Oncology

(See Appendix 2.1)

**Submitted in partial fulfilment for the requirements of the degree of Doctorate in
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Abstract

Background: Reducing the time taken to seek help for symptoms is important in improving prognosis for cancer patients. Delay in help-seeking refers to the period between first noticing symptoms and initial medical consultation. The aim of this study was to investigate if psychological factors were associated with the time taken to seek help for individuals with colorectal or breast cancer.

Method: Participants with colorectal (47) and breast cancer (24) recalled the length of time from first recognising symptoms until seeking medical help. This was calculated in days for two sequential time periods: symptom appraisal (from recognising symptoms until appraising they may be serious) and action appraisal (from recognition of symptoms as serious until organising a medical consultation). Six measures assessing dispositional traits, illness beliefs and current symptomatology were completed, and relevant demographic information recorded.

Result: Symptom appraisal accounted for the largest proportion of time in seeking help for both groups. Initial correlational analysis followed by further Cox regression analysis indicated that age was significantly associated with action appraisal time for the breast cancer group. There were no significant associations between predictor variables and symptom appraisal time for this group. Time-to-event analysis could not be completed for participants with colorectal cancer.

Conclusion: Results are discussed in light of previous research findings and the limitations of the present study.

Introduction

Reducing the time taken to seek help has been highlighted by the Scottish Government and Cancer Research UK as part of broader initiatives to reduce mortality from cancer[1;2]. Data gathered by the Scottish Primary Care Cancer Group, show patients frequently have symptoms for a considerable period of time before seeking help, with delays ranging from 30 to 80 days depending on cancer site[1]. Therefore, an understanding of the factors that determine the timing of treatment remains paramount. This study will focus on colorectal and breast cancer as they often have more identifiable symptoms to a lay person, such as rectal bleeding or a lump[3]. The presence of identifiable symptoms however, does not ensure that individuals will seek help for symptoms. For example, a questionnaire survey regarding rectal bleeding of any cause in general practices indicated that over half the respondents did not seek consultation[4]. Breast cancer is the most frequently diagnosed cancer in Scottish women, accounting for twenty eight percent of all cancers diagnosed in females[1]. Incidences of colorectal cancer in Scotland rank among the world's highest[5]. Studies indicate that survival rates for colorectal cancer in the UK are poorer than in Europe[6], due mainly to late diagnosis, resulting in high emergency rates being linked to higher death rates in the first six months[6;7]. Untreated cancer advances in stages, and early stage treatment improves long term survival prospects[8]. A systematic review found delays greater than twelve weeks from onset of symptoms until treatment commencing in breast cancer patients were associated with poorer survival rates and a more advanced stage[9].

Reasons for Delay in Help-seeking

Understanding the factors influencing time taken to seek help is a prerequisite for the development of strategies to shorten delay. There is evidence that both demographic and psychological factors are associated with delays in seeking medical help[10;11]. Some studies indicated high levels of anxiety and beliefs about prognosis are paramount, while others found low levels of initial emotional distress were associated with treatment delay[12]. A systematic review examining the role of fear in help-seeking concluded that high levels of fear were associated with earlier help-seeking while the evidence for low levels of fear was unclear[13]. The processes involved in help-seeking are probably multifaceted and individual differences such as dispositional traits may mediate these processes.

[Insert Figure 1]

Delay Stages and Psychophysiological Comparison Processes

Andersen and colleagues presented a model of ‘total delay’, which describes the time between an individual first noticing symptoms until receiving treatment[14]. The five dichotomous stages (appraisal, illness, behavioural, scheduling and treatment delay), can facilitate the investigation of factors contributing to delay at each stage (Figure 1). The first three stages are influenced by patient delay only, while scheduling and treatment delay can be influenced by patient delay and professional delay. Research indicates that the majority of delay is accounted for by patient delay with appraisal delay being the longest portion[14-16]. Therefore, the psychological processes involved during this period are of particular interest.

Andersen et al[17] developed an attributional framework, called the Psychophysiological Comparison Theory outlining the psychological processes governing symptom appraisal (see Figure 2). It highlights that an individual's perception of a set of symptoms is influenced by their knowledge of physiological conditions. There is evidence from a study of a general female population that although more marked for older participants, all age groups had limited knowledge about their relative risk of developing breast cancer and the diversity of potential breast cancer related symptoms[18]. The framework also suggests that symptom appraisal is biased to support a positive view of the individual's physiological condition. This suggests a role for both personality factors and illness representations contributing to symptom appraisal. Illness representations are implicit theories individuals hold about an illness and can influence how they respond to a perceived health threat[19]. The model includes both cognitive and emotional representations of an illness which can be highly idiosyncratic[19]. There are five main cognitive components: the identity of the illness; personal beliefs about aetiology; the timeline of the illness; perceived consequences of the illness and the degree of control an individual has. The cognitive component of the model has been shown to account for approximately 22% of the variance in help-seeking intention for breast cancer in a female population[20].

[Insert Figure 2]

Individual Differences & Delay in Help-seeking

There has been limited research into the role of personality traits and health behaviours in relation to cancer and help-seeking. One study investigated the association between patient delay in rectal cancer and a dispositional trait defined as 'Trait Anxiety'[16]. In

the literature this trait has been referred to as ‘Neuroticism’[21], ‘Negative Affectivity’[22] and ‘Trait Anxiety’[23]. These terms reflect different perspectives but there is consensus that it is *the degree of tendency towards anxiety, worry and negative emotions in general* [16] (page340). In this study we will adopt the term Trait Anxiety. Ristvedt & Trinkaus identified two stages of patient delay using Andersen’s model: ‘appraisal delay’ and ‘action delay’[16], of which the latter combines Andersen’s illness and behavioural delay[14]. They examined whether low Trait Anxiety was associated with longer symptom appraisal times and if there was any association with action appraisal times. Trait Anxiety was measured using the Temperament and Character Inventory Harm Avoidance Scale (TCI-HA)[24] and the Spielberger State Trait Anxiety Inventory – Trait Anxiety Scale (STAI-T)[25].

They found no associations for either measure with action appraisal time. Longer symptom appraisal time was associated with low scores on the TCI-HA, while significance was not met using the STAI-T. The psychological measures were trichotomized, with individuals defined as scoring low, medium and high on the variable of interest to compare ‘group’ differences. Methodologically this is not recommended as it results in the loss of information, loss of measurement reliability and reduction in power causing the reliability of this result to be questioned[26-28]. Overall, the study concluded that individuals with a dispositional insensitivity to threat had longer appraisal times. It was postulated that the reason for the difference between the measures was that the STAI-T includes cognitive and somatic aspects of anxiety, while the TCI-HA only focuses on cognitive aspects of anxiety. However, it is also plausible that the construct of optimism was influencing the discrepancy between these

two measures, as individuals scoring lowly on the TCI-HA are characterised as *optimistic*.

Individual Differences & Health Related Behaviour

Highly optimistic individuals tend to hold more positive expectations for their future than pessimists[29]. There is evidence that positive life orientation is beneficial to health; having been associated with better recovery and quality of life after coronary artery bypass surgery[30], and with lower levels of distress pre and post surgery among patients with early stage breast cancer[31]. Optimists tend to use more problem-focused coping strategies than do pessimists[29;31]. Optimism has also been associated with increased frequency of breast self-examination[32]. Therefore, when considering action appraisal time it is likely that optimistic individuals will seek help sooner. Andersen and colleagues propose that symptom appraisal is governed by an optimistic bias (Principle 6)[17], whereby an innocuous transient cause for symptoms is more likely to be generated. Therefore, more optimistic individuals may be expected to have longer symptom appraisal times.

Another personality construct not previously addressed is conscientiousness, which is a dispositional '*tendency to be prudent, planful, persistent (and) dependable*' (page 1099)[33]. There appear to be links between conscientiousness and longevity, with healthier behaviours and adherence to medical advice being likely mechanisms[33;34]. It is possible, therefore, that conscientious individuals may have shorter action appraisal times. Another potentially relevant personality trait is openness to experience. Less open individuals are less aware of the effects of ill health (Costa & McCrae, 1984 cited in[35]). Therefore, individuals who are more open when appraising symptoms may be

better able to notice new symptoms and offer new interpretations, including that the symptom may be serious.

Although the psychological characteristics being investigated in this study are not easily amenable to change, they could provide direction for identifying groups at greatest risk for misinterpreting cancer symptomatology and delaying. The Scottish Primary Care Cancer Group advised that public education programmes on common cancer symptoms be developed and disseminated to encourage patients to present early[36]. Identifying characteristics of at risk populations would have implications for the development of educational material, future public health initiatives and would inform practice, which may reduce delay time and increase survival rates.

Aims and hypotheses

The primary aim is to examine the association between dispositional traits and the time taken to appraise symptoms and seek professional advice. A secondary aim is to examine the association between illness representations and the time taken to seek help.

1. A low level of trait anxiety will be associated with longer symptom appraisal time.
2. High optimism will be associated with longer symptom appraisal times and shorter action appraisal times.
3. Conscientiousness will be associated with shorter action appraisal times.
4. Openness to experience will be associated with shorter symptom appraisal times.

Methods

Participants

Continuous samples of participants receiving treatment for a primary diagnosis of breast cancer or colorectal cancer were recruited from a cancer centre. All participants spoke English and were aged 18 years or over. Participants whose symptoms were detected by a medical health care provider or screening programme independent of self-discovery were excluded as they had no opportunity to appraise their symptoms independently. Individuals with a cognitive impairment or learning disability were also excluded.

Procedure

One hundred and fifty-two individuals met criteria and seventy-four agreed to take part. Reasons for declining to take part included being unwell, additional stressful life events, participation in another study, transport problems and being hearing impaired. Participants completed six measures, followed by a brief semi-structured clinical interview where participants provided an estimate of the time taken to appraise symptoms and seek help in days. A calendar, prompt questions and cues as anchoring events were employed to facilitate recall (Appendix 2.7).

Demographic information was also collected (cancer site, age, gender and socio-economic status). Socio-economic status was defined using the Scottish Index of Multiple Deprivation (SIMD) by quintile categories (1 = most deprived; 5 = least deprived)[37].

Measures

Temperament and Character Inventory – Harm Avoidance Scale (TCI-HA)[24]

TCI-HA is a short self-report form measuring individual differences in sensitivity to signals of possible threat, danger or punishment.

Spielberger State Trait Anxiety Inventory – Trait Anxiety Scale (STAI-T)[25]

STAI-T contains twenty statements assessing the degree of predisposition to respond in an anxious manner to trigger situations. It shows good reliability with coefficients of between 0.75-0.88[38].

NEO Five-Factor Inventory (NEO5)[39]

NEO5 is a 60-item shortened version of the Revised NEO Personality Inventory[40]. It was used to measure Neuroticism (N), Openness to Experience (O) and Conscientiousness (C). Internal consistency for each of the scales indicates coefficients of 0.86, 0.73 and 0.81 respectively[40].

Revised Life Orientation Test (LOT-R)[29]

LOT-R is a 10-item self-report measure assessing individual differences in generalized optimism with higher values indicating higher levels of optimism.

The Brief Illness Perception Questionnaire (BIPQ)[41]

BIPQ is a 9-item self-report measure assessing the cognitive and emotional representations of illness proposed in Leventhal's self-regulatory model[19].

Hospital Anxiety and Depression Scale (HADS)[42]

HADS is a 14-item scale designed to detect the presence of depressive and anxiety symptomatology. Internal consistency has previously been reported to be between 0.80 and 0.90 for both anxiety and depression subscales[43]. This was included to assess any possible confounding variables that may impact on recall.

Sample size and power

Sample size was determined on the basis of a cross-sectional design and according to the procedures required when regression analysis is to be applied to the data[44]. Unfortunately, there were no relevant effects sizes reported in the literature to estimate the effect size for the present study so the convention of a medium effect size of 0.15 was applied. Power was set at 0.80 and alpha at 0.05. As predictor variables with collinearity, for example NEO5-N, TCI-HA and STAI-T cannot be entered simultaneously to a regression analysis; the number of predictive variables was set at seven. Considering this it was estimated that the required sample size to test the hypotheses would be 103 participants[45].

Statistical Analysis

All analyses were performed using the Statistical Package for Social Sciences[46]. After reviewing the data, cancer sites were investigated independently as there were apparent differences in the time taken to seek help. Preliminary analysis of the variables for the colorectal cancer participants indicated a non-normal distribution (Kolmogorov-Smirnov test of normality $p < 0.05$) for time, STAI-T, TCI-HA, BIPQ and HADS. In the breast cancer sample time, STAI-T and items 4 and 7 of the BIPQ had a non-normal distribution. Also a number of variables were skewed across both groups so Spearman's rank order correlations were conducted to examine associations between

variables. As the assumptions of multivariate analyses were not met the intended regression analyses were not conducted.

Cox regression analysis was able to be completed. The event of interest in symptom appraisal is the point when an individual becomes aware of the seriousness of their symptoms. For some participants the event of interest, however, did not occur before seeking a medical consultation. Cox regression analysis allows the inclusion of data points for participants who did not appraise their symptoms as serious prior to medical consultation, as censored observations. Cox regression analysis was repeated to predict action appraisal time. The event of interest here was arranging an appointment. Measures assessing dispositional traits were not trichotomized.

Results

Participant Characteristics & Time Taken to Seek Help

Three of the seventy-four participants were excluded from the analysis as they could not accurately estimate the time taken to seek help. Table 1 summarises the characteristics of the participants by cancer site. Table 2 summarises the time taken to seek help. Fifteen participants with colorectal cancer waited for three or more months; and three waited longer than a year. On average symptom appraisal accounted for 87.83% of the total time taken to seek help. There was a positive medium association between the two appraisal times (Spearman's $\rho = 0.301$; $p=0.04$). Four participants with breast cancer waited for three or more months with none longer than a year. On average symptom appraisal accounted for 89.23% of the total time taken to seek help. There was a positive medium association between the two appraisal times (Spearman's $\rho = 0.398$; $p=0.05$).

Summary Data for Relevant Psychological Data

Table 3a and 3b present outcome data for the measures assessing dispositional traits and current anxiety and depressive symptomatology. Across both groups the data were positively skewed on all measures of trait anxiety, NEO5-O and HADS. Within the colorectal group the LOT-R and NEO5-C were negatively skewed and in the breast group only the LOT-R was negatively skewed. Therefore the frequency of scores across clinical cut off points was explored for the STAI-T, NEO5 and HADS based on published data and are summarised in Table 4. The TCI-HA, LOT-R or BIPQ do not have clinical cut-off points. The majority of the sample in the colorectal group (96%) and all the breast cancer participants scored in the normal to mild range on the STAI-T. The majority of the colorectal group (89%) and breast cancer group (88%) scored in the low to average range on the NEO5-N. Likewise only a very small number of the sample reported a high degree of openness to experience in the colorectal group (4%) while this was only slightly higher in the breast cancer group (25%). Very few of either sample rated low on conscientiousness (colorectal group: 11%; breast cancer group: 17%).

The HADS was administered to assess if current symptomatology impacted on recall of the time taken to seek help. As can be seen in Table 4 the majority of both samples scored in the 'normal' range and only a small number reported significant levels of depressive or anxious symptomatology. These individuals did not have difficulty recalling the time taken to seek help, so HADS scores were not included in the correlational analysis.

Breast Cancer

Table 5a summarises correlations which approached or reached significance between the predictor variables and the time taken to appraise symptoms as serious. Only the predictors which were significantly correlated or close to significance were included in the time-to-event analysis. Two individuals were censored so analysis was based on twenty-two participants and the global null hypothesis was not rejected (chi-square = 7.509; $p = 0.28$; $df = 6$).

Table 5b summarises the correlations which were significantly associated with action appraisal time, which were then included in the time-to-event analysis and was based on twenty-two participants. The global null hypothesis was rejected (chi-square = 9.363; $p = 0.03$; $df = 3$). As seen in Table 6 older participants took less time acting on their symptoms, but no other variables were predictive.

Colorectal Cancer

There were no significant correlations between the predictor variables and the length of time taken to appraise symptoms. The only variable which approached significance was personal control (item three of BIPQ) (Spearman's $\rho = -0.257$, $p = 0.082$). For action appraisal time there was a significant association with the level of deprivation only (Spearman's $\rho = 0.327$, $p = 0.025$). Therefore Cox regression analyses were unable to be performed for this group.

Discussion

This study investigated the association between the time taken to seek help and dispositional traits and illness beliefs, specifically considering the time taken to appraise

symptoms and the time taken to act thereon. The study aimed to examine if findings by Ristvedt & Trinkaus could be replicated in this population[16]. Also other dispositional traits and illness beliefs were included to explore further the possible influence of psychological variables on symptom and action appraisal time.

Time Taken to Seek Help

The results indicated that across both groups there was evidence of delay in help-seeking and the time taken to appraise symptoms on average accounted for the majority of the total time taken to seek help. This supports other findings in the literature [14-16;47;48]. The results indicated that on average participants with colorectal cancer took longer to appraise symptoms and seek help than breast cancer patients (median total time 49 days Vs 12.5 days). The ranges reported in these two samples were longer than the time estimated from the data gathered by the Scottish Primary Care Cancer Group[1]. It is important to note, however, that delay times were skewed and 71% of the breast cancer participants sought help within a month and 83% within three months. For the colorectal group 40% sought help for their symptoms within a month and 70% within three months. The time taken to seek help in this study for breast cancer patients was within similar ranges reported for other studies[8]. The length of time taken to seek help for participants with colorectal cancer was shorter than some of the lengths reported in the literature. A systematic review indicated that median patient delay for patients with colorectal cancer ranged from seven days to five months[49]. The shorter time to presentation in this sample may reflect the NHS setting of this study. This may be a factor to consider in comparison to studies completed in settings without a national health service. Overall, these results highlight that an understanding of the factors that determine the timing of treatment remains of paramount importance.

Dispositional Traits

Hypothesis one proposed that participants with low levels of trait anxiety would have longer symptom appraisal times. Contrary to the previous study by Ristvedt & Trinkaus no significant correlations were found between the TCI-HA and symptom appraisal time[16]. In this study trait anxiety was measured by three scales: TCI-HA, STAI-T and NEO5-N. The latter two measures did not meet significance either although the relationship between symptom appraisal and NEO5-N for the breast cancer group was approaching significance. This was a positive relationship indicating a higher degree of neuroticism resulted in longer symptom appraisal but when this variable was included in the Cox regression model it was not predictive. Data analysis for the scales measuring trait anxiety indicated that they were positively skewed across both groups. The mean and median scores for the STAI-T were within normal limits. The mean and median scores were within the low range for the NEO5N scale. An unequal distribution across the range of scores means it was unlikely that an association with symptom or action appraisal time would have been found. Although there are not clinical cut-offs provided for the TCI-HA the mean and median scores for both groups were well below the median point on the scale. The original study did not report the mean score or range for the TCI-HA or the STAI-T so a proper comparison could not be made.

Hypothesis two predicted that a high degree of optimism may be associated with longer symptom appraisal times and shorter action appraisal times. Although scores for the LOT-R were skewed towards higher levels of optimism there was a significant correlation between the LOT-R and symptom appraisal time in the direction predicted for the breast cancer group. The Cox regression analysis however did not indicate that

symptom appraisal time was significantly associated with the six variables identified as predictive. There was no association between the LOT-R and action appraisal for this group and no associations for either appraisal time in the colorectal group. The correlation between the LOT-R and symptom appraisal time provides some preliminary support for the association between optimism and the symptom appraisal process and therefore warrants further investigation with a larger sample size. This may also result in a more equal distribution in the levels of trait optimism.

Hypothesis three predicted a high degree of conscientiousness would be associated with shorter action appraisal times. There was no association found between these variables for either group. The scores for conscientiousness were negatively skewed for the colorectal group and centred in the middle range for the breast cancer group, which may limit the possibility for an association being found. This may be an artefact of recruitment with more conscientiousness individuals being implicitly more likely to participate in a study.

Hypothesis four predicted that more openness to experience would be associated with shorter symptom appraisal times. There was no association for this trait with symptom appraisal time for either cancer site. It was postulated that individuals with higher levels of openness to experience, may be better able to notice new events and provide new interpretations. In the colorectal group investigation of the score ranges illustrate that the mean and median scores for the openness to experience were in the low to medium range with only two individuals in the high range, which may elude the finding of a significant association. In the breast group, however, scores were more equally distributed across the ranges and there was still no evidence of a significant association.

Using a Cox regression model older age was found to be associated with shorter action appraisal times in the breast cancer group. This finding is contrary with the results of a systematic review of the literature for breast cancer and help-seeking, which indicated that older age was associated with increased patient delay[47]. That review however, did not consider the stages within patient delay but conceptualised it as one time period. One possible explanation for this finding is that the older participants were often retired and may have more time and fewer factors, such as a young family or work as barriers to seeking help after appraising symptoms as serious. This highlights the importance of considering the processes within patient-delay separately to facilitate the investigation of factors that contribute to overall delay, which might otherwise be overlooked. There was no evidence of age being associated with appraisal times in the colorectal cancer group. This is in line with the overall findings in the literature, which indicate that age has no impact on total patient delay for individuals with colorectal cancer[47].

Illness Representations

The second aim of this study was to examine the association between illness representations and the time taken to seek help. Illness representations were explored as the Psychophysiological Comparison theory highlights that the implicit theories individuals have about an illness will influence their attention to symptoms and the appraisal process[17]. The Cox regression models did not find a significant association between illness representations and time taken to appraise or act upon symptoms for either group. Spearman's correlations, however, indicated that in the breast cancer group longer symptom appraisal times were associated with more perceived severe consequences, more symptoms being viewed as being part of the illness, more concern

and a stronger emotional impact. Longer action appraisal times were associated with more perceived severe consequences with regard to the diagnosis and a stronger emotional impact.

Participants had been asked to complete the BIPQ with regard to their perception of their illness at diagnosis. It is likely that many individuals who took longer to seek help were at increased risk of being diagnosed with a later stage of cancer and so have a poorer prognosis. Therefore these individuals may indeed have experienced more symptoms and actual severe consequences and as a result concern when diagnosed. Unfortunately as this is a retrospective study it is difficult to assess illness beliefs about symptoms prior to confirmation of diagnosis using the BIPQ. Anecdotal evidence gathered during data collection indicated that participants who took longer to appraise their symptoms as serious did initially attribute symptoms to benign causes or did not know their symptoms were associated with a particular cancer type. Another study using a regression model found that not having a breast lump and lower initial symptom distress were the most important factors in delaying to seek help[12]. Also a summary of two systematic reviews indicate that across symptomatic cancer sites, non-recognition of symptom seriousness is the main patient-mediated factor resulting in increased time to presentation[47]. Therefore it may have been useful to record information about the type of symptoms and the participant's initial perceptions of them as well as their knowledge of cancer-related symptoms before being diagnosed as it seems likely that this would mediate shorter times to presentation.

Limitations of Study

There are a number of limitations to the present study that must be considered. The use of a cross-sectional design limits the conclusions that can be drawn about causality. As it is retrospective it is subject to recall bias and error. It would however be difficult to measure length of time without medical intervention in any other way as we wanted to identify predictive factors for individuals who took longer to seek help. Retrospective studies such as this can contribute to initial investigations where there are a number of possible interacting factors to identify which are important to explore further in a prospective study.

Another limitation is that the estimate of the time taken to seek help was provided by patient self-report. Firstly, there is the possibility of a recall bias as participants account for their past actions with respect to their current diagnosis. The length of delay reported, however, by many participants was significant and so does not support the hypothesis that individuals underreported the time taken to seek help. Anecdotal evidence indicated that individuals did not underestimate the time taken to seek help but generated explanations for why they took time to seek help. Secondly, the literature indicates that there is significant variability in the recall of illness related information over time[50;51]. Steps were taken to minimise recall error by completing data collection during treatment so to be as close to the actual occurrence of symptoms, while allowing for initial adjustment to the diagnosis. Despite this the time since first recognising symptoms for some participants was up to two years. It could be argued that self report measures assessing individual differences could also be subject to bias. The time constraints of this study did not allow for a prospective study to be carried out, whereby participants completed psychological measures prior to the possible development of any cancer symptoms and were followed up for a significant number of

years. Therefore within the time restrictions of this study the measures assessing dispositional traits have been shown to be relatively stable over time. For example, individual differences based on the TCI-HA are observable in early childhood and are moderately predictive of adult behaviour[52].

The major limitation of this study is that it did not have an adequate sample size; the number of participants was significantly less than the number generated by the *a priori* power calculation resulting in a reduction in the statistical power of the study. Further to this the data for the sample were analysed separately by cancer type reducing the statistical power further. There was evidence that there were significant associations or trends approaching significance between the appraisal times and some of the predictor variables. This initial study would indicate that it would be worthwhile to complete this study over a longer period of time to increase the sample size. Related to this is the finding that the frequencies of scores on the measures assessing dispositional traits were significantly skewed and did not result in large enough numbers at both the lower and upper scales of measures. This may be addressed in some part by a larger sample size but may also be an effect of recruitment; with more optimistic, conscientious and less depressed and neurotic or anxious individuals agreeing to participate. The degree of depressive and anxiety symptomatology reported in this study however does not differ significantly from other studies in the literature[53].

Conclusions

This study aimed to assess whether dispositional traits and illness representations were associated with the length of time taken to seek help. None of the hypotheses were confirmed but as highlighted there were a number of limitations as a result of time

constraints in this particular study. Despite these limitations there does seem to be evidence to suggest that examination of dispositional traits and illness beliefs is worthwhile to enable identification of individuals who are at risk of taking longer to seek help. Specifically this study indicated that with breast cancer patients, it may be worthwhile to further explore the association between neuroticism and symptom appraisal and optimism and both symptom and action appraisal. All further research investigating dispositional traits and illness beliefs would be strengthened by investigating and analysing data for different cancer types separately. Anecdotal evidence indicated that the study would have benefitted from recording the specific type of symptoms experienced by participants and an assessment of their prior knowledge of cancer-related symptoms. Therefore, further studies would benefit from including this information.

If disposition traits and illness beliefs could be identified in further research this would allow the development of interventions in primary care to address change or influence these mechanisms, with the aim of reducing the time taken to seek help. For routine clinical practice, from a psychological perspective, development of knowledge in this area would help to identify possible sources of distress for patients post-diagnosis.

The study has highlighted that there are differences between cancer types and specifically that individuals with symptoms indicative of colorectal cancer take longer to appraise symptoms and seek help. This in part may be due to the various symptoms of colorectal cancer being less identifiable to lay persons, than for example a lump possibly indicating breast cancer. It however, may also be related to the way information about colorectal cancer symptoms is provided at a national level to the

wider public. As highlighted, anecdotal evidence indicated that individuals had a poor knowledge of colorectal cancer symptoms and were not aware of public health information until after they were diagnosed, which they saw in hospital waiting areas. This merits further investigation to identify possible methods of communicating information about symptoms to the wider public prior to the development of symptoms in forums other than medical settings. Lastly, the identification of relevant dispositional traits and illness beliefs would inform the development of educational material and future public health interventions to promote early presentation and increase survival rates.

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Figure 1: Andersen's Model of Total Delay(14)

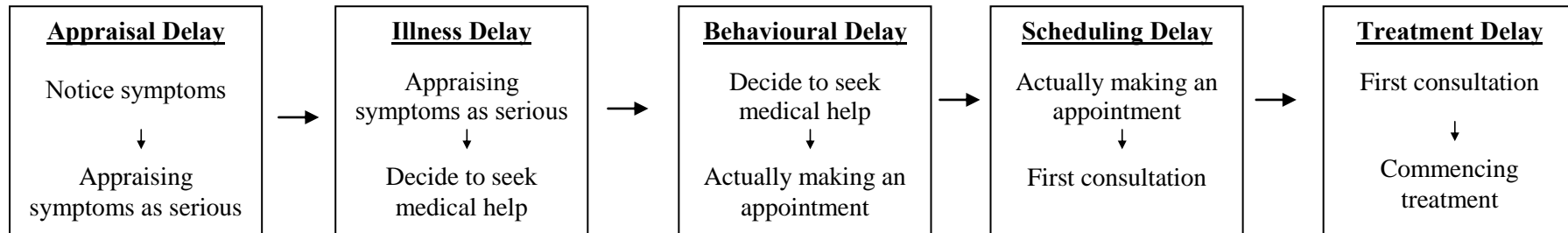


Figure 2: Principles of Psychophysiological Comparison Processes(17)

Assumptions:

Principle 1: People are motivated to maintain an explicable physiological condition.

Principle 2: Symptom perception need not to be accurate in terms of physiological aetiology.

Antecedents:

Principle 3: The strength of the motivation to understand and evaluate one's symptoms is a function of their unexpectedness, salience, personal relevance and perceived consequences.

Psychophysiological Comparisons:

Principle 4: Symptom interpretation involves a comparison of the symptoms with the known consequences of salient situational stimuli (e.g. exposure to pathogens, recent medications) and physiological conditions (e.g. allergies, diseases, that is, illness prototypes).

Principle 5: Symptom interpretation is governed in part by logical consistency. For example the probability of a specific illness inference is a direct function of its accessibility (familiarity) and an inverse function of the discrepancy between the symptoms and the illness prototype.

Principle 6: Symptom interpretation is governed in part by an optimistic bias. For example innocuous explanations (e.g. prototypes which suggest the symptoms are transient or self-correcting) diminish an individual's motivation to obtain additional information or explanations for the condition to a greater degree, *ceteris paribus*, than to threatening explanations.

Principle 7: The more diffuse the symptoms, the greater the number of potential comparisons and consequently, the greater the likelihood of erroneous interpretations of the symptoms and the more susceptible to change are the interpretations.

Effects Of Failing To Find A Comparison:

Principle 8: If a situational stimulus or illness prototype cannot be initially identified to account for the symptoms then the stimuli or prototype(s) which maximizes the logical and optimistic bias principles above will be considered. This will influence the subsequent symptom interpretation on two ways:

- (a) The implicit theories people have about stimuli or prototypes will influence the attention to and detection of symptoms and the production of symptoms for interpretation.
- (b) The particular symptom chosen will influence people's implicit theories about stimuli or prototypes.

Table 1: Participant Characteristics by Cancer Site

	Colorectal Cancer (%) N=47	Breast Cancer (%) N=24
Gender		
Female	40.4 (n=19)	100 (n=24)
Male	59.6 (n=28)	0 (n=0)
Age		
Mean Age (SD)	59.68 (10.81)	54.50 (15.69)
Median	60	51.5
Range	30-84	26-84
Socioeconomic Status		
Quintile 1 (Most Deprived)	36.2 (n=17)	8.3 (n=2)
Quintile 2	17.0 (n=8)	16.7 (n=4)
Quintile 3	8.5 (n=4)	20.8 (n=5)
Quintile 4	12.8 (n=6)	20.8 (n=5)
Quintile 5 (Least Deprived)	25.5 (n=12)	33.3 (n=8)

Table 2: Summary of the Time Taken to Seek Help by Cancer Site

	Colorectal Cancer N=47	Breast Cancer N=24
Symptom Appraisal		
Mean Number of Days (SD)	76.64 (126.95)	36.96 (62.66)
Range	0 – 721	0 – 217
Median	33	8.50
Action Appraisal		
Mean Number of Days (SD)	10.62 (17.16)	4.46 (7.19)
Range	0 – 101	0 – 34
Median	4	2
Total Time		
Mean Number of Days (SD)	87.26 (131.69)	41.42 (65.068)
Range	1 – 728	0 – 225
Median	49	12.5

Table 3a: Psychological Outcome Data for Participants with Colorectal Cancer - Including Range, Mean, SD, Median, Confidence Interval and Tests of Normality

Measure	Range	Range (present study)	Mean (SD)	Median	Skewness (Standard Error)	Kurtosis (Standard Error)	Kolmogorov-Smirnov test of normality (p<0.05)
LOT-R	0-24	4-24	17.13 (4.68)	17	-0.20 (0.35)	-0.26 (0.68)	0.200
TCI-HA	0 – 35	0-29	10.49 (7.61)	8	0.65 (0.35)	-0.51 (0.68)	0.024
STAI-T	20-80	20-62	33.49 (9.96)	31	1.06 (0.35)	0.72 (0.68)	0.001
NEO5N (T score)	0-100	26-74	43.45 (10.42)	44	0.45 (0.35)	0.43 (0.68)	0.200
NEO5O (T score)	0-100	29-64	43.62 (8.26)	45	0.08 (0.35)	-0.21 (0.68)	0.200
NEO5C (T score)	0-100	31-72	54.74 (10.23)	53	-0.09 (0.35)	-0.32 (0.68)	0.083
HADS-A	0-21	0-16	4.98 (4.157)	4	1.09 (0.35)	.820 (0.68)	0.001
HADS-D	0-21	0-13	4.21 (3.432)	3	1.01 (0.35)	-.006 (0.68)	0.000

Measures Key:

LOT-R = Revised Life Orientation Test; TCI-HA = Temperament and Character Inventory–Harm Avoidance scale; STAI-T = State Trait Anxiety Inventory–Trait scale; NEO5N = NEO Five-Factor Inventory - Neuroticism scale; NEO5O = NEO Five-Factor Inventory - Openness to Experience scale; NEO5C = NEO Five-Factor Inventory - Conscientiousness scale; HADS-A = Hospital Anxiety and Depression Scale – Anxiety subscale; HADS-D = Hospital Anxiety and Depression Scale – Depression subscale

**Table 3b: Psychological Outcome Data for Participants with Breast Cancer -
Including Range, Mean, SD, Median, Confidence Interval and Tests of Normality**

Measure	Range	Range (present study)	Mean (SD)	Median	Skewness (Standard Error)	Kurtosis (Standard Error)	Kolmogorov-Smirnov test of normality (p<0.05)
LOT-R	0-24	8-24	17.42 (4.62)	17.5	-0.33 (0.47)	-0.93 (0.92)	0.134
TCI-HA	0 – 35	0-25	9.50 (7.11)	7.5	0.75 (0.47)	-0.38 (0.92)	0.082
STAI-T	20-80	21-53	32 (8.29)	30	0.82 (0.47)	0.08 (0.92)	0.033
NEO5N (T score)	0-100	26-64	41.63 (10.08)	40	0.54 (0.47)	-0.00 (0.92)	0.175
NEO5O (T score)	0-100	31-70	47.96 (11.02)	50	0.19 (0.47)	-0.73 (0.92)	0.200
NEO5C (T score)	0-100	36-71	51.96 (8.37)	52	0.30 (0.47)	0.04 (0.92)	0.200
HADS-A	0-21	0-14	4.17 (4.01)	3.5	1.15 (0.47)	0.66 (0.92)	0.094
HADS-D	0-21	0-8	2.63 (2.16)	2.5	0.84 (0.47)	0.44 (0.92)	0.182

Measures Key:

LOT-R = Revised Life Orientation Test; TCI-HA = Temperament and Character Inventory–Harm Avoidance scale; STAI-T = State Trait Anxiety Inventory–Trait scale; NEO5N = NEO Five-Factor Inventory - Neuroticism scale; NEO5O = NEO Five-Factor Inventory - Openness to Experience scale; NEO5C = NEO Five-Factor Inventory - Conscientiousness scale; HADS-A = Hospital Anxiety and Depression Scale – Anxiety subscale; HADS-D = Hospital Anxiety and Depression Scale – Depression subscale

Table 4: Frequency of Scores across Clinical Cut off Data for STAI-T, NEO5 & HADS

	Colorectal Cancer (%) N=47	Breast Cancer (%) N=24
<u>STAI-T</u>		
Normal (20-39)	74.47 (n=35)	79.17 (n=19)
Mild (40-55)	21.28 (n=10)	20.83 (n=5)
Moderate (56-65)	4.26 (n=3)	0 (n=0)
Severe (65+)	0 (n=0)	0 (n=0)
<u>NEO5-N</u>		
Low (≤ 44)	55.31 (n=26)	70.83 (n=17)
Average (45-55)	34.04 (n=16)	16.67 (n=4)
High (≥ 56)	10.64 (n=5)	12.50 (n=3)
<u>NEO5-O</u>		
Low (≤ 44)	46.81 (n=22)	37.50 (n=9)
Average (45-55)	48.94 (n=23)	37.50 (n=9)
High (≥ 56)	4.26 (n=2)	25 (n=6)
<u>NEO5-C</u>		
Low (≤ 44)	10.64 (n=5)	16.67 (n=4)
Average (45-55)	48.94 (n=23)	54.17 (n=13)
High (≥ 56)	40.43 (n=19)	29.17 (n=7)
<u>HADS-A</u>		
Normal (0-7)	78.72 (n=37)	83.33 (n=20)
Borderline (8-10)	12.77 (n=6)	4.17 (n=1)
Clinical 'caseness' (11+)	8.51 (n=4)	12.50 (n=3)
<u>HADS-D</u>		
Normal (0-7)	80.85 (n=38)	95.83 (n=23)
Borderline (8-10)	12.77 (n=6)	4.17 (n=1)
Clinical 'caseness' (11+)	6.38 (n=3)	0 (n=0)

Table 5a: Spearman's Rho Correlations Between Predictor Variables and Symptom Appraisal Time for Breast Cancer Participants

Measure	LOT-R	NE05-N	BIPQ 1	BIPQ 5	BIPQ 6	BIPQ 8
Symptom Appraisal Correlation co-efficient	0.506	0.391	0.499	0.447	0.581	0.528
Significance (2-tailed)	0.01	0.06	0.01	0.03	0.00	0.01

Table 5b: Spearman's Rho Correlations Between Predictor Variables and Action Appraisal Time for Breast Cancer Participants

Measure	Age	BIPQ 1	BIPQ 8
Action Appraisal Correlation co-efficient	- 0.47	0.466	0.453
Significance (2-tailed)	0.02	0.02	0.03

Table 6: Time to Event Analysis for Age, BIPQ1 and BIPQ8 Predicting Action Appraisal Time for Breast Cancer Participants

Variable	Hazard Ratio	95% Confidence Limits	<i>P</i>
Age	1.049	1.010 - 1.089	0.01
BIPQ1	0.816	0.575 - 1.157	0.25
BIPQ8	0.986	0.740 - 1.313	0.92

CHAPTER THREE:
ADVANCED PRACTICE I - REFLECTIVE CRITICAL ACCOUNT

**A Reflection on Providing Psychological Advice
and Guidance to Others at an Organisational Level**

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**Submitted in partial fulfilment of the requirements for the degree of Doctorate in
Clinical Psychology**

Abstract

Introduction: The experience I identified for reflection was one that caused me to doubt my ability to meet the demands of providing consultancy at an organisational level. I lacked confidence in my communication skills and ability to manage difficult interpersonal relationships and group dynamics that were evident at a meeting I attended. This situation was identified within the wider context of my training, as there is a logical emphasis on the varied skills and roles which, following the completion of my Doctoral training, I will continue to develop as I commence my career as a qualified Clinical Psychologist. The experience on which I chose to reflect on was an observation and I outline the two models I employed to facilitate and structure my reflection.

Reflection: The reflection is on my observation of a Clinical Managed Network meeting I attended, which has relevance to my speciality. This experience highlighted insecurities I had in my ability to communicate psychological principles and promote psychology at a higher organisational level. Equally, it made me aware of the challenges that such a task poses, particularly when considering the individual culture of any given institution and any internal and external political influences. Using a structured approach to reflect on this incident supported my making sense of the experience and enabled me to identify the appropriate learning needs and opportunities to fully develop my skills and confidence in this area.

Reflective Review: I reflect on what I have gained from the experience itself and also the usefulness of the models I identified to help me do that. I found that combining two models to facilitate my reflection was particularly useful, especially in using this type of approach for the first time to reflect.

CHAPTER FOUR:
ADVANCED PRACTICE II REFLECTIVE CRITICAL ACCOUNT

A Reflection on Working within Complex Systems

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**Submitted in partial fulfilment of the requirements for the degree of Doctorate in
Clinical Psychology**

Abstract

Introduction: The focus of this reflective account is on my role as a Trainee Clinical Psychologist, working effectively within complex systems and supporting the development of teams and individuals to enhance performance. The Clinical Psychology Department I currently work in is within a relatively large hospital, which has many services and teams within it, which the Department provides input to. This is a new way of working for me and so I chose this aspect of my current placement as the basis of my reflection. I outline the model I used to structure my reflection on a number of incidents, where I had attended multi-disciplinary team meetings or shadowed other professionals when they were meeting with patients at regular clinics.

Reflection: My reflections on these experiences highlighted to me that I held assumptions about what a team was and how Clinical Psychologists should work within them. Using a structured approach to reflect on these experiences facilitated me challenging these assumptions, identifying goals for learning and developed my conceptual understanding of my role within this area, which has significance for my continued professional development.

Reflective Review: I outline what I have gained from this process of reflection with regard my professional development and current practice and the usefulness of this particular model to facilitate this. I critically appraise the model and summarise my conclusions to facilitate further reflections and identify learning goals.

Appendix 1.1: Guidelines for Submission to The Breast Journal



Author Guidelines

Manuscripts will be considered in the form of original articles, breast images, short communications, description of techniques, and letters. Submission of a paper implies that it reports unpublished work, except in abstract form, and is not being submitted simultaneously to another publication.

Manuscript submission and specifications

Manuscripts should be submitted using our online manuscript processing system, ScholarOne. This system may be accessed at <http://mc.manuscriptcentral.com/tbj>. If an author is unable to access this system, please submit both in hard copy and on disk, to the Editorial office:

Shahla Masood, MD, Editor
The Breast Journal
Department of Pathology
University of Florida Health Sciences Center
655 West 8th Street
Jacksonville, FL 32209-6511
USA

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Authors for whom English is a second language may choose to have their manuscript professionally edited before submission to improve the English. A list of independent suppliers of editing services can be found at http://authorservies.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

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Disks may be either IBM or MacIntosh compatible. Manuscripts should be prepared preferably using the latest versions of Microsoft Word or WordPerfect; alternatively, manuscripts may be saved on disk in ASCII format. Please be sure to indicate platform, software name and version number for all disks submitted (e.g. IBM Wordperfect, version 6.0). Make sure the file is double-spaced and has no hard

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Three clear copies should be submitted, printed or typed double-spaced on one side of an 8½ x 11 paper with margins of at least 3 cm. Three copies of any artwork should also be submitted. All pages, including tables, must be numbered. All art must be labeled with the author's name, the figure number, and the name of the journal. Manuscripts must be submitted exclusively to *The Breast Journal* and will become the copyright of the Publisher. Please submit completed, signed Copyright Transfer Agreement with final accepted manuscript.

The first text page should contain: 1. Title; 2. Full names, medical degrees and affiliations of all authors; 3. Full postal address for the corresponding author, to whom the proofs will be sent, including also telephone, fax numbers, and e-mail for that person; 4. Running title of no more than 45 characters, including spaces; 5. List of keywords.

Research papers

These should be structured as follows: Title page, as above; Abstract; Introduction; Materials and Methods; Results; Acknowledgments (optional); References; Tables; Figure legends (double-spaced); Figures.

Other articles: The above format may be varied between the Introduction and Acknowledgments sections for other articles.

Abstracts

Each paper should have an abstract of no more than 300 words. The abstract should state concisely the goals, methods, principle results and major conclusions of the paper. Incomplete and uninformative descriptions such as 'a new method of analysis was used,' should not be used. Acronyms are not permitted in the abstract. Research notes (six or fewer manuscript pages) do not require abstracts.

References

References for *The Breast Journal* should follow the Vancouver (or numerical) system. References are identified in text in parentheses (1), preceding punctuation. A full list of references should be provided in numerical order, sequentially as they appear in the text. The reference list should conform to the style used by the National Library of Medicine and Index Medicus. All references must be verified by the contributors. They should be double-spaced at the end of the article, in the form of the following examples.

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Article in edited book

Author AB, Author CD, Author EF *et al.* [If six or more] Chapter title. In: Editor AB, Editor CD, eds. *Title of book*. Place: Publisher, 1994: 000-00.

Book

Author AB. *Book Title*, 5th edn. Place: Publisher, 1994.

Illustrations

All figures must be submitted electronically according to the specifications outlined below. Failure to submit images according to these specifications will result in reproductions that are small and illegible or in images that are declined. Color photographs should be saved in CMYK as TIF or JPG files at 300 dpi at 5 inches in width Black and white photographs should be saved in grayscale as TIF files at 300 dpi at 5 inches in width New line drawings should be prepared in Microsoft Word, PowerPoint, or

Illustrator without embedded images from other sources. Existing line drawings should be scanned at 1200 dpi at a minimum of 12.5 cm (5 in) in width and saved as EPS files (flow charts must not exceed 7 inches [18 cm] in width). Any existing images added to Microsoft Word or PowerPoint will be rejected. Send original TIF or EPS files.

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Appendix 1.2: Methodological Quality Criteria Checklist

Quality Criteria	0 points	1 point	2 points
1. Does the study have a clearly focused question? <i>0 = The aim or hypotheses not clearly stated</i> <i>1 = The aim was clearly stated but not hypotheses</i> <i>2 = The aim and hypotheses are clearly described</i>			
2. Was the inclusion & exclusion criteria clearly defined? <i>0 = Not stated</i> <i>1 = Referred to but not clearly stated</i> <i>2 = Clearly stated</i>			
3. Was a power calculation used or sample size justified? <i>0 = not completed</i> <i>1 = issues regarding power or sample size acknowledged in introduction/ findings or post hoc calculation of power completed but a prior analysis not completed/explained</i> <i>2 = a prior sample size calculation provided</i>			
4. Are the characteristics of the participants included in the study clearly described? <i>Gender, age, ethnicity/socioeconomic status, stage of cancer</i> <i>0 = None of the characteristics stated</i> <i>1 = Some of the characteristics stated (1-2)</i> <i>2 = All of the characteristics stated (>2)</i>			
5. What was the method of selection from the target population? <i>0 = Not stated</i> <i>1 = Highly selective sample (volunteers / consecutive sample from a highly pre-selected group i.e. involved in other study)</i> <i>2 = Consecutive sample of convenience / random selection</i>			
6. How were psychological factors in response to diagnosis measured? <i>0 = Self report in an interview only; non-standardised tools</i> <i>1 = Mixture of self report in interview and standardised self-report tools/interview based on research diagnostic criteria</i> <i>2 = Only standardised self-report tools</i>			
7. When was the first measurement of psychological variables recorded after being informed of diagnosis of breast cancer? <i>0 = Not stated; under a month</i> <i>1 = > 6 months after; a large range between participants (from 0 - >12mths)</i> <i>2 = < 6 months & similar range for all participants (> 1 - < 6 months after)</i>			

8. Were there repeated evaluations of the psychological factors over a protracted time period? <i>0 = No</i> <i>1 = >1 - <3</i> <i>2 = ≥3</i>			
9. What was the length of follow up? <i>0 = Only up to a year</i> <i>1 = >1year - <5 (minimum)</i> <i>2 = ≥5 (minimum)</i>			
10. For survival rates was cancer-specific mortality reported / analysed separately from all-cause mortality? <i>0 = Not applicable; Not stated or not clearly defined</i> <i>1 = Only all-cause mortality reported</i> <i>2 = Cancer-specific mortality reported only or as well as all-cause</i>			
11. Were known medical & biological (tumor factors) predictive variables recorded? <i>Size; stage; grade; no. of nodes (stage); estrogen & progesterone receptor status; menopausal status; type of treatment</i> <i>0 = No confounding variables</i> <i>1 = Some medical/biological characteristics stated (≤4)</i> <i>2 = More than 4 medical/biological characteristics stated</i>			
12. Type of analysis used: <i>0 = Not stated; descriptive analysis; univariate analysis only (parametric / non-parametric)</i> <i>1 = Multivariate: X^2; odds ratio; discrimination analyses or RR reported</i> <i>2 = Multivariate: Cox proportional hazards regression model (HR) reported</i>			
13. Were the identified predictive variables accounted for by analysis? <i>0 = Analysis not adjusted for predictive variables</i> <i>1 = Adjusted for ≤4 predictive variables outlined</i> <i>2 = Adjusted for >4 predictive variables outlined</i>			

Total Score: _____/26

Overall %: _____

Appendix 1.3: Full Titles of Assessment Measures Listed in Table 2

HRS	Hamilton Rating Scale
HDHQ	Caine and Foulds Hostility and Direction of Hostility Questionnaire
EPI	Eysenck Personality Inventory
RDC	Research Diagnostic Criteria
POMS	Profile of Mood States
DSM-III	American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders – 3 rd Edition
STAI	State-Trait Anxiety Inventory
CECS	Courtauld Emotional Control Scale
SCL-90-R	Symptom Checklist-90 – Revised
PAIS / PAIS-SR	Psychosocial Adjustment to Illness Scale / Psychosocial Adjustment to Illness Scale – Self Report
BSI	Brief Symptom Inventory
ZQCI	Zurich questionnaire of Coping with Illness
FQCI	Freiburg Questionnaire of Coping with Illness
MAC	Mental Adjustment to Cancer Scale
HADS	Hospital Anxiety and Depression Scale
COPE	General Coping Strategies Scale
PAC	Psychological Adjustment to Cancer Scale
IES	The Impact of Events Scale
WOC-CA	Ways of Coping Questionnaire – Cancer Specific Scale
AX/Scale	Anger Expression Scale
R/ED	Rational/Emotional Defensiveness
DEPS	The Depression Scale
WCC-R	Ways of Coping Checklist - Revised

Appendix 2.1: Guidelines for submission to Psycho-Oncology



Author Guidelines

Manuscript Submission

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Please read the remainder of these instructions to authors and then click <http://mc.manuscriptcentral.com/pon> to navigate to the *Psycho-Oncology* online submission site, ScholarOne Manuscripts (formerly known as Manuscript Central). **IMPORTANT:** Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created.

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An Investigation of Personality
Factors and Beliefs about Illness
that may Influence the Time Taken
to Seek Help for Cancer
Symptoms

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Abstract

The time taken to seek help has been highlighted as a key component in improving prognosis for cancer patients. Delay in help-seeking refers to the period between an individual's first awareness of a symptom of illness and initial medical consultation. This process is seen to be multifaceted, possibly influenced by a person's knowledge of the disease, their interpretation of symptoms and attitude towards professional care. These appraisals and decisions may be influenced by psychological factors. The aim of this study is to investigate possible individual differences and the time taken to seek help for individuals with colorectal or breast cancer.

Introduction

The Scottish Government have identified early reporting of symptoms as a key component of successful cancer management¹. Untreated cancer advances in stage, diminishing the chances of survival². Treatment of cancer at an early stage improves the prospects for long term survival. Evidence from data gathered from the Enhanced Service for Cancer Referrals by the Scottish Primary Care Cancer Group, indicates that patients frequently have symptoms for a considerable period of time before seeking help¹. Delay ranged from 30 to 80 days depending on cancer type¹. Therefore, an understanding of the factors that determine the timing of treatment remains of paramount importance.

Levy has noted that colon and breast cancer have better prognosis if detected at an early stage³. These types of cancer often have more salient identifiable symptoms to the lay person, such as rectal bleeding in colorectal cancer and a lump in the breast area, in breast cancer. Therefore these cancer types will be the focus of this study.

Breast Cancer

Breast cancer is the most commonly diagnosed cancer in women in Scotland¹. A systematic review of observational studies examining the association between survival and the time from onset of symptoms until the commencement of treatment found delays of more than 12 weeks were associated with poorer survival rates⁴. There were three categories of data from the studies identified. Studies of five year survival data showed patients with delays of three months or more had 12% lower 5 year survival compared to those with delays of less than three months⁴. Also longer delays were associated with a more advanced stage and when the effect of stage was controlled for, delay was not associated with poorer survival⁴.

Colorectal Cancer

Scotland has one of the highest incidences of colorectal cancer in the world⁵. Survival rates in the UK are poorer than in Europe⁶. The Eurocare study supports the view that this has mainly been due to late diagnosis, leading to high emergency rates⁷. Differences in long-term survival appear to be a result of differences in death-rates in the first six months after diagnosis; being highest in places where patients were most likely to be treated as emergencies⁷. Countries in which, patients survived longer had a higher proportion of early-stage tumours and were more likely to undergo elective surgery⁸. This indicates that a major factor in survival is disease stage. Studies in the UK have shown that rectal bleeding is commonly experienced although over half of those experiencing it do not seek consultation^{9,10}.

Reasons for Delay in Help-seeking

An understanding of the factors, which influence patient's delaying to seek help, is a prerequisite for the development of strategies to shorten delays. A number of different factors have been considered in investigating the reason for delay in help-seeking. Both demographic and psychological factors are associated with delay in seeking medical help¹¹. Demographic variables associated with delay include lower education and socioeconomic status, older age, and being from an ethnic minority group¹². Psychological factors such as severe anxiety and beliefs about prognosis have been associated with treatment delay, while low levels of initial emotional distress are associated with treatment delay in others¹³. The processes that are required to be completed before help can be sought are seen to be multifaceted, possibly influenced by a person's knowledge of the disease and their interpretation of symptoms and attitude towards professional care. An area that has received

less attention and may mediate these factors are individual differences such as personality constructs.

Delay Stages and Psychophysiological Comparison Processes

Andersen and colleagues presented a model of ‘total delay’, which describes the time between an individual first noticing a symptom until they receive treatment. The model comprises five dichotomous stages (appraisal, illness, behavioural, scheduling and treatment delay), which facilitate the investigation of factors that contribute to delay at each stage¹⁴. Each stage is governed by distinct appraisals, decisions and actions. Appraisal delay constitutes the time between first noticing the symptom and appraising it as serious. Illness delay includes the time from appraising the symptom as serious until deciding to seek medical help. Behavioural delay is the time between making the decision to seek help and actually making an appointment. The time between seeking a first appointment and the first consultation is scheduling delay. Treatment delay is the time lapse between first consultation and commencing treatment. The first three stages are influenced by patient delay, while scheduling and treatment delay can be influenced by both patient delay and professional delay. The majority of delay is accounted for by patient delay¹⁴.

Research indicates that appraisal delay usually accounts for the longest portion of patient delay^{15,16}. Therefore, the psychological processes involved during this period are of particular interest. Andersen et al (1990)¹⁷ developed a general attributional framework outlining the psychological processes governing the detection of symptoms and illness inferences, which may impact on appraisal delay. Psychophysiological Comparison Theory incorporates eight principles proposed to govern symptom appraisal¹⁴. The process is conceptualised as one of psychophysiological comparison (Figure 1) and is often biased to

support a positive view of the individual's physiological condition. Therefore, there is a possible role for personality factors to contribute to this process as well as illness cognitions, which refer to an individual's perception and understanding of their experience of a specific disease and may impact on their coping responses¹⁸.

Figure 1: Principles of Psychophysiological Comparison Processes¹⁴
<u>Assumptions:</u> Principle 1: People are motivated to maintain an explicable physiological condition. Principle 2: Symptom perception need not to be accurate in terms of physiological aetiology.
<u>Antecedents:</u> Principle 3: The strength of the motivation to understand and evaluate one's symptoms is a function of their unexpectedness, salience, personal relevance and perceived consequences.
<u>Psychophysiological Comparisons:</u> Principle 4: Symptom interpretation involves a comparison of the symptoms with the known consequences of salient situational stimuli (e.g. exposure to pathogens, recent medications) and physiological conditions (e.g. allergies, diseases, that is, illness prototypes). Principle 5: Symptom interpretation is governed in part by logical consistency. For example the probability of a specific illness inference is a direct function of its accessibility (familiarity) and an inverse function of the discrepancy between the symptoms and the illness prototype. Principle 6: Symptom interpretation is governed in part by an optimistic bias. For example innocuous explanations (e.g. prototypes which suggest the symptoms are transient or self-correcting) diminish an individual's motivation to obtain additional information or explanations for the condition to a greater degree, <i>ceteris paribus</i> , than to threatening explanations. Principle 7: The more diffuse the symptoms, the greater the number of potential comparisons and consequently, the greater the likelihood of erroneous interpretations of the symptoms and the more susceptible to change are the interpretations.
<u>Effects Of Failing To Find A Comparison:</u> Principle 8: If a situational stimulus or illness prototype cannot be initially identified to account for the symptoms then the stimuli or prototype(s) which maximizes the logical and optimistic bias principles above will be considered. This will influence the subsequent symptom interpretation on two ways: (c) The implicit theories people have about stimuli or prototypes will influence the attention to and detection of symptoms and the production of symptoms for interpretation. (d) The particular symptom chosen will influence people's implicit theories about stimuli or prototypes.

Individual Differences & Delay in Help Seeking

Although there has been extensive research in the area of personality traits and health behaviours there has been limited research into their role in relation to patients with cancer help seeking¹⁹. Ristvedt & Trinkaus investigated the association between patient delay in rectal cancer and ‘Trait anxiety’¹⁶. They adopted this term to describe the psychological dimension that correlates with the occurrence of ‘somatic concern’ as it has been conceptualised in different ways by various researchers, using terms such as ‘neuroticism’ and ‘negative affectivity’¹⁶. This dispositional trait is manifested in *the degree of tendency towards anxiety, worry and negative emotions in general*¹⁶. They identified two stages of patient delay using Andersen’s model¹⁴: ‘appraisal delay’ and ‘action delay’; which combined illness and behavioural delay. They examined whether a low Trait Anxiety was associated with longer symptom appraisal times and if there was any association with action appraisal times.

Sixty nine participants took part in the questionnaire study. Trait Anxiety was measured by the Temperament and Character Inventory Harm Avoidance Scale (TCI - HA)²⁰ and Spielberger State Trait Anxiety Inventory – Trait Anxiety Scale (STAI-T)²¹. Individuals scoring lowly on the TCI-HA are characterised as *relaxed and optimistic*. Cox proportional hazards analysis was used to examine if symptom appraisal time was associated with these measures.

There was a significant finding for the TCI-HA. Longer symptom appraisal time was associated with low scores on the TCI – HA (chi-square = 15.50; $p = 0.0084$; $df = 5$), while significance was not met using the STAI – T (chi-square = 10.80; $p = 0.0556$; $df = 5$). They concluded that individuals with a dispositional insensitivity to threat had longer appraisal

times. They postulated that the reason for this difference between the measures was that the STAI-T includes cognitive and somatic aspects of anxiety, while the TCI-HA only focuses on cognitive aspects of anxiety. However, it is also plausible that the construct of optimism was influencing the discrepancy between these two measures, as individuals scoring lowly on the TCI-HA are characterised as optimistic. They found no associations for either measure with action appraisal time.

Individual Differences & Health Related Behaviour

People with a highly optimistic life orientation tend to hold more positive expectancies for their future than pessimists²². There is evidence that a positive life orientation is beneficial to health and has been associated with better recovery after a serious illness. The effect of dispositional optimism on recovery from coronary artery bypass surgery was examined in a group of middle-aged men²³. Optimism was assessed prior to surgery and it correlated positively with manifestations of problem-focused coping. It was associated with a faster rate of physical recovery during hospitalization, a faster rate of return to normal life activities after discharge and with better postsurgical quality of life at six months²³. A longitudinal study assessing patients with early stage breast cancer found that dispositional optimism is inversely related to level of distress prior to and after surgery up to a year later²⁴. Analysis suggested that optimism was mediated by the use of different coping strategies, such as engaging in acceptance and not engaging in behavioural disengagement²⁴. A general characterization of the findings of this research is that optimists tend to use more problem-focused coping strategies than do pessimists²². Optimism has also been examined in relation to preventive health behavior such as breast self-examination, finding that optimism among other predictors derived from the Health Belief Model was related to the frequency of breast

self-examination²⁵. Variables in this model accounted for about 37% of the variance in breast self-examination²⁵.

Therefore, when considering action appraisal time it is likely that optimistic individuals will engage in more adaptive health behaviours, such as seeking help sooner as they may be more optimistic about the final outcome if early action is taken. However, when considering appraisal delay Andersen and colleagues¹⁴ propose that during symptom appraisal the process of comparison is governed by an optimistic bias (Principle 6). That is an individual is more likely to generate an innocuous cause for new symptoms rather than attribute it to a serious illness. This may have a negative impact on health if it delays help seeking as a result of symptoms being attributed to a less serious, transient self-correcting cause. Therefore, it would be predicted that individuals with higher optimism would have longer symptom appraisal times as they may be more likely to generate innocuous explanations for their symptoms. Consequently, it would be important to investigate if optimism has an impact on the time taken to seek help at each of these stages.

Another personality construct not previously addressed is conscientiousness. Conscientiousness is defined as a dispositional *tendency to be prudent, planful, persistent (and) dependable*²⁶. There appear to be links between conscientiousness and pathways to good health behaviours and adherence with medical advice^{19,26}. Jerram and Coleman¹⁹ found an association between conscientiousness and more positive health perceptions and visits to the GP in older males. It is therefore likely that conscientious individuals may engage in more adaptive health coping strategies when confronted with health stressors. This may facilitate shorter action appraisal times.

Another potentially relevant personality trait is openness to experience. Jerrman and Coleman found an association with positive health perceptions for an older population¹⁹. High scores on the openness to experience scale have also been linked with the ability to notice new events and put new interpretations on observations¹⁹. Therefore, in relation to engaging in seeking help for serious symptoms there may be an inverse association between openness to experience and symptom appraisal time.

The Psychophysiological Comparison theory highlights that the implicit theories individuals have about a particular illness will influence their attention to symptoms and the appraisal process¹⁴. Grunfeld and colleagues examined age and socio-economic variations in relation to knowledge and beliefs about breast cancer among a sample of the general female population²⁷. The findings indicated that although this was more significant for older woman all age groups had limited knowledge of their relative risk of developing breast cancer, of associated risk factors and of the diversity of potential breast cancer-related symptoms. It would therefore appear prudent to consider illness perceptions when considering individual differences. The principal theoretical framework is the self-regulation model developed by Leventhal and colleagues, which describes the process by which individuals respond to a perceived health threat¹⁸. The model proposes that the detection of symptoms generate both cognitive and emotional representations of an illness, which can be highly idiosyncratic. Symptom perceptions and health beliefs has previously been examined as predictors of intentions to seek medical help in a female population for breast cancer²⁸. Analysis revealed that the cognitive component of the self-regulation model accounted for approximately 22% of the variance in help-seeking intention, which further supports the importance of considering illness representations²⁸.

2. Aims and hypotheses

Aims

The primary aim is to examine the association between personality factors and the time taken to appraise and then seek professional advice, on discovery of symptoms indicative of cancer in individuals diagnosed with cancer.

A secondary aim is to examine the association between illness representations and the length of time taken to engage in help-seeking behaviour in individuals diagnosed with cancer.

A further secondary aim is to replicate the findings of the Ristvedt & Trinkaus¹⁶ study and examine if the differences between the TCI-HA & STAI-T are repeated.

Primary Hypotheses

- A low level of ‘trait anxiety’ or neuroticism as measured by the TCI – HA scale, the STAI-T and NEO Five-Factor Inventory (NEO-FFI)²⁹ will be associated with longer symptom appraisal time and shorter action times.
- High optimism will be associated with longer symptom appraisal times and shorter action appraisal times.
- Conscientiousness will be associated with shorter Action Appraisal times.
- Openness to experience will be associated with shorter Symptom Appraisal times.

3. Plan of Investigation

Participants

- Individuals commencing treatment for breast cancer or colorectal cancer. It was decided to include individuals who had a diagnosis of cancer rather than individuals who were uncertain of their diagnosis as this will provide some time for the individual to adjust to the diagnosis.

Inclusion and Exclusion Criteria

- Inclusion criteria:
 - Participants will be aged 18 years or over as some of the measures have been standardised for this age-group. There is no upper age limit.
 - Participants will be English speaking.
- Exclusion criteria:
 - Individuals whose symptoms were detected by a third party such as a medical health care provider, independent of self-discovery of the symptoms will be excluded as there is no opportunity for these individuals to seek help or delay and so measures of appraisal and illness delay will be unable to be measured and analysed. However, the demographic information for these individuals will be analysed.
 - Participants who have received treatment previously for any cancer type will be excluded. However, future research should extend this study to assess time taken to seek help for this population.
 - Participants will be excluded on the basis of any cognitive impairment or learning disability, which may impact on ability to understand and complete measures or reliable recall stages of delay in help-seeking process.

Recruitment Procedures

- Participants will be recruited from the Beatson West of Scotland Cancer Centre (BWoSCC). Consultants will be briefed on the objectives of the study and an outline of the inclusion and exclusion criteria. All individuals, who meet the inclusion criteria, will be invited to participate in the study.
- The consultant will introduce the study to patients during their second clinic appointment, using an information sheet inviting them to participate in the study. Individuals who would like further information will have the opportunity to meet with the researcher and discuss the study. Individuals will be given time to consider if they would like to participate in the study and provided with a copy of the information sheet. If they decide that they would like to participate they will be provided with a consent form and commence with the study.

Measures

- To provide an objective measure of delay the stage of cancer will be recorded. This will provide an indication of how long an individual has had cancer for. Permission will need to be sought to access participants' medical files to record this information.
- Demographic information (sex; age; geographical area; education level) will also be recorded. The Scottish Index of Multiple Deprivation (SIMD) will be calculated using the participants' postcode³⁰.
- The following self report measures will be completed:
 1. An estimate of the time taken to seek help will be measured by interviewing participants utilising the approach proposed by Andersen and colleagues to measure delay by identifying the first three sequential stages involved in help seeking¹⁴.

The nature of this study means that it is subject to recall bias and error as it is relying on retrospective reports. It is possible that there will be a recall bias as participants try to account for their past actions with respect to their current diagnosis. However, qualitative data in a study of reasons for delay in seeking help by participants diagnosed with lung cancer indicated that there was no evidence of this as they did not have a good knowledge of the connections between health changes and lung cancer³¹. The literature indicates that there is significant variability in recall of illness related information over time in physical health settings^{32,33}. As the timing of data collection is extremely important it will be completed as close to the actual occurrence of symptoms within the limits of this study to minimise recall bias while allowing for initial adjustment to this life event. Previous research indicates that the emotional response to a diagnosis of cancer does not impact significantly on the accuracy of recall¹⁴.

An assessment of delay in stages will be calculated in days. The researcher will interview the participant using a calendar to assist recall and complete the record sheet (Appendix 1). Prompt questions will be utilised to facilitate recall and cues employed as anchoring events. An outline of prompt questions and possible cues are outlined:

- Appraisal Delay:
 - What symptom(s) did you detect?
 - When did you first become aware of your symptom(s)?
 - What time of year was it i.e. before or after (cue)?
 - How long after you noticed your first symptom did you decide it may be something serious?

- Illness delay
 - How much time passed before you decided to seek medical help?
 - What other significant events were happening at that time?
 - Did you decide to seek help before or after (cue)?
- Behavioural Delay
 - How long did you wait before making an appointment to see your GP for those symptoms?
 - Can you remember what you were doing that day?

2. Temperament and Character Inventory (TCI)– Harm Avoidance Scale (HA)²⁰

- The short self-report form will be used. The TCI - HA scale measures individual differences in sensitivity to signals of possible threat, danger or punishment.

3. Spielberger State Trait Anxiety Inventory – Trait Anxiety Scale (STAI-T)²¹

- The STAI-T consists of twenty statements, which indicate the degree of habitual anxiety.

4. NEO Five-Factor Inventory (NEO-FFI)²⁹

- The NEO-FFI is a shortened version of the Revised NEO Personality Inventory (NEO PI-R)³⁴. There are 60 items rated on a five point scale, based on the Five Factor Model. It will be used to measure Conscientiousness, Neuroticism, and Openness to Experience as there is some evidence that these three factors may be associated with time taken to seek help.

5. Revised Life Orientation Test (LOT-R)²²

The LOT-R was used to assess individual differences in generalized optimism (Appendix 2). It consists of ten items and higher values indicate higher levels of optimism.

6. The Brief Illness Perception Questionnaire (Brief IPQ)³⁵

- Consists of nine-items using a ten point Likert scale designed to assess the cognitive and emotional representations of illness proposed in Leventhal's self-regulatory model.

7. Hospital Anxiety and Depression Scale (HADS)³⁶

- This is a self screening questionnaire to detect the presence and severity of depression and anxiety in a medical population. This is included to assess confounding variables that may impact on recall.

Design

- The study will use a cross-sectional correlational design.

Research Procedures

- Consent forms will be completed if individuals wish to participate.
- Demographic information (sex; age; geographical area; education level) will be recorded.
- Participants will be asked to complete the six measures and questionnaire.
- The time taken to complete these measures should be approximately 60 minutes.

Justification of sample size

- Sample size was calculated according to the procedures required when regression analysis is to be applied to the data³⁷. The calculation involves four input parameters: (1) alpha (probability) level; (2) number of predictors; (3) anticipated effect size; (4) desired statistical power level.
- Unfortunately, there are no relevant effects sizes reported in the literature from which to estimate the effect in the present study. By convention in such situations, therefore, the assumption was made of a medium effect size of 0.15. Power was set at 0.80 and alpha at 0.05.
- The independent (predictor) variables are those derived from the psychological assessments outlined above. They are as follows: (1) personality variables of Conscientiousness, Neuroticism, and Openness to Experience (NEO Five Factor Personality Inventory); (2) Optimism (Revised Life Orientation Test); (3) Illness Beliefs (Brief Illness Perception Questionnaire); (4) Harm Avoidance (Temperament and Character Inventory); (5) Trait Anxiety (State-Trait Anxiety Inventory). In addition, analysis will determine whether socio-economic status (DEPCAT) influences the dependent variable in light of evidence that those of lower socio-economic status are more likely to delay presentation. Equally, the relationship between current symptomatology and the variables will be analysed to assess the impact of this on recall. As there is likely to be co-linearity between Neuroticism, Harm Avoidance and Trait Anxiety these variables will be unable to be entered simultaneously into the regression.
- With predictors as above, the calculation based on seven probable non-correlated predictor variables estimates that the required sample size to test the hypotheses is 103 participants. This was calculated using an online power calculator G*power³⁸.

Data Analysis

- The Statistical Package for Social Sciences (SPSS) will be used to store and analyse the data. To ensure confidentiality of participant information, participants will be identified by a unique code for storage of information.
- Participant characteristics will be defined using descriptive statistics. Prior to formal analysis data will be checked for skewness and kurtosis. As a prelude to the regression analysis, correlational analysis will be conducted between the dependent and independent variables and between the independent variables. This is to detect co-linearity between the independent variables. Then a regression analysis will be applied to assess the association between the independent and dependent variables.
- The independent variables are Conscientiousness, Neuroticism, and Openness to Experience scales on the NEO-FFI; Optimism as measured by LOT-R, illness representations as measured by the IPQ-R, Trait Anxiety as measured by the TCI-HA scale and STAI-T, presence of current symptomatology as measured by the HADS and demographic information. As there is likely to be co-linearity between neuroticism and Trait Anxiety these variables will be unable to be entered simultaneously into the regression. Therefore, there will be a total of seven variables used in the regression analysis. The dependent variable is the time in days from first recognizing the symptoms to seeking medical help.
- As a secondary outcome measure time-to-event analysis will be completed using Cox proportional hazard analysis to assess whether symptom appraisal time and action appraisal time are associated with scores on the measures of personality constructs. The event of interest in symptom appraisal is the point when the individual becomes aware of the seriousness of their symptoms but some participants will not appraise their symptoms as serious before seeking a medical consultation. Time to event analysis allows inclusion of data for those participants where the event of interest is not observed.

Settings and Equipment

The study will be carried out in a quiet room at the BWoSCC. It will require no special equipment other than the measures and questionnaire. The HADS, NEO-FFI, IPQ-R and STAI-T are readily available in the Department of Psychological Medicine. The LOT-R is available freely but the TCI will have to be purchased.

4. Health and Safety Issues

- Participants will be seen at the BWoSCC, during working hours and medical health professionals will be in close proximity in case of emergency.

5. Ethical Issues

- Ethics approval will be sought from the BWoSCC In-House Trials Advisory Board (IHTAB) and the Greater Glasgow Primary Care NHS Trust Research Ethics Committee before the study is carried out. Participants may be experiencing distress as a result of recently receiving a diagnosis of cancer and as part of routine procedures will be monitored for levels of distress by the responsible team. The psychological assessments proposed are used routinely and there is no evidence that these cause harm or distress. The questionnaire used to assess the time taken to seek help focuses on progression of events rather than emotional aspects of the process. However, if an individual did experience distress in recalling events that occurred prior to consultation with a health care professional the researcher is a Trainee Clinical Psychologist and is trained to provide immediate support to the individual. If there is evidence of any psychological

issues these will be highlighted to the responsible Consultant and referral made to the Psychology Service at the BWoSCC as necessary.

6. Financial Issues

- The TCI will have to be purchased.

7. Timetable

- After receiving ethics approval I will proceed with data collection at the end of January 2010. Individuals will be recruited within a four month period. Data will be analysed in May 2010.

8. Practical Applications

- The problem of 'delay' in diagnosing cancer as a result of late presentation to a health professional by the individual experiencing symptoms has been highlighted as part of broader initiatives to reduce mortality rates as a result of cancer. Cancer Research UK has indicated that their main aim is to reduce mortality and that reducing delay is one of the primary areas of their focus³⁹. Although the psychological characteristics being investigated in this study are not easily amenable to change, they could provide direction for identifying groups at the greatest risk for misinterpreting cancer symptomatology and delay. The Scottish Primary Care Cancer Group advised that public education programmes on common cancer symptoms should be developed and disseminated to encourage patients to present early⁴⁰. Identifying characteristics of at risk populations would have implications for the development of educational material, future public health

initiatives and would inform practice. This could reduce delay time and increase survival rates.

Appendix 1: Overview of Time Taken To Seek Help

2 0 0 9

January

Mo	Tu	We	Th	Fr	Sa	Su
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

February

Mo	Tu	We	Th	Fr	Sa	Su
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	

March

Mo	Tu	We	Th	Fr	Sa	Su
30	31					1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29

April

Mo	Tu	We	Th	Fr	Sa	Su
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

May

Mo	Tu	We	Th	Fr	Sa	Su
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

June

Mo	Tu	We	Th	Fr	Sa	Su
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30					

July

Mo	Tu	We	Th	Fr	Sa	Su
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31		

August

Mo	Tu	We	Th	Fr	Sa	Su
31					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

September

Mo	Tu	We	Th	Fr	Sa	Su
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

October

Mo	Tu	We	Th	Fr	Sa	Su
		1	2	3	4	
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

November

Mo	Tu	We	Th	Fr	Sa	Su
30						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29

December

Mo	Tu	We	Th	Fr	Sa	Su
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			

2 0 1 0

January

Mo	Tu	We	Th	Fr	Sa	Su
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

February

Mo	Tu	We	Th	Fr	Sa	Su
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28

March

Mo	Tu	We	Th	Fr	Sa	Su
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

April

Mo	Tu	We	Th	Fr	Sa	Su
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30		

May

Mo	Tu	We	Th	Fr	Sa	Su
31					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

June

Mo	Tu	We	Th	Fr	Sa	Su
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

1. First became aware of symptom(s): ____/____/____

Decided symptom(s) may be serious: ____/____/____

2. First decided to seek medical help: ____/____/____

3. Arranged an appointment: ____/____/____

Symptom Appraisal: ____ days

Illness Delay: ____ days

Behavioural Delay: ____ days

Action Appraisal: ____ days

Appendix 2: Life Orientation Test - Revised

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no “correct” or “incorrect” answers. Answer according to your own feelings, rather than how you think “most people” would answer.

	I agree a lot	I agree a little	I neither agree or disagree	I disagree a little	I disagree a lot
1. In uncertain times, I usually expect the best.					
2. It's easy for me to relax.					
3. If something can go wrong for me, it will.					
4. I'm always optimistic about my future.					
5. I enjoy my friends a lot.					
6. It's important for me to keep busy.					
7. I hardly ever expect things to go my way.					
8. I don't get upset too easily.					
9. I rarely count on good things happening to me.					
10. Overall, I expect more good things to happen to me than bad.					

Scheier M.F., Carver C.S. & Bridges M.W. (1994)

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Appendix 2.3: Ethics Committee Approval Letters

West of Scotland Research Ethics Committee West of Scotland REC 3

Ground Floor, The Tennent Institute
Western Infirmary
38 Church Street
Glasgow
G11 6NT

Telephone: 0141 211 2123
Facsimile: 0141 211 1847
15 January 2010

Miss Lynn Steele
Flat 2/1
11 Kelvindale Gardens
Glasgow G20 8DW

Dear Miss Steele

Study Title:	An Investigation of Personality Factors and Beliefs about Illness that may Influence the Time Taken to Seek help for Cancer Symptoms
REC reference number:	10/S0701/3
Protocol number:	Vers.3

The Research Ethics Committee reviewed the above application at the meeting held on 14 January 2010. Thank you for attending to discuss the study.

Ethical opinion

The members of the Committee present 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.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) 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 the only involvement of the NHS organisation is as a Participant Identification Centre, management permission for research is not required but the R&D office should be notified of the study. Guidance should be sought from the R&D office where necessary.

Sponsors are not required to notify the Committee of approvals from host organisations.

1) The Committee had concerns around the location of the interviews and whether privacy would be an issue. It was noted in discussion that there was good support from the Beatson for the research and that an appropriate room would be provided for the interviews.

2) The Committee considered that perhaps participants may feel distressed because they did not report the symptoms earlier. In discussion the Committee noted that should a participant become distressed during the interviews then they could if they wished have immediate access to Clinical Health Psychology at the Beatson.

3) The Committee also noted in discussion that access to medical records was necessary to confirm the diagnosis.

4) In the Participant Information Sheet at "If I had a complaint about any aspect of the study" it is not enough to say that the NHS complaints mechanism is available. Contact details of an appropriate person independent of the study should be given. A revised Participant Information Sheet should be submitted to the Committee Co-ordinator.

It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
REC application	Vers.1	28 November 2009
Protocol	Vers.3	18 December 2009
Investigator CV		
Participant Information Sheet	Vers.1	10 December 2009
Participant Consent Form	Vers.1	10 December 2009
Letter of invitation to participant	Vers.1	18 December 2009
GP/Consultant Information Sheets	Vers.1	18 December 2009
Questionnaire: Self-Evaluation	Validated	
Questionnaire: Neo 5-Factor Inventory	Validated	
Questionnaire: Life Orientation Test	Validated	
Questionnaire: TCI	Validated	
Questionnaire: Brief Illness Perception	Validated	
University proposal agreement		13 October 2009
Student CV		09 August 2007
Outline Proposal application		30 November 2009
HADS Questionnaire	Validated	

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for

Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

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.

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
- 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.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email referencegroup@nres.npsa.nhs.uk.

10/S0701/3

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely

Liz Jamieson
Committee Co-ordinator on behalf of Dr Paul Fleming, Chair

Email: Liz.Jamieson@ggc.scot.nhs.uk

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments
"After ethical review – guidance for researchers"

Copy to: Dr Susie Porteous
R&D office for NHS care organisation at lead site

WoSRES
West of Scotland Research Ethics Service



West of Scotland REC 3
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT
www.nhsggc.org.uk

Miss Lynn Steele
Trainee Clinical Psychologist
Flat 2/1
11 Kelvindale Gardens
Glasgow G20 8DW

Date 17th February 2010
Your Ref
Our Ref
Direct line 0141 211 2123
Fax 0141 211 1847
E-mail Liz.Jamieson@ggc.scot.nhs.uk

Dear Miss Steele

Full title of study: An Investigation of Personality Factors and Beliefs about Illness that may Influence the Time Taken to Seek help for Cancer Symptoms
REC reference number: 10/S0701/3
Protocol number: Vers.3

Thank you for your letter received on 29th January 2010. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 14 January 2010. Please note these documents are for information only and have not been reviewed by the committee.

Documents received

The documents received were as follows:

Document	Version	Date
Covering Letter		29 January 2010
Participant Information Sheet	Version 2	22 January 2010
Participant Consent Form	Version 2	22 January 2010

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

10/S0701/3	Please quote this number on all correspondence
-------------------	---

Yours sincerely


Mrs Liz Jamieson
Committee Co-ordinator
Copy to:  Dr Susie Porteous
R&D

Delivering better health

www.nhsggc.org.uk

Appendix 2.4: Research & Development Approval Letter

Research & Development
R&D Management Office
1st Floor, Tennent Institute
Western Infirmary
GLASGOW G11 6NT
Tel: 0141 252 9447



Our Ref: RPHB
Enquiries to: Dr Erica Packard
Direct Line: 0141 211 8544
e-mail: Erica.packard@ggc.scot.nhs.uk

25 February 2010

Miss Lynn Steele
Trainee Clinical Psychologist
Section of Psychological Medicine
Gartnavel Royal Hospital
Great Western Road
Glasgow
G12 0XH

R&D Management Approval

Dear Lynn,

R&D Reference: GN09GN661
GG&C Sites: The Beatson West of Scotland Cancer Centre
Chief Investigator: Miss Lynn Steele
Project Title: An Investigation of Personality Factors and Beliefs about Illness that may influence the Time Taken to Seek Help for Cancer Symptoms

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant Management Approval for the above study.

As a condition of this approval the following information is required during the lifespan of the project:

1. SAES/SUSARS - If the study is a **Clinical Trial** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004 (CTIMP only)
2. Recruitment Numbers on a quarterly basis (not required for commercial trials)
3. Any change of Staff working on the project named on the ethics form
4. Change of CI
5. Amendments – Protocol/CRF etc
6. Notification of when the Trial / study has ended
7. Final Report
8. Copies of Publications & Abstracts

Please add this approval to your study file as this letter may be subject to audit and monitoring.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Erica Packard'.

Dr Erica Packard
Research Co-ordinator

Cc: Jan Wallis, Regulatory Administrator, BWOSCC

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Appendix 2.5: Participant Information Sheet



University
of Glasgow



Information Sheet

Study: An investigation of personality factors and beliefs about illness that may influence time taken to seek medical advice for cancer symptoms

My name is Lynn Steele and I am a final-year Trainee Clinical Psychologist at the University of Glasgow. As part of my training I am carrying out research looking at how personality factors and beliefs about illness may influence the time taken to seek help for cancer symptoms.

You are being invited to take part in this study and this leaflet provides information about it. If you have any questions please do not hesitate to speak to me. My contact details are also at the end of the leaflet.

What is the purpose of this research?

The primary purpose of this research is to examine whether the time taken to seek medical advice, by presenting with self-detected symptoms of cancer, is associated with particular personality factors and beliefs about illness. An understanding of the factors that may influence the time taken to seek help is of considerable importance in the treatment of cancer.

Why have I been chosen to take part?

All individuals attending the Beatson West of Scotland Cancer Centre for treatment for breast cancer or colorectal cancer are being invited to take part in this study.

Do I have to take part?

No. Your participation in this study is entirely voluntary and it is up to you to decide whether or not you would like to take part. If you do decide to take part you are free to withdraw at any time without giving a reason. Your decision to withdraw, or not to take part, will not affect your on-going care in any way.

What will happen if I agree to take part?

If you do agree to take part you will be asked to complete a consent form. I will then meet with you to complete some short questionnaires that assess different aspects of personality, your beliefs about cancer and your general wellbeing. You will also be asked to take part in an interview with me to recall the time points when you made the decisions that led you to seek professional advice about your symptoms. The interview and questionnaires should take no longer than 60 minutes. I would intend to hold the interview when you are attending for routine appointments at the Beatson Centre.

With your consent I will also access your medical notes for information relating to the stage of your cancer at diagnosis.

PSYCHOLOGICAL MEDICINE

Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH

22/01/2010

Version 2

Are there risks or benefits to taking part?

You will not be asked to take any medication or take part in any medical procedures. You will be asked to recall your symptoms and the decisions that led to you seeking professional advice. You will also be asked about your beliefs about illness and cancer. It is possible that these questions may arouse emotional reactions, or indicate that you are having difficulty coping with aspects of your diagnosis or treatment. If so, and you agree that you may benefit from professional psychological support, then such support can be organised for you.

The results of this study could inform the development of public education programmes and materials on common cancer symptoms to encourage individuals to present early. It could also lead to further studies to help health professionals to provide targeted interventions aimed at promoting appropriate help-seeking behaviour to ensure we provide the best care. These developments could result in a reduction in the time taken to seek help and in turn improve prognosis.

Will my taking part in the study be kept private?

Your identity and personal information will be completely confidential and known only to the research team. The information obtained will remain confidential and stored within a locked filing cabinet. The information is held in accordance with the Data Protection Act, which means that we keep it safely and cannot reveal it to other people without your permission. Any information that is reported in summarising the findings of the study will have all identifiable information removed and will only include general findings. If you decide to withdraw from the study, all personal information collected before that point will either be kept with your consent or destroyed if that is what you would prefer.

What will happen to the results of the study?

It is intended that the results will be published in a journal that specialises in research in psychology and oncology. You can obtain a copy of the publication by contacting me.

If I had a complaint about any aspect of the study to whom should I address it?

If you are unhappy about any aspect of the study and wish to make a complaint, you can contact me (contact details below) or Anne Snape, Complaints Department, Glasgow Royal Infirmary, 84 Castle Street, Glasgow, G4 0SF. Telephone: 0141 2115556.

Thank you very much for taking the time to read this leaflet. Please ask any questions you may have.

For Further Information Please Contact:

Lynn Steele, Trainee Clinical Psychologist, Department of Psychological Medicine, Gartnavel Royal Hospital (Tel: 0141 301 7379, Email: lynnsteele@nhs.net)

PSYCHOLOGICAL MEDICINE
Academic Centre, Gartnavel Royal Hospital, 1055 Great Western Road, Glasgow G12 0XH

Appendix 2.6: Participant Consent Form



University
of Glasgow



Lynn Steele
Trainee Clinical Psychologist
Department of Psychological Medicine
Garthnavel Royal Hospital
1055 Great Western Road
Glasgow
G12 0XH

Centre Number: 1

Study Number: GN09ON661

Patient Identification Number for this trial:

CONSENT FORM

Title of Project: An investigation of personality factors and beliefs about illness that may influence time taken to seek help for cancer symptoms

Name of Researcher: Lynn Steele, Trainee Clinical Psychologist

Please initial box

1. I confirm that I have read and understand the information sheet dated 22/01/10 (Version 2) 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, and without my medical care or legal rights being affected.
3. I understand that sections of my medical notes (with regard to stage of the tumour at diagnosis) may be accessed as part of this study. I understand that only clinicians involved in the study will have access to these. I give my permission for the research team to have access to my records.
4. I agree to take part in the above study.

☐☐☐☐

Name of Patient

Date

Signature

Name of Person
taking consent

Date

Signature

Appendix 2.7: Recording Sheet for Estimation of Symptom and Action Appraisal

Participant: _____

Date: _____

Overview of Time Taken To Seek Help

2 0 0 9

January

Mo	Tu	We	Th	Fr	Sa	Su
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

February

Mo	Tu	We	Th	Fr	Sa	Su
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	

March

Mo	Tu	We	Th	Fr	Sa	Su
30	31					1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29

April

Mo	Tu	We	Th	Fr	Sa	Su
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

May

Mo	Tu	We	Th	Fr	Sa	Su
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

June

Mo	Tu	We	Th	Fr	Sa	Su
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30					

July

Mo	Tu	We	Th	Fr	Sa	Su
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31		

August

Mo	Tu	We	Th	Fr	Sa	Su
31					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

September

Mo	Tu	We	Th	Fr	Sa	Su
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

October

Mo	Tu	We	Th	Fr	Sa	Su
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30	31	

November

Mo	Tu	We	Th	Fr	Sa	Su
30						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29

December

Mo	Tu	We	Th	Fr	Sa	Su
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30	31			

2 0 1 0

January

Mo	Tu	We	Th	Fr	Sa	Su
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

February

Mo	Tu	We	Th	Fr	Sa	Su
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28

March

Mo	Tu	We	Th	Fr	Sa	Su
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

April

Mo	Tu	We	Th	Fr	Sa	Su
			1	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20	21	22	23	24	25
26	27	28	29	30		

May

Mo	Tu	We	Th	Fr	Sa	Su
31					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

June

Mo	Tu	We	Th	Fr	Sa	Su
	1	2	3	4	5	6
7	8	9	10	11	12	13
14	15	16	17	18	19	20
21	22	23	24	25	26	27
28	29	30				

1. First became aware of symptom(s): ____/____/____

Decided symptom(s) may be serious: ____/____/____

Symptom Appraisal: ____ days

2. First decided to seek medical help: ____/____/____

Illness Delay: ____ days

3. Arranged an appointment: ____/____/____

Behavioural Delay: ____ days

Action Appraisal: ____ days