

This electronic thesis or dissertation has been downloaded from the King's Research Portal at <https://kclpure.kcl.ac.uk/portal/>



The patterns and predictors of disease disclosure by patients with cancer

Munro, Heather Alison

Awarding institution:
King's College London

The copyright of this thesis rests with the author and no quotation from it or information derived from it may be published without proper acknowledgement.

END USER LICENCE AGREEMENT



Unless another licence is stated on the immediately following page this work is licensed

under a Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International

licence. <https://creativecommons.org/licenses/by-nc-nd/4.0/>

You are free to copy, distribute and transmit the work

Under the following conditions:

- Attribution: You must attribute the work in the manner specified by the author (but not in any way that suggests that they endorse you or your use of the work).
- Non Commercial: You may not use this work for commercial purposes.
- No Derivative Works - You may not alter, transform, or build upon this work.

Any of these conditions can be waived if you receive permission from the author. Your fair dealings and other rights are in no way affected by the above.

Take down policy

If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

VOLUME I

MAIN RESEARCH PROJECT & SERVICE EVALUATION PROJECT

Heather Munro

May 2012

Thesis submitted in partial fulfilment of the degree of
Doctorate in Clinical Psychology,
Institute of Psychiatry, Kings College London

ACKNOWLEDGEMENTS

I am extremely thankful to my placement supervisors - Catherine O'Leary, Kate Le Marechal, Claire Kenyon, Angela Costello, Rachael Buxey, Samantha Riches, Alex King and Amita Jassi - for providing supportive learning environments, and to my personal support tutor, Nicky Reynolds, for her guidance and support along the way. I would also like to express my appreciation of Sue Rutter for patiently organising, and dealing with the paperwork required for, various honorary contracts.

I am grateful to Dr Beth Grunfeld for helping to conceive my thesis study, to Dr Suzanne Scott and Dr Alex King who supervised me on the project and to Patrick Smith for his guidance on feasibility. Also I am grateful for the statistical advice provided by Daniel Stahl and to Carole Barnham for always being so helpful with the administrative elements.

Recruitment would not have been possible without the consultants - Karen Harrison-Phipps, Juliet King, Tom Routledge, Loic Lang-Lazdunski, and John Pilling working in lung cancer; Mark George and Vivek Datta working in colorectal cancer; and Katharine Acland and Mary Wain working in skin cancer - who gave me permission to access their patients, and the nurse specialists - Sophia Holden, Jason Simons, Rebecca Myatt, Claire McGilly and Roni Cummings - who assisted with this at the ground level, and a special thanks to Danuta Orlowska who recruited directly from the Melanoma Clinic's. I must also thank the administrators, Debby Millard and Morag McGuire, who always kept an eye out for my post and stored it securely for me, and Mike Cox for his help with extracting names from the database.

I am eternally grateful to the patients that took part in the study, and to the people I have worked with clinically, as without them I would not have been afforded such rich learning opportunities.

Finally, but by no means least, I sincerely thank my colleagues, friends and family for helping me along the way.

CONTENTS

PART A: MAIN RESEARCH PROJECT

The patterns and predictors of disease disclosure by patients with cancer

Supervisors: Dr Suzanne Scott

Dr Alex King

Pages 4 – 150

PART B: SERVICE EVALUATION PROJECT

A description of the psychological well-being of the first forty patients to complete a pre-orthognathic psychology assessment in a Cleft Service

Supervisor: Dr Catherine O'Leary

Pages 151 – 206

PART A

MAIN RESEARCH PROJECT

**The patterns and predictors of
disease disclosure by patients with
cancer**

Heather Munro

Supervisors:
Dr Suzanne Scott
Dr Alex King

ABSTRACT

Previous qualitative research has identified that disclosing a diagnosis to loved ones, is one of the hardest aspects of having cancer (Hilton et al, 2009). Although there is an extensive literature on disclosure of general information about the self, less is known about the extent to which people go on to talk about their diagnosis and the helpfulness of such disclosure within the specific context of cancer. Therefore the current study aimed to quantify disclosure patterns by measuring the degree of disclosure as well as the perceived helpfulness of disclosure. It also sought to determine the factors associated with disclosure and helpfulness of disclosure. The study was a cross-sectional postal questionnaire survey of 120 patients who had recently received a diagnosis of either lung, colorectal or skin cancer. Results indicated that the majority of patients disclosed to a variety of social targets, and most found it helpful to disclose. 'Dispositional openness' and 'perceived social support' were found to predict the extent of disclosure, as well as the helpfulness of disclosure. The results suggest that individual differences and situational factors may impact on disclosure and that medical professionals may play an important role in the disclosure process. With reference to the limitations, directions for future research are discussed, as well as the implications for clinical practice.

TABLE OF CONTENTS

1.0 INTRODUCTION	10
1.1 CANCER	10
1.2 INCIDENCE & PREVALENCE	10
1.3 CANCER TREATMENTS	11
1.3.1 Surgery	11
1.3.2 Chemotherapy	12
1.3.3 Radiotherapy	12
1.4 RECEIVING A CANCER DIAGNOSIS.....	13
1.5 PSYCHOLOGICAL IMPACT OF CANCER.....	14
1.5.1 Prevalence of anxiety & depression.....	15
1.5.2 Positive growth from cancer	17
1.5.3 Adjustment to cancer	18
1.6 DEFINING AND MEASURING DISCLOSURE.....	20
1.6.1 Theories offering a framework for disclosure.....	21
1.6.2 Theories developed for, and applied to, health-related disclosure.....	23
1.7 IS DISCLOSURE BENEFICIAL?	26
1.7.1 Is disclosure beneficial in the context of cancer?.....	28
1.8 DEGREE OF DISCLOSURE AND HOW IT UNFOLDS IN CANCER	31
1.8.1 Method of telling.....	32
1.8.2 Important confidants & content of disclosures	32
1.8.3 Patterns of family communication	33
1.8.4 Disclosure in the workplace	34
1.8.5 Avoidance, obligations & selective disclosure	34
1.8.6 Summary	35
1.9 PREDICTING DISCLOSURE	35
1.9.1 Demographic factors	36
1.9.2 Characteristics of the disease	37
1.9.3 Social support & unsupportive social interactions.....	38
1.9.4 Stigma	40
1.9.5 Psychological distress	41
1.9.6 Individual differences & disposition to disclose.....	42
1.10 SUMMARY	42

1.11 AIMS & HYPOTHESES	43
2.0 METHODS	45
2.1 DESIGN	45
2.2 SAMPLE	45
2.3 PROCEDURE	46
2.4 PILOTING	47
2.5 ETHICAL CONSIDERATIONS	47
2.6 MEASURES	48
2.6.1 Disease disclosure patterns: outcome variables	48
2.6.2 Predictors of disclosure	51
2.7 STATISTICAL ANALYSES	54
2.8 POWER CALCULATION	55
2.8.1 A Priori Tests	55
2.8.2 Post Hoc Tests	55
3.0 RESULTS	56
3.1 RESPONSE RATE	56
3.2 SAMPLE CHARACTERISTICS	57
3.2.1 Disease-related information	59
3.2.2 Perceived social support.....	59
3.2.3 Unsupportive social interactions	59
3.2.4 Perceived stigma	60
3.2.5 Psychological distress	60
3.2.6 Dispositional openness.....	61
3.3 PRELIMINARY ANALYSES	61
3.4 DISCLOSURE PATTERNS	61
3.4.1 Question 1) To what extent do patients with cancer talk about their diagnosis across a range of social targets?	61
3.5 QUESTION 2) IS IT HELPFUL TO TALK?	64
3.5.1 Quantitative responses	64
3.5.2 Qualitative responses	64
3.5.2.1 Reasons why talking is helpful	64
3.5.2.2 Reasons why talking is unhelpful	67
3.6 QUESTION 3) WHAT FACTORS ARE ASSOCIATED WITH THE DEGREE OF DISCLOSURE?	69

3.6.1 Univariate analyses	69
3.6.2 Multivariate analyses	72
3.7 QUESTION 4) WHAT FACTORS ARE ASSOCIATED WITH HELPFULNESS OF DISCLOSURE?	73
3.7.1 Univariate analyses	73
3.7.2 Multivariate analyses	75
4.0 DISCUSSION	76
4.1 FINDINGS	76
4.1.1 Psychological characteristics of the sample	76
4.2 DISCLOSURE PATTERNS	78
4.2.1 To what extent do patients with cancer talk about their diagnosis across a range of social targets?	78
4.2.2 Is it helpful to talk?	81
4.2.3 What factors are associated with the degree of disclosure?	83
4.2.4 What factors are associated with the helpfulness of disclosure?	86
4.3 LIMITATIONS	87
4.4 FUTURE RESEARCH	90
4.5 IMPLICATIONS	92
4.5.1 Implications for theory	92
4.5.2 Implications for clinical practice	93
4.6 CONCLUSIONS	96
REFERENCES	97
APPENDICES	122
APPENDIX 1 - Recruitment Cover Letter	122
APPENDIX 2 - Participant information sheet	123
APPENDIX 3 - Questionnaire	125
APPENDIX 4 - Follow-up reminder letter	135
APPENDIX 5 - Letter summarising the results of the study	136
APPENDIX 6a - Ethics Committee Approval Letter	137
APPENDIX 6b - Ethics Committee Approval of Amendment	142
APPENDIX 7 - Research Governance Approval Letter	146
APPENDIX 8 - Correlations	148
APPENDIX 9 - Scatterplots	149
APPENDIX 10 - Guidance for Cancer Specialists	150

LIST OF TABLES

Table 1.	Demographic Characteristics of a Sample of Patients with Lung, Colorectal and Skin cancer.....	58
Table 2.	Unsupportive Social Interactions Inventory Scores in a Sample of Patients with Lung, Colorectal and Skin Cancer.....	60
Table 3.	Hospital Anxiety and Depression Scale scores in a Sample of Patients with Lung, Colorectal and Skin Cancer.....	60
Table 4.	Frequencies, Percentages and Mean Degree of Disclosure Reported by Patients with Cancer across a Range of Social Targets.....	63
Table 5.	Percentages and Mean Degree of Disclosure Reported by Patients with Cancer Across Social Categories.....	64
Table 6.	One-tailed Correlational Analysis Detailing the Relationship Between the Degree of Disclosure and Demographic, Disease-Related and Psychological Variables in a Sample of Patients with Cancer.....	70
Table 7.	Two-tailed Correlational Analysis Detailing the Relationship Between the Degree of Disclosure and Demographic and Disease-Related Variables in a Sample of Patients with Cancer.....	71
Table 8.	Results of the Kruskal-Wallis Tests Comparing the Degree of Disclosure Across the Categories Comprising Demographic and Disease-Related Variables in a Sample of Patients with Cancer.....	72
Table 9.	Summary of the Multivariate Hierarchical Regression Analysis for Variables Predicting the Degree of Disease Disclosure in Patients with Cancer.....	73
Table 10.	Results of each of the Univariate Logistic Regression Analyses for Psychological, Demographic and Disease-Related Variables Predicting the Helpfulness of Disclosure in a Sample of Patients with Cancer.....	74
Table 11.	Summary of the Multivariate Logistic Regression Analysis for Variables Predicting the Helpfulness of Disclosure in Patients with Cancer.....	75

LIST OF FIGURES

Figure 1.	Recruitment Flowchart.....	56
-----------	----------------------------	----

1.0 INTRODUCTION

This project is an investigation of disclosure in cancer. This section will provide an introduction by first describing cancer, its incidence and prevalence, treatments and their side effects, the psychological impact of cancer, and the positive growth and adjustment that occurs following a diagnosis. The topic of disclosure will then be introduced by considering how disclosure is defined and measured, and with reference to theoretical underpinnings. This will be followed by a consideration of whether disclosure is beneficial, first in general terms, then with specific reference to cancer-related disclosure. Finally, by considering the degree of disclosure in cancer, and the factors associated with it, this section will provide the background to the aims and objectives of this study.

1.1 CANCER

Cancer is a group of diseases characterised by excessive and abnormal cell division (Hughes, 1987). It can occur in any of the bodily organs and over 200 different types have been identified (Cancer Research UK, 2010). The tissue in which the cancer first occurs is known as the primary site and if it is not detected or treated effectively at this stage then it may spread to other parts of the body, via the bloodstream or lymphatic system, and become metastatic (Hughes, 1987). Since cancer spread has often occurred before the initial diagnosis has been made (McCready & MacDonald, 2006), metastases are the major cause of death from cancer (WHO, 2011).

1.2 INCIDENCE & PREVALENCE

Globally, the lifetime risk of developing cancer is now greater than 1 in 3, with the probability increasing with age, to the extent that three quarters of all cancers occur in those aged over 60 years (Cancer Research UK, 2011b). An estimated 10.9 million people are diagnosed each year, and 6.7 million die, making cancer one of the leading causes of death worldwide (WHO, 2011). In the UK, breast, lung, colorectal and prostate are the most common cancer types, accounting for over half (54%) of all new cases (Cancer Research UK, 2011a). In 2008, cancer was responsible for 1 in 4 (27%)

deaths in the UK and, although mortality rates have decreased by 20% in the last 20 years, incidence rates have increased by 25% over the same period. Given that there is a growing ageing population, it is likely that there will continue to be an increase in cancer prevalence throughout the UK. There was an estimated 2 million cancer survivors living in the UK in 2008, and this figure is set to rise by 3% each year, given improvements in the detection and treatment of cancer (Maddams et al., 2009). These statistics make cancer one of the most significant diseases of our times and has led the NHS to develop an investment plan, prioritising the treatment of cancer (Department of Health, 2000).

1.3 CANCER TREATMENTS

“Cancer and its management is now one of the most complex and demanding aspects of medicine.”

(Souhami & Tobias, 2002, p. 4)

Cancer costs the NHS in the region of £5.13 billion per year (Featherstone & Whitham, 2010). The highest cost burden is reported to coincide with the initial treatments and end of life care (Brown, Riley, Potosky, & Etzioni, 1999). The three main types of treatment for cancer are surgery, radiotherapy and chemotherapy, which can be used independently or in combination. These are outlined in sections 1.3.1 – 1.3.3. Other less common treatments include: endocrine therapies, which use hormones to treat cancers arising in organs that are influenced by hormones (e.g. breast, prostate, thyroid and uterus); biotherapy, which uses biological agents that operate on the body’s immune system causing it to destroy the cancerous cells; stem cell transplants, which involve implanting early blood cells, from which red and white cells as well as platelets can develop; and gene therapy, a currently emerging treatment that aims to destroy cancer by correcting genetic defects and/or manipulating genes (Cancer Research UK, 2012).

1.3.1 Surgery

Surgery brings the greatest chance of cure when the tumour is a solitary, well-defined mass that can be removed (McCready & MacDonald, 2006). When detected early, surgery is often the main cancer treatment (Macmillan, 2010) and an estimated 60% of

patients will undergo some form of tissue removal (Foulds, 2002). Typically there is a resection of the tumour to remove the cancerous tissue, as well as some of the surrounding healthy tissue, in order to create a safe margin. Surgery can be used prophylactically, to prevent cancer developing in any high-risk, non-vital tissue (e.g. removal of a healthy breast where there is a strong family history of breast cancer) and is used in a palliative context, to remove tissue that is causing excess pressure, undue pain and discomfort. Recovery time from surgery will vary, and immediate after effects can include pain, and the risk of wound infection or bloodclots (Macmillan, 2010).

1.3.2 Chemotherapy

Chemotherapy is a drug treatment which uses chemical agents to eradicate or control the growth of the cancer by restricting cells from dividing and reproducing. The treatment is systemic, in that it is applied to the entire body, and is most commonly administered intravenously. Chemotherapeutic drugs are highly toxic and are unable to discriminate between different cells meaning that they impact on both cancerous and healthy cells, particularly fast-dividing cells, such as hair follicles, bone marrow cells and cells lining the gut. As a result, patients commonly experience side effects including, hair loss, nausea, vomiting, diarrhoea, fatigue, altered taste, and have an increased susceptibility to infection, anaemia and clotting (McCready & MacDonald, 2006).

1.3.3 Radiotherapy

Radiotherapy uses ionizing radiation to destroy cancers locally at the site. The radioactivity causes cell death and again impacts on both cancerous and healthy cells, although the healthy cells will regenerate. Over 50% of patients will receive radiotherapy at some stage in their cancer treatment (McCready & MacDonald, 2006). Methods of delivery are via: external beams, whereby x-rays are presented at a distance from the skin surface and prevents skin damage; brachytherapy, which delivers the radiation directly onto the site of the cancer and affects the surrounding tissue; and orally or via injection. Immediately after therapy, patients commonly experience skin irritation and reactions which leave them feeling 'burnt' by therapy (McCready &

MacDonald, 2006). These reactions include erythema (skin reddening) and moist desquamation (outer layer of skin removal) which produce physical discomfort and impact more widely on one's body image and sexuality, as well as affecting everyday functioning and causing sleep disturbance (McCready & MacDonald, 2006). Other significant side effects associated with radiotherapy are fatigue, diarrhoea, skin soreness and infections (Nevidjon & Sowers, 2000).

1.4 RECEIVING A CANCER DIAGNOSIS

“Major disease brings anxiety and worry, but few diseases are associated with such dread as cancer, with its imagined inevitable sequel of certain death, pain, lingering and suffering.” (Souhami & Tobias, 2002, p. 98)

Given the mortality rates and the challenging course of some treatments, receiving a cancer diagnosis can be a frightening and shocking experience. The term ‘Cancer’ often has dreaded connotations and is commonly interpreted as being a ‘death sentence’ (Gordon, 1990; Maher, 1982; Muzzin, Anderson, Figueredo, & Gudelis, 1994). Historically, cancer was thought to be so devastating and horrific that medical staff would refrain from sharing the diagnosis with the patient (Oken, 1961), and this practice continues today in some countries including Italy (Gordon, 1990), Japan (Hosaka, Awazu, Fukunishi, Okuyama, & Wogan, 1999), Romania (Dégi, 2009) and various ethnic American cultures such as Korean, Chinese, Mexican, Hispanic and African (Mitchell, 1998). However, in the Western world the importance of disclosing a diagnosis to the patient has been recognised and it is now general practice that all patients are fully informed of their health status (Hodgkiss & Mascarenhas, 2012). This progression towards disclosure has resulted in the development of guidelines on how best to deliver the ‘bad news’ (Baile et al., 2000; Ellis & Tattersall, 1999; Girgis & Sanson-Fisher, 1995). Despite the body of literature on the ethical considerations that professionals have in disclosing a cancer diagnosis, comparatively little is known about how patients themselves then go on to disclose their diagnosis to others.

Receiving a life threatening diagnosis forces a person to confront their mortality (Lee, 2008), and can trigger an acute stress reaction involving an ‘existential plight’; a

significant and distressing time period where one is preoccupied by life/death concerns and must search for meaning that one's life has order and purpose (Weisman & Worden, 1976). A range of emotions may be aroused including fear, shock, disbelief, anger, bitterness, hostility, depression, and self-pity (Weisman & Worden, 1976). The complex crisis situation evoked on receiving a diagnosis is so powerful that it permeates all aspects of a person's functioning, including biological, psychological, social and spiritual domains (Dégi, 2009). Not only can it impact on an individual level, but the diagnosis and treatment often become a 'family affair', with the emotional demands having implications for how the family unit functions (Mor, Allen, & Malin, 1994). 'Cancer families' have been described to experience a 'social death' whereby they become isolated and cut-off from society (Muzzin et al., 1994). It has also been recognised that a significant minority of family members or partners, that become the key support for the cancer patient, will themselves experience clinical levels of distress and affective disorders (Pitceathly & Maguire, 2003).

1.5 PSYCHOLOGICAL IMPACT OF CANCER

With the development of psycho-oncology as a discipline, the psychological impact of cancer has been assigned greater importance in recent years (Greer, 1994). In fact, one medical textbook states that "...the psychological aspects of the disease are as important as the physical" (Souhami & Tobias, 2002, p. 100). One of the major difficulties cancer brings is a pervasive sense of loss; including loss of health, opportunities, choice and control (McCready & MacDonald, 2006). There may also be a sense of guilt, particularly if the person holds a belief that their own actions are responsible for their cancer development (Souhami & Tobias, 2002). 'Uncertainty' is another key factor that most patients will grapple with and permeates each stage of the disease process from before the initial diagnosis through to remission. There will be uncertainty surrounding how one will cope with treatment, whether treatment will be a success, how long it will take, the chance of recurrence and future outcomes of the illness. All of this uncertainty can lead to anxiety and depression (Grosser, 2003) with 'fear of recurrence' being particularly problematic for psychological well-being (Lee-Jones, Humphris, Dixon, & Bebbington Hatcher, 1997). 'Fear of recurrence' is said to be universally present regardless of prognosis (O'Neill, 1975) and can linger on for years plaguing cancer

survivors (Ferrell, Hassey Dow, & Grant, 1995). Even following successful treatment for breast cancer, either by mastectomy or breast conserving treatment, approximately 70% of women experience fear of recurrence (Meyer & Aspegren, 1989) and the completion of active treatment is now recognised as a particularly difficult time for patients that may incur a spike in anxiety levels (Maher, 1982).

1.5.1 Prevalence of anxiety & depression

Cancer and its treatments can result in many of the symptoms typically characteristic of depression, for example fatigue, low energy, and loss of appetite (Hughes, 1987). As a result, symptoms of depression can be difficult to distinguish (Deshields, Tibbs, Fan, & Taylor, 2006; Massie, 2004) and depression and anxiety are often undetected and untreated in cancer populations (Berard, 2001; Carlson et al., 2004; Fallowfield, Ratcliffe, Jenkins, & Saul, 2001). Despite this, studies have endeavoured to estimate the rates of depression, anxiety and thus distress in cancer patients. One of the first studies considering the prevalence of distress, in patients in the U.S., used structured interviews to assess 215 patients and found that 47% had a psychiatric disorder meeting DSM-III criteria (Derogatis et al., 1983). A U.K. study, using the Hospital Anxiety and Depression Scale (HADS) with a sample of 1260 patients, found that 23% suffered from anxiety and/or depression (Greer et al., 1992). This has led to the estimation that 23-40% of cancer patients will experience clinically significant levels of anxiety and depression (Greer, 1994). Furthermore, 90% of these occur where there has been no history of psychiatric disorder and so are thought to be a direct result of the diagnosis and treatment of cancer (Shakin, Heiligenstein, & Holland, 1991).

A meta-analysis which reviewed 58 studies, carried out between 1980 and 1994, found that although cancer patients were significantly more depressed than the normal population, there was no difference in terms of anxiety and psychiatric disorders (van't Spijker, Trijsburg, & Duivenvoorden, 1997). Moreover, when compared to a psychiatric population, cancer patients had significantly less psychological and psychiatric problems. Interestingly, when comparing studies carried out before 1988, with those published after 1987, significantly less distress was reported in the more

recent studies. The authors posit that this may be due to advancements in patient education, treatments, and awareness leading to earlier detection and better prognosis.

More recent studies have reported a variety of prevalence estimates of depression in cancer patients: Berard (2001) has suggested that 15-20% of cancer patients are depressed; a large scale community study of 5000 adults found an increased likelihood of depression (odds ratio=3.6) in those diagnosed with cancer in the previous year (Honda & Goodwin, 2004); and 10% of a breast cancer sample had major depression on completion of chemotherapy (Morasso et al., 2001). A review of 100 studies, concluded that the prevalence of depression in cancer patients ranges from 0 – 58% (Massie, 2004).

One reason for the range of prevalence estimates is that studies have measured distress at a variety of single time points in the cancer experience (van't Spijker et al., 1997) and distress fluctuates over time (Avery & Weisman, 1979; Zabora et al., 1997). A prospective study looking at distress levels in men with prostate cancer found that low-moderate rates of distress were common at diagnosis, and around the time of treatment decision, but that distress decreased after treatment with only a minority (12%) remaining distressed beyond treatment (Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2004). These authors suggest that distress was more related to diagnosis than treatment per se. Deshields et al (2006), have explored how depression varies over time by assessing breast cancer patients at several points; at the conclusion of treatment, and then again at 3 and 6 months later. They identified 5 patterns following treatment cessation: 1) 'stay depressed', 2) 'recover', 3) 'become depressed', 4) 'never depressed', and 5) 'vacillate'. They found that those who experienced depression were more likely to also be anxious, and those who had never had depression had better quality of life. Interestingly, the majority of patients (61%) fell into the 'never depressed' group, suggesting again that most patients are resilient to the effects of cancer and do not experience clinically significant psychological distress.

At the time of diagnosis, the level of psychological distress appears to be unrelated to the physical aspects of the disease such as diagnostic and prognostic factors (Cella, Mahon, & Donovan, 1990; Mor, 1987). Rather, cancer-related emotional distress has been suggested to arise from the individuals' appraisals of the personal meaning of the

cancer as well as the available resources for coping (Folkman & Greer, 2000). An example of this is the consistent finding that younger patients experience greater levels of distress than older patients (Edlund & Sneed, 1989; Mor et al., 1994; van't Spijker et al., 1997); this has been suggested to be a result of a cancer diagnosis, and the possibility of dying, not fitting with the current 'life-cycle phase' of younger patients (Brown, 1989).

Overall, reviews suggest that the majority of cancer patients do not experience more psychological distress (indexed by anxiety and psychiatric disorders) than the normal population, but they do experience higher levels of depression. However, given that most studies consider group mean scores, it is still possible that a small proportion of cancer patients may suffer clinically significant problems (van't Spijker et al., 1997). Importantly, the psychological distress associated with the process of trying to make sense of the cancer, and searching for meaning, is considered a difficult but normal part of adjusting to a life threatening illness (Greer, 2008; Lee, 2008).

1.5.2 Positive growth from cancer

Cancer does not just have the potential to leave a legacy of pain and upset but has also been associated with a range of positive outcomes. Historically the focus of research has been on negative psychological states rather than examining positive states and well-being (Diener, Suh, Lucas, & Smith, 1999). This tendency to focus on distress and dysfunction has been criticised for providing a misleading picture of the cancer experience (Cordova & Andrykowski, 2003), particularly as adjustment to cancer can also involve positive outcomes, evidenced by the fact that many patients cope well with the experience of cancer (Brennan, 2001). Moreover, critics suggest that cancer should be viewed as a psychosocial transition that provides the opportunity for both post-traumatic growth as well as post-traumatic stress, and at times these may co-occur (Cordova & Andrykowski, 2003).

A spectrum of positive changes have been noted to arise in response to a potentially negative experience, including: 1) changes in self-perception, 2) changes in interpersonal relationships, and 3) changes in life philosophy (Tedeschi & Calhoun,

1996). A common consequence of traumatic events is for people to reappraise themselves as being more confident and better able to cope. Indeed, patients with cancer have reported feeling 'stronger' and more 'self-assured' following their experience of the disease (Collins, Taylor, & Skokan, 1990). A study investigating post-traumatic growth after breast cancer, found that patients, and their partners, experienced growth shortly after diagnosis and it increased over the following 1.5 years (Manne et al., 2004). Elements of growth included closer relationships with others, greater appreciation of life, better recognition of personal qualities and strengths, and a more developed spiritual understanding. These authors conclude that post-traumatic growth is common with 60-90% of cancer survivors reporting positive changes.

1.5.3 Adjustment to cancer

A major task following a life-threatening diagnosis is to master the challenge of 'adjustment', defined as a psychological process whereby 'the individual, and those in their social world, manage, learn from and adapt to the multitude of changes which have been precipitated by the illness and its treatment' (Brennan, 2001, p. 1). A diagnosis of cancer is not something that is ordinarily built into a person's beliefs about themselves, their life and the world, and so when it occurs it can threaten fundamental assumptions (Moorey & Greer, 2002) and shake the person's internal working model of the world (Brennan, 2001). When this fracturing and unsettling of one's beliefs occur, the notion of cancer must either be 'assimilated' (where new information is merged into existing assumptions) or 'accommodated' (where existing assumptions are modified to incorporate the new information) to regain an equilibrium (Brennan, 2001).

Watson and colleagues (1988) have identified five different adjustment or coping styles used in response to cancer, these are: 'denial/avoidance', 'fighting spirit', 'fatalism', 'helplessness/hopelessness' and 'anxious preoccupation'. Some styles have been found to be more functional than others. For example 'fighting spirit' has consistently been associated with healthier outcomes and lower levels of distress (Watson et al., 1991) whereas 'helplessness/hopelessness' has been linked to increased levels of distress (Burgess, Morris, & Pettingale, 1988; Osborne, Elsworth, Kissane, Burke, & Hopper, 1999). The strategy of 'denial' has evoked mixed results, with some studies linking

denial to lower psychological distress (Watson, Greer, Blake, & Shrapnell, 1984) and others finding the absence of a relationship between denial and distress (Nelson, Friedman, Baer, Lane, & Smith, 1989). To explain these contradictory findings, it has been speculated that denial is perhaps a useful strategy in the short term, as it helps defend against intolerable feelings (Lloyd, 1977). However in the long term, such as is the case with an enduring condition like cancer, acceptance of the situation is important for adjustment (Brennan, 2001) and talking with a supportive other may facilitate this (Lepore, 2001).

It is suggested that following the diagnosis, most people will be able to re-establish their 'pre-cancer emotional equilibrium' (Brennan, 2001). The Social Cognitive Processing Model of emotional adjustment to cancer (Lepore, 2001), purports that people achieve adjustment by talking about their trauma to others. Talking to a supportive other is thought to be crucial in facilitating cognitive processing as it: enables contemplation and discussion of thoughts and feelings; allows for empathy and validation which serve to maintain one's self-concept; reaffirms that one is loved and esteemed (Albrecht & Adelman, 1987); helps regain a coherent world view (Janoff-Bulman, 1992); provides new information, positive perspectives, and offers ways to cope; and helps the person accept the situation and consolidate the traumatic memory (Lepore, Ragan, & Jones, 2000). Thus, according to this model, talking is considered crucially important in making the adjustment to a cancer diagnosis and it highlights the relevance of investigating the extent of disclosure, such as how much the diagnosis is talked about, and whether emotions are expressed in cancer.

Preliminary qualitative research in this field has identified that, for patients, disclosing their diagnosis to loved ones is one of the hardest aspects of having cancer (Hilton, Emslie, Hunt, Chapple, & Ziebland, 2009; Yoo, Aviv, Levine, Ewing, & Au, 2009). Currently, patients must proceed with such disclosures relatively independently since there are no official structures for supporting people with this difficult task. Given the paucity of research in this area, it is first necessary to understand and quantify current patterns of disclosure and its potential determinants before developing effective ways of supporting the process.

1.6 DEFINING AND MEASURING DISCLOSURE

The research into disclosure in cancer remains in its early stages. There have been several qualitative studies examining the process and some quantitative studies have attempted to measure disclosure patterns. They have commonly used the following definition of disclosure; ‘the extent to which cancer patients openly discuss with others their diagnosis and thoughts and feelings about their disease’ (Figueiredo, Fries, & Ingram, 2004; Henderson, Davison, Pennebaker, Gatchel, & Baum, 2002; Hilton et al., 2009; Porter, Keefe, Hurwitz, & Faber, 2005). However, attempts to measure disclosure across health conditions have revealed its complex and multifaceted nature. Careful definition is required since there are many nuances to the concept (Ellison, Russinova, MacDonald-Wilson, & Lyass, 2003); these include who is told, when they’re told and what they’re told, partial versus full disclosure, disclosure to some as well as non-disclosure to others, the possibility that disclosure may not necessarily be a deliberate act (chosen versus brought about), and that disclosure may be verbal or more subtle via behaviours. Added to the complexity is the idea that disclosure is not an individual act but involves a dyadic interaction where there will be responses, questions and concerns (Moskowitz & Roloff, 2007). Such reactions can be extremely important since they influence how patients manage subsequent disclosures (Yoo et al., 2009). There are a variety of disclosure options that lie between the ‘extremes of flagrant self-exposure and fearful hiding’ (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000, p. 274). Qualitative studies have identified strategies whereby people tend to carefully manage their disclosure (Gray et al., 2000), and divulge information on a ‘need to know’ basis (Munir, Leka, & Griffiths, 2005). Charmaz (1993) has distinguished between ‘protective’ disclosure which is void of emotions and purely provides factual information, and ‘spontaneous’ disclosure which involves freely expressing oneself in an authentic way. Thus there are a variety of disclosure behaviours which may be apparent and it is important to try to capture these disclosure patterns quantitatively. One way this has been done is by using self-report methods to measure the extent to which people have talked to a range of social targets (Figueiredo et al., 2004; Henderson et al., 2002; Pistrang & Barker, 1992).

1.6.1 Theories offering a framework for disclosure

Disclosure may be viewed as a planned behaviour (Greene, 2009) or coping mechanism (Holt et al., 1998), motivated by attempts to prevent stigma (Beatty, 2004), reconcile a new identity and enhance one's self-concept (Lepore, 2001), or to elicit support, care and information (Roberts, Lepore, & Helgeson, 2006).

Several theoretical models provide an overarching framework for thinking about disclosure and most involve a social element. For example, Social Exchange Theory (Blau, 1964; Emerson, 1962, 1976; Homans, 1958, 1961) provides a concept of social behaviour based on exchange. It posits that people avoid costly interactions and seek rewarding ones in order to maximise the profits gained from interpersonal communications. The key assumption is that, when forced with numerous choices, people will choose the actions that provide the most rewards and least associated costs. This theory bridges disciplines of anthropology, social psychology and sociology and has been most influential in explaining workplace behaviour (Cropanzano & Mitchell, 2005) as well as being applied to understand cultural ideas and social norms around gift-giving and marriage (Befu, 1977). The theory has not been directly applied to cancer-related disclosure, however the ideas of social exchange may apply to disclosure decisions whereby there is a careful balancing act of weighing up the perceived costs and benefits, with disclosure occurring at the point when the perceived rewards outweigh the costs (Serovich, 2001). These notions have been incorporated into theories of HIV disclosure which are discussed in the next section.

Social Penetration Theory (SPT: Altman & Taylor, 1973) may also be relevant since it suggests that an individual is comprised of multiple layers of information; with deep seeded values, beliefs and experiences being at the core and demographic and conspicuous information being closer to the surface. The theory posits that as relationships develop, more layers will be exposed, explored, and shed through self-disclosure, such that the more time spent with others the more one will disclose. Research into disclosure has not applied this theory (Petronio, 2004) and it has been criticised for being over-simplistic and neglectful of the range of factors, such as gender, ethnicity and culture, that may also impact on the degree of self disclosure.

Social Comparison Theory (Festinger, 1954; Schacter, 1959) predicts that in times of stress, people will look to others, who are similar to themselves, for comparison information. The dimensions of similarity in the comparison person include whether they have similar attitudes and personality, as well as whether they have experienced or are experiencing the same situation. It is thought that one turns to similar people because they will provide the most relevant information for making an accurate judgement of how to respond. This theory has mainly been researched in relation to self-evaluation and self-enhancement (Wills, 1981) and has not been considered by disease-disclosure research. However, in the context of cancer disclosure it would suggest that an important confidant for the patient may be those who have similarly experienced cancer before.

Communication Privacy Management Theory (CPM: Petronio, 2002) concerns the way information is managed. It suggests that disclosing private information can leave people feeling vulnerable and in turn metaphorical boundary structures are set up to separate those who are privy to the information from those who aren't. In order to determine whether information is shared beyond the boundary, or protected within, a rules-based management system is used to govern how rigid the boundaries are. Such rules are built up between people, over time, and are based on a number of criteria including: cultural values about privacy; personal motivations and preferences for sharing information; situational factors; gender; and the cost of revealing (Petronio & Caughlin, 2006). The process of deciding whether to disclose or conceal information has been described as calculus since it involves a careful calculation of the rules. CPM theory has been fine-tuned over the course of Petronio's 30 year career and has been informed by qualitative accounts provided by her students and colleagues on how information flow is managed within families (see Petronio, 2004). The theory has seen several iterations and has received confirmation from qualitative studies (e.g. Petronio, Sargent, Andea, Reganis & Cichocki, 2004). The theory has not been directly tested in a quantifiable way, but rather a translational research approach has been used (Petronio, 2007) in applying the theory to understand family dynamics (Afifi, 2003), the disclosure of childhood sexual abuse (Petronio, Reeder, Hecht & Mon't Ros-Mendoza, 1996), and the disclosure of HIV status (Cline & McKenzie, 2000). Thus, although the theory has not been applied specifically to disclosure of a cancer diagnosis, it has obvious

relevance as a guiding framework and offers a significant heuristic in understanding the process of revealing and concealing private information (Petronio, 2004).

1.6.2 Theories developed for, and applied to, health-related disclosure

Several theories have been developed specifically in the service of understanding disclosure of health conditions. With the exception of one (the Social Cognitive Processing Model), these have largely been developed and applied to disclosure in the context of HIV. These will be discussed in turn.

The Social Cognitive Processing Model of Emotional Adjustment, mentioned earlier, has been used to understand the social influences on adjustment to life crises, such as bereavement (Lepore, Silver, Wortman, & Wayment, 1996), and has also been specifically applied to cancer (Lepore, 2001). The theory explains how people use talking to others about their disease as a way of processing the information, adjusting and adapting to it (Lepore & Helgeson, 1998). Talking through thoughts and feelings with others may help people confront ‘why me’ questions and insight from others may help the person to construct meaning (Redd et al., 2001). Having social support and opportunities to safely disclose information about cancer may increase the person’s ability to assimilate or accommodate their cancer experience (Roberts et al., 2006). On the other hand, the theory suggests that constraints on the ability to disclose can impede cognitive processing and adjustment (Lepore, 2001). A number of empirical studies have provided support for this social-cognitive processing model in cancer groups. For example, in a cross-sectional study of 178 good-prognosis prostate cancer survivors, a subset of men reported constraints on their ability to talk with significant others about their cancer. These men also reported more cancer-related intrusive thoughts and were more likely to avoid thinking and talking about their cancer, when compared to their peers who experienced less constraints in talking (Lepore & Helgeson, 1998). Moreover, constraints on talking potentiated the positive association between intrusive thoughts and poor mental health. A more rigorous longitudinal study of 100 women with either breast or colon cancer also confirmed that intrusive thoughts are associated with an increase in negative affect in those with high social constraints, but are unrelated to negative affect in those with relatively few social constraints (Lepore,

1997). Thus these studies are particularly supportive of the notion that constraints on disclosure impede healthy adjustment and suggest that this aspect of the theory does apply in cancer populations.

Several theories have arisen in the context of HIV status disclosure. In particular Disease Progression Theory suggests that as people become increasingly ill and require more hospitalisations, the disease progression mandates individuals to explain their illness (Babcock, 1998; Kalichman, 1995). Studies using various indices of disease progression have provided support for this theory in relation to HIV disclosure to friends and families. For example, in Hispanic men, disclosure to others increased with increasing levels of overall symptom severity (Marks, Bundek, Richardson, Ruiz, Maldonado & Mason, 1992) and symptomatic men have been found to be more likely to disclose their HIV status to friends and family than asymptomatic men (Hays et al., 1993). However, studies of disease progression and HIV disclosure to sexual partners have failed to find this relationship (Mansergh et al. 1995), leading Serovich (2001) to propose The Theory of Competing Consequences. This theory suggests that the relationship between disease progression and disclosure is moderated by the consequences one anticipates from disclosing. Serovich (2001) tested both Disease Progression Theory and The Theory of Competing Consequences in a sample of 138 men with HIV, using quantitative measurement and structural equation modelling, and found little evidence for Disease Progression Theory. She recommended that researchers focus on the intentions and consequences of disclosure as predictive factors. Serovich and colleagues (2008) revisited these theories in a sample of 125 women with HIV and found further support for the Theory of Competing Consequences, in particular, 15% of the variance in disclosure was explained by the perceived consequences of disclosure. Serovich concluded that, prior to disclosing, women carefully evaluate the risks and benefits, and in particular the reward associated with disclosing (notions also consistent with Social Exchange Theory).

The Disclosure Decision-Making Model (DD-MM; Greene, 2009) is an integrated model of health information sharing that focuses on how people make the decision to reveal or conceal. The model applies to both physical and mental health information and aims to predict the likelihood of disclosure, viewing it as a planned behaviour. The model posits three stages prior to disclosure occurring: the first involves assessing the

information, followed by an evaluation of the potential receiver (including relational quality and anticipated response) and finally there is an exploration of perceived disclosure efficacy. The DD-MM argues that disclosures are encouraged or discouraged by the relative evaluation of these factors and the person may exit the model at any stage should they make the decision to conceal. Importantly the model also acknowledges interruptions to planned disclosures which may bring about ‘unplanned’ disclosure such as third parties becoming involved with spreading the information, questions from others and reciprocity of recipients. Although the DD-MM possesses face-validity it has been criticised for failing to theorise about the interrelations between successive parts of the disclosure process and why disclosure may be beneficial (Chaudoir & Fisher, 2010). It has not been applied in the context of cancer, but studies have begun to test the theory in other health conditions. For example research with 203 patients diagnosed with heart-related conditions confirmed that the three stages of the DD-MM (i.e. assessing information, receiver and efficacy) are related to the depth, breadth and frequency of disclosure (Checton & Greene, 2012). Moreover, in a sample of 187 participants with significant non-visible physical or mental health conditions, variables representing ‘information assessment’, ‘anticipated response’, ‘relational quality’ and ‘disclosure efficacy’ each explained sufficient variance in the likelihood of disclosure (Greene et al., 2012). Thus there is mounting evidence supporting the model in other health conditions.

Finally, the Disclosure Processes Model (DPM; Chaudoir & Fisher, 2010) is the most recent to advance ideas about *when* and *why* disclosure may be beneficial in relation to concealable stigmatised identities. It suggests that the disclosure process involves antecedent goals, the disclosure event itself, mediating processes and outcomes, and a feedback loop. It specifies that the goals of disclosure (i.e. one’s motivations to approach or avoid disclosure) will moderate the effect on multiple disclosure outcomes, which are mediated by three distinct processes: 1) alleviation of inhibition, 2) social support, and 3) changes in social information. As such, this complex framework advances current theory by offering some elucidation of the mediating mechanisms involved in disclosure and it also considers the outcomes or consequences of disclosure (ways in which disclosure can be beneficial or detrimental to well-being) which previous theories have overlooked due to them viewing disclosure behaviour as the endpoint. The DPM has not been applied in cancer but a systematic review of the

existing HIV disclosure literature involving 210 studies found support for the notion that motivations around disclosure do predict disclosure likelihood in a pattern consistent with activation of approach versus avoidance goals (Chaudoir, Fisher & Simoni, 2011). This review also found evidence for the notion that aspects of the disclosure event can affect outcomes such as psychological distress and sexual risk (Hays et al. 1993). However, the state of the HIV research, largely formed of cross-sectional studies and measuring single episodes of disclosure, means that there is no existing evidence on how single disclosures might affect subsequent disclosure via a feedback loop. In the context of HIV, Chaudoir and colleagues recommend that empirical research should focus on the likely consequences of disclosing so that strategies can be designed to help people with the challenges that arise.

1.7 IS DISCLOSURE BENEFICIAL?

Before considering disclosure in the context of cancer, it is helpful to consult the wider literature surrounding disclosure. An extensive body of research has accumulated with a focus on revealing personal information or secrets about the self, in relation to past trauma's or negative experiences. Self-disclosure is typically defined as 'the act of revealing personal information about oneself to another' (Collins & Miller, 1994, p. 457). In the therapeutic field, Freud's early psychoanalytic work (1913/1958), was based on the premise that open expression about one's innermost secrets was important for therapeutic success. As a result, talking therapies are founded on the assumption that talking helps people work through their difficulties. Thus the notion that it is helpful to talk freely about oneself has gained momentum and it is now generally accepted that it is better to 'get things off your chest'; this knowledge is incorporated in the adage that 'a problem shared is a problem halved'.

There is now mounting experimental and clinical literature pointing towards the value of disclosing information about oneself. Self-disclosure is considered vital in the development and maintenance of relationships (Stokes, 1987). It facilitates free-flowing social communications essential for in-depth conversations. In contrast concealment leads to awkward and stilted interactions, conversation is reduced to superficial levels, and renders relationships more shallow (Smart & Wegner, 2000) and dissatisfying

(Caughlin, 2004). A meta-analytic review has identified several links between self-disclosure and liking, whereby 1) those who engage in more intimate disclosures are liked more than those who do not; 2) people disclose more to those they like; and 3) people like others as a result of having disclosed to them (Collins & Miller, 1994). Self-disclosure is thought to nurture ‘interpersonal solidarity’; a feeling of closeness between two individuals that comes from sharing common interests or characteristics (Wheeless, 1978). Thus disclosure serves an important function in the formation of meaningful relationships. It has also been linked to physical health, whereby disclosure of traumatic experiences can lead to better immune functioning and better health in the long term (Pennebaker, Kiecolt-Glaser, & Glaser, 1988a).

On the other hand, non-disclosure (differentially referred to as concealment, repression, inhibition, secrecy and topic avoidance) is generally considered an unhelpful strategy since it requires constant vigilance in social interactions, which has a significant psychological cost (Smart & Wegner, 2000). Importantly, it is noted that ‘secrecy’ is not just the converse of disclosure (Collins & Miller, 1994) but rather it is an active process which requires cognitive resources and can be experienced as an emotional burden (Lane & Wegner, 1995; Wegner, Lane, & Dimitri, 1994). Engaging in deceptive practices involves constantly having to monitor what is said in conversation, being aware of who knows what and how much they know, and edit what is said to whom accordingly (Smart & Wegner, 2000).

Smart & Wegner (2000) have written about the challenges of concealing an invisible stigma, such as a physical illness, where one can choose whether or not to disclose the information. They suggest that concealment creates an ‘inner turmoil’; an internal struggle which can create anguish and lead to psychopathology. They explain how these effects arise by drawing upon the thought suppression literature, where it is well established that in trying to suppress unwanted thoughts (such as those associated with a secret or concealable stigma) they will paradoxically become hyper-accessible. The salience of suppressed thoughts mean they are more likely to intrude into conscious awareness, rendering it very difficult to maintain secrecy. These notions are captured in the ‘preoccupation model of secrecy’ (Lane & Wegner, 1995) where it is suggested that unwanted thoughts about the stigma will be held in mind thus enabling them to permeate one’s judgements and behaviours. So although a person may think they are

hiding their stigmatised identity, the associated (suppressed) thoughts may still influence their perceptions and actions without realisation (Smart & Wegner, 2000). The mental effort required to maintain secrecy becomes burdensome and can impact on one's day-to-day functioning. Thus concealment can be problematic for the individual. Pennebaker's work (1986; 1987; 1988b) has indeed identified that those who inhibit disclosure have more anxiety and lower emotional well-being than those who freely disclose.

Although much of the literature suggests disclosure is beneficial and non-disclosure is detrimental, Kelly and McKillop (1996) provide a more balanced view suggesting that there may be circumstances when it is better to conceal information. In particular, they suggest that the reactions received from the confidant can be critical in determining whether the person will benefit from the disclosure. They highlight the possibility that the discloser may receive unsatisfactory responses, rejection and negative feedback which may lead the person to construct a negative identity. Thus it is important to acknowledge that there may be times when concealment is protective. This is particularly true of disclosing psychiatric diagnoses or chronic illness in the workplace (Allen & Carlson, 2003; Beatty, 2004; Dalgin & Gilbride, 2003; Ellison et al., 2003; Goldberg, Killeen, & O'Day, 2005; Munir et al., 2005; Stewart et al., 2001) and may be crucial if one wants to engage in a social life (Smart & Wegner, 2000).

1.7.1 Is disclosure beneficial in the context of cancer?

An early review, of over 200 clinical papers, written between 1966 and 1986, recognised the importance of effective communication in cancer and suggested that one of the major communication issues for patients is around disclosing feelings (Northouse & Northouse, 1988). There is now mounting empirical evidence of the salutary effects of disclosure in cancer whereby it harnesses social support, leads to lower levels of psychological distress and a better quality of life for the patient (Porter et al., 2005). Women with breast cancer reported that through talking they received advice and information from others, and felt closer to the people they had told (Stewart et al., 2001). In line with the Social Cognitive Processing Model (Lepore, 2001), disclosure allows the individual to process cancer-related concerns, provides opportunities for

validation and helps find meaning in the experience, which facilitates adjustment (Lepore & Helgeson, 1998; Lepore, Silver, Wortman, & Wayment, 1996). Moreover, it has been suggested that allowing patients to talk to nurses is beneficial, even when no answers are given and nurses are purely used as a ‘sounding board’ (Quinn, 1999). Semi-structured telephone interviews with 35 survivors of prostate cancer, found the men to report an increase in positive emotions, a sense of relief and reduction of worries after disclosing (Jackson et al., 2010). Open communication between spouses, about cancer-related concerns, has been found to be associated with better marital and psychological adaptation for both parties (Kornblith et al., 2006; Manne et al., 2006). A questionnaire based study which looked at the level of ‘relationship talk’ (talk about the nature and state of one’s relationship), between patients recently diagnosed with lung cancer and their spouses, found that couples who reported more frequent relationship talk had less distress (effect size $r=0.16$) and better marital adjustment over time (effect size $r=0.21$; Badr, Acitelli, & Carmack Taylor, 2008). These authors suggest that people who begin talking about the impact of the cancer on the relationship early on will be better placed to face the challenges that the cancer brings as it progresses (Badr et al., 2008). Disclosing and unburdening negative feelings has also been linked to survivorship, since it was found that patients with breast cancer who were more communicative about their distress lived longer than those who were less able to express feelings of anger and depression (Derogatis, Abeloff, & Melisaratos, 1979). Moreover, the degree to which breast cancer survivors talked about their cancer in the past, predicted greater levels of personal growth (Cordova, Cunningham, Carlson, & Andrykowski, 2001a).

Although there is mounting evidence that disclosure is a productive and helpful process, self-concealment is commonly used by both staff and patients as a way of coping in oncology settings. The detrimental effects of self-concealment include an increase in stress whilst simultaneously diminishing the likelihood of gaining helpful, empathic responses from others (Larson, 1993). Cancer patients may conceal feelings and shield their concerns from others, so as not to be a burden, which leads to increased isolation and loneliness from their usual support networks (Ferrell et al., 1995). This phenomenon of ‘protective buffering’ (Porter et al., 2005), avoiding the discussion of fears or concerns in order to protect the other person (Dunkel-Schetter, 1984), is noted to be common amongst patients and their spouses. Both men and women with cancer

share the desire to protect relatives (Hilton et al., 2009) and despite living with constant fear, cancer patients may withdraw and isolate themselves rather than sharing this with family, friends and healthcare staff (Spiegel, 1992). This strategy is considered particularly unhelpful for female patients (Manne, Dougherty, Veach, & Kless, 1999). A study of 80 patients with blood cancer, about to undergo stem cell transplant treatment, found that the more patients buffered their partners and the more they felt buffered themselves, the lower their relationship satisfaction and the poorer their mental health (Langer, Brown, & Syrjala, 2009). In addition, Langer et al. suggest that buffering enacted by the patient, with the view to protecting their loved one, can prove counter-productive and actually hurt the object of such protection.

Failure to disclose cancer-related concerns has been associated with poor emotional well-being, low social support and high unsupportive social interactions (Figueiredo et al., 2004). Women with breast cancer, who talked less about their cancer, or perceived social barriers to cancer conversations, were found to have higher levels of depression (Cordova et al., 2001a). Moreover, high levels of holding back have been associated with poorer relationship functioning between patients with gastrointestinal cancer and their spouses (Porter et al., 2005).

Despite the general consensus that disclosure is beneficial, it is important to acknowledge that, as with disclosure in general, the typical gains from disclosure may not generalise across individuals with cancer and the variety of situations they encounter. In fact, one study found that psychological maladjustment and depression were not an inevitable outcome of disclosure avoidance (Steward et al., 2011). Furthermore, negative consequences of disclosure have been reported by cancer patients, including; strained relationships, inability to handle responses of others, and loss of control and autonomy (Yoo et al., 2009), as well as changes in the way they are perceived, those who are told can become distant, and it can cause work and/or family-related problems (Stewart et al., 2001). Contrary to gaining social support, some women actually encountered a dropping off of support and friendship following disclosure of their breast cancer diagnosis; this has been referred to as the 'weeding out' of unsupportive people in the network (Yoo et al., 2009). Ultimately disclosure of health conditions galvanises attention to a problem process (Charmaz, 1993) and in HIV

has been suggested to serve as both a stressor and coping mechanism (Holt et al., 1998; Moskowitz & Roloff, 2007).

1.8 DEGREE OF DISCLOSURE AND HOW IT UNFOLDS IN CANCER

Based on the studies to date, there is accumulating knowledge on the extent to which people with cancer talk about it. A qualitative study using narrative interviews to investigate the experiences of disclosing a cancer diagnosis, in respondents aged 18 to 34 years, found that most of the 37 people studied were open about their diagnosis (Hilton et al., 2009). However the authors highlight a potential bias in that their sample all agreed to having their accounts recorded for a website and consequently may comprise a group of people who find it relatively easy to talk about their cancer. They further suggest that it may be hard to attract ‘silent and uncomplaining types’ to this area of research.

A quantitative study of 378 breast cancer survivors in Canada, found that over 70% had disclosed their diagnosis to friends, children, siblings, and partners and over 50% had disclosed to work colleagues and supervisors (Stewart et al., 2001). The study found that 97% told friends, 80% children, 76% brothers/sisters, 76% husband/partner, 51% work colleagues, 48% parents, and 41% told their boss/supervisor. 35% of survivors told everyone and just 1 person (0.3%) told no-one, indicating that total concealment is rare. Similarly, a questionnaire study of 270 women with breast cancer found that the majority had talked about their cancer to some extent with at least one other person in the last month and the degree of disclosure across the different social categories (e.g. family, friends and health professionals) was consistent (Henderson et al., 2002). However, 20 (7.4%) reported little or no disease disclosure to anyone beyond their spouse or doctor and 20-30% reported little or no disclosure to entire subgroups of their social network. Of the women identified as ‘low-disclosers’; some preferred to keep it a secret and others felt they lacked the opportunity to share it. Moreover half of the low-disclosers reported a desire to talk more about their cancer, leading the authors to conclude that these women were experiencing constraints on discussing their cancer. Both of the above studies are limited in that their samples were on average 12 years and 6 years post-diagnosis respectively, introducing the possibility of recall bias and it is

unclear how this may impact on the reported disease disclosure patterns (Henderson et al., 2002).

1.8.1 Method of telling

Qualitative interviews have further identified a particular sequence to diagnosis disclosure, whereby women with breast cancer tell intimate partners first, followed by children, and then after the initial shock subsides there is a pattern of revealing to the extended network including family, friends, co-workers/employers, and members of their religious communities (Yoo et al., 2009). Interestingly, the method of telling differs depending on the relationship, whereby patients tend to sit down with family members in a serious manner and develop a plan for what to do, whereas humour is involved in sharing the news with colleagues. In trying to manage the worry for others, some women wait until after their initial treatment to disclose, and others deliberately postpone disclosure until they are free of the cancer or at least less dependent.

1.8.2 Important confidants & content of disclosures

Studies of women with breast cancer have looked at disclosure of cancer-related concerns and found that women aired their concerns to a wide range of social targets, with 79% confiding in their spouse/partner, 78% talking to a friend/neighbour and 73% had spoken to a close relative (Pistrang & Barker, 1992). Again, a small minority of women (4%, n=3) reported to not confiding in anyone. 'Informal helpers' (such as partners, close female relatives and friends) were typically classified as the most important confidant, rather than 'formal helpers' (such as medical personnel). Communication with partners tended to be more problematic than discussions with friends as the women perceived less empathy and felt less understood by male partners. The study also sought to determine whether the women tended to use the same helpers as before their cancer experience or whether they sought new helpers in the context of cancer. 34% (n=26) had in fact changed their preferred helper, and 9 women who previously used their partner as a helper had selected a new helper to discuss their cancer-related concerns. In terms of the content of the concerns discussed, the areas of most concern were not necessarily the areas that were discussed the most. Thoughts

about death and dying were discussed significantly less than other concerns such as uncertainty of recurrence, physical problems, changes in appearance and effect of the illness on others. Pistrang and Barker (1992) warn that those who do not confide in anyone may be at particular risk of depression.

A further study, using similar methodology, looked at 66 women with early stage breast cancer and confirmed the findings that women disclose their concerns to a range of social targets, with family and friends being rated as more important confidants than mental health workers (Figueiredo et al., 2004). Moreover, they classified the overall extent of disclosure, about a range of cancer-related concerns, to be 'moderate'; with 33.3% of respondents reporting a 'great deal' of disclosure, 51.5% of respondents reporting a 'moderate' amount of disclosure, and 12.1% reporting 'only a little' disclosure. This study also measured 'helpfulness' of disclosure and found that the majority (72.7%) rated their disclosure as being 'moderately to very helpful'. Although informative, both of the aforementioned studies were limited to female participants with breast cancer.

1.8.3 Patterns of family communication

A qualitative study investigated the patterns of family communication following a melanoma diagnosis (Hay et al., 2008) and found that discussions are guided by an implicit set of rules that determine what is said, who is involved in the conversation and when they occur. In this study, women tended to take the lead in instigating discussion around melanoma diagnosis, treatment and prevention, and were more likely to 'spread the word' that there had been a melanoma diagnosis through the family system. Interestingly, the perceived cause of the melanoma impacted on how much the family discussed it, with for example patients who developed melanoma on a non-sun-exposed site sharing less about their disease in comparison to families where it was perceived to 'run in the family'. The degree of emotional and geographical closeness also determined whether and when discussions occurred. When targeting which family members to involve in discussion, extensive deliberation was noted, with those thought to be at most risk being singled out for more intensive discussion around prevention. The content of discussions were also noted to evolve over time, with the initial focus

being on the patient with the diagnosis and their impending treatment, then following resolution of the acute treatment phase, conversations widen to discuss family risk and prevention. This American study was based on a sample of nineteen families which were exclusively of white origin.

1.8.4 Disclosure in the workplace

Disclosure of cancer, specifically in the context of the workplace, has also received attention. One study looked at this indirectly by asking peers of people with cancer to report on the content of disclosures they had received from a self-identified colleague with cancer (Wittenberg-Lyles & Villagran, 2006). Of the 126 people in this study, 65.5% had experienced a disclosure interaction from a female colleague with cancer and 34.5% had experienced disclosure from a male colleague with cancer. A common approach to disclosure in the workplace was via third parties and the content of disclosures was partly based on the type of peer relationship, (whether it was 'informational', 'collegial' or 'special'). Disclosure content was commonly focussed on recovery, with discussion of treatment plans, minimising the potential for emotional reactions. Although this study advances knowledge of disclosure in the workplace, it relies on indirect measurement.

1.8.5 Avoidance, obligations & selective disclosure

Much of the research suggests that the majority of people with cancer will disclose their diagnosis at some point to someone, however a longitudinal qualitative study of men with prostate cancer found that most men avoided disclosure about their illness where possible in an attempt to maintain normality (Gray et al., 2000). The men in this study carefully selected their audience and placed parameters on how many people they would disclose to. If possible men would have preferred to have only told their spouse. However, the crucial decider on whether to inform another, was determined by a felt sense of obligation to inform e.g. whether it be around possible genetic risks or not wanting to hide things. In this sense, disclosure served an altruistic purpose in that it was done to benefit others rather than oneself and, for men who were employed, bosses and/or colleagues were viewed as people who needed to know for practical reasons.

Similarly a study of 35 survivors of prostate cancer found men would disclose based on the belief that others had a ‘right to know’ and that it was the ‘right thing to do’ (Jackson et al., 2010). Furthermore, in a sample of patients recently diagnosed with lung cancer, over a third reported avoiding or having difficulties talking about cancer in general (Badr & Carmack Taylor, 2006). In addition two thirds of the spouses in this study also had difficulties or avoided discussing issues around prognosis and death for fear of upsetting the patient. These notions are akin to ‘protective buffering’ mentioned earlier.

1.8.6 Summary

Overall, it seems that most people experiencing cancer will disclose their diagnosis and talk about their thoughts, feelings and concerns to another person. However, a potentially important minority of people will completely refrain from any level of disclosure. This insight is based on the existing literature, which has largely focussed on disclosure patterns by women with breast cancer. It is therefore important to expand investigations to consider other cancer types across both genders. This is particularly the case given the few studies with male patients indicate a greater reluctance to tell.

1.9 PREDICTING DISCLOSURE

As well as identifying the patterns of disclosure (i.e. how much is told and to whom) and the extent to which it is helpful, it is important to understand the determinants of disclosure. The only known multivariate study that has attempted this directly found that, in patients with breast cancer, greater disease disclosure was predicted by younger participant age, greater disease severity, optimism, stress-related growth, and disclosure-oriented attitudes (Henderson et al., 2002). Overall these factors accounted for 26% of the variance in the degree of disclosure. It is likely that a range of other factors may also influence the decisions related to disclosure. The following sections (1.9.1 – 1.9.6) consider the factors that may be predictive of disclosure. Given the lack of quantitative studies in cancer, these are drawn from literature that has considered disclosure in other physical health conditions and taken from insights that have been gained by the qualitative literature in cancer.

1.9.1 Demographic factors

Demographic factors, such as age, gender and ethnicity, may play a role in disclosure patterns. Regarding age, younger adults with HIV were more likely to disclose their disease, across a range of social targets, compared to older adults (Emlet, 2006). In cancer, a study using narrative interviews to capture young adults' (aged under 25 years) experiences of disclosing their diagnosis, found that almost half of the sample learned of their diagnosis whilst accompanied by parents (Hilton et al., 2009). This indicates that age, or perhaps dependant status, can act as a constraint when considering who to tell about one's diagnosis and it remains unclear whether the young adults in this sample would have gone on to share their diagnosis anyway. Younger age has been associated with higher degrees of disclosure in breast cancer (Henderson et al., 2002), however age was not associated with the level of 'holding back' from disclosure in a sample with gastrointestinal cancer (Porter et al., 2005). Therefore, the extent to which age impacts on cancer diagnosis disclosure remains uncertain. The findings above also indicate that the relationship between age and degree of disclosure is complex and may be confounded by the presence of a parent, or supportive other, during the initial receipt of the diagnosis.

Gender may also be an important determinant of disclosure given the general tendency for women to disclose more than men about stressors in a variety of contexts (see Tamres, Janicki, & Helgeson, 2002 for a review). For instance, in relation to the disclosure of fertility problems, women have reported higher disclosure than men (Slade, O'Neill, Simpson, & Lashen, 2007). Disclosure may be more difficult for men, since they may try to conform to the socially constructed idea of a strong un-emotional male identity (Hilton et al., 2009). For example, men with testicular cancer were noted to regulate their discussions being aware that, 'as a guy you don't usually talk about things like that' (Gurevich, Bishop, Bower, Malka, & Nyhof-Young, 2004, p. 1600). A qualitative study of men with prostate cancer found that the majority avoided disclosure about their illness where possible (Gray et al., 2000) and their female partners took it upon themselves to share their partners' illness. A 'highly gendered division of labour' has been suggested whereby women take on the emotional work of disclosing even when the illness belongs to someone else (Yoo et al., 2009). Women may even take on the role of managing the emotions of the entire family (Reay, Bignold, Ball, & Cribb,

1998). However another study, in a mixed cancer group, found that, although men were less open about their diagnosis, most patients in their young adult sample did freely disclose their diagnosis (Hilton et al., 2009). Thus, they documented that there is diversity among men and among women with regards to disclosure and warn against the stereotypes surrounding 'expressive' women versus 'stoical' men. So despite the general consensus that women have the tendency to disclose more than men, it remains unclear whether this generalises to the case of cancer diagnosis disclosure.

Ethnicity and cultural diversity may also impact on the degree to which illness is spoken about. In a study of HIV, 'ethnicity' emerged as a significant factor determining disclosure, with rates of disclosure being lower in Black-African/Asian respondents compared to Caucasian respondents (Pettrak, Doyle, Smith, Skinner, & Hedge, 2001). These authors suggest this may be due to differences in how ethnic groups access support, as well as minority groups having limited opportunities for disclosure. In relation to cancer, ethnicity has received less attention and as yet has not been recognised as relevant in disclosure. This may be because studies have failed to consider it in their investigations (e.g. Pistrang & Barker, 1992) or samples have comprised largely of Caucasian participants (e.g. 97% in the study by Henderson et al., 2002).

1.9.2 Characteristics of the disease

Characteristics of the disease such as cancer type, stage and treatment may also conceivably have implications for disclosure. To date, study samples have tended to comprise of a single cancer type (largely breast cancer) and so have been unable to offer information on whether disclosure differs between cancer types. The visibility of the disease may be crucial to disclosure and this varies between and within cancer types. If the cancer is invisible then the person has the option of concealing it and can make a conscious decision regarding disclosure. Moreover, even if the cancer is invisible, the treatment type (e.g. surgery, radiography, or chemotherapy) may result in physical changes, such as hair loss, and result in a visibility that will necessitate disclosure. It may therefore be hypothesised that cancer visibility (due to cancer type or treatments) may impact on disclosure, with greater visibility compelling the person to disclose at

some level. Findings across a variety of diseases (particularly HIV) has suggested that disclosure is more likely the more visible the disorder is, the more symptoms are present, and the sicker the person is (Hays et al., 1993; Mansergh, Marks, & Simoni, 1995). A qualitative study, of cancer patients, revealed that disclosure coincided with times when important treatment decisions had to be made (Yoo et al., 2009). Indeed greater disease severity has been associated with greater disease disclosure in breast cancer (Henderson et al., 2002), however greater time since diagnosis was negatively correlated with disclosure in a sample of patients with gastrointestinal cancers, suggesting that the longer patients had been dealing with their disease, the less likely they were to disclose their illness-related concerns to their spouse (Porter et al., 2005). Thus the findings are mixed and it is unclear the extent to which disease-related variables impact on diagnosis disclosure.

1.9.3 Social support & unsupportive social interactions

Social support is a concept which has been widely studied in the medical, social science and mental health fields and has been found to predict general health and mortality (House, Landis, & Umberson, 1988), psychiatric symptoms (Kessler, Kendler, Heath, Neale, & Eaves, 1992) and the emotional adjustment to stress (Monroe & Steiner, 1986). Its protective effects have been encapsulated in the ‘buffering hypothesis’ which states that, “psychosocial stress will have deleterious effects on the health and well-being of those with little or no support, while these effects will be lessened or eliminated for those with stronger support systems” (Cohen & McKay, 1984, p. 253). Despite the obvious benefits of social support, it is a complex concept with a multifaceted nature. Barrera (1986) has distinguished between *perceived social support* and *actual or enacted support*. The former being defined as “the belief or faith that support is available from network members, whereas actual support is its mobilization and expression” (Gottlieb & Bergen, 2010, p. 512). It is perceived support, rather than the actual materialization of it, that is responsible for the much heralded buffering effects (Cohen & Wills, 1985).

In relation to the diagnosis and treatment of cancer, social support has emerged as one of the strongest predictors of psychological adaptation (Porter et al., 2005). Since

disclosure may be part of the adjustment process, it is possible that social support may influence the decision to disclose. Preliminary studies in the cancer field have indeed implicated social support, and particularly emotional support from loved ones, in the disclosure process (e.g. Figueiredo et al., 2004; Pistrang & Barker, 1992; Porter et al., 2005). However, these studies are limited as they either exclusively consider women with breast cancer or do not explicitly measure perceived social support.

The social support literature highlights the importance of measuring not only the quantity of support available, but also its qualitative adequacy from the recipients' perspective (Gottlieb & Bergen, 2010), since it is important to recognise that not all social support is positive and even those who mean well may respond in unsupportive or distressing ways to someone experiencing a life crisis (Wortman & Lehman, 1985). People can experience 'social constraints' (i.e. unsupportive/critical responses, avoidance and denial) on their ability to disclose cancer-related concerns (Lepore & Revenson, 2007) and in relationships people can be a source of problems as well as support (Hughes, 1987). For example, support may be offered grudgingly, with strings attached or make the recipient feel indebted or incompetent (Gottlieb & Bergen, 2010). Such unhelpful reactions may play an influential role in disclosure given the dyadic nature of the process.

The unsupportive reactions that people might receive in response to disclosing their cancer diagnosis have been considered in patients with breast cancer. Pistrang & Barker (1992) have found evidence of 'misguided helping efforts' whereby women found that their partner would try to cheer them up and distract them from their worries, when in fact they wanted to talk. Moreover, these unhelpful reactions have been associated to the level of disclosure, whereby there were higher levels of 'holding back' from disclosure in women who received unsupportive social interactions (Figueiredo et al., 2004). The effect of unhelpful responses, as a result of disclosing, is potentially pivotal for subsequent disclosures since according to 'crisis theory' (Moos & Schaefer, 1986), during times of change and uncertainty, people are particularly affected by and receptive to outside influences. In fact the deleterious effects of unsupportive social interactions and difficult relationships are considered to be more problematic than the absence of a relationship and social support (Coyne & DeLongis, 1986). Thus it is necessary to consider the degree of social support available as well as the level of

unhelpful reactions received when considering how social support might be related to disclosure since the nature of the social support (whether positive or negative, available or not) may make subtle differences in disclosures. Though this has been considered, it has yet to be explored beyond the context of breast cancer.

1.9.4 Stigma

Goffman's (1963) stigma theory informs the disclosure literature by suggesting that people avoid disclosure so as to avoid being stigmatized. Patients have reported that there is a level of stigma associated with having a cancer diagnosis (Colyer, 1996; MacDonald & Anderson, 1984; Muzzin et al., 1994) whereby they may be treated differently as people either avoid them or be overly solicitous. In fact when compared to other medical conditions, cancer comes second only to AIDS in terms of being perceived as negative (Stahly, 1989). The assumed connection between cancer and death gives rise to concerns in cancer patients that they will be pitied or treated as vulnerable (Gray et al., 2000). Cancer bears the stigma of being a life threatening illness, but also particular cancer types and treatments will bring their own stigmatizing issues such as sexual dysfunction in prostate cancer and the socially held idea associating cervical cancer with early and promiscuous sexual behaviour in women.

It may be hypothesised that higher perceived stigma will lead to greater efforts to conceal. This is found to be true in a range of physical health conditions. A longitudinal study of 198 people with HIV found that 'felt normative' stigma (i.e. perceptions of stigma prevalence) correlated with disclosure avoidance (Steward et al., 2011). In relation to fertility problems, for men in particular higher perceived stigma was associated with lower disclosure levels (Slade et al., 2007). In sickle cell disease the aversion to widely advertising the diagnosis to others was underpinned by fears that people would not understand or stigmatize them for their dependence on medication (Booker, Blethyn, Wright, & Greenfield, 2006). In dementia, 100% of one study sample were worried about other people finding out; fears of being humiliated, pitied, laughed at, and talked about impacted on disclosure behaviours whereby they would avoid telling friends, would ask relatives to maintain secrecy, or would avoid doctors and hospitals (Husband, 2000). A qualitative study of men with prostate cancer, has

similarly found that decisions around disclosure were influenced by the degree to which they felt their diagnosis to be stigmatizing; those who saw it as socially dangerous or believed they would be judged negatively, were less willing to disclose (Gray et al., 2000). The studies noted above would suggest that perceptions of stigma do exist in cancer patients and that anticipation of stigma may lead to concealment.

Equally however, stigma may act as a motivator to disclose since early disclosure gives the opportunity to correct any misinformation about cancer and limit the likelihood of further stigma. Tröster (1997) has evidenced this by describing how patients with epilepsy attempt to forestall any stigmatization processes by using 'preventative disclosure'. Similarly in relation to disclosing chronic illness in the workplace it has been reasoned that, people disclose pre-emptively to retain control over potentially stigmatizing personal information and to justify illness behaviours (Beatty, 2004). Thus the relationship between perceived stigma and disclosure is unclear and it may depend on the extent to which the individual feels stigmatised by cancer and also how willing they are to correct such stigma. It is therefore necessary to investigate further and clarify how stigma plays out in cancer disclosure.

1.9.5 Psychological distress

The heightened anxiety and depression associated with non-disclosure, of general concerns and traumatic experiences, suggests that psychological distress may also be implicated in disclosure patterns in cancer. Psychological state has been found to affect the extent to which concerns are expressed in a sample of Hospice patients, with those who were depressed and anxious being less likely to disclose their concerns to a nurse (Heaven & Maguire, 1997). A study of disclosure between patients with gastrointestinal cancer and their spouses found that psychological distress was higher in cases characterised by high levels of holding back and lower levels of disclosure (Porter et al., 2005). Given the correlational nature of these studies, the direction of the relationship between distress and disclosure is unclear (i.e. distress may be the reason for the lower levels of disclosure or result from the lack of disclosure). Also, as already noted a degree of psychological distress is considered normal in the adjustment to cancer and is likely to be affected by a variety of other variables and wax and wane at

different points of the cancer journey. So although distress may be related to disclosure, it is likely to be a complex relationship that requires further investigation and scrutiny.

1.9.6 Individual differences & disposition to disclose

Individual differences (e.g. traits such as personality or coping) are often recognised as important determinants of, and responses to, health and illness. Henderson and colleagues (2002) measured dispositional optimism (one's expectations for positive versus negative outcomes) in a sample of patients with breast cancer and found that this variable did contribute to predictions of disclosure.

The disposition to be open and disclose personal information may also be an important factor in disease disclosure; as the adage suggests that the best predictor of future behaviour is past behaviour. Only one study has measured the disposition towards talking about one's problems in everyday life, something they termed 'general disclosure', in a sample of women with breast cancer and found that three quarters of the women agreed to being open (Figueiredo et al., 2004). However, since their main outcome was distress levels, they did not consider whether this disposition of 'general disclosure' was related to cancer-specific disclosure levels. It may be hypothesised that those who tend to be more open about general information in their everyday lives, may also disclose more in relation to their cancer, however this is yet to be explored.

1.10 SUMMARY

The literature into disclosure of health conditions is mounting and there is an accumulating body of research specifically in the context of cancer. This is an important area of investigation given that in the U.K. more than 1 in 3 people will receive a cancer diagnosis in their lifetime and disclosing this diagnosis to others is one of the toughest challenges of the disease. There is a need to quantify current levels of disclosure and understand it better, before developing interventions to support the process. The current study expands on existing knowledge by quantifying disclosure, in a mixed cancer sample, and extends the work in this area by using both univariate and

multivariate analyses to consider a range of variables that may be important in determining the extent of disclosure.

1.11 AIMS & HYPOTHESES

This study aims to answer the following research questions:

- 1) To what extent do patients with cancer talk about their diagnosis across a range of social targets?
- 2) Is it helpful to talk?
- 3) What factors are associated with the degree of disclosure?
- 4) What factors are associated with the helpfulness of disclosure?

Questions 1 and 2 were purely research questions and so no testable hypotheses were made.

In relation to question 3, the hypotheses to be tested were:

- Higher levels of disclosure will be associated with:
 - Being female.
 - Younger age.
 - Cancer visibility.
 - Higher levels of perceived social support.
 - Lower levels of unsupportive social interactions.
 - Lower levels of perceived stigma.
 - Lower levels of psychological distress.
 - A general disposition towards disclosure.

Also in relation to question 3, exploratory analyses were conducted to investigate whether any of the other demographic and disease related variables (including ethnicity, education, living arrangements, employment status, cancer type, time since diagnosis, treatment type, and whether the person had company whilst receiving the diagnosis), are associated with disclosure.

In relation to question 4, this study sought to investigate whether any of the variables measured would predict the helpfulness of disclosure. However no specific hypotheses were made in relation to this and the analyses were exploratory.

2.0 METHODS

2.1 DESIGN

The study was a cross-sectional, retrospective, questionnaire survey with two main dependent variables: 1) the degree of disclosure across social targets (i.e. the extent to which people talked about their cancer to others) and 2) the extent to which this ‘disclosure’ was helpful or not. These were termed the primary and secondary outcomes respectively. Independent variables consisted of the factors investigated as potential predictors of disclosure. These were: demographic and disease related variables (age, gender, and cancer visibility), and psychological variables (perceived social support, unsupportive social interactions, perceived stigma, psychological distress and a general disposition to disclose). Independent variables used for exploratory analyses included ethnicity, education, living arrangements, employment status, cancer type, time since diagnosis, treatment type, and whether the person had company whilst receiving the diagnosis. All of the above independent variables were also investigated to see whether they were associated with the helpfulness of disclosure. The study collected quantitative data, using the variables mentioned above, as well as qualitative data on the reasons why disclosure can be helpful and unhelpful.

2.2 SAMPLE

The participants for this study were patients diagnosed with skin cancer, colorectal cancer or lung cancer. Inclusion criteria were the following: 1) aged 18 or above with a first time diagnosis of cancer (i.e. not a recurrence); 2) diagnosis occurred in the past 2 years and no sooner than 8 weeks previously; 3) in (or about to begin) treatment with curative intent or likely long-term remission; and 4) sufficient English language in order to understand and complete the questionnaire. Exclusion criteria were: 1) patients with metastatic cancer (which has spread); 2) those receiving palliative treatment; or 3) any clinical reason deeming it inappropriate to send the questionnaire.

The rationale for considering only those with a single diagnosis of cancer (and not those with metastases) was so that it would be clear which diagnosis and disclosure-related period the person had to remember, and responses to the questionnaire would not be confounded by recalling more than one diagnosis event. The time boundary of 8 weeks to 2 years was selected for two reasons; firstly, the lower boundary of at least 8 weeks was to ensure enough time had passed since diagnosis to allow for the opportunity to disclose, and secondly the upper limit of approximately 2 years was used to optimally enhance the self-report data, since recall of information about the diagnosis and disclosure period may erode with increasing time spans since the event of disclosure.

2.3 PROCEDURE

Potential participants, who met the inclusion criteria, were identified by the specialist cancer teams responsible for their care at Guy's and St Thomas' Hospital's. The method of approach was adapted to the requirements of each specific cancer team. Those meeting the criteria were either given a questionnaire pack in clinic (skin cancer) or sent the pack in the post (colorectal and lung cancer). The pack contained several recruitment documents including; a covering letter explaining the reason for contact (see Appendix 1), a participant information sheet (see Appendix 2), the questionnaire (see Appendix 3) and a freepost envelope. Participants were asked to complete the questionnaire and return it in the freepost envelope provided. Those preferring not to participate were given the option of returning a reply slip indicating their reason for not participating. If no response had been received within three weeks of the initial pack being sent to those with colorectal or lung cancer, a follow-up reminder letter was sent (see Appendix 4). There were no reminders sent to those with skin cancer since these patients were approached directly in clinic by staff responsible for their medical care, and it was felt that a single approach would suffice. In the interests of confidentiality, the questionnaires were pseudo-anonymised and identified via a unique numerical code. This code was only traced back to the participants contact details in cases where feedback on the study findings had been requested. On completion of the study a summary of the results was sent to these participants (see Appendix 5). Participation was on a voluntary basis and completion and return of the questionnaire was seen as implicit consent to take part. This was clearly stated in the information sheet.

2.4 PILOTING

The questionnaire was initially piloted with a sample of patients to determine its acceptability and whether it was comprehensible. Minor amendments were made as a result. These included changes to the formatting so that there was clear separation between sections and so that the multiple choice options relating to a single question did not span across two pages. Section headings were altered to become more meaningful. For example Section 1 originally titled ‘Disclosure Patterns’ was renamed ‘Talking about the diagnosis’ and ‘Social Support’ was renamed ‘General Social Support in Everyday Life’. A further option of ‘other’ was added to the multiple choice options for the question asking about the treatments received; this ensured that respondents were not restricted to selecting purely the treatment options provided in the list and allowed for any unknown treatment options or combinations of treatments to be stated.

2.5 ETHICAL CONSIDERATIONS

This study was approved by the Camberwell and St Giles, South East London Regional Ethics Committee (study reference 11/LO/0341), and research governance was received by Guy’s and St Thomas’ Research and Development Office (registration number RJ111/N230). The approval letters for both are contained in Appendix 6 and 7 respectively.

The main ethical considerations were related to the burden placed on participants and whether completion of the questionnaire, requiring reflection on their diagnosis, may orient respondents towards their troubles. To secure against such burden, participants were directed to contact the Psycho-Oncology Support Team at the Dimpleby Cancer Care Centre (based at Guy’s and St Thomas’ Trust) should they find that the questionnaire had raised any issues that they would like to discuss. A further consideration was that the Hospital Anxiety and Depression Scale (used in the questionnaire) had the potential to identify those suffering from elevated levels of distress. Given that responses were pseudo-anonymised, the measure was purely used for research purposes, as an index of distress, and it was assumed that the clinical teams

responsible for the patients' care would have procedures in place to identify those with abnormal levels of distress as part of their Holistic Needs Assessment.

Any patient identifiable information gained in this study was stored securely in accordance with clinical governance requirements and the questionnaire ID code was only linked back to the individual patients' details if feedback was requested (as mentioned earlier), and thus the data generated by the study remained anonymous.

2.6 MEASURES

The measures were administered in the form of a questionnaire booklet comprising of outcome measure variables (extent of disclosure and helpfulness of disclosure), psychological predictor variables (perceived social support, unsupportive social interactions, perceived stigma, psychological distress, and disposition to disclose), and demographic and disease-related variables. These are detailed below.

2.6.1 Disease disclosure patterns: outcome variables

Extent of disclosure

Disease disclosure patterns were measured by refining the approach used in previous studies (namely Figueiredo et al., 2004; Henderson et al., 2002; Pistrang & Barker, 1992; Ullrich, Rothrock, Lutgendorf, Jochimsen, & Williams, 2008). A single item ("How much have you talked to the following people about your cancer?"), modelled on that used by Henderson et al (2002) measured the extent of disease disclosure across a range of social targets, by asking patients to rate the degree to which they talked about their cancer following their diagnosis. The scale ranged from 0-4 with higher ratings indicating greater levels of disclosure. The current measure expanded the scale previously used by Henderson et al, by delineating between 'purposefully choosing not to talk' and 'did not have the opportunity to talk'. It also separated the 'parents' category into two items, one for 'mother' and one for 'father'. In line with Henderson et al, the range of social targets were similarly categorised into three main groups: *family members* (spouse, siblings, children, parents), *friends* (friends/neighbours, co-workers, and other cancer patients), and *medical personnel* (doctors and nurses). Other

social targets were ‘professional therapist/counsellor’ or ‘minister, rabbi, pastoral counsellor’. The mean overall level of disclosure was calculated for each participant across all social targets as well as the mean level to each of the categories of social targets. For the purposes of analysis, the mean disclosure scores were based on the scale 0 = N/A; 1 = did not talk at all (comprised of ‘purposefully chose not to talk’ & ‘did not have the opportunity to talk’); 2 = talked a little; 3 = talked somewhat; 4 = talked very much. Previous studies have not provided an index of reliability when using disclosure scales similar to the current study, however Ullrich and colleagues (2008) found strong internal consistency for their scale measuring the frequency of discussions across a variety of concerns ($\alpha = 0.84$). According to Cronbach’s alpha (Cronbach, 1951), the internal consistency of the scale used in this study was found to be acceptable ($\alpha = 0.765$). Streiner (2003) suggests a satisfactory alpha should be above 0.7.

Helpfulness of disclosure

Given the recognition that it is important to measure the ‘quality’ and not just the quantity of disclosure (Henderson et al., 2002), a second set of items measured how helpful/unhelpful disclosure was. A single quantitative item asked patients to rate how helpful/unhelpful it had been to talk about their cancer to the range of social targets listed in the previous question. The scale ranged from 0 = ‘very unhelpful’ to 5 = ‘very helpful’. As in previous studies (e.g. Pistrang & Barker, 1992) this was used as a global index of helpfulness. When the data were explored using K-S Lilliefors, this quantitative measure of helpfulness did not fall on a normal distribution, $D(112)=0.29$, $p<0.01$, and so data transformation was conducted by using e^x (where x = data point). However this did not improve the distribution and so the variable was dichotomised for the purposes of analysis. A median split was used where scores of ≥ 4 (i.e. 4 and 5) were given a score of 1, representing the ‘helpful’ category and scores of <4 were given a score of 0, and categorised as being ‘unhelpful’.

A further two open-ended, qualitative items were used so that patients could specify in what ways disclosure had been helpful or unhelpful. The written responses generated by these items, were analysed using Thematic Analysis, a widely used method for identifying, analysing and reporting patterns or themes within data (Braun & Clark, 2006). It is a flexible approach that is independent of theory and epistemology, and is able to minimally organise and describe data in rich detail. Given that it is important to

be explicit about how qualitative analysis is conducted (Attride-Stirling, 2001), the current analysis involved a recursive process and used the six phases of Thematic Analysis, as described by Braun and Clark (2006) which includes 1. Data familiarisation, 2. Generation of initial codes, 3. Searching for themes, 4. Reviewing themes, 5. Defining and naming themes, and 6. Producing the report. Firstly, in order to gain familiarity with the data in this study the hand-written responses from the questionnaires were typed into a spreadsheet and were initially examined by reading through all of the responses. Interesting features of the data were coded in a systematic fashion by adding brief verbal descriptions to each of the responses. On the basis of these coded descriptions, themes were identified that integrated substantial sets of these codes by gathering together all the data relevant to each potential theme. Themes were identified both at an explicit level, where they were directly manifest in the written descriptions (e.g. use of the word 'stigma'), as well as at a more latent or interpretative level (e.g. a sentence which alludes to the sense of stigma without directly stating the term), as it is common for Thematic Analysis to draw on both types of theme (Joffe & Yardley, 2004). The themes were drawn from the raw data itself (using an inductive coding approach), however it must be acknowledged that the prior literature review conducted by the researcher may have led to existing knowledge and theoretical ideas colouring this process and introducing an element of deductive coding. The themes were then re-examined to ensure that the main themes accommodated all of the data and ongoing analysis of the data was used to refine the specifics of each theme and to generate a clear definition and name for each theme. The complete responses to the questions were then rated for the presence of these themes by two separate raters. Correlational analyses were used to assess the level of agreement between the two independent raters on the presence of the various themes. Both raters' codings for all of the themes were significantly correlated (ρ 0.637 – 1.0) at the 0.01 level. The details of these correlations can be found in Appendix 8. An explanation of each theme and example quotations are given in the results section, alongside a numerical indication of the prevalence of each theme.

2.6.2 Predictors of disclosure

Perceived social support

Perceived social support was measured using the ENRICHD Social Support Inventory (ESSI; Mitchell et al., 2003), which assesses several elements of social support including emotional, instrumental, informational and appraisals. It contains 7 items, 6 of which are rated on a scale ranging from 1 (none of the time) to 5 (all of the time), and an additional item is scored 4 if the person indicates they are ‘living with spouse’, or 2 if they are not. Higher scores represent greater levels of support with the possible range being 8-34. Originally developed for use with patients following a myocardial infarction, the scale has been found to have acceptable internal consistency with a Cronbach alpha co-efficient of 0.86 (Mitchell et al., 2003). In a further sample of cardiac patients, the scale was found to be a reliable and valid measure when compared to another measure of social support (Vaglio et al., 2004). The original authors suggest the scale is suitable for use following any chronic medical illness and that it captures emotional support rather than structural or tangible aspects of support (Mitchell et al., 2003). Given that perceived social support is a better predictor of health outcome than actual social support (Cohen & Wills, 1985), the ESSI was thus chosen as an effective and brief measure in the current study. Question 7 of the scale was re-worded in the current study to obtain additional information regarding marital status, such that rather than asking ‘Are you currently married or living with a partner?’ to which the respondent can choose ‘yes’ or ‘no’, the question in this study asked ‘Are you currently...’ and gave the multiple choice options of ‘single’, ‘married/living with partner’, ‘divorced/separated’ or ‘widowed’. A score of 4 was allocated to those selecting ‘married/living with partner’, and all other responses were allocated a score of 2. The reliability of this scale was found to be good (Cronbach’s $\alpha = 0.927$).

Unsupportive Social Interactions

Unsupportive Social Interactions were measured using the Unsupportive Social Interactions Inventory (USII; Ingram, Betz, Mindes, Schmitt, & Smith, 2001). The USII was designed to measure the unsupportive or upsetting reactions that can be received from other people in relation to the experience of a stressful life event. The scale has 24 items and generates 4 subscales: *Distancing* (behavioural or emotional disengagement); *Bumbling* (which includes behaviours that are awkward,

uncomfortable, intrusive or inappropriately focused on fixing the individual's problems); *Minimizing* (which includes any attempts to force optimism or to downplay the importance of a person's concerns) and *Blaming* (which includes criticism and fault-finding). In the past, the total scale has been found to be internally reliable with a Cronbach's alpha of 0.86 (Ingram et al., 2001). The USII can be applied to any stressful life event, but has mainly been developed in accordance with health-related stressors. The original USII, which asks people to indicate how much of a particular type of response they have received from other people in response to their illness, was used in this study. However, the wording was changed so that the questions related specifically to cancer. The rating scale ranged from 0 indicating 'none' of the response was received to 4 indicating 'alot' of that type of response was received; therefore higher scores represent greater levels of unsupportive social interactions. Due to missing data in the current sample, pro-rating was used to estimate an average score for the missing item(s). This was done by calculating an average score for the particular subscale from which the missing item belonged, under the proviso that at least 4/6 items were completed in order for pro-rating to be used. The reliability of this scale was found to be good (Cronbach's $\alpha = 0.89$).

Perceived Stigma

Perceived stigma was measured by the 3-item Felt Stigma Scale which was originally used with stroke patients (Hyman, 1971) then developed by Jacoby (1994) for a sample of people with epilepsy where it had 'satisfactory' levels of internal consistency (Cronbach's $\alpha = 0.72$). The questions ask whether the patient feels that others are 1) uncomfortable with them, 2) treat them as inferior, or 3) avoid them, due to their illness. In this study, the questions were re-worded to ask specifically about cancer. Since the items are binary, requiring a yes/no response, the KR-20 statistic was used as an indicator of internal consistency in this study. A satisfactory level was achieved (KR-20 = 0.652). A score of 1 point was allocated for each item endorsed, with the sum providing an index of perceived stigma (higher scores represent a higher level of felt stigma). As recommended by the original author (Hyman, 1971) the scores were combined to form a Guttman quasiscale where 0 = 'low', 1 = 'moderate', and 2 or 3 = 'high' levels of stigma.

Psychological Distress

Psychological distress was captured using the 14-item Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) consisting of 7 items that measure anxiety and 7 which measure depression and thus generate 2 subscale scores. The HADS was originally developed for use with hospital outpatients, as a measure of anxiety and depression that is robust to the effects of physical ill health and symptomatology. It has proven reliability and validity and can be applied in a variety of settings. Each item is scored on a scale of 0 - 3, with a total score range of 0 - 21 being possible for each scale (the original authors of the scale recommend that scores of 0-7 represent 'normal', 8-10 are 'mild', 11-14 are 'moderate', and 15-21 represent 'severe' cases). The clinical cut-offs for the HADS, as well as the two-factor structure have attracted controversy, particularly as normative data has revealed mean scores of 6.14 for anxiety and 3.68 for depression in the general population (Crawford, Henry, Crombie, & Taylor, 2001). As anxiety and depression are often co-morbid and difficult to distinguish, it has been suggested that it would be more valid for the HADS to be uni-dimensional and measure a single factor of mixed emotional disturbance. Indeed, Crawford et al (2001) found a moderate correlation between the anxiety and depression scales ($r=.53$) and recommended combining the scales to produce a total score indexing overall psychological distress. Razavi et al (1990) also found support for the uni-dimensional measure of distress in a sample of 210 Belgian cancer patients. However, an exploratory factor analysis of the HADS in a sample of 568 patients with cancer found that the HADS does tap two separate but related constructs of anxiety and depression and thus found support for using the HADS as a measure of emotional distress in cancer patients (Moorey et al., 1991). In an early study, investigating the use of a variety of screening instruments in 514 patients with cancer, the HADS out-performed several other measures of distress (Ibbotson, Maguire, Selby, Priestman, & Wallace, 1994) and has been considered to have excellent psychometric properties (Carlson & Bultz, 2003). Therefore the HADS, and its original conception of 2 subscales, was selected for use in this study. Moorey et al (1991) previously found good levels of reliability with Cronbach's $\alpha = 0.93$ for the anxiety scale and 0.90 for the depression scale. In this study both the anxiety and depression subscales were found to have good reliability (Cronbach's $\alpha = 0.861$ and 0.872 respectively).

Disposition to disclose

The disposition towards disclosure, labelled as ‘general openness’ was measured by a single item, ‘I am a person who usually talks to other people about my problems, concerns and daily life events’, and was rated on a scale of 1 – 6 ranging from ‘strongly disagree’ to ‘strongly agree’. This item was based on that previously used by Figueiredo, Fries and Ingram, (2004).

Demographic details and disease related variables

Socio-demographic and disease-related information was gained by using a variety of questions asking for age, gender, ethnicity, education, marital status, living arrangements, employment status (both prior to and following diagnosis), time since diagnosis, cancer type, treatment type, whether the cancer was visible and whether anyone else was present when they received their diagnosis. The majority of these questions were standard multiple choice questions used to gain information on the demographic characteristics of the sample. However, the latter questions referring to disease-related variables were generated specifically for this study.

2.7 STATISTICAL ANALYSES

PASW Statistical Package (version 18.0) was used for the analysis of this study. Descriptive statistics were used to describe the sample, disease disclosure patterns and psychological measures. Preliminary calculations (K-S Lilliefors) were used to test for parametric assumptions. Correlational analyses, Kruskal-Wallis tests and Independent samples Mann-Whitney U tests were used to investigate which of the variables were associated with the main outcome measure of disclosure. Those variables associated with disclosure were entered into a hierarchical regression analysis to explore how strongly they predicted disclosure, whilst taking covariance into account. Univariate logistic regressions were used to investigate which of the variables were associated with the secondary outcome variable of helpfulness of disclosure. In the interests of being conservative, and given that multiple testing can increase the likelihood of finding a result by chance, only those relationships reaching the 0.01 level of significance (i.e. social support and general openness) were considered significant and entered into the

subsequent multiple logistic regression to explore how strongly these factors predicted the helpfulness of disclosure, whilst controlling for covariance.

2.8 POWER CALCULATION

2.8.1 A Priori Tests

GPower version 3.1.3 (Faul, Erdfelder, Buchner, & Lang, 2009) was used to calculate the sample size required. The effect size (R^2) for this study was based on the previous study by Henderson et al (2002). A priori calculations, with a large effect size of 0.26, a significance level of $\alpha = 0.05$, power = 0.80, and 9 main predictor variables indicated the required sample size was 70. Given the additional exploratory part of the current study, which meant a total of 23 variables may potentially predict the outcome of disclosure, a priori calculations with $R^2 = 0.26$, $\alpha = 0.05$, power = 0.80, and 23 predictor variables indicated a required sample size of 104. Based on this calculation and the likelihood that missing data would diminish the number of questionnaires that would be usable in the multiple regression analysis, a target sample size of 120 was aimed for in this study. This sample size would also give sufficient power for univariate analyses.

2.8.2 Post Hoc Tests

Post hoc calculations, based on a medium effect size of 0.13, a sample size of 109, a significance level of $\alpha = 0.05$, and 3 predictor variables, indicated that the power in this study was actually 89%.

3.0 RESULTS

3.1 RESPONSE RATE

Of the 207 possible recruits, 121 participants completed the questionnaire yielding a 58.5% response rate. See Figure 1 for a detailed description of the recruitment process and sample composition.

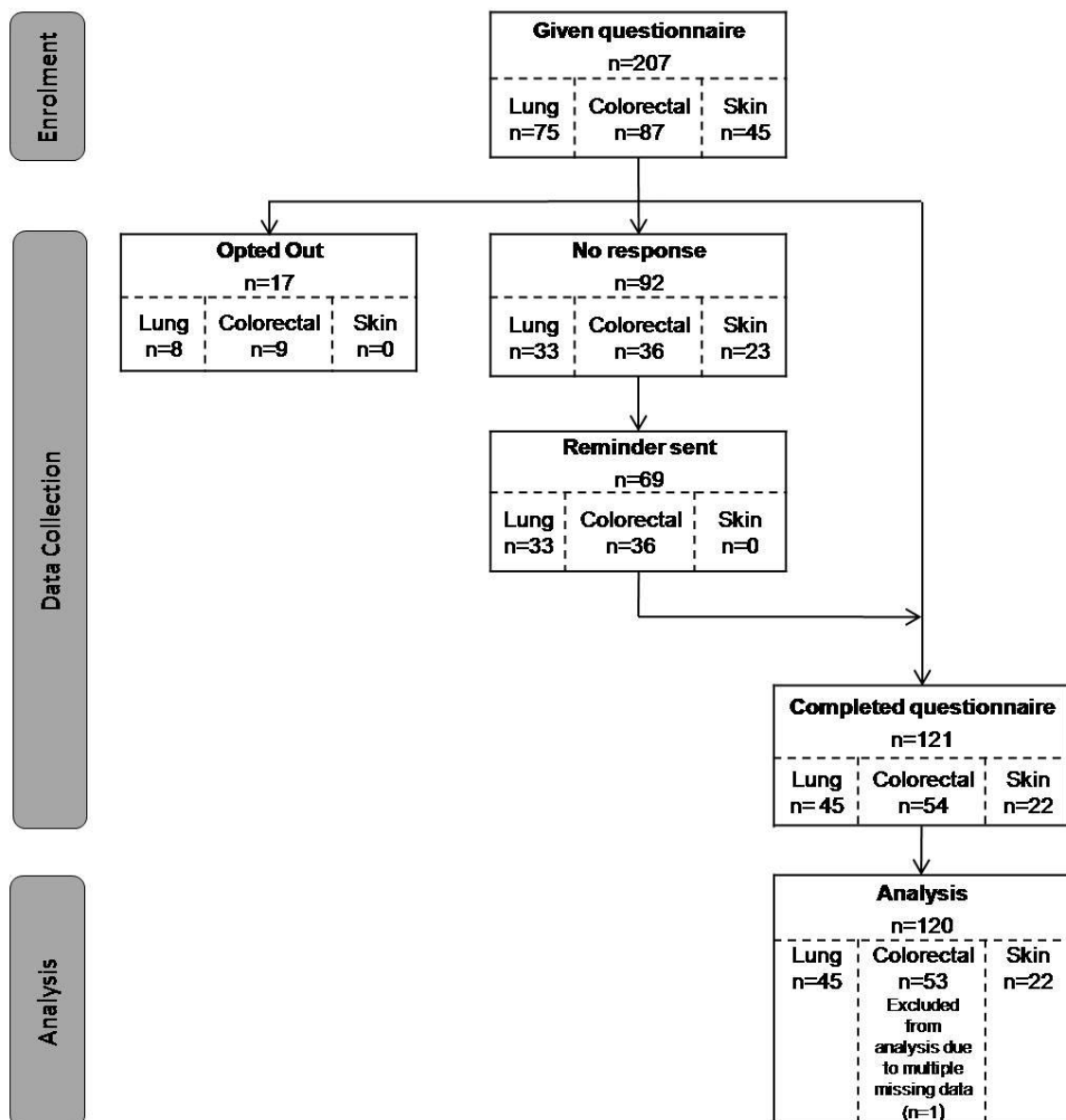


Figure 1. Recruitment Flowchart

Seventeen people (8.2%) opted out by returning the reply slip. Of these 8 specified 'I don't want to think about it', 4 specified 'I do not wish to say' and 5 gave 'other' reasons such as: not wanting to talk about it; being mid-treatment and not wishing to answer the questions presently; self-identifying as ineligible due to a previous diagnosis; finding the questions too difficult to answer; and due to already participating in other research. The study generated a sample of 120 questionnaires that were suitable for analysis and, according to the power calculation, this sample size was appropriate to test the hypotheses.

3.2 SAMPLE CHARACTERISTICS

The sample comprised of 75 males and 45 females with an average age of 64 years (sd=12yrs, range 29–86yrs). The majority of the sample were of white ethnicity (87.3%) and had a range of academic qualifications. Approximately two thirds were married or living with a partner (67.5%) and one quarter were living alone (26.7%). Prior to receiving the diagnosis, half of the sample were retired (51.3%), over one third were either employed or self-employed (34.4%), a small percentage were home-makers (1.7%) and the remainder were unemployed (5.9%) or on long term sick leave (5.9%). This compares to post diagnosis where more people had retired (57.1%), were unemployed (6.7%), on long term sick leave (7.6%) or home-makers (2.5%), and less than one third (22.7%) were currently in some form of employment. The sample characteristics can be seen in Table 1.

Table 1. Demographic Characteristics of a Sample of Patients with Lung, Colorectal and Skin cancer

	N	(%)
Gender		
Males	75	62.5
Females	45	37.5
Ethnicity (n=118)		
Black – Carribean	3	2.5
Black – African	5	4.2
Indian	1	0.8
White	103	87.3
Bangladeshi	1	0.8
Chinese	2	1.7
Other	3	2.5
Highest level of education (n=118)		
No academic qualifications	37	31.4
GCSE/O-level/Equivalent	27	22.9
A-level/Equivalent	11	9.3
Degree level or higher	29	24.6
Other	14	11.9
Relationship status		
Single	18	15.0
Married/living with partner	81	67.5
Divorced/separated	9	7.5
Widowed	12	10.0
Living arrangements*		
Lives alone	32	26.7
Lives with partner	79	65.8
Lives with children	20	16.7
Lives with housemates	1	0.8
Lives with parents	1	0.8
Other	5	4.2
Employment status prior to diagnosis (n=119)		
Unemployed	7	5.9
Employed	25	21.0
Self-employed	16	13.4
Home-maker	2	1.7
Long-term sick	7	5.9
Retired	61	51.3
Other	1	0.8
Employment status following diagnosis (n=119)		
Unemployed	8	6.7
Employed	17	14.3
Self-employed	10	8.4
Home-maker	3	2.5
Long-term sick	9	7.6
Retired	68	57.1
Other	4	3.4

n = 120 unless otherwise stated

* Percentages add to greater than 100 as participants could endorse more than one option

3.2.1 Disease-related information

The sample comprised of 22 (18.3%) with skin cancer, 45 (37.5%) with lung cancer and 53 (44.2%) with colorectal cancer. 54 (45.5%) had received their diagnosis within the last year and 65 (54.6%) had received their diagnosis 1-2 years previously. In terms of the first treatment received (n=119): 3 (2.5%) had radiotherapy, 9 (7.6%) had chemotherapy, 97 (81.5%) had surgery and 10 (8.4%) reported having ‘other’ treatments which most often comprised of a combination of the aforementioned treatments. Of the 118 people who responded to the question, ‘Is your cancer visible, or does the treatment you received for it, make it visible to a stranger?’, the majority (83.1%) said ‘no’, and the remaining 20 (16.9%) said ‘yes’, of which 13 had skin cancer, 3 had colorectal cancer and 4 had lung cancer. 41 (34.5%) were informed of their diagnosis when alone, whilst the majority (65.5%) reported that they had someone else present. Most commonly the diagnosis was heard in the presence of a spouse or partner (72.4%), followed by children (11.8%) or some other relative (7.9%), parents (3.9%) or a friend (3.9%).

3.2.2 Perceived social support

The mean ESSSI score was 28.7 (sd=6.4, range 8-34). The median score was 31 and the mode was 34 indicating high levels of perceived social support in the sample (n=119).

3.2.3 Unsupportive social interactions

The total and subscale mean scores of the USII are detailed in Table 2. On the individual items within the scale, the highest means were for: Item 4 “Someone didn’t know what to say, or seemed afraid of saying/doing the ‘wrong’ things” (mean=1.08, sd=1.21); Item 7 “Someone said I should look on the bright side” (mean=1.15, sd=1.45); Item 14 “Someone felt that I should focus on the present and/or the future, and that I should get on with my life” (mean=1.23, sd=1.32); Item 17 “Someone told me to be strong, to keep my chin up, or that I shouldn’t let it bother me” (mean=1.31, sd=1.32).

Table 2. Unsupportive Social Interactions Inventory Scores in a Sample of Patients with Lung, Colorectal and Skin Cancer

Scale	Mean	Standard Deviation	Range
Distancing	0.48	0.63	0.00-3.17
Bumbling	0.91	0.78	0.00-3.00
Minimizing	0.91	0.83	0.00-3.17
Blaming	0.35	0.51	0.00-2.00
Total	0.66	0.56	0.00-2.58

Ratings on a 5-point scale, from 0 = 'none' to 4 = 'a lot'

3.2.4 Perceived stigma

The majority of the sample (77%) did not endorse any of the stigma items and were categorised as reporting 'low' perceived stigma, with 14% reporting 'moderate' levels and 9% reporting 'high' levels of felt stigma. The mean felt stigma score for the sample (n=118) was 0.35 (sd=0.72, range 0-3) and the median and mode were both equal to 0.

3.2.5 Psychological distress

The results of the HADS can be seen in Table 3. The majority of the sample scored within the normal range for anxiety (mean=6.51, sd=4.30) and depression (mean=4.29, sd=3.90). 17% of cases would be considered as reaching the clinical cut-off for anxiety and 8% for depression (when a score of ≥ 11 is used as a clinical threshold).

Table 3. Hospital Anxiety and Depression Scale scores in a Sample of Patients with Lung, Colorectal and Skin Cancer

Scale	Frequency n (%)	Mean	Standard Deviation	Range
Anxiety (n=116)				
Normal	68 (59%)	6.51	4.30	0-19
Mild	28 (24%)			
Moderate	15 (13%)			
Severe	5 (4%)			
Depression (n=118)				
Normal	97 (82%)	4.29	3.90	0-20
Mild	12 (10%)			
Moderate	6 (5%)			
Severe	3 (3%)			

3.2.6 Dispositional openness

The majority of the sample agreed to being dispositionally open with 23 (19%) ‘strongly agreeing’, 25 (21%) ‘moderately agreeing’, 30 (25%) ‘slightly agreeing’ and the remaining 42 (35%) disagreeing to some extent that they are a person who usually talks to other people about their problems, concerns and daily life events. The group mean was 3.88 (sd=1.63), with the median and mode both being 4.

3.3 PRELIMINARY ANALYSES

Each variable was investigated to see whether it met the parametric assumptions of having a normal distribution. For the primary outcome variable detailing the mean level of disclosure across all social targets, the distribution was found to be normal according to K-S Lilliefors, $D(111)=0.07$, $p>0.05$, and so a parametric linear regression model was used. According to the K-S Lilliefors test of normality, many of the psychological predictor variables differed significantly from a normal distribution, including: the ESSI measure, used as an index of perceived social support, $D(119)=.212$, $p<0.01$; the Unsupportive Social Interactions Inventory data, $D(118)=.136$, $p<0.01$; the felt stigma scale, $D(118)=.456$, $p<0.01$; the HADS Anxiety subscale, $D(116)=.094$, $p<0.05$, and the HADS Depression subscale, $D(118)=.163$, $p<0.01$; and the measure of ‘general openness’, $D(120)=.181$, $p<0.01$. Thus non-parametric equivalents were used for the correlational analyses.

3.4 DISCLOSURE PATTERNS

3.4.1 Question 1) To what extent do patients with cancer talk about their diagnosis across a range of social targets?

The degree of disclosure across the range of social targets can be seen in Table 4. The majority talked at least to some extent to spouses (80%), doctors (93%), nurses (93%), siblings (68%), friends (84%), children (71%) and other cancer patients (52%). Complete non-disclosure was less common, with only 1% reporting non-disclosure to spouses, 4% to nurses, 5% to doctors, 6% to children, 8% to siblings, 9% to colleagues, 9% to fathers, and 11% to mothers. Higher levels of complete non-disclosure were

reported to professional friends/neighbour (13%), therapist/counsellor (26%), other cancer patients (27%) and minister/rabbi/pastoral counsellor (31%). The study was able to discriminate between those who did not disclose due to not having the opportunity versus those who purposefully chose not to disclose. Of those choosing not to disclose, the greatest level of purposeful non-disclosure was found for ministers (19%), followed by professional therapist (13%), friends/neighbour (10%), other cancer patients (9%), mother (7%), colleagues (6%), father (5%), followed by children and siblings (both 3%), other (2%), with only 1% choosing not to disclose to doctors and nurses, and no-one purposefully did not speak to their spouse.

Inspection of the mean degree of disclosure to each social target across the group revealed the highest level of disclosure was to doctors, nurses, spouses, friends and children, with notably less disclosure on average to parents. This coincides with a large proportion of the sample reporting that the social targets of mother and father were not applicable to them (69% and 77% respectively). Averaging across all social targets the group tended to talk between 'a little' and 'somewhat', with the overall group mean level of disclosure being 2.71 (sd=0.64). This represents the primary outcome variable of disclosure.

On average, people reported at least some level of talk to 7 different social target categories (sd=2.0, range 2-11, median=6, mode=6). Two people (1.8%) reported only talking to 2 social target categories; for one person this included their spouse and doctors, for the other this was colleagues and nurses. Overall, 81% of the sample (n=90) spoke to between 5 and 9 social targets. Therefore, these results support the hypothesis that the majority of patients will disclose to a range of social targets.

Table 4. Frequencies, Percentages and Mean Degree of Disclosure Reported by Patients with Cancer across a Range of Social Targets

	Degree of Disclosure n (%)						Disclosure score	
	Purposefully chose not to talk	Did not have the opportunity to talk	Talked a little	Talked somewhat	Talked very much	N/A	Mean	Standard deviation
Disclosure target								
Spouse/romantic partner	0 (0%)	1 (1%)	12 (10%)	20 (17%)	64 (53%)	23 (19%)	2.84	1.55
Co-workers/colleagues (n=118)	7 (6%)	3 (3%)	18 (15%)	21 (18%)	12 (10%)	57 (48%)	1.33	1.47
Doctors (n=116)	1 (1%)	5 (4%)	23 (20%)	37 (32%)	48 (41%)	2 (2%)	3.06	0.99
Nurses (n=117)	1 (1%)	4 (3%)	29 (25%)	38 (33%)	41 (35%)	4 (3%)	2.91	1.04
Siblings i.e. brothers/sisters (n=116)	3 (3%)	6 (5%)	30 (26%)	21 (18%)	28 (24%)	28 (24%)	2.10	1.48
Professional therapist/counsellor (n=118)	16 (13%)	15 (13%)	8 (7%)	10 (8%)	9 (8%)	60 (51%)	0.96	1.27
Friend(s)/neighbour (n=119)	12 (10%)	4 (3%)	45 (38%)	34 (29%)	20 (17%)	4 (3%)	2.42	1.03
Other cancer patients (n=119)	11 (9%)	21 (18%)	33 (28%)	18 (15%)	11 (9%)	25 (21%)	1.65	1.23
Minister/Rabbi/Pastoral counsellor (n=119)	23 (19%)	14 (12%)	3 (3%)	4 (4%)	4 (4%)	71 (58%)	0.60	0.95
Mother (n=119)	8 (7%)	5 (4%)	10 (8%)	7 (6%)	7 (6%)	82 (69%)	0.69	1.21
Father (n=118)	6 (5%)	5 (4%)	8 (7%)	5 (4%)	4 (3%)	90 (77%)	0.49	1.03
Children	4 (3%)	3 (3%)	23 (19%)	22 (18%)	40 (34%)	28 (23%)	2.33	1.56
Other (n=119)	2 (2%)	3(2.5%)	3 (2.5%)	6 (5%)	6 (5%)	99 (83%)	0.45	1.10
Group Mean^a & Standard Deviation							2.71	0.64

^aMean calculated from each person's individual mean level of disclosure across all available social targets
N = 120 unless otherwise stated

When the subgroups of potential disclosure targets were aggregated into mutually exclusive categories of family, friends and medical personnel, as seen in Table 5, little or no disclosure was reported by 21% to family members, 27% to medical personnel, and 43% to friends. The degree of disclosure was fairly consistent across disclosure categories, with higher levels of disclosure reported to medical personnel (mean=3.07, sd=0.81, median=3) and family (mean=2.83, sd=0.82, median=3), followed by friends (mean=2.39, sd=0.86, median=2.3).

Table 5. Percentages and Mean Degree of Disclosure Reported by Patients with Cancer Across Social Categories

	Degree of Disclosure %						Disclosure score	
	Purpose-fully chose not to talk	Did not have the opportunity to talk	Talked a little	Talked somewhat	Talked very much	N/A	Mean	SD
Disclosure category								
Family members (n=103)	4%	3%	14%	13%	24%	42%	2.83	0.82
Medical Personnel (n=114)	1%	4%	22%	32%	38%	3%	3.07	0.81
Friends (n=116)	8%	8%	27%	21%	12%	24%	2.39	0.86

3.5 QUESTION 2) IS IT HELPFUL TO TALK?

3.5.1 Quantitative responses

The overall ratings of how helpful it was to talk were high (mean=4.09, sd= 0.97) with the majority (67.8%) rating helpfulness as either 4 or 5 on the scale, and 94.6% rating it as either 3, 4 or 5. These ratings were negatively skewed towards talking being helpful (median=4). Overall, the findings support the hypothesis that most people find it helpful to disclose.

3.5.2 Qualitative responses

3.5.2.1 *Reasons why talking is helpful*

In relation to the ways in which talking was found to be helpful, the following eight themes were identified:

1. CLARIFY THOUGHTS

Eleven participants (10%) indicated disclosure helped to clarify thoughts. They reported that talking allows for clarification of thoughts and feelings, processing and making sense of their circumstances, and helps with decision making.

“Helps get things straight in my head” Participant CR02, colorectal cancer.

“Helps to focus your mind on what you think...” Participant LU52, lung cancer.

2. PRACTICAL PLANNING

Nine participants (8%) indicated that disclosure helped with practical planning. They reported that it allows for pragmatic life planning and for gaining assistance in these areas.

“Just to let them know, as I have no progeny, ... in the event of my death, my body will be offered to the school of anatomy, any part that can be of use to other’s or the furtherance of medical science...I made these arrangements...I want to be useful after I’m gone.” Participant CR11, colorectal cancer.

3. REASSURANCE AND SUPPORT

Forty-six participants (42%) indicated that disclosure helped to gain reassurance and support from others and also, hearing the experience of others, helped normalise the experience. Thus talking helped patients realise they are not alone and reminded them that there is support from others.

“In many cases they suffered from similar ailments and it was comforting to find that I was not alone with the problem.” Participant CR03, colorectal cancer.

4. PERSPECTIVE

Twenty participants (18%) indicated that disclosure helped gain or maintain a sense of perspective, and engendered hope and optimism helping one remain positive.

“There was much reassurance and a realisation that the diagnosis was not an immediate death sentence” Participant CR35, colorectal cancer.

“It made me feel positive about the future” Participant CR37, colorectal cancer.

5. GIVING INFORMATION

Twenty-three participants (21%) indicated that disclosure helped with giving information. They reported that talking allows for the education of others, to help others understand cancer and the treatments, which may help reduce their worries and help them relax. It helps demystify the disease, prevent stigma and misinformation.

“[To] Give others an understanding of my type of cancer and what my operations would achieve” Participant SK04, skin cancer.

“To make them feel relaxed and not to worry” Participant CR24, colorectal cancer.

6. ADJUSTMENT

Nine participants (8%) indicated that disclosure helped with adjustment. They reported that talking helps with coming to terms with the diagnosis, and promotes acceptance (e.g. allows one to incorporate the cancer into their identity and sense of self).

“...has helped make something abstract become easier to accept” Participant CR29, colorectal cancer.

7. GAIN INFORMATION

Eighteen participants (17%) indicated that talking was helpful for gaining information. They reported that talking helps gain medical knowledge and a better understanding of the disease, prognosis, treatments etc.

“To fully understand what was wrong with me; how the treatment would proceed; the final outcome; likelihood of cancer returning” Participant LU75, lung cancer.

“[It was] very helpful to get as much information as possible, to what was for me an unknown cancer, and the likely outcome” Participant SK51, skin cancer.

8. EMOTIONAL EXPRESSION

Twenty-eight participants (26%) indicated that talking helped with emotional expression. They reported that verbalisation permits sharing and emotional expression which is cathartic and releases internal pressure and stress, as well as relieving fears.

“Took the pressure off me, from bottling [it] up inside. Made me feel a bit better for sharing my fears” Participant LU37, lung cancer.

3.5.2.2 Reasons why talking is unhelpful

In relation to the ways in which talking was unhelpful, 40% (n=48) gave some sort of written response, and 60% (n=72) left the item blank or indicated that the item was not applicable either by writing ‘N/A’, or by writing a statement that suggested they did not find it unhelpful to talk (e.g. “I have not found talking about melanoma unhelpful” and “Nothing experienced of an unhelpful or negative sort”). The following seven themes were identified from the 48 responses:

1. PITY

Seven participants (15%; 6% of total sample) indicated that talking led to unwanted pity or resulted in being treated differently.

“The more people (outside main circle of friends) know the more I feel like I am this month’s sad story...and feel like lots of people are looking at us”
Participant CR02, colorectal cancer.

2. PERSONALLY UPSETTING

Eleven participants (23%; 9% of total sample) indicated that talking was personally upsetting. They reported that it can act as a reminder, or lead to hearing scary stories and accounts. This makes talking a negative experience or shifts the focus to the negative.

“I found it too upsetting to talk to the people I loved” Participant CR06, colorectal cancer.

“It was...depressing to be reminded of my illness” Participant CR38F, colorectal cancer.

3. BURDEN

Eight participants (17%; 7% of total sample) indicated that talking can be a burden. They reported that it can be upsetting for others and place a burden on others. They believed that others wouldn’t cope with their levels of distress and/or wished to protect them. They found it hard seeing the emotional distress of others.

“I was sorry to cause so much upset and fear for my family” Participant SK40, skin cancer.

“Watching their reactions and emotions showing through” Participant CR72, colorectal cancer.

4. POOR UNDERSTANDING

Thirteen participants (27%; 11% of total sample) indicated that talking was unhelpful due to others having a poor understanding. They reported that people lack a medical and/or emotional grasp of their circumstances. Other people over- or under-estimate the severity of the disease, or make assumptions based on other people they know rather than having an understanding of your personal case.

“To speak to laymen re this particular cancer was very difficult as they just saw it as a mole removal, then get back to how you were. No-one seemed to understand how severe this was” Participant SK07, skin cancer.

“...when they had an unrealistic view of the future” Participant LU57, lung cancer.

5. UNHELPFUL REACTIONS

Ten participants (21%; 8% of total sample) indicated that talking led to unhelpful reactions. They reported that often people do not know how to react or respond. They don't know what to say and it can feel very awkward. They can give unwanted advice and even be blaming.

“Some ‘friends’ made unhelpful/hurtful remarks or disappeared” Participant CR84, colorectal cancer.

“Sometimes felt as though it is portrayed as my fault to have the disease” Participant CR78F, colorectal cancer.

6. STIGMA

Five participants (10%; 4% of total sample) indicated that talking is unhelpful due to stigma. They reported that cancer has a level of stigma attached to it, it is a 'taboo' subject and people fear the worst e.g. they think you will 'keel over' or 'write you off'. Cancer's bad reputation means people are reluctant to talk about it.

“They wrote you off as someone on a death roll” Participant CR78F, colorectal cancer.

7. UNCERTAINTY

Four participants (8%; 3% of total sample) indicated that talking was unhelpful due to uncertainty around the severity of the disease, the prognosis, and likely benefit of treatment. Having unclear or limited information can often raise more questions

from others and it can be difficult when you don't have an answer to give, or when the questions feel personally intrusive.

"Did not want friends/acquaintance to know until I knew the final outcome" Participant LU75, lung cancer.

3.6 QUESTION 3) WHAT FACTORS ARE ASSOCIATED WITH THE DEGREE OF DISCLOSURE?

3.6.1 Univariate analyses

It was hypothesised that higher levels of disclosure would be associated with being female, younger age, cancer visibility, higher levels of perceived social support, lower levels of unsupportive social interactions, lower levels of perceived stigma, lower levels of psychological distress, and a general disposition towards disclosure.

The one-tailed correlational analyses, used to test this hypothesis, can be found in Table 6. Using Spearman's rho correlation co-efficient, the degree of disclosure was significantly correlated with social support, $rho=.163$, $p<0.05$, and general openness, $rho=.270$, $p<0.01$. These correlations were both positive, such that higher levels of disclosure were associated with higher levels of perceived social support and greater levels of general openness. Scatterplots depicting these relationships are contained in Appendix 9.

Table 6. One-tailed Correlational Analysis Detailing the Relationship Between the Degree of Disclosure and Demographic, Disease-Related and Psychological Variables in a Sample of Patients with Cancer

		Degree of Disclosure
Age (n=106)	Spearman's rho	.051
	p-value	.303
Gender	Spearman's rho	-.029
	p-value	.380
Cancer visibility (n=110)	Spearman's rho	-.012
	p-value	.452
Social Support (n=110)	Spearman's rho	.163*
	p-value	.045
Unsupportive Social Interactions Inventory	Spearman's rho	-.053
	p-value	.290
Stigma (n=109)	Spearman's rho	-.111
	p-value	.125
HADS-Anxiety (n=108)	Spearman's rho	-.145
	p-value	.067
HADS-Depression (n=109)	Spearman's rho	-.131
	p-value	.088
General Openness	Spearman's rho	.270**
	p-value	.002

*Correlation is significant at the 0.05 level

**Correlation is significant at the 0.01 level

n=111 unless stated otherwise

Further exploratory analyses were conducted to investigate whether any of the other demographic and disease related variables (including ethnicity, education, living arrangements, employment status, cancer type, time since diagnosis, treatment type, and whether the person had company whilst receiving the diagnosis), were associated with the degree of disclosure.

The relationships were explored either using correlational analyses (where variables consisted of two categories) or the Kruskal-Wallis Test (where variables contained more than two categories). The exploratory correlations can be seen in Table 7. The two-tailed analyses revealed that disclosure was not significantly correlated with any of the additional variables.

Table 7. Two-tailed Correlational Analysis Detailing the Relationship Between the Degree of Disclosure and Demographic and Disease-Related Variables in a Sample of Patients with Cancer

		Degree of Disclosure
Ethnicity (n=109)	Spearman's rho	-.102
	p-value	.293
Lives alone	Spearman's rho	-.016
	p-value	.866
Lives with partner	Spearman's rho	-.026
	p-value	.787
Lives with children	Spearman's rho	.016
	p-value	.870
Lives with housemates	Spearman's rho	-.153
	p-value	.108
Lives with parents	Spearman's rho	-.137
	p-value	.152
Lives with other	Spearman's rho	.081
	p-value	.396
Time since diagnosis (n=110)	Spearman's rho	.039
	p-value	.688
Company when received diagnosis (n=110)	Spearman's rho	-.024
	p-value	.803

*Correlation is significant at the 0.05 level

**Correlation is significant at the 0.01 level

n=111 unless otherwise stated

The results of the independent samples Kruskal-Wallis Test, used to explore whether the mean level of disclosure differed according to demographic and disease factors, can be found in Table 8. The Kruskal-Wallis Test indicated that the mean level of disclosure did not significantly differ according to education, employment status (either prior to or following diagnosis), or cancer type. However the mean level of disclosure did significantly differ according to treatment type. Mann-Whitney U Tests revealed that those receiving chemotherapy disclosed significantly more (mean=3.10, sd=0.17) than those having surgery (mean=2.63, sd=0.07), [U=193.00; $z=-2.168$, $p<0.05$], and that those receiving 'other' treatments disclosed significantly more (mean=3.13, sd=0.17) than those having surgery (mean=2.63, sd=0.07), [U=246.50; $z=-2.340$, $p<0.05$]. This difference was taken into consideration and 'treatment type' was controlled for in the linear regression used to predict the degree of disclosure.

Table 8. Results of the Kruskal-Wallis Tests Comparing the Degree of Disclosure Across the Categories Comprising Demographic and Disease-Related Variables in a Sample of Patients with Cancer.

Variable	Mean	Median	χ^2	p-value
Education (n=109)				
No academic qualifications	2.55	2.45	6.707	0.152
GCSE/O-level/Equivalent	2.71	2.58		
A-level/Equivalent	2.58	2.54		
Degree level of higher	2.82	2.84		
Other	2.96	3.00		
Employment status prior to diagnosis (n=110)				
In employment	2.61	2.64	1.154	0.561
Retired	2.77	2.67		
Other	2.76	2.80		
Employment status following diagnosis (n=110)				
In employment	2.61	2.27	.932	0.628
Retired	2.78	2.67		
Other	2.65	2.62		
Cancer type (n=111)				
Skin	2.55	2.60	2.098	0.350
Colorectal	2.77	2.82		
Lung	2.70	2.68		
Treatment type (n=110)				
Radiotherapy	2.66	2.66	9.424	0.024*
Chemotherapy	3.10	2.98		
Surgery	2.63	2.60		
Other	3.13	3.35		

*Significant at the 0.05 level

3.6.2 Multivariate analyses

Hierarchical multiple regression was used to assess the ability of two psychological variables (social support and general openness) to predict levels of disclosure, after controlling for the influence of treatment type and the potential covariance between psychological variables. The results can be seen in Table 9. Treatment type was entered at block 1, explaining 6% of the variance in disclosure, $F(1,107)=8.303$, $p<0.01$. After entry of social support and general openness at block 2, the total variance explained by the model as a whole was 13%, $F(3,105)=6.387$, $p<0.01$, indicating that the psychological variables explain an extra 7% of the variance. In the final model, two measures were statistically significant, with treatment type ($B=-.240$, $p<0.01$) and general openness ($B=.233$, $p<0.05$) being independent predictors of the degree of disclosure.

Table 9. Summary of the Multivariate Hierarchical Regression Analysis for Variables Predicting the Degree of Disease Disclosure in Patients with Cancer.

Variable	Beta	T	p-value	R ²	Adjusted R ²	F	p-value
Block 1 Treatment type	-.240	-2.666	0.009	0.072	0.063	8.303	0.005
Block 2 Openness	0.233	2.582	0.011	0.154	0.130	6.387	0.001
Social support	0.155	1.725	0.087				

3.7 QUESTION 4) WHAT FACTORS ARE ASSOCIATED WITH HELPFULNESS OF DISCLOSURE?

3.7.1 Univariate analyses

Simple logistic regressions were carried out to investigate which of the factors were significantly related to ‘helpfulness’ of disclosure. As can be seen in Table 10, ‘helpfulness’ was significantly related to the variables of social support, (OR=1.11; 95% CI=1.039-1.180; $p<0.01$), depression (OR=0.90; 95% CI=0.809-0.993; $p<0.05$), and general openness (OR=1.39; 95% CI=1.085-1.784; $p<0.01$). This indicates that those who perceived more social support, those who were generally more open and those who were less depressed were more likely to perceive disclosure as being helpful. None of the other psychological, demographic or disease related variables were associated with the helpfulness of disclosure.

Table 10. Results of each of the Univariate Logistic Regression Analyses for Psychological, Demographic and Disease-Related Variables Predicting the Helpfulness of Disclosure in a Sample of Patients with Cancer.

Variable	Beta	Standard Error	Odds Ratio	p-value	95% Confidence Interval
Psychological variables					
Social support	.102	.033	1.107	0.002**	1.039-1.180
Unsupportive Social Interactions (n=111)	-.018	.015	.983	0.232	.955-1.011
Stigma (n=110)	-.175	.270	.839	0.516	.495-1.424
HADS-Anxiety (n=109)	-.034	.047	.967	0.471	.882-1.060
HADS-Depression (n=110)	-.110	.052	.896	0.036*	.809-.993
General Openness	.330	.127	1.391	0.009**	1.085-1.784
Demographic variables					
Age (n=107)	-.014	.017	.986	0.429	.953-1.020
Gender	.394	.431	1.482	0.361	.637-3.451
Ethnicity (n=111)	.208	.630	1.231	0.742	.358-4.229
Education (n=111)					
No academic qualifications	-	-	1.0	0.146	Ref.
GCSE/O-level/Equivalent	.693	.565	2.000	0.220	.660-6.056
A-level/Equivalent	1.199	.857	3.316	0.162	.618-17.800
Degree level of higher	.994	.580	2.702	.086	.867-8.417
Other	-.460	.658	.632	.485	.174-2.296
Lives alone	.477	.445	1.611	0.284	.674-3.852
Lives with partner	-.675	.420	.509	0.108	.224-1.160
Lives with children	-.031	.541	.969	0.954	.336-2.799
Employment status prior to diagnosis (n=111)					
Other	-	-	1.0	0.756	Ref.
In work	.423	.627	1.527	0.550	.447-5.221
Retired	.156	.588	1.168	0.791	.369-3.703
Employment status following diagnosis (n=111)					
Other	-	-	1.0	0.586	Ref.
In work	.460	.638	1.583	0.471	.454-5.527
Retired	-.095	.508	.909	0.851	.336-2.460
Disease-related variables					
Cancer type					
Skin	-	-	1.0	.436	Ref.
Colorectal	.641	.559	1.897	.252	.635-5.673
Lung	.182	.559	1.200	.744	.402-3.586
Time since diagnosis (n=111)	-.372	.413	.689	.367	.307-1.548
Treatment type (n=111)	-1.245	.661	.288	0.06	.079-1.051
Cancer visibility (n=111)	-.353	.566	.703	.533	.232-2.130
Company when received diagnosis (n=111)	.059	.429	1.061	.890	.458-2.459

*p<0.05, **p<0.01, n=112 unless otherwise stated

3.7.2 Multivariate analyses

Direct logistic regression was performed to assess the impact of social support and general openness on the helpfulness of disclosure. The model containing these 2 independent variables was statistically significant, $\chi^2 (2, N=112) = 17.194, p<0.01$, indicating that the model was able to distinguish between those who did and did not find talking helpful. The model as a whole explained between 14% (Coz and Snell R Square) and 20% (Nagelkerke R Squared) of the variance in helpfulness status, and correctly classified 73.2% of the cases. As shown in Table 11, both of the independent variables made a unique statistically significant contribution to the model (General Openness: OR=1.40; 95% CI=1.074-1.821; $p<0.05$; Social Support: OR=1.109; 95% CI=1.037-1.186). The strongest predictor of whether talking was helpful was general openness. The odds ratio of 1.4 suggests that the odds of regarding disclosure as being helpful increase 1.4 fold for each unit increase in ‘general openness’.

Table 11. Summary of the Multivariate Logistic Regression Analysis for Variables Predicting the Helpfulness of Disclosure in Patients with Cancer.

Variable	Beta	Standard Error	Odds Ratio	95% Confidence Interval	-2 log likelihood	Nagelkerke R ²
Social support	.103	.034	1.109**	1.037-1.186	123.465	.199**
General openness	.336	.135	1.399*	1.074-1.821		

* $p<0.05$, ** $p<0.01$

4.0 DISCUSSION

This study was a cross-sectional, questionnaire survey of cancer patients that sought to quantify the degree of disclosure (i.e. how much patients talk about their thoughts and feelings surrounding the diagnosis of cancer) and the helpfulness of disclosure. It also aimed to identify the factors associated with each of these variables. The main advantage of this study over previous work was that the sample comprised of a range of cancer types (skin, colorectal and lung) and was of mixed gender.

This chapter will discuss the findings of the study, firstly by referring to the psychological characteristics of the sample, and then in relation to the research questions posed in the introduction. Attention will be drawn to the limitations of the study and recommendations for future research will be made, as well as giving consideration to the study's implications.

4.1 FINDINGS

4.1.1 Psychological characteristics of the sample

The patients in this study reported high levels of perceived social support, low levels of unsupportive social interactions, low levels of stigma and distress, and the majority reported high levels of general openness. These findings are largely consistent with previous literature. Like the study sample in which the ENRICHD Social Support Inventory was developed (Mitchell et al., 2003), the distribution of social support scores was skewed negatively with the mean close to the maximum score, suggesting that the current sample felt well supported by their social network.

Regarding the Unsupportive Social Interactions Inventory, the current sample reported slightly lower overall levels of unhelpful reactions (mean=0.66) compared to a previous sample of patients with breast cancer (mean=0.71; Figueiredo et al., 2004). However ratings of 'blaming' reactions were slightly higher in the current sample (mean=0.35) than in the breast cancer sample (mean=0.24; Figueiredo et al., 2004). Like the previous study, the 'minimising' and 'bumbling' subscales were rated as being the

highest type of unhelpful reaction received. The fact that patients felt others minimised their concerns or were ‘bumbling’, insofar as their responses were awkward and uncomfortable, is in-keeping with some of the reasons given - by the current sample - for why talking was unhelpful. Most notably there are parallels between the minimising and bumbling subscales, and the reported themes of ‘poor understanding’ and ‘unhelpful reactions’. However, overall the mean scores for unsupportive reactions received by the group tended to be low.

In the current sample, the majority (77%) reported no sense of felt stigma and the remainder (23%) indicated some sense of stigma. The percentage of patients feeling stigmatised to some degree is slightly higher than in a sample of patients with epilepsy, where 14% reported feeling some sense of stigma using the same scale (Jacoby, 1994). This disparity is in-keeping with the notion that apart from AIDs, cancer is more stigmatising than any other medical condition (Stahly, 1989). Interestingly, in an earlier study of patients with rectal cancer as many as half felt some sense of stigma (MacDonald & Anderson, 1984). Although this was found using a different stigma scale, it is interesting to compare these higher rates of stigma, found over 20 years ago, to the lower rates of stigma felt by the current sample (which incidentally also included people with rectal cancer). Taken together, these findings suggest that, although almost one quarter of the current sample did feel some stigma, cancer is perhaps no longer quite as stigmatising as it once was; this may reflect better knowledge and awareness generated through health promotional advertising and the investments in research leading to better treatments. The finding that the majority did not feel stigmatised is reassuring, given the literature that suggests stigma can have implications for the social responses of others as well as a negative impact on the individual’s self-concept (e.g. Fife & Wright, 2000).

A range of anxiety and depression scores were reported by the current sample, but mean scores for anxiety (6.5) and depression (4.3) both fell within the normal range for the group as a whole and are not dissimilar to a previous study of 568 cancer patients that found a mean score of 5.4 for anxiety and 3.0 for depression (Moorey et al., 1991). Also these scores are surprisingly consistent with the average levels established in a large sample (n=1792) in the general population (Crawford et al., 2001). Thus distress levels reported by the current sample are consistent with the literature which suggests

that patients with cancer are fairly normal and that only a minority will experience clinically significant levels of psychological distress (van't Spijker et al., 1997). In the current sample 17% met the clinical cut-off for anxiety and 8% for depression. This compares to 13% that met the clinical cut-off for depression in a sample (comprising of breast and prostate cancer patients) when using the Centre for Epidemiological Studies Depression Scale (CES-D: Ullrich et al., 2008). Although the discrepancy in those being classified as depressed is small, it is important to consider the reasons. It may be that the CES-D is more sensitive than the HADS at detecting possible cases of depression or it may be that the current sample were just less depressed compared to a sample of patients with breast and prostate cancers; which often involve hormone treatments that can impact on mood (Cancer Research UK, 2012).

Regarding the disposition to disclose, indexed by 'general openness', a substantial proportion (40%) moderately or strongly agreed that they generally disclosed in their everyday life, 25% slightly agreed, and 35% strongly, moderately, or slightly disagreed. These findings are largely consistent with those reported in a breast cancer sample, where 51.5% moderately or strongly agreed, 18.2% slightly agreed, and 24.2% strongly, moderately or slightly disagreed (Figueiredo et al., 2004). The results suggest that approximately one third of the current sample do not class themselves as generally being open. This variation in dispositional openness is important, since a common criticism of studies investigating disclosure is that samples are comprised of people that are naturally more open and willing to share their experiences and tend not to attract more reticent types (Hilton et al., 2009).

4.2 DISCLOSURE PATTERNS

4.2.1 To what extent do patients with cancer talk about their diagnosis across a range of social targets?

This study sought to quantify disease disclosure patterns. In line with previous quantitative research in this area (Figueiredo et al., 2004; Henderson et al., 2002; Pistrang & Barker, 1992), it found that the majority of patients do disclose at least to some degree, to a variety of social targets. The average number of social targets that

people disclosed to was seven, with the greatest levels of disclosure being to doctors and nurses, spouses, friends and children. Despite these high levels of disclosure across the range of social targets, 21-43% reported little or no disclosure to entire subgroups of their social network. This is largely consistent with Henderson et al (2002) who found that 20-30% of their sample reported little to no disclosure to entire subgroups.

This study advanced previous work by delineating between those who ‘purposefully chose not to talk’ to others and those who ‘did not have the opportunity to talk’. There was a fairly even split between these two categories across the range of social targets. However, regarding ‘other cancer patients’, 9% expressed they had chosen not talk, 18% suggested that they had not had the opportunity to, and a further 21% rated this category as not applicable to them (which may have meant that they did not have the opportunity to talk or did not have access to other cancer patients). Taken together, almost half (48%) of the sample reported complete non-disclosure to other cancer patients. This is surprising given the time spent in clinic waiting rooms, the likelihood that someone within their social network will have experienced cancer (given that more than 1 in 3 are affected), and the wide availability of support groups across the range of cancer types. Moreover, this finding challenges the prediction based on notions of Social Comparison Theory (Festinger, 1954) which suggests that, at times of stress, people who have had similar experiences (i.e. other cancer patients) will be important referents for comparison information and thus be approached for discussions. However, it is consistent with the findings of Pistrang and Barker (1992) whereby few women in their breast cancer sample preferred a confidant who had themselves had cancer and the women in their sample had not attended cancer support groups (despite knowing that they were available). Together these findings are in accordance with research on cancer support groups which finds that only a small proportion of the population utilise such groups, only 8% of one cancer sample (Sherman et al., 2008), and possibly do so when support from other sources is lacking or is unsatisfactory (Taylor, Falke, Shoptaw, & Lichtman, 1986). Given that the current sample reported high levels of perceived social support, it is likely that the support they received from their immediate network was adequate and did not necessitate talking to other cancer patients.

Consideration of disclosure levels to different social subgroups indicated that the average level of disclosure was highest to medical personnel (mean = 3.07), followed by

family members (mean = 2.83) and then friends (mean = 2.39). These findings replicate those of Henderson et al (2002) who found consistent levels of disclosure across the subgroups: medical personnel mean = 3.13; family members mean = 3.12; and friends mean = 2.81. The current findings lend weight to their proposal that, “health care providers may play a more important role than previously recognised in the social sharing needs of (breast) cancer patients” (Henderson et al., 2002, p. 58), and help confirm this beyond a breast cancer sample. Taken together these findings challenge the earlier work that tended to emphasize the importance of informal helpers and confidants (e.g. Pistrang & Barker, 1992). Perhaps this reflects a change in times and expansion of the roles of medical professionals whereby there is a broader focus beyond the physical aspects of care, to the holistic needs of the patient, which includes providing time for having supportive conversations. It may in part be driven by the patients’ desire to gain medical information and the value placed on the greater knowledge and information that is now available for the patient. A further possibility is that informal helpers (such as family and friends) still remain among the most important confidants, but are able to provide support in many subtle ways and through behaviours (e.g. via a hug, or purely just providing company) which is not reflected in the reported level of talk, whereas medical professionals provide support that is more verbally based leading to higher ratings of talk to professional staff. This suggestion is partly consistent with the study which found that patient and spouse disclosure scales showed only modest associations and led to the suggestion that emotional support from the spouse may be in the form of expressions of care and concern (Porter et al., 2005).

A further point of note in the exploration of this finding is that, the ‘medical personnel’ subgroup comprised of the disclosure targets ‘doctors’ and ‘nurses’. The generic terms used to describe these targets in the questionnaire mean that the patient may have rated these items with reference to oncology doctors, involved in their cancer care, as well as general practitioners. It would be expected that doctors working in oncology, would already possess knowledge of the person’s diagnosis, and in delivering the diagnosis these doctors may introduce further conversation and ask about the patient’s thoughts and feelings in relation to their diagnosis. Therefore in this context the patient does not necessarily have to initiate the disclosure. This crucial difference in the nature of disclosure (i.e. whether self-initiated or prompted) may account for finding a higher level of disclosure to medical personnel in this study. Future research should overcome

this difficulty by clearly labelling and distinguishing between the different types of doctors that are potential disclosure targets, or by asking specifically about instances of self-initiated disclosure.

It is important to note that, like Henderson et al (2002), the current study explored disclosure in a general quantitative way and did not explore the more qualitative aspects of disclosure, such as the content of disclosures to different social targets. It is possible that the types of discussions with medical personnel were qualitatively different from the more informal conversations had with family members and friends and this may be something for future research to consider, particularly as the nature and content of discussions have been found to relate to whether the outcomes are adaptive or maladaptive (Ullrich et al., 2008). The current study did however incorporate some qualitative data by asking participants to specify the ways in which talking was helpful and unhelpful. Although not directly able to offer insights into the actual content of disclosure, the themes that arose do lend some support to the notion that talking with medical personnel was helpful for gaining factual information on the disease. This data will be discussed in the next section.

4.2.2 Is it helpful to talk?

With regards to the question of whether it was helpful to talk, as hypothesised, the majority agreed it was, with 95% rating it as moderately to very helpful. This compares to 73% of a previous study of people with breast cancer (Figueiredo et al., 2004). The finding that discussions are generally considered helpful is consistent with the notions of Social Exchange Theory (e.g. Blau, 1964) and the HIV disclosure literature (Serovich, 2001) which suggests that people balance out the rewards and costs of disclosing and seek out social interactions that will be the most rewarding. Perhaps the high levels of helpfulness reported by participants in this study reflect their tendency and ability to seek out discussions that provide beneficial outcomes. 91% in the current sample elaborated on how disclosure was helpful by providing a response to the open-ended question of this nature. Thematic analysis of the open-ended questions revealed several ways in which talking was helpful. These included how disclosure helps clarify thoughts; assists with practical planning; provides reassurance and support; helps gain

perspective; allows for the communication of information (by giving and informing people as well as receiving medical knowledge); helps with adjustment; and allows for emotional expression. These themes are consistent with the Social Cognitive Processing Model of emotional adjustment to cancer which asserts that talking to a supportive other helps promote cognitive processing through a variety of ways (Lepore, 2001). It is also noted that one important reason talking was helpful was for gaining medical information about the disease. Eighteen people (17%) reported this, which may provide further explanation for the high levels of talk reported to the 'medical professionals' subgroup by this sample. The finding that 'emotional expression' was helpful can be explained by research in breast cancer that has linked emotional expression with better adjustment (Stanton et al., 2000) improved physical health (Low, Stanton, & Danoff-Burg, 2006) and increased quality of life, indexed by improvements in mood and decreased perceptions of pain (Goodwin et al., 2001).

In relation to the ways in which talking can be unhelpful, less than half (40%) provided a written response to the open-ended question with the majority either leaving it blank or indicating that it was not applicable. This pattern of responding again confirms that the majority found talking to be more helpful than not. However, important insights were gained from the responses that were provided and the themes that were identified confirmed previous findings: these included how talking can lead to an unwanted feeling of being pitied by others (Gray et al., 2000); it can be personally upsetting, or place a burden on others (Gray et al., 2000; Hilton et al., 2009); people can have a poor understanding and respond in unhelpful ways (Figueiredo et al., 2004; Wortman & Dunkel-Schetter, 1979); the level of stigma attached to cancer can mean people do not want to talk about it and it can create a social distance (Stahly, 1989); and the uncertainty surrounding a diagnosis can make conversations difficult. In an early study, Worden and Weisman (1980) looked at cancer patients who either 'accepted' or 'refused' counselling and identified a group of 'soft refusers' comprised of people hesitant to engage in talking therapy due to fears that it would add to their burden by making them more upset, depressed or agitated. These 'refusers' worried that their mental or emotional equilibrium would be unsettled by talking. These ideas fit with those in the current study who reported that talking was personally upsetting, as it acted as a reminder and shifted the focus onto the negative.

4.2.3 What factors are associated with the degree of disclosure?

In considering the factors associated with disclosure, only some of the hypotheses were confirmed. It was initially hypothesised that higher levels of disclosure would be associated with being female, younger age, cancer visibility, higher levels of perceived social support, lower levels of unsupportive social interactions, lower levels of stigma, lower levels of psychological distress, and a general disposition towards disclosure. As hypothesised, the degree of disclosure was found to be related to perceived social support and a disposition to disclose (i.e. 'general openness'). Results indicated small positive correlations such that greater levels of social support and general openness were related to higher levels of disclosure. The multivariate analyses indicated that these psychological variables were able to predict disclosure, after treatment type was controlled for. Together these variables accounted for 13% of the variance in disclosure, with general openness being an independent predictor. This compares to the previous study by Henderson et al (2002) who were able to predict 26% of the variance in disclosure using a different combination of variables.

However, against initial hypotheses, age, gender, cancer visibility, unsupportive social interactions, stigma and psychological distress were not found to be associated with the level of disclosure. One potential reason for this may be that the outcome measure of disclosure used in this study was very general and, by using average levels of disclosure, some of the variability in disclosures across social targets may have been lost. Interestingly with regards to gender, Ullrich and colleagues (2008) found that although men and women did not differ in the overall frequency of cancer discussions, they did show differences in relation to specific cancer topics. They found that females with breast cancer were more likely to discuss the threat of further treatment and threats to physical health, whereas males with prostate cancer were more likely to discuss threats to sexual relationships. Thus it remains possible that disclosure is affected by gender but in rather subtle ways that the current study was unable to detect due to the global measure of 'extent' of disclosure, rather than content.

The lack of a significant relationship between the extent of disclosure and the unsupportive social interactions people had is somewhat surprising and contrasts with previous research which found a small positive correlation between the unsupportive

social interactions measure and ‘failure to disclose’ (Figueiredo et al., 2004). One explanation for this may again be that the general measure of disclosure used by this study was not sensitive enough to pick up on the subtle differences in the amount disclosed to different social targets. Thus it may be that unhelpful and unsupportive reactions were received from one particular disclosure target, and led to less disclosure to that specific person, but that average levels of disclosure across social targets obscures such intricacies. Another more likely explanation is that unsupportive social interactions are implicated in disclosure, but rather than being associated with the ‘extent of disclosure’ measured by the current study, they are linked to the levels of ‘holding back’ from disclosure, which was measured in previous work. This suggestion is in-keeping with the notion that ‘secrecy’ (i.e. failure to disclose) is not just the converse of disclosure, but rather it is a qualitatively different process that one must actively engage with (Collins & Miller, 1994). As the current study did not measure levels of ‘holding back’ from disclosure, it remains possible that unsupportive interactions do affect disclosures, but in terms of how much one conceals and restricts disclosure, rather than how much one talks.

Regarding the hypotheses around stigma, the degree of stigma associated with cancer is thought to differ across the range of educational backgrounds, ethnicities, age groups and socioeconomic status (Yoo et al., 2009). However, the current sample was fairly narrow in these dimensions e.g. the majority were of White ethnicity, aged over 60 years, retired and reported low levels of perceived stigma. This may be one explanation as to why stigma did not appear to be associated with the degree of disclosure in this study. It may however also be a result of cultural shifts in time and cancer now being less stigmatising, as suggested earlier.

The hypothesis that higher levels of disclosure would be associated with lower levels of distress was rejected. The mixed findings in the literature, with regards to distress in cancer, suggest that any relationship between distress and disclosure is likely to be complex. Indeed, there are inconsistent findings with regards to disclosure and distress. For example, like the current study, Manne (1999) found no significant association between a single-item measure of cancer discussion and distress measures. Cordova and colleagues (2001b) found that higher rates of disclosure, on a single item measure of cancer discussion, were related to lower levels of depression and greater sense of

well-being in patients with breast cancer. Whereas, Ullrich and colleagues (2008) in fact found the opposite, with higher frequencies of cancer discussion being related to increased depression levels and poorer quality of life in their mixed cancer sample. One suggestion for the incongruence among studies is a result of measurement timing. Ullrich and colleagues (2008) suggest that discussions that occur early on in the cancer journey - under times of acute stress, active treatments and uncertain prognoses – may be better able to reduce distress. Whereas frequent discussion, years after treatment, may be an indication of poorer adjustment, lingering distress and ongoing ruminative process that may contribute to depression (Nolen-Hoeksema, 1991). To clarify whether this is the case it would be important to examine the content of disclosure discussions, since it is conceivable that even discussions early on in the disease process could be of a ruminative and unhelpful nature, and so could lead to higher levels of distress.

This study also conducted exploratory analyses to investigate whether additional demographic and disease related variables (i.e. ethnicity, education, living arrangements, employment status, cancer type, time since diagnosis, treatment type, and whether the person had company whilst receiving the diagnosis) were related to disclosure. Differences in disclosure were noted according treatment type, whereby those receiving treatments other than surgery disclosed to a greater extent. This may be explained by the fact that those having surgery may be able to attend hospital and complete successful treatment over a relatively short period of time and thus disclosure may not be required. Whereas, those embarking on chemotherapy, radiotherapy or a combination of treatments are likely to have longer treatment schedules with regular appointments and potentially more visible side effects, which then necessitate greater levels of disclosure.

This study had its strength in being one of the first to consider disclosure in a sample of mixed cancer types. Therefore the finding that cancer type did not impact on the degree of disclosure is of note. Together the results suggest that disclosure is a result of the type of person you are (i.e. dispositionally open) and how well supported you feel (i.e. perceived social support), rather than resulting from external factors such as the type of cancer you have or the responses you receive from others. Thus disclosure appears to extend from intrinsic qualities of the individual, which is consistent with early notions in the general self-disclosure literature suggesting that self-disclosure behaviour is

primarily determined by stable personality differences (Jourard, 1964). It is also in-keeping with the reliable finding linking the trait of extroversion with general self-disclosure (see Stokes, 1987 for a review). Despite the stability and consistency of these findings, researchers warn that predicting disclosure based on stable personality traits can be complicated by situational factors (Cozby, 1973; Omarzu, 2000), as people tend to evaluate the situational context in which disclosures occur; thus it is important to be mindful of both. Since treatment type was found to impact on the level of disclosure in the current study, certain intricacies of the disease may still conceivably have implications for disclosure.

4.2.4 What factors are associated with the helpfulness of disclosure?

There were no initial hypotheses on which factors would be related to helpfulness of disclosure. The exploratory analyses indicated that, like the degree of disclosure, 'helpfulness' was associated with perceived social support and general openness. Higher levels of social support and openness were associated with disclosure being helpful. The multivariate analyses indicated that these psychological variables were able to predict helpfulness, and together accounted for 20% of the variance in whether disclosure was helpful or not. Both social support and general openness were found to be significant independent predictors.

These findings again underscore the importance of individual differences by suggesting that those who are generally more open in everyday life, will find talking about their cancer most helpful. Additionally, the results highlight the importance of perceived social support and are consistent with previous work which found that satisfaction with social support was related to perceptions of the helpfulness of disclosure (Figueiredo et al., 2004). Moreover, the finding that unsupportive social interactions were not related to helpfulness in the current study indicates that, perceived social support plays a more pivotal role than unhelpful interactions in determining whether disclosure is helpful. This perhaps contradicts the general social support literature which suggests that unsupportive interactions are more problematic than the absence of social support (Coyne & DeLongis, 1986). In the current study, social support played a more

influential role in determining successful outcomes of disclosure. The remaining uncertainty in relation to this finding is whether talking is more helpful because the person has lots of support or whether having lots of support leads to talking being more helpful. Ultimately, it is less important to establish the direction of this relationship and more key to attend to the notion that support and helpfulness of disclosure go together; thus it may be important to bolster the patients' perceptions of social support if one is to achieve a successful outcome of disclosure.

4.3 LIMITATIONS

The insights gained in this study should be considered in accordance with the limitations. Firstly, the study is susceptible to all of the shortcomings associated with self-report methods, such as the possibility of the person misinterpreting the question, responding in a biased manner, or making an error in transcribing his or her response (Streiner & Norman, 2008). Greene (2009) highlights a further difficulty of using retrospective reports in that there may be a bias whereby, with the passage of time, the discloser recalls that talking was not as bad as when they first experienced it. Additionally, it has been suggested that, 'Reliance on retrospective reports may reflect the selective recall of information congruent with the mood that the subject was in at the time of completing the questionnaire' (Pennebaker & O'Heeron, 1984, p. 476). Attempts were however made to minimise any difficulty with memory recall, by selecting a sample that had received their diagnosis within a reasonable timescale (within two years). Also the piloting process highlighted that, despite the passage of time, patients feel competent that they remember their diagnosis and the surrounding events as if it was yesterday, and reports are likely to have enhanced accuracy due the 'flashbulb memory' phenomenon (Brown & Kulik, 1977). This is something commonly reported in the literature (e.g. Mager & Andrykowski, 2002).

Furthermore, the study design was cross-sectional with correlational analyses, which limits conjectures about causation. For example, this study identified that high levels of social support are associated with higher levels of disclosure; however the direction of causality remains inconclusive. It may be that the more one discloses the more social support is elicited. However, by using correlational analyses, it is inappropriate to

imply causation from this study. A further point to note when considering correlational relationships is the possibility that a third unidentified, extraneous variable may be impacting on the relationship between the other two variables, something referred to as a 'tertium quid' (Field, 2005). For example the relationship between disclosure and dispositional openness may be confounded by one's motivation to disclose; something suggested by the Disclosure Processes Model to moderate the effect of disclosure outcomes (Chaudoir & Fisher, 2010).

Cross-sectional data is also limited in that it provides a snapshot in time, which has implications for measuring certain variables that fluctuate over time, such as distress (Ramirez, 1989). The HADS measure, used as an index of distress in this study, asks people to rate their distress based on the previous week, and given that the study comprised of people at different stages in their cancer journey, it is conceivable that the distress ratings would differ according to the phase they are in (e.g. soon after diagnosis, pre-treatment, mid-treatment, or post-treatment). It has been suggested that 'acute stress reactions' soon after diagnosis may give rise to higher levels of psychological distress and thus higher scores on the HADS (Razavi et al., 1990). Also if the measurement of distress comes a long time after diagnosis and treatment for cancer, then perhaps distress is due to factors other than cancer (van't Spijker et al., 1997). A model of psychosocial phasing in cancer has proposed that distress occurs intermittently over the course of the disease, with different problems and concerns arising alongside the different clinical phases of diagnosis, treatment and disease progression (Avery & Weisman, 1979). However, other authors have suggested that distress is relatively constant during the early phases, and that it is only in the later phases of recurrence and advancing disease that distress will intensify (Zabora et al., 1997). The current study attempted to overcome these issues by generating a uniform sample of people who had recently received their diagnosis between 8 weeks and 2 years previously. However, even within this specific time boundary there is still likely to have been variability amongst individuals as to the course of their disease and treatment and thus associated distress levels. For example in the context of lung cancer, if the treatment is surgical removal with curative intent, the likely time scales from the point of diagnosis to having completed successful treatment would be short. Whereas for those embarking on other treatment modalities, such as chemo or radiotherapy, the treatment schedule is likely to have been much longer. So if distress in cancer is fairly transient, with psychological

reactions occurring in relation to disease-related events, then it is likely that the current sample comprised of patients at disparate points in their cancer journey and therefore consists of a range of distress levels. This is likely to have further complicated the results regarding distress and disclosure, and limits extrapolations that can be made from cross-sectional data.

Regarding the sample characteristics, the majority of the present sample were of white ethnic origin which does not reflect the diversity of people affected by cancer, and so the generalizability of the findings may be limited. It is also important to be aware of the ways in which the selection criteria may have biased the current sample e.g. by not approaching anyone where it was deemed as clinically inappropriate by the direct treatment team. Also those with metastatic cancer or receiving palliative or end of life care were excluded from the current study, resulting in a sample of patients mainly being treated with curative intent. The nature of this group may differ in a number of ways (e.g. attitudes, coping, adjustment, distress) to those where the prognosis is poorer, and it is unknown how this would impact on disclosure behaviour and whether the current findings would generalise to patients where disease progression has occurred. For this reason, it is important for future research to include people with more limited prognoses also.

The results of this study suggest that the majority of patients with cancer will disclose to some extent to a variety of others. However, it is unclear whether this generalises beyond the present sample and if it would be the case for everyone who experiences cancer. A well-recognised, inherent difficulty in conducting studies on disclosure is the bias that can be introduced by patients self-electing to participate, and the potential for qualitative differences in those choosing not to (Henderson et al., 2002; Hilton et al., 2009). Although this study tried to be inclusive by sending questionnaires to a cross-section of patients, and generated a good response rate (59%), it is still important to consider those who were invited but did not participate in this study either actively (by returning the opt-out slip) or passively (by not responding). The extent to which these people talked about their cancer to others remains unknown and it is conceivable that the non-responders (33%) comprised of people that preferred not to talk about their cancer diagnosis. In an attempt to overcome this uncertainty, the current study incorporated an opt-out slip which revealed that a common reason for not taking part (in

7 out of 18 cases) was, 'I don't want to think about it'. It may be speculated that having a preference 'not to think about it', means that these people were also less likely to have engaged in discussions about their cancer. However this is unclear and there remains a variety of possible explanations for why one might not respond, including benign reasons such as having changed address and not receiving the questionnaire, or not having time to complete it, or more specific reasons intimately linked to the research question of this study, i.e. whether they talked or not. Therefore, the question regarding the reason for non-completion remains and is something that researchers of disclosure must be aware of.

Some of the variables investigated in this study were measured using a single item (i.e. helpfulness and dispositional openness). Although these items possess face validity and were specifically chosen to replicate those used in previous studies, it is not possible to establish the reliability of these single-item measures. Moreover, the measure of disclosure modelled on previous work, was fairly general and unable to pick up on the complexities and multiple nuances of disclosure. For example the Disclosure Decision Making Model (Greene, 2009) suggests that people will consider the 'message features', such as where and when disclosure will take place. Such contextual factors were not measured by this study and so it is not possible to comment on these nor the accuracy of their model.

4.4 FUTURE RESEARCH

Future research should aim to overcome these limitations by using longitudinal methodology to assess variables over time, such as the pattern of disclosure and distress. This would provide better information on causation and, alongside a more detailed measure of the intricacies of disclosure, may reveal more specific patterns of how disclosure unfolds. By following-up patients longitudinally, it is likely that some patients would experience disease progression, meaning that the findings would include a more severely affected sample and be more informative of whether the current findings generalise to those being treated palliatively.

Given the complexities of measuring disclosure, it would be helpful to combine quantitative and qualitative techniques, so that as well as having a measure of the extent of disclosure, it is also possible to explore the nature and context of disclosure and any individual idiosyncrasies that might arise. For example, disclosure may have been planned, or accidental, direct or indirect via third parties or through an alternative medium such as email, telephone or a letter. Greene (2009) highlights these preferred alternative means of enacting disclosure if a person does not have enough self-efficacy to deliver the information verbally yet still wants to disclose. Such detail is difficult to measure using quantitative means and as a result, was not captured in the current study. Thus, given the many nuances to disclosure, it is important to combine qualitative and quantitative methodologies to generate a richer understanding of disclosure patterns.

It would be worthwhile attempting to replicate the findings by combining the insights from the current study and previous work by Henderson et al (2002) in order to define a better predictive model. Such research might consider psychological variables found to be of importance in this study (i.e. social support and dispositional openness) as well as those previously found to be of importance (i.e. age, cancer stage, optimism, stress-related growth, and disclosure attitudes).

This study only considered disclosure from the patients' point of view, however given the dyadic nature of disclosure, it is important for future research to also consider the recipient of disclosure. Kelly and McKillop (1996) suggest that it is important to look more closely at the role of the confidant in predicting the consequences of disclosures. Some studies have begun to consider disclosure between couples and the impact that talking has on the relationship and adjustment (Badr et al., 2008; Badr & Carmack Taylor, 2006; Langer et al., 2009; Manne et al., 2004; Manne, Taylor, Dougherty, & Kemeny, 1997; Porter et al., 2005). These studies have consistently found that partner responses play a role in adaptation to cancer, with disclosure between spouses being associated with better adjustment and higher levels of relationship satisfaction. Perhaps more crucial is the finding that negative aspects of close relationships play a comparatively stronger role than positive aspects in their associations with psychological distress and well-being (Manne et al., 1997) and so it will be important to extend work in this area beyond the spousal relationship dyad to other disclosure recipients.

4.5 IMPLICATIONS

4.5.1 Implications for theory

Although the current study did not directly test a specific theory or model of disclosure, the findings do have some implications for existing theory. For example, the current findings lend support to part of the Disclosure Processes Model (DPM: Chaudoir & Fisher, 2010). In particular the model specifies that one of the mechanisms by which disclosure affects people's lives is through social support, which is contingent on the confidant's evaluative reaction. The authors propose that disclosure renders the individual vulnerable to social evaluation that can either result in greater social support or greater stigmatisation. The fact that the current sample reported low levels of unsupportive reactions (indicative of a favourable confidant's evaluative reaction) and low levels of stigma, whilst high levels of disclosure were related to social support, confirms this part of the DPM in finding that patients experienced good reactions to their disclosures and had high levels of social support whilst experiencing low levels of stigma.

Moreover, apart from treatment type, none of the disease-related variables were associated with disclosure in the current study, which implies that such factors may be less important in cancer-related disclosures. This provides insights for the Disclosure Decision Making Model (DD-MM: Greene, 2009) which suggests that an individual weighs up five components before making the decision to disclose, including: 1) the risk of stigma; 2) how prepared they were to hear the diagnosis prior to receiving it; 3) prognosis; 4) symptom visibility and complications; and 5) whether it is relevant to tell others. The current findings that 'cancer type' and 'disease visibility' are not related to disclosure, casts doubt on some of the elements of this model (particularly 'prognosis' and 'symptoms'). Since the DD-MM applies to information sharing across health conditions, it may be that in the specific context of cancer, characteristics of the disease are less relevant when deciding whether to disclose.

4.5.2 Implications for clinical practice

If future research was able to replicate and advance on the current study, there are potentially important implications, particularly for clinical practice.

Based on the research to date, it is clear that disclosing a cancer diagnosis to loved ones is a particularly difficult task and, given that the number of people being diagnosed is continually rising, more and more people will be facing this challenge. Currently there are no official structures to support this process, meaning that patients are largely being left to deal with the diagnosis and navigate their way through uncharted territory of disclosure alone.

If disclosure was certain to benefit all, then ideally systemic procedures offering guidance to patients could be designed and rolled out across hospital settings to have maximum effect. However, given the complexities of disclosure and the insights from research suggesting that disclosure can also be unhelpful, then generic guidelines on how one should disclose, what one should disclose and to whom one should disclose, would be inappropriate and would not satisfy the needs of the range of patients with cancer. Rather, it is likely that each individual will need to consider their own unique circumstances and social network and decide what is best on an individual basis. These notions are in-keeping with theories describing the management of information (Communication Privacy Management) and theories of decisional balance (e.g. Social Exchange Theory, The Disclosure Decision-Making Model, and The Theory of Competing Consequences).

Studies examining the effectiveness of psychosocial interventions for distress in cancer, identified that, “Clinicians may discover early in their experience that all cancer patients are not equally eager to talk about their problems” and that ‘A willing ear is not enough” (Worden & Weisman, 1980, p. 102). This aptly describes the importance of considering each patient as an individual, and despite the knowledge that most people find talking helpful, it is important to take an idiosyncratic approach as each patient will have their own unique set of circumstances and preferences around disclosure. Therefore, the efforts and skills of a professional counsellor or therapist would be best directed at developing an individualised formulation that best supports and meets the

needs of each individual patient with regards to disclosure. By weighing up the risks and benefits associated with disclosing, the patient could be supported to develop a 'disclosure plan' which would contain precise details of who would disclose, to whom, when, where, why and what. This is something that has been recommended particularly in the context of managing employment transition (Allen & Carlson, 2003). However, with the limited resources of the NHS and the sheer number of people being diagnosed with cancer, it is unlikely that such individual psychological formulations and support packages would be possible for all patients.

A more feasible clinical intervention would be for medical professionals, or clinicians working with cancer patients, to raise the issue of disclosure as part of their routine clinical contacts with the patient. Some patients may prefer not to enter into a discussion around disclosure, but others may welcome the invitation to have a more in-depth conversation to consider the issue. A discussion on the topic of disclosure could involve sharing the research knowledge to date, in particular understanding that disclosing can be an incredibly difficult task, and that most people do choose to disclose to a variety of people. Clinicians may also wish to share the reasons why some people find it helpful to disclose, as well as the reasons why it can be unhelpful (such as those found by the current study). In providing this knowledge, the patient may be better placed to make an informed plan around disclosure and what is best for them. Such planned, 'strategic announcements' have been suggested to preserve control and autonomy, and maintain one's sense of self, which is vital when managing a threatening illness (Charmaz, 1993).

During these conversations it will be important to listen to the patient and elicit their preferences for sharing as well as being mindful of their circumstances and who might be around in their support network for them to confide in. One outcome might be to identify an appropriate confidant for the individual. Kelly and McKillop (1996) recommend taking a conservative approach towards disclosure, by evaluating the qualities of the confidant first and only sharing information with them if they are trustworthy, able to offer new insights and are non-judgemental. It might be helpful to use these criteria with the patient to assist them with their decisions.

Discussions around disclosure may also open up the opportunity for giving advice should it be requested. For example, it might be helpful to inform people of the variety of options they have for delivering the disclosure message, and share information on how others have done this either directly themselves, through another medium (e.g. telephone, email or letter), or by selecting a person who distributes the information on their behalf. A further possibility is that medical personnel may offer to support people with their endeavours to disclose, as this helps make the information more credible (Charmaz, 1993). Interestingly, one study found that in cases where the doctor had helped tell others about the diagnosis, patients reported higher levels of satisfaction with how their diagnosis had been discussed with them, and reported lower levels of anxiety and depression both at baseline and follow-up, compared to cases where the doctor had not helped tell others the diagnosis (Schofield et al., 2003). Thus medical staff could potentially play a crucial role in assisting the disclosure process.

Since disclosure is unlikely to be a one-off procedure, but rather consist of multiple, subsequent disclosures, as the patient journeys through investigations and treatment, it will be important for medical professionals to check-in with the patient and revisit disclosure discussions. One might enquire how they are getting on with disclosure, who they have told, how it went, how the news was received, whether it was helpful or not, and if they have received any unhelpful responses leading to more distress. In routine practice, this procedure might help identify any patients who are particularly struggling with disclosure and reveal any cases where maintaining secrecy is problematic or where disclosure led to particularly distressing outcomes, such as rejection. If such difficulties arise, and are impacting on the person's overall mood, adjustment and quality of life, one may wish to consider offering the patient a referral to speak with a professional counsellor or therapist.

Perhaps one of the most important points for clinicians working in cancer care is to have a working knowledge of the disclosure literature and be mindful of the issues patients face in disclosing to loved ones. Given the regularity of appointments and check-ups, clinicians may be best placed to incorporate these suggestions around disclosure into their routine practice, which will hopefully improve the patients' holistic care package. Based on the literature and findings of this study, some best practice guidelines have been drawn up and can be found in Appendix 10.

4.6 CONCLUSIONS

This study provides useful information on the psychological characteristics of a group of patients with colorectal, lung and skin cancers. Moreover, it has advanced on previous study samples, and has its strengths in having a good response rate and generating a sample of patients of mixed gender and cancer types.

This study has added to the existing literature by confirming the findings of Henderson et al (2002), who were the first to conduct a systematic evaluation of disease disclosure patterns in women with breast cancer, indicating that the majority of patients with cancer do talk about their disease with many people in their social network. Furthermore, the current study identified that social support and dispositional openness are related to the extent to which one discloses as well as the helpfulness of disclosure.

Overall, this study has contributed to knowledge in the disclosure field by finding that dispositional openness and social support are important determinants of disclosure in cancer. It is important for researchers to build on these findings and continue to enhance our understanding of the complexity of disclosing a cancer diagnosis, given the ever increasing number of people that will face this difficult task. A sophisticated knowledge of how people go about disclosure would ideally help inform strategies for supporting the process, minimise unhelpful disclosures and lead to a better overall experience of care for the patient.

REFERENCES

- Afifi, T.D. (2003). "Feeling caught" in stepfamilies: managing boundary turbulence through appropriate communication privacy rules. *Journal of Social and Personal Relationships*, 20, 729-755.
- Albrecht, T. L., & Adelman, M. B. (1987). *Communicating social support*. Newbury Park, CA: Sage Publications, Inc.
- Allen, S., & Carlson, G. (2003). To conceal or disclose a disabling condition? A dilemma of employment transition. *Journal of Vocational Rehabilitation*, 19(1), 19–30.
- Altman, I., & Taylor, D. A. (1973). *Social penetration: The development of interpersonal relationships*. New York: Holt, Rinehart & Winston.
- Attride-Stirling, J. (2001). Thematic networks: an analytic tool for qualitative research. *Qualitative Research*, 1(3), 385-405.
- Avery, D., & Weisman, M. (1979). A model for psychosocial phasing in cancer. *General Hospital Psychiatry*, 1(3), 187–195.
- Babcock, J.H. (1998). Involving family and significant others in acute care. In D.M. Aronstein & B.J. Thompson (Eds.), *HIV and social work*, (pp. 101-108), Binghamton, NY: The Haworth Press, Inc.
- Badr, H., Acitelli, L. K., & Carmack Taylor, C. L. (2008). Does talking about their relationship affect couples' marital and psychological adjustment to lung cancer? *Journal of Cancer Survivorship*, 2(1), 53–64.
- Badr, H., & Carmack Taylor, C. L. (2006). Social constraints and spousal communication in lung cancer. *Psycho-Oncology*, 15(8), 673–683.

- Baile, W. F., Buckman, R., Lenzi, R., Glober, G., Beale, E. A., & Kudelka, A. P. (2000). SPIKES—A Six-Step Protocol for Delivering Bad News: Application to the Patient with Cancer. *The Oncologist*, 5(4), 302–311.
- Barrera, M. (1986). Distinctions between social support concepts, measures, and models. *American journal of community psychology*, 14(4), 413–445.
- Beatty, J. (2004). *Chronic Illness as invisible diversity: Disclosing and coping with illness in the workplace*. Boston College, The Carroll Graduate School of Management.
- Befu, H. (1977). Social Exchange. *Annual Review of Anthropology*, 6, 225–281.
- Berard, R. (2001). Depression and anxiety in oncology: the psychiatrist's perspective. *The Journal of clinical psychiatry*, 62, 58–63.
- Blau, P. M. (1964). *Exchange and power in social life*. New York: Wiley.
- Booker, M. J., Blethyn, K. L., Wright, C. J., & Greenfield, S. M. (2006). Pain management in sickle cell disease. *Chronic illness*, 2(1), 39–50.
- Braun, V. & Clark, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2): 77–101.
- Brennan, J. (2001). Adjustment to cancer—coping or personal transition? *Psycho-Oncology*, 10(1), 1–18.
- Brown, F. (1989). The impact of death and serious illness on the family life. In B. Carter & M. McGoldrick (Eds.), *The changing family life cycle: A framework for family therapy*. (pp. 457–482). Boston: Allyn & Bacon.
- Brown, M. L., Riley, G. F., Potosky, A. L., & Etzioni, R. D. (1999). Obtaining long-term disease specific costs of care: application to Medicare enrollees diagnosed with colorectal cancer. *Medical care*, 37(12), 1249–1259.
- Brown, R., & Kulik, J. (1977). Flashbulb memories. *Cognition*, 5(1), 73–99.

- Burgess, C., Morris, T., & Pettingale, K. W. (1988). Psychological response to cancer diagnosis—II. Evidence for coping styles (coping styles and cancer diagnosis). *Journal of Psychosomatic Research*, 32(3), 263–272.
- Cancer Research UK. (2010, October 3). How many different types of cancer are there? Document. Retrieved April 18, 2012, from <http://info.cancerresearchuk.org/cancerandresearch/all-about-cancer/what-is-cancer/different-types-of-cancer/how-many-different-types-of-cancer-are-there2>
- Cancer Research UK. (2011a). Cancer incidence for common cancers - UK statistics. Document. Retrieved April 2, 2012, from <http://info.cancerresearchuk.org/cancerstats/incidence/commoncancers/>
- Cancer Research UK. (2011b, January 12). Statistics on the risk of developing cancer. Document. Retrieved February 6, 2012, from <http://info.cancerresearchuk.org/cancerstats/incidence/risk/>
- Cancer Research UK. (2012, May 1). Cancer treatments. Document. Retrieved February 6, 2012, from <http://cancerhelp.cancerresearchuk.org/about-cancer/treatment/>
- Carlson, L. E., Angen, M., Cullum, J., Goodey, E., Koopmans, J., Lamont, L., MacRae, J., et al. (2004). High levels of untreated distress and fatigue in cancer patients. *British Journal of Cancer*, 90(12), 2297–2304.
- Carlson, L. E., & Bultz, B. D. (2003). Cancer distress screening: Needs, models, and methods. *Journal of psychosomatic research*, 55(5), 403–409.
- Caughlin, J. P. (2004). When is Topic Avoidance Unsatisfying? *Human Communication Research*, 30(4), 479–513.
- Cella, D. F., Mahon, S. M., & Donovan, M. I. (1990). Cancer Recurrence as a Traumatic Event. *Behavioral Medicine*, 16(1), 15–22.

- Charmaz, K. (1993). *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Jersey: Rutgers University Press.
- Chaudoir, S. R., & Fisher, J. D. (2010). The disclosure processes model: Understanding disclosure decision-making and post-disclosure outcomes among people living with a concealable stigmatized identity. *Psychological bulletin*, *136*(2), 236–256.
- Chaudoir, S.R., Fisher, J.D. & Simoni, J.M. (2011). Understanding HIV disclosure: A review and application of the Disclosure Processes Model, *Social Science & Medicine*, *72*, 1618-1629.
- Checton, M.G. & Greene, K. (2012). Beyond Initial Disclosure: The Role of Prognosis and Symptom Uncertainty in Patterns of Disclosure in Relationships. *Health Communication*, *27*, 145-157.
- Cline, R.J., & McKenzie, N.J., (2000). Dilemmas of disclosure in the age of HIV/AIDS: Balancing privacy and protection in the health care context. In S. Petronio (Ed.), *Balancing the secrets of private disclosures*, (pp.71-82), Mahwah NJ: Lawrence Erlbaum Associates, Inc.
- Cohen, S., & McKay, G. (1984). Social support, stress, and the buffering hypothesis: A theoretical analysis. *Handbook of psychology and health*, *4*, 253–267.
- Cohen, S., & Wills, T. A. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, *98*, 310–357.
- Collins, N. L., & Miller, L. C. (1994). Self-disclosure and liking: A meta-analytic review. *Psychological Bulletin*, *116*(3), 457–475.
- Collins, R. L., Taylor, S. E., & Skokan, L. A. (1990). A better world or a shattered vision? Changes in life perspectives following victimization. *Social Cognition*, *8*(3), 263–285.

- Colyer, H. (1996). Women's experience of living with cancer. *Journal of Advanced Nursing*, 23(3), 496–501.
- Cordova, M. J., & Andrykowski, M. A. (2003). Responses to cancer diagnosis and treatment: posttraumatic stress and posttraumatic growth. *Seminars in Clinical Neuropsychiatry*, 8(4), 286–296.
- Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., & Andrykowski, M. A. (2001a). Posttraumatic growth following breast cancer: A controlled comparison study. *Health Psychology*, 20(3), 176–185.
- Cordova, M. J., Cunningham, L. L., Carlson, C. R., & Andrykowski, M. A. (2001b). Social constraints, cognitive processing, and adjustment to breast cancer. *Journal of Consulting and Clinical Psychology*, 69(4), 706–711.
- Coyne, J. C., & DeLongis, A. (1986). Going beyond social support: The role of social relationships in adaptation. *Journal of Consulting and Clinical Psychology*, 54(4), 454–460.
- Cozby, P. C. (1973). Self-disclosure: a literature review. *Psychological Bulletin*, 79(2), 73–91.
- Crawford, J. R., Henry, J. D., Crombie, C., & Taylor, E. P. (2001). Normative data for the HADS from a large non-clinical sample. *British Journal of Clinical Psychology*, 40(4), 429–434.
- Cronbach, L. J. (1951). Coefficient alpha and the internal structure of tests. *Psychometrika*, 16(3), 297–334.
- Cropanzano, R., & Mitchell, M.S., (2005). Social Exchange Theory: An Interdisciplinary Review. *Journal of Management*, 31, 874-900.
- Dalgin, R. S., & Gilbride, D. (2003). Perspectives of people with psychiatric disabilities on employment disclosure. *Psychiatric Rehabilitation Journal*, 26(3), 306–310.

- Dégi, C. L. (2009). Non-disclosure of cancer diagnosis: an examination of personal, medical, and psychosocial factors. *Supportive care in cancer*, 17(8), 1101–1107.
- Department of Health. (2000). *The NHS Cancer plan: a plan for investment, a plan for reform* (Publication). Retrieved from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009609
- Derogatis, L. R., Abeloff, M. D., & Melisaratos, N. (1979). Psychological Coping Mechanisms and Survival Time in Metastatic Breast Cancer. *JAMA: The Journal of the American Medical Association*, 242(14), 1504 –1508.
- Derogatis, L. R., Morrow, G. R., Fetting, J., Penman, D., Piasetsky, S., Schmale, A. M., Henrichs, M., et al. (1983). The prevalence of psychiatric disorders among cancer patients. *JAMA: The journal of the American Medical Association*, 249(6), 751–757.
- Deshields, T., Tibbs, T., Fan, M., & Taylor, M. (2006). Differences in patterns of depression after treatment for breast cancer. *Psycho-Oncology*, 15(5), 398–406.
- Diener, E., Suh, E. M., Lucas, R. E., & Smith, H. L. (1999). Subjective well-being: Three decades of progress. *Psychological bulletin*, 125(2), 276–302.
- Dunkel-Schetter, C. (1984). Social support and cancer: Findings based on patient interviews and their implications. *Journal of Social Issues*, 40(4), 77–98.
- Edlund, B., & Sneed, N. (1989). Emotional responses to the diagnosis of cancer: age-related comparisons. *Oncology nursing forum*, 16(5), 691–697.
- Ellis, P. M., & Tattersall, M. H. . (1999). How should doctors communicate the diagnosis of cancer to patients? *Annals of medicine*, 31(5), 336–341.

- Ellison, M. L., Russinova, Z., MacDonald-Wilson, K. L., & Lyass, A. (2003). Patterns and correlates of workplace disclosure among professionals and managers with psychiatric conditions. *Journal of Vocational Rehabilitation, 18*(1), 3–13.
- Emerson, R. M. (1962). Power-dependence relations. *American sociological review, 27*(1), 31–41.
- Emerson, R. M. (1976). Social Exchange Theory. *Annual Review of Sociology, 2*, 335–362.
- Emler, C. A. (2006). A comparison of HIV stigma and disclosure patterns between older and younger adults living with HIV/AIDS. *AIDS Patient Care & STDs, 20*(5), 350–358.
- Fallowfield, L., Ratcliffe, D., Jenkins, V., & Saul, J. (2001). Psychiatric morbidity and its recognition by doctors in patients with cancer. *British Journal of Cancer, 84*(8), 1011–1015.
- Faul, F., Erdfelder, E., Buchner, A., & Lang, A.-G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods, 41*(4), 1149–1160.
- Featherstone, H., & Whitham, L. (2010, February). The Cost of Cancer. Research Note. Retrieved from http://www.policyexchange.org.uk/publications/category/item/the-cost-of-cancer?category_id=24
- Ferrell, B., Hassey Dow, K., & Grant, M. (1995). Measurement of the quality of life in cancer survivors. *Quality of life Research, 4*(6), 523–531.
- Festinger, L. (1954). A theory of social comparison processes. *Human Relations, 7*, 117–140.

- Field, A. P. (2005). *Discovering Statistics Using SPSS: (and Sex, Drugs and Rock'n'roll)*. London: Sage Publications.
- Fife, B. L., & Wright, E. R. (2000). The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer. *Journal of Health and Social Behavior, 41*(1), 50–67.
- Figueiredo, M. I., Fries, E., & Ingram, K. M. (2004). The role of disclosure patterns and unsupportive social interactions in the well-being of breast cancer patients. *Psycho-Oncology, 13*(2), 96–105.
- Folkman, S., & Greer, S. (2000). Promoting psychological well-being in the face of serious illness: when theory, research and practice inform each other. *Psycho-Oncology, 9*(1), 11–19.
- Foulds, E. (2002). Surgical Oncology. *Cancer Nursing Practice, Cancer Nursing Practice, 1*(2), 33–38.
- Freud, S. (1958). *On beginning the treatment (Further recommendations on the technique of psycho-analysis I)*. London: Hogarth Press.
- Girgis, A., & Sanson-Fisher, R. W. (1995). Breaking bad news: consensus guidelines for medical practitioners. *Journal of Clinical Oncology: Official Journal of the American Society of Clinical Oncology, 13*(9), 2449–2456.
- Goffman, E. (1963). *Stigma: notes on the management of spoiled identity*. New York: Simon and Schuster.
- Goldberg, S. G., Killeen, M. B., & O'Day, B. (2005). The Disclosure Conundrum: How People With Psychiatric Disabilities Navigate Employment. *Psychology, Public Policy, and Law, 11*(3), 463–500.
- Goodwin, P. J., Leszcz, M., Ennis, M., Koopmans, J., Vincent, L., Guther, H., Drysdale, E., et al. (2001). The Effect of Group Psychosocial Support on Survival in

- Metastatic Breast Cancer. *New England Journal of Medicine*, 345(24), 1719–1726.
- Gordon, D. R. (1990). Embodying illness, embodying cancer. *Culture, Medicine and Psychiatry*, 14(2), 275–297.
- Gottlieb, B. H., & Bergen, A. E. (2010). Social support concepts and measures. *Journal of psychosomatic research*, 69, 511–520.
- Gray, R. E., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000). To tell or not to tell: patterns of disclosure among men with prostate cancer. *Psycho-Oncology*, 9(4), 273–282.
- Greene, K. (2009). An Integrated Model of Health Disclosure Decision-Making. In T. D. Afifi & W. A. Afifi (Eds.), *Uncertainty and information regulation in interpersonal contexts: Theories and applications* (pp. 226–253). New York: Routledge.
- Greene, K., Magsamen-Conrad, K., Venetis, M.K., Checton, M.G., Bagdasarov, Z., & Banerjee, S.C., (2012). Assessing Health Diagnosis Disclosure Decisions in Relationships: Testing the Disclosure Decision-Making Model, *Health Communication*, 27(4), 356-368.
- Greer, S. (1994). Psycho-oncology: Its aims, achievements and future tasks. *Psycho-Oncology*, 3(2), 87–101.
- Greer, S., Moorey, S., Baruch, J. D., Watson, M., Robertson, B. M., Mason, A., Rowden, L., et al. (1992). Adjuvant psychological therapy for patients with cancer: a prospective randomised trial. *BMJ: British Medical Journal*, 304(6828), 675–680.
- Greer, Steven. (2008). CBT for emotional distress of people with cancer: some personal observations. *Psycho-Oncology*, 17(2), 170–173.

- Grosser, L. (2003). Meeting the needs of younger women with breast cancer. *Nursing Times*, 99(42), 20–22.
- Gurevich, M., Bishop, S., Bower, J., Malka, M., & Nyhof-Young, J. (2004). (Dis)embodying gender and sexuality in testicular cancer. *Social Science & Medicine*, 58(9), 1597–1607.
- Hay, J., Shuk, E., Brady, M. S., Berwick, M., Ostroff, J., & Halpern, A. (2008). Family communication after melanoma diagnosis. *Archives of dermatology*, 144(4), 553–554.
- Hays, R. B., McKusick, L., Pollack, L., Hilliard, R., Hoff, C., & Coates, T. J. (1993). Disclosing HIV seropositivity to significant others. *AIDS*, 7(3), 425–431.
- Heaven, C. M., & Maguire, P. (1997). Disclosure of concerns by hospice patients and their identification by nurses. *Palliative Medicine*, 11(4), 283–290.
- Henderson, B., Davison, K., Pennebaker, J., Gatchel, R., & Baum, A. (2002). Disease Disclosure Patterns Among Breast Cancer Patients. *Psychology & Health*, 17(1), 51–62.
- Hilton, S., Emslie, C., Hunt, K., Chapple, A., & Ziebland, S. (2009). Disclosing a cancer diagnosis to friends and family: a gendered analysis of young men's and women's experiences. *Qualitative Health Research*, 19(6), 744–754.
- Hodgkiss, A., & Mascarenhas, S. (2012). Psycho-oncology. In E. Guthrie, S. Rao, & M. Temple (Eds.), *Seminars in Liaison Psychiatry* (2nd ed., pp. 186–204). London: RCPsych Publications.
- Holt, R., Court, P., Vedhara, K., Nott, K. H., Holmes, J., & Snow, M. H. (1998). The role of disclosure in coping with HIV infection. *AIDS Care*, 10(1), 49–60.
- Homans, G. C. (1958). Social behavior as exchange. *American journal of sociology*, 597–606.

- Homans, G. C. (1961). *Social behavior: its elementary forms*. New York: Harcourt, Brace.
- Honda, K., & Goodwin, R. D. (2004). Cancer and Mental Disorders in a National Community Sample: Findings from the National Comorbidity Survey. *Psychotherapy and Psychosomatics, 73*, 235–242.
- Hosaka, T., Awazu, H., Fukunishi, I., Okuyama, T., & Wogan, J. (1999). Disclosure of true diagnosis in Japanese cancer patients. *General hospital psychiatry, 21*(3), 209–213.
- House, J. S., Landis, K. R., & Umberson, D. (1988). Social relationships and health. *Science, 241*(4865), 540–545.
- Hughes, J. (1987). *Cancer and emotion: psychological preludes and reactions to cancer*. Chichester: John Wiley & Sons.
- Husband, H. J. (2000). Diagnostic disclosure in dementia: an opportunity for intervention? *International Journal of Geriatric Psychiatry, 15*(6), 544–547.
- Hyman, M. D. (1971). The stigma of stroke. Its effects on performance during and after rehabilitation. *Geriatrics, 26*(5), 132–141.
- Ibbotson, T., Maguire, P., Selby, P., Priestman, T., & Wallace, L. (1994). Screening for anxiety and depression in cancer patients: the effects of disease and treatment. *European Journal of Cancer, 30*(1), 37–40.
- Ingram, K. M., Betz, N. E., Mindes, E. J., Schmitt, M. M., & Smith, N. G. (2001). Unsupportive responses from others concerning a stressful life event: Development of the Unsupportive Social Interactions Inventory. *Journal of Social and Clinical Psychology, 20*(2), 173–207.

- Jackson, T., Davis, K., Haisfield, L., Dawson, D., Lynch, J., Regan, J., Kwart, A., et al. (2010). Disclosure of diagnosis and treatment among early stage prostate cancer survivors. *Patient Education and Counseling*, 79(2), 239–244.
- Jacoby, A. (1994). Felt versus enacted stigma: A concept revisited:: Evidence from a study of people with epilepsy in remission. *Social Science & Medicine*, 38(2), 269–274.
- Janoff-Bulman, R. (1992). *Shattered Assumptions* (1st Edition, 2nd printing.). New York: Free Press.
- Joffe, H. & Yardley, L. (2004). Content and Thematic Analysis. In D.F. Marks & L. Yardley (Eds.), *Research Methods for Clinical and Health Psychology*. (pp. 56-68). London: Sage Publications.
- Jourard, S. M. (1964). *The transparent self: self-disclosure and well-being*. Princeton, New Jersey: Van Nostrand Company, Inc.
- Kalichman, S.C. (1995). *Understanding AIDS: A guide for mental health professionals*. Washington DC: American Psychological Association.
- Kelly, A. E., & McKillop, K. J. (1996). Consequences of revealing personal secrets. *Psychological Bulletin*, 120(3), 450–465.
- Kessler, R. C., Kendler, K. S., Heath, A., Neale, M. C., & Eaves, L. J. (1992). Social support, depressed mood, and adjustment to stress: A genetic epidemiologic investigation. *Journal of Personality and Social Psychology*, 62(2), 257–272.
- Kornblith, A. B., Regan, M. M., Kim, Y., Greer, G., Parker, B., Bennett, S., & Winer, E. (2006). Cancer-related communication between female patients and male partners scale: a pilot study. *Psycho-Oncology*, 15(9), 780–794.
- Lane, J. D., & Wegner, D. M. (1995). The cognitive consequences of secrecy. *Journal of Personality and Social Psychology*, 69(2), 237–253.

- Langer, S. L., Brown, J. D., & Syrjala, K. L. (2009). Intrapersonal and interpersonal consequences of protective buffering among cancer patients and caregivers. *Cancer, 115*(S18), 4311–4325.
- Larson, D. G. (1993). Self concealment: Implications for stress and empathy in oncology care. *Journal of psychosocial oncology, 11*(4), 1-16
- Lee, V. (2008). The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning. *Supportive Care in Cancer, 16*(7), 779–785.
- Lee-Jones, C., Humphris, G., Dixon, R., & Bebbington Hatcher, M. (1997). Fear of cancer recurrence—a literature review and proposed cognitive formulation to explain exacerbation of recurrence fears. *Psycho-Oncology, 6*(2), 95–105.
- Lepore, S.J. (1997, April). Social constraints, intrusive thoughts, and negative affect in women with cancer. Paper presented at the meeting of the Society of Behavioural Medicine, San Francisco, CA.
- Lepore, S. J. (2001). A social-cognitive processing model of emotional adjustment to cancer. In A. Baum & B. L. Andersen (Eds.), *Psychosocial interventions for cancer*. (pp. 99–116). Washington, DC, US: American Psychological Association.
- Lepore, S. J., & Helgeson, V. S. (1998). Social Constraints, Intrusive Thoughts, and Mental Health after Prostate Cancer. *Journal of Social and Clinical Psychology, 17*(1), 89–106.
- Lepore, S. J., Ragan, J. D., & Jones, S. (2000). Talking facilitates cognitive–emotional processes of adaptation to an acute stressor. *Journal of Personality and Social Psychology, 78*(3), 499–508.

- Lepore, S. J., & Revenson, T. A. (2007). Social Constraints on Disclosure and Adjustment to Cancer. *Social and Personality Psychology Compass*, *1*(1), 313–333.
- Lepore, S. J., Silver, R. C., Wortman, C. B., & Wayment, H. A. (1996). Social constraints, intrusive thoughts, and depressive symptoms among bereaved mothers. *Journal of personality and social psychology*, *70*(2), 271–282.
- Lloyd, G. G. (1977). Psychological reactions to physical illness. *British Journal of Hospital Medicine*, *18*(4), 352, 355–358.
- Low, C. A., Stanton, A. L., & Danoff-Burg, S. (2006). Expressive disclosure and benefit finding among breast cancer patients: Mechanisms for positive health effects. *Health Psychology*, *25*(2), 181–189.
- MacDonald, L. D., & Anderson, H. R. (1984). Stigma in patients with rectal cancer: a community study. *Journal of epidemiology and community health*, *38*(4), 284–290.
- Macmillan. (2010). Treatment types. Document. Retrieved February 6, 2012, from <http://www.macmillan.org.uk/Cancerinformation/Cancertreatment/Treatmenttypes/Treatmenttypes.aspx>
- Maddams, J., Brewster, D., Gavin, A., Steward, J., Elliott, J., Utley, M., & Møller, H. (2009). Cancer prevalence in the United Kingdom: estimates for 2008. *British Journal of Cancer*, *101*(3), 541–547.
- Mager, W. M., & Andrykowski, M. A. (2002). Communication in the cancer “bad news” consultation: patient perceptions and psychological adjustment. *Psycho-Oncology*, *11*(1), 35–46.
- Maher, E. L. (1982). Anomic aspects of recovery from cancer. *Social Science & Medicine*, *16*(8), 907–912.

- Manne, S. L., Dougherty, J., Veach, S., & Kless, R. (1999). Hiding worries from one's spouse: Protective buffering among cancer patients and their spouses. *Cancer Research Therapy and Control*, 8, 175–188.
- Manne, S. L., Ostroff, J. S., Norton, T. R., Fox, K., Goldstein, L., & Grana, G. (2006). Cancer-related relationship communication in couples coping with early stage breast cancer. *Psycho-Oncology*, 15(3), 234–247.
- Manne, S. L., Ostroff, J., Winkel, G., Goldstein, L., Fox, K., & Grana, G. (2004). Posttraumatic growth after breast cancer: Patient, partner, and couple perspectives. *Psychosomatic Medicine*, 66(3), 442–454.
- Manne, S. L., Taylor, K. L., Dougherty, J., & Kemeny, N. (1997). Supportive and Negative Responses in the Partner Relationship: Their Association with Psychological Adjustment Among Individuals with Cancer. *Journal of Behavioral Medicine*, 20(2), 101–125.
- Mansergh, G., Marks, G., & Simoni, J. M. (1995). Self-disclosure of HIV infection among men who vary in time since seropositive diagnosis and symptomatic status. *AIDS*, 9(6), 639–644.
- Marks, G., Bundek, N.I., Richardson, J.L., Ruiz, M.S., Maldonado, N., & Mason, H.R.C. (1992). Self-disclosure of HIV infection: Preliminary results for a sample of Hispanic men. *Health Psychology*, 11(5), 300-306.
- Massie, M. J. (2004). Prevalence of Depression in Patients With Cancer. *JNCI Monographs*, 2004(32), 57 –71.
- McCready, T., & MacDonald, J. (2006). *An Introduction to Cancer Care* (1st ed.). Chichester, England: Whurr Publishers Limited.

- Meyer, L., & Aspegren, K. (1989). Long-term psychological sequelae of mastectomy and breast conserving treatment for breast cancer. *Acta Oncologica*, 28(1), 13–18.
- Mitchell, J. L. (1998). Cross-Cultural Issues in the Disclosure of Cancer. *Cancer Practice*, 6(3), 153–160.
- Mitchell, P. H., Powell, L., Blumenthal, J., Norten, J., Ironson, G., Pitula, C. R., Froelicher, E. S., et al. (2003). A short social support measure for patients recovering from myocardial infarction: the ENRICHD Social Support Inventory. *Journal of Cardiopulmonary Rehabilitation and Prevention*, 23(6), 398–403.
- Monroe, S. M., & Steiner, S. C. (1986). Social support and psychopathology: Interrelations with preexisting disorder, stress, and personality. *Journal of Abnormal Psychology*, 95(1), 29–39.
- Moorey, S., & Greer, S. (2002). *Cognitive behaviour therapy for people with cancer*. Oxford: Oxford University Press.
- Moorey, S., Greer, S., Watson, M., Gorman, C., Rowden, L., Tunmore, R., Robertson, B., et al. (1991). The factor structure and factor stability of the hospital anxiety and depression scale in patients with cancer. *The British Journal of Psychiatry*, 158(2), 255–259.
- Moos, R. H., & Schaefer, J. A. (1986). *Coping with life crises: an integrated approach*. New York: Plenum Press.
- Mor, V. (1987). Cancer patients' quality of life over the disease course: lessons from the real world. *Journal of chronic diseases*, 40(6), 535–544.
- Mor, V., Allen, S., & Malin, M. (1994). The psychosocial impact of cancer on older versus younger patients and their families. *Cancer*, 74(S7), 2118–2127.

- Morasso, G., Costantini, M., Viterbori, P., Bonci, F., Del Mastro, L., Musso, M., Garrone, O., et al. (2001). Predicting mood disorders in breast cancer patients. *European Journal of Cancer*, 37(2), 216–223.
- Moskowitz, D., & Roloff, M. (2007). On HIV Disclosure: A Literature Review. Presented at The annual meeting of the International Communication Association, San Francisco. Retrieved from http://www.allacademic.com/meta/p168463_index.html
- Munir, F., Leka, S., & Griffiths, A. (2005). Dealing with self-management of chronic illness at work: predictors for self-disclosure. *Social Science & Medicine*, 60(6), 1397–1407.
- Muzzin, L. J., Anderson, N. J., Figueredo, A. T., & Gudelis, S. O. (1994). The experience of cancer. *Social Science & Medicine*, 38(9), 1201–1208.
- Nelson, D. V., Friedman, L. C., Baer, P. E., Lane, M., & Smith, F. E. (1989). Attitudes to cancer: Psychometric properties of fighting spirit and denial. *Journal of behavioral medicine*, 12(4), 341–355.
- Nevidjon, B. M., & Sowers, K. W. (2000). *A Nurse's Guide to Cancer Care* (1st ed.). Philadelphia: Lippincott Williams & Wilkins.
- Nolen-Hoeksema, S. (1991). Responses to depression and their effects on the duration of depressive episodes. *Journal of Abnormal Psychology*, 100(4), 569–582.
- Northouse, P., & Northouse, L. (1988). Communication and Cancer. *Journal of Psychosocial Oncology*, 5, 17–46.
- O'Neill, M. P. (1975). Psychological aspects of cancer recovery. *Cancer*, 36(S1), 271–273.
- Oken, D. (1961). What to Tell Cancer Patients. *JAMA: The Journal of the American Medical Association*, 175(13), 1120–1128.

- Omarzu, J. (2000). A Disclosure Decision Model: Determining How and When Individuals Will Self-Disclose. *Personality and Social Psychology Review*, 4(2), 174–185.
- Osborne, R., Elsworth, G., Kissane, D., Burke, S., & Hopper, J. (1999). The Mental Adjustment to Cancer (MAC) scale: replication and refinement in 632 breast cancer patients. *Psychological medicine*, 29(6), 1335–1345.
- Pennebaker, J. W., & Beall, S. K. (1986). Confronting a traumatic event: Toward an understanding of inhibition and disease. *Journal of Abnormal Psychology*, 95(3), 274–281.
- Pennebaker, J. W., Hughes, C. F., & O’Heeron, R. C. (1987). The psychophysiology of confession: Linking inhibitory and psychosomatic processes. *Journal of Personality and Social Psychology*, 52(4), 781–793.
- Pennebaker, J. W., Kiecolt-Glaser, J. K., & Glaser, R. (1988a). Disclosure of traumas and immune function: health implications for psychotherapy. *Journal of Consulting and Clinical Psychology*, 56(2), 239–245.
- Pennebaker, J. W., Kiecolt-Glaser, J. K., & Glaser, R. (1988b). Disclosure of traumas and immune function: Health implications for psychotherapy. *Journal of Consulting and Clinical Psychology*, 56(2), 239–245.
- Pennebaker, J. W., & O’Heeron, R. C. (1984). Confiding in others and illness rate among spouses of suicide and accidental-death victims. *Journal of Abnormal Psychology*, 93(4), 473–476.
- Petrak, J. A., Doyle, A., Smith, A., Skinner, C., & Hedge, B. (2001). Factors associated with self-disclosure of HIV serostatus to significant others. *British Journal of Health Psychology*, 6(1), 69–79.

- Petronio, S. S. (2002). *Boundaries of privacy: Dialectics of disclosure*. Albany, New York: State University of New York Press.
- Petronio, S. S. (2004). Road to Developing Communication Privacy Management Theory: Narrative in Progress, Please Stand By. *Journal of Family Communication*, 4(3-4), 193-207.
- Petronio, S. S. (2007). Translational Research Endeavors and the Practices of Communication Privacy Management. *Journal of Applied Communication Research*, 35(3), 218-222.
- Petronio, S. S., & Caughlin, J. P. (2006). Communication Privacy Management Theory: Understanding Families. In D. O. Braithwaite & L. A. Baxter (Eds.), *Engaging theories in family communication: Multiple perspectives* (pp. 35–49). Thousand Oaks CA: Sage Publications, Inc.
- Petronio, S.S., Reeder, H.M., Hecht, M.L., & Mon't Ros-Mendoza, T.M. (1996). Disclosure of sexual abuse by children and adolescents. *Journal of Applied Communication Research*, 24, 181-199.
- Petronio, S.S., Sargent, J., Andea, L., Reganis, P., & Cichocki, D., (2004). Family and Friends as Healthcare Advocates: Dilemmas of Confidentiality and Privacy. *Journal of Social and Personal Relationships*, 21, 33-52.
- Pistrang, N., & Barker, C. (1992). Disclosure of concerns in breast cancer. *Psycho-Oncology*, 1, 183–192.
- Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: a review. *European Journal of Cancer*, 39(11), 1517–1524.

- Porter, L. S., Keefe, F. J., Hurwitz, H., & Faber, M. (2005). Disclosure between patients with gastrointestinal cancer and their spouses. *Psycho-Oncology, 14*(12), 1030–1042.
- Quinn, S. (1999). Lung cancer: the role of the nurse in treatment and prevention. *Nursing Standard, 13*(41), 49–54.
- Ramirez, A. J. (1989). Liaison Psychiatry in a Breast Cancer Unit. *Journal of the Royal Society of Medicine, 82*(1), 15–17.
- Razavi, D., Delvaux, N., Farvacques, C., & Robaye, E. (1990). Screening for adjustment disorders and major depressive disorders in cancer in-patients. *The British Journal of Psychiatry, 156*(1), 79–83.
- Reay, D., Bignold, S., Ball, S. J., & Cribb, A. (1998). “He just had a different way of showing it”: Gender dynamics in families coping with childhood cancer. *Journal of Gender Studies, 7*(1), 39–52.
- Redd, W. H., DuHamel, K. N., Vickberg, S. M. J., Ostroff, J. L., Smith, M. Y., Jacobsen, P. B., & Manne, S. L. (2001). Long-term adjustment in cancer survivors: Integration of classical-conditioning and cognitive-processing models. In A. Baum & B. L. Andersen (Eds.), *Psychosocial interventions for cancer*. (pp. 77–97). Washington, DC: American Psychological Association.
- Roberts, K. J., Lepore, S. J., & Helgeson, V. (2006). Social-Cognitive Correlates of Adjustment to Prostate Cancer. *Psycho-oncology, 15*(3), 183–192.
- Schacter, S. (1959). *The psychology of affiliation*. Stanford, CA: Stanford University Press.
- Schofield, P. E., Butow, P. N., Thompson, J. F., Tattersall, M. H. N., Beeney, L. J., & Dunn, S. M. (2003). Psychological responses of patients receiving a diagnosis of cancer. *Annals of Oncology, 14*(1), 48–56.

- Serovich, J. M. (2001). A Test of Two HIV Disclosure Theories. *AIDS Education and Prevention, 13*(4), 355–364.
- Serovich, J. M., Lim, J. Y., & Mason, T. L. (2008). A Retest of Two HIV Disclosure Theories. *Health & social work, 33*(1), 23–31.
- Shakin, E., Heiligenstein, E., & Holland, J. (1991). Psychiatric complications of cancer. In P. N. Plowman, T. J. McElwain, & A. T. Meadows (Eds.), *Complications of Cancer Management* (pp. 423–435). Oxford: Butterworth-Heinemann.
- Sherman, A., Pennington, J., Simonton, S., Latif, U., Arent, L., & Farley, H. (2008). Determinants of participation in cancer support groups: The role of health beliefs. *International Journal of Behavioral Medicine, 15*(2), 92–100.
- Slade, P., O'Neill, C., Simpson, A. J., & Lashen, H. (2007). The relationship between perceived stigma, disclosure patterns, support and distress in new attendees at an infertility clinic. *Human Reproduction, 22*(8), 2309–2317.
- Smart, L., & Wegner, D. (2000). The hidden costs of hidden stigma. In T. Heatherton, R. Kleck, M. Hebl, & J. Hull (Eds.), *The Social Psychology of Stigma* (pp. 220–242). New York: Guilford Press.
- Souhami, R. L., & Tobias, J. S. (2002). *Cancer and Its Management* (4th ed.). Oxford: Blackwell Publishing.
- Spiegel, D. (1992). Effects of psychosocial support on patients with metastatic breast cancer. *Journal of Psychosocial Oncology, 10*(2), 113–120.
- Stahly, G. B. (1989). Psychosocial Aspects of the Stigma of Cancer. *Journal of Psychosocial Oncology, 6*(3-4), 3–27.
- Stanton, A. L., Danoff-Burg, S., Cameron, C. L., Bishop, M., Collins, C. A., Kirk, S. B., Sworowski, L. A., et al. (2000). Emotionally expressive coping predicts

- psychological and physical adjustment to breast cancer. *Journal of Consulting and Clinical Psychology*, 68, 875–882.
- Steginga, S. K., Occhipinti, S., Gardiner, R. A., Yaxley, J., & Heathcote, P. (2004). Prospective study of men's psychological and decision-related adjustment after treatment for localized prostate cancer. *Urology*, 63(4), 751–756.
- Steward, W. T., Chandy, S., Singh, G., Panicker, S. T., Osmand, T. A., Heylen, E., & Ekstrand, M. L. (2011). Depression is not an inevitable outcome of disclosure avoidance: HIV stigma and mental health in a cohort of HIV-infected individuals from Southern India. *Psychology, Health & Medicine*, 16(1), 74–85.
- Stewart, D. E., Cheung, A. M., Duff, S., Wong, F., McQuestion, M., Cheng, T., Purdy, L., et al. (2001). Long-term breast cancer survivors: confidentiality, disclosure, effects on work and insurance. *Psycho-Oncology*, 10(3), 259–263.
- Stokes, J. P. (1987). The Relation of Loneliness and Self-Disclosure. In V. J. Derlega & J. H. Berg (Eds.), *Self-Disclosure: Theory, Research, and Therapy* (pp. 175–202). New York: Springer.
- Streiner, D. L. (2003). Starting at the beginning: an introduction to coefficient alpha and internal consistency. *Journal of Personality Assessment*, 80(1), 99–103.
- Streiner, D. L., & Norman, G. R. (2008). *Health Measurement Scales: A practical guide to their development and use* (4th ed.). Oxford: Oxford University Press.
- Tamres, L. K., Janicki, D., & Helgeson, V. S. (2002). Sex differences in coping behavior: A meta-analytic review and an examination of relative coping. *Personality and Social Psychology Review*, 6(1), 2–30.
- Taylor, S. E., Falke, R. L., Shoptaw, S. J., & Lichtman, R. R. (1986). Social support, support groups, and the cancer patient. *Journal of Consulting and Clinical Psychology*, 54(5), 608–615.


- Tedeschi, R. G., & Calhoun, L. G. (1996). The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of traumatic stress, 9*(3), 455–471.
- Tröster, H. (1997). Disclose or Conceal? Strategies of Information Management in Persons with Epilepsy. *Epilepsia, 38*(11), 1227–1237.
- Ullrich, P. M., Rothrock, N. E., Lutgendorf, S. K., Jochimsen, P. R., & Williams, R. D. (2008). Adjustment and discussion of cancer: A comparison of breast and prostate cancer survivors. *Psychology & Health, 23*, 391–406.
- Vaglio, J., Conard, M., Poston, W. S., O’Keefe, J., Haddock, C. K., House, J., & Spertus, J. A. (2004). Testing the performance of the ENRICH Social Support Instrument in cardiac patients. *Health and Quality of Life Outcomes, 2*(1), 2–24.
- van’t Spijker, A., Trijsburg, R. W., & Duivenvoorden, H. J. (1997). Psychological sequelae of cancer diagnosis: a meta-analytical review of 58 studies after 1980. *Psychosomatic Medicine, 59*(3), 280–293.
- Watson, M., Greer, S., Blake, S., & Shrapnell, K. (1984). Reaction to a diagnosis of breast cancer relationship between denial, delay and rates of psychological morbidity. *Cancer, 53*(9), 2008–2012.
- Watson, M., Greer, S., Rowden, L., Gorman, C., Robertson, B., Bliss, J. M., Tunmore, R., et al. (1991). Relationships between emotional control, adjustment to cancer and depression and anxiety in breast cancer patients. *Psychological Medicine, 21*(1), 51–57.
- Watson, M., Greer, S., Young, J., Inayat, Q., Burgess, C., & Robertson, B. (1988). Development of a questionnaire measure of adjustment to cancer: the MAC scale. *Psychological Medicine, 18*(01), 203–209.

- Wegner, D. M., Lane, J. D., & Dimitri, S. (1994). The allure of secret relationships. *Journal of Personality and Social Psychology*, 66(2), 287–300.
- Weisman, A. D., & Worden, J. W. (1976). The existential plight in cancer: significance of the first 100 days. *The international journal of psychiatry in medicine*, 7(1), 1–15.
- Wheless, L. R. (1978). A follow-up study of the relationships among trust, disclosure, and interpersonal solidarity. *Human Communication Research*, 4(2), 143–157.
- WHO | Cancer. (2011). *Cancer*. World Health Organization. Retrieved November 7, 2011, from <http://www.who.int/mediacentre/factsheets/fs297/en/index.html>
- Wills, T.A. (1981). Downward comparison principles in social psychology. *Psychological Bulletin*, 90, 245-271.
- Wittenberg-Lyles, E. M., & Villagran, M. M. (2006). Disclosure of a Cancer Diagnosis in Organizational Peer Relationships. *Communication Research Reports*, 23, 251–257.
- Worden, J. W., & Weisman, A. D. (1980). Do cancer patients really want counselling? *General Hospital Psychiatry*, 2(2), 100–103.
- Wortman, C. B., & Dunkel-Schetter, C. (1979). Interpersonal Relationships and Cancer: A Theoretical Analysis. *Journal of Social Issues*, 35(1), 120–155.
- Wortman, C. B., & Lehman, D. R. (1985). Reactions to victims of life crisis: support attempts that fail. In I. G. Sarason & B. R. Sarason (Eds.), *Social Support: Theory, Research and Applications* (pp. 463–489). Dordrecht, The Netherlands: Martinus Nijhoff.
- Yoo, G. J., Aviv, C., Levine, E. G., Ewing, C., & Au, A. (2009). Emotion work: disclosing cancer. *Supportive Care in Cancer*, 18, 205–215.

- Zabora, J. R., Blanchard, C. G., Smith, E. D., Roberts, C. S., Glajchen, M., Sharp, J. W., Locher, J. W., et al. (1997). Prevalence of Psychological Distress Among Cancer Patients Across the Disease Continuum. *Journal of Psychosocial Oncology*, *15*, 73–87.
- Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, *67*(6), 361–370.


APPENDICES


APPENDIX 1 - Recruitment Cover Letter

<p style="text-align: center;"><i>Recruitment letter version 2.1 (12.9.11)</i></p> <p style="color: red; font-weight: bold;"> Department of Psychology Health Psychology Section Institute of Psychiatry, KCL 5th Floor, Thomas Guy House Guy's Campus London SE1 9RT </p>	<p style="text-align: center;"><i>REC Reference Number: 11/LO/0341</i></p> <div style="text-align: right;">  <p style="font-weight: bold; margin-top: 5px;">University of London</p> </div>				
<p style="text-align: right;">Date:</p> <p>Dear</p> <p>Invitation to participate in research study I am a Trainee Clinical Psychologist studying at Kings College London. As part of my final year thesis project I am conducting a study in collaboration with Guy's and St Thomas' NHS trust, investigating the patterns of disease disclosure in people diagnosed with cancer. In other words I am interested in the extent to which people with cancer openly discuss their diagnosis, and thoughts and feelings about their disease.</p> <p>I am contacting you, as a person with a previous diagnosis of cancer, to invite you to take part in this research study. You have been contacted because you have been treated by consultants/nurse specialists that are supporting the study at Guy's and St Thomas' Hospitals. I will be asking approximately 120 people to participate by completing the enclosed questionnaire, which should take no more than 20 minutes. Further details of this study can be found on the enclosed participant information sheet.</p> <p>If you decide that you do wish to participate please complete the enclosed questionnaire and return it in the FREEPOST envelope provided. Please keep the 'Participant Information Sheet' for your reference.</p> <p>If you do not wish to participate please complete and detach the reply slip below and send it back to me in the FREEPOST envelope provided. This will ensure that I do not approach you again to take part in the study.</p> <p>Thank you for considering to take part in this research. Your participation is greatly appreciated.</p> <p>Kind regards,</p> <p>Heather Munro Trainee Clinical Psychologist</p> <table style="width: 100%; margin-top: 10px;"> <tr> <td style="width: 50%;"> Project Supervised by Dr Suzanne Scott Clinical Health Psychologist </td> <td style="width: 50%;"> Dr Alex King Clinical Health Psychologist </td> </tr> </table>		Project Supervised by Dr Suzanne Scott Clinical Health Psychologist	Dr Alex King Clinical Health Psychologist		
Project Supervised by Dr Suzanne Scott Clinical Health Psychologist	Dr Alex King Clinical Health Psychologist				
<p>✂ ----- Reply Slip -----</p> <p>I do not wish to take part in the above study and would prefer not to be contacted about it again.</p> <p>Signed:..... Print:..... Date:.....</p> <p>Please indicate your reason for not taking part:</p> <table style="width: 100%; border: none;"> <tr> <td style="width: 25%; border: none;"> <input type="checkbox"/> Not interested in research </td> <td style="width: 25%; border: none;"> <input type="checkbox"/> I don't want to think about it </td> <td style="width: 25%; border: none;"> <input type="checkbox"/> Do not wish to say </td> <td style="width: 25%; border: none;"> <input type="checkbox"/> Too busy </td> </tr> </table> <p><input type="checkbox"/> Other (please specify)</p>		<input type="checkbox"/> Not interested in research	<input type="checkbox"/> I don't want to think about it	<input type="checkbox"/> Do not wish to say	<input type="checkbox"/> Too busy
<input type="checkbox"/> Not interested in research	<input type="checkbox"/> I don't want to think about it	<input type="checkbox"/> Do not wish to say	<input type="checkbox"/> Too busy		
<p><i>'The Patterns & Predictors of Disease Disclosure by Patients with Cancer'</i></p>					
<table border="1" style="border-collapse: collapse;"> <tr> <td style="padding: 2px;">Office Use</td> </tr> <tr> <td style="padding: 2px;">ID:</td> </tr> </table>		Office Use	ID:		
Office Use					
ID:					

APPENDIX 2 - Participant information sheet

PIS Version 2.1 (12.9.11) REC Reference Number: 11/LO/0341

Guy's and St Thomas' 
NHS Foundation Trust


University of London

Participant Information Sheet

Title: 'The patterns and predictors of disease disclosure by patients with cancer'

I would like to invite you to participate in this postgraduate research project. Participation in the project is on a voluntary basis. You should only participate if you want to; choosing not to take part will not affect the standard of care you receive. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take the time to read the following information carefully.

Research aims: Little is known about the extent to which people with cancer openly discuss with others their diagnosis, and thoughts and feelings, about their disease. We know that telling a loved one about a cancer diagnosis is one of the hardest aspects of having cancer. It is important for us to understand who people disclose to, and what leads to this, so that we can develop effective ways of supporting this process. The purpose of this research is to look at the extent to which people talk to others about their cancer and how helpful/unhelpful this has been.

Who is invited to participate? People with a first-time diagnosis of cancer, aged 18 or above.

What does participation involve? Participation involves completing the enclosed questionnaire and returning it in the FREEPOST envelope. The questionnaire should take no longer than 20 minutes to complete. Participation is for research purposes only and will not form part of your ongoing clinical monitoring. By completing and returning the questionnaire I will assume you are giving your implicit consent to take part.

Will I be reimbursed for my time? Participation in this study is voluntary and unfortunately it is not possible to reimburse you for your time.

Are there any benefits involved in participating? There are no direct benefits, nor benefits to your health, by participating in this particular study, although it is hoped that the information you provide will help contribute to the future care of people diagnosed with cancer, who then face the task of disclosing to their loved ones.

Are there any risks involved in participating? I hope that the risks involved in participating are minimal. However, should completion of the questionnaire raise any issues for you, during your clinical care, you are invited to talk to a counsellor or psychologist on the details below.

1

Participant Information Sheet continued

PIS Version 2.1 (12.9.11) REC Reference Number: 11/LO/0341

Need to talk to a counsellor or psychologist? Psychological support is available to all patients with cancer being treated at Guy's and St Thomas' and to those carers or family members who may be affected. Please contact the psychological support team, at Dimpleby Cancer Care, directly on 020 7188 5918 to request further information or an appointment. Further information can be found at: www.guysandstthomas.nhs.uk/services/cancer/treatment_support/dimpleby.aspx

How will my privacy and confidentiality be maintained? Your questionnaire will be given an identification (ID) number to replace any personally identifiable information (such as your name). The ID number will only be traced back to your name so that I can identify who has already completed the questionnaire, and to prevent me from asking you a second time. The responses in your questionnaire will be *completely anonymous* and linked only to the ID number (i.e. they will not be linked to your personal data or medical file).

Can I withdraw my data? You can withdraw your data after submission, should you wish to, by contacting the researcher (Heather Munro). However it will not be possible to withdraw your data after statistical analysis has been performed (approximately Dec 2011).

Who is organising the research? This research is part of my Clinical Psychology course, which is being undertaken at Kings College London. This project is organised in conjunction with Dr Alex King (Clinical Health Psychologist with Dimpleby Cancer Care) and the cancer team responsible for your care at Guy's and St Thomas' NHS Foundation Trust.

What if I have complaints about the research? In the first instance please direct any complaints to the supervisor for this project, Dr Alex King (Clinical Health Psychologist) at alex.king@gstt.nhs.uk, or telephone 020 7188 5921, or in writing to 2nd Floor, Gassiot House, St Thomas' Hospital, LONDON, SE1 7EH

What if I have questions about this specific project? Please contact the researcher, Heather Munro, at Heather.Munro@kcl.ac.uk, by phone at 020 7848 0733, or by post at Kings College London, 3rd Floor, ASB, 4 Windsor Walk, LONDON, SE5 8AF.

Please keep this information sheet for your reference

APPENDIX 3 - Questionnaire



QUESTIONNAIRE PACK

Project Title

“The patterns & predictors of disease disclosure by patients with cancer”

Questionnaire information

This questionnaire pack is divided into a number of sections with questions examining areas such as who you have disclosed your diagnosis to, the social support and possible reactions you have received from others, the degree of stigma you have felt and your emotional well-being.

Try to answer all of the questions.

Office Use:

ID:

Questionnaire continued

SECTION 1. Talking about the diagnosis

1. This section asks about the extent to which you have talked about your diagnosis, and thoughts and feelings about cancer, since your diagnosis.

Instructions: Using the scale below, please indicate the degree to which you have talked to each of the following individuals about your cancer since your diagnosis. Please mark N/A for any categories that do not apply to you.

How much have you talked to the following people about your cancer? (please circle one option for each of the people below)	Purposefully chose not to talk	Did not have the opportunity to talk	Talked a little	Talked somewhat	Talked very much	N/A
1. Spouse or romantic partner	0	1	2	3	4	N/A
2. Co-workers/colleagues	0	1	2	3	4	N/A
3. Doctors	0	1	2	3	4	N/A
4. Nurses	0	1	2	3	4	N/A
5. Sibling(s) i.e. brothers /sisters	0	1	2	3	4	N/A
6. Professional therapist /counsellor	0	1	2	3	4	N/A
7. Friend(s) / Neighbour	0	1	2	3	4	N/A
8. Other cancer patients	0	1	2	3	4	N/A
9. Minister/Rabbi/Pastoral counsellor	0	1	2	3	4	N/A
10. Mother	0	1	2	3	4	N/A
11. Father	0	1	2	3	4	N/A
12. Children	0	1	2	3	4	N/A
13. Other (please describe)	0	1	2	3	4	N/A

Helpfulness

0 = very unhelpful → 5 = very helpful

2. Overall, how helpful/unhelpful to you has it been to talk about your cancer to the people above? (please circle one option to summarise)	0	1	2	3	4	5
--	---	---	---	---	---	---

Questionnaire continued

3. a) Please specify in what ways it was **helpful** to talk to others:.....

.....
.....
.....

b) Please specify in what ways it was **unhelpful** to talk to others:.....

.....
.....
.....

SECTION 2. Predictors of disclosure

This section asks about various factors that may be associated with how much you have talked about your diagnosis.

General openness

4. **I am a person who usually talks to other people about my problems, concerns and daily life events?** (please circle the option which best fits with you)

1	2	3	4	5	6

strongly disagree	moderately disagree	slightly disagree	slightly agree	moderately agree	strongly agree

*Questionnaire Version 2.1 (5.9.11)
Rec Reference No.11/LO/0341*

PLEASE TURN OVER →

Questionnaire continued

Perceived stigma

5. Because of your cancer, have you felt that other people...	Yes	No
1) were uncomfortable with you?	1	0
2) treated you as inferior?	1	0
3) preferred to avoid you?	1	0

General Social Support in everyday life

6. Please read the following questions and circle the response that most closely describes your <u>current situation</u> .	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. Is there someone available to you whom you can count on to listen to you when you need to talk?	1	2	3	4	5
2. Is there someone available to give you good advice about a problem?	1	2	3	4	5
3. Is there someone available to you who shows you love and affection?	1	2	3	4	5
4. Is there someone available to help you with daily chores?	1	2	3	4	5
5. Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?	1	2	3	4	5
6. Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide?	1	2	3	4	5

Questionnaire Version 2.1 (5.9.11)
Rec Reference No.11/LO/0341

PLEASE TURN OVER →

Questionnaire continued

Reactions received from others

7. Listed below are a number of responses that you may, or may not, have received from other people about your cancer.

Instructions: For each statement, please indicate (by circling the relevant number) how much of that type of response you received from other people .

0 = None of the time → 4 = A lot of the time

1) Someone felt that I was over-reacting to my cancer	0	1	2	3	4
2) When I was talking with someone about my cancer, the person did not give me enough of his or her time, or made me feel like I should hurry	0	1	2	3	4
3) Someone made “should/shouldn’t have” comments about my cancer, such as, “you should/shouldn’t have ……”	0	1	2	3	4
4) Someone didn’t seem to know what to say, or seemed afraid of saying/doing the “wrong” things	0	1	2	3	4
5) Someone refused to provide the type of help or support I was looking for	0	1	2	3	4
6) After becoming aware of my cancer, someone responded to me with uninvited physical touching, such as hugging	0	1	2	3	4
7) Someone said I should look on the bright side	0	1	2	3	4
8) Someone said, “I told you so”, or made some similar comment about my cancer	0	1	2	3	4
9) Someone seemed to be telling me what he or she thought I wanted to hear	0	1	2	3	4
10) In responding to me about my cancer, someone seemed disappointed in me	0	1	2	3	4
11) When I was talking to someone about my cancer, the person changed the subject before I wanted to	0	1	2	3	4
12) Someone felt that I should stop worrying about my cancer and just forget about it	0	1	2	3	4

Questionnaire continued

0 = None of the time → 4 = A lot of the time

13) Someone asked me “why” questions about my role in my illness, such as, “why did/didn’t you ………”	0	1	2	3	4
14) Someone felt that I should focus on the present and/or the future, and that I should get on with my life	0	1	2	3	4
15) Someone tried to cheer me up when I was not ready to cheer up about my illness	0	1	2	3	4
16) In responding to me about my cancer, someone refused to take me seriously	0	1	2	3	4
17) Someone told me to be strong, to keep my chin up, or that I shouldn’t let it bother me	0	1	2	3	4
18) When I was talking to someone about my cancer, he or she did not seem to want to hear about it	0	1	2	3	4
19) Someone told me that I had gotten myself into the situation in the first place, and that now I must deal with the consequences	0	1	2	3	4
20) Someone did some things for me that I wanted to do and could have done myself	0	1	2	3	4
21) Someone discouraged me from expressing feelings about my cancer, such as anger, hurt or sadness	0	1	2	3	4
22) Someone felt that it could have been worse or that it was not as bad as I thought	0	1	2	3	4
23) From the person’s tone of voice, expression, or body language, I got the feeling that he or she was uncomfortable talking with me about my cancer	0	1	2	3	4
24) Someone made comments that blamed me or tried to make me feel responsible for my cancer	0	1	2	3	4

Questionnaire continued

Emotional well-being

8. The questions below are about how you feel.

Instructions: Read each item and circle the reply which comes closest to how you have been feeling in the past week. Please do not take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought out response.

1) I feel tense or 'wound up'	Most of the time	A lot of the time	From time to time, occasionally	Not at all
2) I still enjoy the things I used to enjoy	Definitely as much	Not quite so much	Only a little	Hardly at all
3) I get a sort of frightened feeling as if something awful is about to happen	Very definitely and quite badly	Yes, but not too badly	A little, but it doesn't worry me	Not at all
4) I can laugh and see the funny side of things	As much as I always could	Not quite so much now	Definitely not so much now	Not at all
5) Worrying thoughts go through my mind	A great deal of the time	A lot of the time	Not too often	Very little
6) I feel cheerful	Never	Not often	Sometimes	Most of the time
7) I can sit at ease and feel relaxed	Definitely	Usually	Not often	Not at all
8) I feel as if I am slowed down	Nearly all the time	Very often	Sometimes	Not at all
9) I get a sort of frightened feeling like 'butterflies' in the stomach	Not at all	Occasionally	Quite often	Very often
10) I have lost interest in my appearance	Definitely	I don't take as much care as I should	I may not take quite as much care	I take just as much care as ever
11) I feel restless as if I have to be on the move	Very much indeed	Quite a lot	Not very much	Not at all
12) I look forward with enjoyment to things	As much as I ever did	Rather less than I used to	Definitely less than I used to	Hardly at all
13) I get sudden feelings of panic	Very often indeed	Quite often	Not very often	Not at all
14) I can enjoy a good book or radio or television programme	Often	Sometimes	Not often	Very seldom

Questionnaire Version 2.1 (5.9.11)
Rec Reference No.11/LO/0341

PLEASE TURN OVER →

Questionnaire continued

SECTION 3. Information about you

Instructions: Please indicate your relevant personal information by placing a tick in the appropriate boxes.

1. Please state your current age:.....

2. Gender: Male Female

3. Ethnicity: Are you...

- | | | |
|--|------------------------------------|---|
| <input type="checkbox"/> Black-Caribbean | <input type="checkbox"/> Indian | <input type="checkbox"/> Bangladeshi |
| <input type="checkbox"/> Black-African | <input type="checkbox"/> White | <input type="checkbox"/> Chinese |
| <input type="checkbox"/> Black-Other | <input type="checkbox"/> Pakistani | <input type="checkbox"/> Other (please specify):..... |

4. What is your highest level of education?

- | | |
|---|--|
| <input type="checkbox"/> No academic qualifications | <input type="checkbox"/> GCSE / O-Level / Equivalent |
| <input type="checkbox"/> A-Level / Equivalent | <input type="checkbox"/> Degree Level or Higher |
| <input type="checkbox"/> Other (please specify):..... | |

5. Are you currently...

- | | |
|---|--|
| <input type="checkbox"/> Single | <input type="checkbox"/> Married / living with partner |
| <input type="checkbox"/> Divorced / separated | <input type="checkbox"/> Widowed |

6. Do you...(please tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Live alone | <input type="checkbox"/> Live with a partner |
| <input type="checkbox"/> Live with children | <input type="checkbox"/> Live with housemates |
| <input type="checkbox"/> Live with parents | <input type="checkbox"/> Other (please specify):
..... |

Questionnaire continued

7. a) What was your employment status prior to receiving your diagnosis:

- Unemployed Employed Self-employed
 Student Home-maker Long-term sick
 Retired Other (please specify):.....

7. b) What is your current employment status:

- Unemployed Employed Self-employed
 Student Home-maker Long-term sick
 Retired Other (please specify):.....

8. Approximately how long has it been since you received your diagnosis?

- Less than 6 months 6 months – 1 year 1 – 1½ years
 1½ - 2 years 2 years +

9. Please indicate your cancer type:

- Skin cancer Colorectal cancer
 Lung cancer Other (please specify):.....

10. Please indicate the first treatment you received:

- Radiotherapy Chemotherapy Surgery / tissue removal
 Biological therapy e.g. Interferon injections Other (please specify):.....

11. Is your cancer visible, or does the treatment you have received for it, make it visible to a stranger?

- Yes No

12. Was anyone else present with you when you received your diagnosis of cancer?

- Yes No

If yes, please state their relationship to you (e.g. mother, friend, brother):.....

*Questionnaire Version 2.1 (5.9.11)
Rec Reference No.11/LO/0341*

Questionnaire continued

Please state the date you completed this questionnaire: ___/___/___ (Day/Month/Year)

Thank you
*for taking part in this study which is being undertaken by
the Department of Psychology, Kings College London*

Collaborators:

Skin Cancer Unit, St John's Institute of Dermatology,
Colorectal Cancer Unit,
Department for Thoracic Surgery,

at Guy's and St Thomas' NHS Foundation Trust

Please tick if you would like to be sent a summary of the results of the study

If you have any questions regarding the completion of this questionnaire please e-mail:
Heather.Munro@kcl.ac.uk

If completion of this questionnaire has raised any issues for you, please contact the:
Dimbleby Cancer Care, Psychological Support Team on 020 7188 5918

*Questionnaire Version 2.1 (5.9.11)
Rec Reference No.11/LO/0341*

APPENDIX 4 - Follow-up reminder letter

Follow-up letter version 1 (11.2.11)

REC Reference Number: 11/LO/0341

Department of Psychology
Health Psychology Section
Kings College London
5th Floor, Thomas Guy House
Guy's Campus
London SE1 9RT



Date:

Dear

Reminder to participate in research study

I am following up on a letter I sent you a few weeks ago which invited you to take part in my research study. I have yet to hear from you and I am writing to ask whether you would re-consider participating.

I am a Trainee Clinical Psychologist based at Kings College London. As part of my final year thesis project I am conducting a study in collaboration with Guy's and St Thomas' NHS trust. I am investigating the patterns of disease disclosure in people diagnosed with cancer. In other words I am interested in the extent to which people with cancer openly discuss their diagnosis, and thoughts and feelings about their disease.

I am contacting you, as a person with a previous diagnosis of cancer, because you have been treated by consultants/nurse specialists that are supporting the study at Guy's and St Thomas' Hospitals.

If you decide that you **do wish to participate** please complete the enclosed questionnaire and return it in the FREEPOST envelope provided. Please keep the attached information sheet for your reference.

Thank you for considering to take part in this research. If you have already completed the questionnaire and returned it, please ignore this reminder letter. Your participation is greatly appreciated.

Kind regards,

Heather Munro
Trainee Clinical Psychologist

Project Supervised by

Dr Suzanne Scott
Clinical Health Psychologist

Dr Alex King
Clinical Health Psychologist

'The Patterns & Predictors of Disease Disclosure by Patients with Cancer'

APPENDIX 5 - Letter summarising the results of the study



Health Psychology Department
Kings College London
5th Floor, Thomas Guy House
Guy's Hospital
London SE1 9RT

18th May 2012

Dear

Participant Feedback

Study title: 'The patterns and predictors of disease disclosure by patients with cancer'

Thank you for taking part in the above study and helping us reach our target of 120 participants. We have now finished the study and analysed the results. From this study we have learnt that:

- Most patients with cancer talk about their diagnosis to a variety of people and that the majority find it helpful to talk.
- Talking helps clarify thoughts, make practical plans, gain reassurance and support, gain perspective, helps with adjustment, allows for communication of information, and permits emotional expression. However, talking can sometimes bring unwanted pity, or be personally upsetting. Some patients fear they will burden others, or find it difficult to talk in times of uncertainty.
- Those patients who believe they have good social support in general and those who have a disposition towards being an open person (i.e. the tendency to discuss general thoughts and feelings in everyday life) were more likely to talk to others about their cancer and find it useful to do so.
- Age, gender, cancer visibility, perceived stigma, and the responses received from others did not affect how much people talked about their cancer or how helpful they found talking about their cancer.

Based on these findings, it is hoped that we can provide advice to professionals on the best ways to support people with the difficult task of disclosure.


Thank you once again for participating in this study. Your contribution has helped advance the work in this field.

Yours sincerely

Heather Munro
Chief Investigator

Supervisors: Dr Suzanne Scott, Health Psychologist
Dr Alex King, Clinical Psychologist

APPENDIX 6a - Ethics Committee Approval Letter

		 National Research Ethics Service NRES Committee London - Camberwell St Giles <small>(Formerly known as The Joint South London and Maudsley and Institute of Psychiatry Research Ethics Committee)</small> 1st Floor, Camberwell Building 94 Denmark Hill London SE5 9RS
		Telephone: 020 3299 5033 Facsimile: 020 3299 5085
09 May 2011		
Miss Heather A Munro Floor 3 Addiction Science Building PO BOX 078, 4 Windsor Walk LONDON SE5 8AF		
Dear Miss Munro		
Study Title:	The patterns and predictors of disease disclosure by patients with cancer.	
REC reference number:	11/LO/0341	
Protocol number:	CSA/11/010	
The Research Ethics Committee reviewed the above application at the meeting held on 15 April 2011. Thank you for attending to discuss the study.		
Documents reviewed		
The documents reviewed at the meeting were:		
Document	Version	Date
Letter of invitation to participant	1	11 February 2011
REC application	3.1	02 March 2011
CV: Elizabeth Alice Grunfeld		04 March 2011
Reminder to participate in research study	1	11 February 2011
Participant Information Sheet: Participant Information Sheet	1	11 February 2011
Covering Letter		02 March 2011
Questionnaire: Questionnaire Pack	1	11 February 2011
Evidence of insurance or indemnity		09 July 2010
Referees or other scientific critique report		31 January 2011
Protocol	1	11 February 2011
CV: Dr Alex King		04 March 2011
This Research Ethics Committee is an advisory committee to London Strategic Health Authority The National Research Ethics Service (NRES) represents the NRES Directorate within		

Ethics Committee Approval Letter continued

11/LO/0341

Page 2

Provisional opinion*Summary*

This is a student project and is part of a Doctorate in Clinical Psychology. The study is to consider to what extent people with Cancer talk about their diagnosis and what are the predictors of such disclosure. The main aim of the study is to measure the extent to which people talk to others in their social network, about their Cancer and how helpful/unhelpful this has been. The second aim is to investigate the factors that lead to people disclosing for example, age, gender, cancer type, social support, stigma, disposition towards disclosure and psychological well-being.

The sample size is 120 but up to 360 potential participants will be sent letters, since Questionnaires tend to attract 1/3 response rates.

Key issues of concerns were:

- Consent is implied by completing and returning a questionnaire;
- Whether to participate or not requires the Participant to complete and tear off a reply slip giving reasons as to why they do not want to participate.

Interview

- The CI explained that this is a qualitative study to explore factors and reasons why Cancer sufferers do not talk about their Cancer and what the impact of this maybe. She went on to say that participants will be recruited through the Cancer clinic list. She said the clinicians are aware of the study and would mention the study to potential participants. Those that expressed an interest in the study will be contacted by the research team. Thereafter the participant will be sent a letter and a questionnaire to be completed and returned.
- The Committee asked the purpose of the reply slip in relation to knowing why the participant did not want to take part in the study. The CI stated that it was important for the study to gather this information as it is often those who do not disclose their feelings towards Cancer who will typically not want to be part of research projects.
- The Committee went on to ask about the questionnaires. The CI explained that they were validated questionnaires and are also used in research for other illnesses such as Diabetes. A Committee member said that a participant may have a diagnosis that does not include the term Cancer; was it possible to amend the questionnaire to include the participant's stated illness rather than the term Cancer. The CI reiterated that the questionnaire was a validated one, but would enquire whether it was possible to amend as the Committee required.
- A Committee member asked if any psychological support will be available to participants. The CI confirmed that arrangements were in place for this.

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

The Committee delegated authority to confirm its final opinion on the application to the Chair.

Ethics Committee Approval Letter continued

11/LO/0341

Page 3

Further information or clarification required

Decision: Provisional Opinion – The Committee delegated authority to the Chair for granting final approval to the study following a satisfactory response to the following points:

- Please amend the Information Sheet to explain that participation in the project is on a voluntary basis and ensure that this is mentioned at the beginning;
- Please amend the Invitation Letter to say "Dear Mr, Mrs or Miss" and include the participant's name;
- The CI should provide evidence to the Committee that ensures the insurance cover deductibles do not fall on the participant. The CI can seek guidance from the local R&D office on this matter;
- The Committee believe that it is inappropriate to use the return of a questionnaire and reply slip as consent, asking for reasons why the participant does not want to participate in the study. Please amend this process by either explaining the reasons why you want to know the reason for the participants not wanting to take part in the study; or by deleting the requirement to complete the reply slip;
- Please ensure that the initial consent is obtained within the clinic;
- The section heading on the Information Sheet could be misleading, please amend the title;

Please amend the Consent Form by including a paragraph(s) that says:

- 1) The Participants have had the opportunity to ask questions **AND**
- 2) The Researcher has explained the project and has answered questions honestly and fully.

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 06 September 2011.

Membership of the Committee

The members of the 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.

Please quote this number on all correspondence: 11/LO/0341

Ethics Committee Approval Letter continued

11/LO/0341

Page 4

Yours sincerely


R Mr Tony Eaton
Chair

Email: audrey.adams@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments.*

Copy to: *Ms Jennifer Liebscher
R&D Department for NHS care organisation at lead site*

Ethics Committee Approval Letter continued

11/EO/0341

Page 5

NRES Committee London - Camberwell St Giles

Attendance at Committee meeting on 15 April 2011


Committee Members:

Name	Profession	Present	Notes
Mr Sean Bell - Briggs		Yes	
Mrs Jennifer Bostock	Lay Member	Yes	
Prof Nelarine Cornelius	Prof. of Human Resource Management & Organisation Studies	Yes	
Mr Tony Eaton	Lay Member	Yes	
Dr Nicola Fear	Senior Lecturer in Military Epidemiology	No	
Prof Raymond Feldman		Yes	
Dr Theresa Joyce	Consultant Clinical Psychologist	Yes	
Dr Richard A A Kanaan	Consultant Psychiatrist	Yes	
Dr Veena Kumari	Senior Research Fellow in Basic Biomedical Science & Senior Lecturer	Yes	
Dr Morven Leese	Senior Lecturer in Statistics	Yes	
Ms Nour Shahara		Yes	
Mr Evan Stone QC	Lay Member	Yes	
Mr James Uwalaka	Sickle Cell Research Co-ordinator	Yes	
Mr Jonathan Watkins	Independent Social Worker	Yes	
Cllr Ian Wingfield	Deputy Leader Southwark Council	No	

Also in attendance:

Name	Position (or reason for attending)
Audrey Adams	Co-ordinator
Ms Sally Gordon - Boyd	Observer

APPENDIX 6b - Ethics Committee Approval of Amendment

 National Research Ethics Service NRES Committee London - Camberwell St Giles (Formerly known as The Joint South London and Maudsley and Institute of Psychiatry Research Ethics Committee) Administrative address: Victoria House Capital Park Fulbourn Cambridge CB21 5XB Tel: 01223 597509 Fax: 01223 597646	
25 August 2011	
Miss Heather A Munro Floor 3 Addiction Science Building PO BOX 078, 4 Windsor Walk LONDON SE5 8AF	
Dear Miss Munro	
Study title:	The patterns and predictors of disease disclosure by patients with cancer.
REC reference:	11/LO/0341
Protocol number:	CSA/11/010
Amendment number:	Amendment 1
Amendment date:	01 August 2011
Amendment summary:	
<ul style="list-style-type: none">• Change in recruitment procedure for skin cancer patients:<ul style="list-style-type: none">○ Rather than being sent the information sheet and questionnaire, skin cancer patients who meet the inclusion criteria will be approached in the clinic.○ Skin cancer patients are will be approached on just one occasion to take part and thus will not be sent a follow-up reminder letter.• Change in study team:<ul style="list-style-type: none">○ Dr Beth Grunfeld (Clinical Health Psychologist) to be replaced by Dr Suzanne Scott (Clinical Health Psychologist)• Poster:<ul style="list-style-type: none">○ For display in clinic rooms, purely to inform patients that the study is currently ongoing in the department.	
The above amendment was reviewed at the meeting of the Sub-Committee in correspondence.	
Ethical opinion	
The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.	
<small>This Research Ethics Committee is an advisory committee to the East of England Strategic Health Authority The National Research Ethics Service (NRES) represents the NRES Directorate within the National Patient Safety Agency and Research Ethics Committees in England</small>	

Ethics Committee Approval of Amendment continued

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Advertisement	Poster	
Letter of invitation to participant	Version 3 SK	01 August 2011
Participant Information Sheet	Version 3	01 August 2011
Notice of Substantial Amendment (non-CTIMPs)	Amendment 1	01 August 2011
Covering Letter: from Heather Munro		08 August 2011

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

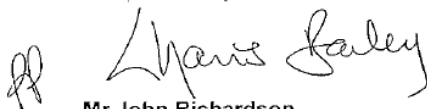
All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

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.

11/LO/0341:	Please quote this number on all correspondence
--------------------	---

Yours sincerely



Mr John Richardson
Chair

E-mail: charis.bailey@eoe.nhs.uk

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority
The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England

Ethics Committee Approval of Amendment continued

Encs: List of names and professions of members who took part in the review

CC: Mrs Jenny Liebscher
Research and Development Office,
King's College, University of London
Institute of Psychiatry / South London and Maudsley NHS Foundation Trust
De Crespigny Park
London
SE5 8AF

Dr. Karen Ignatian
Guy's and St Thomas' NHS Trust
R&D Dept,
16th Floor, Tower Wing
Guy's Hospital
Great Maze Pond
London
SE1 9RT

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority
*The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England*

Ethics Committee Approval of Amendment continued


NRES Committee London - Camberwell St Giles

Attendance at Sub-Committee of the REC meeting on 24 August 2011

<i>Name</i>	<i>Profession</i>	<i>Capacity</i>
Mrs Jennifer Bostock	Philosopher of Psychiatry	Lay
Professor Veena Kumari	Professor of Experimental Psychology	Expert
Mr John Richardson	Retired Director of COREC; Ecumenical Officer for Churches Together in South London	Lay
Mr Evan Stone QC	Retired Queens Counsel	Lay Plus

This Research Ethics Committee is an advisory committee to East of England Strategic Health Authority
*The National Research Ethics Service (NRES) represents the NRES Directorate within
the National Patient Safety Agency and Research Ethics Committees in England*

APPENDIX 7 - Research Governance Approval Letter

	
	Research & Development 16th Floor Tower Wing Guy's Hospital Great Maze Pond London SE1 9RT Tel: 020 7188 7188
<p>Dr Alex King Guys and St Thomas' NHS Foundation Trust 2nd Floor, Gassiot House St Thomas' Hospital Westminster Bridge Road London SE1 7EH</p>	
<p>3rd August 2011</p>	
<p>Dear Dr King</p>	
<p>Title: The pattern and predictors of disease disclosure by patients with cancer</p>	
<p>In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.</p>	
<ul style="list-style-type: none"> • Ethics Number: 11/LO/0341 • Sponsor: Institute of Psychiatry, King's College Hospital • Funder: Institute of Psychiatry, King's College London • End Date: 01/05/2012 • Protocol: Version 1.0 dated 11/02/2011 • Site: GSTFT • R&D Approval Date: 25/07/2011 • Chief Investigator: Miss Heather Munroe 	
<p>NHS permission for the above research has been granted on the basis described in the application form, protocol and supporting documentation as listed in the ethics letter of favourable opinion dated 20/06/2011. I am pleased to inform you that we are approving the work to proceed within Guy's and St Thomas' NHS Foundation Trust and that the study has been allocated the Trust R&D registration number RJ111/N230. Please quote the R&D registration number in any communications with the R&D Department regarding your project.</p>	
<p>Conditions of Approval:</p> <ul style="list-style-type: none"> • The principal investigator must ensure that the recruitment figures are reported. • The principal investigator must notify R&D of the actual end date of the project. • R&D must be notified of any changes to the protocol prior to implementation. • The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management. • Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract. 	

Research Governance Approval Letter continued

Data Protection:

Please ensure that you are aware of your responsibilities in relation to The Data Protection Act 1998, NHS Confidentiality Code of Practice, NHS Caldicott Report and Caldicott Guardians, the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.

The Principal Investigator is responsible for ensuring that Data Protection procedures are observed throughout the course of the project.

If the project is a clinical trial under the European Union Clinical Trials Directive the following must also be complied with:

1. The EU Directive on Clinical Trials (Directive 2001/20/EC) and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials) Regulations 2004;
2. The EU Directive on Principles and Guidelines for Good Clinical Practice (EU Commission Directive 2005/28/EC); and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials) Amendment Regulations 2006;
3. If a clinical trials team has to keep a subject in a department "out of hours" for whatever reason, the Senior Nurse for the Hospital should be informed of their presence – as should the Resuscitation Team.

Amendments:

Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

ISRCTN registration:

If appropriate it is recommended that you register with the Current Controlled Trials website <http://isrctn.org/>. Find out more about registering for an [International Standard Randomised Controlled Trial Number](#) (ISRCTN) as part of the Portfolio application process. Non-commercial studies with an interventional component that are eligible for NIHR CRN support can register for an ISRCTN for free via the Portfolio Database.

Annual Progress Report:

It is obligatory that an annual report is submitted by the Chief Investigator to the research ethics committee, and we ask that a copy is sent to the R&D Department. The yearly period commences from the date of receiving a favourable opinion from the ethics committee.

Please submit a copy of the progress report on the anniversary of the Ethics favourable opinion **(20th June)**

Should you require any further information please do not hesitate to contact us.

Thank you for registering your research project.

Yours sincerely



Janahi Visakan
R&D Governance Co-ordinator

cc: Ms Jennifer Liebscher
cc: Miss Heather Munroe

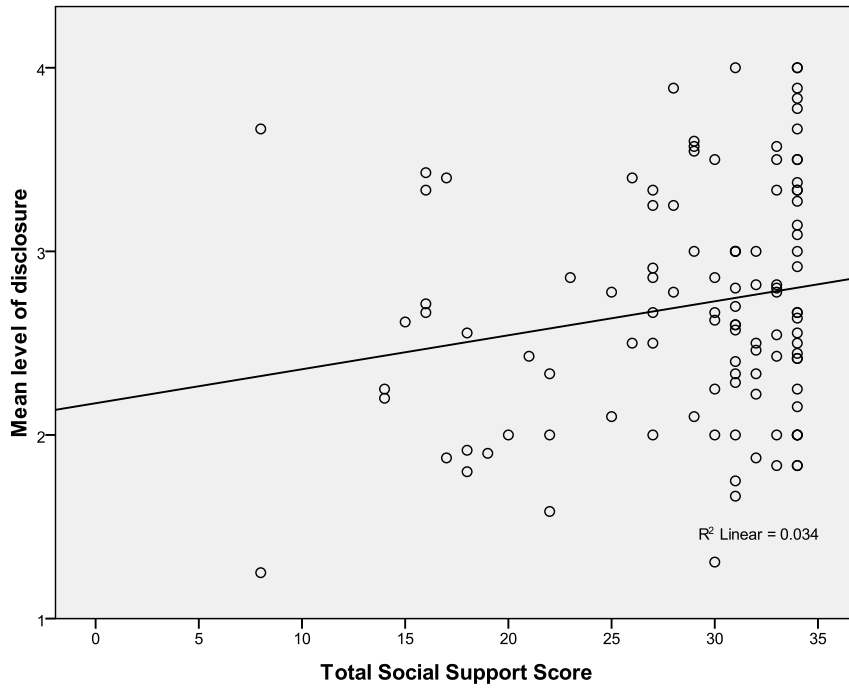
APPENDIX 8 - Correlations

Coding responses to the questions of how disclosure is helpful and unhelpful: A table of correlations indicating the level of agreement between two independent raters on the themes present in responses.

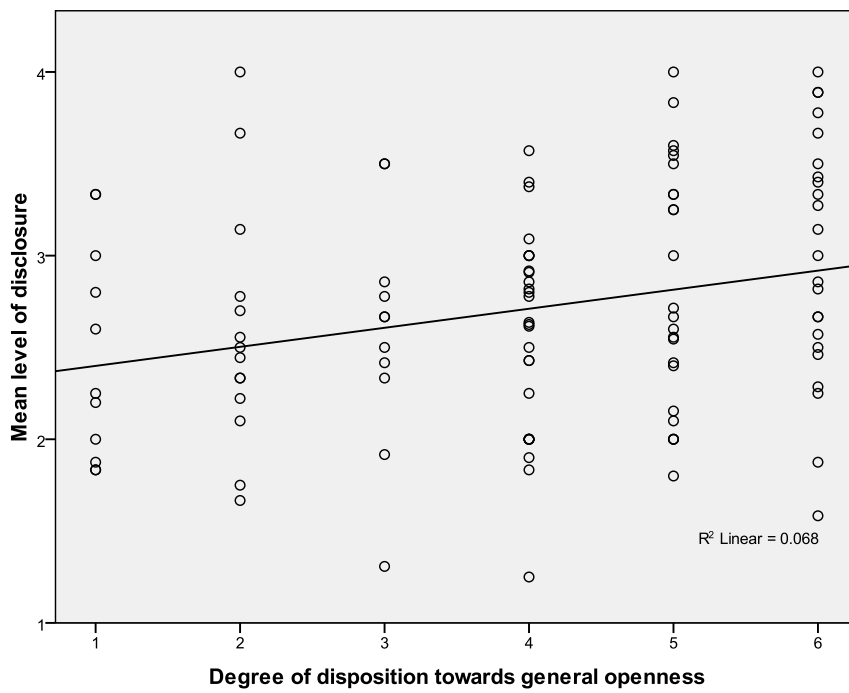
THEMES	Spearman's rho correlation co-efficient
Q3a Helpful (n=109)	
Theme 1: Clarify thoughts	.723**
Theme 2: Practical planning	.805**
Theme 3: Reassurance & Support	.814**
Theme 4: Perspective	.706**
Theme 5: Give information	.945**
Theme 6: Adjustment	.637**
Theme 7: Gain information	.815**
Theme 8: Emotional expression	.952**
Theme 9: Inappropriate response	.953**
Q3b Unhelpful (n=48)	
Theme 1: Pity	1.000**
Theme 2: Personally upsetting	.754**
Theme 3: Burden	1.000**
Theme 4: Poor understanding	.895**
Theme 5: Unhelpful reactions	.819**
Theme 6: Stigma	.777**
Theme 7: Uncertainty	.884**
Theme 8: Inappropriate response	.860**

**Correlation is significant at the 0.01 level (1-tailed)

APPENDIX 9 - Scatterplots



Scatterplot showing the relationship between social support and disclosure



Scatterplot showing the relationship between general openness and disclosure

APPENDIX 10 - Guidance for Cancer Specialists

HOW TO DISCUSS DISCLOSURE WITH YOUR PATIENTS – AN EVIDENCE-BASED GUIDE FOR CANCER SPECIALISTS

(Based on insights from the literature and local research)

Disclosing the diagnosis to loved ones is one of the hardest aspects of having cancer (Hilton et al, 2009; Yoo et al, 2009). Despite this, most people do disclose to a variety of social targets (Henderson et al, 2002). In the main, disclosure is thought to be beneficial as it can help with adjustment (Lepore, 2001). However, this is not necessarily the case for everyone across circumstances. Research carried out at Guy's and St Thomas' Hospitals with patients with lung, colorectal and skin cancer revealed the following ways in which disclosure can be helpful and unhelpful:

REASONS DISCLOSURE IS HELPFUL	REASONS DISCLOSURE IS UNHELPFUL
<ul style="list-style-type: none"> • Clarification of thoughts • Allows for practical planning • Helps gain reassurance & support • Helps gain perspective • Allows for communication of information • Promotes adjustment • Emotional expression 	<ul style="list-style-type: none"> • Evokes pity • Can be personally upsetting • Fear of being a burden • People can have a poor understanding • People can have unhelpful reactions • Stigma • Uncertainty

FIVE STEPS TO BEST PRACTICE

1. Be mindful that patients face the challenge of disclosing & raise the topic as part of your routine clinical contact with the patient; offer the opportunity to have an in-depth conversation considering the issue.
2. Share our knowledge on the topic & the reasons why people have found it helpful/unhelpful (see above). Providing knowledge means the patient will be better placed to make an informed plan around disclosure. 'Strategic announcements' help preserve control and autonomy, and helps maintain a sense of self, which is vital when managing a threatening illness (Charmaz, 1993).
3. Listen carefully to the patient & elicit their preferences for disclosure. Ask them who they are considering telling. Qualities of a good confidant include being trustworthy, non-judgemental and able to offer new insights (Kelly & McKillop, 1996).
4. You may also encourage the patient to consider an appropriate context for disclosure e.g. the place and timing of when it should occur, as well as the variety of options for disclosure e.g. face to face, telephone, via email or letter, or through another person who they select to share the information on their behalf. You may even offer to help the patient disclose in the medical setting, as this enhances the credibility of the information (Charmaz, 1993).
5. Remember to revisit disclosure conversations. Regularly check-in with the patient how they are getting on, who they have told, how it went and whether it was helpful. Pay particular attention to any difficulties they have encountered either through maintaining secrecy or any unhelpful responses they have received leading to more distress. If such difficulties are impacting on their overall mood, adjustment or quality of life, please consider offering the patient a referral to speak with a professional in the Psycho-Oncology Support Team (POST).

For more information, or to discuss further, contact:

Alex King at Alex.King@gstt.nhs.uk or Heather Munro at HeatherMunro@nhs.net

PART B

SERVICE EVALUATION PROJECT

**A description of the psychological
well-being of the first forty patients
to complete a pre-orthognathic
psychology assessment in a Cleft
Service**

Heather Munro

Supervisor: Dr Catherine O'Leary

ABSTRACT

The aim of this project was to examine the psychological well-being of patients considering orthognathic (jaw) surgery in a cleft service. 40 patients (23M/17F) received a psychology assessment comprising of a semi-structured interview and completed 3 questionnaires: the Hospital Anxiety and Depression Scale, the Satisfaction with Appearance Questionnaire and the Orthognathic Quality of Life Questionnaire. Following the assessment 30 patients decided to have surgery, 4 decided against and 6 were undecided. As a group, patients had normal levels of anxiety and depression, were less satisfied with their nose, lips and teeth and demonstrated a normal distribution of QoL scores. Those seeking surgery were more anxious and had poorer orthognathic QoL than those who were not. There were no differences by gender or cleft type. Overall, the patients in this sample had normal levels of psychological well-being pre-surgery. The importance of information-giving to assist with an informed decision is discussed, as well as the recommendation to adhere to the protocol for psychological input in orthognathic proceedings in the future.

TABLE OF CONTENTS

1.0	Introduction.....	156
1.1	Orthognathic surgery.....	156
1.2	Cleft and the need for orthognathic surgery.....	157
1.3	Literature review.....	158
1.4	Facial attractiveness and the effects of facial deformity.....	159
1.5	Psychological well-being of pre-orthognathic patients.....	160
1.5.1	Satisfaction with Appearance.....	161
1.5.2	Quality of life.....	162
1.6	Reasons for having surgery.....	162
1.7	Satisfaction with surgery.....	163
1.8	Current psychology protocol preceding orthognathic surgery in the South Thames Cleft Service.....	163
1.9	Aims.....	165
2.0	Methods.....	166
2.1	Participants.....	166
2.2	Procedure.....	166
2.3	Measures.....	166
2.3.1	Hospital Anxiety and Depression Scale.....	166
2.3.2	Satisfaction with Appearance Questionnaire.....	167
2.3.3	Orthognathic Quality of Life Questionnaire.....	167
2.4	Statistical analysis.....	168
3.0	Results.....	169
3.1	Descriptive Statistics.....	169
3.2	Inferential Statistics.....	174
4.0	Discussion.....	179
4.1	Discussion of results.....	179
4.2	Implications and following the protocol.....	185
4.3	Communication of findings.....	185
4.4	Limitations and future research.....	185
4.5	Conclusion.....	186
	References.....	188

Appendices.....	194
Appendix 1 Protocol for psychological input with patients undergoing orthognathic surgery.....	194
Appendix 2 Interview schedule.....	197
Appendix 3 HADS.....	199
Appendix 4 SwA.....	202
Appendix 5 OQLQ.....	205

LIST OF TABLES

Table 1.	Demographic characteristics.....	169
Table 2.	The number of patients who made various decisions around surgery according to gender, cleft type and overall group.....	170
Table 3.	Group results on the Hospital Anxiety and Depression Scale.....	171
Table 4.	Mean, median and mode scores from the Satisfaction with Appearance Questionnaire.....	172
Table 5.	Group means and standard deviations on the OQLQ.....	173
Table 6.	Results of t-tests comparing males versus females on the four questionnaire outcomes.....	174
Table 7.	Results of t-tests comparing those who decided ‘Yes’ versus ‘No’ to surgery on the four questionnaire outcomes.....	175
Table 8.	Results of the One-way ANOVA comparing cleft type on the four questionnaire outcomes.....	177
Table 9.	Pearson’s Correlations Matrix.....	178

LIST OF FIGURES

Figure 1.	Side profile before and after orthognathic surgery.....	156
Figure 2.	Variations of cleft type.....	157
Figure 3.	Boxplot showing the normal distribution of responses to Question 2 – ‘How satisfied are you with your whole appearance?’	172
Figure 4.	Bar chart illustrating the difference in anxiety scores between those who said ‘Yes’ versus ‘No’ to surgery.....	176
Figure 5.	Bar chart illustrating the difference in total QoL between those who said ‘Yes’ versus ‘No’ to surgery.....	176

1.0 INTRODUCTION

1.1 ORTHOGNATHIC SURGERY

Orthognathic (jaw) surgery has become a well established procedure which aims to correct dentofacial deformity, and malfunction of the jaws, and to produce a more harmonious skeletal appearance (Modig, Andersson & Wardh, 2006). It involves the division and repositioning of the jaw bones in order to achieve a more proportionate facial profile. The two most commonly cited reasons for proceeding with such surgery are to improve aesthetics and to alleviate functional problems (Cunningham, Hunt & Feinmann, 1995; Khan, 2005). Figure 1 displays a side profile before and after orthognathic surgery and reveals the extent to which facial misalignment can be corrected.



Figure 1. Side profile before and after orthognathic surgery.

Before orthognathic surgery is carried out, preparatory orthodontic procedures, which can take up to two years to complete, are usually required (Lello, 2001). This orthodontic work aims to prevent relapse by ensuring that the mouth is suitably prepared for surgery but can mean that the person's appearance, i.e. the apparent jaw and tooth discrepancy (overjet and underbite), may essentially appear worse before better. Fixed orthodontic appliances, such as arch wires and braces, are used before, during and post surgery to achieve accurate positioning of the teeth and to help fine tune the bite with the aid of elastic bands.

The surgery itself tends to last between 3 and 6 hours and involves administration of a general anaesthetic. The hospitalisation period varies but is typically between 3-5 days. The immediate consequences following surgery can include pain, swelling, bruising

and/or numbness, and in a small number of cases this numbness remains indefinitely. In one sample of post-operative patients, 49% reported lingering paraesthesia (Kiyak, 1993). As well as practical concerns, the patient has to come to terms with changes in their appearance and potential changes in their speech.

The overall process, including the combined orthodontic and orthognathic procedures, is lengthy and can take between 12 and 36 months, during which, frequent appointments are required. Given the complexity and protracted duration of the procedure, as well as the post-surgical implications, it has been suggested that orthognathic surgery should only be undertaken when the patient fully understands what is involved and is entirely prepared to co-operate (Lello, 2001). The enormity of the procedure is reflected in the finding that patients take an average of 4 years when deciding whether to undergo surgery (Garvill, Garvill, Kahnberg & Lundgren, 1992).

1.2 CLEFT AND THE NEED ORTHOGNATHIC SURGERY

Cleft lip and or palate refers to a gap which occurs when the lip or roof of the mouth fail to fuse during foetal development (Children's Craniofacial Association, 2009). It is one of the most common congenital defects with a mean prevalence of 1 to 2 in every 1000 births (Robin, Baty, Franklin et al, 2006). The severity of the cleft can vary and, since the lip and palate form independently, there are several possible combinations of deformity including: cleft lip only (CL), cleft palate only (CP), unilateral (one-sided) cleft lip and palate (UCLP) and bilateral (two-sided) cleft lip and palate (BCLP). Figure 2 shows the variations of cleft type.

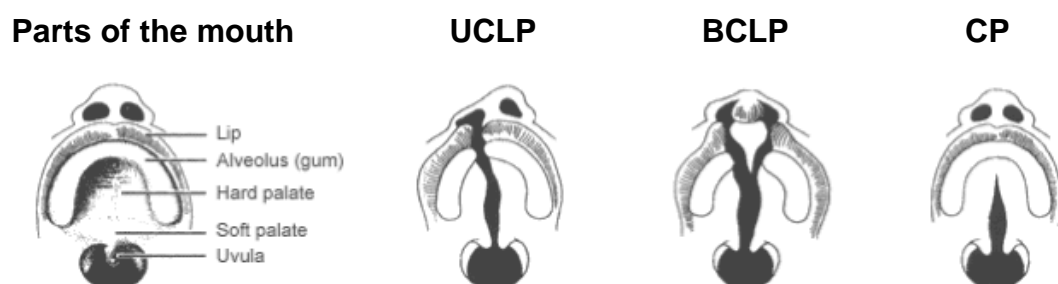


Figure 2. Variations of cleft type

Patients with cleft commonly require a number of corrective surgical procedures throughout childhood and the resulting scarring to the palate can often interrupt the growth of the maxilla (upper jaw). Thus there is often the need for orthognathic surgery to correct the maxillary deficiency in patients with cleft palate.

Ideally, surgical correction of the jaw would be carried out as early as possible given the pain, speech abnormalities and potential psychosocial problems associated with dento-facial deformity. However, extensive surgery to the maxilla at an early age can cause damage to un-erupted teeth, contribute to retardation of future maxilla growth, or create an occlusion which is later disrupted by disproportionate maxillary and mandibular growth (Lello, 2001). Therefore, orthognathic surgery in patients with cleft is typically delayed until late childhood or early adulthood; when facial growth is complete, in order to reduce the need for the repetition of surgery at a later date. This timing is particularly important since relapse rates tend to be greater in the cleft population (Banks, 1986; Chong, Portnof, Haisong & Salyer, 2009; Ross, 1987).

Orthognathic surgery is considered a secondary procedure, in the cleft population, since it addresses residual functional or aesthetic deficiencies and failures of growth. It is directed at enhancing the outcomes or addressing the complications of primary palate operations (Robin et al, 2006). Since the surgery does not usually have life or death consequences, there is an element of choice as to whether one goes ahead with it or not. As a result, determining the need for orthognathic surgery is no simple matter and debate can arise, particularly when the main purpose of surgery is for aesthetic enhancement. It has been found that clinicians and patients do not always agree on the need for surgery, and that even the subjective opinions of professionals (i.e. surgeons and orthodontists) can differ (Juggins, Nixon & Cunningham, 2005).

1.3 LITERATURE REVIEW

There is a fairly detailed literature on the psychological impact of having a cleft, but comparatively little is known about the psychological processes involved in orthognathic surgery for the cleft population. The existing literature has tended to focus

on a wider 'non-cleft' population with dento-facial deformities and typically consists of retrospective studies. However, the relevant literature will be reviewed here.

1.4 FACIAL ATTRACTIVENESS AND THE EFFECTS OF FACIAL DEFORMITY

It has long been established that facial attractiveness is defined by 'symmetry' (Perrett, Burt, Penton-Voak, Lee, Rowland & Edwards, 1999) and 'averageness' (Langlois & Roggman, 1990). Moreover, 'attractiveness' has been linked to superior mental health, intelligence, ability and performance, with those who are considered more physically attractive experiencing greater achievement and psychological well-being (Umberson & Hughes, 1987). These life enhancing effects of attractiveness imply that being beautiful is advantageous and tends to serve people the 'upper hand' in life. Whereas for people with less symmetrical, and less 'average' faces, (who are considered less attractive), the converse has been found to be true.

It has been shown that facial and dental anomalies, that are sufficient to affect a person's appearance, can put that person at a social disadvantage (Heldt, Haffke & Davis, 1982; Shaw, Meek & Jones, 1980) and that facial deformity in the nasal region can influence the ability to find a job, gain social credit, or find a spouse (Zapotoczky & Marlovits, 1993). More specifically, within the cleft population, children have been reported to be underachievers and experience decreased expectations by both parents and teachers (Richman & Eliason, 1982). Children with cleft are more anxious, less satisfied with their appearance and speech, have lower self-esteem, greater behavioural problems, and are teased more often which is predictive of having greater psychosocial problems (Hunt, Burden, Hepper, Stevenson & Johnston, 2007). Adolescents with cleft, in particular girls, have been found to be more socially inhibited which leads to their isolation (Kapp-Simon & McGuire, 1997), and therefore puts them at greater risk of developing depression (Richman & Millard, 1997).

In spite of this, a number of reviews have found that most people with cleft do not suffer from major psychosocial problems or any significant psychopathology (Hunt, Burden, Hepper, Johnston & Orth, 2005) and in fact many show positive psychosocial adjustment and self-perception (Eiserman, 2001). However, for a select few, the

challenges of living with a facial deformity mean that clinically significant problems will be present (Hunt et al, 2005).

Interestingly, a consistent finding across conditions is that there is no clear relationship between the severity of the facial deformity and psychological outcome (MacGregor, 1979; Lansdown, Lloyd & Hunter, 1991). Naini and Gill (2008) comment that, ‘the psychological distress caused by a facial deformity is not in proportion to its severity’ (p.107). Moreover, Berger and Dalton (2011) have found that, although cleft type alone is not a predictor of adjustment: social experiences, maternal well-being, satisfaction with appearance, perceived speech problems and use of avoidant coping strategies are all important factors associated with psychosocial adjustment in adolescents with cleft. Therefore, there should be a cautious approach in screening people with dento-facial deformity since a myriad of social and environmental factors are likely to impact on their psychological well-being beyond what are purely the biological effects of the deformity.

In summary, facial deformity is considered to be a serious condition with effects that may prohibit adjustment and can ultimately restrict a person from reaching their potential.

1.5 PSYCHOLOGICAL WELL-BEING OF PRE-ORTHOGNATHIC PATIENTS

A recent systematic review has carefully considered the psychosocial well-being of pre-orthognathic patients (Alanko, Svedstrom-Oristo & Tuomisto, 2010). To the exclusion of studies involving cleft populations, it reviewed 35 articles and concluded that, patients considering orthognathic surgery do not suffer from psychiatric problems. The review implied that pre-orthognathic patients are ‘psychologically stable’ and come from a ‘normal’ group. However, the authors suggest that this finding should be interpreted cautiously given that many studies report group means on measures of anxiety and depression, thus obscuring the possibility that a significant few will suffer from clinically significant problems in these areas. Phillips and colleagues (1998) have further suggested that distress levels may fluctuate throughout the orthognathic process, with the potential for greater distress at the treatment-seeking phase compared to later

stages. However, it has also been found that the anxiety and depression scores in a sample of women going ahead with surgery did not differ from those of untreated controls (Williams, Bentley, Cobourne et al, 2009).

In relation to cleft, the literature suggests that most people do not suffer from psychological distress, but that a clinically significant minority will experience impaired psychological well-being. For example, Ramstad and colleagues (1995) found higher levels of anxiety and depression among adults with repaired CLP, compared to controls. Interestingly, a study comparing the psychological adjustment of patients, before and after orthognathic surgery, found that those with cleft were happier and had lower levels of social anxiety and distress than the non-cleft group, suggesting that those with cleft may cope better (Cheung, Loh & Ho, 2006). Given the mixed findings it is thus unclear whether pre-orthognathic patients with cleft will experience elevated levels of psychological distress.

1.5.1 Satisfaction with Appearance (SwA)

It has been established, in a sample of women, that the only difference between those seeking orthognathic surgery and untreated controls was that the former have more dissatisfaction with their facial appearance (Williams et al, 2009). These authors conclude that, in their sample, the desire for surgery was fuelled by a genuine desire to correct facial deformity rather than an exaggerated perception of aesthetic problems (since all other measures of appearance and self-concept matched those of controls). A further finding is that orthognathic patients are less happy, specifically with their teeth and face, when compared to controls (Johnston, Hunt, Burden, et al, 2010).

In relation to cleft, it is frequently found that those with visible deformity are less satisfied with their appearance when compared to healthy controls (Marcusson, Pauline & Ostrup, 2002) and those with invisible anomalies (Thomas, Turner, Rumsey, et al, 1997). Importantly, dissatisfaction with appearance has been found to be the best predictor of depression in both cleft and healthy adult groups (Marcusson et al, 2002). In an adolescent sample, an interaction has been found between cleft visibility and gender, whereby girls with a visible cleft are least satisfied with their appearance (Feragen & Borge, 2010). However, the relationship between cleft visibility and satisfaction with appearance is complex, and has been found to be fully mediated by

experiences of social interaction whereby only those who suffered peer harassment were dissatisfied with their appearance (Feragen & Borge, 2010). Overall, the literature suggests that there is potential for those with facial deformity, seeking orthognathic surgery, to have some level of dissatisfaction with their facial appearance.

1.5.2 Quality of Life (QoL)

In the 'non-cleft' population, dento-facial deformity has been found to negatively impact on various aspects of a person's life and the profound functional, social and psychological effects mean that affected individuals may have poorer overall QoL than those without dento-facial deformities (Lee, McGrath & Samman, 2007). With specific reference to the cleft population, the findings are less discrete in that there appears to be no difference in the overall levels of QoL between healthy controls and those with cleft in both child (Bressman, Sader, Ravens-Sieberer, et al, 1999; Locker, Jokovic & Thompson, 2005) and adult samples (Marcusson, Akerlind & Paulin, 2001). However, major differences in QoL have been found between those seeking further treatments versus those who are not. One study, evaluating the outcomes in adult patients with cleft, found that those considering further surgical treatments (in the form of nose and lip revisions) had significantly poorer health-related QoL than those who did not desire further treatments (Sinko, Jagsch, Prechtel, et al, 2005). In fact 44.3% of their overall sample desired more treatment, with women expressing such desires twice as often as men (62.5% versus 34.8%). The authors suggest that this gender difference may be because men identify themselves more with social status, money and power, therefore physical attractiveness is less important to them. Additionally, men have the possibility of hiding scars or concealing a retruded maxilla with a moustache and so have the option to camouflage their deformity rather than drastically opting for surgery.

1.6 REASONS FOR HAVING SURGERY

The motivations for requesting surgery are many and varied, with 60% of patients providing at least three reasons (Garvill et al, 1992). These reasons tend to fall into 3 broad categories: 1) functional, 2) aesthetic, and 3) a drive to improve self-esteem and self-confidence (Alanko et al, 2010).

1.7 SATISFACTION WITH SURGERY

Generally people tend to report being satisfied after orthognathic surgery, and experience both functional and psychosocial gains (Modig, Andersson & Wardh, 2006). A review (of 29 retrospective and prospective studies) found benefits to include improved self-confidence, satisfaction with body and facial image, and social adjustment (Hunt, Johnston, Hepper & Burden, 2001).

Patients' pre-surgical expectations and psychological well-being have been found to influence perceptions of, and satisfaction with, the outcomes of orthognathic surgery (Phillips, Kiyak, Bloomquist & Turvey, 2004). For example, expectations of problems prior to surgery predicted post-surgical dissatisfaction and mood disturbances, with those anticipating fewer problems reporting better overall psychological well-being (Kiyak, Vitaliano & Crinean, 1988). Furthermore, patients who were psychologically distressed before surgery have been found to report a higher overall recovery burden and experience more discomfort and difficulty with symptoms, social/self concerns, and poorer general health in the first one or two months after surgery (Phillips et al, 2004). These findings highlight the importance of identifying those prone to being more psychologically distressed prior to surgery so that the appropriate support may be offered and outcomes can be improved.

Overall, the literature highlights the role of psychological factors in orthognathic surgery both in terms of them being a driving force for having surgery and for their impact on outcome. As such psychology has an important role in orthognathic proceedings and it has been recognised that Clinical Psychologists could 'contribute to the assessment of suitability for surgery, assist with patient decision making and provide therapeutic interventions' (Morris, 2006, p.149).

1.8 CURRENT PSYCHOLOGY PROTOCOL PRECEEDING ORTHOGNATHIC SURGERY IN THE SOUTH THAMES CLEFT SERVICE

The Clinical Standards Agency Group (CSAG) published a report in 1998 that led to the re-organisation of cleft services, in the UK, from 57 regional units into 10 specialist

centers. In recognising the emotional and psychosocial needs of cleft patients, the report recommended that psychological support should be routinely offered in cleft care, which led to Clinical Psychology becoming an integral part of the multidisciplinary South Thames Cleft Service (STCS). The National Cleft Psychology Special Interest Group (SIG) then identified a particular area of need surrounding orthognathic surgery; leading to the drafting of a protocol for psychological involvement in orthognathic proceedings (see Appendix 1). The protocol incorporates the need for longitudinal assessment throughout the orthognathic journey including: Time 1, the Pre-orthodontic stage; Time 2, Pre-operatively; and Time 3, Post-operatively. Since 2007, the STCS has begun to implement this protocol by offering a pre-orthognathic psychology assessment to all those considering orthognathic surgery.

The psychology assessments aim to ascertain whether the patient is mentally prepared for surgery and whether there is a need for support throughout the process. To date the Time 1 pre-orthognathic psychology assessment has involved a semi-structured interview and the completion of three questionnaires; The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), The Satisfaction with Appearance Questionnaire (SwA; Cleft Psychology SIG, 2007) and the Orthognathic Quality of Life Questionnaire (OQLQ; Cunningham, Garratt & Hunt, 2000). The semi-structured interviews are carried out by a Clinical Psychologist within the South Thames Cleft Service. The interview component lasts approximately 45 mins – 1 hour and includes questions covering the following: expectations of surgery (physical and psychological), understanding of the procedure, previous experiences of surgery and coping strategies used, as well as the support networks available to the person. The interview assessment proforma can be found in Appendix 2.

To date, the psychological assessments have been offered at various times throughout the process leading up to surgery, with some being carried out early on in the decision making process (prior to orthodontic work commencing) and some occurring after the patient has decided and treatment has begun. However there is a drive to implement the protocol sufficiently so that psychological involvement occurs with timely efficiency at pre-decision, pre-surgery and post-surgery stages.

1.9 AIMS

The aim of this study was to examine the psychological well-being of pre-orthognathic patients by exploring the data pertaining to the first 40 pre-orthognathic psychology assessments, and by answering the following questions:

1. Who are the patients considering jaw surgery (in terms of gender, age, ethnicity, cleft type and co-morbidities) and who were they referred by?
2. What was the outcome of the pre-orthognathic psychology assessment? (e.g. what were the recommendations and did they decide to have surgery?)
3. What is the psychological well-being of pre-orthognathic patients based on the 3 questionnaire measures (HADS, SwA & OQLQ)?
4. Are there any significant differences on the questionnaires by gender, decision (yes or no to surgery) or cleft type?
5. Are there any relationships between the scores on the different questionnaires?

2.0 METHODS

2.1 PARTICIPANTS

The participants included the first forty patients, considering jaw surgery, to receive a psychology assessment within the South Thames Cleft Service. The sample comprised of 23 (57.5%) males and 17 (42.5%) females, with ages ranging from 14 to 46 years (mean=21.8yrs, sd=8.7yrs). There were no exclusion criteria.

2.2 PROCEDURE

This service-related research project was granted approval by the Guy's and St Thomas' Clinical Governance Department (Project number 1399). The procedure involved reviewing the data gathered from the first forty pre-orthognathic psychology assessments carried out between March 2007 and January 2010. This involved a retrospective exploration of the clinical notes, reports and questionnaires resulting from the assessment sessions. The questionnaire responses were recorded in an anonymised excel spreadsheet and the total scores were calculated. Additional demographic and treatment information, for each patient, was drawn from the patients' hospital electronic records. The data for each person was then collated in an SPSS spreadsheet and coded prior to analysis.

2.3 MEASURES

2.3.1 Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) is an easily administered, self-report questionnaire used to screen for the presence of depression and anxiety in patients receiving medical care. The measure generates two subscales scores: one for anxiety (HADS-A) and one for depression (HADS-D). Scores can range from 0 – 21 (≤ 7 is 'normal', 8 – 10 is 'mild', 11 – 14 is 'moderate' and 15+ represents 'severe').

2.3.2 Satisfaction with Appearance Questionnaire

The Satisfaction with Appearance Questionnaire (SwA) was originally developed by Emerson and colleagues (2004) and has since been adapted by the Psychology Special Interest Group, Craniofacial Society of Great Britain and Ireland (2007) who retain the copyright. It consists of 20 items which ask the patient how they feel about different aspects of their looks and requires a response on a scale of 0 to 10, where 0 represents 'very unhappy' and 10 represents 'very happy'. There is currently no established way of scoring the questionnaire and it tends to be used in clinical practice to compare how satisfied the patient is with certain features (such as teeth, lips and nose) relative to how they feel about other features (such as their hair or overall appearance). The scale has been found to possess good internal consistency, with Cronbachs $\alpha = .90$ when speech and hearing items are excluded (Emerson, Spencer-Bowdage & Bates, 2004).

2.3.3 Orthognathic Quality of Life Questionnaire

The Orthognathic Quality of Life Questionnaire (OQLQ; Cunningham, Garratt & Hunt, 2000) is a condition-specific measure of quality of life. It was designed for use with patients who present with severe dentofacial deformity, who are requesting orthognathic treatment, and has been found to have good reliability, validity and responsiveness (Cunningham, Garratt & Hunt, 2002). As yet it has never been normed specifically within a cleft population, although the content of the questionnaire is obviously relevant. It consists of 22 statements rated on a four-point scale whereby the patient has to indicate whether the content of the statement, (1) 'bothers you a little' to (4) 'bothers you a lot'. There is also the option to circle 'N/A' meaning the statement does not apply to you or 'does not bother you'. A total OQLQ score is generated (with higher scores indicating a poorer QoL). Each of the 22 items contribute to four domains which include: Facial Aesthetics, Oral Function, Awareness of Dentofacial Aesthetics and Awareness of Dentofacial Deformity.

The above questionnaires can be found in Appendices 3, 4, and 5 respectively.

2.4 STATISTICAL ANALYSIS

Analysis was performed using SPSS for Windows package Version 17.0 (SPSS Corporation, Chicago, USA). Descriptive and inferential statistics were used to characterise the study variables of interest. Descriptive statistics were used to answer questions 1, 2 and 3 thereby describing the demographic details, outcome of the psychology assessment and responses to the questionnaires respectively. Inferential statistics were used to answer questions 4 and 5. For question 4, which asked about any significant differences in the measures, independent samples t-tests were used to compare questionnaire scores across gender and decision type ('Yes' or 'No' to surgery) and a one-way ANOVA was used to compare the cleft types on the questionnaires. In the interests of being conservative, analysis was restricted to four elements from the questionnaires: HADS Anxiety score, HADS Depression score, Satisfaction with Appearance Question 2 (which refers to the whole appearance) and the OQLQ total score. Despite the small sample size, initial exploration of the data suggested that it was largely normally distributed and so parametric tests were selected since they tend to be more robust. The level of significance was determined as 5%; thus a difference was considered to be significant when $p < 0.05$.

In line with Cohen's (1969 and 1988) cautious definitions of effect size, for the t-tests, a Cohen's d of 0.2 was considered 'small', 0.5 was considered 'medium' and 0.8 was considered 'large'. Similarly for the ANOVA a partial eta squared of .05 was considered 'small', 0.1 was considered 'medium' and 0.2 was considered to be 'large'. Finally, for question 5, two-tailed Pearson's Correlations were used to look for relationships between the variables of interest.

3.0 RESULTS

3.1 DESCRIPTIVE STATISTICS

1. Who were the patients considering orthognathic surgery and who were they referred by?

Table 1 details the demographic composition of the sample in terms of gender, age, ethnicity, cleft type, co-morbidities and referral source.

Table 1. Demographic characteristics

	No. (%)		No. (%)		No. (%)
GENDER		AGE CATEGORIES		ETHNICITY	
Male	23 (57)	14-19yrs	27 (67)	White British	28 (70)
Female	17 (43)	20-29yrs	6 (15)	Other White	2 (5)
		30-39yrs	4 (10)	Asian	1 (2)
		40+ yrs	3 (8)	Not Stated	9 (23)
CLEFT TYPE		COMORBIDITIES		REFERRER	
UCLP	23 (57)	Aspergers Syndrome	2 (5)	Surgeons	34 (85)
BCLP	8 (20)	Cleft Related Syndromes	5 (13)	Orthodontics	4 (10)
CL	1 (3)	Depression	4 (10)	Nursing	1 (2.5)
CP	8 (20)	Diabetes	1 (2)	Psychology	1 (2.5)
		None	28 (70)		

The sample comprised of slightly more males (23/40). The age of the patients, at the time of assessment, ranged from 14 to 46 years (mean=21.8yrs, sd=8.7yrs). The majority of patients fell into the youngest age category (14-19yrs) with the most common age being 18yrs (10 patients fell into this year group). There was a bias towards White British ethnicity and an uneven distribution in terms of cleft type, whereby most had UCLP and only one had CL. In terms of co-morbidities, the majority had none of note and the five with cleft related syndromes included three with Pierre Robin Sequence, one with Ehler's Danlos Syndrome and one with Ectodermal Dysplasia Syndrome. The majority of the referrals for a pre-orthognathic psychology assessment (85%) came from surgeons.

2. What was the outcome of the pre-orthognathic psychology assessment?

Firstly in terms of the recommendations made, four possible outcomes were identified in the psychology assessment reports;

1. 57% received a one-off consultation (n=23)
2. 5% required more information (n=2)
3. 28% were offered support prior to surgery (n=11)
4. 10% were offered support following surgery (n=4)

Secondly, three different types of decisions were made at the end of the assessment;

1. 75% decided 'yes' to having surgery (n=30)
2. 10% decided 'no' to having surgery (n=4)
3. 15% were 'undecided' (n=6)

These decisions were further analysed in terms of gender and cleft type. A breakdown of this can be found in Table 2.

Table 2. The number of patients who made various decisions around surgery according to gender, cleft type and overall group

DECISION	'Yes'	'No'	'Undecided'
<i>By Gender</i>			
Male	18 (78%)	2 (9%)	3 (13%)
Female	12 (70%)	2 (12%)	3 (18%)
<i>By Cleft Type</i>			
Unilateral Cleft Lip and Palate	16 (70%)	3 (13%)	4 (17%)
Bilateral Cleft Lip and Palate	6 (75%)	1 (12.5%)	1 (12.5%)
Cleft Lip Only	0 (0%)	0 (0%)	1 (100%)
Cleft Palate Only	8 (100%)	0 (0%)	0 (0%)
Overall Group	30 (75%)	4 (10%)	6 (15%)

NB Percentages represent the proportion of cases within each sub-group category

3. What is the psychological well-being of pre-orthognathic patients?

Hospital Anxiety and Depression Scale (HADS)

In total 39 of the 40 patients completed the HADS. One 14 yr old did not complete the measure as they were thought to be too young, however it has previously been established that the HADS is suitable for use with adolescents (White, Leach, Sims, Atkinson & Cottrell, 1999) and so should be used with all patients from now on. The results of the HADS are detailed in Table 3. It can be seen that the majority of the sample fell within the ‘normal’ range in terms of anxiety (mean=5.8, sd=3.5) and depression scores (mean=3.5, sd=3.2).

Table 3. Group results on the Hospital Anxiety and Depression Scale

HADS subscale	Mean (SD)	Min-Max scores	Range possible	Frequencies falling into each category			
				Normal	Mild	Moderate	Severe
Anxiety	5.8 (3.5)	1-15	0-21	29 (74%)	7 (18%)	2 (5%)	1 (3%)
Depression	3.5 (3.2)	0-12	0-21	35 (90%)	1 (3%)	3 (7%)	0 (0%)

Satisfaction with Appearance Questionnaire (SwA)

The 6 questions felt to be most relevant from the SwA questionnaire are detailed in the analysis. A total SwA score was also calculated for each patient by adding together their score on these 6 items. As with the individual questions, higher scores indicate greater happiness with their overall appearance.

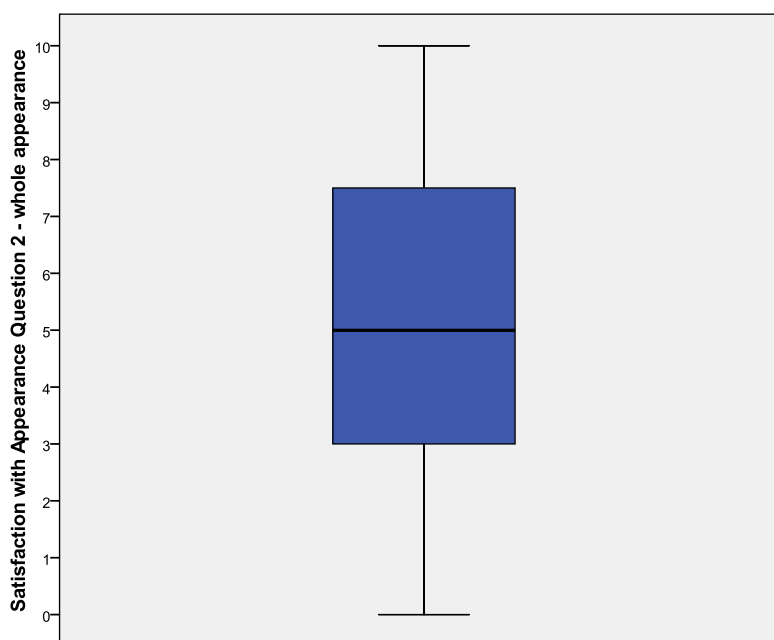
All 40 patients completed this questionnaire, the results of which can be found in Table 4. On average, the group were neither happy nor unhappy with their overall appearance (mean=5.5, sd=2.6). Overall, as a group, they tended to be less happy with their nose (mean=3.3, sd = 3.1), lips (mean=4.4, sd=3) and teeth (mean=4.2, sd=3.5), and more happy with their chin (mean=6.2, sd=3.1) and cheeks (mean=7.1, sd=2.5).

Table 4. Mean, median and mode scores from the Satisfaction with Appearance Questionnaire.

<i>Satisfaction with Appearance Scores</i>	<i>Mean (SD)</i>	<i>Median</i>	<i>Mode</i>	<i>Min-max score possible</i>
Q2 – whole appearance	5.5 (2.6)	5	5	0-10
Q5 – nose	3.3 (3.1)	3	0	0-10
Q6 – lips	4.4 (3)	4.5	1	0-10
Q7 – chin	6.2 (3.1)	6.5	10	0-10
Q8 – teeth	4.2 (3.5)	3.5	0	0-10
Q9 – cheeks	7.1 (2.5)	7.5	10	0-10
SwA total score	30.6 (12.9)	27.5	24	0-60

Since the items of the SwA Questionnaire generated responses on a scale of 0-10, the mean scores obscure some of the variability in responses, therefore the mode (most common response) is more informative and provides a better indication of how satisfied the sample were with various aspects of their looks.

In terms of how satisfied they were with their whole appearance (as indicated by their response to Question 2 of the questionnaire) most people chose 5, being neither ‘very unhappy’ nor ‘very happy’. The responses were considered to be normally distributed (as indicated in Figure 3) and so the data from Question 2 was used in the later analyses to represent Overall Satisfaction with Appearance.

**Figure 3.** Boxplot showing the normal distribution of responses to Question 2 – ‘How satisfied are you with your whole appearance?’

In terms of the satisfaction with nose, lips and teeth, most people were very unhappy with the modal responses being 0, 1 and 0 respectively. However in terms of chin and cheeks, the most common response was 10 indicating people were very happy with these features.

Orthognathic Quality of Life Questionnaire (OQLQ)

In total 38 patients completed this measure. The scores are detailed in Table 5. To put the scores into context, control data was taken from Lee, McGrath & Samman (2007) who administered this questionnaire on a sample of patients who received a consultation for asymptomatic wisdom teeth. On average the current sample had higher scores than the control group across all the domains suggesting the current sample had a poorer quality of life in relation to their orthognathic status. However, the full range of scores possible was endorsed across all scales. The total QoL scores for the sample were found to be normally distributed.

Table 5. Group means and standard deviations on the OQLQ

OQLQ	Mean (SD)	Min-Max scores	Range possible	*Control's Mean (SD)
Total score	38.8 (21.2)	0-88	0-88	21.4 (13.7)
Social Aspects of dento-facial deformity	15.5 (9.4)	0-32	0-32	7.5 (6.8)
Facial Aesthetics	12.0 (6.7)	0-20	0-20	6.6 (4.1)
Oral Function	6.3 (5.1)	0-20	0-20	2.2 (3.2)
Awareness of dento-facial aesthetics	4.9 (3.7)	0-16	0-16	5.1 (3.5)

*control data taken from Lee, McGrath & Samman (2007)

3.2 INFERENCE STATISTICS

4. Are there any significant differences on the questionnaires by gender, decision ('yes' or 'no' to surgery) or cleft type?

GENDER

Independent t-tests that compared males (n=23) and females (n=17) on the four questionnaire outcomes (HADS-A, HADS-D, overall SwA, and total QoL) did not reveal any significant differences. Table 6 details the results of these tests. Despite there being no statistically significant differences by gender, Cohen's d suggests there may be a very large effect size for both overall SwA and total QoL between males and females should there have been power to detect an effect (i.e. females are less satisfied with their appearance and have poorer QoL than males).

Table 6. Results of t-tests comparing males versus females on the four questionnaire outcomes.

Gender	<i>T</i>	<i>Significance</i>	<i>Mean difference</i>	<i>Cohen's d</i>
Anxiety Score	.007	.994	.008	.003
Depression Score	-.218	.829	-.225	-.072
SwA Q2 – whole appearance	.555	.582	.460	.180
QoL Total Score	-.452	.654	-3.160	-.148

*significant at the 0.05 level (2-tailed)

**significant at the 0.01 level (2-tailed)

DECISION OVER SURGERY

Three decision outcomes were initially identified including 'Yes', 'No' and 'Undecided'. However, in order to decrease ambiguity in the results, the 'undecided' group was excluded from the subsequent analyses.

Independent samples t-tests were used to compare those who said 'Yes' to surgery (n=30) versus those who said 'No' (n=4) on the four selected questionnaire outcomes. Given the disproportionate sample size in each group, it was necessary to consider the

Levene's test for homogeneity of variance. This test indicated that the assumption of variance had not been broken, however given the small sample size in the 'No' group ($n=4$), the power of this test is limited. Therefore, the second line of the t-test, which does not assume equal variances, was used as a more conservative measure. As such the adjusted degrees of freedom are reported.

Comparisons of the group who decided 'Yes' to surgery versus those who decided 'No' revealed significant differences between the levels of anxiety reported and quality of life. However, there were no significant differences between levels of depression or satisfaction with appearance. Table 7 indicates the results of the t-tests.

Table 7. Results of t-tests comparing those who decided 'Yes' versus 'No' to surgery on the four questionnaire outcomes.

Decision: Yes/No to Surgery	<i>T</i>	<i>Significance</i>	<i>Mean difference</i>	<i>Cohen's d</i>
Anxiety Score	3.745	.003**	3.466	1.427
Depression Score	1.445	.207	1.836	0.662
SwA Q2 – whole appearance	-.762	.495	-1.417	-0.458
QoL Total Score	3.319	.024*	28.679	1.606

*significant at the 0.05 level (2-tailed)

**significant at the 0.01 level (2-tailed)

In terms of anxiety, those who said 'Yes' to surgery reported significantly higher levels of anxiety (mean=6, $sd=3.6$) compared to those who said 'No' (mean=2.5, $sd=1.3$) $t(11.3)=3.745$, $p<0.01$, $d=1.427$. The effect size for this finding, as determined by Cohen's d , was very large. Figure 4 depicts this result.

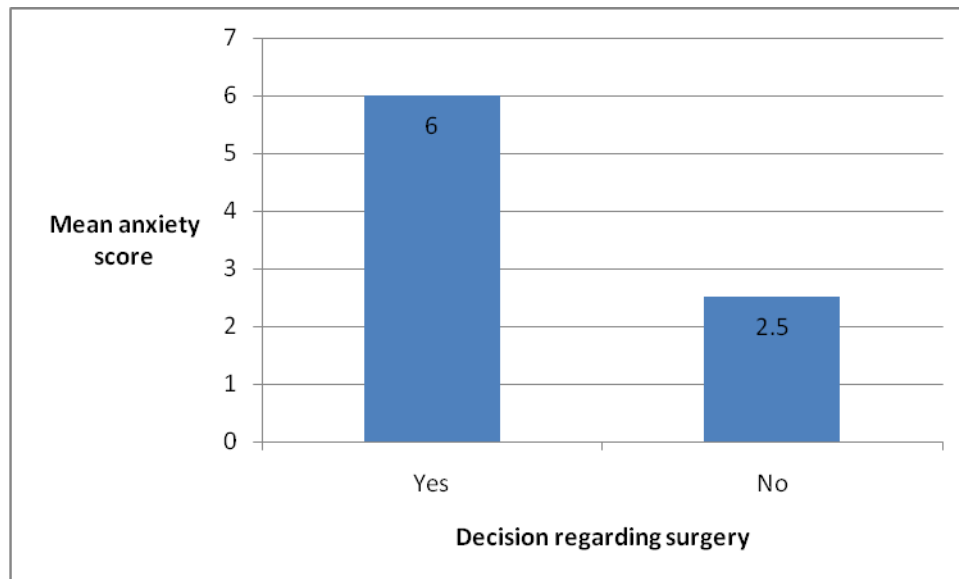


Figure 4. Bar chart illustrating the difference in anxiety scores between those who said ‘Yes’ versus ‘No’ to surgery.

In terms of Quality of Life, those who said ‘Yes’ to surgery had a significantly poorer overall quality of life (mean=42.4, sd=20.2) than those who said ‘No’ (mean=13.8, sd=15.5); $t(4.604)=3.319$, $p<0.05$, $d=1.606$. Again the effect size, as indicated by Cohen’s d , is very large. This difference is depicted in Figure 5.

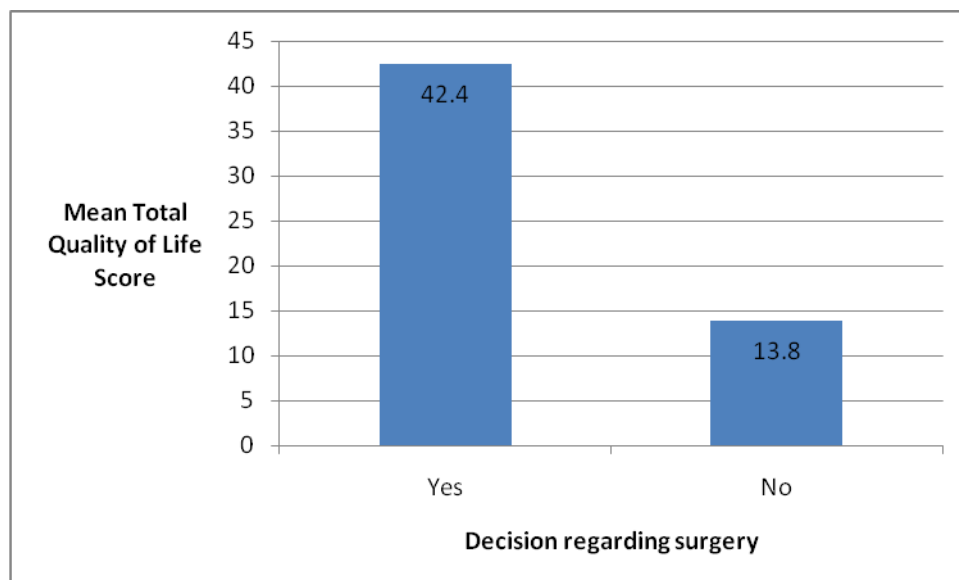


Figure 5. Bar chart illustrating the difference in total QoL between those who said ‘Yes’ versus ‘No’ to surgery.

CLEFT TYPE

There were 4 types of cleft classifications that could potentially be compared. However the Cleft Lip Only (CL) category comprised of a single patient and so the one-way ANOVA was restricted to comparing the other 3 cleft types, namely Unilateral Cleft Lip and Palate (n=23), Bilateral Cleft Lip and Palate (n=8) and Cleft Palate Only (n=8).

The ANOVA revealed that there were no statistically significant differences according to cleft type (see Table 8 for the results). Despite there being no statistical differences (perhaps due to lack of power in the small sample size), the partial eta squared suggests there is a small effect size of .05 for the depression factor and a small to medium effect size of .08 for the anxiety factor. However, partial eta squared is unable to specify where (between the 3 groups) the effect comes from.

Table 8. Results of the One-way ANOVA comparing cleft type on the four questionnaire outcomes.

CLEFT TYPE/DIAGNOSIS	<i>F</i>	<i>Significance</i>	<i>Partial eta squared</i>
Anxiety Score	1.55	.227	.081
Depression Score	.936	.402	.051
SwA Q2 – whole appearance	.194	.825	.011
QoL Total Score	.242	.787	.014

*significant at the 0.05 level

**significant at the 0.01 level

5. Are there any relationships between the scores on the different questionnaires?

Inspection of the Q-Q plots suggested that the data did conform to a normal distribution and so Pearson's parametric correlations were used to look for relationships between the four outcomes: HADS-A, HADS-D, SwA-Q2 and QoL total score. The additional variable 'Age' was also included in the correlational analysis. In the interests of being conservative, only those correlations reaching the 1% level of significance ($p < 0.01$) were considered. Table 9 details the results of the Pearson's correlations.

Table 9. Pearson's Correlations Matrix

Pearson's Correlations Matrix	Age at time of assessment	HADS - Anxiety Score	HADS - Depression Score	SwA Q2 – whole appearance	OQLQ total score
Age at time of assessment	1				
HADs - Anxiety Score	.181	1			
HADs - Depression Score	.310	.638**	1		
SwA Q2 – whole appearance	-.382*	-.434**	-.421**	1	
OQLQ total score	.584**	.392*	.468**	-.717**	1

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

Significant positive correlations were found between: Age and Quality of Life ($r=.584$, $n=38$, $p<0.01$), Anxiety and Depression ($r=.638$, $n=39$, $p<0.01$), and Depression and Quality of Life ($r=.468$, $n=37$, $p<0.01$).

Significant negative correlations were found between Anxiety and Satisfaction with whole appearance ($r=-.434$, $n=39$, $p<0.01$), Depression and Satisfaction with whole appearance ($r=-.421$, $n=39$, $p<0.01$), and Satisfaction with whole appearance and Quality of Life ($r=-.717$, $n=38$, $p<0.01$).

4.0 DISCUSSION

4.1 DISCUSSION OF RESULTS

1. Who were the patients considering orthognathic surgery and who were they referred by?

Contrary to past research where more women seek surgery than men (Nicodemo, Pereira & Ferreira, 2008; Sinko et al, 2005), the current sample comprised of a greater number of males considering surgery. They were mainly white British, perhaps reflecting the demographic area, and of teenage years. Most had UCLP which is again discrepant with previous findings that suggest there is a greater need for surgery in those with BCLP (Daskalogiannakis & Mehta, 2009). Moreover, the current sample comprised of 77% with CLP, 3% with CL and 20% with CP; this differs from the proportions typically found in the cleft population whereby 50% of cases are represented by CLP, 20% are CL and 30% are CP (Robin et al, 2006). The fact that the current sample was not entirely representative of the larger cleft population may be an artifact of the small sample size and the inclusion criteria which selected the first 40 patients to receive a pre-orthognathic psychology assessment.

In terms of psychological co-morbidities, the majority of patients did not have any that could be identified in the notes. This fits with the multiple reviews that suggest most people with cleft do not go on to experience any significant psychopathology (Hunt et al, 2005; Richman & Eliason, 1982). However also in line with these reviews, was the finding that a small, but clinically significant, portion may go on to have psychological difficulties. In the current sample, 10% were identified as having depression according to their clinical notes; this was in-keeping with the four people who scored above the clinical cut-off for depression in the HADS.

The majority of the referrals (85%) came from surgeons, with the next most common referrer being orthodontists (10%). These are important referral sources since, prior to developing ways of identifying patients systematically, referral relies on surgeons and orthodontists referring on the patients to whom they offer surgery.

Although the current study did not specifically record the number of patients who were not referred for a psychology assessment, it is unlikely that many slipped through the net, given the team commitment to identifying patients pre-orthognathically. For example, all patients prior to surgery are also seen by Speech and Language Therapy to assess for Velopharyngeal Insufficiency (VPI), thus providing a further opportunity to identify patients who have yet to receive a psychology assessment. Given that the majority of referrals (95%) came from surgeons and orthodontists, there is some indication of a commitment, to the current protocol, within the South Thames Cleft Service and patients are being signposted on appropriately for a psychology assessment. This is important since a study by Juggins and colleagues (2006) found that, although 40% of consultants thought that up to 10% of their patients would benefit from psychological input, over half of the consultants did not refer any of their patients for psychological assessment.

2. What was the outcome of the psychology assessment?

In terms of the recommendations stemming from the assessments, just over half (57%) involved a one-off consultation. This suggests that the majority of patients in this sample were suitably prepared for surgery and the assessing psychologist did not feel there was a need for any further consultation or psychological input. This is in line with the research that suggests pre-orthognathic patients are no different to controls in terms of psychological well-being (Alanko, Svedstrom-Oristo & Tuomisto, 2010). It may also in part reflect the good practice of the South Thames Cleft Service whereby the majority of orthognathic patients are in fact well prepared and felt to be psychologically ready.

Over one third of the current sample were considered, by the psychologist, to need further psychological support, either prior to the surgery (28%) or following the surgery (10%). *Prior* to surgery, the support may have been to assist with the decision making process, or for those who had already reached a definitive decision it was felt that they would benefit from some variant of psychological therapy to assist them as they progress with the orthognathic process. Those offered support *following* the surgery,

were typically those who appeared ready for the surgery but there remained some concern over how well they might adjust to the changes following surgery.

Only 5% of the assessments recommended that the patient required further information around what the surgery involved for them (i.e. were referred back to the MDT). As such this was the least common outcome for the current sample, representing only two cases. This is surprising given that retrospective research typically finds that, post-operatively, people suggest they would have preferred to have had more information prior to surgery (Khan, 2005; Modig, Andersson & Wardh, 2006; Murphy, 2005).

It is possible that the majority of patients in this sample did not require further information, because the psychologists involved in carrying out the assessments were very knowledgeable in the surgical procedures and were able to provide information and answer questions as necessary. Alternatively, this finding could have been an artifact of the way information is recorded. It may be that the psychologists recommended to everyone that they should seek further information, about the implications of surgery, but that this was only explicitly recorded as an outcome in the report of two of the cases. On balance, it is likely that both of these suggestions were manifest in the current study. Given the retrospective realisation that more information would be helpful, and where assessments are carried out by less experienced psychologists, it may be a useful precautionary measure to provide further information (in the form of a written handout) to all pre-orthognathic patients to ensure that they are fully informed about all aspects of the treatment. An information leaflet is currently being produced by the Cleft Psychology SIG for this purpose.

In terms of the decisions around whether or not to have orthognathic surgery; 75% of the current sample decided to go ahead with it, 10% decided against it and 15% remained undecided. Given the lack of research into the uptake of surgery by those to whom it is offered, it is uncertain whether this sample is representative of the general population. The finding that most decide to go ahead with surgery may simply reflect the stage at which the assessments were carried out during the orthognathic process. Since the STCS were just beginning to apply the orthognathic protocol, the psychological assessments were a relatively new addition to the proceedings and many of the patients may have received their assessments after having already decided to have

surgery and thus had commenced with the necessary orthodontic work. This highlights the need to develop a procedure which complements the protocol and is effective in systematically identifying all patients from the outset, when surgery is first mooted, to ensure that patients receive a psychological assessment at Time 1 of the protocol (prior to decision making and before any orthodontic treatment commences) as well as at Time 2 (prior to surgery).

Moreover, it is necessary to be aware of the flexibility of the decisions made, particularly since the extended period required for the preparatory orthodontic work (usually 12-18 months) provides ample opportunity for the patient to change their mind. The process of decision-making itself involves weighing up the costs and benefits of the surgery which will include a consideration of all of the variables surrounding the person, such as their stage in life, whether they have educational or work commitments that may be interrupted, whether they have appropriate social support etc. Thus a multitude of biological, social and psychological factors impacting upon the decision may change over time, and this may tip the balance in the direction of surgery being favourable or not. Given this and the human propensity to change one's mind, it is imperative that the entire protocol (involving psychological assessment at several time points throughout the orthognathic process) is adhered to, since inevitably there may be changes in people's life circumstances which may impact on their decision at any one time.

Furthermore, research has recognised that even those who elect not to have surgery can experience psychological deterioration, indexed by a decline in their self-concept (Kiyak, 1993). Therefore, it may be prudent to follow-up *all* patients offered orthognathic surgery *including* those who initially decide against surgery. This notion may be usefully added to the existing protocol, which is currently limited to only considering the longitudinal review of those proceeding with surgery.

3. What is the psychological well-being of pre-orthognathic patients?

According to the three questionnaires used by this study, the majority of pre-orthognathic patients had normal levels of well-being. This is in line with a review of the previous literature (Alanko, Svedstrom-Oristo & Tuomisto, 2010). As indicated by

the HADS, most had 'normal' levels of anxiety (74.4%) and depression (89.7%), with only a few falling into the 'moderate to severe' ranges. As indicated by the SwA questionnaire, as a group, they tended to be less satisfied with their nose, lips and teeth in comparison to their chin and cheeks. When considering their overall appearance, the most common rating was a score of 5, being neither extremely happy nor unhappy with their appearance. This may indicate a degree of ambivalence around their looks. Alternatively, the neutral rating may reflect the tendency to prefer some features and dislike others. Regardless of how the scores are accounted for, the ratings of overall SwA formed part of a normal spectrum with most people falling in the middle and only a few indicating extreme satisfaction or dissatisfaction with their appearance.

Dissatisfaction with certain elements of one's appearance is not confined to pre-orthognathic patients, but has also been found in the normal population. In a sample of 18-30 year olds (which largely corresponds with the age group of the current sample), 46-56% of men and 69% of women were concerned with at least one aspect of their appearance (Sinko et al, 2005) and up to one third of women in a non-cleft group had concerns about their noses, lips, mouths, chins and faces (Harris & Carr, 2001). Although there were no control data collected in the current study, there is no reason to believe that the current sample were any less satisfied with their looks than the normal population.

In terms of Orthognathic QoL, the current sample had higher scores, indicating poorer QoL across all domains when compared to the control data taken from Lee et al (2007). Although this finding is in-keeping with the general literature on pre-orthognathic patients (Lee, McGrath & Samman, 2007), it is discrepant with findings in the cleft literature (Bressman et al, 1999; Locker et al, 2005; Marcusson et al, 2001). The poorer QoL scores in the current sample may result from the over-representation of those seeking treatment (30/40), as previous literature has indeed found that those seeking surgery have poorer QoL than those who are not (Sinko et al, 2005). The finding may also reflect the state of the literature whereby other studies have used a variety of questionnaires measuring different aspects of QoL, whereas the OQLQ used in this study is highly specific and focused on orthognathic related aspects.

In summary, the current study suggests that the pre-surgical patients in this sample, on the whole, had normal levels of anxiety and depression, disliked certain features of their appearance and had poorer Orthognathic QoL, although a normal distribution of scores were obtained.

Research suggests that psychological distress (anxiety and depression), SwA and QoL all improve following surgery (Hunt et al, 2001). Thus, with the pre-orthognathic psychology assessments in the STCS establishing baseline characteristics of the samples' psychological well-being, it will be important to adhere to the longitudinal aspects of the protocol to monitor their scores at follow-up time points. At post-surgery it will be important to investigate whether the expected gains have been made, and perhaps most importantly to identify cases where favourable outcomes have not been achieved.

4. Are there any significant differences on the questionnaires by gender, decision (Yes or No to surgery) or cleft type?

There were no significant differences on the questionnaire measures according to gender or cleft type. There were however differences found according to decision, whereby those seeking surgery were more anxious and had a poorer QoL. Despite the higher anxiety levels in patients deciding yes to surgery, both the yes and no groups, on average, had levels of anxiety which fell within the normal range (≤ 7) thus remaining subclinical.

5. Are there any relationships between the scores on the different questionnaires?

The results of the correlational analysis revealed 6 significant relationships (3 positive and 3 negative correlations) with intuitive appeal. The positive correlations suggested that with increasing age there is a poorer QoL, with increasing anxiety comes a greater level of depression, and that with increasing depression there is a poorer QoL. The negative correlations suggest that those who are more anxious or depressed are also less satisfied with their appearance, and that those who are less satisfied with their appearance have a poorer overall QoL.

4.2 IMPLICATIONS AND FOLLOWING THE PROTOCOL

Establishing whether someone is suitable for surgery requires not only the comprehensive assessment of their physical appearance, but also careful consideration of their psychological status and ability to cope. Thus it is imperative that the Cleft Team (particularly surgeons and psychologists) work cohesively and that the existing protocol is well-integrated into proceedings so that every patient is systematically identified and offered psychological assessment and input at appropriate stages throughout the orthognathic process.

4.3 COMMUNICATION OF FINDINGS

The results of this service-related research project were shared with the South Thames Cleft Service in a presentation at their monthly clinical audit, research and outcome meeting. Discussion ensued between the MDT and, along with previous research and insights from this study, it was decided that the existing protocol for psychological involvement in the orthognathic process should be followed more robustly in the future, so that psychological assessments occur at the time points dictated by the protocol, and that the patients from this study receive the necessary input beyond Time 1 Assessment.

4.4 LIMITATIONS & FUTURE RESEARCH

In order to carry out later comparisons between those who said ‘yes’ and ‘no’ to surgery, groups were defined according to their decision at the time of assessment. The majority of these decisions were detailed clearly in the clinical notes and psychologist’s assessment report. Occasionally however, it was less clear what the patients’ decision was and in some cases a definite decision had not been reached by the end of the assessment, particularly in cases where further information was required to help make their decision. This lack of clarity introduced subjective judgement into the categorization process and it is important to be explicit about this since it may have implications not only for current comparisons of the ‘yes’ and ‘no’ group, but also for research that aims to repeat these findings. At the time of the analysis, it is known that six patients had already completed surgery and fulfilled their ‘yes’ status. However, it is uncertain whether the remaining 24 (allocated to the ‘yes’ group) would have gone

through with their original decision. Also, those who said 'no' may have included people who did not want surgery at the time but may re-visit the idea in the future. As such comparisons of the 'yes' versus 'no' groups are tentative and would perhaps helpfully be re-analysed once surgery is completed so that the allocation to 'yes' versus 'no' group is more objective and definitive. Also, realisation of the eventual decisions in the 'undecided' group would allow for these people to be allocated into the 'yes' or 'no' groups. Given the length of time that the overall orthognathic procedures take, it was not possible to carry out such re-analysis in this study.

The current study was limited to measuring psychological well-being of patients in the pre-surgical stage. This preliminary design is justified by the research that suggests that health-related QoL and psychological well-being, in particular pre-surgery anxiety levels, predicts post-surgery QoL and well-being (Azuma, Kohsuki, Saeki et al, 2008). These authors thus suggest that it is important to aim towards identifying the psychological profile that may affect orthognathic outcome. Although desirable, it has also been found that, pre-operatively, it is not possible to identify the psychologically 'bad risk' patient (Pogrel & Scott, 1994). Therefore the post-operative appointment may be of central importance for identifying any patients struggling with the aftermath of surgery. Thus, future research would helpfully follow-up patients longitudinally, in line with the suggested protocol, to investigate whether the benefits to psychological status are realised in the outcome assessment and to pick up on the 'unidentifiable' risky patients.

4.5 CONCLUSION

Overall, the current study has demonstrated that pre-orthognathic patients deciding to have surgery were significantly more anxious and had poorer orthognathic QoL than those deciding against surgery. Despite this, the majority of the sample had normal psychological well-being. It identified that, prior to surgery, the protocol for psychological involvement in orthognathic proceedings was being loosely followed by the STCS but that assessments were occurring across a variety of time points pre-surgery. Moreover, in the initial stages of implementation, only one psychological assessment was offered in the pre-surgery stages, as opposed to the two recommended in the protocol. These findings highlighted the need to establish procedures for

systematically identifying patients so that the protocol can be adhered to at the specified time points. This will ensure that cleft patients receive the best possible care throughout their orthognathic journey.

REFERENCES

- Alanko, O.M.E., Svedstrom-Oristo, A.L., & Tuomisto, M.T. (2010). Patients' perceptions of orthognathic treatment, well-being, and psychological or psychiatric status: a systematic review. *Acta Odontologica Scandinavica*, 68, 249-260
- Azuma, S., Kohsuki, M., Saeki, S., Tajima, M., Igarashi, K., & Sugawara, J. (2008) Beneficial effects of orthodontic treatment on quality of life in patients with malocclusion. *The Tohoku Journal of Experimental Medicine*, 214, 39-50
- Banks, P. (1986). Orthognathic surgery for the adult patient with cleft lip and palate. *Annals Academy of Medicine Singapore*, 15, 346-354
- Berger, Z.E., & Dalton, L.J. (2011). Coping with a cleft II: Factors associated with psychosocial adjustment of adolescents with a cleft lip and palate and their parents. *The Cleft Palate-Craniofacial Journal*, 48(1), 82-90
- Bressman, T., Sader, R., Ravens-Sieberer, U., Zeilhofer, H.F., & Horsch, H.H. (1999). Quality of Life research in patients with cleft lip and palate: preliminary results. *Mund Kiefer Gesichtschir*, 3, 134-139
- Cheung, L.K., Loh, J.S., & Ho, S.M. (2006). The early psychological adjustment of cleft patients after maxillary distraction osteogenesis and conventional orthognathic surgery: a preliminary study. *Journal of Oral Maxillofacial Surgery*, 64(12), 1743-1750
- Children's Craniofacial Association. (2009). *A Guide to understanding cleft lip and palate*, Children's Craniofacial Association: Dallas TX, website: <http://www.ccakids.com/Syndrome/CleftLipPalate.PDF>, retrieved on 30/03/2011
- Chong, D.K., Portnof, J.E., Haisong, X.U., & Salyer, K.E. (2009). Reviewing the orthognathic surgical care of the patient with cleft lip and palate: the single surgeon experience. *The Journal of Craniofacial Surgery*, 20(2), 1895-1904
- Clinical Standards Advisory Group. (1998). *Cleft Lip and/or Palate*, London: Her Majesty's Stationary Office
- Cohen, J. (1969). *Statistical Power Analysis for the Behavioral Sciences*, San Diego, CA: Academic Press
- Cohen, J., (1988). *Statistical Power Analysis for the Behavioral Sciences (2nd edition)*, Hillside, NJ: Erlbaum

- Cunningham, S.J., Garratt, A.M., & Hunt, N.P. (2000). Development of a condition-specific quality of life measure for patients with dentofacial deformity: I. Reliability of the instrument. *Community Dentistry and Oral Epidemiology*, 28, 195-201
- Cunningham, S.J., Garratt, A.M., & Hunt, N.P. (2002). Development of a condition-specific quality of life measure for patients with dentofacial deformity: II. Validity and Responsiveness Testing. *Community Dentistry and Oral Epidemiology*, 30: 81-90
- Cunningham, S.J., Hunt, N.P., & Feinmann, C. (1995). Psychological aspects of orthognathic surgery: a review of the literature. *International Journal of Adult Orthodontics and Orthognathic Surgery*, 10 (3), 159-172
- Daskalogiannakis, J., & Mehta, M. (2009). The Need for Orthognathic Surgery in Patients with repaired complete unilateral and complete bilateral cleft lip and palate. *The Cleft Palate-Craniofacial Journal*, 46(5), 498-502
- Eiserman, W. (2001). Unique outcomes and positive contributions associated with facial difference: expanding research and practice. *The Cleft Palate-Craniofacial Journal*, 38, 236-244
- Emerson, M., Spencer-Bowdye, S., & Bates, A. (2004). *Relationships between self-esteem, social experiences and satisfaction with appearance: Standardisation and construct validation of two cleft audit measures*. The Craniofacial Society of Great Britain and Ireland. Annual Scientific Conference. "Setting a positive agenda in cleft and craniofacial care".
- Feragen, K.B., & Borge, A.I.H. (2010). Peer harassment and satisfaction with appearance in children with and without a facial difference. *Body Image*, 7, 97-105
- Garvill, J., Garvill, H., Kahnberg, K.E., & Lundgren, S. (1992). Psychological factors in orthognathic surgery. *Journal of Craniomaxillofacial Surgery*, 20(1), 28-33
- Harris, D.L., & Carr, A.T. (2001). Prevalence of concern about physical appearance in the general population. *British Journal of Plastic Surgery*, 54, 223-226
- Heldt, L., Haffke, E.A., & Davis, L.F. (1982). The psychological and social aspects of orthognathic treatment. *American Journal of Orthodontics*, 82, 318-328
- Hunt, O.T., Johnston, C.D., Hepper, P.G., & Burden, D.J. (2001). The psychosocial impact of orthognathic surgery: A systematic review. *American Journal of Orthodontics and Dentofacial Orthopedics*, 120(5), 490-497

- Hunt, O.T., Burden, D.J., Hepper, P.G., & Johnston, C.D. (2005). The Psychosocial effects of Cleft Lip and Palate: A systematic review. *European Journal of Orthodontics*, 27, 274-285
- Hunt, O.T., Burden, D.J., Hepper, P.G., Stevenson, M., Johnston, C.D., & Orth, M. (2007). Parents reports on the psychosocial functioning of children with cleft lip and/or palate. *The Cleft Palate-Craniofacial Journal*, 44(3), 304-311
- Johnston, C., Hunt, O., Burden, D., Stevenson, M., & Hepper, P. (2010). Self-perception of dentofacial attractiveness among patients requiring orthognathic surgery. *The Angle Orthodontist*, 80(2), 361-366
- Juggins, K.J., Nixon, F., & Cunningham, S. (2005). Patient- and clinician- perceived need for orthognathic surgery. *American Journal of Orthodontics and Dentofacial Orthopedics*, 128(6), 697-702
- Juggins, K.J., Feinmann, C., Shute, J., & Cunningham, S.J. (2006). Psychological support for orthognathic patients – what do orthodontists want? *Journal of Orthodontics*, 33, 107-115
- Kapp-Simon, K.A., & McGuire, D.E. (1997). Observed social interaction patterns in adolescents with and without craniofacial conditions. *The Cleft Palate-Craniofacial Journal*, 34(5), 380-384
- Khan, Z. (2005). Patients' perspective in orthognathic surgery. *Journal of the Pakistan Dental Association*, 14(2), 104-108
- Kiyak, H.A. (1993). Psychological aspects of orthognathic surgery. *Psychology and Health*, 8(2&3), 197-212
- Kiyak, H.A., Vitaliano, P.P., & Crinean, J. (1988). Patients' expectations as predictors of orthognathic surgery outcomes. *Health Psychology*, 7(3), 251-268
- Langlois, J.H., & Roggman, L.A. (1990). Attractive faces are only average. *Psychological Science*, 1, 115-121
- Lansdown, R., Lloyd, J., & Hunter, J. (1991). Facial deformity in childhood: severity and psychosocial adjustment. *Child: Care, Health and Development*, 17, 165-171
- Lee, S., McGrath, C., & Samman, N. (2007). Quality of Life in patients with dentofacial deformity: a comparison of measurement approaches. *International Journal of oral and maxillofacial surgery*, 36, 488-492
- Lello, G.E. (2001). Orthognathic Surgery. In A.C.H. Watson, D.A. Sell, & P. Grunwell (Eds.), *Management of Cleft Lip and Palate*, London: Whurr Publishers

- Locker, D., Jokovic, A., & Thompson, B. (2005). Health Related Quality of Life of children aged 11 – 14 yrs with orofacial conditions. *The Cleft Palate-Craniofacial Journal*, 42(3), 260-266
- MacGregor, F.C. (1979). *After Plastic Surgery: adaptation and adjustment*, New York: Praeger Publishers
- Marcusson, A., Akerlind, I., & Paulin, G. (2001). Quality of Life in Adults with repaired complete cleft lip and palate. *The Cleft Palate-Craniofacial Journal*, 38(4), 379-385
- Marcusson, A., Paulin, G., & Ostrup, L., (2002). Facial Appearance in adults who had cleft lip and palate treated in childhood. *Journal of Plastic Surgery and Hand Surgery*, 36(1), 16-23
- Modig, M., Andersson, L., & Wardh, I. (2006). Patients' perception of improvement after orthognathic surgery: Pilot study. *British Journal of Oral and Maxillofacial Surgery*, 44, 24-27
- Morris, D.O. (2006). Improving standards in orthognathic care: the bigger picture (a national and international perspective). *Journal of Orthodontics*, 33,149-151
- Murphy, T.C. (2005). The diary of an orthognathic patient aged 30 ³/₄. *Journal of Orthodontics*, 32, 169-174
- Naini, F.B., & Gill, D.S. (2008). Facial Aesthetics: 1. Concepts and Canons, Dental Update, Document 102-107. Retrieved July 8, 2011, from www.watfordorthodontics.co.uk/dentist_information/facial%20aesthetics%201.pdf
- Nicodemo, D., Pereira, M.D., & Ferreira, L.M. (2008). Self-esteem and depression in patients presenting with angle class III malocclusion submitted for orthognathic surgery. *Medicina Oral Patologia Oral y Cirugia Bucal*, 13(1), 48-51
- Perrett, D.I., Burt, D.M., Penton-Voak, I.S., Lee, K.J., Rowland, D.A., & Edwards, R. (1999). Symmetry and human facial attractiveness. *Evolution and Human Behavior*, 20(5), 295-307
- Phillips, C., Bennett, E., & Broder, H. (1998). Dentofacial disharmony: Psychological status of patients seeking treatment consultation. *The Angle Orthodontist*, 68(6), 547-556
- Phillips, C.P., Kiyak, H.A., Bloomquist, D., & Turvey, T.A. (2004). Perceptions of recovery and satisfaction in the short term after orthognathic surgery. *International Journal of oral and maxillofacial surgery*, 62 (5), 535-544

- Pogrel, M.A., & Scott, P. (1994). Is it possible to identify the psychologically “bad risk” orthognathic surgery patient preoperatively? *International Journal of Adult Orthodontics and Orthognathic Surgery*, 9(2), 105-110
- Ramstad, T., Ottem, E., & Shaw, W.C., (1995). Psychosocial adjustment in Norwegian adults who had undergone standardised treatment of complete cleft lip and palate. II Self-reported problems and concerns with appearance. *Scandinavian Journal of Plastics and Reconstructive Surgery Hand Surgery*, 29, 329-336
- Richman, L.C., & Eliason, M. (1982). Psychological characteristics of children with cleft lip and palate: intellectual, achievement, behavioural and personality variables. *Cleft Palate Journal*, 19(4), 249-257
- Richman, L.C., & Millard, T. (1997). Brief report: Cleft Lip and Palate: Longitudinal behaviour and relationships of cleft conditions to behaviour and achievement. *Journal of Pediatric Psychology*, 22(4), 487-494
- Robin, N.H., Baty, H., Franklin, J., Guyton, F.C., Mann, J., Wooley, A.L., Waite, P.D., & Grant, J. (2006). The multidisciplinary evaluation and management of cleft lip and palate. *Southern Medical Journal*, 99(10), 1111-1120
- Ross, R.B. (1987). Treatment variables affecting facial growth in complete unilateral cleft lip and palate. *Cleft Palate Journal*, 24, 5-77
- Shaw, W.C., Meek, S.C., & Jones, D.S. (1980). Nicknames, teasing, harassment and the salience of dental features among school children. *British Journal of Orthodontics*, 7, 75-80
- Sinko, K., Jagsch, R., Prechtel, V., Watzinger, F., Hollman, K., & Bauman, A. (2005). Evaluation of esthetic functional and quality of life outcome in adult cleft lip and palate patients. *The Cleft Palate-Craniofacial Journal*, 42(4), 355-361
- Thomas, P.T., Turner, S.R., Rumsey, N., Dowell, T., & Sandy, J.R. (1997). Satisfaction with facial appearance among subjects affected by a cleft. *The Cleft Palate–Craniofacial Journal*, 34(3), 226-231
- Umberson, D., & Hughes, M. (1987). The impact of physical attractiveness on achievement and psychological well-being. *Social Psychology Quarterly*, 50(3), 227-236
- White, D., Leach, C., Sims, R., Atkinson, M., & Cottrell, D. (1999). Validation of the Hospital Anxiety and Depression Scale for use with adolescents. *The British Journal of Psychiatry*, 175, 452-454

- Williams, D.M., Bentley, R., Cobourne, M.T., Gibilaro, A., Good, S., Huppa, C., Matthews, N.S., O'Higgins, E., Patel, S., & Newton, J.T. (2009). Psychological characteristics of women who require orthognathic surgery: comparison with untreated controls. *British Journal of Oral and Maxillofacial Surgery*, 47, 191-195
- Zapotoczky, W.P., & Marlovits, S. (1993). Changes in the sociomedical situation of patients with cleft lip, jaw and palate in 1975 and 1990 in Vienna, *Z Stomatolol*, 90, 137-148
- Zigmond, A.S., & Snaith, R.P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 67, 361-370

APPENDICES

Appendix 1

Protocol for psychological input with patients undergoing orthognathic surgery

Time 1: Pre-Orthodontic Psychology Assessment

(To be completed as soon as the surgeons begin considering Orthognathic Surgery)

1. Assessment of expectations of surgery

- Why have the individuals decided to proceed with treatment (aspirations, aims, reasons)?
- Are the expectations of the physical changes to their appearance realistic?
- Is the impact of changes to their appearance on their lives realistic?
- Are they aware of, and do they understand, the potential complications?
- What are family, friends and partners' views on the patient having surgery?
- Discuss self-image adjustment, coping with and preparing for the reactions, comments and questions from others now and post-operatively.

2. Information about orthognathic surgery

- Check knowledge and understanding of treatment.
- Encourage patient to ask questions about surgery.
- Provide written information and ratified web addresses.

e.g. Information leaflets, www.faceforward.org.uk, CLAPA

3. Discuss the process of undergoing orthognathic surgery

- This includes the timeframe and how the surgery will fit into their life (e.g. in Gap year, interference with further education plans, time needed off work).
- Assessment of specific fears or phobias relating to surgery, anaesthesia or hospital stay.
- Previous experiences of hospitalisation.
- Specific coping techniques employed in the past.
- Facilitate the decision-making process and acknowledge the difficulties in decision-making and understanding risks.

4. Formal assessment is completed using questionnaires in order to assess mood, anxiety and expectations etc

- Orthognathic Quality of Life Questionnaire (OQLQ)
- Hospital Anxiety and Depression Scale (HADS)
- Self-Image Profile for adults (SIP-AD)
- Satisfaction with Appearance scale

5. Information is relayed to the Maxillofacial team (with consent) regarding concerns, mood disorder, unrealistic expectations (e.g. BDD) and the treatment plan revised if surgery is contraindicated

6. Psychological intervention offered if required

7. Record and disseminate information as appropriate (e.g. medical records/report)

Time 2: Pre-Surgery Psychology Assessment

(To be completed at the pre-admission point for orthognathic surgery)

It is important for patients to be seen again prior to surgery so that the topics discussed in the pre-orthodontic assessment can be revisited.

8. Assessment of expectations of surgery :

- Why have the individuals decided to proceed with treatment (aspirations, aims, reasons)?
- Are the expectations of the physical changes to their appearance realistic?
- Is the impact of changes to their appearance on their lives realistic?
- Are they aware of, and do they understand, the potential complications?
- What are family, friends and partners' views on the patient having surgery?
- Discuss self-image adjustment, coping with and preparing for the reactions, comments and questions from others now and post-operatively.

In addition the following areas should be covered:

- Concerns over low mood or anxiety.
- Uncertainty about whether or not to undergo orthognathic surgery.
- The patient may be satisfied with the orthodontic treatment and not wish to undergo orthognathic surgery.
- General uncertainty about the procedure.
- Specific team members having concerns about a patient, e.g. mood/ability to cope with surgery/unrealistic expectations, etc
- Discuss self-image adjustment, coping with and being prepared for the reactions, comments and questions from others now and post-operatively.
- In conjunction with the team, discuss likely side-effects of treatment e.g. discomfort and post-operative care e.g. blending food.

9. Information about orthognathic surgery

- Check knowledge and understanding of treatment.
- Encourage patient to ask questions about surgery.
- Provide written information and ratified web addresses.

e.g. Information leaflets, www.faceforward.org.uk, CLAPA

10. Discuss the process of undergoing orthognathic surgery

- This includes the timeframe and how the surgery will fit into their life (e.g. in Gap year, interference with further education plans, time needed off work).
- Assessment of specific fears or phobias relating to surgery, anaesthesia or hospital stay.
- Previous experiences of hospitalisation.
- Specific coping techniques employed in the past.
- Facilitate the decision-making process and acknowledge the difficulties in decision-making and understanding risks.

11. Formal assessment is completed using questionnaires in order to assess mood, anxiety and expectations etc

- Orthognathic Quality of Life Questionnaire (OQLQ)
- Hospital Anxiety and Depression Scale (HADs)
- Self-Image Profile for adults (SIP-AD)
- Satisfaction with Appearance scale

12. Information is relayed to the Maxillofacial team (with consent) regarding concerns, mood disorder, unrealistic expectations (e.g. BDD) and the treatment plan revised if surgery is contraindicated

13. Psychological intervention offered if required

14. Record and disseminate information as appropriate (e.g. medical records/report)

Time 3: Post operative Orthognathic assessment (12 months after surgery as a minimum)

Ideally a post-operative assessment should also take place sooner than 12 months. Where this is not possible the Maxillo-facial team should refer patients to the psychology team if concerns arise.

1. Assessment of outcome

- Assessment of patient's opinion of and satisfaction with surgical outcome.
- Discussion about the process of surgery and recovery.
- Provide any intervention as necessary
- Input if disappointed with the outcome of surgery
- Input to consolidate the benefits of surgery
- Support psychological adjustment to both psychological and medical complications.
- Discuss self-image adjustment and coping with the reactions, comments and questions from others.
- Facilitate further decision-making about surgery, as required.

2. Formal assessment is completed using questionnaires in order to assess mood, anxiety and expectations etc

- Orthognathic Quality of Life Questionnaire (OQLQ)
- Hospital Anxiety and Depression Scale (HADs)
- Self-Image Profile for adults (SIP-AD)
- Satisfaction with Appearance scale

3. Information is relayed to the Maxillofacial team (with consent) regarding outcomes from a psychological perspective

4. Psychological intervention offered if required

5. Record and disseminate information as appropriate (e.g. medical records/report)

Appendix 2 - Interview Schedule

South Thames Cleft Service

Orthognathic Psychology Assessment

Date of Assessment:.....

Name:..... DOB:.....

Male/Female (delete one)

Address:..... Tel:.....

Present at Interview:.....

GP.....
 Tel:.....

Previous Contacts:.....

Consent to contact GP: Yes/No

Consent to contact other agencies: Yes/No

Referrer:

Reason for Referral:

Assessment Scores:	
HADs Score	
SwA Score	
OQLQ Score	

EXPECTATIONS

- What is your expectation of surgery (physical and emotional):
(What are you hoping to achieve? Anything you'd like to change? Why?)
- How will the process fit in with life, work, education etc:
- Previous experience of surgery:

- Coping Strategies:
- Family Background/Domestic circumstances:
(*Who do you live with? How is it? Can you talk to family about any problems?*)

CLEFT HISTORY AND IMPACTS

“I’d like to ask you a few questions about your cleft.....”

- Type of cleft? (circle one)
CPO CLO CLAP Uni/Bi Other syndrome
- Previous Operations (e.g. *on lip, on palate, alveolar bone graft, further plastic surgery*)?
- When was palate repaired? (*Is there still a hole? Escaping fluids down nose?*)
- Past dental treatment/orthodontics? (*Brace? Other jaw/teeth work?*)
- Any other health problems? (e.g. serious illnesses, injuries, operations)

IMPACTS & RESPONSES

- Has your cleft had a big impact on your life so far? (*e.g. School? Growing up? Getting on with others? Bullying? Verbal abuse?*)
- In public/ with strangers?
- What about nowadays?
- How have you coped/do you cope with above? (*e.g. ignore, get upset, talk to friends/family*)
- Did you ever have to see a counsellor to help you cope?
- How have you dealt with people who are curious?
- Is there any avoidance? (*e.g. photos, socialising, disguising self, covering up*)

Appendix 3

Hospital Anxiety and Depression Scale (HADS)

Please choose one response from the four given for each question. Answer each question according to how you feel in the past week. Do not spend too long thinking about your answer.

A	I feel tense or 'wound up':
<input type="checkbox"/>	Most of the time
<input type="checkbox"/>	A lot of the time
<input type="checkbox"/>	From time to time, occasionally
<input type="checkbox"/>	Not at all

D	I still enjoy the things I used to enjoy:
<input type="checkbox"/>	Definitely as much
<input type="checkbox"/>	Not quite so much
<input type="checkbox"/>	Only a little
<input type="checkbox"/>	Hardly at all

A	I get a sort of frightened feeling as if something awful is about to happen:
<input type="checkbox"/>	Very definitely and quite badly
<input type="checkbox"/>	Yes, but not too badly
<input type="checkbox"/>	A little, but it doesn't worry me
<input type="checkbox"/>	Not at all

D	I can laugh and see the funny side of things:
<input type="checkbox"/>	As much as I always could
<input type="checkbox"/>	Not quite so much now
<input type="checkbox"/>	Definitely not so much now
<input type="checkbox"/>	Not at all

A	Worrying thoughts go through my mind:
<input type="checkbox"/>	A great deal of the time
<input type="checkbox"/>	A lot of the time
<input type="checkbox"/>	From time to time, but not too often
<input type="checkbox"/>	Only occasionally

D	I feel cheerful:
	Not at all
	Not often
	Sometimes
	Most of the time

A	I can sit at ease and feel relaxed:
	Definitely
	Usually
	Not Often
	Not at all

D	I feel as if I am slowed down:
	Nearly all the time
	Very often
	Sometimes
	Not at all

A	I get a sort of frightened feeling like 'butterflies' in the stomach:
	Not at all
	Occasionally
	Quite Often
	Very Often

D	I have lost interest in my appearance:
	Definitely
	I don't take as much care as I should
	I may not take quite as much care
	I take just as much care as ever

A	I feel restless as I have to be on the move:
	Very much indeed
	Quite a lot
	Not very much
	Not at all

D	I look forward with enjoyment to things:
	As much as I ever did
	Rather less than I used to
	Definitely less than I used to
	Hardly at all

A	I get sudden feelings of panic:
	Very often indeed
	Quite often
	Not very often
	Not at all

D	I can enjoy a good book or radio or TV program:
	Often
	Sometimes
	Not often
	Very seldom

Appendix 4 – Satisfaction with Appearance Questionnaire

How do you feel about the way you look?

(Please tick one box for each question)

1. How your face looks:

Very happy ☺ ☹ Very unhappy

10 **0**

2. The whole of your appearance:

Very happy ☺ ☹ Very unhappy

10 **0**

3. Side view / profile:

Very happy ☺ ☹ Very unhappy

10 **0**

4. How good-looking do you think you are?

Very good-looking ☺ ☹ Not at all good-looking

10 **0**

How do you feel about these parts of your face?

5. Nose:

Very happy ☺ ☹ Very unhappy

10 **0**

6. Lips:

Very happy ☺ ☹ Very unhappy

10 **0**

7. Chin:

Very happy ☺ ☹ Very unhappy

10 **0**

8. Teeth:

Very happy ☺ ☹ Very unhappy
10 0

9. Cheeks:

Very happy ☺ ☹ Very unhappy
10 0

10. Hair:

Very happy ☺ ☹ Very unhappy
10 0

11. Ears:

Very happy ☺ ☹ Very unhappy
10 0

12. Eyes:

Very happy ☺ ☹ Very unhappy
10 0

13. How happy are you with your speech?

Very happy ☺ ☹ Very unhappy
10 0

14. How happy are you with your hearing?

Very happy ☺ ☹ Very unhappy
10 0

15. Do you wear a hearing aid? Yes / No

16. If yes, how happy are you wearing it?

Very happy ☺ ☹ Very unhappy
10 0

17. Do you have braces? Yes / No

18. If yes, how happy are you with the way they look?

Very happy ☺ ☹ Very unhappy

10 0

19. Overall how noticeable do you feel your cleft is to other people?

Not at all noticeable ☺ ☹ Very noticeable

10 0

20. Does the way you look make a difference to how you get on with other people?

Makes it easier ☺ ☹ Makes it harder

10 makes no difference 0

Thank you for completing this questionnaire

Appendix 5 – Orthognathic Quality of Life Questionnaire

Please read the following statements carefully. Please circle N/A or 1, 2, 3, 4 where:

- N/A** means the issue covered by the statement either **does not apply to you** or **if it does apply to you, it does not bother you at all**
1 means the issue covered in the statement **bothers you a little**
4 means the issue covered in the statement **bothers you a lot**
2 + 3 lie **between “a little and a lot”**

	1	2	3	4			
	Bothers you a little				Bothers you a lot		
1. I am self-conscious about the appearance of my teeth			1	2	3	4	N/A
2. I have problems biting			1	2	3	4	N/A
3. I have problems chewing			1	2	3	4	N/A
4. There are some foods I avoid eating because the way my teeth meet makes it difficult			1	2	3	4	N/A
5. I don't like eating in public places			1	2	3	4	N/A
6. I get pains in my face or jaw			1	2	3	4	N/A
7. I don't like seeing a side view of my face (profile)			1	2	3	4	N/A
8. I spend a lot of time studying my face in the mirror			1	2	3	4	N/A
9. I spend a lot of time studying my teeth in the mirror			1	2	3	4	N/A
10. I dislike having my photograph taken			1	2	3	4	N/A
11. I dislike being seen on video			1	2	3	4	N/A
12. I often stare at other people's teeth			1	2	3	4	N/A
13. I often stare at other people's faces			1	2	3	4	N/A
14. I self-conscious about my facial appearance			1	2	3	4	N/A
15. I try to cover my mouth when I meet people for the first time			1	2	3	4	N/A

16. I worry about meeting people for the first time	1	2	3	4	N/A
17. I worry that people will make hurtful comments about my appearance	1	2	3	4	N/A
18. I lack confidence when I am out socially	1	2	3	4	N/A
19. I do not like smiling when I meet people	1	2	3	4	N/A
20. I sometimes get depressed about my appearance	1	2	3	4	N/A
21. I sometimes think that people are staring at me	1	2	3	4	N/A
22. Comments about my appearance really upset me, even when I know people are only joking	1	2	3	4	N/A