An investigation of cancer stigma and its impact on posttraumatic growth among cancer patients

Student: Jennifer Lindsay Threader

Supervisory Panel: Emeritus Professor Don Byrne, Associate Professor Elizabeth Rieger, Dr Lynne McCormack

A thesis submitted for the degree of Doctor of Philosophy (Clinical Psychology) at the Australian National University December 2014
Declaration

I, Jennifer Lindsay Threader, declare that the work presented in this thesis is original and my own work. This thesis contains original research undertaken during the Doctor of Philosophy (Clinical Psychology) at the Research School of Psychology of the Australian National University. This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is noted in the thesis itself.

Signed

Date 07/05/2015
Acknowledgments

I am indebted to the men and women who participated in this research program. Their contribution furthered the understanding of contemporary beliefs about cancer and provided insight into some of the psychological aspects of the cancer experience. My sincere gratitude to the head and neck cancer patients who were willing to be open and share with me their sensitive experiences of stigma and psychological growth during their cancer journey. Without participants’ input and feedback, and sharing in their cancer narratives, this project would have never been able to move from concept to completion. In a small way, I hope to requite their generosity by contributing to the understanding of cancer stigma and posttraumatic growth in both research and practice.

I would like to recognize my supervisory panel members for their guidance and input throughout the process. I am grateful for my research chair, Emeritus Professor Don Byrne, for his encouragement and for providing me with independence to be able to study an area that I am passionate about. Associate Professor Elizabeth Rieger, thank you for your unwavering support and encouragement. Your warmth, empathy, and excellence are truly remarkable and inspiring. Thank you, Dr Lynne McCormack, for opening my eyes to the area of qualitative research. I am truly thankful for your expertise and input in my research. I am also grateful for the Australian National University for supporting my academic journey by providing a nurturing and welcoming environment.

I am very lucky to have formed lifelong friendships throughout this experience. For me, the PhD journey was not a sole lonely one. To
Rosemary Allen, Olivia Twigg and Kristy Zwickert, for providing support, laughter and friendship. I am very much looking forward to the next chapters of our lives, what they will bring, how we will grow, and how we will continue to be each others unfailing support.

To my amazing family half way across the world, there is no way I would have been able to complete this journey without you. My Mum and Dad have provided so much love and support, and have been my source of energy and encouragement by providing a positive and optimistic outlook. To my not-so-little brother, Matty, for his hard work and pursuit of excellence, in both athletics and academia, that will enable him to join us in this beautiful country soon. To Daphne and Alan for being a constant source of love and support to Mike and I. To my extended family for their love, understanding of my absence in the last four years and for their support of my academic pursuits. To my best friend Jen and the Conlons, my other extended family, for their love and boundless friendship.

I owe my greatest gratitude and thanks to my husband, Mike. To being my editor in chief, my constant source of support and always believing in me, you played a pivotal role in seeing this PhD through. You have been my constant, through both the highs and lows, of this graduate journey. We have seen, experienced, and grown so much together on this amazing adventure in Australia. I love you.
Abstract

Increased cancer incidence and decreased disease mortality has resulted in higher rates of cancer diagnosis, treatment and survivorship. Therefore, understanding the psychological impact of coping with cancer is paramount. Stigma can be among the challenges associated with the cancer experience but research into the specific causes and consequences is limited. Stigma reflects a devalued identity, which results in lowered self-esteem and strained social relationships. In addition to these negative changes, positive experiences such as posttraumatic growth (PTG) have also been documented among cancer patients. PTG refers to psychological development in an individual’s life after a traumatic event that surpasses their pre-trauma level of functioning. While the benefits of PTG are noteworthy, cancer-related stigma may leave some patients without the support and validation they need to develop PTG. The present program of research presents an examination of cancer-related stigma, by considering the perceptions of community members and the experience of cancer patients. The research also examines and how stigma may impact on the positive and negative changes following cancer diagnosis.

The first two studies examined perceptions of cancer stigma among community members (n = 373). Study 1 presents the results of experimental research, which investigated three potential causes of cancer stigma. Findings demonstrated consistent support for the role of blameworthy attributions, some support for the role of physical changes associated with cancer treatment, and minimal support for the role of poor prognosis in eliciting stigmatising responses. Guided by attribution theory, Study 2
assessed community perceptions of cancers perceived to be blameworthy versus non-blameworthy. Using Structural Equation Modelling, controllability in the blameworthy cancer groups (i.e., lung, throat and skin cancers) was found to directly impact on sympathy and hypothetical charitable donation. Study 3 presents the results of a questionnaire that was administered to cancer patients ($n = 113$), to examine the potential pathways, namely through social support and stigma, that ultimately contribute to well-being among cancer patients. Findings demonstrated the positive effect of social support, and the deleterious effect of stigma, on influencing post-diagnosis psychological change. Core belief examination was found to be a protective factor against any negative effects. Study 4 examined the ‘lived experience’ of nine head and neck cancer patients who had undergone facial surgical treatment. Using Interpretative Phenomenological Analysis, this study explored participants’ journey of coping with a range of stigmas, how they were able to find meaning, and the unique growth that developed from their experiences.

Findings of the four studies contribute to cancer-related stigma literature and provides evidence for the ways in which stigma contributes to positive and negative changes among cancer patients. The discussion considers how this program of research augments our understanding of cancer-related stigma, from both community and cancer patients’ perspective. Using both quantitative and qualitative methodology, the research demonstrated how stigma can have deleterious consequences, but also how some patients have used their stigmatising experience to promote positive change. Finally, this program of research proposes areas for future
research and promising implications for clinical practice in relation to stigma and posttraumatic growth.
# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Declaration</td>
<td>2</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>3</td>
</tr>
<tr>
<td>Abstract</td>
<td>5</td>
</tr>
<tr>
<td>Table of Contents</td>
<td>8</td>
</tr>
<tr>
<td>List of Tables</td>
<td>13</td>
</tr>
<tr>
<td>List of Figures</td>
<td>14</td>
</tr>
</tbody>
</table>

## Chapter 1

Foreword ...........................................................................................................15

Psychological Impact of Cancer: Stigma and Posttraumatic Growth ....16

1.1 Cancer ........................................................................................................16

1.2 Cancer Incidence, Prevalence and Survival Rates .............................16

1.3 Causes of Cancer Linked to Onset and Outcomes ...............................23

1.3.1 Smoking ......................................................................................23

1.3.2 Obesity ......................................................................................25

1.3.3 Alcohol ......................................................................................26

1.3.4 Summary of cancer causes ...................................................27

1.4 Psychological Impact of Cancer .......................................................28

1.4.1 Depression..................................................................................31

1.4.2 Anxiety ......................................................................................34

1.4.2.1 Post-traumatic Stress Disorder .....................................35

1.4.3 Cancer-related stigma ..............................................................36

1.5 Origins of Stigma Theory .................................................................40

1.5.1 Health-related Stigma ................................................................41

1.5.2 Categorisation of Stigma ..........................................................41

1.6 Theoretical Evidence for Stigmatising Attitudes ................................43

1.6.1 In-group enhancement and self-enhancement ............................44

1.6.2 Self-justification and system-justification ...............................45

1.6.3 Anxiety-buffering ........................................................................46

1.7 Effects of stigma ..................................................................................47

1.8 Lazarus and Folkman’s Transaction Model of Stress and Coping ..........48

1.8.1 Stress appraisal ........................................................................48
Chapter 4

Foreword ..............................................................................................................171
Declaration ...........................................................................................................173
The Impact of Stigma, Social Support, and Core Belief Examination on Psychological Well-being among Cancer Patients ..............................................175
Abstract .............................................................................................................176
Background .........................................................................................................178
Method ..................................................................................................................183
Participants .................................................................................................183
Measures ..............................................................................................................185
Procedure ............................................................................................................187
Statistical analysis .............................................................................................187
Results ..................................................................................................................189
Preliminary analyses ..........................................................................................189
Model 1: Stigma, negative change, core belief examination and psychological well-being ..................................................................................191
Model 2: Social support, positive change, core belief examination and psychological well-being ..................................................................................192
Discussion ...........................................................................................................194
Limitations and Future Directions .....................................................................196
Conclusions .........................................................................................................197
References ..........................................................................................................198

Chapter 5

Foreword ..............................................................................................................203
Declaration ..........................................................................................................204
Cancer Related Trauma, Stigma and Growth: The ‘Lived’ Experience of Head and Neck Cancer .................................................................206
Abstract .............................................................................................................206
Introduction .........................................................................................................206
Method ..................................................................................................................208
Participants ........................................................................................................208
Procedure ..........................................................................................................208
Epistemology .....................................................................................................208
Analysis .................................................................................................................209
List of Tables

Chapter 2
Table 1  Mean (SD) Difference Scores for the Emotional Reactions to Mental Illness Scale and Social Distance Scale across the Eight Experimental Conditions ................................................. 116

Chapter 3
Table 1  Sample \((n = 373)\) Characteristics ............................................. 142
Table 2  Chi square Cancer Type Comparisons across Causal Attributions ................................................................. 148
Table 3  Standardised Path Coefficients and Fit Indices for each Cancer ..................................................................................... 151
Table 4  Standardised Path Coefficients and Fit Indices for each Cancer for New Model ................................................................. 153

Chapter 4
Table 1  Participant Characteristics \((n = 113)\) ....................................... 184
Table 2  Pearson Correlations Between Study Variables ................. 190

Chapter 5
Table 1  Participant Characteristics .................................................................................................................. 209
Table 2  Outline of the Stages Involved in Interpretative Phenomenological Analysis ................................................................. 210
Table 3  Superordinate Theme: Distress, Stigma, and Psychological Growth Overarching Subordinate Themes ................. 210
# List of Figures

## Chapter 1

| Figure 1.1 | Global estimates of aged-standardised incidence and mortality for all cancers in 2008 data from the GLOBOCAN 2008 database | 19 |
| Figure 1.2 | 5-year prevalence, incidence and mortality rates in 2010 in Australia of the four most common cancers diagnosed among men and women | 21 |
| Figure 1.3 | Theoretical model of the stress and coping process, original by Lazarus and Folkman (1984) | 50 |
| Figure 1.4 | Revised theoretical model of the stress and coping process, by Folkman (1997), including positive states of coping | 54 |

## Chapter 3

| Figure 1 | Causal Attribution (Percentage) across Cancer Type | 149 |

## Chapter 4

| Figure 1 | Hypothesized Conceptual Models (Model 1 top) for Analysis | 182 |
| Figure 2 | Final Study Models Demonstrating Pathways to High and Low Psychological Well-being. Model 1 Represents the Influence of Stigma on Psychological Well-Being (top) and Model 2 Models the Influence of Social Support on Psychological Well-being | 193 |

## Chapter 5

| Figure 6.1 | Weiner’s Original Models of Attribution Theory (1986). Attribution-affect-help Model (top) and Model Supported by Study 2 (bottom) | 226 |
Chapter 1: Foreword

This chapter focuses on the psychological concerns facing cancer patients, namely cancer-related stigma and posttraumatic growth. Firstly, the definition, prevalence, mortality rates, and causes of cancer are documented. The nature of psychological difficulties that cancer patients can experience is clarified, with the deleterious consequences of cancer-related stigma highlighted. The chapter then moves to provide an overview of stigma, by considering its definition and categorisation, presenting theoretical explanations of cancer stigmatisation and reporting on its social and psychological effects. Lazarus and Folkman (1984) and Folkman’s (1997) model of stress and coping is used to explain the deleterious and positive consequences associated with cancer. Subsequently, a definition of posttraumatic growth is provided, highlighting the positive change which may be experienced following a traumatic experience, including after a cancer diagnosis. A review of the empirical research on posttraumatic growth and cancer are reviewed. Theories of posttraumatic growth and its reported benefits are explored. Finally, this chapter summarises the link between cancer stigma and posttraumatic growth, with a rationale for the current program of research.
Chapter 1: Psychological impact of Cancer: Stigma and Posttraumatic Growth

1.1 Cancer

The term cancer encompasses a diverse group of over 100 diseases all characterised by the body’s cells becoming abnormal, and multiplying out of control (Australian Institute of Health and Welfare [AIHW] and Australasian Association of Cancer Registries [AACR], 2012). These cancerous cells have the ability to damage adjacent tissue and eventually spread, or metastasise, to other areas of the body, interfering with the tissue’s normal functioning. While most cancers form a solid tumour, some cancers, such as leukaemia, invade the body through the blood stream. Cancer types are distinguished from one another based on the location where the cancer began and the type of cell involved, and each respond differently to medical intervention. Cancer treatment typically involves surgery, radiotherapy, chemotherapy, hormone therapy or a combination of these. If cancer remains untreated, it can result in severe illness and death (American Cancer Society, 2014). Cancer has a significant impact on those diagnosed, their families and the health care system (AIHW & AACR, 2012).

1.2 Cancer Incidence, Prevalence and Survival Rates

The incidence and prevalence of cancer is rising (AIHW, 2012a; AIHW & AACR, 2012). The AIHW (2012a) estimated that in 2014, approximately 128,290 individuals in Australia would be diagnosed with
cancer, which is the highest number of new cancer cases reported to date (AIHW, 2014). The rate of cancer has been steadily increasing, with the overall age-standardised incidence of all cancers increasing 13% between 1991 and 2009. During that same time period, the number of new cases of cancer nearly doubled from 66,278 to 115,897 new cases (AIHW, 2014) with a projection of 149,990 new cases in 2020 (AIHW, 2012a). These upward Australian trends are similar to what is being experienced globally (Bray, Ren, Masuyer, & Ferlay, 2013; Ferlay et al., 2013; Frankish, 2003).

In 2008 the estimated number of new cancer cases around the world was 12.7 million (Ferlay et al., 2010), and the global five-year survival rate for cancer was approximately 28.8 million (Bray et al., 2013). The incidence and mortality of cancer in Australia compared to other countries and regions can be found in Figure 1.1, using data from the GLOBOCAN 2008 database, prepared by the International Agency for Research on Cancer (IARC). The incidence rate of cancer in Australia (314 per 100,000) was found to be comparable to that of New Zealand (309 per 100,000), but significantly higher than rates estimated in other parts of the world (Ferlay et al., 2010). This high rate of cancer is attributed to melanoma of the skin, as Australia is found to have the world’s highest age-standardised incidence rate of skin cancer (Ferlay et al., 2010); however, the high incidence may also be due to the mandatory reporting of each cancer case and cancer registries in Australia, which is not requirement that is held universally. Despite the high rate of cancer incidence, the number of cancer-related deaths in Australia compares well internationally, as it is slightly lower than the average global rate for both men (125.6 versus 128.8, per 100,000) and women (86.0 versus 87.6, per 100,000). However, it is still
cause for concern considering cancer is the second leading cause of death in Australia, exceeded only by cardiovascular disease (AIHW, 2012b).
Figure 1.1 Global estimates of aged-standardised incidence and mortality for all cancers in 2008, data from GLOBOCAN 2008 database (Ferlay et al., 2010).
While cancer-related mortality is high in Australia compared to other causes of death, the five-year relative survival rate has improved for all cancers over recent years. This statistic refers to a cancer patient’s chance of survival after five years since diagnosis, in the absence of other causes of death. Approximately 66% of people recently diagnosed with cancer in Australia are still alive five years after diagnosis, in contrast to the five-year survival rate of 47% in 1982 (AIHW & AACR, 2012). At the end of 2007, it was estimated that there were 774,674 living cancer survivors (1.6% of the Australian population) who had been diagnosed with cancer in the past 26 years (AIHW & AACR, 2012). As a result of increases in incidence, prevalence, and survival, there are now more men and women who have been diagnosed and treated with cancer, and dealing with survivorship, than ever before.

The incidence, prevalence and survival rates of cancer vary greatly as a result of disease and individual characteristics including type of cancer, stage of disease and age at diagnosis. In Australia, prostate cancer and breast cancer are the most commonly diagnosed cancers among men and women, respectively; bowel cancer, melanoma of the skin, and lung cancer account for the second, third and fourth most common cancers, respectively, among both sexes (AIHW, 2012b, 2014b, 2014c, 2014d, 2014e, 2014f). The prevalence, incidence and mortality of the most common cancers diagnosed among men and women are presented in Figure 1.2. In addition, while overall cancer survival has improved over time, this gain has not been consistent across all cancer types. Over the past three decades, cancers that experienced the largest survival improvement were prostate cancer, kidney cancer, and non-Hodgkin’s lymphoma. Small survival gains were
experienced among cancers which already had low survival 30 years prior; these included mesothelioma (5% to 6% survival), brain cancer (20% to 22% survival), pancreatic cancer (3% to 5% survival) and lung cancer (9% to 14% survival).

Figure 1.2 5-year prevalence, incidence and mortality rates in 2010 in Australia of the four most common cancers diagnosed among men and women (AIHW, 2012b, 2014b, 2014c, 2014d, 2014e, 2014f).

Lung cancer is the leading cause of cancer mortality in Australia (Australian Bureau of Statistics [ABS], 2012) and globally (Ferlay et al., 2010). It is attributable to the most cancer-related deaths among men and women, accounting for 1 in 5 cancer mortalities (19%) (AIHW & AACR, 2012). In Australia, lung cancer is the second leading cause of death among men, following coronary artery disease; and the fourth leading cause among women following coronary artery disease, cerebrovascular diseases, dementia and Alzheimer’s disease (ABS, 2012b). The poor survival rates for lung cancer are likely because it is most commonly detected at an advanced stage, when evidence-based treatment options are limited (Spiro & Silvestri, 2005).
In addition to the variance in cancer types, age at diagnosis has a significant impact on cancer prevalence and mortality, as 75% of new cancer cases among men and 65% among women are diagnosed in those who are over 60 years of age (AIHW & AACR, 2012). Cancer-related mortality also increases past 60 years of age, accounting for 85% of cancer deaths in men and 83% of cancer deaths in women. The association of age with prevalence and mortality poses a risk as our population ages, with the burden of cancer estimated to significantly increase (Ferlay et al., 2010).

In Australia, cancer is the leading cause of disease-related burden (AIHW & AACR, 2012). Burden of disease is calculated by disability-adjusted life years (DALYs), which take into account the number of years of life lost due to premature death (YLL) and number of years of healthy life lost due to disease, disability or injury (YLD). Overall, cancer contributes to 19% of total DALYs in Australia, with most cancers contributing to disease burden in YLL rather than in YLD (AIHW & AACR, 2012). Also contributing to disease burden, cancer was responsible for 1 in 10 hospitalisations in Australia in 2010, accounting for 2.31 million patient days (AIHW & AACR, 2012). This poses a challenge to health care systems as increased pressure on resources is expected, given the increasing cancer incidence and prevalence.

In recent years, there have been considerable efforts to reduce cancer burden by targeting a reduction in the number of new cancer cases. In 1996, the Australian Government designated cancer as a National Health Priority Area. Since this decision, there have been national efforts targeting cancer prevention, detection, treatment and research (AIHW & Department
of Health and Family Services [DHFS], 1997). Specifically, focus has been assigned to lung, melanoma skin, non-melanocytic skin, cervical, breast, colorectal and prostate cancers, and non-Hodgkin's lymphoma. The aim of this initiative was to target areas which contribute significantly to burden of disease and have the potential for significant health gains, through public awareness and public policy efforts.

1.3 Causes of cancer linked to onset and outcomes

While the rate of cancer diagnosis is rising, the increase in absolute cancer cases can only be partly explained by a combination of ageing and an increased population size in Australia (AIHW & AACR, 2012). Other aetiological factors including lifestyle behaviours have also been implicated in the rise in new cancer cases. Indeed, cancer has been deemed a preventable disease amenable to lifestyle change (Anand et al., 2008), given that family history and genetic susceptibility only account for 5% to 10% of cancer cases (Lichtenstein et al., 2000). While several environmental and lifestyle factors are likely to contribute to cancer onset, smoking, obesity and alcohol consumption have been identified as the most important causes of cancer (Danaei, Vander Hoorn, Lopez, Murray, & Ezzati, 2005).

1.3.1 Smoking. The leading cause of cancer among humans has been attributed to smoking, accounting for 20% to 30% of new cancer cases (AIHW & AACR, 2012). The association between tobacco and lung cancer is the most well-known detrimental effect of tobacco on human health; however many individuals are unaware that it also contributes to risk of urinary, bladder, head and neck, kidney, uterine, cervix, pancreas and breast cancer (World Health Organisation [WHO], 2011). While smoking causes
80% to 90% of lung cancer cases in both current and past smokers (Doll & Peto, 1981; Godtfredsen, Prescott, & Osler, 2005; Jemal et al., 2008; Peto, 1994), it has also been found to cause an estimated 40% to 70% of all cases of urinary, bladder, and kidney cancer and 30% of pancreatic cancer cases. It has been associated with a 60% higher risk of developing breast cancer (among women who smoked more than 30 years) and the attributable risk of smoking for head and neck cancers is 27 times that for non-smokers (WHO, 2011).

Smoking can also have a detrimental impact on individuals once cancer has been diagnosed. The carcinogens present in tobacco can impact on smoking-related genetic changes (Sanchez-Cespedes et al., 2001), tissue damage (Phillips, 2002) and immune suppression (Giovannucci et al., 1999), thereby facilitating malignant tumour progression. These biochemical effects can have a negative influence on a cancer patient’s treatment, recovery and survivorship. For example, compared to non-smokers, smokers have found to have more aggressive disease status, defined by tumour type and disease stage, at diagnosis among melanoma of the skin and leukaemia patients (Chelghoum et al., 2002; Shaw & Milton, 1981). Smoking is also linked with reduced radiotherapy treatment efficacy and survival among head and neck cancer patients (Browman et al., 1993); and is associated with prostate, lung, and head and neck cancer recurrence, metastasis and disease-related mortality (Deleyiannis, Thomas, Vaughan, & Davis, 1996; Kenfield, Stampfer, Chan, & Giovannucci, 2011; Pantarotto, Malone, Dahrouge, Gallant, & Eapen, 2007; Parsons, Daley, Begh, & Aveyard, 2010). Considering these adverse smoking related outcomes, it has been suggested that implementation of smoking cessation programs be
routinely implemented in hospital settings to improve patients’ quality of life and treatment success (Schnoll et al., 2004).

1.3.2 Obesity. The factors contributing to increased body mass, as well as obesity alone, have been implicated in the development of several cancers. According to Lim and colleagues (2013) physical inactivity, diet (i.e., high caloric intake) and high body mass index (BMI; greater than 30 kg/m²) have been specifically linked to cancers of the colon, rectum and breast. Without taking into account these aforementioned factors, obesity is associated with 20% of all new cancer cases (Wolin, Carson, & Colditz, 2010). The severity of obesity also impacts on cancer risk, as each 5kg/m² increase in BMI has been associated with higher risks of cancers of the uterus, gallbladder, kidney, colon, cervix, ovary, breast (among post-menopausal women), pancreas, rectum and blood (Bhaskaran et al., 2014).

A concerning upward trend in obesity-related cancer occurrence is projected as rates and severity of obesity is rapidly increasing globally (Ng et al., 2014; Seidell, 2014). In 2011, it was estimated that 1.46 billion adults were overweight (BMI = 25.0 – 29.9), with 502 million of those individuals in the obese range (BMI ≥ 30.0) (Finucane et al., 2011); should obesity remain a global concern, it is estimated that in 2030 3.28 billion adults will be overweight or obese (Kelly, Yang, Chen, Reynolds, & He, 2008). The increased prevalence of obesity can also be seen in Australia, where rates are 2.5 times greater in 2000 than they were in 1980 (Cameron et al., 2003). In 2012, 63.4% of the Australian population were overweight, with 28.3% of these individuals in the obese range (ABS, 2012a). Australia places fifth highest in the world for rates of obesity, following the United States
(36.5%), Mexico (32.4%), Hungary (28.4%) and New Zealand (28.4%) (Organisation for Economic Co-operation and Development, 2013).

The increased rate and severity of obesity poses a concern for cancer incidence considering, from their population-based sample of over 10 million, Bhaskaran and colleagues (2014) estimate that a population-wide 1kg/m² increase in BMI would contribute to an additional 3,790 cancer cases in the United Kingdom. If obesity continues to increase, by 2030 approximately 492,000 to 669,000 new cases of obesity-related cancer will be diagnosed in the United Kingdom and the United States (Wang, McPherson, Marsh, Gortmaker, & Brown, 2011).

The mechanism by which obesity increases cancer risk has been linked to biochemical changes in the metabolism of steroids including androgens, oestrogens and progesterone (Dickson, Thompson, & Lippman, 1990), insulin, and insulin-like growth factor-1 (Khandwala, McCutcheon, Flyvbjerg, & Friend, 2000). Once cancer develops, obesity also detrimentally impacts on the course of the disease, disease recurrence, the affected individual’s overall health and their survival (Marian & Thomson, 2014). The process by which obesity impacts on these factors are complex and unclear (Demark-Wahnefried et al., 2012), and beyond the scope of this dissertation.

1.3.3 Alcohol. Following smoking and obesity, alcohol is the most prevalent – and prominent – known cause of cancer (Boffetta, Hashibe, La Vecchia, Zatonski, & Rehm, 2006). The role of alcohol consumption as a human carcinogen is an important, yet underestimated, factor implicated in cancer onset. Its role in causing cancers of the oral cavity, pharynx,
oesophagus, liver, colon, rectum and breast (in women), has been established (Boffetta et al., 2006). These health impacts of alcohol on cancer are widespread, being associated with cancer onset in both high-income and low-to-middle-income countries (Danaei et al., 2005). This is cause for concern particularly because alcohol consumption is increasing rapidly in many parts of the world (WHO, 1999).

The joint effect of alcohol consumption and smoking has been reported to account for at least 75% of head and neck cancers (Blot et al., 1988), and may explain the increase in prevalence reported for this cancer type (Bray, Brennan, & Boffetta, 2000). The impact of these two carcinogens has a strong multiplicative effect (Andre, Schraub, Mercier, & Bontemps, 1995; Lewin et al., 1998). It has been suggested that the alcohol toxicity damages the body’s cells, which may induce rapid cell division. The probability hyperproliferation increases with accompanying consumption or inhalation of other carcinogens, such as tobacco (Kornfehl, Hager, Gedlicka, & Formanek, 2002). Not surprisingly, the severity and chronicity of alcohol and tobacco consumption has been associated with greater risk of head and neck cancer (Andre et al., 1995).

1.3.4 Summary of cancer causes. In summary, smoking, obesity and alcohol have a significant and cumulative impact on cancer development. Indeed, overall lifestyle factors have been found to cause approximately a third of new cancer cases (Parkin, Boyd, & Walker, 2011) and are attributable to approximately 35% of cancer deaths (Danaei et al., 2005). As the burden of cancer continues to increase globally the
development of early prevention interventions is becoming more important (Jemal et al., 2011).

Strategies for modifying behaviour would indisputably improve prevalence and mortality (Anand et al., 2008). Indeed, there has been an increase in campaigns and strategies aimed to educate the public regarding lifestyle factors that contribute to cancer risk (Rassaby, Larcombe, Hill, & Wake, 1983). Highlighting and promoting the preventable nature of cancer is likely to impact on public perceptions of cancer. Benefits include advocating healthy living behaviours, and empowering the population to take control over its own health (Marks, 1999). However, attention must be paid to prevent undue blame experienced by the cancer patient, for having engaged in lifestyle behaviours which may have put them at risk for developing their cancer (Marlow, Waller, & Wardle, 2010).

1.4 Psychological impact of cancer

Being diagnosed with a life-threatening illness such as cancer can be a distressing, and even traumatic, experience. From diagnosis to treatment, and subsequent recovery, individuals diagnosed with cancer experience many challenges and distressing events. These include, but are not limited to: existential distress as a result of having a life-threatening illness (Murata & Morita, 2006); the onset of relationship difficulties, with avoidance and withdrawal of social support after diagnosis (Peters-Golden, 1982); financial challenges related to instability to attend work and high medical expenses (Fife & Wright, 2000; Hoffman, 2005); and the uncertainty associated with the possibility of disease progression or recurrence (Butler et al., 2005; Nerenz, Leventhal, & Love, 1982).
Contributing to the distress, a diagnosis of cancer can come as a surprise and cause those affected to reflect on their own mortality. While Sontag (1991) reports that everyone is vulnerable to illness and disease, as "everyone who is born holds dual citizenship, in the kingdom of well and in the kingdom of sick" (p. 3), when compared to other diseases and illnesses; "cancer is a disease that strikes each person, punitively", and causes those diagnosed to question "'Why me?' (meaning it's not fair)” (p. 39). While individuals will try to derive adaptive meaning from their diagnosis, the process may be compounded by ongoing distress. For example, among individuals exposed to a variety of different traumatic events, Foa, Ehlers, Clark, Tolin and Orsillo (1999) found that heightened distress was associated with negative appraisals of meaning associated with the trauma.

Cancer-related distress has been found to result from medical intervention including surgery, radiotherapy and chemotherapy, in addition to their side effects, and in some cases, permanent physical changes. Overall, treatment for cancer has been found to cause significant fatigue in most cancer patients, which has led to a reduced quality of life (Cella, 1998). Surgical intervention can result in a painful recovery process and, depending on the cancer site, can result in significant changes in appearance. For example, head and neck cancer patients may experience significant facial changes, and breast cancer patients may require breast removal. Cancer surgery can also result in disablement, with prostate cancer patients susceptible to sexual dysfunction, and head and neck cancer patients at risk of swallowing difficulties. Radiotherapy has been associated with appetite loss, nausea, and severe fatigue, which may cause significant disruption to daily living (Cancer Council Victoria, 2014). The side effects
of chemotherapy are also notable and widespread, causing nausea, vomiting and fatigue, in addition to hair loss (National Cancer Institute [NCI], 2012), which has been associated with secondary distress given it is a visual reminder of the life-threatening nature of cancer, symbolising a loss of physical strength, poor health and possible death (Rosman, 2004). Being diagnosed with cancer is also associated with occupational and financial challenges for many patients (Chapple, Ziebland, McPherson, & Summerton, 2004; Hoffman, 2005). For example, in their review of issues in cancer survivorship, Boyes, Hodgkinson, Aldridge and Turner (2009) report that cancer survivors experience discrimination in the workplace, impacting on their ability to advance their career. In addition, the review identified that there were cases of reported employment dismissal and demotion following cancer diagnosis and treatment. These occupational concerns, in addition to medical expenses, can make cancer survivors prone financial difficulties.

In summary, being confronted with a cancer diagnosis and treatment, and coping with the aftermath, can have a significant impact on those affected. For instance, in addition to assessing for other key medical indicators including temperature, respiration, heart rate, blood pressure, and pain, the high levels of emotional distress experienced among cancer patients has warranted regular monitoring as the sixth vital sign, to gauge overall physical health and well-being among patients (Bultz & Carlson, 2006). Specifically, depression and anxiety as a result of cancer has been associated with a range of morbidities that significantly reduce an individual’s quality of life, such as impaired physical, social and familial functioning, poor treatment adherence, worsening of symptoms, poor self-
care and diminished will to live (Rayner et al., 2011). As a result of the diverse physical and psychosocial effects impacting on cancer types, the degree of distress appears to vary according to cancer type (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001)

In addition to depression and anxiety, cancer-related stigma may also contribute to distress among cancer patients (Chambers et al., 2012). Stigma is a devalued and negatively perceived aspect of an individual’s identity (visual or symbolic) that results in negative consequences (Goffman, 1963). For example, in relation to cancer, stigma may be associated with treatment side effects, including both temporary (e.g., chemotherapy induced alopecia; Rosman, 2004) and permanent (e.g., facial change following head and neck cancer surgery; Bonanno & Esmaeli, 2012) changes. Cancer-related stigma has been found to lead to strained social relationships (Dakof & Taylor, 1990; Peters-Golden, 1982), reduced self-esteem (Fife & Wright, 2000) and delayed symptom reporting (Tod, Craven, & Allmark, 2008), which may contribute to ongoing psychopathology and increased disease burden. However, research investigating cancer-related stigma and its consequences is limited (Lebel et al., 2013; Lebel & Devins, 2008).

1.4.1 Depression. The onset of depression among cancer patients is considered a common and serious comorbid condition (Cordella & Poiani, 2014). There is an overall consensus that the prevalence of depression is higher among cancer patients as compared to the general public (Dalton, Laursen, Ross, Mortensen, & Johansen, 2009; Honda & Goodwin, 2004; Massie, 2004; Raison & Miller, 2003; Rasic, Belik, Bolton, Chochinov, &
Rates of depression among cancer patients have also been found to be higher than individuals diagnosed with other medical conditions, such as stroke, diabetes and heart disease (Patten et al., 2005; Polsky et al., 2005). The likely triggers of depressive states among cancer patients may include being diagnosed with a life-threatening illness, physical changes following surgical intervention, and cancer pain (Laird, Boyd, Colvin, & Fallon, 2009).

Research investigating Major Depressive Disorder (MDD) among cancer patients has documented variable prevalence rates (Massie, 2004; Raison & Miller, 2003), with one meta-analysis reporting rates of depression ranging from 0% to 46% (van't Spijker, Trijsburg, & Duivenvoorden, 1997). The specific type of cancer assessed may account for the variability (Cordella & Poiani, 2014). The prevalence rates of depression appear to differ between cancer types: breast cancer (10% to 32% of patients; Wong-Kim & Bloom, 2005), colon cancer (13% to 35% of patients; Massie, 2004), head and neck cancer (22% to 57% of patients; Archer, Hutchison, & Korszun, 2008), lung cancer (11% to 44% of patients; Massie, 2004), Lymphoma (8% to 19% of patients; Massie, 2004) and pancreatic cancer (33% to 55% of patients; Massie, 2004). These results suggest that there are unique physical and psychosocial factors implicated in the experience of different types of cancer, as these cancers differ in terms of treatment trajectory, impact of treatment, recovery rates and long-term disability.

In addition to increased reports of depression in cancer patients, relatedly, rates of suicidality are also high within this medical group. A
large cohort analysis found cancer patients have nearly twice the incidence of suicide, when compared to the general population (Misono, Weiss, Fann, Redman, & Yueh, 2008). There is psychological distress specific to the cancer experience, in relation to diagnosis, treatment and survivorship that increases risk of suicidality in cancer patients. For example, a study conducted by Akechi, Nakano, Akizuki, Nakanishi, Yoshikawa, Okamura, and Uchitomi (2002), among cancer patients referred for suicidal ideation or attempt, or request for euthanasia, found that while suicidality was associated with MDD, it was also linked with cancer disease factors such advanced cancer stage, pain and inability to perform normal life functions, as a result of poor physical functioning. Cancers with the highest rate of suicide among both men and women included those affecting the lung and bronchus, stomach, and oral cavity. Therefore, there may also be specific factors relating to cancer type which contribute to increased emotional distress and reduced physical health, which may influence feelings of hopelessness and helplessness (Akechi, Okamura, Yamawaki, & Uchitomi, 1998).

Depression among cancer patients has been found to impact on treatment outcomes and psychological well-being. For instance, it has been found to be associated with poor treatment adherence, increased hospital stay (Colleoni et al., 2000; Prieto et al., 2002), and reduced quality of life (Bui, Ostir, Kuo, Freeman, & Goodwin, 2005). Consequently, there have been recent efforts to develop effective treatments and strategies to reduce depression among cancer patients. For example, multicenter randomized control clinical trials assessing the efficacy of rigorous and complex assessment and intervention have been recently conducted among cancer
patients with depression (Sharpe et al., 2014; Walker et al., 2014). These clinical trials have used a multicomponent intervention, which included antidepressant medication and psychological treatment (i.e., problem-solving therapy and behavioural activation). The intervention was been found to be beneficial among cancer patients with good prognosis (i.e., expected survival greater than 12 months) and lung cancer patients with less favorable prognosis (i.e., expected survival greater than 3 months). These programs have demonstrated promising results and may assist to prevent depression-related disease burden among cancer patients.

While depression is a concern for cancer patients during diagnosis and treatment, the longitudinal data are more promising. For instance, a meta-analysis by Mitchell, Ferguson, Gill, Paul, and Symonds (2013) found that the relative risk of depression among cancer patients who had been diagnosed at least two years prior (11.6%) and among healthy controls (10.2%) was not significantly different. Therefore, while cancer patients are prone to increased rates of depression at diagnosis and during treatment, these effects appear to be not long-lasting.

1.4.2 Anxiety. In addition to depression, anxiety has also been associated with cancer. A meta-analysis using a mixed cancer sample found that on average 19% of cancer patients showed clinical levels of anxiety, and a further 22.6% reported subclinical symptoms (Linden, Vodermaier, MacKenzie, & Greig, 2012). Higher rates of anxiety were found among gynaecological, lung and head and neck cancers. The onset of anxiety may be a result of several factors such as poor social support, pain, advanced disease and disease burden (Hill et al., 2011; Nordin, Berglund, Glimelius,
Anxiety following cancer diagnosis can significantly lower quality of life (Stark et al., 2002).

Anxiety can exert a significant impact on individuals following diagnosis and treatment, and symptoms are likely to persist as a significant psychological problem in the long-term. The meta-analysis conducted by Mitchell and colleagues (2013) found that the relative risk of anxiety among long-term cancer survivors (17.9%), or those alive more than 2 years after diagnosis, was significantly greater when compared to healthy controls (13.9%). These higher rates of anxiety may be attributed to the ongoing fear of recurrence. Nearly half (47%) of cancer survivors have reported a fear of cancer recurrence, and while it may be considered a normal and expected response to cancer, it has been associated with reduced quality of life and functional impairment (Simard et al., 2013).

**1.4.2.1 Posttraumatic Stress Disorder (PTSD).** PTSD, a type of anxiety disorder, may also present among those diagnosed with cancer. Clinical and sub-clinical diagnoses of PTSD have been reported among cancer patients at various points of their experience including diagnosis, treatment and survivorship. The rate of PTSD among cancer patients, assessed by structured clinical diagnostic interview ranges from 2% to 35%, with most studies reporting prevalence rates of 4% to 6% (Kangas, Henry, & Bryant, 2002). However, sub-clinical PTSD has been reported more frequently and has been identified in up to 50% of cancer patients (Gurevich, Devins, & Rodin, 2002). Among cancer survivors who had undergone bone marrow transplant, three to four symptoms of PTSD were reported on average following treatment (Widows, Jacobsen, & Fields,
The most prominent symptoms included a sense of a limited future (avoidance and numbing cluster; reported in 41% of participants), difficulty staying or falling asleep (arousal cluster; reported in 30% of participants), difficulty concentrating (arousal cluster; reported in 26% of participants), and inability to remember important aspects of their cancer experience (avoidance and numbing cluster; reported in 26% of participants). The psychosocial impact of sub-clinical symptoms is noteworthy, causing disruption to employment and social relations and leading to difficulties at home (Stein, Walker, Hazen, & Forde, 1997).

It has only been within the past 20 years that the experience of cancer has been identified as a potential traumatic event. The diagnostic criteria for PTSD changed in 1994 (American Psychiatric Association, 1994) to include a life-threatening illness as a stressor which may precipitate a PTSD response. Since that time, there has been a significant research and clinical focus on PTSD and cancer (Kangas et al., 2002; Smith, Redd, Peyser, & Vogl, 1999). In support of its inclusion as a stressor that triggers PTSD, empirical research has found that over 60% of breast cancer patients reported their cancer to be life-threatening, and reported experiencing fear, helplessness or horror (Andrykowski, Cordova, Studts, & Miller, 1998; Cordova, Cunningham, Carlson, & Andrykowski, 2001). Posttraumatic stress disorder may have an ongoing impact on cancer patients, given one study's finding that almost 50% continued to experience cancer-related thoughts three years after treatment (Matsuoka et al., 2002).

1.4.3 Cancer-related stigma. Commonly, cancer patients report that they have experienced stigma as a result of their diagnosis (Colyer,
A diagnosis of cancer is associated with fear and stigma usually because it is not well-understood by others; for instance, community members are often misinformed and believe that, despite treatment, a cancer diagnosis always results in death (Ramers-Verhoeven, Geipel, & Howie, 2013). Furthermore, according to Sontag (1991), cancer is “felt to be obscene – in the original meaning of that word: ill-omened, abominable, and repugnant to the senses” (p. 9). As a result of these beliefs, cancer patients may attempt to conceal their diagnosis from others. For example, a study among prostate cancer patients found that limiting disclosure of their cancer diagnosis was associated with fear of stigmatisation from others (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000). Concealing a stigma may lead to concern that others will learn about their devalued attribute, cause isolation from other members of the stigmatised group (e.g., for instance, not attending cancer support groups) and lead to a sense of detachment from the individual’s sense of self; these issues may have psychosocial implications, including elevating anxiety, depression, guilt and shame, reducing self-efficacy and straining social relationships (Pachankis, 2007).

However, some cancer patients are confronted with no choice of disclosing their diagnosis, as they display visible signs of cancer treatment, specifically, hair loss, scars, or physical changes. This may uniquely contribute to the experience of stigma (Rosman, 2004). Conversely, disclosure of a cancer diagnosis may also have positive outcomes for patients. While research investigating disclosure among cancer patients is limited, disclosure of HIV/AIDS status, another stigmatising condition (Malcolm et al., 1998), has been found to promote treatment adherence
(Chesney & Smith, 1999), increase psychological well-being (Beals, Peplau, & Gable, 2009), strengthen personal relationships (Parsons, VanOra, Missildine, Purcell, & Gómez, 2004) and increase provision of social support (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003).

There are also disadvantages associated with disclosing a cancer diagnosis. For instance, disclosure has been found to lead to discrimination, harassment and social isolation (Clair, Beatty, & MacLean, 2005). It is common for cancer patients to report isolation and avoidance from others (Lebel & Devins, 2008); this in turn may lead to a negative self-concept and social withdrawal (Crandall & Coleman, 1992). This isolation may lead to reduced psychological well-being and impact on adjustment, given social support has been found to assist in helpful coping and recovery in chronic illness (Gallant, 2003).

Disclosure of a cancer diagnosis may also lead to other stigmatising experiences. For instance, cancer patients who are perceived to have contributed to their cancer onset, by engaging in unhealthy lifestyle behaviours such as smoking cigarettes, report heightened stigmatisation. These individuals report being doubly stigmatised as a result of their experience with cancer and their own lifestyle choices which may have functioned as contributing factors (Lebel & Devins, 2008). Research into the stigmatisation of lung cancer and its association with smoking has been the focus of much research investigating cancer-related stigma. Research among lung cancer patients (Chapple, Ziebland, & McPherson, 2004; Chapple, Ziebland, McPherson, et al., 2004; Else-Quest, LoConte, Schiller, & Hyde, 2009; Tod et al., 2008) and medical professionals treating lung
cancer, or familiar with it (Conlon, Gilbert, Jones, & Aldredge, 2010; Wassenaar et al., 2007) has consistently demonstrated that this causal link with smoking and perception of blame is associated with increased overt and felt stigma. Cancer stigma has been found to have a deleterious effect on those diagnosed, as it can be a cause of distress leading to depression and reduced quality of life (Cataldo, Jahan, & Pongquan, 2012; Chambers et al., 2012); it has also been associated with reduced self-esteem (Fife & Wright, 2000) and strained social relationships (Peters-Golden, 1982), which are likely to negatively impact on adaptive coping following diagnosis (Suls, 1982).

Despite the evidence for the stigmatisation of lung cancer patients, research investigating overt discrimination and stigmatising attitudes among community members to cancer patients is conflicting and limited. Some researchers have speculated that Western cultural norms have changed about cancer, and therefore stigma is no long a concern for cancer patients (Hoffman, 2005). In support of this opinion, Bloom and Kessler (1994) found that women with early stage breast cancer reported that they received more social support after their diagnosis compared to other women receiving other types of surgery (i.e., cholecystectomy or benign breast biopsy). However, a study by Peters-Golden (1982) among 100 community members (male and female) and 100 female breast cancer patients, found that 61% community members reported they would avoid contact with a cancer patient; and 71% of cancer patients identified that they had been treated differently by others since their cancer diagnosis. Therefore, understanding stigma from the basis of the stigmatiser (i.e., community
members) and the stigmatised (i.e., cancer patients) is a crucial area for future research.

1.5 Origins of stigma

Cancer-related stigma is potentially a significant source of psychological distress among cancer patients. However, research into the causes and consequences are limited. Most of the contemporary literature on stigma stemmed from the seminal work of sociologist Erving Goffman (1963). Goffman (1963) defined stigma as an “attribute that is deeply discrediting” (p. 3). The etymology of the word ‘stigma’ is traced back to the ancient Greek period when a ‘mark’ was cut or burned into the body to signify that an individual was immoral. Such individuals were usually identified as slaves, criminals or traitors. This mark or physical brand identified these individuals as outcasts in their society, to be avoided and devalued. Although the mark originally functioned to visually expose blemished individuals, the judgmental and moral nature of the sign has become more important than the mark itself. Indeed, development of the term stigma now applies to individuals whose stigma is visible and non-concealable – the “discredited” – to those who bear an attribute that is concealable – the “discreditable” (Goffman, 1963, p. 13).

Since Goffman’s (1963) classic piece, there has been a profusion of research on the origins, sources and consequences of stigma. Research has been productive, with increasingly sophisticated methodology leading to an elaboration of conceptual theories as well as repeated demonstration of the presence of stigma and its impact (Link & Phelan, 2001). These advancements have stemmed from research within physical health (de Boer,
Mula, & Sander, 2008; Rafferty, 2005) and mental health domains (Angermeyer & Matschinger, 1996; Corrigan & Penn, 1999).

1.5.1 Health-related stigma. As a result of its application to a range of conditions and due to the complexity of the phenomenon (Link & Phelan, 2001), there has been significant variability regarding the operational definition of stigma (Stafford & Scott, 1986). For the purpose of examining cancer-related stigma, the following definition of health-related stigma will be adopted in the current program of research:

Stigma is typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group. This judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted. In addition to its application to persons or a group, the discriminatory social judgment may also be applied to the disease or designated health problem itself with repercussions in social and health policy (Weiss, Ramakrishna, & Somma, 2006, p. 280)

1.5.2 Categorisation of stigma. Researchers have long sought to differentiate between stigmatising conditions by categorising stigma to facilitate research about the different antecedents and consequences. Goffman (1963) provided the first typology of stigma, differentiating between the discredited (i.e., an individual’s stigma is visible to others) and the discreditable (i.e., an individual’s stigma is concealed to others), within three main categories: (1) abominations of the body, or those with physical
defects; (2) *blemishes of individual character*, referring to individuals with character flaws or supposedly immoral behaviour or profession; and (3) *tribal identity* including those devalued by affiliations through lineage, such as race. Depending on the circumstance, individuals labelled with one of these stigmatising attributes can be either discredited or discreditable. For example, a cancer patient with chemotherapy induced alopecia, an effect of treatment prone to induce stigma, may choose to wear a wig to cover their hair loss (the discreditable), or not (the discredited).

Following Goffman’s (1963) categorisation, Jones, Farina, Hastorf, and French (1984) developed a classification system based on the contextual nature of stigma, and suggested six new dimensions of stigma: (1) *concealability*, the extent to which the stigma is visible to others; (2) *course*, the extent to which the stigma changes in saliency or disablement over time; (3) *disruptiveness*, the degree to which the stigma disrupts social interaction; (4) *aesthetic qualities*, the subjective degree of unattractiveness of the stigma; (5) *origin*, the degree to which the individual is perceived to be responsible for having the stigma; and (6) *peril*, the danger posed to the subject or other by the stigmatising attribute.

While cancer patients are at risk for being impacted by all types of stigmatising conditions, empirical evidence has identified that peril, abominations of the body, and blemishes of individual character are the attributes of a stigma central to the process of stigmatisation (Deaux, Reid, Mizrahi, & Ethier, 1995; Frable, 1993), for both the stigmatised and the stigmatiser (Dovidio, Major, & Crocker, 2000). For instance, peril may be associated with the status of cancer as a life-threatening illness.
Abominations of the body may relate to temporary physical changes, such as chemotherapy-induced alopecia, or permanent changes, such as changes to facial appearance from head and neck surgery. The dimension of blemishes of individual character may relate to the behaviour attributed to cancer onset, such as smoking cigarettes or alcohol consumption. Therefore, these categories can all be mapped to the cancer experience, in at least some cases, and therefore heighten the risk of stigma for this vulnerable group. These three stigmas can also exert a cumulative effect and may overlap and reinforce each other (Kurzban & Leary, 2001). For example, cancer patients may be doubly stigmatised as a result of being diagnosed with a life-threatening illness (peril) and if they have engaged in lifestyle behaviours that would have put them at risk for cancer onset (blemishes of individual character) (Lebel & Devins, 2008).

1.6 Theoretical Evidence for Stigmatising Attitudes

Overall the process of stigmatisation occurs when an individual possesses a ‘mark’ or attribute which is devalued. As Crocker and colleagues (1998) explain, “...stigmatised individuals possess (or are believed to possess) some attribute, or characteristic, that conveys a social identity that is devalued in a particular context” (p. 505). While stigma may be depend on context, it is a ubiquitous phenomenon which occurs in every society (Crocker et al., 1998; Dovidio et al., 2000). This suggests that stigmatisation has a functional value with the individual who stigmatises, and for the group for which he or she identifies (Jost & Banaji, 1994). Stigmatising may allow individuals to elevate their social identity and increase personal self-esteem (in-group enhancement and self-
enhancement), justify that they are worthy of their experience and the world is fair (self-justification and system-justification), and reinforce that their world-view is valid (anxiety-buffering) (Crocker et al., 1998). Theories that attempt to explain the functions of stigma for those who possess stigmatising attitudes, as well as for cancer patients themselves, are discussed below.

1.6.1 In-group enhancement and self-enhancement. Social Identity Theory (Tajfel, 1982; Tajfel & Turner, 1979, 1986) and Self-Categorisation Theory (Haslam, 1997) posit that individuals identify with social groups to establish a social identity. These groups, defined by a social or physical characteristic, differentiate a group of people based on factors such as race, age or occupation. This identity establishes group membership, and provides a source of an individual’s self-concept and self-esteem. As a result of these social identities, stigma develops due to the need to maintain or elevate the value of one’s social group, the in-group, relative to another individual’s social group, the out-group. Socio-functional models posit that stigma provides benefit to the stigmatiser as derogating another social group enables downward comparison processes. For example, degrading other’s social group, and favouring one’s own, may increase the social standing of one’s own group (Tajfel & Turner, 1979) and increase personal self-esteem (Wills, 1981).

For cancer patients, the experience of cancer has been found to lead to the integration of a new, sometimes permanent, social identity (Zebrack, 2000). This new identity may include being perceived as sick, or as being characterised as primarily a ‘cancer patient’, above and beyond other
identities or signifiers. This can contribute to reduced self-worth or perceived competence among individuals who strongly associate with being a ‘cancer patient’ (Fife, 1994).

1.6.2 Self-justification and system-justification. Guided by Social Dominance Theory (Sidanius & Pratto, 1993), one function of stigma is to legitimise inequality between groups in society. Thus, those who subscribe to a higher status group stigmatise those from a lower status group in order to justify their advantages. While this differentiation of status has been based on individual’s social, economic and political systems (Kurzban & Leary, 2001), it may also specifically relate to the basis of an individual’s illness versus wellness. Legitimising these systems validates the sense of privilege felt by those from a higher status group (Major, 1994) and prevents inter-group conflict (Sidanius & Pratto, 1993). From this perspective, the maintenance of group inequality results in discrimination, which is perceived to be justified.

To maintain the status quo, this paradigm must be widely accepted by members of society. The functioning of society and the misfortune of others seems to fit with self-apparent realities. For example, the association between intelligence, hard work, and success is a legitimising myth, which subsequently attributes those affected by poverty to the individual’s wrongdoing or fault. Consistent with this, belief in a just world (Lerner & Miller, 1978) is a legitimising myth which posits that people “get what they deserve and deserve what they get” (p. 1030). In accordance with these system justification theories is the propensity to hold an individual responsible for his or her condition or experience (Crandall, 1994). As this
theoretical framework relates to cancer, empirical research has found that lung cancer is stigmatised as it perceived to be self-inflicted (Chapple, Ziebland, & McPherson, 2004); whereas breast and prostate cancer patients do not report the same degree stigmatisation due to perceived external causes linked to cancer onset (Else-Quest et al., 2009; LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008).

1.6.3 Anxiety-buffering. Terror Management Theory suggests that stigma may occur as a result of possessing a worldview and meaning system which buffers against existential anxiety (Greenberg, Pyszczynski, & Solomon, 1986; Solomon, Greenberg, & Pyszczynski, 1991a, 1991b). Unique to humans, Terror Management Theory occurs as a result of being cognitively aware that death can occur prematurely which creates overwhelming anxiety. The term ‘death anxiety’ has been used to describe the persistent fear individuals experience in regard to their death or their own process of dying. However, research assessing Terror Management Theory and cancer is in its infancy and the findings are inconsistent. For instance, one study found that participants’ level of reported death anxiety was correlated with negative attitudes towards cancer (Berrenberg, 1991); however, Mosher and Danoff-Burg (2007) found that death anxiety was not found to be directly correlated with either behavioural (i.e., social distance) or negative emotional responses of participants to cancer patients.

As a result of death anxiety, individuals establish a cultural worldview that things happen for a reason in an uncertain and unpredictable world. Stigma occurs as individuals will reject and avoid others who are different as they deviate from, and have the ability to, disrupt this
perspective; they "threaten our confidence in the absolute validity of our own worldviews" (Solomon et al., 1991b, p. 125). Therefore, stigmatisation may occur among individuals with a life-threatening illness, such as cancer, as a "cancer patient may make us starkly and disagreeably aware that a similar fate can befall us" (Jones et al., 1984, p. 66). Furthermore, the visible signs of dealing with cancer, both the non-permanent treatment effects and permanent surgical changes, may reinforce such stigma, as "abominations of the body" (Goffman, 1963) can remind others of this possibility of tragedy, pain and death (Jones et al., 1984). In this way, healthy individuals can be primed to make negative value judgments about those who are ill or physically disabled (Kurzban & Leary, 2001).

1.7 Effects of stigma

Stigma has a significant impact on both the affected individual, and those who do not share the particular attribute, or the non-stigmatised. The bearer of a stigmatising attribute becomes labelled an outcast, or outsider, and becomes the target of disproval, embarrassment, shame and discrimination (Smart & Wegner, 2000). As a result, interactions between the stigmatised and the stigmatiser may be difficult and awkward (Hebl, Tickle, & Heatherton, 2000). Specifically, the non-stigmatized may experience feelings of anxiety, discomfort, fear, and aversion to stigmatized individuals (Dovidio et al., 2000). This may prompt non-stigmatized individuals to avoid interacting with the stigmatized to prevent experiencing adverse emotional states.

Social withdrawal may also be prompted by the stigmatized. For instance, if cancer patients perceive that their identities have been
stigmatised, they may experience discomfort and a desire to withdraw from social interaction (Fife, 1994). Through either mechanism, individuals who have a stigmatising attribute are at risk of becoming socially isolated, which can in turn lead to psychopathology including increased distress, anxiety and depression (Cordella & Poiani, 2014). Shame and stigma may impact on accessing appropriate professional support, given these factors were found to be significant barriers to attending support groups (Devitt et al., 2010).

1.8 Lazarus and Folkman’s transactional model of stress and coping

It is evident that stigma can result in discrimination and devaluation and can have deleterious impacts on individuals affected, including threatening their social identity (Fife, 1994). Indeed, stigma has been deemed a salient and powerful stressor (Crocker et al., 1998; Major & O'Brien, 2005). Lazarus and Folkman’s (1984) transactional model of stress and coping can provide a useful framework to understand the impact of a cancer diagnosis and stigma on cancer patients. The model is transactional in that it describes stress and coping in relation to the interaction between the individual and his/her environment.

1.8.1 Stress appraisal Environmental stressors (such as a cancer diagnosis, or dealing with the effects of stigma) can strain an individual’s body and/or mind, which subsequently can change their physical and/or emotional state (Lazarus & Folkman, 1984). Initially when a stressor is identified, a primary appraisal occurs whereby the individual assesses the stressor and determines whether it is a harm/loss, threat or challenge (Figure 1.3). In relation to cancer, harm may relate to pain experienced by an individual following cancer treatment, while threat may relate to the
perception that cancer is a threat to their life. Belief that the stressor is challenge may relate to a cancer patient changing his/her lifestyle behaviour (e.g., quitting smoking) to prevent disease progression or recurrence. In relation to stigma, those affected may perceive that their identity is being devalued and negatively evaluated (harm/threat); or that the impact of stigma is a challenge enhance and improve aspects of their identity (Berjot & Gillet, 2011).
Figure 1.3 Theoretical model of the stress and coping process, original by Lazarus and Folkman (1984)
When an event is deemed stressful, secondary appraisal subsequently occurs whereby individuals assess their personal, social and cultural resources to cope with the stressor. In their model Lazarus and Folkman (1984) also identified that characteristics of the individual, and of the situation, are important antecedents that will directly impact on how individuals appraise and cope with the situation. For example, personal characteristics such as hope, optimism, and self-efficacy, and situational factors such as social resources, and additional life-stressors (e.g., marriage breakdown), may explain why some people appraise and cope differently with cancer. In relation to stigma, personal factors including aspects of self (personality, intelligence, physical appearance etc.) and hypervigilance to rejection; situational factors including social support; in addition to characteristics of stigma, relating to visibility and controllability, may contribute to the different appraisals and coping responses among individuals who are stigmatised (Berjot & Gillet, 2011).

**1.8.2 Coping.** According to Folkman and Lazarus (1991), individuals engage in two forms of coping to deal with their stressor. Problem-focused coping is likely to occur if the stressor is perceived to be able to change, while emotion-focused coping is used when it is perceived to be unchangeable. As cancer is a life-threatening illness, individuals coping with cancer are likely to rely more heavily on emotion-focused strategies by managing the distress, rather than problem-focused strategies by trying to change the situation (Stanton et al., 2000). Individuals faced with stigmatisation are likely to engage in both emotion-focused and problem-
focused strategy aimed at managing their social and personal identities (Berjot & Gillet, 2011).

1.8.3 Event and emotional outcomes. The final stage to the transactional stress coping model includes the consequent emotional response to the event, which is based on its outcome. If individuals are able to find a resolution to their distress the coping process ends with positive emotion. However, if there is no resolution or unfavourable resolution, such as dealing with a chronic illness or the ongoing fear of recurrence among cancer patients, the individual will experience continued distress. This ongoing distress has the ability to subsequently impact on the individual’s future appraisal and coping. In relation to stigma, the emotional component to the transactional stress coping model has not yet been established, as stigma is a complex phenomenon (Berjot & Gillet, 2011), and in relation to cancer, it is not well understood (Lebel & Devins, 2008).

After the development of Lauzarus and Folkman’s (1984) original model of stress and coping, Folkman (1997) noted that positive emotions occur even in the aftermath of unchanging stressful life experiences, including following cancer diagnosis (Sears, Stanton, & Danoff-Burg, 2003). Subsequently, a new model of stress and coping was developed to account for the processes by which unfavourable, or no resolution outcomes, can lead to positive emotional states (Figure 1.4). Consequently, a pathway to meaning based coping was included in the model, which describes how some individuals cope by activating beliefs, values or goals that facilitate finding positive meaning from their experience. Meaning making as a form of coping with cancer has been reported in the literature
(Lee, Robin Cohen, Edgar, Laizner, & Gagnon, 2006). Being able to find meaning from the event can lead to positive emotion (Moskowitz, Folkman, Collette, & Vittinghoff, 1996), sustaining renewed energy to cope with the stressor.

1.8.4 Summary of Folkman’s model of transactional stress and its relationship to cancer diagnosis and stigma. In summary, Folkman’s (1997) revised version of the transactional stress and coping model provides a framework to understand how factors associated with cancer diagnosis and treatment can lead to on-going distress, but also positive emotion. However, while the model accounts for stigma-related threat appraisal, coping strategies and outcomes, there is a paucity of research to understand an individual’s emotional outcomes for dealing with stigma and a devalued identity. Furthermore, it is unclear how the combination of dealing with the distress associated with cancer itself in addition to stigma, may affect an individual’s emotional coping. Situational factors associated with stigma, including strained relationships (Peters-Golden, 1982), and personal factors such as reduced self-esteem (Fife & Wright, 2000), may significantly impact on individuals’ appraisal and coping with stressful cancer experiences. Therefore, research examining the range of coping responses to cancer-stigma, including both negative and positive outcomes, is an important area of investigation.
Figure 1.4 Revised theoretical model of the stress and coping process, by Folkman (1997), including positive states of coping.
1.9. Posttraumatic Growth

Until recently research into post-trauma changes focused solely on negative emotional reactions. Depression, distress and PTSD, have mainly dominated the trauma research in psychology. It has now been recognised that positive changes and functional adaptation can be included in the range of experiences and reactions following a distressing event, such as cancer (Manne et al., 2004; Sears et al., 2003). Some clinicians and researchers have argued that focusing solely on the negative psychosocial reactions may not provide an complete representation of the full range of post-trauma experiences (Tedeschi & Calhoun, 1995).

A major shift in the literature began after Tedeschi and Calhoun (1995) coined the term “posttraumatic growth” to define positive psychological change experienced as a result of the struggle with highly challenging and stressful life circumstances. Positive changes following adversity have been long recognised in religion, philosophy and literature. Indeed, psychological growth following suffering has been found in early religious writings of Christianity, Hinduism, and Buddhism (Tedeschi & Calhoun, 1995).

For the past two decades, research has been growing in the area of posttraumatic growth. Empirical research has documented positive changes following many trauma-related events including bereavement (e.g. Calhoun & Tedeschi, 1989), myocardial infarction (e.g. Affleck, Tennen, Croog, & Levine, 1987), severely disabling accidents (e.g. Brickman, Abbey, & Halman, 1987), shipping disasters (Joseph, Williams, & Yule, 1993);
primary and vicarious war-related trauma (McCormack, Hagger, & Joseph, 2011) and after cancer diagnosis and treatment (Manne et al., 2004; Sears et al., 2003).

1.9.1 Posttraumatic growth related constructs and definition. In addition to the term posttraumatic growth, positive change in the aftermath of a traumatic event has been also referred to as stress-related growth (Park, Cohen, & Murch, 1996), positive illusions (Taylor & Brown, 1988), flourishing (Ryff & Singer, 1998), and thriving (O'Leary & Ickovics, 1994). However, posttraumatic growth is favoured over other terms as it captures important aspects of the phenomenon in many ways. Posttraumatic growth refers to a significant life crisis, such as a cancer diagnosis, rather than outcomes from lower level stress events; it proposes that the significant life event causes a shattering of core life assumptions which terms such as flourishing and thriving do not imply; and it relates to observable life changes, rather than “illusions” (Tedeschi & Calhoun, 2004).

Posttraumatic growth occurs in the process of struggling through adversity, which creates changes enabling the individual to attain a higher level of functioning than that which existed prior to the event (Calhoun & Tedeschi, 1998; Calhoun & Tedeschi, 2001). In the experience of cancer, being confronted with one’s own mortality may be so distressing that it causes individuals to question their core beliefs about themselves and the world. This re-examination can lead to positive psychological change in personal, relational and philosophical domains (Joseph, 2011): for instance, personal growth may relate to finding new inner strength; relationship growth can be associated with an increased appreciation of close friends.
and/or family; while philosophical growth has been described as a new sense of what is important in life. In this way, posttraumatic growth is one potentially positive aspect to the cancer experience that should not be overlooked.

**1.9.2 Posttraumatic growth and cancer.** The prevalence of posttraumatic growth among cancer survivors has been reported in the range of 60 – 90% (Collins, Taylor, & Skokan, 1990; Fromm, Andrykowski, & Hunt, 1996; Petrie, Buick, Weinman, & Booth, 1999). A longitudinal study among early stage breast cancer patients has found 83% of the women in the study reported at least one benefit from their experience with cancer, with relating to others being the most common perceived benefit (Sears et al., 2003). Reports of posttraumatic growth and psychosocial functioning have been found to be higher among cancer patients than among similar healthy age-matched controls (Andrykowski et al., 1996; Cordova et al., 2001).

With the exception of perceived impact of cancer (i.e., high threat), other personal, social, disease and medical variables have not consistently been found to predict posttraumatic growth among cancer patients (Stanton, Bower, & Low, 2006). It has been argued that contextual factors deserve greater attention, such as aspects of social environments, including the quality of interpersonal relationships (Armeli, Gunthert, & Cohen, 2001; McMillen, 2004; Wortman, 2004). Investigations into the predictors of posttraumatic growth, in addition to the emotional, cognitive and motivational processes in growth, using both qualitative and quantitative methodology, is recommended for future research (Cordova, 2008; Stanton et al., 2006).
1.10 Posttraumatic Growth Framework

In their definition of posttraumatic growth, Tedeschi and Calhoun (2004) posit that it is the very nature of the struggle with a highly distressing event that is necessary for this growth to occur. Posttraumatic growth has been considered an “existential wake-up call” (Joseph, 2011, p. 7) as individuals become confronted with the uncertainty and fragility of life. This awakening can result in a psychological transformation which can buffer the distressing impacts of trauma and improve psychological well-being. The theoretical explanations for the development of posttraumatic growth, and how this process may relate to the cancer experience, are discussed below.

1.10.1 Shattered assumptive world. According to Parkes (1971), the assumptive world is defined by “everything we know or think we know” (p. 103) about ourselves and the world. Developed in childhood, the assumptive world encompasses our beliefs and schemas, and provides a framework under which we operate. Being diagnosed with a life-threatening condition, such as cancer, clashes with fundamental beliefs that “the world is benevolent”, “the world is meaningful”, and “the self is worthy” (Janoff-Bulman, 1992, p. 6). The event must be so psychologically distressing that it “severely shakes, threaten or reduces to rubble” (Tedeschi & Calhoun, 2004, p. 5) these ingrained and long-held beliefs. An individual’s ability to cognitively work through this uncertainty and chaos is what determines whether psychological growth develops.

1.10.2 Cognitive processing. According to Horowitz (1976), individuals typically move through stages of cognitive processing in the
aftermath of a traumatic event. Initially, there is often a period of *outrage and confusion* when individuals realise that the stressor has occurred. Central to symptoms associated with PTSD, individuals then commonly experience cognitive avoidance and intrusions as they try to integrate trauma-related material. This is described as the *working through* phase where individuals attempt to process their distress. With the progression of this phase, the intensity of intrusions tends to reduce. At the end of this processing, troubling memories that were stored in active memory become transferred to long-term memory, and individuals achieve a state of *completion* (Horowitz, 1976). Following a highly distressing event, most individuals are able to move through these cognitive stages; however some may get caught and are unable to fully process their experience. Becoming stuck in one of these stages can inhibit growth when rumination remains intrusive, negative and ongoing (Calhoun, Cann, Tedeschi, & McMillan, 2000). Specifically, when integration does not occur, and the oscillation of intrusive thoughts and avoidance becomes chronic, significant distress and PTSD may ensue (Horowitz, 1986).

The type of cognitive processing following a traumatic event has also been shown to influence whether posttraumatic growth occurs. For instance, ruminative brooding is a maladaptive thinking pattern characterised by passive and judgemental thinking about one's emotion and situation. Reflective pondering, on the other hand, refers to purposefully turning inward to engage in helpful problem solving and emotion-focused coping (Treynor, Gonzalez, & Nolen-Hoeksema, 2003). By engaging in reflective pondering, individuals seek to reach a state of completion and posttraumatic growth by searching for meaning, reframing and establishing
a new narrative for their life (Gangstad, Norman, & Barton, 2009; Stockton, Hunt, & Joseph, 2011; Taku, Calhoun, Cann, & Tedeschi, 2008). Indeed, among cancer patients, reflection about perceived benefits about their experience has been associated with posttraumatic growth (Morris & Shakespeare-Finch, 2011).

Through these cognitive processes, individuals will either assimilate trauma-related material by attempting to integrate the information into their long-held assumptions, or accommodate by changing previous assumptions to fit with the new information. Resolving the discord between pre-trauma core beliefs and trauma-related information can be a long and difficult process. It often consists of a struggle between protecting developed and familiar worldviews and open-mindedness to new life experiences. Research has shown the more successful method to be accommodating and learning from the new information; after this, posttraumatic growth can develop (Joseph, 2011). In order to develop posttraumatic growth, therefore individuals must find meaning from their traumatic event. Individuals who try to assimilate trauma related material have been found to be more fragile and defensive (Joseph, 2011).

1.10.3 Meaning-making of experience. Deriving meaning from a traumatic event leads to a new sense of purpose and redefined goals, which is essential to psychological well-being (Ryan & Deci, 2000; Ryff, 1989). However, the diagnosis and treatment of cancer brings about difficult existential questions which are often complex to understand and process, and are commonly unrecognized and untreated (Holland, 2000). Without the ability to narrate and make sense of their experience, individuals in the
aftermath of any traumatic event are at risk for traumatic memories to be involuntarily triggered, causing physiological arousal and fragmented flashbacks (Brewin, Dalgleish, & Joseph, 1996). Through meaning-making, individuals are able to reconcile their shattered assumptive world (Janoff-Bulman, 1989) by rebuilding their meaning systems. In the aftermath of a cancer diagnosis, those who are able to transform their global worldview have shown improved psychological adjustment (Tomich & Helgeson, 2002), namely in the improvement of self-efficacy (Taylor, 1983), self-esteem (Carpenter, Brockopp, & Andrykowski, 1999) and optimism (Thompson & Pitts, 1994).

1.10.4 Social support. In addition to the cognitive elements, a positive support environment has been found to facilitate posttraumatic growth. It has been widely accepted that when an individual becomes ill, support systems promote helpful coping and recovery (Suls, 1982). Indeed, theorists have suggested that psychological growth is dependent on social support (Joseph & Linley, 2005; Ryff, 1989; Tedeschi & Calhoun, 1995). Relatedly, the Social-Cognitive Processing Model (Lepore, 2001) posits that having a supportive and positive social environment allows enables cancer patients to cognitively and emotionally process their experiences. Strong social support enables cancer patients to talk about their experience and may validate thoughts and feelings which affirm to the cancer patient that they are cared for (Silver & Wortman, 1980), especially as it provides them with space to express their emotions and cope with their problems. In addition, talking with supportive others may promote the development of novel, positive perspectives (Clark, 1993) and can help cancer patients find meaning from their experience (Helgeson & Cohen, 1996). By engaging in
discussion about their cancer diagnosis, the individual must confront their illness and its meaning, in place of maladaptive behaviours such as avoiding or fearing discourse.

Although theoretical models of posttraumatic growth have identified social support to be a critical factor for growth (Joseph & Linley, 2005; Tedeschi & Calhoun, 1995), empirical evidence for its role in predicting positive change among cancer patients is inconsistent (Schulz & Mohamed, 2004; Weiss, 2004; Widows et al., 2000). While Schulz and Mohamed (2004) found social support predicted psychological growth at 12 months following surgical intervention, other empirical findings have failed to find a significant relationship (Weiss, 2004; Widows et al., 2000). However, methodology between studies varies; for instance, schedule of data collection. While Schulz and Mohamed (2004) examined social support one month after surgery, Widows et al.'s study (2000) participants were at least six months post-discharge and attending follow up session, and Weiss (2004) studied women who were disease-free after being diagnosed 1 to 1.5 years earlier. Therefore, the need for social support during different stages may vary, with greater relevance earlier in the cancer journey.

1.11 Benefits of Posttraumatic Growth

Developing posttraumatic growth following a distressing event has been found to lead to a better quality of life (Joseph, 2011; Lelorain, Bonnauad-Antignac, & Florin, 2010). While posttraumatic stress has been consistently found to reduce quality of life, self-reported posttraumatic growth among early stage breast cancer patients significantly attenuated this relationship (Morrill et al., 2008). Another study of cancer patients found
that following surgical treatment, those with self-reported posttraumatic growth reported significantly greater quality of life and lower levels of worry and depression at the one-year follow-up, even after controlling for outcome variables pre-surgery. Among individuals exposed to a variety of traumas, such as individuals who have experienced sexual assault, been exposed to tornadoes or survived a plane crash, compared to distressed individuals, posttraumatic growth was consistently related to lower mental health issues and reduced prevalence of depression and suicidality (Helgeson, Reynolds, & Tomich, 2006).

The benefits of posttraumatic growth have been well documented in relation to mental-health, as it promotes psychological well-being. Also known as eudemonic well-being, psychological well-being refers happiness that develops when individuals are engaged in living a meaningful life (Ryan & Deci, 2000). This form of well-being has been found to be associated with better mental health outcomes in the long-run (Wood & Joseph, 2010). It also improves positivity and helps people grow in areas relating to increased kindness, social intelligence, creativity, gratitude, hope and zest for life (Peterson, Park, Pole, D'Andrea, & Seligman, 2008).

1.12 Summary: Cancer Stigma and Posttraumatic Growth

The preceding literature review has documented the deleterious effects of stigma, and the beneficial impact of posttraumatic growth. Each of these constructs may relate to an individual’s cancer experience. For instance, research has demonstrated that stigma related to cancer can have a negative effect on the quality of interpersonal relationships which, in turn, leaves patients without the validation and support they need (Dakof &
Taylor, 1990; Peters-Golden, 1982). While all cancers pose a risk for stigmatisation as it is a life-threatening illness, some cancers may confer greater disadvantage as they are prone to additional devaluing attributes. For instance head and neck cancer patients may experience increased stigmatising reactions from others due to facial changes following surgery, and because this form of cancer is associated with alcohol consumption and smoking (Castellsagué et al., 2004); however research examining stigma among head and neck cancer patients remains limited. Most of the cancer-related stigma research has focused on the experience of lung cancer patients who experience stigmatising experiences as a result of lung cancer being perceived to be a primarily self-induced disease (Chapple, Ziebland, & McPherson, 2004). The detrimental impact of stigma on lung cancer patients is notable as it has been found to increase distress, reduce quality of life and lead to a reluctance to seek treatment (Cataldo et al., 2012; Else-Quest et al., 2009; Raleigh, 2010). Given these findings, future research would benefit from assessing the impact of various stigmatising conditions that affect cancer patients, and which cancers are prone to high levels of stigma.

The impact of stigma, such as causing strained relationships and avoidance from others, may have a deleterious effect on developing posttraumatic growth, given social support has been theorised to be a critical component in its development. While speaking with others can help facilitate cognitive processing, cancer patients at risk of increased stigmatisation may have an issue confiding in friends or family. If a cancer patient’s support network responds negatively to them with criticism, withdrawal, avoidance or conflict, it can hinder cognitive and emotional
processing (Lepore, Silver, Wortman, & Wayment, 1996), which in turn will in turn reduce the likelihood of developing posttraumatic growth. The area of posttraumatic growth, however, is in its infancy and there may be aspects of positive change that are not captured in growth measures, but which are experienced among cancer patients who experience high stigmatisation.

1.13 Current Program of Research

As a result of an increase in cancer prevalence and reduced mortality rates, there are now more individuals diagnosed with cancer than ever before. Understanding the psychological impact of diagnosis, treatment and survivorship is critical. In addition to the well-documented impact of cancer-related depression and anxiety, stigma resulting from an individual’s cancer experience may also be contributing to their distress. However, research into the specific causes of cancer-related stigma, and which cancers are most stigmatised is limited. As stigma is a ubiquitous phenomenon, the need to understand these factors from both a non-stigmatised and stigmatised viewpoint is evident. Finally, as the benefits of posttraumatic growth have been documented, an understanding of the specific factors which promote or reduce positive change is required. The first two studies in the present program of research assess cancer-related stigma from a community perspective. The final two studies explore the impact of stigma on posttraumatic growth among cancer patients. A brief outline of the research questions and contribution of each research study contained in this program of research is outlined below.
1.13.1 Study 1. The first study, entitled “The Impact of Blameworthy Attributions, Physical Disfigurement, and Poor Prognosis on Cancer-related Stigma” was designed to assess the impact of several stigmatising conditions that relate to cancer. Specifically, it targeted stigmatising conditions that have been deemed most critical to the experience of stigmatisation: (1) blemishes of individual character, (2) abominations of the body and (3) peril. Using a community sample, the study assessed cognitive and affective reactions to vignettes. The study sought to identify which stigmatising factors result in the most negative reactions from a community perspective. Study 1 was submitted to the Journal of Psychosocial Oncology on May 25th 2014.

1.13.2 Study 2. The rationale for Study 2 was based on the findings from Study 1 that blemishes of individual character resulted in the greatest stigmatisation. Entitled “A Test of Attribution Theory in Understanding Stigma in Cancers Perceived to be Blameworthy Versus Non-Blameworthy”, Study 2 used attribution theory to assess stigma among eight common cancers. This study was designed to address which types of cancer experience the greatest negative reactions by examining cognitive, affective and behavioural responses of community members. Study 2 was submitted to The Journal of Psychosocial Oncology on August 6th 2014.

1.13.3 Study 3. The third study is entitled “The impact of stigma, social support and core belief examination on psychological well-being among cancer patients”. It explores the potential pathways to psychological well-being by examining the impact of social support and stigma on positive
and negative changes, respectively, among cancer patients. Study 3 was submitted to Psycho-Oncology on August 26th 2014.

1.13.4 Study 4. The rationale for Study 4 was determined by Study 3’s findings that core belief examination was a protective factor against negatives change following diagnosis. Entitled "Cancer related trauma, stigma and growth: The ‘lived’ experience of head and neck cancer”, it uses interpretative phenomenological analysis to explore the positive and negative changes following surgery for head and neck cancer, and how participants found meaning from their experience. Study 4 was published in the European Journal of Cancer Care on April 21\textsuperscript{st} 2015.
References


Posttraumatic stress disorder after treatment for breast cancer: 
Prevalence of diagnosis and use of the PTSD Checklist—Civilian 
Version (PCL—C) as a screening instrument. *Journal of Consulting 
and Clinical Psychology, 66*, 586-590. doi: 10.1037/0022-
006X.66.3.586

Andrykowski, M. A., Curran, S. L., Studts, J. L., Cunningham, L., 
Psychosocial adjustment and quality of life in women with breast 
cancer and benign breast problems: A controlled comparison. 
*Journal of Clinical Epidemiology, 49*, 827-834. doi: 10.1016/0895-
4356(96)00028-5

experience with mental illness on the attitude towards individuals 
suffering from mental disorders. *Social Psychiatry and Psychiatric 
Epidemiology, 31*, 321-326. doi: 10.1007/BF00783420

Archer, J., Hutchison, I., & Korszun, A. (2008). Mood and malignancy: 
Head and neck cancer and depression. *Journal of Oral Pathology & 
Medicine, 37*, 255-270. doi: 10.1111/j.1600-0714.2008.00635.x

coping, and post-event outcomes: The dimensionality and 
ancecidents of stress-related growth. *Journal of Social and Clinical 

Results 2011-2012*. Canberra, ACT: Commonwealth of Australia.

Australian Bureau of Statistics. (2012b). *Causes of Death in Australia, 
2010*. Canberra, ACT: Commonwealth of Australia.

CAN 62. Canberra: AIHW.


tobacco-related cancer mortality in Central Europe. *International

theory of posttraumatic stress disorder. *Psychological Review, 103*,


Browman, G. P., Wong, G., Hodson, I., Sathy, J., Russell, R., McAlpine,
efficacy of radiation therapy in head and neck cancer. *New England
Journal of Medicine, 328*, 159-163. doi: 10.1056/NEJM199301213280302

Bui, Q.-U. T., Ostir, G. V., Kuo, Y.-F., Freeman, J., & Goodwin, J. S.
(2005). Relationship of depression to patient satisfaction: Findings
from the barriers to breast cancer study. *Breast Cancer Research and

doi: 10.1002/pon.1022

predict traumatic stress symptoms among partners of
metastatic/recurrent breast cancer patients. *Psycho-Oncology, 14*,
492-502. doi: 10.1002/pon.865

correlational test of the relationship between posttraumatic growth,


European Journal of Oncology Nursing, 16, 264-269. doi: 10.1016/j.ejon.2011.06.008


and neck cancer. *Journal of the National Cancer Institute, 88*, 542-549. doi: 10.1093/jnci/88.8.542


and neoplastic growth. *Endocrine Reviews, 21*, 215-244. doi: 10.1210/er.21.3.215


type, gender, and age. *Journal of Affective Disorders, 141*, 343-351. doi: 10.1016/j.jad.2012.03.025q


Marks, R. (1999). Two decades of the public health approach to skin cancer control in Australia: Why, how and where are we now? *Australasian


Page intentionally left blank
Chapter 2: Foreword

One of the primary directions of the present research program is to understand factors which underline cancer-related stigma. Chapter 2 and Chapter 3 assess stigmatising responses among community members to hypothetical cancer patients, and general perceptions of certain types of cancers. The initial experimental investigation manipulates three stigmatising attributes that may impact on cancer patients, and which are known factors central to the stigmatising experience for both the stigmatiser and the stigmatised: blemishes of individual character, abominations of the body, and peril. Study 1 examines stigma in the form of cognitive and affective responses to vignettes that documented a hypothetical target with head and neck cancer, with varying levels of these factors.

Results demonstrated that blameworthy attributions, or with blemishes of individual character, evoked stigmatizing reactions including increased fear, anger, and social distancing; and reduced pity and willingness to prioritise to health care for the target. There was partial evidence for the role of facial changes following cancer treatment, or abominations of the body, as this was associated with negative responses. However, poor prognosis, or peril, did not elicit stigmatisation. The findings of Study 1 highlight that, from a community perspective, individuals who are perceived to have caused their cancer may be at an increased risk for negative reactions from others. The results also support the role for stigma associated with ‘blaming the victim’ for understanding the basis of cancer-related stigma.
Declaration

Title

The Impact of Blameworthy Attributions, Physical Disfigurement, and Poor Prognosis on Cancer-related Stigma

Authorship

Jennifer Threader, Professor Don Byrne and Dr Elizabeth Rieger

Publication Outlet

The Journal of Psychosocial Oncology

Current Status

Manuscript was submitted on May 25th 2014.

Candidate Contribution

The Candidate proposed the research question, which was refined with feedback from Professor Byrne and Dr Rieger. The study vignettes were developed by the Candidate and were modified with assistance from Dr Rieger. The study measures that were included to assess cognitive and affective stigmatizing responses, were chosen by the Candidate and were reviewed and approved by co-authors. The Candidate recruited study participants, conducted the statistical analyses, and developed the initial manuscript. Professor Byrne and Dr Rieger provided input on successive drafts of the manuscript.
Co-Author Signatures:

Professor Don Byrne

Dr Elizabeth Rieger
Article title:
The Impact of Blameworthy Attributions, Physical Disfigurement, and Poor Prognosis on Cancer-related Stigma

Authors:
Jennifer Threader, Professor Donald Byrne, and Dr Elizabeth Rieger
Research School of Psychology, Australian National University

Running title:
An investigation of cancer stigma

Address for correspondence:
Jennifer Threader, Research School of Psychology,
Australian National University, Canberra, ACT 0200, Australia
Telephone: (02) 6125 4582, Fax: (02) 6125 0499
E-mail: jennifer.threader@anu.edu.au

Conflict of interest statement:
Jennifer Threader, Donald Byrne and Elizabeth Rieger declare no potential conflict of interest.
Abstract

Stigma can be among the challenges associated with the cancer experience but the factors underlying cancer stigma are not thoroughly understood. The present experimental study investigated three potential causes of cancer stigma – blameworthy attributions, facial changes stemming from surgery, and poor prognosis. Three hundred and seventy-three community members were randomly assigned to read vignettes about a hypothetical oral cancer patient. The vignettes variously provided blameworthy or non-blameworthy attributions for the target’s cancer; the presence or not of facial changes; and a good versus a poor prognosis. The results indicated consistent support for the role of blameworthy attributions in eliciting stigmatizing responses; some support for the role of physical changes associated with cancer treatment, and minimal support for the role of poor prognosis. The strong evidence for blameworthy attributions in triggering stigma indicates that individuals with cancers linked to behavioral etiologies may be at risk for increased stigma and discrimination.

Keywords: cancer stigma, Attribution Theory, facial disfigurement, Terror Management Theory, oral cancer.
Introduction

Those who undergo cancer treatment can face a range of impairments in both physical and psychosocial functioning (Stein, Syrjala, & Andrykowski, 2008). These difficulties can be related to being diagnosed with a potentially life-threatening illness, as well as the negative consequences associated with treatment. The experience of cancer and its treatment may lead to a reduced quality of life, including negative impacts on mental health and emotional distress (Weisman, 1976). Furthermore, the known behavioral risk factors linked with some specific cancers may induce feelings of blame among those affected, leading to social isolation (Chapple, Ziebland, & McPherson, 2004) and delayed symptom reporting (Tod, Craven, & Allmark, 2008).

Cancer and its treatment have been associated with stigma (Stahly, 1988). Stigma refers to an attribute or ‘mark’ that identifies an individual as being different and is associated with negative evaluations and stereotypes (Jones, Farina, Hastorf, & French, 1984); it leads bearers to become set-apart, avoided, and discredited (Goffman, 1963). While stigma is a ubiquitous phenomenon, it is dependent on the social context (Jones et al., 1984); that is, what is stigmatizing in one social group, may not be stigmatizing in another. The stigma ‘mark’ has been associated with a range of characteristics, physical or symbolic, and calls into question the individual’s full humanity; it reduces the stigmatized “in our minds from a whole and usual person to a tainted and discounted one” (Goffman, 1963, p. 3).

Stigma associated with a health-related condition, such as cancer, has been associated with physical, social, and psychological morbidity. From a psychological perspective, stigma is associated with reduced self-esteem
(Fife & Wright, 2000), distress (Mak et al., 2007), increased isolation, and strained social relationships (Peters-Golden, 1982). While stigma research in other health areas is well established, there is currently a dearth of research surrounding the investigation of cancer-related stigma. Hence, understanding the mechanisms underlying stigma in the context of cancer warrants further investigation.

Several factors are worthy of investigation as potential causes of cancer stigma. One such factor relates to the degree to which the individual is perceived to be responsible for his/her condition. Although cancerous tumor development has been related to many different biological and environmental causes, stigma theory suggests that some cancers may be more likely to evoke stigmatizing responses from others due to their association with behavioral risk factors. Attribution Theory (Weiner, 1986, 1995; Weiner, Perry, & Magnusson, 1988) asserts that conditions that are perceived to be onset controllable, and subsequently associated with perceived responsibility, are stigmatized; individuals with these conditions are subject to more anger and rejection, less altruistic action, and are more harshly treated, when compared to conditions which are perceived as being unavoidable (Dooley, 1995; Reisenzein, 1986; Rush, 1998; Schmidt & Weiner, 1988; Weiner, Graham, & Chandler, 1982; Weiner et al., 1988). Attribution Theory has been assessed in several different areas, including within mental and physical health domains to assess stigmatizing attitudes. Results from these findings have indicated that perceptions associated with onset-controllable attributions shape reactions in important ways, including cognitive (e.g., the amount of blame ascribed) (Weiner, 1993), emotional (e.g., responding with less pity) (Menec & Perry, 1998), and behavioral
(e.g., choosing not to help) (Peters, Den Boer, Kok, & Schaalma, 1994) responses. Offering preliminary support for the role of blameworthy attributions for cancer stigma, research has demonstrated that a link between smoking and lung cancer, and the human papillomavirus and cervical cancer, leads to increased stigma within these groups (Chambers, et al., 2012; Chapple, Ziebland, & McPherson, 2004; Chapple, Ziebland, McPherson, & Summerton, 2004; Conlon, Gilbert, Jones, & Aldredge, 2010; Else-Quest, LoConte, Schiller, & Hyde, 2009; Kahn et al., 2007; Tod et al., 2008; Waller, Marlow, & Wardle, 2007; Wassenaar et al., 2007). As stigma occurs in a social context, the increase in public health campaigns to reduce engagement in health-risk behavior (Marlow, Waller & Wardle, 2007) may strengthen the relationship between cancer stigma and blameworthy attributions for certain cancer groups.

In addition to blame-based attributions, stigmatizing responses towards individuals with cancer may stem from any physical changes that are a result of cancer or its treatment. Cancer treatment can cause temporary and permanent changes to an individual’s appearance. For example, despite advances in prosthetics and plastic surgery, permanent changes to facial appearance are a common side effect of treatment for oral cancer (American Cancer Society, 2014).

Stigma theory categorizes facial changes as “abominations of the body” (Goffman, 1963), or concealment stigmas (Jones et al., 1984), which are physical characteristics that visibly differentiate and devalue an individual. Facial changes can be particularly distressing because the face is a highly visible area of the body and difficult to conceal; it “can provide the primary
schema through which everything about them is understood" (Crocker, Major, & Steele, 1998, p. 507). Research has found that facial changes can have a detrimental effect on social interactions as the facial region plays an important role in communication (Koster & Bergsma, 1990), and that physical changes stemming from cancers of the oral cavity can result in strained relationships and feelings of isolation for cancer patients (Gamba et al., 1992; Pruyn et al., 1986). A growing body of literature has suggested that individuals with “facial disfigurement” engender stigmatizing responses from others in society (Bonanno & Choi, 2011; Bonanno & Esmaeli, 2012; Hagedoorn & Molleman, 2006; Macgregor, 1990; Rumsey, Bull, & Gahagan, 1982).

Another factor that might elicit stigmatizing responses relates to the potentially life-threatening nature of cancer, despite advancements in treatment and improving survival rates. Jones et al. (1984) assert that the “peril” associated with cancer and other life-threatening illnesses can evoke a stigmatizing response from others because it can remind them of their own mortality. This potential basis of cancer stigma is conceptually similar to Terror Management Theory (Greenberg, Pyszczynski, & Solomon, 1986; Solomon, Greenberg, & Pyszczynski, 1991), which posits that the animal instinct of self-preservation and survival, coupled with the uniquely human awareness of the inevitability of death, results in terror. The self-defense systems that are used to avoid the terror associated with death become threatened during an encounter with a person with a serious physical illness, such as cancer, because a “cancer patient may make us starkly and disagreeably aware that the same fate can befall us” (Jones et al., 1984, p. 66). Research assessing Terror Management Theory and cancer is in its
infancy and the findings are inconsistent. One study found that participants’ level of reported death anxiety was correlated with negative attitudes towards cancer (Berrenberg, 1991), while death anxiety was not found to be directly correlated with either behavioral (i.e., social distance) or negative emotional responses to cancer patients in another study (Mosher & Danoff-Burg, 2007).

In summary, research to date has documented that cancer stigma may be related to blame-based attributions, disfiguring physical (especially facial) changes, and the potentially life-threatening nature of the illness. However, studies have been few, have generally examined stigma causal factors in isolation, and the findings have been somewhat contradictory. Thus, using a community sample, the present study aims to examine the impact of each of the three aforementioned factors on participants’ affective and behavioral responses to a hypothetical oral cancer patient. It is hypothesized that blameworthy attributions, facial changes, and poor prognosis will elicit greater negative affective and behavioral reactions towards a fictional target with oral cancer.

Method

Participants

Four hundred and seventy-nine participants were recruited through online psychology-based research websites. Incentive to participate in the research involved a $1 donation to the Australian Cancer Council for every survey completed. One hundred and six participants were excluded due to incomplete responses. The final sample consisted of 373 participants (74% female, 26% male; 1 participant identified as “other”), with a mean age of
38 years ($SD = 15.91$, range $= 18-78$). The highest level of education achieved was a University or College degree for the majority of participants (46.5%). The study received ethical approval from the Australian National University’s Human Research Ethics Committee and online informed consent was obtained from all participants. Participants were not required to provide identifiable demographic information.

**Design**

The study utilized a $2 \times 2 \times 2$ factorial design (blameworthy versus non-blameworthy; facial changes versus no facial changes following treatment; good prognosis versus poor prognosis). The dependent variables consisted of stigmatizing attitudes towards the target individual (i.e., emotional reactions, desire for social distance, and priority for health care).

**Measures**

The Social Desirability Scale – Short Form (SDS-MC; Reynolds, 1982) was used to ensure that any differences across conditions were not due to differences in socially desirable responding. Items on the SDS-MC include, “There have been occasions when I took advantage of someone” and “I sometimes feel resentful when I don’t get my way”. Participants are required to respond “true” or “false” to a series of 13 questions, based on their agreement with the item. Higher scores indicate higher levels of socially desirable responding. The short form correlates well ($r = 0.93$) with the original 33-item Marlowe-Crowne Social Desirability Scale and has acceptable internal consistency (Cronbach’s $\alpha = 0.75$) (Reynolds, 1982). Cronbach’s alpha in the current study was 0.69.
The Emotional Reaction to Mental Illness Scale (ERMIS; Angermeyer & Matschinger, 2003) was administered to assess a variety of emotional responses towards the target individual. The ERMIS has been previously used in stigma research as a measure to assess emotional reactions to individuals with mental illness (Rüscher, Corrigan, Todd, & Bodenhausen, 2011; Walker & Scior, 2013; Wolkenstein & Meyer, 2008). The ERMIS consists of nine items, with responses on a Likert scale ranging from “Applies completely (to me)” to “Doesn’t apply at all (to me)”. There are three higher order constructs of fear, anger, and pity. Higher scores indicate lower levels of these emotional reactions towards the fictional character. The scale has established reliability and validity (Link, Yang, Phelan, & Collins, 2004). In the current study, Cronbach’s alpha was 0.77 for the Fear subscale, 0.62 for the Anger subscale, and 0.74 for the Pity subscale.

The Social Distance Scale (SDS; Penn et al., 1994) is commonly used in stigma research as a proxy measure of behavioral stigmatization towards a target individual (Link et al., 2004). In the current study, participants completed the SDS to assess their willingness to have social contact (e.g., live in share house) with the target individual. An additional item was included to measure participants’ willingness to have the target individual as a Facebook friend, likely relevant to the current sample. Each of the eight items were presented on a four-point Likert Scale (0 = “definitely unwilling” to 3 = “definitely willing”), with higher scores indicating a greater willingness to have social contact with the target individual. Angermeyer, Matschinger, and Corrigan (2004) have reported high internal consistency for the SDS (Cronbach’s α = 0.90) and Penn et al. (1994) have
also reported good validity. Chronbach’s alpha for the SDS in the present study was 0.93.

Priority to health care was assessed by one binary yes or no question that stated, “If medical resources became scarce, do you think [the target individual] should be given priority to health care?” This question was adapted from similar stigma-related studies (Angermeyer et al., 2004; Beck, Dietrich, Matschinger, & Angermeyer, 2003), which compared financial allocations across a range of physical illnesses.

Materials

One baseline vignette (Vignette A) and eight additional vignettes (Vignettes B1-8) were developed to assess the impact of blameworthy attributions, facial changes following surgery, and poor prognosis on stigmatizing attitudes and behaviors (an overview of the vignette content is provided in the Appendix). Vignette A described a man, “Justin”, who had been diagnosed with mouth cancer. The eight versions of Vignette B entailed combinations of attribution (blameworthy versus non-blameworthy), facial changes (present or not), and prognosis (good versus poor). Specifically, Vignette B described Justin as engaging in behaviors (i.e., smoking cigarettes and drinking alcohol) generally perceived to contribute to cancer onset (blameworthy attribution condition) or described the target’s condition as being largely due to genetic influences (non-blameworthy attribution condition); stated that Justin had experienced significant facial changes (changing bone structure, scarring, and discoloration) as a result of surgery (facial changes condition) or that the target had undergone surgery with no changes to physical appearance (no facial changes condition); and stated
that Justin’s cancer was in the early stage of development with a good prognosis (95% chance of survival) or that the target’s cancer was in the advanced stage, with a poor prognosis (30% chance of survival). The prognosis percentages were based on five-year survival rates of different forms of mouth cancer reported in the literature (Ries et al., 2007).

Procedure

Participants completed a series of demographic questions, including their personal contact with cancer, and subsequently completed the social desirability measure. All participants were then asked to read Vignette A and to complete a series of self-report questionnaires assessing their attitudes towards “Justin” in terms of stigmatizing responses (i.e., the ERMIS and SDS). Participants were then randomly assigned to one of eight experimental groups, varying on the combinations obtained by three factors. They were asked to read the version of Vignette B appropriate to the condition to which they had been allocated, after which the self-report measures were re-administered. At this stage, participants were also asked whether “Justin” should be assigned priority to health care. Following study completion, participants were debriefed, including being informed that “Justin” was a hypothetical character and that some of the information they received could have been misleading. They were provided with education about the range of etiologies, range of treatment consequences, and prognosis information relating to oral cancer, as well as provided with additional resources for more information.
Statistical Analysis

The statistical analyses for the present study were performed using the Statistical Package for Social Sciences (SPSS, Version 22) software program. Preliminary tests were performed to assess violations of statistical assumptions including normality, linearity, homogeneity of variance, and homoscedasticity. Due to violations of normality and heterogeneity of variance, non-parametric testing was used for the subsequent analyses.

The impact of the manipulation was assessed by difference scores calculated by subtracting time 1 scores (after reading Vignette A) from time 2 (after reading Vignette B) for the dependent variables (i.e., ERMIS and SDS). The Mann-Whitney U test was applied to assess for significant differences on the dependent variables between conditions. Negative difference scores on the ERMIS (Anger, Fear, and Pity) indicated that participants showed an increase in that specified emotion towards the target from Time 1 to Time 2. Negative difference scores on the SDS indicated greater desire for social distance between administrations. Responses to the priority to health care question were analyzed using a chi-square test for independence. All comparisons were calculated with the significance level (two-tailed) set at $p < 0.05$.

Results

Preliminary analyses were conducted to investigate whether the eight conditions were comparable in terms of mean age, level of education, levels of social desirability, alcohol and smoking consumption, and exposure to cancer (i.e., how many friends and/or relatives of the participant had been
diagnosed with cancer). A one-way between groups ANOVA revealed that there were no significant differences between the conditions on these variables. For categorical data, chi-square analyses were conducted to assess whether gender and contact with cancer (i.e., binary “yes” or “no” to personal diagnosis and diagnosis of family/friends) differed significantly between the eight conditions. Analyses revealed no significant differences between conditions for these constructs. Considering these results, the aforementioned constructs were not controlled for in subsequent analyses.

**Manipulation Checks**

Manipulation checks were undertaken to ensure that participants were able to recall the vignette content based on their responses to questions relating to Vignette B. The majority of participants (91%) were able to accurately report on the content to which they had been randomly assigned. For those with incorrect recall, 8% incorrectly recalled the content from one of the attribution, facial changes or prognosis conditions, while 1% incorrectly recalled the content of more than one condition. Subsequent analyses were conducted with and without omission of cases from participants with incorrect responses to the recall manipulation checks. When comparing these results, no differences were found and therefore all results described below are from the full data set.

**The Effect of Blameworthy Attributions on Stigma**

Mean difference scores on changes from Time 1 to Time 2 on the measures of stigmatizing attitudes and behaviors across the eight experimental conditions are shown in Table 1. As expected, planned contrasts revealed significantly greater increases from Time 1 to Time 2 in the blameworthy
relative to non-blameworthy attribution conditions on the Anger (U = 12430.0, z = -5.265, p < 0.001) and Fear (U = 14535.5, z = -3.131, p < 0.001) subscales of the ERMIS, and significantly greater reductions in Pity (U = 10016.0, z = 7.450, p < 0.001). There was also a significantly greater increase in desire for social distance from the target (as indexed via the SDS) in the blameworthy compared to the non-blameworthy attribution condition (U = 8945.5, z = -8.603, p < 0.001) scores. A chi-square test for independence (with Yates Continuity correction) indicated a significant association between conditions regarding access to priority medical resources ($X^2 (1, n = 373) = 8.79, p < 0.005$), indicating that those in the non-blameworthy attribution condition (75.4% responded “yes”), compared to the blameworthy attribution condition (60.5% responded “yes”), were significantly more likely to identify that they would give priority to the target, if medical resources became scarce.
Table 1.

Mean (SD) Difference Scores for the Emotional Reactions to Mental Illness Scale and Social Distance Scale across the Eight Experimental Conditions.

<table>
<thead>
<tr>
<th>Attribution</th>
<th>Conditions</th>
<th>Prognosis</th>
<th>Facial Changes</th>
<th>Blameworthy Attribution</th>
<th>Non-Blameworthy Attribution</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Good</td>
<td>Poor</td>
<td>Good</td>
<td>Poor</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Prognosis</td>
<td>Prognosis</td>
<td>Prognosis</td>
<td>Prognosis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n = 49</td>
<td>n = 46</td>
<td>n = 47</td>
<td>n = 48</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n = 46</td>
<td>n = 46</td>
<td>n = 47</td>
<td>n = 48</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n = 47</td>
<td>n = 47</td>
<td>n = 48</td>
<td>n = 48</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n = 47</td>
<td>n = 48</td>
<td>n = 47</td>
<td>n = 48</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n = 47</td>
<td>n = 48</td>
<td>n = 47</td>
<td>n = 48</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n = 47</td>
<td>n = 48</td>
<td>n = 47</td>
<td>n = 48</td>
</tr>
<tr>
<td></td>
<td></td>
<td>n = 47</td>
<td>n = 48</td>
<td>n = 47</td>
<td>n = 48</td>
</tr>
<tr>
<td>ERMIS: Fear</td>
<td>M</td>
<td>-0.98</td>
<td>-0.35</td>
<td>-0.09</td>
<td>-0.02</td>
</tr>
<tr>
<td></td>
<td>(SD)</td>
<td>(2.05)</td>
<td>(2.08)</td>
<td>(1.70)</td>
<td>(1.04)</td>
</tr>
<tr>
<td>ERMIS: Pity</td>
<td>M</td>
<td>2.00</td>
<td>0.89</td>
<td>1.64</td>
<td>0.81</td>
</tr>
<tr>
<td></td>
<td>(SD)</td>
<td>(3.20)</td>
<td>(3.13)</td>
<td>(2.30)</td>
<td>(2.25)</td>
</tr>
<tr>
<td>ERMIS: Anger</td>
<td>M</td>
<td>-1.65</td>
<td>-0.20</td>
<td>-0.68</td>
<td>-0.40</td>
</tr>
<tr>
<td></td>
<td>(SD)</td>
<td>(2.18)</td>
<td>(2.75)</td>
<td>(1.75)</td>
<td>(1.65)</td>
</tr>
<tr>
<td>Social</td>
<td>M</td>
<td>-4.43</td>
<td>-3.63</td>
<td>-2.49</td>
<td>-2.04</td>
</tr>
<tr>
<td>Distance</td>
<td>(SD)</td>
<td>(5.61)</td>
<td>(4.06)</td>
<td>(5.26)</td>
<td>(3.40)</td>
</tr>
</tbody>
</table>

Note. Lower values on the ERMIS indicate greater increases in the specified feeling. Lower values on the Social Distance Scale indicate greater increases in a desire for social distance.
The Effect of Treatment-Induced Facial Changes on Stigma

Planned contrasts revealed significant increases between the facial changes versus no facial changes conditions on the Fear (U = 15100.0, z = -2.517, \( p < 0.05 \)) and Anger (U = 18513.5, z = -2.675, \( p < 0.01 \)) but not on the Pity (U = 16711.5, z = -0.687, \( p = 0.492 \)) subscales of the ERMIS. As expected, there were also significantly greater increases in SDS scores in the facial changes versus the no facial changes condition (U = 15206.5, z = -2.226, \( p < 0.05 \)). However, there were no significant differences between helping judgments, in relation the participants' endorsing that the target should be given health priority, when comparing between the facial changes (i.e., 70.1% “yes”) versus no facial changes (i.e., 65.6% “yes”) conditions (\( \chi^2 (1, n = 373) = 0.659, p = 0.417 \)).

The Effect of a Poor Prognosis on Stigma

There were significant increases from Time 1 to Time 2 in the poor relative to the good prognosis conditions on the Pity subscale of the ERMIS (U = 15224.5, z = -2.187, \( p < 0.05 \)). There was a marginally significant increase on the Fear subscale (U = 15654.0, z = -1.905, \( p = 0.057 \)). However, there were no significant differences between conditions in relation to Anger difference scores (U = 17143.5, z = -0.260, \( p = 0.795 \)), SDS difference scores (U = 16516.0, z = -0.889, \( p = 0.374 \)) or helping judgments (i.e., 66.3% and 69.3% priority to health care assigned, for poor and good prognosis, respectively) (\( \chi^2 (1, n = 373) = 0.261, p = 0.609 \)).
Discussion

The goal of this study was to assess three possible factors that may trigger stigmatizing attitudes in the context of cancer and its treatment. Specifically, using an experimental design, the study investigated the effect of blameworthy attributions, treatment-induced facial changes, and a poor prognosis on negative emotional reactions towards a fictional character with cancer, a desire for social distance from the target, and the degree to which the target should be prioritized in terms of access to scarce health resources.

Main Findings of the Present Study

Informed by Attribution Theory, it was hypothesized that stigmatizing attitudes and behaviors would be held towards the target who had engaged in behaviors (i.e., smoking and drinking) perceived to contribute to cancer etiology. Consistent with this hypothesis, participants in the blameworthy attribution condition reported a significant increase in desire for social distance than those in the non-blameworthy attribution condition. Negative discrimination was also apparent as participants were less willing to assign priority to health care to the target when they had been informed that he had engaged in behaviors that may have contributed to his cancer onset. Indeed, significant differences between conditions on priority to health care were not replicated in the context of facial changes or poor prognosis, suggesting that the negative effects of blame-based attributions may be especially pervasive.

In terms of affective responses to the target, increases in feelings of anger and reductions in pity were found after participants were informed that the target had engaged in health risk behaviors. These results are consistent with
those of Rush (1998) who found that, in support of Attribution Theory, controllability (but not race and gender) information impacted on participants’ affective reactions towards the target across a range of stigmatized conditions (i.e., blindness, drug use, homelessness, AIDS, cancer, and obesity). The pervasive feeling of anger in the blameworthy attribution condition is also consistent with Averill’s (1983) influential analysis of anger, in which he concluded that, “more than anything else, anger is an attribution of blame” (p. 1150). Of each of the factors investigated in the present study, the attribution of blame was the only one that had a negative impact on each of the dependent variables assessed.

These negative reactions align with the current increase in health promotion campaigns that seek to prevent illness and disease by placing blame and shame on those who engage in health-risk behaviors (Gritz, Sarna, Dresler & Healton, 2007).

Yet there was also evidence obtained for the role of facial changes in triggering stigma. In relation to treatment-induced facial changes, participants endorsed more fear, anger, and a desire for social distance after reading about the target undergoing facial changes, compared to no facial changes, after surgical treatment. This finding is in line with the prejudice and discrimination that has been reported in the literature on those affected by visible stigmas such as “facial disfigurement” (Bonanno & Esmaeli, 2012; Macgregor, 1990; Rumsey et al., 1982).

The current study found that being informed of facial changes did not affect reactions of pity. This is contrary to previous research, which has suggested that treatment-induced facial changes may in fact be associated with
reduced stigma in the form of greater pity. That is, a study conducted by Bonanno and Esmaeli (2012) found, in their Grounded Theory approach, that sympathy was one of the three primary patterns of interactions experienced by those with "facial disfigurement" due to cancer surgery. These results, however, have been based on accounts from "facially disfigured" individuals and their families, unlike in the current study, which assessed reactions from individuals who did not know the hypothetical target. Thus, the affective reactions of strangers towards those with changes to their "normal" facial appearance may be characterized in terms of fear and anger, as opposed to the sympathy reported family members.

Contrary to the hypothesis, there were few significant differences in the poor versus good prognosis conditions, and the only significant finding was contrary to the hypothesis. That is, positive rather than negative reactions were observed in the poor prognosis condition, with participants expressing significantly greater increases in feelings of pity toward the target after being informed that he had a 30% versus 95% likelihood of survival. Analysis of anger, social distance, and helping judgments showed no significant differences between conditions. However, the increase in fear after having been informed of the target's poor prognosis showed a trend towards significance, which is consistent with the role of death anxiety as a potential negative reaction towards those with life-threatening illnesses. The general lack of support for negative reactions towards the target with a poor prognosis may have been due to participants in this study not believing that the "same fate can [could] befall" (Jones et al., 1984, p. 66) them, and therefore mortality salience was not evoked. For instance, men are 2 to 4 times more likely to be diagnosed with oral cancer, and rates of diagnosis
are highest in people aged 55-64 years of age (Ries et al., 2007), whereas the sample in the current study was predominantly female (74%) with a median age of 32. Furthermore, oral cancer is not as common as other types of cancers (constituting the 15th most common cancer in the United States) and comprises 2.5% of all new cancer cases (Ries et al., 2007). Thus, the study may have not adequately evoked the "fundamental anxiety" (Schutz, 1962, p. 228) associated with death because participants may have experienced a minimal sense of risk for developing oral cancer.

Limitations and Future Directions

In addition to those already noted, there are several limitations in the present study that must be noted in interpreting the findings. First, the vignette study design may not have allowed for a true representation of the stigmatizing conditions assessed. For instance, although detailed, it is possible that the written descriptions of facial changes following surgery did not elicit the same type and/or degree of affective and behavioral reactions as a visual depiction. Furthermore, the study assessed participants' presumed, rather than actual, reactions to hypothetical situations. Future research would benefit from more ecologically-valid investigations.

The second limitation is that the study may not have assessed the full scope of emotional reactions expressed by participants. For instance, the ERMIS was designed to assess affective reactions in mental health research. Therefore, this tool may have failed to capture emotional reactions that are relevant to stigmatizing conditions associated with physical illness, such as cancer. For instance, the literature on obesity stigma, which is another visible stigmatized condition, has identified disgust as a main affective
stigmatizing response (Vartanian, 2010). Future research would benefit from identifying the range of affective reactions relevant to cancer stigma. Relatedly, the internal consistency of some measures (i.e., SDS and Anger subscale of ERMIS) used in this study were found to be poor, indicating both a limitation to the study and the need to assess other affective reactions and instruments to assess these.

The third limitation is that the study sample was not representative of a general community sample. That is, younger females who were educated at the university level were overrepresented in this study. This may have impacted on the results as women have been found to express greater pity and willingness to help targets in similar cancer-related vignette-based studies (Mosher & Danoff-Burg, 2008). In addition, the participation incentive included a $1 donation to the Australian Cancer Council, which may have resulted in the recruitment of a more altruistic sample.

Conclusions

The present study contributes to the limited literature on understanding the precipitants of stigmatizing attitudes and behaviors towards individuals with cancer. Of the three potential triggers of cancer stigma investigated in the current study, the most consistent support was obtained for the role of blame-based attributions in triggering anger, fear, and a desire for social distance, while reducing pity and willingness to prioritize the target individual for healthcare. Thus, cancers that have etiologies linked to behavior appear to be at risk for pervasive discrimination and negative evaluation. These reactions may shape an individual’s self-worth and self-efficacy, therefore highlighting the need to monitor these factors in a
clinical setting. Negative evaluations may be further exacerbated as a result of physical changes induced by cancer and its treatment, while the role of negative prognostic information in increasing stigma, in the form of fear, requires further clarification.
References


Rüsch, N., Corrigan, P. W., Todd, A. R., & Bodenhausen, G. V. (2011). Automatic stereotyping against people with schizophrenia,


Chapter 3: Foreword

The present study builds upon the findings from Chapter 2 (Study 1); that, in comparison with other stigmatising characteristics blameworthy attributions, consistently resulted in negative responses from community members. The aim of Study 2 was to establish whether certain cancer types are at increased risk of heightened stigma, given that the onset of cancers varies in regards to the contributory genetic and lifestyle factors. Guided by attribution theory, Study 2 explored community participants’ responses to eight common cancers, assessing the roles of perceived cancer cause, perceived controllability of the cancer, sympathy, and participant’s willingness to provide support research and treatment for individuals with the target cancer.

Study 2 employed structural equation modelling to assess the following path: perceived cause, controllability, emotional response, behavioural reaction. Results demonstrated improved model fit when controllability of the cancer was directly linked to both affective and behavioural reactions, which suggests that stigmatisation is directly impacted by blameworthy attributions. In particular, lung, skin and throat cancer patients may be at a greater risk of stigmatisation, with the present study finding these cancers to be attributed to mostly blameworthy causes. Therefore, the results of Study 1 and Study 2 offer worthy evidence regarding both what is particularly stigmatising about cancer, and what cancers are at risk for increased stigmatisation.
Declaration

Title

A Test of Attribution Theory in Understanding Stigma in Cancers Perceived to be Blameworthy Versus Non-Blameworthy

Authorship

Jennifer Threader, Professor Don Byrne and Dr Elizabeth Rieger

Publication Outlet

The Journal of Psychosocial Oncology.

Current Status

Manuscript was submitted on August 6th 2014

Candidate Contribution

Threader designed the study, which was reviewed by Professor Byrne and Dr Elizabeth Rieger. The Candidate recruited study participants, conducted the statistical analyses, and developed the initial manuscript. Professor Byrne and Dr Rieger provided input on successive drafts of the manuscript.
Co-Author Signatures

Dr Elizabeth Rieger

Professor Don Byrne
Article title:
A Test of Attribution Theory in Understanding Stigma in Cancers Perceived to be Blameworthy Versus Non-Blameworthy

Authors:
Jennifer Threader, Professor Donald Byrne, and Dr Elizabeth Rieger

Research School of Psychology, Australian National University

Running title:
Attribution theory and cancer stigma

Address for correspondence:
Jennifer Threader, Research School of Psychology,
Australian National University, Canberra, ACT 0200, Australia
Telephone: (02) 6125 4582, Fax: (02) 6125 0499
E-mail: jennifer.threader@anu.edu.au

Conflict of interest statement:
Jennifer Threader, Donald Byrne and Elizabeth Rieger declare no potential conflict of interest.
Abstract

Attribution theory, which explains stigma as resulting from conditions perceived to be onset-controllable, has not been extensively investigated in cancer. This study aimed to examine this theory among cancers perceived to be blameworthy versus non-blameworthy. Three hundred and seventy-three community members reported on the perceived cause and controllability of various cancers (to assess attribution type) as well as levels of sympathy towards affected individuals and willingness to make a hypothetical donation for different cancers (to assess stigma). Significantly more behavioral versus non-behavioral causes were attributed to throat, skin and lung cancers, while the opposite was true for breast, leukemia, lymphoma and cervical cancer. Path-analyses found non-behavioral causation predicted lower controllability judgments and higher sympathy, but the association with donation was inconsistent. A new model, with a direct link from controllability to donation improved fit across all cancers. Therefore the controllability in the blameworthy cancer groups assessed may influence factors contributing to charitable donation.

Keywords: Attribution Theory, cancer stigma, cancer, oncology, stigma, blame.
Introduction

Illness and disease have long been associated with stigma (Sontag, 1989). In particular, cancer patients may be at a greater risk as they may face a range of physical and psychosocial impairments due to their illness (Stein, Syrjala, & Andrykowski, 2008), and some may feel responsible for engaging in behaviors contributing to cancer onset. These characteristics make cancer patients prone to several different stigmatizing factors that have been reported in the literature (Goffman, 1963; Jones, Farina, Hastorf, & French, 1984). While conceptually the different types of stigma vary, they share a common feature of being associated with a negative attribute or ‘mark’ (Goffman, 1963). Depending on the social context and perception an attribute may, or may not, develop into a stigmatizing characteristic (Jones et al., 1984). Physical or symbolic, the stigma ‘mark’ identifies an individual as being different to others in a social group and is associated with negative evaluations and stereotypes (Jones et al., 1984), and it leads bearers to become set-apart, avoided, and discredited (Goffman, 1963). The nature of the attribute allows the bearer to be treated in a dehumanized manner (Jones et al., 1984), as observers adopt different rules of conduct, thereby reducing prosocial behavior towards the stigmatized.

Attribution theory (Weiner, 1986, 1995; Weiner, Perry, & Magnusson, 1988) has provided a dominant model for understanding the basis of stigma across a diverse range of conditions, including cancer. This theory posits that individuals are continually seeking a causal explanation for events to make sense of their environment and experiences. These perceived judgments can impact on affective responses, and subsequently, behavioral reactions.
Specifically, individuals with conditions that are perceived to be blameworthy engender more anger and rejection, less altruistic action, and are more harshly treated, when compared to conditions which are perceived as being out of one’s control, or non-blameworthy (Weiner, 1993).

Researchers have examined attribution theory comparing across several types of stigmatizing conditions. For example, Weiner and colleagues (1988) examined attribution theory in the context of mental-behavioral conditions (i.e., AIDS, child abuse, obesity and Vietnam War Syndrome) and physical conditions (i.e., Alzheimer’s disease, blindness, cancer, heart disease and paraplegia). As compared to mental-behavioral conditions, physical conditions were perceived to be onset-uncontrollable, and elicited more pity, less anger, and increased helping intentions towards a hypothetical target. Menec and Perry (1998) also assessed the role of attributions in eliciting stigma in a study that experimentally manipulated controllability among different conditions, including lung cancer, and assessed stigmatizing responses to hypothetical individuals with these conditions. To test the sequential nature of the theory, path-analytic procedures were employed and results supported the attributional model. Therefore, low controllability was linked with more pity and less anger towards the hypothetical target. Pity was found to be predictive of willingness to help the target, however, no association was found in relation to anger. In addition, personal contact with each condition was added to the attribution model. Results demonstrated that knowing someone with the specified condition significantly increased helping intentions towards the target, while no significant association was found in relation to personal contact and
controllability judgments.

In the aforementioned studies assessing attribution theory, only one cancer type has been examined in the model or cancer was treated as a unitary concept. There are several forms of cancer, however, all with varying behavioral risk factors (Danaei, Vander Hoorn, Lopez, Murray, & Ezzati, 2005), which may render patients with certain types of cancer more prone to stigmatization. Marlow, Waller, and Wardle (2010) conducted a study among women to assess attributions of blame amongst five cancer types. The results identified that attributions of blame varied across different cancer types. For instance, attributions of blame were significantly higher for lung cancer compared to the other cancer types assessed (i.e., leukemia, breast, bowel, and cervical cancers), with 70% of participants identifying that lung cancer patients were at least partially to blame.

Smoking has been identified as the most consistent behavioral risk factor associated with cancer (Redeker, Wardle, Wilder, Hiom, & Miles, 2009). There has been growing interest in the link between smoking and lung cancer, likely as a result of an increase in ant-tobacco campaigns and health promotion advertisements aimed to prevent disease and illness (Gritz, Sarna, Dresler, & Healton, 2007). Research among lung cancer patients (Chappie, Ziebland, & McPherson, 2004; Chappie, Ziebland, McPherson, & Summerton, 2004; ElseQuest, LoConte, Schiller, & Hyde, 2009; Tod, Craven, & Allmark, 2008) and medical professionals (Conlon, Gilbert, Jones, & Aldredge, 2010; Wassenaar et al., 2007) has consistently demonstrated that this link is associated with increased stigma. While the link between smoking and incidence of throat
cancer is well-established (International Agency for Research on Cancer, 2004), investigation of stigma in this group is scarce (Lebel & Devins, 2008). This lack of investigation could be related to limited public knowledge of the behavioral risk factors (e.g., smoking, alcohol consumption, and human papillomavirus [HPV] infection) associated with throat cancer (Blot et al., 1988; Herrero et al., 2003).

While HPV infection has been linked to throat cancer in men, it is responsible for nearly all (99.7%) cases of cervical cancer in women (Walboomers et al., 1999). The strain of HPV linked to these cancers is sexually transmitted and women with the infection have reported being negatively evaluated and labeled as "promiscuous" (Kahn et al., 2007). The stigma related to the association between HPV and cervical cancer may be linked to the belief that the cancer is onset-controllable, and therefore increased blameworthy attributions might be expressed towards those affected. However, public knowledge of HPV and its link to cervical cancer remains low (Marlow, Waller, & Wardle, 2007; Tiro, Meissner, Kobrin, & Chollette, 2007) so that the attribution of blame among community members towards those with cervical cancer remains unknown.

During the past 30 years, there has been increased public knowledge regarding sun protection due to the link between sun exposure and skin cancer (Marks, 1999). A broad range of prevention strategies, including restricting sun exposure and advising against tanning bed use, has led to increased knowledge, understanding, and changed attitudes and beliefs regarding suntans and prolonged exposure to sunlight. While these preventive messages may be
efficacious for shifting lifestyle behaviors and ultimately reducing the prevalence of skin cancer, they may also have an impact on public perceptions of skin cancer as an onset controllable condition, which could in turn increase the stigma experienced by those affected.

While some cancers may be at risk for increased stigmatization due to a link with behavioral risk factors, others may not be at risk due to a lack of public awareness regarding their behavioral links or a minimal role for behavioral factors. For instance, while breast cancer has been associated with lifestyle factors, including obesity, physical inactivity, and alcohol use (Danaei et al., 2005), heritability is the most well-known risk factor (Grunfeld, Ramirez, Hunter, & Richards, 2002; Paul, Barratt, Redman, Cockburn, & Lowe, 1999). Similarly, while prostate cancer has been associated with physical inactivity, risk factors remain largely misunderstood by community members (Steele, Miller, Maylahn, Uhler, & Baker, 2000). Other cancers, such as lymphoma and leukaemia, may not be associated with blameworthy attributions because they have a minor behavioral influence (Caporaso, Goldin, Anderson, & Landgren, 2009; Zeeb & Blettner, 1998).

In summary, research to date using attribution theory in the context of cancer has been limited, as studies have typically treated cancer as a single entity or have not fully examined the effect of various cancer types in relation to attribution theory. Using a community sample, the present study aims to assess differences across cancer groups in regards to perceived behavioral and non-behavioral risk factors, and how these perceptions regarding causation predict stigmatizing affective and, in turn, behavioral responses according to attribution
theory. It is hypothesized that cancers with known behavioral risk factors (i.e., lung cancer, throat cancer, cervical cancer, and skin cancer) will be associated with more behavioral causal attributions than other cancers with risk factors that are misunderstood or have a minor behavioral influence (i.e., breast cancer, prostate cancer, leukemia, and lymphoma). Secondly, it is hypothesized that constructs relating to attribution theory will demonstrate a good fit when examining cancer stigma across these eight cancer types. Specifically, it is predicted that non-behavioral causal attribution would significantly reduce controllability judgments; and high controllability would significantly reduce affective sympathetic reactions. Finally, an increase in sympathy would increase behavioral response through hypothetical monetary donation. It was also hypothesized that personal contact would reduce controllability judgments and increase hypothetical monetary donation.

Methods

Participants

Participants were recruited through online psychology research websites, and they were informed that the purpose of the study was to understand their attitudes and beliefs about different cancer types. Participants were not provided with a monetary incentive to participate, however were informed that a $1 donation to the Australian Cancer Council would be made for every survey completed. Four hundred and seventy-nine participants took part in the study, however 106 were excluded due to incomplete responses. Demographic characteristics for the final sample of 373 participants are contained in Table
I. The study received ethical approval from the Australian National University's Human Research Ethics Committee. Informed consent was obtained from all participants.

Table 1.

*Sample (n=373) characteristics*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>37.56</td>
<td>15.9</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>273</td>
<td>74.2</td>
</tr>
<tr>
<td>Male</td>
<td>90</td>
<td>24.7</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>0.3</td>
</tr>
<tr>
<td>Education (highest level)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year 10 certificate or below</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Year 12 certificate</td>
<td>70</td>
<td>19.1</td>
</tr>
<tr>
<td>Trade certificate/Diploma</td>
<td>46</td>
<td>12.5</td>
</tr>
<tr>
<td>University or College degree</td>
<td>169</td>
<td>46.1</td>
</tr>
<tr>
<td>Postgraduate Degree</td>
<td>81</td>
<td>22.1</td>
</tr>
</tbody>
</table>

*Note.* Frequency values do not all sum to 373 because of missing data.

**Measures**

The Social Desirability Scale – Short Form (SDS-MC; Reynolds, 1982) was used to ensure that differences in stigmatizing responses across cancer types could not be attributed to differences in socially desirable responding. Items on the SDS-MC include, “There have been times when I felt like rebelling against people in authority even though I knew they were right” and “There have been
times when I was quite jealous of the good fortune of others.” Based on their agreement with the item, participants are required to respond “true” or “false” to a series of 13 questions. Higher scores indicate higher levels of socially desirable responding. The short form correlates well ($r = 0.93$) with the original 33-item Marlowe-Crowne Social Desirability Scale. Cronbach’s alpha in the original paper was 0.75 (Reynolds, 1982) and 0.69 in the present study.

Five questions were included to test Weiner’s attribution theory. One question asked participants in an open-text format what they thought had caused the particular cancer. Responses to this open-ended question were categorized into either behavioral, combination (of behavioral and non-behavioral), and behavioral causes. The allocation of each response to a causal category was based on criteria developed by Ferrucci and colleagues (2011) from a study of causal attributions among cancer patients. The coding was independently reviewed by the first two authors.

Two questions pertained to controllability and blameworthy attributions, that is, “How much personal control do you think people with [target cancer] have over the prevention of their condition?” and “How much do you blame [target cancer] patients for their diagnosis?”, respectively (Menec & Perry, 1998). The two items were presented on a five point Likert Scale ranging from “No control/ Not at all to blame” to “Total control/Totally to blame”.

One question addressed participants’ sympathetic responses to an individual with the specified cancer types (Menec & Perry, 1998). Similar to the aforementioned questions, this item was based on a five-point Likert scale
ranging from "Not sympathetic" to "Extremely sympathetic".

The final question was in regards to helping behavior, which was assessed through a hypothetical charitable donation (Weiner et al., 1988). Specifically, participants were asked, "If you had $100 to donate to cancer research and support groups, which cancer group(s) would you wish to donate your money?" They had the option to apportion the $100 amongst the different cancer types.

Procedure

Participants provided demographic information, including their personal contact with cancer, and then completed the social desirability scale. Subsequently, participants were randomly assigned to one of two conditions in which they answered the series of five questions pertaining to prostate cancer, lung cancer, lymphoma, and throat cancer, or questions regarding breast cancer, cervical cancer, leukemia, and skin cancer. The assignment of condition was provided by Qualtrics Software Package random allocation system. This grouping was undertaken to reduce participant burden. The allocation of cancer type per condition was based on equal dispersion of cancers hypothesized to be perceived as blameworthy versus non-blameworthy cancers, as agreed upon by the researchers. Following study completion, participants were debriefed and provided with education about the complex etiologies linked to different cancers, and information regarding the adverse effects of stigma.

Statistical Analysis

The preliminary statistical analyses for the present study were performed using the Statistical Package for Social Sciences (SPSS, Version 22) software
program. Differences in age, level of education, social desirability, alcohol and smoking consumption and exposure to cancer (i.e., how many friends and/or relatives of the participant had been diagnosed with cancer) between the two groups was assessed using an independent samples t-test. A chi-square analysis was conducted among categorical variables, including gender and contact with cancer (i.e., binary “yes” or “no” to personal diagnosis and diagnosis of family/friends), to determine whether they differed significantly between the two groups. All comparisons were calculated with the significance level (two-tailed) set at $p < 0.05$.

To assess differences between cancers in regards to causal attributions, a series of chi-square tests were conducted. First, differences in causal attributions between the blameworthy cancer group and the non-blameworthy cancer group were examined. Second, differences between cancers within each the blameworthy and non-blameworthy groups were assessed.

To assess attribution theory, a path analysis was conducted whereby participants’ perceptions of cancer onset as being due to behavioral, non-behavioral or a combination of factors (causation) was modeled to influence blameworthy attributions (control and blame judgments), sympathetic affective reactions, and charitable contribution (hypothetical monetary donation). Preliminary analyses were conducted to assess statistical assumptions relating to Structural Equation Modelling (SEM). In particular, SEM requires a large number of observations; at a minimum, it has been recommended that the ratio of cases per estimated parameter is 5:1 (Bentler & Chou, 1987). The ratio for
the cancer (i.e., Lymphoma) with the smallest number of observations \( n = 134 \) in the present study is 6:1, indicating a large enough sample to perform this analysis.

Statistical assumptions relating to normality, linearity, multicollinearity and singularity were also analyzed. Due to non-normal distribution among dependent variables, non-parametric analyses and the bootstrap method for structural equation modeling (Byrne, 2013) were applied in all subsequent analyses. Linear relationships were observed between dependent variables and there was an absence of multicollinearity and singularity.

Structural equation modeling analysis was conducted using the Statistical Package for Social Sciences Analysis of Moment Structures (SPSS AMOS, Version 20) software program. Maximum likelihood procedure and bootstrapping on 500 samples (using the ML estimator) was applied. The model fit was assessed by examining the chi-square statistic, the Normed Fit Index (NFI; Bentler & Bonett, 1980), the Non-Normed Fit Index (NNFI; Tucker & Lewis, 1973), the Comparative Fit Index (CFI: Bentler, 1990) and the Root Mean Square Error of Approximation (RMSEA; Browne & Cudeck, 1993). Fit indices were chosen based on previous research using SEM to test the attribution model (Menec & Perry, 1998).

To account for the two categorical variables in the model (causation and personal contact), Bayesian models were computed (Byrne, 2013). The convergence statistic was obtained for all estimations. For all analyses, estimates between Bayesian and Maximum Likelihood procedures were
comparable, and therefore supported the validity of the hypothesized structure. Maximum likelihood estimates were used in the following analyses to allow for significance testing between relationships.

Results

Sample Characteristics

Preliminary analyses were conducted to investigate whether there were significant differences between the two cancer groups in relation to age, level of education, smoking status, alcohol use, socially desirable responding, and exposure to cancer (i.e., how many friends and/or relatives of the participant had been diagnosed with cancer). Two-tailed independent samples t-test identified no significant differences between groups on these variables. Chi-square analyses revealed no significant differences between groups in terms of gender and personal contact with cancer (i.e., binary “yes” or “no” to personal diagnosis and diagnosis of family/friends). Considering that the two groups were comparable on demographic variables, these were not controlled for in subsequent analyses.

Perceptions of causation for hypothesized blameworthy and non-blameworthy conditions

A series of chi-square analyses was conducted to determine whether perceptions of causation (i.e., behavioral, non-behavioral or their combination) differed significantly between cancers. Analyses between cancers hypothesized to be perceived as blameworthy (i.e., lung cancer, skin cancer, throat cancer,
and cervical cancer) and non-blameworthy (i.e., breast cancer, prostate cancer, leukemia, and lymphoma) revealed significant differences ($X^2 (2, n = 373) = 517.62, p < 0.001$), with more behavioral causes identified in the blameworthy group ($n = 333$ versus $n = 34$). Significant differences were also found between cancers in both blameworthy and non-blameworthy groups. Table 2 outlines a series of chi-square analyses, comparing between cancer types in each blameworthy and non-blameworthy group. A distribution of causal attributions across each cancer type is outlined in Figure 1.

<table>
<thead>
<tr>
<th>Cancer comparisons for Group 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung</td>
</tr>
<tr>
<td>x Throat**</td>
</tr>
<tr>
<td>x Skin*</td>
</tr>
<tr>
<td>x Cervical***</td>
</tr>
<tr>
<td>Throat</td>
</tr>
<tr>
<td>x Skin</td>
</tr>
<tr>
<td>x Cervical***</td>
</tr>
<tr>
<td>Skin</td>
</tr>
<tr>
<td>x Cervical***</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cancer comparisons for Group 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate</td>
</tr>
<tr>
<td>x Lymphoma</td>
</tr>
<tr>
<td>x Breast**</td>
</tr>
<tr>
<td>x Leukaemia***</td>
</tr>
<tr>
<td>Lymphoma</td>
</tr>
<tr>
<td>x Breast***</td>
</tr>
<tr>
<td>x Leukemia</td>
</tr>
<tr>
<td>Leukaemia</td>
</tr>
<tr>
<td>x Breast***</td>
</tr>
</tbody>
</table>

Table 2.

*Chi square cancer type comparisons across causal attribution*

* p < 0.05 ** p < 0.01, *** p < 0.001
Figure 1. *Causal attribution (percentage) across cancer type*
Structural model for each cancer type

The model fit was adequate for most cancer types, as reflected by fit indices above .90, and RMSEA below 0.6. However responses for prostate cancer, skin cancer, and leukemia did not fit the attribution model. Table 3 outlines the standardized path coefficients for each cancer type.
Table 3.

*Standardized path coefficients and Fit indices for each cancer.*

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>Standardized path coefficients</th>
<th>Fit indices</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>CA-CJ</td>
<td>PC-CJ</td>
</tr>
<tr>
<td>Prostate</td>
<td>-0.41***</td>
<td>-0.05</td>
</tr>
<tr>
<td>Lung</td>
<td>-0.67***</td>
<td>-0.04</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>-0.54***</td>
<td>0.07</td>
</tr>
<tr>
<td>Throat</td>
<td>-0.52***</td>
<td>0.05</td>
</tr>
<tr>
<td>Breast</td>
<td>-0.41***</td>
<td>-0.25*</td>
</tr>
<tr>
<td>Skin</td>
<td>-0.46***</td>
<td>0.06</td>
</tr>
<tr>
<td>Leukemia</td>
<td>-0.64***</td>
<td>-0.15</td>
</tr>
<tr>
<td>Cervical</td>
<td>-0.67***</td>
<td>0.03</td>
</tr>
</tbody>
</table>

*Note. CA = cause, CJ=controllability judgments, PC=personal contact, SY=sympathy, DN=donation. NFI= Normed Fit Index, NNFI= Non-normed Fit Index (NNFI), CFI= Comparative Fit Index, RMSEA= Root Mean Square Approximation (RMSEA) *p > 0.05, **p > 0.01, ***p > 0.001*
In partial support of attribution theory, the association between causation and control judgments was consistently significant across cancer types, whereby greater non-behavioral causation predicted lower control judgments. Furthermore, for each cancer type, control judgments were consistently shown to predict lower feelings of sympathy. Personal contact predicted lower blameworthy attributions in breast cancer, and higher charitable donations among lung and cervical cancers.

However, with the exception of throat and lung cancer, the link between sympathy and helping behavior, in the form of donation, was not supported. To account for this non-association, the model was adjusted to remove this regression coefficient. A new relationship was tested in the model to assess the direct link between control judgments (or blameworthy attributions) and donation. Table 4 outlines the standardized path coefficients for each cancer type in the new model.
Table 4.

**Standardized path coefficients and Fit indices for each cancer for new model**

<table>
<thead>
<tr>
<th>Cancer Type</th>
<th>CA-CJ</th>
<th>PC-CJ</th>
<th>CJ-SY</th>
<th>CJ-DN</th>
<th>PC-DN</th>
<th>X² (8)</th>
<th>NFI</th>
<th>NNFI</th>
<th>CFI</th>
<th>RMSEA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate</td>
<td>-0.40***</td>
<td>-0.05</td>
<td>0.34**</td>
<td>0.16</td>
<td>0.01</td>
<td>10.80</td>
<td>0.87</td>
<td>0.92</td>
<td>0.96</td>
<td>0.05</td>
</tr>
<tr>
<td>Lung</td>
<td>-0.66***</td>
<td>-0.04</td>
<td>-0.43***</td>
<td>-0.16*</td>
<td>0.17*</td>
<td>13.31</td>
<td>0.95</td>
<td>0.96</td>
<td>0.98</td>
<td>0.05</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>-0.54***</td>
<td>0.07</td>
<td>-0.28***</td>
<td>-0.14</td>
<td>0.11</td>
<td>4.21</td>
<td>0.97</td>
<td>1.05</td>
<td>1.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Throat</td>
<td>-0.52***</td>
<td>0.04</td>
<td>-0.18*</td>
<td>-0.21*</td>
<td>0.08</td>
<td>9.78</td>
<td>0.95</td>
<td>0.98</td>
<td>0.99</td>
<td>0.03</td>
</tr>
<tr>
<td>Breast</td>
<td>-0.42***</td>
<td>-0.26*</td>
<td>-0.48***</td>
<td>-0.21</td>
<td>0.09</td>
<td>2.58</td>
<td>0.96</td>
<td>1.20</td>
<td>1.00</td>
<td>0.00</td>
</tr>
<tr>
<td>Skin</td>
<td>-0.42***</td>
<td>0.06</td>
<td>-0.39***</td>
<td>-0.18*</td>
<td>0.08</td>
<td>22.46**</td>
<td>0.82</td>
<td>0.75</td>
<td>0.87</td>
<td>0.09</td>
</tr>
<tr>
<td>Leukemia</td>
<td>-0.65***</td>
<td>-0.16</td>
<td>-0.30**</td>
<td>0.21*</td>
<td>0.08</td>
<td>22.02**</td>
<td>0.81</td>
<td>0.74</td>
<td>0.86</td>
<td>0.10</td>
</tr>
<tr>
<td>Cervical</td>
<td>-0.48***</td>
<td>0.03</td>
<td>-0.25*</td>
<td>-0.12</td>
<td>0.20*</td>
<td>8.66</td>
<td>0.96</td>
<td>0.99</td>
<td>1.00</td>
<td>0.02</td>
</tr>
</tbody>
</table>

**Note.** CA = cause, CJ = controllability judgments, PC = personal contact, SY = sympathy, DN = donation. NFI = Normed Fit Index, NNFI = Non-normed Fit Index (NNFI), CFI = Comparative Fit Index, RMSEA = Root Mean Square Approximation (RMSEA).

*p > 0.05, **p > 0.01, ***p > 0.001
While the model fit remained poor for skin cancer and leukemia, the fit indices across all cancer types improved in the new model. Similar results were found between causation and control judgments (or blameworthy attributions); control judgments and sympathy; as well as personal contact and donation. Control judgments were shown to predict lower hypothetical donations among lung, throat, and skin cancers, yet unexpectedly higher donation for leukemia.

Discussion

The primary aims of the present study were to assess the level of blameworthiness associated with eight different cancer types and to assess attribution theory in the context of these various cancers. To test this model as it relates to cancer stigma, the study investigated participant responses to different cancer groups, in terms of controllability and blameworthy attributions, affective sympathetic responses, and behavioral intention through a hypothetical charitable donation.

Main Findings of the Present Study

Guided by literature concerning community perceptions of causes for certain cancer types, it was hypothesized that lung, throat, skin, and cervical cancers would be perceived as having more behavioral risk factors associated with onset compared to prostate cancer, lymphoma, breast cancer, and leukemia. In support of this hypothesis, there was a significant difference between causation perceptions, with the former group of cancers perceived as having more behavioral risk factors than the latter group of cancers.
Investigating the specific cancer types, cervical cancer alone failed to yield the hypothesized responses. The finding that the causality linked to cervical cancer was comparable to patterns in the hypothesized non-blameworthy group could suggest that the public are generally unaware of the link between sexually transmitted HPV infection and cervical cancer (Marlow et al., 2007; Tiro et al., 2007). Alternatively, these results could be associated with increased knowledge regarding the prevalence of HPV infections (80–85% lifetime prevalence; Jenkins, Sherlaw-Johnson, & Gallivan, 1996) as a result of a recent increase of HPV vaccinations among young women (Centre for Disease Control and Prevention, 2010), and now in young men (Cullen, Stokley, & Markowitz, 2014). Therefore, HPV may be seen as a ubiquitous infection (rather than occurring in a ‘deviant’ group) that leads to cervical cancer in a small percentage of women (Helmerhorst & Meijer, 2002).

Also contrary to the suggestion in previous research that stigma towards lung cancer may be especially elevated (Marlow et al., 2010), the current results demonstrated that throat and skin cancers (rather than lung cancer) were perceived to have the highest level of behavioral risk factors. While there has been an increase in literature around the stigma associated with smoking and lung cancer, these findings suggest that perhaps this increased awareness has led to knowledge of both the behavioral and non-behavioral (e.g., air pollution and asbestos) factors that can influence lung cancer onset (Alberg & Samet, 2003). Conversely, increased public awareness of the behavioral risk factors associated with skin cancer may result in this cancer type being susceptible to heightened stigmatization. These results suggest that appropriate public
awareness of the non-behavioral risk factors associated with the development of throat and skin cancer may be beneficial.

Casual attributions also varied significantly among the hypothesized non-blameworthy group, with breast cancer being the least likely to be attributed to a genetic cause. These results support a recent review which identified that more cases of breast cancer, in comparison with prostate cancer, leukemia, and lymphoma, are attributed to lifestyle factors (Danaei et al., 2005), and suggests that the public are more aware of these behavioral etiologies than previously documented (Grunfeld et al., 2002; Paul et al., 1999).

The present study also hypothesized that cancer stigma could be accounted for, at least in part, by attribution theory. As expected, and in support of previous research assessing attribution theory across different types of stigma (Menec & Perry, 1998; Weiner et al., 1988), perceptions of non-behavioral causation significantly reduced blameworthiness, while increased blameworthiness in turn significantly reduced the degree of sympathy felt by participants, across all cancers. However, with exception of throat and lung cancer, the model could not account for the relationship between affective reactions (sympathy) and behavioral response (donation). A new model was therefore tested which investigated the direct path between controllability and amount of hypothetical donation. This model demonstrated improved fit across all cancer types and suggests that affective and behavioral reactions to cancer stigma may be better accounted for by controllability, rather than through the attribution-affect-help pathway.
The finding that controllability directly influenced behavioral response could be in part due to the study design, which included perceptions based on cancer types, rather than an individual identifiable target. Similar to Marlow and colleagues (2010), the present study assessed the degree to which participants responded to study constructs based on what they thought generally of patients within that cancer group. Therefore, had a vignette been utilized in the present study, participant sympathetic response may have influenced hypothetical behavioral reaction as the personal connection could have been perceived as more salient. While reactions to specific target individuals were not tested in the present study, results suggest that, overall, the controllability of certain cancers directly impacts on monetary donation to support research and patient support.

In regards to the influence of personal contact on controllability and helping judgments, the study hypothesis was only partially supported. For instance, in comparison to all other cancers assessed, breast cancer was the only cancer type to have personal contact significantly reduce controllability judgments. This finding supports the results of Marlow and colleagues' (2010) study, and suggests that due to the high prevalence of breast cancer, individuals are more likely to have friends and family diagnosed with it, and therefore are less likely to attribute blame. In addition, the influence of personal contact on helping judgments was only found for lung and cervical cancers, whereby contact significantly increased hypothetical monetary donation. The reason for this finding is unclear. The association in lung cancer could be due to family and
friends being aware of the research disparity in lung cancer (Gritz et al., 2007), highlighting the need for more support.

While the new model demonstrated improved fit for all cancers, it could only account for changes in hypothetical monetary donation for lung cancer, throat cancer, skin cancer, and leukemia. Control judgments resulted in a significant reduction in charitable donation among lung, throat, and skin cancers; while the opposite was true for leukemia. Therefore, cancers which are perceived as being mostly due to lifestyle factors are at risk for negative behavioral responses as a result of blame-based attributions. On the contrary, leukemia was the least likely to be attributed to behavioral causes (and, the highest level of genetic attribution), and greater blameworthiness resulted in an increase in charitable donation. The reasons for this unexpected finding are unclear but could in part reflect that fact that leukemia is the most common cancer to be diagnosed in children (Parkin, Stiller, Draper, & Bieber, 1988), which could result in more pro-social behaviors.

The results regarding the behavioral outcome of charitable donations is consistent with previous research which has identified that tobacco-related cancers are grossly underfunded in relation to their societal burden (Gritz et al., 2007), and extend this finding to other cancers, namely, skin cancer. For instance, in 2013 funding and grants awarded by the National Health and Medical Research Council in Australia for breast cancer ($19,857,446; 108 grants), prostate cancer ($14,142,006; 67 grants), lymphoma ($10,002,733; 27 grants), and leukemia ($20,438,829; 98 grants) is substantially more than research funding and grants for lung cancer ($5,710,985; 39 grants), all head
and neck cancers ($1,547,758; 10 grants), and all skin cancers ($10,564,385; 53 grants). Therefore, the controllability of certain cancers may render them vulnerable to receiving reduced charitable donations as well as research funding.

**Clinical Implications**

The present findings document the role of perceived controllability for the onset of certain cancers in the subsequent stigmatization of affected individuals by members of the community. In relation to informing clinical practice, these results highlight the importance of assessing patients’ experiences of stigma, particularly among individuals with a diagnosis of skin, lung or throat cancer. In particular, assessing for factors that are consequences of stigma such as distress (Mak, Cheung, Law, Woo, Li, & Chung, 2007), reduced self-esteem and self-worth (Fife & Wright, 2000), isolation and strained relationships (Peters-Golden, 1982) may be helpful in identifying affected individuals. Routinely screening for exposure to discrimination and sensitively addressing such experiences in psychological practice may enhance an individual’s well-being, given research indicating that stigmatizing experiences can result in distress and delayed symptom reporting (Chapple et al., 2004; Tod et al., 2008). For example, at-risk patients may benefit from encouragement to seek helpful social support from their family and friends (Raleigh, 2010), or patient-centered support groups (Heijnders & Van Der Meij, 2006).

**Limitations**
There are several limitations in the present study that must be noted in interpreting the findings. First, to test affective responses and behavioral intentions, following previous research assessing attribution theory (Menec & Perry, 1998), the present study employed only one item for each of these constructs. Therefore, the dependent variables may have not completely assessed each construct. For instance, future research would benefit by assessing other affective responses in the attribution model including pity, anger, and indignation. Replicating the current research by using multiple items to assess the latent affective and behavioral constructs is therefore recommended.

Another limitation relates to the study sample. Firstly, although minimum sample size for SEM was obtained in the current study, it is a large sample technique. Secondly, the study sample was not representative of the general public. That is, college or university educated younger females were overrepresented in the study population. Therefore both models should be examined among a larger and more representative sample. Thirdly, there may have been variables not measured or controlled for (such as involvement in a cancer charity), which may have impacted on the present results. Although randomization with counterbalancing participants across conditions provides greater confidence in the results.

Conclusions

Findings of this research indicate that public perception differentiates between cancer types on the basis of whether they are seen as largely preventable by
behavior and lifestyle choice, or by genetic or other uncontrollable factors. Therefore, research examining cancer stigma as a unitary construct is not appropriate. It was also found that perceptions of behavioral causation may make cancer patients more prone to stigmatization. These results support previous research which highlights negative affective reactions (e.g., pity, anger, and contempt) and behavioral responses triggered by controllability, and sheds light on the underfunding among some cancer groups (Gritz et al., 2007; Marlow et al., 2010).

In light of these results, there is a challenge between increasing public knowledge regarding risk factors associated with cancer, and preventing blame-based attributions that trigger stigmatizing reactions. As the burden of cancer continues to increase globally, early prevention strategies through health promotion has been recommended (Jemal et al., 2011). Yet the current results argue for a more nuanced public health message (e.g., informing the public which health behaviors can prevent disease and illness, while recognizing that changing engrained lifestyle factors is often difficult) such that information regarding the role of behavioral risk factors does not translate into increased stigmatization.
References


Chapter 4: Foreword

While Study 1 and Study 2 focused on examining cancer related stigma, Study 3 explores how stigma may impact on psychological well-being; in particular, its effects on cancer patients. Study 3 expands on Study 1’s findings, which demonstrated that cancer related stigma can lead to increased anger, fear, social distancing and reduced pity. Study 3 builds upon these results by exploring the role stigma has in a social context. The present research also sought to expand on Study 2’s findings that certain cancers are more stigmatised because of their “blameworthiness”, or association with lifestyle factors. Study 3 sought to recruit lung and skin cancer patients (perceived blameworthy), and breast and prostate cancer patients (perceived non-blameworthy) to compare their varied experiences of stigma. A comparison of stigma, social support and psychological well-being between blameworthy and non-blameworthy groups was difficult due to a surfeit of breast cancer patients. Study 3 nevertheless investigated how stigma can have a detrimental impact, and social support a positive impact, on cancer patients following diagnosis.

Study 3 used Structural Equation Modeling to examine two pathways (as described above) that ultimately impact on well-being among cancer patients. The positive role of social support was found to increase perceived positive change following diagnosis, and increase reported psychological well-being. Stigma negatively affected cancer patients as it was found to increase perceived negative changes following diagnosis and reduce psychological well-being. Unexpectedly, core belief examination was found to be a protective factor against the impact of negative change on
psychological well-being. When individuals engaged in high levels of cognitive processing about their beliefs about themselves and their world, this resulted in increased psychological well-being, whether or not changes after cancer were perceived to be positive or negative. The results offer increases understanding to the current understanding of the interplay between stigma, cognitions, positive and negative change, and psychological well-being.
Declaration

Title
The impact of stigma, social support and core belief examination on psychological well-being among cancer patients

Authorship
Jennifer Threader, Dr Sayed Ali, Professor Don Byrne and Dr Elizabeth Rieger

Publication Outlet
Psycho-Oncology

Current Status
Manuscript was submitted on August 26th 2014

Candidate Contribution
Threader designed the study, which was reviewed by Dr Ali, Professor Byrne and Dr Elizabeth Rieger. The Candidate recruited study participants, conducted the statistical analyses, and developed the initial manuscript. Dr Ali, Professor Byrne and Dr Rieger provided input on successive drafts of the manuscript.
Co-Author Signatures

Dr Sayed Ali

Professor Don Byrne

Dr Elizabeth Rieger
Article title:
The impact of stigma, social support and core belief examination on psychological well-being among cancer patients

Authors:
Jennifer Threader¹, Dr Sayed Ali¹², Professor Don Byrne¹ and Dr Elizabeth Rieger¹

¹Research School of Psychology, Australian National University, Australian Capital Territory, Australia
²Medical Oncology, The Canberra Hospital, Australian Capital Territory, Australia

Running title:
Cancer stigma, social support and psychological adjustment

Address for correspondence:
Jennifer Threader, Research School of Psychology,
Australian National University, Canberra, ACT 0200, Australia
Telephone: (02) 6125 4582, Fax: (02) 6125 0499
E-mail: jennifer.threader@anu.edu.au

Conflict of interest statement:
Jennifer Threader, Sayed Ali, Donald Byrne and Elizabeth Rieger declare no potential conflict of interest.
Abstract

Objective: Positive and negative changes occur in the aftermath of a traumatic event, including a cancer diagnosis. While social support may promote positive change, cancer patients may experience unhelpful support and stigma, which may increase negative change. Perceptions of positive versus negative changes may in turn impact on psychological well-being. The study aim was to examine potential pathways that ultimately result in well-being in cancer patients.

Methods: Breast, lung, skin, and prostate cancer patients (n = 113) completed an online survey of widely-used measures which assessed stigma, unsupportive interactions, social support, post-traumatic positive and negative changes, core belief examination and psychological well-being.

Results: Two structural equation models were used to predict low (Model 1) versus high (Model 2) well-being. Model 1 found stigma significantly predicted negative change. While core belief examination mediated the influence of negative change on well-being, unexpectedly, the relationship promoted well-being. In Model 2, social support (number of support partners, not satisfaction with support) increased positive change. Core belief examination mediated the influence of positive change and well-being.

Conclusions: Stigma increased negative change and subsequently reduced psychological wellbeing, which suggests that stigma has a deleterious effect post-cancer diagnosis. Core belief examination appeared to buffer these
deleterious effects, and suggests that it may be a protective factor. An increased number of support partners predicted positive change. Core belief examination positively mediated the relationship between positive change and well-being. The study highlights the impact of stigma and social support in influencing post-diagnosis psychological change, and core belief examination in buffering any negative effects.

**Key terms:** cancer stigma; oncology; social support; posttraumatic growth; negative change; psychological well-being
Background

The life-threatening and unpredictable nature of cancer can have a devastating impact on those diagnosed. Symptoms of posttraumatic stress disorder (PTSD) have been reported among cancer patients [1] and the high level of emotional distress has warranted regular monitoring as the sixth medical vital sign [2]. While evidence for adverse effects has been well documented among cancer patients, there is a more recent body of literature that has shown positive outcomes are also prevalent [3]. As the literature in the area of post-trauma changes continues to develop, one of the main research interests is to understand what factors influence continued distress in some cancer patients and psychological growth in others.

Posttraumatic growth refers to positive psychological changes (such as personal, relationship and philosophical growth) that develop as a result of confronting a challenging life circumstance [4]. It is proposed that, by struggling through these events, individuals are able to grow beyond their pre-trauma levels of adaptation. The benefits of posttraumatic growth are noteworthy, with increased growth found to predict psychological well-being among individuals exposed to a range of traumatic experiences (e.g., bereavement and rape) [5].

Experiencing posttraumatic growth, however, is not a definite outcome of trauma, and individuals may struggle with distress over the long-term following the experience of a traumatic event. For instance, a study conducted by Vin-Raviv and colleagues [1] found that, among the 1,139 breast cancer patients interviewed, 23% met criteria for PTSD at diagnosis. While symptoms decreased over time for most participants, at the six-month follow-up, 12.6% continued to experience PTSD. These symptoms can have
a lasting effect on well-being, as PTSD symptoms among breast cancer patients at diagnosis are associated with poorer functioning and lower quality of life 18 months later [6].

The investigation of specific post-traumatic factors influencing psychological change is an important area of research. For instance, post-trauma factors (e.g., failed social support and life stress) have been found to have a larger effect on PTSD than pre-trauma factors (e.g., education, psychiatric history, or child abuse) in a meta-analysis among traumatized individuals [7].

Following a range of adversities, social support has been identified as one such factor that is associated with posttraumatic growth [8]. The function of support can be expressed in many ways, including emotional support (e.g., demonstrating love and care), instrumental support (e.g., providing transportation to doctors' appointments), informational support (e.g., providing guidance on treatment decisions) and appraisal support (e.g., providing constructive feedback, affirmation) [9]. Empirical evidence has supported the role of social resources in predicting psychological well-being among cancer patients [10]. While there are likely multiple pathways that link social support with well-being, one potential trajectory is via the role of social support in producing positive changes in the patient's life (e.g., patients experiencing a greater sense of the degree to which they are cared for as a result of the social support they received). In turn, as cancer patients examine their experience in terms of how it has positively impacted on their beliefs about themselves, the world and the future, greater psychological well-being may ensue.
While social support may be beneficial in promoting well-being, a diagnosis of cancer can lead to strained communication, with resultant negative effects to the quality of interpersonal relationships [11]. Individuals who are trying to integrate trauma-related material might seek to talk with others about their experience [12]. However, significant others might provide unhelpful responses, such as minimizing the cancer patient's experience [13]. Indeed, a study among breast cancer patients found that, overall, the support provided to them by friends and family was inappropriate, and was often expressed as forced cheerfulness and optimism [14]. These reactions can have a lasting detrimental effect as negative interactions have been found to have a stronger impact than positive interactions on well-being and distress among cancer patients [15].

Unsupportive interactions may occur as a result of cancer-related stigma, which in itself can disrupt the normal course of social interaction [16]. Among cancer patients, stigma has been implicated in causing strain in relationships [14] and increasing distress [17]. Stigma refers to a devaluing attribute that leads the bearer to be set apart and rejected [18], and may contribute to the social avoidance and withdrawal that have been shown to be commonly reported among cancer patients following diagnosis [19]. Therefore, stigmatizing and unhelpful responses from social networks as a result of having cancer may influence post-diagnosis negative changes (e.g., reduced coping abilities and strained relationships). As patients examine the negative changes that have occurred in their life post-diagnosis (e.g., a deterioration in their relationship with others), psychological well-being may be reduced.
The primary aim of the present study is to understand what factors influence continued distress in some cancer patients and posttraumatic growth in others. Among individuals diagnosed with four common cancers, the present study seeks to investigate the role of stigma and social support in influencing negative versus positive post-diagnosis psychological change respectively and, in turn, how these changes predict well-being. As shown in Figure 1, two hypothesized models will be tested. In the first model, it is hypothesized that stigma will predict negative change via its impact on the quality of the cancer patient’s interactions with others (i.e., unsupportive interactions will mediate the relationship between stigma and negative change). It is further hypothesized that negative change will predict lower psychological well-being, and that this relationship will be mediated by the cancer patient’s reflection on the negative changes to their core beliefs. For the second model, it is hypothesized that social support (both number of support partners, and satisfaction with support) will significantly predict positive change; and that core belief examination will mediate the relationship between positive change and increased psychological well-being.
Figure 1. Hypothesized conceptual models (Model 1 top) for analysis
Method

Participants

Participants included breast, lung, prostate and skin cancer patients, over 18 years of age, who had been diagnosed in 2013 at a leading teaching hospital in Australia. Letters were sent to the homes of eligible participants in March 2014, informing them of an online study being conducted to understand their experience with cancer. One hundred and thirty seven participants (40% response rate) followed the online link and consented to participate in the study. There was no incentive to participate. Twenty-four entries were excluded from analyses due to incomplete responses, resulting in a final sample of 113 participants (n = 77 breast cancer patients, n = 20 lung cancer patients, n= 8 prostate cancer patients and n = 8 skin cancer patients). Demographic details are contained in Table 1.
Table 1.

*Participant characteristics (n = 113)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>62.86</td>
<td>12.88</td>
</tr>
<tr>
<td>Time Since Diagnosis (months)</td>
<td>9.41</td>
<td>3.24</td>
</tr>
<tr>
<td>Gender % Female</td>
<td>80.5</td>
<td></td>
</tr>
<tr>
<td>Relationship</td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>Single</td>
<td>29</td>
<td>25.6</td>
</tr>
<tr>
<td>In a relationship</td>
<td>8</td>
<td>7.1</td>
</tr>
<tr>
<td>Married</td>
<td>75</td>
<td>66.4</td>
</tr>
<tr>
<td>Education (highest level)</td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>Year 10 certificate or below</td>
<td>23</td>
<td>20.4</td>
</tr>
<tr>
<td>Year 12 certificate</td>
<td>18</td>
<td>15.9</td>
</tr>
<tr>
<td>Trade certificate/Diploma</td>
<td>25</td>
<td>22.1</td>
</tr>
<tr>
<td>University or College degree</td>
<td>30</td>
<td>26.5</td>
</tr>
<tr>
<td>Postgraduate Degree</td>
<td>17</td>
<td>15.0</td>
</tr>
<tr>
<td>Employment status</td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>Working</td>
<td>47</td>
<td>41.6</td>
</tr>
<tr>
<td>Not working</td>
<td>20</td>
<td>17.7</td>
</tr>
<tr>
<td>Retired</td>
<td>46</td>
<td>40.7</td>
</tr>
<tr>
<td>Smoking status</td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>Never Smoked</td>
<td>50</td>
<td>44.2</td>
</tr>
<tr>
<td>Past smoker (&gt; 3 months)</td>
<td>57</td>
<td>50.4</td>
</tr>
<tr>
<td>Current smoker</td>
<td>6</td>
<td>5.3</td>
</tr>
<tr>
<td>Treatment for current cancer</td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>Currently being treated</td>
<td>66</td>
<td>58.4</td>
</tr>
<tr>
<td>Surgery</td>
<td>90</td>
<td>79.6</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>72</td>
<td>63.7</td>
</tr>
<tr>
<td>Radiotherapy</td>
<td>74</td>
<td>65.5</td>
</tr>
<tr>
<td>New cancer</td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>New cancer</td>
<td>88</td>
<td>77.9</td>
</tr>
<tr>
<td>Recurrence</td>
<td>24</td>
<td>21.2</td>
</tr>
<tr>
<td>Stage</td>
<td>Frequency</td>
<td>%</td>
</tr>
<tr>
<td>Local</td>
<td>60</td>
<td>53.1</td>
</tr>
<tr>
<td>Advanced</td>
<td>40</td>
<td>35.4</td>
</tr>
</tbody>
</table>

NOTE. Some frequency values do not all sum to 113 because of missing data. *Treatment for current cancer* reflects the type of treatments individuals received and do not sum to 113.
Measures

Social Impact Scale (SIS; [20])

The SIS is a 24-item scale that was used to examine cancer-related stigma. It was developed based on HIV and cancer patients' perceptions of being stigmatized. Respondents are required to respond on a four-point Likert scale ranging from “Strongly agree” to “Strongly disagree”. Items on the SIS include, “I feel I am at least partially to blame for my illness.” Higher scores indicate higher levels of perceived stigma. The scale has established reliability and validity [20]. In the current study, Cronbach’s alpha was 0.92.

Unsupportive Social Interactions Inventory (USII; [21])

The USII is a 24-item scale that was used to measure unhelpful responses that someone may receive following a stressful life event. On a five-point Likert scale (“None” to “A lot”) respondents rate how often they have received the particular unsupportive response (e.g., “Told me to be strong, to keep my chin up, or that I should not let it bother me”). Internal consistency reliability has been established [21]. In the current study, the Cronbach’s alpha was 0.90.

Social Support Questionnaire-Brief (SSQ-B; [22])

The SSQ-B is a six-item measure which was used to assess participant’s social support. Each question has two components: firstly, participants identify the number of people whom they feel provide support in a particular situation (SSQN subscale); and secondly, participants rate how satisfied they are with their support (SSQS subscale). Mean scores from
both subscales are used to assess the degree of perceived social support, with higher scores indicating greater support. The SSQ-B is strongly correlated with the original 27-item Social Support Questionnaire, which has shown good psychometric properties [23]. Chronbach’s alpha for the SSQN in the current study was 0.73, while the SSQS was 0.93.

*Changes in Outlook Questionnaire – Short form (CiOQ-S; [24])*

The CIOQ-S is a shortened version of the 26-item Changes in Outlook Questionnaire (CiOQ), and contains 10 self-report items to assess the positive and negative changes that can result from a traumatic event. This scale was used to understand psychological changes after being diagnosed with cancer. Respondents are required to respond, on a six-point Likert scale ranging from “Strongly disagree” to “Strongly agree”, to questions based on positive changes (CiOP short; “I'm a more understanding and tolerant person now”) and negative changes (CiON short; “I don't look forward to the future anymore”). The CiOP and CiON scales of the short form correlate well with the original scales on the CIOQ ($r = 0.93$ and $r = 0.89$, respectively) [24]. In the current study, Chronbach’s alpha was 0.83 for the CiOP and 0.78 for the CiON.

*Core Beliefs Inventory (CBI;[25])*

The CBI was used to examine the degree to which participants’ core beliefs had been examined as a result of dealing with cancer. The CBI consists of nine items, with responses on a six-point Likert scale ranging from “Not at all” to “To a very great degree”, to questions including “Because of the event, I seriously examined my beliefs about my relationships with other people”. The CBI has established construct validity and good internal
consistency [25]. Chronbach's alpha for the CBI in the present study was 0.90.

Psychological Well-Being—Post-Traumatic Changes Questionnaire (PWB-PTCQ; [5])

The PWB-PTCQ is an 18-item self-report measure, which is used to examine perceived changes in psychological well-being following a traumatic event. Respondents are asked to respond on a five-point Likert scale ("Much less so now" to "Much more so now"), with higher scores indicating greater well-being. Items on the PWB-PTCQ include, "I accept who I am, with both my strengths and weaknesses". The PWB-PTCQ has high internal consistency ($\alpha > 0.87$), and high convergent and predictive validity [5]. Chronbach’s alpha for the PWB-PTCQ in the present study was 0.92.

Procedure

Prior to study commencement, ethics approval was cross-institutionally obtained from The Australian National University and the participating hospital. Participants completed a demographic survey and the self-report questionnaires, and were subsequently debriefed, online. All participants received the same questionnaire order, which were administered as follows: (1) SSQ-B, (2) USII, (3) SIS, (4) CBI, (5) CiOQ, (6) PWB-PTCQ.

Statistical Analysis

The preliminary statistical analyses for the present study were performed using the Statistical Package for Social Sciences (SPSS, Version 22)
software program. Specifically, statistical assumptions relating to Structural Equation Modelling (SEM) were conducted. SEM requires a large number of observations and at a minimum the ratio of cases per estimated parameter should be greater than 5:1 [26]. The ratio for both final models was above this cut-off mark (i.e., 9:1 for Model 1, 10:1 for Model 2), indicating a large enough sample to perform this analysis. Statistical assumptions relating to normality, linearity, multicollinearity and singularity were also analyzed. Due to non-normal distribution among dependent variables (i.e., significant skew in USII, CiON and PWB-PTCQ scales), the bootstrap method for structural equation modeling [27] was applied in all subsequent analyses. Linear relationships were observed between dependent variables and there was an absence of multicollinearity and singularity. Prior to testing the hypothesized models, relationships between variables were assessed using Pearson correlations.

Structural Equation Modeling analysis was conducted using the Statistical Package for Social Sciences Analysis of Moment Structures (SPSS AMOS, Version 22) software program. Maximum likelihood procedure and bootstrapping on 1,000 samples (using the ML estimator) was applied. The hypothesized covariates (i.e., age, education level and employment status) were added in to the path analysis, to assess whether they had significant influence on each SEM and would be included in the final models. The model fit was assessed by examining the chi-square statistic, the Normed Fit Index (NFI;[28]) the Incremental Fit Index (IFI;[29]) and the Comparative Fit Index (CFI:[30]). These fit indices were chosen based on previous research examining similar constructs to the present study [3, 31]. In addition, index choice was made based on the current small sample size and
degrees of freedom [32-34].

**Results**

**Preliminary Analyses**

Correlations, means and standard deviations for each variable are shown in Table 2. Most variables were associated with each other to support study hypotheses. In support of the first model, stigma and unsupportive interactions significantly positively correlated with negative change, and negative change was positively associated with core belief examination and negatively psychological well-being. In regards to the second model, both forms of social support were positively associated with positive change, and positive change was significantly positively associated with core belief examination and psychological well-being. Age, education level and gender variables were added into each model as covariates. While age and education level did not significantly influence both models, gender approached significance \((p = 0.07)\) in the first model, and was a significant covariate in the second \((p < 0.05)\). Therefore, gender was only added as a covariate in the second model.
Table 2.

*Pearson correlations between study variables*

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. USII</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. SIS</td>
<td>.38***</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. CiON</td>
<td>.24*</td>
<td>.52***</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. SSQN</td>
<td>-.17</td>
<td>-.16</td>
<td>-.21*</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. SSQS</td>
<td>-.20*</td>
<td>-.33**</td>
<td>-.24*</td>
<td>.26**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. CiOP</td>
<td>.06</td>
<td>.05</td>
<td>.00</td>
<td>.32**</td>
<td>.15</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. CBI</td>
<td>.40***</td>
<td>.34***</td>
<td>.26**</td>
<td>.04</td>
<td>-.11</td>
<td>.30**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. PWB-PTC</td>
<td>.13</td>
<td>-.07</td>
<td>-.34***</td>
<td>.28**</td>
<td>.15</td>
<td>.38***</td>
<td>.35***</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p < .05, **p < .01, ***p < .005*
Model 1: Stigma, negative change, core belief examination and psychological well-being

The hypothesized model was only partially supported. That is, while stigma significantly predicted negative change, unsupportive interactions did not ($p = 0.64$). In addition, the model was not a good fit to the data, as the chi-square statistic was significant ($X^2 (4, n = 104) = 19.07, p < 0.01$) and indices were below the 0.90 cut-off (i.e., NFI = 0.84, IFI = 0.87, CFI = 0.87).

Post hoc model modifications were performed in an attempt to improve model fit. The unsupportive interactions construct was removed from the analysis as it did not significantly contribute to the model. The final model is shown in Figure 2. Model fit improved, as evidenced by a non-significant chi-square statistic ($X^2 (2, n = 104) = 5.26, p > 0.05$) and fit indices above 0.90 (i.e., NFI = 0.94, IFI = 0.96, CFI = 0.96), which supported the appropriateness of the new model. As predicted, stigma significantly predicted increased negative changes experienced by participants, which in turn significantly predicted reduced psychological well-being. The predicted influence of core belief examination mediating the effect of negative change on psychological well-being was only partially supported. While negative change significantly increased core belief examination, unexpectedly core belief examination predicted increased psychological well-being.
Model 2: Social support, positive change, core belief examination and psychological well-being

The hypothesized model (Figure 1) demonstrated poor fit, as the SEM was unidentified. Post hoc model changes were conducted in order to improve fit. Based on theoretical relevance, three residual covariances were estimated (residual covariance between number of support partners and satisfaction with support, and the residual covariances between both forms of support and gender). The model fit improved, as evidenced by the fit indices (NFI = 0.88, IFI = 0.95, CFI = 0.95), and by a non-significant chi-square statistic ($X^2 (6, n = 109) = 9.32, p > 0.05$). The role of social support in predicting positive change was only partially supported. That is, number of support partners, but not satisfaction with support, predicted increased positive change. Thus an additional post-hoc modification was performed to remove satisfaction with support. Model fit improved, as evidenced by a non-significant chi-square statistic ($X^2 (4, n = 109) = 5.76, p > 0.05$), and indices of fit above the 0.90 cut-off (i.e., NFI = 0.91, IFI = 0.97, CFI = 0.97), which supported the appropriateness of the new model (Figure 2).

As predicted, when gender was controlled for as a covariate, social support (i.e., number of support partners) significantly predicted increased positive change, which in turn predicted a significant increase in psychological well-being. As hypothesized, core belief examination mediated the positive relationship between positive change and psychological well-being.
Figure 2: Final study models demonstrating pathways to high and low psychological well-being. Model 1 represents the influence of stigma on psychological well-being (top) and Model 2 models the influence of social support on psychological well-being.
Discussion

The primary aim of the present study was to identify factors that predict positive versus negative change following cancer diagnosis, and ultimately psychological well-being, with a focus on the role of social factors. Guided by stigma theory [18] and literature detailing the emergence of unsupportive interactions following cancer diagnosis [13, 14], it was hypothesized that high levels of stigma (which result in unsupportive interactions) would significantly increase the degree of perceived negative change post-diagnosis. Furthermore, it was hypothesized that an examination of these negative changes to the cancer patient’s core beliefs would result in reduced well-being.

Our results partially supported this model as stigma, but not unsupportive interactions, significantly predicted greater negative change. It is unclear as to why unsupportive interactions were not associated with negative change. One possible reason is that the questionnaire does not assess the respondent’s perceptions of whether the interaction was positive or not; instead it assumes that these responses are negative. Additionally, perceived negative change was found in the present study to significantly predict reduced psychological well-being. The latter finding supports previous research which found stigma to be associated with psychological distress [17], increased depression, and reduced quality of life [35]. Therefore, stigmatizing reactions may have ongoing negative consequences for cancer patients, as post-trauma effects have been found to have a stronger impact than pre-trauma characteristics on negative adjustment among traumatized individuals [7].
The role of core belief examination in mediating the impact of negative change and psychological well-being was only partially supported. That is, while negative change predicted increased core belief examination, unexpectedly, core belief examination promoted psychological well-being. The present results suggest that examining core beliefs following a traumatic event may be a protective factor in terms of psychological well-being. For instance, it may be that individuals who have experienced negative change as a result of stigmatizing reactions are able to adjust their expectations of others through the process of examining their core beliefs, with this greater sense of acceptance in turn promoting psychological well-being. This conclusion supports previous research which has found that following a traumatic event, if individuals engage self-reflection (i.e., attempt to derive meaning from the event) which results in changing previously held core beliefs, it promotes psychological growth [36].

In terms of the second model, the hypothesized role of social support in predicting positive change, and in turn psychological well-being, was only partially supported in that the number of support partners increased positive change, but satisfaction with support did not. Having many support partners could have impacted on the diversity of support available (i.e., various forms of both structural and functional support) [37], which may have promoted positive psychological change despite the stressors of the cancer experience [38]. The finding that satisfaction with social support did not predict positive change was unexpected. Perhaps an alternative measure of satisfaction with support, such as relationship-specific satisfaction [39], may have been implicated in influencing positive change. Alternatively, the lack
of a relationship between satisfaction with support and positive change may have been due to a ceiling effect on the measure of satisfaction, which is often found in social support measures [22].

The hypothesized role of core belief examination in mediating the relationship between positive change and psychological well-being was also supported. Therefore, perceived positive change leads to the development of psychological well-being, particularly when individuals have engaged in cognitive processing about their experience, namely, examining their core beliefs about themselves, the world and the future [36].

**Limitations and Future Directions**

There are several limitations in the present study that must be noted in interpreting the findings. Firstly, the cross-sectional design employed in the present study prevented drawing firm conclusions regarding causal interpretations of the results. Therefore, future research would benefit from prospective studies examining the role of stigma and unsupportive interactions as a potential post-traumatic factor leading to low psychological well-being, and the roles of multiple support partners and the processing of core beliefs in buffering these effects.

Secondly, there were various limitations pertaining to the sample. While four common cancers were targeted in the study, the majority of participants were breast cancer patients. Therefore, the generalizability of these findings to other cancers may be limited. Relatedly, the current sample included an over-representation of women. This may have biased results as women have been found to be more inclined than males to seek social support in times of distress [40] and disruption to this through stigmatizing reactions may have
therefore had a more prominent impact on negative changes. In addition, although minimum sample size for SEM was obtained in the current study, it is a large sample technique. Future research would benefit from a larger, more representative oncology sample. Finally, while the study response rate (44.0%) was consistent with what has been reported in previous literature examining psychosocial outcomes among cancer patients [3], those who did not participate may have significantly differed from the study sample (e.g., the nature of the topics investigated – stigma and unsupportive interactions – may have impacted on study participation).

Conclusions

The present study extends findings in the post-trauma literature concerning the impact of stigma and social support on psychological outcomes among cancer patients. Specifically, stigma was found to significantly predict negative change, while an increased number of support partners significantly predicted positive change. Cognitive processing, through an examination of core beliefs, was found to positively influence psychological well-being, in the context of either positive or negative changes following a cancer diagnosis. Therefore, core belief examination may act as a protective factor against the adverse impact of perceived negative changes on well-being.
References


8. Prati G, Pietrantoni L. Optimism, social support, and coping strategies as factors contributing to posttraumatic growth: A meta-


Chapter 5: Foreword

Chapter 5 describes the final study in this program of research which used qualitative methodology to explore the distress and stigma associated with head and neck cancer, and how individuals were able to find meaning from their experience, and the positive and negative changes that resulted. The study included nine head and neck cancer patients, who had surgical resection to remove cancerous areas. Head and neck cancer patients were chosen as the study population, given they have been found to report high levels of distress compared to individuals with other cancer types, and are prone to high stigmatisation as a result of facial changes which can result from surgical resection (abomination of the body), lifestyle factors perceived to be linked with onset (blemishes of individual character), and as a result of poor prognosis commonly diagnosed among head and neck cancers (peril).

Using Interpretative Phenomenological Analysis, Study 4 identified that head and neck cancer patients face high levels of distress associated with diagnosis, treatment and survivorship. Contributing to this distress was the stigma that participants felt and experienced as a result of physical changes following cancer, their lifestyle choices prior to onset and as a result of having a life-threatening illness. The psychological growth that developed from these experiences included increased altruism, understanding and self-acceptance. Study 4 provides evidence for both the positive and negative changes that can result from distress and stigma.
Declaration

Title

Cancer related trauma, stigma and growth: The ‘lived’ experience of head and neck cancer

Authorship

Jennifer Threader, Dr Lynne McCormack

Publication Outlet

European Journal of Cancer Care

Current Status

Manuscript was submitted on October 8th 2014.

Candidate Contribution

The Candidate and Dr McCormack co-designed the study and co-developed the interview schedule. The Candidate conducted recruitment, qualitative interviews, and transcribed interviews verbatim. Both authors independently conducted preliminary analysis of themes, which were reviewed and refined during a collaborative meeting on May 21st 2014. The candidate developed the initial manuscript and Dr McCormack provided input on successive drafts of the manuscript.
Co-Author Signature:

Mc Cormack Ph.D.

Dr Lynne McCormack
Cancer-related trauma, stigma and growth: the 'lived' experience of head and neck cancer

J. THREADER, PHD, CANDIDATE, Research School of Psychology, Australian National University, Canberra, ACT & L. MCCORMACK, PHD, SENIOR LECTURER/CLINICAL PSYCHOLOGIST, Faculty of Science and IT, School of Psychology, University of Newcastle, Callaghan, NSW, Australia


Head and neck cancer is associated with multiple layers of distress including stigma. Stigma attraction or devalued social identity is twofold: [1] it is a cancer associated with lifestyle risk factors and [2] treatment often results in confronting facial disfigurement. Subjective interpretations from nine head and neck cancer patients were analysed using Interpretative Phenomenological Analysis. An overarching superordinate theme – Distress, Stigma and Psychological Growth – encompassed four subordinate themes. Two themes captured the expressed trauma and terror as a result of diagnosis and treatment, and two the redefining of self despite stigma through meaning making. Distress was interpreted as a catalyst for awakening new life interpretations and combined with social support to facilitate two distinct pathways of growth: [1] psychological growth without support; [2] psychological and relational growth with support. Previously unfelt empathetic understanding and altruism for others with cancer emerged from the impact of stigma on ‘self’. Acceptance allowed a new sense of identity that recognised cancer-related traumatic distress as integral to growth for these participants. The present study offers a unique insight into cancer-related trauma and stigma and the potential to redefine a more accepting, empathic and altruistic ‘self’ for psychological growth. Implications are discussed.

Keywords: IPA, stigma, cancer-related trauma, post-traumatic growth.

INTRODUCTION

Dealing with a cancer diagnosis and its associated treatments can be fear-provoking and life-altering. Many report helplessness and/or horror sensing that their life had been threatened as a result of their experience (Cordova et al. 2007). In addition to the terrifying shock at diagnosis, each cancer brings with it unique challenges to physical and psychosocial functioning (Stanton 2006). In particular, head and neck cancer patients may be at risk for increased distress (Frampton 2001; Zabora et al. 2001; Carlson et al. 2004), as life-saving surgical intervention often leave them with significant and visually confronting changes to their facial appearance. Unfortunately, these physical changes may also impact on their functional ability to eat, swallow and speak, resulting in a reduced quality of life. Compounding the distress, disfigurement and disablement can attract unpredictable and even stigmatising responses from others (Macgregor 1990). Despite these known physical and psychosocial consequences, there is a paucity of research exploring the ‘lived’ experience of head and neck cancer. Therefore, this study will explore both positive and negative subjective interpretations of experiencing head and neck cancer. Through reflective semi-structured interviews, it seeks to understand how these participants have socially constructed, interpreted and made sense of: [1] being diagnosed with head and neck cancer; [2] disfiguring and invasive surgical intervention; and [3] social support and societal responses to this type of cancer.
Stigma refers to an attribute, visible or non-visible, that identifies the individual as being part of a social category that is undesirable [Jones et al. 1984]. The bearer of stigma becomes segregated, 'devalued' and 'discredited' [Goffman 1963, p. 3]. For those struggling with the aftermath of a cancer diagnosis, cancer-related stigma increases illness burden and can lead to physical, social and psychological morbidity [Peters-Golden 1982; Gamba et al. 1992; Fife & Wright 2000]. For example, stigma can result in reduced self-esteem [Fife & Wright 2000], is likely to increase isolation and strain social relationships [Peters-Golden 1982], and lead to delayed symptom reporting [Tod et al. 2008]. These consequences do not independently impact on cancer patients; they are likely to be multifaceted, inter-related and exacerbate each other. Furthermore, given positive social support has been found to assist in helpful coping and recovery in chronic illness [Suls 1982], the effects of stigma pose challenges to a cancer patient's self-concept and recovery.

There are several stigmatising factors that uniquely impact on the aftermath of head and neck cancers. For instance, as the facial region is an important aspect of an individual's identity, changes to facial appearance often cause extreme distress and embarrassment [Macgregor 1990; Fingeret et al. 2012]. Consequently, body image concerns are highly prevalent among head and neck cancer patients [Fingeret et al. 2012]. Furthermore, facial disfigurement may impact on an individual's sense of self [Callahan 2005] and well-being [Dropkin 1999] as a visible stigma '… can provide the primary schema through which everything about them is understood' [Crocker et al. 1998, p. 507]. In fact, facial surgery associated with head and neck cancer has been described as a destruction of self [Turpin et al. 2009].

Head and neck cancer has been described as one of the most emotionally traumatic types of cancer [Breitbart & Holland 1988; Dropkin 1989]. Those with head and neck cancer face a 'dual burden'; in addition to adjusting to the physical change and debilitation following treatment, treatment itself for head and neck cancer can be particularly distressing, as it has been associated with increased anxiety and significant pain [Dropkin et al. 1983; Dropkin 2001]. These negative effects can lead to physical and psychosocial impairment. Physically, treatment can cause extreme pain and dryness in mouth and neck areas, impacting on difficulties eating and drinking. Consequently, recovery can be long, resulting in delayed return to work, limited ability to engage in social activities and isolation [Krouse et al. 1989]. For many, resultant functional debilitations may further exacerbate and prolong psychosocial difficulties by impairing communication, interfering with social interactions and relationships [Koster & Bergsma 1990] resulting in feelings of isolation and restricting social activities [Gamba et al. 1992]. Sadly, stigma associated with facial disfigurement and disfigurement following surgery can add to that emotional distress, impacting on reduced self-esteem, social anxiety, self-consciousness, depression and quality of life [Krouse et al. 1989; Devins et al. 1994; Clarke 1999].

Beliefs about personal behaviours associated with certain cancers may also impact on feelings of stigmatisation, the trajectory of recovery and sense of self. Lifestyle risk factors associated with head and neck cancers, including alcohol and tobacco consumption [Castellsague et al. 2004], and human papilloma virus (HPV) infection [Hererro et al. 2003], can attract blame and stigma. Yet, research investigating stigma associated with perceived onset controllability among head and neck cancer is very limited [Lebel & Devins 2008]. However, there is a growing research base documenting the stigmatisation associated with smoking and lung cancer. Several research studies have reported that lung cancer patients are more stigmatised than individuals diagnosed with other cancer types, because lung cancer is perceived to be a self-inflicted disease [Chapple et al. 2004]. Among lung cancer patients, this stigma has been found to lead to delayed symptom reporting and increased distress [Raleigh 2010] including feelings of guilt and depression [Kuo & Ma 2002]. Behavioural risk factors associated with head and neck cancer, such as alcohol consumption and smoking cigarettes, can elicit blameworthy attributions. As a result, patients are at risk of encountering stigmatising attitudes. Therefore, patients with head and neck cancer are at risk of psychological distress due to both the impact of the cancer diagnosis and its associated stigmatising reactions.

While distress has been associated with poorer functioning [Hegel et al. 2008], a growing body of research has documented that it can be the catalyst for psychological growth and personal development and helps explain why some individuals achieve increased psychological well-being after a traumatic event [Joseph & Linley 2005; Joseph 2011; Joseph et al. 2012]. These individuals find meaning from the event and accommodate trauma-related material in a way that strengthens personal, philosophical and relationship values [Joseph 2011]. Understanding how individuals find meaning and develop positive change following cancer diagnosis and treatment is important, given post-traumatic growth has been associated with increased quality of life and protection from depression among breast cancer survivors [Morrill et al. 2008].

While post-traumatic growth theory highlights the critical role of positive social support [Ryff 1989; Tedeschi &
Calhoun 1995; Joseph & Linley 2005), recent research suggests that an individual's intrinsic drive to make meaning of distressing events may facilitate a positive redefining of self over time irrespective of positive, and despite negative, external support (McCormack & Joseph 2014). Similarly, a small but burgeoning literature suggests that positive outcomes can occur despite the stigma experienced by head and neck cancer patients (Ruf et al. 2009; Thambyrajah et al. 2010; Llewellyn et al. 2013). In fact, early findings suggest that post-traumatic growth can lessen the negative effect of cancer stigma on psychosocial outcomes (Lebel et al. 2013a).

Several aspects of journeying with head and neck cancer are poorly explored. The role of positive social support for psychological growth is posited as necessary (Joseph 2011) suggesting growth is unachievable post-trauma without positive support. Recent studies, however, suggest that growth is possible without support, though delayed (McCormack & Joseph 2013, 2014). Several studies have posited that the relationship between post-traumatic distress and growth following trauma is curvilinear with a critical point for cognitive processing (Butler et al., 2005). Purposeful rumination is said to be the central tenet to that curvilinear relationship and is therefore regarded as key to growth following trauma (Calhoun & Tedeschi, 1999; Nolen-Hoeksema & Davis, 2004). How social support impacts on that central tenet is currently unknown.

Similarly, distress, stigma (Peters-Golden 1982; Gamba et al. 1992; Fife & Wright 2000) and post-traumatic growth (Lebel, 2013b) are recognised individually in the cancer literature, but little is known regarding subjective interpretations of the co-experience of all three among those who have experienced head and neck cancer. Therefore, using Interpretative Phenomenological Analysis (IPA; Smith 1996), this study aims to add to the extant literature by exploring both positive and negative subjective interpretations of experiencing head and neck cancer. Particularly, it seeks to understand how these participants have socially constructed, interpreted and made sense of: (1) being diagnosed with head and neck cancer, (2) experiencing invasive surgical intervention, and (3) social support and societal responses to this type of cancer.

**METHOD**

**Participants**

Nine participants, eight male and one female, with a history of head and neck cancer were recruited through nursing referral at a leading teaching hospital in Australia. Participants were eligible if they had been surgically treated for head and neck cancer, which had resulted in changes to their facial appearance. This was assessed by the Cancer Nurse Coordinator who had many years of experience working with individuals diagnosed and treated for head and neck cancer. All participants had been treated with a neck dissection to remove cancerous areas. Table 1 outlines demographic characteristics of each participant. Pseudonyms are used to protect confidentiality.

**Procedure**

Following human ethical clearance, participants were sourced through referral from head and neck cancer nurse coordinators, who had been briefed about the project and provided with information regarding eligibility criteria for the study. Participants were subsequently contacted by telephone with information about the study. Study materials including the participant information form, consent form and outline of the semi-structured interview were sent to participants prior to the interview, to help ensure that participants were fully aware of the study's purpose and the material to be covered (Smith et al. 2009). The one-on-one interviews were conducted at a time and location most convenient for both parties.

All interviews were audio-recorded using a digital voice recorder and ranged in duration from 40 to 93 min. Participants received a $25(AUD) gift voucher. The interviews were guided by semi-structured questions, which 'funnelled down' interview material to the topic of interest (Smith & Osborn 2008). The flexible nature of the interviews allowed participants to engage in the double hermeneutics of the dialogue freely and openly, exposing the phenomenon of study interest.

**Epistemology**

The philosophical underpinnings of the present study rely on phenomenology, critical realism and symbolic interactionism (Denzin 1995). Therefore, it aimed to describe the way in which each participant's world was constructed, interpreted and understood (Spinelli 2005) by allowing the participants to reflectively interpret the immensurable realities of their experience of head and neck cancer (Blaikie 1991). As symbolic interactionism (Blumer, 1969) is the process of interaction in the formation of meanings for individuals, phenomenological studies offer the opportunity for researchers and participants to understand how individuals are influenced by their social interaction, and by the dynamic nature of meaning, which is modified through their interpretation. As the participant's world is always dependent on interpretation of their environment the meaning participants of
Table 1. Participant characteristics

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Time between surgery and interview [approx.]</th>
<th>Specific Head and Neck cancer</th>
<th>Onset information</th>
<th>Stage</th>
<th>Other treatments</th>
</tr>
</thead>
<tbody>
<tr>
<td>'Shannon'</td>
<td>89</td>
<td>F</td>
<td>9 months</td>
<td>Parotid sweat gland adenocarcinoma</td>
<td>N/A</td>
<td>T1N1M0</td>
<td>Radiotherapy</td>
</tr>
<tr>
<td>'James'</td>
<td>72</td>
<td>M</td>
<td>9 months</td>
<td>Squamous cell carcinoma - floor of mouth</td>
<td>Non-viral – participant attributes to smoking</td>
<td>T4N0M0</td>
<td>Radiotherapy</td>
</tr>
<tr>
<td>'Kevin'</td>
<td>75</td>
<td>M</td>
<td>6 months</td>
<td>Metastatic squamous cell carcinoma</td>
<td>Non-viral</td>
<td>TxN1Mx</td>
<td>Radiotherapy</td>
</tr>
<tr>
<td>'Matt'</td>
<td>57</td>
<td>M</td>
<td>1 year, 2 months</td>
<td>Squamous cell carcinoma – of tongue base</td>
<td>Viral [p16 positive] – participant attributes to HPV</td>
<td>T2N2aM0</td>
<td>Radiotherapy and chemotherapy</td>
</tr>
<tr>
<td>'Felix'</td>
<td>42</td>
<td>M</td>
<td>10 months</td>
<td>Squamous cell carcinoma – floor of mouth</td>
<td>Non-viral – participant attributes to smoking</td>
<td>T2N0M0</td>
<td>Radiotherapy and chemotherapy</td>
</tr>
<tr>
<td>'Derek'</td>
<td>36</td>
<td>M</td>
<td>1 year, 2 months</td>
<td>Basaloid squamous cell carcinoma – right mandible</td>
<td>Viral [p16 positive] – participant attributes to HPV</td>
<td>T0T2bMx</td>
<td>Radiotherapy, incomplete chemotherapy Radiotherapy</td>
</tr>
<tr>
<td>'Don'</td>
<td>51</td>
<td>M</td>
<td>3 months</td>
<td>Squamous cell carcinoma – floor of mouth</td>
<td>Non-viral</td>
<td>T2N1M0</td>
<td>Radiotherapy</td>
</tr>
<tr>
<td>'Ralph'</td>
<td>56</td>
<td>M</td>
<td>1 month</td>
<td>Squamous cell carcinoma – right neck</td>
<td>Non-viral</td>
<td>TxN2Mx</td>
<td>Radiotherapy and chemotherapy</td>
</tr>
<tr>
<td>'Paul'</td>
<td>58</td>
<td>M</td>
<td>2 months</td>
<td>Squamous cell carcinoma – lateral tongue</td>
<td>Non-viral</td>
<td>T1N1Mx</td>
<td>Radiotherapy and chemotherapy</td>
</tr>
</tbody>
</table>

F, female; M, male.

this study ascribed to their experience with head and neck cancer were influenced by the subjective meaning participants brought to them. Relatedly, a critical realist perspective embraces hermeneutic exploration where individuals are constantly finding meaning and interpreting their environment to inform their behaviours (Gadamer 1983). This methodological approach highlights the multiple ways in which an experience can be construed, and moves beyond the discord between objectivism and relativism paradigms (Bernstein 1983). These interpretations fit with both the objectivism stance, which argues that there is only a single valid perspective for meaning making, and the relativism perspective, which contends that there is no absolute truth and that perspectives vary by individual. Through this lens, the study used IPA to analyse the data.

Analysis

Data were collected by use of an audio recording device. Interviews were transcribed verbatim by the first author. Following steps outlined by Smith et al. (2009), first, each author independently read and re-read the transcripts, with initial note taking made on the left-hand side; specific font style denoted descriptive, linguistic and conceptual content. Second, material was reviewed independently, incorporating psychological theories and abstractions. These specific themes and short phrases were placed on the right-hand side of the transcript. Third, each author collated emergent themes that began to develop by identifying the inter-connections and patterns in the exploratory notes. When the procedure was complete for each transcript, the two authors met for robust discussion to agree on convergent and divergent themes. The process was repeated for each transcript. The final stage included developing higher order themes and subthemes across the data set. A step-by-step analysis of the analytic process is provided in Table 2.

Credibility

Rather than provide evidence for inter-reliability and causal relationships often found in quantitative research, the current research employed a detailed audit trail for data review (Smith et al. 2009). That is, the audit sought to provide the reader with an account of the data that was analysed in a systematic manner. Data achieved internal coherence, credibility and interpretive rigour, through this detailed audit trail (i.e. raw data, transcripts, notes, diagrams) with robust discussions checking for biases and presuppositions at every level (Smith & Osborn 2008).

The first author conducted and transcribed each of the interviews verbatim. Both authors conducted completely independent analyses of the transcripts. Authors met to review independently reviewed transcripts, during which common themes were checked for authenticity, and inde-
Table 2. Outline of the stages involved in the Interpretative Phenomenological Analysis

<table>
<thead>
<tr>
<th>Stage</th>
<th>Process</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Re-listening, verbatim transcription, preparation of first transcript</td>
</tr>
<tr>
<td>2</td>
<td>Independent first interpretation by both authors – noting, paraphrasing and summarising the participant’s experience; development of emerging themes</td>
</tr>
<tr>
<td>3</td>
<td>Robust discussion by authors for credibility of first analysis – thematic development of first transcript to identify meaning making in the face of multiple needs of self and others, distressing experience and cancer stigma</td>
</tr>
<tr>
<td>4</td>
<td>Stages 1–3 repeated for eight additional transcripts – identifying convergence and divergence across cases. Clustering of themes that support evidence of subordinate theme</td>
</tr>
<tr>
<td>5</td>
<td>Development of overarching theme, ‘Distress, Stigma and Psychological Growth’</td>
</tr>
<tr>
<td>6</td>
<td>Identification and listing of themes for connectedness</td>
</tr>
<tr>
<td>7</td>
<td>Continued assessment of themes and subthemes, including how they related and linked to meaning making, redefining self and well-being</td>
</tr>
<tr>
<td>8</td>
<td>Clustering of themes in relation to constructs and theories</td>
</tr>
<tr>
<td>9</td>
<td>Data from transcripts reviewed by authors to verify the validity of interpretations from within the text</td>
</tr>
<tr>
<td>10</td>
<td>Central theme of ‘Distress, Stigma and Psychological Growth’ re-assessed</td>
</tr>
<tr>
<td>11</td>
<td>Subjective analysis of interpretations for themes representing the phenomenon of the lived experience of head and neck cancer within the context of distress and stigma to develop pathways to personal and relationship growth and well-being</td>
</tr>
<tr>
<td>12</td>
<td>Development of narrative by weaving theoretical links to themes with verbatim excerpts from the transcripts</td>
</tr>
<tr>
<td>13</td>
<td>Generation of links from several levels of distress and stigma to meaning making and psychological well-being</td>
</tr>
</tbody>
</table>

Interpretative Phenomenological Analysis, which involves double hermeneutics, is influenced by the researchers’ own experiences and preconceptions [Smith 1996]. In essence, it is a process of reiterative sense making where the researchers strive to make sense of the participant making sense of their experiences. Through an iterative process, the relationship between each researcher and script was considered to reduce biases, and prevent a major shift in interpretation from the participant’s experience and world view to the researchers. Without this, there is the risk that preconceptions and interpretation will be moulded by our own human experience [Heidegger, 1927/1962]. Previous experience and knowledge about psycho-oncology and post-trauma reactions challenged the authors to reflect and recognise their own biases and presuppositions that may have impacted on the interpretation of the data. In the present study, we sought to externalise these preconceptions through reflective practices, independent audit, audit trails and ongoing discussion throughout the analysis.

Author’s perspective

The following results include the study’s thematic outcomes, presented in narrative descriptive analysis. An overarching theme – Distress, Stigma and Psychological Growth – encompassed four superordinate themes: (1) Head and neck cancer: trauma trajectory; (2) THIS cancer: stigma and distress; (3) Looking beyond the previous self; and (4) Positive change – self. Two of these themes captured the expressed trauma and terror as a result of diagnosis and treatment whereas themes 3 and 4 captured the redefining of self despite stigma through meaning making. Distress was interpreted as a catalyst for awakening new life interpretations and combined with social support to facilitate two distinct pathways of growth: (1) psychological growth without support; (2) psychological and relational growth with support. Previously unfelt empathetic understanding and altruism for others with cancer emerged from the impact of stigma on ‘self’. Acceptance allowed a new sense of identity that recognised cancer-related traumatic distress as integral to growth for these participants. The present study offers a unique insight into cancer-related trauma and stigma and the potential to redefine a more accepting, empathic and altruistic ‘self’ for psychological growth. The quotations were not chosen based on prevalence within the data, rather they reflect rich evidence from the transcripts.
Head and neck cancer: trauma trajectory

Compounding trauma

This theme captures the intensity and multiple layers of distress through diagnosis, treatment and recovery faced by head and neck cancer patients. The fast pace at which they were thrust into an unfamiliar medical system made them feel caught off-guard and vulnerable:

“It’s extremely confronting ... when you can get into a specialist in 4 hours, you then know you are in trouble. [Matt]

While at the same time, attempts at mentally preparing seemed futile. They were never going to be ready for the journey ahead of them:

“It all happened at once. And that was so much to take in ... if I only had a few more months, I’d be prepared but I guess you’re never really prepared. [Derek]

Distressing procedures and lengthy recovery times overwhelmed their coping abilities. Cognitive blocking was used as a means to escape and avoid intrusive images associated with losing functional ability to speak and eat, a significant impairment to quality of life:

[With] surgery you could lose ... all of your tongue ... [it] really messes with your head... you’re trying to think that one through. [Matt]

Intense feelings of anxiety during the procedures imprinted indelible vivid memories on their consciousness. This meant that physical manifestations of emotional responses to the multiple distressing and traumatic events often unexpectedly overwhelmed them:

I got started again; a few weeks between surgery and radiation ... lots of anxiety ... I was having panic attacks. [Derek]

Terror of collaboration

Although adverse events often occur unexpectedly, medical procedures have their own way of inflicting trauma through complicit consent to the fearful physical invasion of their body. These participants spoke of their panic, horror and fear dealing with the tracheotomy tube. Unable to breathe, handing trust to staff during suctioning of their airway, they felt they had been taken to the brink of life or death:

Absolute panic mode ... I didn’t know that they’d suction out my throat and lungs, that I would have a tube poked down there regularly to suction out the phlegm. You feel like you are choking... the sheer terror. [Felix]

Other highly invasive treatment compounded their distress. The participants spoke of the refinement of medical tools as a symbolic representation of the seriousness of their cancer and the fragility of their life:

At each of these steps you sort of realise that you are getting progressively more seriously into the system and down in terms of ah the subtlety of the tools that are being used. [Paul]

Their memories of the event were vivid and extremely distressing. The removal of the tracheostomy tube was a symbol of being handed back control over life. It was a major hurdle and a symbol of recovery.

That was a new lease on life, taking the trachy out – cause that was probably the worst week of my life. [Derek]

‘Why me!’ versus ‘This is it’

‘Why me?’ was commonly asked for sense making of distressing experiences, particularly among those participants whose lifestyle was healthy prior to diagnosis with cancer. They spoke of feeling punished and undeserving of this fateful narrative:

It was a bit of a shock. Why? I had a healthy lifestyle, why me? ...you do the right thing and you’re still punished. [Derek]

Feelings of disconnectedness, a mind struggling to accept a body needing medical intervention, these participants described experiencing shock and disbelief:

I never expected it to happen to me so in some ways it’s this out of body experience going on here. [Paul]

However, for older participants there was acceptance, even embracement, of a diagnosis that aligned appropriately with their narrative of life. The three eldest participants, James, Shannon and Kevin recognised the journey they had lived as a long and valuable life, and welcomed cancer as part of their mortality:

Before I went into hospital, I didn’t really know whether I would be coming out. And I didn’t really ask, but I suppose – I think I would accept what has happened to me. [James]
Some found their own acceptance of cancer was at odds with others' desire to extend their lives. If death was inevitable, they had no desire to extend life:

Once you get to 83 you have had a good life. All I could think at the time was if it is going to happen let it be quick. Don't linger on. [Shannon]

Confronting the unimaginable

Multiple distressing procedures brought raw trauma that overwhelmed all participants. Pragmatic coping statements seemed relevant for distancing anxiety, fear and terror. It was a stopgap that allowed time for more purposeful rumination and reframing:

You are going to treat it as a job ... a really shitty job to do ... we kept on going back to that ... when, you know, we were getting sort of those dark days. [Matt]

Each imagined that other cancer patients were experiencing greater suffering. This allowed distance and a level of detachment from personal multiple and ongoing traumatic experiences:

And you know, I mean there is always someone worse off, as bad as you think things are someone is getting it worse. Yah? It makes you think, all these little things. [Derek]

Having difficulty confronting the unimaginable, some participants required the assistance of a support partner to guide them through their journey. These partners became intimately involved in their experience, to be their eyes and ears to absorb information:

At the bed day-by-day, and having to watch me go through... the nightmare of surgery ... being able to talk to her about it afterwards, debrief. [Felix]

These participants described a dual conflict of sense making. First, their personal narrative of consensual trauma, along with the pain and acceptance of permanent disablement challenged their world view of themselves. Second, unexpected responses from others ingeminated the degree to which their physical identity had changed. Witnessing visible shock in others was an added burden to their unwelcomed relationship with cancer. It was as if mortality was reflected back through the expressions of others:

People's reaction ... was confronting ... you could see it in their face, their facial reactions. Like a deer in the headlights ... the word cancer, they think you are going to die. [Derek]

**THIS cancer: stigma and distress**

*Identity struggle*

Cumulative upon the fearful experience of undergoing invasive medical procedures, participants were challenged with the permanent aftermath of changes to their facial appearance. Physically, as head and neck cancer participants they became unrecognisable from a previous 'self'. This traumatic journey felt unending as adjusting to a new physical 'self' confronted their sense of former sense:

I wasn't recognised by a very close friend... quite a few actually... that was a bit of a shock. [Derek]

The impact of physical changes was juxtaposed with changes to their personality. Struggling with a dichotomous identity, they had to re-evaluate and redefine who am I. Embarrassed to engage in once common social experiences they recognised a tendency to isolate themselves more than ever:

I feel a bit shut in... I don't want to go out ... if there is a barbecue on I won't go. It is just too hard to constantly explain... why I have got the scars. [Felix]

While medical treatment left these participants physically exhausted, confronting others' furtive stares and learning how to cope with stigmatising reactions took its toll emotionally. Grief and loss persisted throughout the interviews as these participants struggled to reconcile visual changes. Coming to terms with their new appearance was a twisting game of disappointments and lost identity:

The physical, the weight ...were negative impacts ... it still hurts, it really hurts actually, that's what upset me the most. ... I just didn't feel myself. [Derek]

**Change to self: a need to belong**

While no longer feeling part of their once extended social circles, a sense of inclusion grew among other stigmatised groups. Comfort was experienced, from a shared sense of understanding and struggle to belong again:

Other people with disfigurement or disablement don't even look at me... will give me a nod and that's it. So that's kind of the style of brotherhood or sisterhood ... because they go through the same stigmatisation. [Felix]
Close friends and family were seen as integral to adjusting to new ‘self’. Looking past the physicality they were able to buffer situations, which enabled processing. By interacting in a way that was consistent with their previous ‘self’, a slow transition to a new ‘self’ occurred:

The ones that treat me the same, which I appreciated more because … they just didn’t treat me like I was wrapped in cotton wool, didn’t baby me. And that’s all you wanted to be, is treated as you were. [Derek]

A deviant past

In addition to the physical stigmatising changes, head and neck cancer patients are confronted with personal lifestyle factors (i.e. alcohol, smoking and HPV infection), which may have made them vulnerable to developing this cancer in the first place. Participants who attributed their cancer onset to past behaviour were regretful of their past and bitter about the consequences.

It’s my own stupid fault. I smoked for 28 years … smoking causes my cancer’ [Felix]

Secrecy and invisibility were maintained by many as if holding onto a deep regret about their role in developing cancer. Privately, they acknowledged their own contribution to developing this feared illness, often perceived to develop by unlucky chance. However, fear of rejection and abandonment struggled with feelings of self-blame and guilt:

I suppose sexually transmitted infections, or diseases, that’s something we left out quite a lot...there is such a stigma attached. [Derek]

They sensed a wide-spread stigma associated with a blameworthy cancer. For some, self blame was expressed as underserving of the level of compassion afforded other cancers. Feeling shunned they sensed a general lack of support was associated with stigma. Quietly, they felt anger and a sense of injustice:

There is just no information available no level of support for us at all...because its head and neck cancer, it’s not popular... because its smoking related... it’s not a poster-boy cancer. [Felix]

Looking beyond previous self

Awakenings

Confronting the possibility of an early death, there were moments that could be described as awakenings for these participants. Their future was now on a different and unfamiliar journey:

You’ve sort of confronting something that’s released a lot of um… inhibition or things you’d always sort of and grown up and been part of you. [Matt]

Uncertainty about the future and fragility of life brought a focus to what is most important to them. This was experienced differently for participants whether they had approached their journey with independence and stoicism, or had become vulnerable and reliant on their family. While the former had developed a sense of focusing on personal insight and growth:

It’s a wakeup call that you’re not going to live forever. I have a long list of things of things I want to do... that was always vaguely in the future but I’m thinking now I should just do them. [Paul]

The latter had become more engaged in building stronger meaningful relationships:

This focuses the mind more, at looking at things you value more in life ... like your family and relationships... you’ve only got them for a finite time so you should make the most interactions with them. [Ralph]

Those, however, who had accepted cancer as a part of their narrative in life, had embraced these changes and came to a humbled understanding of their place and impact in the world.

It’s one day at a time, I can’t alter the world now. [Shannon]

Positive change – self

Empathetic understanding

In the struggle to understand new ‘self’, a greater sense of compassion emerged in the participants. Personal adversities and an empathic understanding of others was described, enabling these participants to communicate more effectively and meaningfully. Their journey with cancer brought unexpected positive changes to their life perspectives and an openness not previously experienced in their close relationships:

I have become close to them...I find it easier to talk to them [his children]. Not that it was hard, but... in a different style. You know! [Matt]

These participants expressed a change in interpretation of life from their struggle with ‘self’ on this journey.
Experiencing unexpected stigma despite their personal suffering, they began to find a new acceptance of others. Redefining self through a stigmatising cancer became the catalyst for increased understanding and a new insider’s perspective:

I now see people with either, illnesses or disabilities and I’m a lot more understanding of what they are ... until you go through it - I don’t think you sort of appreciate. [Matt]

**Altruism**

The uniqueness of the head and neck cancer journey and the invasive procedures that terrorised the patients, paradoxically facilitated a desire to help others. Consciously, their personal experience of stigma while at their most vulnerable appeared to facilitate a growth in altruism. Defining a new altruistic identity became a vehicle for personal acceptance allowing others in turn to accept:

This cancer, you can’t hide it, you can’t sort of put a great big hat on or cover half your face ...where many other cancers you wouldn’t know, you don’t have the visual impact...so in one way, it helps you to help other people too. [Kevin]

Having positive support from a partner appeared interwoven with this increased desire to help others. As vanguards, these supportive loved appeared to enable participants to re-integrate into society:

I often wonder what would happen if I was here by myself and [my wife] wasn’t here; how different it would have been... because I would then, by nature would have hidden away. [Kevin]

Endurance was made more possible through positive partner support allowing empathy and support of others to be projected forward. Passing on optimism to others starting the journey with head and neck cancer became important. Head and neck cancer was perceived as bringing both positive and negative outcomes inclusive of psychological well-being and a new purpose in life:

I am going to share it [my experience] with people... if what I’ve got can help people, then I am very happy. [Matt]

**DISCUSSION**

This study highlighted cancer-related traumatic distress and stigma in these participants as a result of dealing with head and neck cancer. However, despite this distress, positive changes emerged from finding meaning of the stigma and traumatic distress. The participants expressed experiencing trauma and terror as a result of diagnosis and treatment, and unexpected stigma from society as a result of their particular cancer. Over time however, distress became a catalyst for awakening new life interpretations and psychological growth to varying degrees with these participants. Sometimes, this occurred with positive social support and sometimes without support. When support was present, relational growth appeared to be experienced. For all participants, previously unfelt empathetic understanding and altruism for others with cancer emerged from the impact of stigma on ‘self’. Similarly, acceptance allowed psychological well-being to emerge out of their experience with cancer-related traumatic distress.

The present study offers a unique insight into cancer-related trauma and stigma and the potential to redefine a more accepting, empathic and altruistic ‘self’ for psychological growth. By shedding light on the relatively unexplored influence of stigma on psychological growth, within a relevant and understudied population, the current findings can be used to inform hypotheses for future idiographic and nomothetic research. Implications are discussed.

For these participants, psychological growth was experienced differently, depending on social support. Psychological growth was reported among participants without social support; on the other hand, psychological and relationship growth was described among those with social support. Importantly, with or without support, these participants experienced positive change as a result of their exposure to cancer-related trauma and stigma which supports earlier studies recognising that with or without support, post-traumatic growth can occur (McCormack et al. 2011; McCormack & Joseph 2013, 2014).

Psychological growth was described among individuals who had approached their cancer journey with independence and stoicism. This domain of post-traumatic growth is defined as becoming more compassionate, gaining wisdom and discovering inner strength (Joseph 2011). For participants in the present study, psychological growth developed as a result of finding inner strength in the face of cancer-related distress and stigma, by redefining their lives through purposeful reflection and engaging in valued activities and experiences. Participants found meaning from their lone journey by creating a new personal narrative. While social support has been found to increase positive adjustment with chronic illness (Suls 1982), here, independence and the need to rely on their own abilities and inner strength to cope led to increased confidence. This new found sense of strength and wisdom was a turn-
ing point, facilitating personal growth. The current findings support previous qualitative [McCormack & Joseph 2014] and quantitative [Widows et al. 2000; Weiss 2004] research which found that post-traumatic growth is not dependent on social support. Indeed, individuals are innately driven towards growth, in the pursuit of increased well-being [Joseph & Linley 2005]. In the present study, developing their sense of self and actively taking time to live out their own dreams, such as accomplishing their 'bucket list', was put at the forefront of their priorities to improve greater life satisfaction and fulfillment. Relying on themselves through their journey offered a period of self-discovery, where participants' increased their own psychological well-being through self-acceptance, inner strength, autonomy and redefining their purpose in life.

Participants who had become dependent on family for support additionally reported increased growth in their relationships. This was represented by an increased appreciation for significant others. Meaning making from their cancer experience and distress was found to develop from their social support. On their journey, support partners were able to facilitate the participants' needs, aiding them in treatment and recovery. While most core beliefs about themselves and the world had been disrupted as a result of cancer (Holland & Reznik 2005), the availability of positive social support validated that they were loved and cared for, enabling them to find meaning (Silver & Wortman 1980). As such, their distressing experiences had been interpreted as a catalyst for illuminating their important relational bonds. Participants identified they had changed their lives by making more time for loved ones, valuing and appreciating that time, thereby improving the quality of interactions with them. Therefore, the cancer journey brought with it a realisation that life is finite, and redefined purpose in life by strengthening relationships.

While cancer diagnosis and treatments was distressing, which increased awareness of what is important in life, head and neck treatment brought with it stigmatisation that also increased distress. For example, facial changes following surgery resulted in a visible stigma that was not able to be concealed. As one participant noted: 'this cancer, you can't hide it, you can't sort of put a great big hat on or cover half your face'. The visibility of their facial changes made participants vulnerable to stigmatising reactions from others. These responses became internalised, impacting on their self-concept (Livingston & Boyd 2010). The present results highlighted the persistent and intense feelings of grief, loss and ongoing distress regarding the visual changes.

Prior research reporting the distressing and deleterious effects of facial disfigurement, including stigmatising responses from the public [Hagedoorn & Molleman 2006], strained social relationships and subsequent social isolation [Myers et al. 1999], is supported in the present results. Consequently, participants reported significant distress in regards to their facial changes, and struggled to redefine who they were. What these participants uniquely experienced was that through active self-discovery and self-acceptance, they were able to move towards positive transformation. Cognitive processing involved making meaning from the societal stigmatisation and forced new identity through the development of a personal narrative. As a result of their traumatic and stigmatising head and neck cancer journey, and their struggle through this experience, growth was seen in increased altruism and empathetic understanding. While these post-traumatic growth domains are not currently captured in measures assessing psychological growth, the phenomenological interpretation of these findings supports previous qualitative research, which has also documented these domains of growth [McCormack & Joseph 2014].

The results suggest that by finding meaning from the stigma, participants had developed a new sense of purpose in life to help and understand others. The capacity to see beyond their physical identity lead to a sense of self-acceptance. In turn, participants felt more accepted by others. Consequently, participants found new meaning in their lives, by self and other acceptance and personal growth through self-discovery. Therefore, while stigmatisation can lead to discrimination and prejudice, reducing quality of life (Fingeret et al. 2012), straining social relationships (Macgregor 1990), the present findings highlight that this distress can facilitate personal meaning making and psychological growth.

LIMITATIONS

The present findings should be considered in the light of study limitations. Using an interpretative approach, results are open to the subjective biases as a result of the researchers own self-world, encompassing personal experiences and understandings. However, study methodologies were employed to illuminate biases and presuppositions, which involved completely independent audits and robust discussion.

While quantitative research strives to recruit a sample which would allow for generalisability of results, qualitative research, and IPA in particular, seek a homogenous cohort for in-depth, subjective exploration by individuals who have experienced a unique phenomenon previously.
unexplored. The current findings contribute to the literature on distress, growth and stigma, and provide direction for future qualitative and quantitative research.

CONCLUSIONS

These findings provide further insight into cancer-related traumatic distress and stigma, uniquely specific to head and neck cancer. Similar to earlier studies, the participants felt stigmatised adding to their burden of trauma, fear and loss of self-esteem (Peters-Golden 1982; Gamba et al. 1992, Fife & Wright 2000). Socially they felt ostracised, isolated and struggled to recognise supportive social relationships (Peters-Golden 1982). When positive support was forthcoming, they honoured it as helping them to cope with the difficult challenges of this protracted journey (Suls 1982).

These participants’ traumatic responses mirrored the dual burden of physical debilitation and fear of treatment described in other studies (Breitbart & Holland 1988; Dropkin 1989). They similarly described the distress associated with medical procedures and the ongoing psychosocial impact of other stigmatising factors relevant to the head and neck cancer experience.

Importantly, this study raises awareness that psychological growth is possible from the stigmatising and complex physical and psychological journey with head and neck cancer. For these participants, a positive redefinition of self, evolved over time and was enhanced by positive support. Similarly, these findings offer hope to health care professionals that positive psychological growth is possible despite cancer-related trauma and stigma associated with head and neck cancer and with facial changes following surgery. As a qualitative study, it offers hypotheses for future nomothetic research. Nonetheless, in a therapeutic framework this study emphasises the importance of providing space for head and neck patients to elicit a narrative that explores the likelihood that trauma psychopathology and growth may co-exist. Equally, therapeutic intervention can provide a positive framework for growth out of traumatic distress.

REFERENCES


Head and neck cancer: trauma, stigma and growth


Chapter 6: Foreword

The final chapter commences with a summary of each study in the present program of research and how each contributed to addressing the research questions proposed in Chapter 1. The overall purpose of the present research was to investigate the cause and impact of cancer-related stigma, and to investigate its role in influencing post-diagnostic psychological changes. Studies 1 and 2 examined the stigmatisation of cancer patients among community members by exploring factors which may contribute to cancer stigma. Drawing on attribution theory, these studies also sought to assess the variation of stigmatising attitudes towards eight common cancers. Study 3 and Study 4 also uniquely contributed to the current literature by investigating the impact of stigmatisation on post-diagnostic positive and negative psychological changes. By using quantitative and qualitative research methods, the final two studies explored the detrimental impact stigma has on cancer patients. Using self-report measures, Study 3 found that social support increased, while stigma reduced, cancer patients’ psychological well-being. Study 4 explored qualitatively how individuals with head and neck cancer, a highly stigmatised cancer, are able to find meaning from their distress and stigmatising experiences, which resulted in personal and relationship growth. The findings of the present program of research are summarised below with an overview of how the findings are integrated with, and contribute to, previous empirical and theoretical literature. Clinical implications and limitations in regards to the overall program of research are addressed, with a subsequent discussion regarding future directions. Last, an overall conclusion about the program of research is provided.
Chapter 6: Overview and Implications of the Present Program of Research

6.1 Study 1: The Impact of Blameworthy Attributions, Physical Disfigurement, and Poor Prognosis on Cancer-related Stigma

The present program of research commenced with an investigation of how certain stigmatising attributes relevant to cancer, namely blemishes of individual character, abominations of the body, and peril impact on community perceptions and attitudes towards individuals with cancer. While cancer has long been associated with stigma (Sontag, 1991; Stahly, 1989) and cancer patients are prone to several stigmatising factors this was the first known study that experimentally compared the impact of important and relevant stigmatising attributes (Deaux, Reid, Mizrahi, & Ethier, 1995; Frable, 1993) concurrently. Investigating the conditions which give rise to cancer-related stigma has been identified as a crucial challenge (Lebel & Devins, 2008), and therefore Study 1’s findings provide a contribution to understanding the area of cancer stigma, of which there is limited research. While cancer patients are prone to stigmatisation at cancer onset, diagnosis and treatment, Study 1 contributed to the limited research on cancer stigma by identifying which stigmatising factor elicited the strongest negative evaluations and reactions from community members.

As stigma develops within a social context (Jones, Farina, Hastorf, & French, 1984), Study 1 assessed stigmatising attitudes of community members towards cancer patients. Assessing public responses contributes to the literature, given there is a dearth of recent empirical evidence about the
attitudes and behaviours of the general public towards cancer patients 
(Lebel & Devins, 2008). Some researchers have suggested that cultural 
norms about cancer have changed in Western societies, making cancer-
related stigma obsolete (Hoffman, 2005; Holland & Reznik, 2005). 
Therefore, specific investigation of stigma towards cancer patients among 
community members was considered a priority, and contributed as a 
secondary aim to Study 1.

Study 1 relied on vignettes about a hypothetical oral cancer patient 
to assess the impact of the various stigmatising characteristics on 
participants’ cognitive, affective and behavioural responses. Findings 
showed support for the role of blameworthy attributions, or blemishes of 
individual character; partial support for the role of facial changes following 
surgery, or abominations of the body; and minimal support for the impact of 
poor prognosis, or peril, on eliciting stigmatising reactions from 
participants. When the target was perceived to have engaged in behaviours 
that may have contributed to their cancer, participants reported increased 
fear, anger and social distance, reduced pity and likelihood of assigning 
priority medical care. The consistent support for blameworthy attributions in 
eliciting stigmatising reactions from community members was a main 
finding. Therefore, while cancer is prone to several stigmatising factors, 
blemishes of individual character appear to make a substantial contribution 
to cancer-related stigma.

In addition to these empirical findings, Study 1 also provided a 
theoretical framework to help explain cancer-related stigma. The results of 
Study 1 provide support for the Just-World Hypothesis (Lerner & Miller, 
1978) in relation to the development of blameworthy attributions. For
instance, one common cognitive bias is the belief that “individuals get what they deserve and deserve what they get” (Lerner & Miller, 1978, p. 1030). In relation to cancer, an individual is perceived as blameworthy versus non-blameworthy based on whether they have engaged in behaviour purportedly linked to the cause of their cancer (i.e., whether their actions may have contributed to cancer onset). In Study 1, blameworthiness was assessed by manipulating lifestyle factors (blameworthy) such as cigarette smoking and alcohol consumption, and genetic heritability (non-blameworthy) associated with cancer onset. The cognitive and affective reactions that result from blameworthy attributions are consistent with attribution theory (Weiner, 1993, 1995; Weiner, Perry, & Magnusson, 1988). Study 1’s findings support attribution theory, as when an individual’s cancer was perceived to have been onset-controllable (i.e., blameworthy), they were subjected to more anger, less pity, and treated more harshly than if the onset of their cancer was perceived to be uncontrollable.

The findings of Study 1 are comparable with the extant literature examining other stigmatising conditions which also fit the model posed by attribution theory. For instance, an extensive body of research has identified that mental illness is a highly stigmatised condition, as a result of misinformed beliefs that diagnosed individuals are to blame for their illness (Corrigan, 2000). Commonly, individuals who experience stigmatising reactions from the community internalise these responses. The internalised guilt and blame for having a mental illness can lead to decreased self-esteem, quality of life, and social withdrawal (Livingston & Boyd, 2010). Similarly, internalised stigma has also been associated with increased depression, anxiety, and hopelessness among individuals with HIV/AIDS.
Qualitative research has demonstrated that both societal stigma and internalised stigma are reported among lung cancer patients (Hamann et al., 2014). While in the present study stigma was not assessed among cancer patients themselves, these results suggest that cancer patients’ susceptibility to public stigmatisation as a result of blameworthy attributions, which may be internalised by affected individuals, is also likely to lead to negative psychosocial outcomes; however future research is required to buttress or confute this inference.

Given recent appeals for research which identifies conditions that increase a cancer patient’s experience of stigmatisation, through assessment from a community perspective (Lebel & Devins, 2008), the present study makes important contributions to the body of literature. Findings addressed an important gap in the cancer-related research, and demonstrated that blameworthy attributions evoked discrimination and negative evaluation. Additionally, results provide support for a theoretical framework, namely the Just World Hypothesis and attribution theory, to partially explain cancer-related stigma. Finally, given the present findings, Study 1 also contends that cancer stigmatisation occurs at a community level. With these findings, Study 1 provides an important contribution to the small research base exploring cancer-related stigma.

In summary, Study 1 helped identify from a community level, what in particular is stigmatising about cancer. The negative affective reactions and pervasive discriminatory behaviour associated with blameworthiness suggests that cancer patients who are perceived to have contributed to their cancer onset are at heightened risk for negative reactions from others. Specifically, the increased anger, fear and reduced pity reported by
community members may contribute to distress among cancer patients, which has been found to be at concerning levels (Bultz & Carlson, 2006). The findings of this work suggest that rather than attracting sympathy and support during a time of personal suffering, some cancer patients will instead encounter negative judgments and behaviour from others which has the potential to lead to a sense of demoralisation and devaluation beyond the illness itself.

6.2 Study 2: A Test of Attribution Theory in Understanding Stigma in Cancers Perceived to be Blameworthy Versus Non-Blameworthy

Building upon Study 1’s findings, the second study further explored the stigmatisation of cancer; specifically, it assessed community members’ cognitive, affective, and behavioural responses towards eight common cancer types. This reflected a novel application of attribution theory (Weiner, 1993, 1995; Weiner et al., 1988) among different cancers to assess community stigmatising reactions. According to attribution theory, individuals will search for the cause of an event (e.g., what caused an individual’s cancer), and depending on whether it is perceived to be the result of internal (e.g., genetics) versus external (e.g., unhealthy lifestyle) factors, influences subsequent affective and behavioural reactions towards the individual (e.g., the cancer patient), or those involved in the event. From this framework, it was hypothesised that some cancers would elicit more negative reactions from community members than others, given the different perceptions of genetics versus environmental factors contributing to the onset of different cancers. Results demonstrated that lung, throat, and skin cancers were mostly associated with behavioural, or lifestyle, causal
factors; while breast, prostate, leukaemia and lymphoma cancers were associated with non-behavioural, or genetic, causal factors. Moreover, when people identified a ‘non-behavioural cause’ as the reason for cancer onset, there were fewer controllability judgements. This suggests that an individual’s beliefs about why someone developed cancer has a significant impact on their cognitions about him or her.

As expected, results from Study 2 also demonstrated that increased perceived controllability significantly reduced sympathy reported by participants. The impact of affective reactions in moderating behavioural cause, however, was inconsistent across cancer types. The main finding of Study 2 was that results demonstrated better statistical fit in a new model, which found that controllability directly impacted on both affective and behavioural responses, rather than through Weiner’s (1986) attribution-affect-help pathway (Figure 1).
Figure 6.1. Weiner's original models of attribution theory (1986).

Attribution-affect-help model (top) and model supported by Study 2 (bottom).

While attribution theory (Weiner, 1993, 1995; Weiner et al., 1988) using the attribution-affect-help pathway has provided a dominant framework for understanding stigma, the present study suggests that in relation to cancer-related stigma, both affect and behaviour are both influenced by attribution (Figure 1). While discrimination is theorised to develop through the attribution-affect-help pathway, in his original development of his theory, Weiner (1986) proposed that thoughts (attribution) may produce both feelings (affect) and behaviour (helping intention) (Figure 1), which supports the present findings. The direct impact of controllability on helping behaviour may be explained by The Just-World Hypothesis (Lerner & Miller, 1978). That is, if a cancer patient is perceived to have caused their illness, they are confronted with less altruistic behaviour as they are perceived to be responsible for their fate; in essence, they “get what they deserve and deserve what they get” (Lerner & Miller, 1978, p. 1030).
The influence of perceived controllability on behaviour may also help to explain the disparity of research investment provided to certain cancer types (Branton, 2008; Gritz, Sarna, Dresler, & Healton, 2007). That blameworthy cancer groups experience discrimination, with respect to research funding, fits with the common definition of health-related stigma that “discriminatory social judgment [leads to]... repercussions in social and health policy” (Weiss, Ramakrishna, & Somma, 2006, p. 280). For example, the amount of funding and number of grants provided by the National Health Medical Research Council in Australia (NHMRC) in 2013 to breast, prostate, leukaemia and lymphoma was significantly greater than that provided to lung, all head and neck cancers, and all skin cancers. This imbalance is not unique to Australia, as a similar pattern of inequitable funding and grant allocation has been documented in other countries such as Canada, the United Kingdom, and the United States with a particularly pronounced disparity in lung cancer funding (Branton, 2008; Gritz et al., 2007). Lung cancer has repeatedly been allocated less funding when compared to the other three most common cancers – breast, prostate and colorectal cancers – despite it contributing to the greatest cancer-related mortality in Australia (Australian Bureau of Statistics [ABS], 2012), and globally (Ferlay et al., 2010). Lung cancer also contributes highly to burden of disease in Australia (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2012), with the greatest number of years of life lost compared to any other type of cancer.

The relationship between funding allocation, disease burden and cancer stigma appears to form a deleterious cycle. For example, in the case of lung cancer, meagre funding is likely associated with the low five-year
cancer survival rate, leaving few to advocate for more equitable research investment (Branton, 2008). Furthermore, among cancers perceived to be blameworthy, or self-inflicted, poor funding also maintains others’ belief in the Just World hypothesis by blaming the victim (Lerner & Miller, 1978). This stigma reinforces poor advocacy in reduced support, funding, and fewer resources, which in turn may impede research efforts to improve prognosis (Conlon, Gilbert, Jones, & Aldredge, 2010). The combination of stigmatisation and inequitable research investment perpetuates cancer-related disease burden (Branton, 2008), which is already high among the cancers generally (AIHW & AACR, 2012) and continues to increase globally (Jemal et al., 2011). While there has been a considerable effort to reduce cancer burden through cancer prevention (AIHW & Department of Health and Family Services [DHFS], 1997), with campaigns aimed to encourage the public to engage in healthy living behaviours, stigmatisation of patients with cancers linked with these lifestyle factors may also be contributing to disease burden.

The findings from Study 2 contribute empirically and theoretically to the body of literature examining cancer stigma. It elaborated on previous research which has documented that some illnesses are perceived to be self-inflicted, speculating why there is low funding among tobacco-related diseases (Gritz et al., 2007). The current findings were able to buttress this inference, by assessing the impact of cancer type and blameworthiness on negative evaluations and discrimination, and extend these findings to highlight that stigmatisation is also prevalent for skin cancer patients. Theoretically, the study provides evidence to describe how
blameworthiness, or blemishes of individual character, directly exerts effects on negative affective and behavioural reactions from others.

In summary, Study 2 highlights that cancers, which are perceived to be associated with lifestyle factors, are at greater risk of increased stigmatisation. The present findings are consistent with previous research which has identified that some cancer patients, such as those with lung cancer, appear to be at risk for increased stigmatisation because it is a cancer perceived to be self-inflicted (Chapple, Ziebland, & McPherson, 2004), and extend these findings to other cancers perceived to be blameworthy. This was the first known study to shed light on why stigmatisation of patients with certain cancers may occur, in the context of perceived cancer controllability, which has been proposed in the literature.

6.3 Study 3: The Impact of Stigma, Social Support and Core Belief Examination on Psychological Well-being among Cancer Patients

While Study 1 and Study 2 assessed cancer-related stigma from a community perspective, the final two studies assessed stigmatisation from the perspective of those living with cancer. Examination was given to the impact of stigmatisation on posttraumatic psychological changes, including on-going distress and psychological growth.

Posttraumatic growth refers to positive changes that develop in relationship, personal and philosophical domains, as a result of dealing with a challenging life circumstance (Tedeschi & Calhoun, 1995). The event must be distressing enough that it shatters an individual’s core beliefs about themselves and the world. This area of post-trauma research is in its infancy, and understanding factors which promote or reduce positive change
is an important area for future research, given posttraumatic growth has been associated with increased psychological well-being (Joseph et al., 2012) and quality of life (Joseph, 2011).

Social support is considered critical to the promotion of posttraumatic growth (Joseph & Linley, 2005; Ryff, 1989; Tedeschi & Calhoun, 1995). As such, Study 3 hypothesised that stigma would impede positive change, as it has been associated with strained social relationships (Dakof & Taylor, 1990; Peters-Golden, 1982). In particular, Study 3 tested models of psychological well-being. In the first model, stigma significantly increased perceived negative change following cancer diagnosis, which subsequently reduced psychological well-being. Core belief examination, however, attenuated this relationship. The second model identified that the number of support partners significantly increased perceived positive change following cancer diagnosis, which subsequently increased psychological well-being, through a mediating effect of core belief examination. Study 3 was novel in its exploration of the deleterious impact of stigma impeding the development of posttraumatic growth, and ultimately lowers psychological well-being.

The findings of Study 3 contribute to the posttraumatic growth literature by identifying that social support promotes positive change, and quantifying the deleterious impact stigma on growth outcomes. Stigma has been found to strain relationships (Dakof & Taylor, 1990; Peters-Golden, 1982), and increase secrecy, shame and discrimination (Smart & Wegner, 2000), and appears to function in direct contrast to the socio-cognitive elements required for posttraumatic growth to develop. For instance, stigmatisation can impair social relationships that facilitate emotional
expression and cognitive processing required to accommodate trauma-related material and find positive meaning. These effects of stigma may account for reduced levels of posttraumatic growth reported among highly stigmatised cancer groups. For example, lung cancer patients appear to report less psychological growth (Posttraumatic Growth Inventory [PTGI] $M = 43.0$; Lebel & Devins, 2013) when compared to breast cancer patients (PTGI $M = 64.1$; Cordova, Cunningham, Carlson, & Andrykowski, 2001). The findings of this research elucidate a possible explanatory mechanism for such findings and therefore a potentially fruitful direction for future research.

While cancers prone to heightened stigmatisation may render the sufferer at greater risk for reduced levels of posttraumatic growth, certain patients may nonetheless derive meaning from the event. Study 3 showed that core belief disruption was a protective factor against the effects of negative change following cancer diagnosis. This finding suggests that cognitive processing of the perceived negative change, partly associated with stigmatisation, may itself cause some cancer patients to re-examine their core assumptions, which increases psychological well-being. Therefore, struggling with negative changes after cancer diagnosis was distressing enough that it influenced participants to examine their long-held assumptions about themselves and the world (Janoff-Bulman, 1992). Indeed, core belief disruption has been identified as the key factor implicated in posttraumatic growth, as participants positively reflect on their experience by engaging in helpful problem solving and emotion-focused coping (Treynor, Gonzalez, & Nolen-Hoeksema, 2003). By engaging in this form of cognitive processing, individuals are able to finding meaning from
their experience, by reframing and establishing a new narrative for their life (Gangstad, Norman, & Barton, 2009; Stockton, Hunt, & Joseph, 2011; Taku, Calhoun, Cann, & Tedeschi, 2008). Therefore, participants in the present study may have been cognitively processing and finding meaning from their negative post-diagnostic changes, and experiencing posttraumatic growth, in domains not currently captured by growth measures. Therefore while Study 3 outcomes highlight the impact that an individual’s social environment can have on post-diagnostic perceived positive and negative change; it also provides support for the role of qualitative exploration of posttraumatic growth, to investigate whether individuals are able to find meaning from their stigmatising and distressing experiences, in ways not currently captured by measurement tools.

In summary, Study 3’s findings contribute to posttraumatic growth literature by highlighting the impact of stigma on cancer survivors, as an impediment to the development of posttraumatic growth. Social support, however, promotes this growth. Study 3 also highlights how stigma and social support ultimately reduce or strengthen psychological well-being, respectively. Therefore, in support of the Social-Cognitive Processing Model (Lepore, 1995), the present findings suggest that in a supportive environment, cancer patients are able to positively adjust following diagnosis. Likewise, these findings also reinforce the importance of reducing cancer-related stigma to ameliorate its negative psychological consequences. The present findings contribute to the literature by identifying factors that impede well-being, which has been deemed an important area of research in psycho-oncology, given the number of cancer survivors is greater than ever before (AIHW & AACR, 2012).
6.4 Study 4: The ‘Lived’ Experience of Stigma, Distress and Psychological Growth on the Journey with Head and Neck Cancer

Study 4 examined the impact of stigma and distress on posttraumatic growth outcomes among head and neck cancer patients who had experienced facial changes following surgical intervention to remove cancerous areas. Investigating the experience of head and neck cancer was chosen given it is an understudied population and it has been found to be a highly distressing cancer, prone to stigmatisation (Lebel et al., 2013). For example, head and neck cancer is perceived to be caused by lifestyle factors, treatment may cause physical facial changes and prognosis can be poor. Indeed, Interpretative Phenomenological Analysis (IPA; Smith 1996) revealed that head and neck cancer patients experience numerous traumatic and distressing experiences during their diagnosis, treatment and at several points in their coping trajectory. Amidst these distressing experiences, participants showed psychological growth described as an “awakening” which brought them closer to aspects of their lives which they valued.

Psychological growth was experienced differently, whether individuals had support partners during their experience, or not. Personal growth was experienced for individuals who had approached their cancer journey with independence and stoicism; while relationship growth was reported by individuals who had become dependent on family for support. Personal growth has been defined as becoming more compassionate, gaining wisdom, and discovering inner strength (Joseph, 2011). For participants in Study 4, personal growth was represented by a focus on patients making space in their lives to participate in valued activities and experiences. This meant shifting the balance in their lives, including
spending more time on developing their self rather than on external factors, including work and extracurricular commitments. Relationship growth for those who had strong support partners in their experience was represented as an increased appreciation of significant others and value in these relationships (Joseph, 2011). Participants in Study 4 identified they had changed their lives by making more time for loved ones, valuing and appreciating that time, and improving communication with them.

The findings from Study 4 offer an interesting and relevant contribution to posttraumatic growth theory by delineating growth patterns, in the absence or presence of social support. This finding supports previous qualitative (McCormack & Joseph, 2014) and quantitative (Weiss, 2004; Widows, Jacobsen, & Fields, 2000) research that in some instances, posttraumatic growth is not dependent on social support. Study 4 also extends these findings by highlighting which forms of growth develop with and without social support. Evidently, different pathways to self-discovery can eventuate under various contexts, ultimately leading to increased psychological well-being.

Study 4 also reported on the growth that developed as a result of participants’ experiences of stigma. These findings support previous quantitative research reports of head and neck cancer patients with psychological growth (Harding, Sanipour, & Moss, 2014; Lebel et al., 2013; Llewellyn et al., 2013; Ruf, Büchi, Moergeli, Zwahlen, & Jenewein, 2009; Thambyrajah, Herold, Altman, & Llewellyn, 2010). Study 4 has helped to identify type of growth that can develop as a result of dealing with stigmatisation. Visual facial changes caused distress as participants struggled with a new identity and understanding of their sense of self.
Consequently, participants were able to find meaning from their experience, through self-acceptance, which was expressed through increased empathetic understanding and altruism towards others. Therefore, participants developed a more accepting, empathic and altruistic ‘self’ for psychological growth.

In summary, findings from Study 4 contribute to the posttraumatic growth literature by reporting on different growth patterns when support is available or unavailable. It also highlights that participants were able to find meaning from the stigmatisation and distress they had experienced. By exploring the relatively unknown influence of stigma on psychological growth, within a relevant and understudied population, the current findings offer promising directions to inform future quantitative research.

6.5 Implications for Clinical Practice

Findings from the present program of research help inform clinical practice by highlighting the impact of cancer-related stigma, specifically blameworthy attributions, and how stigma may contribute to on-going distress, but also psychological growth, among cancer patients. The high level of distress reported among cancer patients has resulted in recommendations for regular distress monitoring as part of clinical practice (Bultz & Carlson, 2006). While increased psychopathology may be associated with existential concerns relating to diagnosis, and side effects associated with treatment, the present findings suggest that cancer-related stigma may be contributing to heightened distress. While this distress may negatively impact psychological well-being, under some circumstances it may also facilitate psychological growth. Cancer-related stigma, distress
and psychological growth are important factors to consider in clinical practice, given the risk of negative psychosocial outcomes but, conversely, the potential to foster positive changes under certain circumstances.

6.5.1 Addressing cancer-related stigma. The present program of research documents that cancer-related stigma is prevalent among community members, and reported by cancer patients themselves. In relation to informing clinical practice, the present findings highlight the importance of assessing patients' experiences of stigma, particularly among individuals who might be perceived to have contributed to their cancer onset. Building a strong therapeutic relationship is important in addressing stigma, given it has been associated with shame (Chappie et al., 2004) and reduced self-worth (Fife & Wright, 2000). Routinely screening for exposure to discrimination and sensitively addressing such experiences in psychological practice may enhance an individual's well-being, given the detrimental impact stigma may have on an individual's sense of self (Fife, 1994) and participation in medical care (Tod, Craven, & Allmark, 2008). Providing psycho-education in regards to cancer-related stigma, identifying and accessing helpful social support (Raleigh, 2010), in addition to recommending patient-centred support groups (Heijnders & Van Der Meij, 2006) may be helpful for cancer patients.

Support groups may be particularly beneficial for cancer patients as it may buffer against the inadequate support from friends and family (Lechner, Stoelb, & Antoni, 2008). Engaged in a group environment, among individuals with similar experiences, cancer patients may feel the ability to disclose about their shared experiences. The group may create a safe environment to discuss fears and distress. Indeed, support groups have been
found to have a positive influence on members’ identity, self-esteem, coping skills and social integration (Ablon, 2002; Benbow & Tamiru, 2001). Furthermore, group therapy may lessen the impact of stigma as it has been found to reduce personal blame and guilt (Chapple et al., 2004).

6.5.2 Assessing for distress and growth. The findings of the present program of research highlight the deleterious impact of stigma, but also how stigmatised cancer patients may find meaning in their experiences. Given the range of possible psychological reactions, it is important to provide psycho-education and normalise a patient’s emotional response in clinical practice. Their reaction may include depressed mood, hopelessness, anxiety, and shame. Family members may also experience such reactions and may subsequently avoid thinking and talking about the patient’s experience in an attempt to avoid emotional arousal. This may be compounded by pressures to “stay positive” during times of distress (Cordova, 2008). However, continued cognitive avoidance may lead to intrusive thoughts and worry (Horowitz, 1986). Providing patients and their families with education regarding common reactions following cancer diagnosis may enable them to accept, process, and cope with their reactions. In addition, providing families with effective communication strategies may increase overall support, improve support satisfaction, and strengthen relationships. Providing a safe environment to express themselves may assist cancer patients to feel more at ease in disclosing their experiences to close family and friends, therefore aiding cognitive processing (Cordella & Poiani, 2014).

When significant others are unable to provide helpful support, cancer patients may benefit from professional assistance to help with their
coping abilities and adjustment. Providing patients with cognitive-behavioural skills such as progressive muscle relaxation, diaphragmatic breathing, imagery and mindfulness may assist them in reducing arousal and fatigue (Tatrow & Montgomery, 2006). In addition, aiding patients to construct a narrative about their experience may help them make sense of their experience and contribute to an increased sense of control over their situation. Engaging with the cancer patient to reflect on their lives before cancer may help them increase self-awareness and self-understanding, given cancer can have a significant impact on personal identity (Fife, 1994). Recognising parts of their lives which have, and have not changed, may also be an important part of re-defining themselves. Providing space to grieve what may have been lost and discussing their on-going worries and distress, while highlighting parts of them that are unchanged, may help them increase their personal insight. Given cancer is a traumatic stressor that may cause those affected to re-evaluate their life priorities, identifying important values may be helpful. Through collaboration, assistance may be provided to help the cancer patient engage in behavioural and cognitive changes to live in accordance with these values. In turn, cancer patients may develop a greater sense of meaning, psychological growth, and ultimately greater psychological well-being from their experience (Cordova, 2008).

Finally, recognising the seriousness of cancer, and that it can be a horrendous life-event is important for individuals working with cancer patients. Ultimately, cancer sufferers may have to come to terms with on-going pain, disability and possibly death. Thus it is important to meet clients where they are at in their coping process and recognise that chronic disability may ensue, which will not easily go away.
6.6 Limitations

While the present program of research provides a contribution to the literature concerning cancer stigma and posttraumatic growth, there are several limitations that must be noted while interpreting the findings. These limitations relate to participant characteristics and study methodology. These limitations, as well as recommended approaches to these issues for future research, are provided below.

6.6.1 Sample size. While the present program of research addresses the dearth of research examining cancer-related stigma, Study 2 and Study 3 were limited by small sample size. Structural equation modelling, a large sample technique, was employed in these two studies; yet while the sample sizes in Studies 2 and 3 were deemed large enough by standards developed by Bentler and Chou (1987), other researchers have recommended much larger sample sizes \( n \geq 200 \) for more complex models (Thompson & Subotnik, 2010). In order to account for the relatively small sample sizes, indices to assess model fit were chosen on the basis of the data, and sample characteristics. However, future research investigating cancer-related stigma and posttraumatic growth using path analyses would benefit from recruiting larger samples, where feasible. Notwithstanding, the present findings demonstrated stigmatisation among community members was increased for perceived blameworthy cancer groups, and how social support and stigma impacted on post-diagnostic psychological changes.

6.6.2 Generalisability. In addition to sample size, participant characteristics may limit the generalisability of the overall conclusions in the present program of research. The sample recruited for Study 1 and Study
2 examining cancer-related stigma from perceptions of community members included predominantly young university-educated women. Therefore caution should be exercised when generalising results to the broader community. Higher educated participants have been found to report less anger and fear, and more pity, than less educated participants (Angermeyer & Matschinger, 2003, 2004; Peluso & Blay, 2009); and women have been found to report greater levels of pity and willingness to help targets compared to men, in similar vignette-based studies (Mosher & Danoff-Burg, 2008). Therefore, future research would benefit from a more representative community sample to uncover whether stigmatising responses would differ as a result of participant demographics.

Study 3 and Study 4 examined the impact of stigma on post-diagnostic changes; however, these were also limited by participant characteristics and methodology. Study 3 aimed to assess cancer-related stigma and posttraumatic changes among four common cancers; however, the recruited sample included mostly breast cancer patients (68% of participants). Given the evidence for variable psychosocial experiences between cancer types, it is conceivable that such sample imbalance may have impacted on the results. Future research examining cancer-related stigma and posttraumatic changes would benefit from comparing these variables among different cancer types. In particular, examining these effects among lung, skin, and head and neck cancer patients may be beneficial, given Study 2’s findings that these cancer groups may be at risk for heightened stigma. Nevertheless, the findings of study 3 extend past research on the contribution of stigma to poor psychological adjustment, and social support in positive change and well-being.
The qualitative methodology chosen for Study 4 to assess the impact of stigma, distress and posttraumatic growth among head and neck cancer patients, utilised a small sample size in order to capture nuanced and rich data. As such, while it may be considered a limitation, the generalisability of findings utilising Interpretative Phenomenological Analysis is not expected (Smith, 1996; Smith, Flowers, & Larkin, 2009). The findings from Study 4 helped inform posttraumatic growth theory, and provided the underpinnings from which future quantitative research can validate and generalise the present results.

6.6.3 Cross-sectional analysis. Another important limitation to the present program of research was the cross-sectional methodology. This meant that while findings from Study 3 are theoretically grounded, the study design impeded the inference of causality between constructs. This is a broad problem in the literature; posttraumatic growth theorists have repeatedly called for longitudinal designs to explore the processes of developing psychological growth and improving psychological well-being (Calhoun & Tedeschi, 2006).

Longitudinal methodology was initially attempted in the present program of research, but as a result of recruitment difficulties and high withdrawal rates, the study was amended to recruit a cross-sectional sample. Future research would benefit from adopting a longitudinal design to refute or buttress conclusions, and to assess the impact of stigma on the survivorship trajectory in terms of: predicting perceived positive and negative changes; impacting on the on-going cognitive processing of the experience; and influencing well-being. Nonetheless, the present findings contribute to the literature by examining pathways leading to psychological
well-being, providing an important framework that may help address why some individuals adjust well following cancer diagnosis, while others do not.

6.7 Future Directions

The present program of research provides a significant contribution to the area of cancer-related stigma, of which there is limited research. Furthermore, the current program of research is the first to assert that stigma may significantly add to the burden of the cancer experience, which in turn can lead to both on-going distress, but also to psychological growth. As a result of these novel findings, there are a myriad of avenues for future research, and additional investigation is required in both fields of cancer-related stigma and posttraumatic growth. Specifically, future research would benefit from: assessing community-based programs to target cancer-related stigma reduction; exploring the stigma, distress and growth trajectory; and on-going investigations of posttraumatic growth methodology and domains. Addressing these research areas would potentially extend the current findings and improve understanding of the cancer experience.

6.7.1 Stigma reduction strategies. Based on findings from Study 1 and Study 2, blameworthy attributions may account for a significant amount of cancer-related stigma. Therefore, programs aimed to reduce 'victim blaming' would be of benefit to cancer patients, particularly those types with high levels of perceived blameworthiness. While programs addressing stigma among cancer patients may be beneficial in reducing distress, stigma reduction programs should be targeted at reducing public stigmatising perceptions and attitudes (Campellone, 2014), given programs aimed at
reducing internalised stigma have been mostly unsuccessful (Campellone, Caponigro, & Kring, 2014).

One possible way of reducing public stigmatisation of cancer may be through campaigns that highlight both the behavioural and non-behavioural contributions to cancer onset. As attributions are not factual understandings of a cause, but rather an individual’s perception of the cause (Weiner, 1993, 1995), altering public attributions by advertising appropriate educational information about cancer onset may lead to stigma reduction (Corrigan, 2000).

Weiner (1985) argues that replacing misinformed attributions with more balanced and well-informed attributions would alter previous knowledge structures, thereby changing previous affective and behavioural responses. This approach has been demonstrably effective in the past for other similar health behaviour interventions. For example, obesity has been found to be a particularly blameworthy condition, attracting a significant amount of stigma (Puhl & Heuer, 2009). Crandall (1994) implemented a stigma reduction program to alter attributions relating to obesity. The study provided education to community members about the biological and genetic factors associated with obesity. As a result, the level of stigmatising attitudes towards obese individuals significantly decreased among participants.

Relatedly, it would be beneficial for public awareness and public policy efforts aimed at reducing cancer burden to focus on an asset, rather than deficit, health promotion model (Morgan & Ziglio, 2007). For instance, healthy living interventions are becoming more commonplace (AIHW &
DHFS, 1997), with campaigns such as ‘Slip! Slop! Slap!’ and plain cigarette packaging in Australia aimed at reducing the high rates of skin cancer, and lung cancer, respectively (Freeman, Chapman, & Rimmer, 2008; Marks, 1999). While such campaigns aim to reduce engagement in health-risk behaviours, this may indirectly serve to place blame on others and increase stigmatisation. Health promotion strategies, particularly those involved in reducing tobacco use, are based within a deficit model (Ritchie, Amos, & Martin, 2010) which focuses on the problems and needs of individuals (Morgan & Ziglio, 2007). Public education and equitable health campaigns that adopt this model focusing less blame on individuals and more awareness of the challenges they face, may result in a reduction in cancer stigma. Such health promotions could incorporate a more balanced approach utilising the asset model, whereby campaigns are aimed to improve the self-esteem and coping abilities of individuals and focus on the pre-existing positive attributes and resources in the community, rather than focusing primarily on what is negative and lacking from these sources (Morgan & Ziglio, 2007). There is some evidence to suggest that in the face of disadvantage (e.g., poverty), individuals living in cohesive communities maintain and sustain their health and well-being (Kawachi, Kennedy, Lochner, & Prothrow-Stith, 1997).

Therefore, health promotion campaigns that highlight the multiple factors that contribute to cancer onset may lessen community blameworthy attributions. Furthermore, using an assets-based public health approach by promoting support and community cohesion may help improve public health and well-being (Kawachi et al., 1997; Morgan & Ziglio, 2007). Research investigating the best promotional techniques, as well as their
effectiveness, may assist in implementing strategies to reduce cancer-related stigma.

6.7.2 Stigma, distress and growth trajectory. The present program of research extended the evidence base in terms of how stigma may contribute to on-going distress, but also posttraumatic growth, approximately one year post-cancer diagnosis. However, there is still much to be learned about how different stigmatising factors impact on cancer patients in the long-term. For instance, while current findings demonstrated that blameworthy attributions had the most negative reactions from community members, it is unclear how the effect of this stigmatising attribute would influence people over time. Perhaps other stigmatising factors, such as abominations of the body as a result of head and neck cancer, may lead to continued distress as it is a non-concealable and salient stigma that persists long beyond recovery. For example, rates of depression and post-traumatic stress disorder appear to increase over time following facial burn injury, with the severity of facial change directly impacting on psychological adjustment (Madianos, Papaghelis, Ioannovich, & Dafni, 2001). Therefore, future research would benefit from exploring cancer-related stigmatising attributes over time to see how they affect psychological well-being.

It is also unclear how stigma may impact longitudinally on posttraumatic changes. By its nature, posttraumatic growth is a process that unfolds over time. Indeed, Manne and colleagues (2004) found that breast cancer patients’ reports of posttraumatic growth steadily increased over their 18 month follow up. While Organismic Valuing Theory (Joseph & Linley, 2005), posits that individuals are intrinsically motivated towards optimal
functioning, it is unknown how posttraumatic growth will present over time. On-going stigmatisation can create an environment that is not socially, and hence cognitively, conducive to the on-going development of growth.

6.7.3 Posttraumatic growth methodology and domains. The present program of research utilised both quantitative and qualitative methodology to investigate posttraumatic growth. The use of quantitative measures enabled exploration of two pathways to psychological well-being. Study 3’s findings highlighted the deleterious impact that stigma can have on promoting negative changes following cancer diagnosis, ultimately leading to reduced psychological well-being. Revision of previously held schemas acting as a buffering factor in this relationship highlighted that positive change may be present, but not captured in quantitative measures, given that core belief disruption is the active ingredient for the development of posttraumatic growth. Study 4 qualitatively found that empathy and altruism, not assessed in posttraumatic growth inventories, can develop following the impact of stigmatisation.

The present program of research supported the use of both quantitative and qualitative methodology to assess study constructs, in particular posttraumatic growth. Quantitative studies are advantageous as they include large-scale samples to advance knowledge of psychological growth following a highly distressing or traumatic event. Large representative samples allows for generalising research findings, which is important in progressing the understanding of predictors of posttraumatic growth (Stanton, Bower, & Low, 2006). Despite these benefits, the validity of retrospective self-report posttraumatic growth scales, and use of general scales to assess for growth following a range of traumatic experiences, have
been called into question (McFarland & Alvaro, 2000; Morris, Shakespeare-Finch, & Scott, 2012). Refining measurement tools by developing comprehensive and valid instruments is an important area for future research (Park & Lechner, 2006).

As posttraumatic growth is a relatively new area of psychology, there is still no consensus of the specific posttraumatic domains and there is evidence that positive change may occur in areas not currently being assessed quantitatively (Park & Lechner, 2006). In relation to research into cancer survivorship, future research would benefit from developing cancer-specific posttraumatic growth scales, given positive growth may be underestimated among cancer patients as a result of measurement tools not specifically addressing cancer-specific growth domains (Morris et al., 2012). In support of a targeted measurement tool, Curbow, Somerfield, Baher, Wingard, and Legro (1993) used a mixed method approach to investigate cancer-related posttraumatic growth among cancer patients who had undergone bone marrow transplantation. Open-ended responses revealed other growth domains such as re-direction in life and increased time spent engaging in pleasurable activities. Although refining measurement tools may therefore be beneficial the present program of research suggests that there are psychosocial factors unique to each cancer which may be neglected by a single cancer-related posttraumatic growth measure.

Qualitative research may help uncover posttraumatic growth domains that are relevant to cancer generally, and unique to cancer types specifically. This methodology allows for participants to report on posttraumatic changes without being prompted by survey questions,
capturing posttraumatic growth that is likely to be genuine, meaningful and personally relevant for the participant (Park & Lechner, 2006). In particular, Interpretative Phenomenological Analysis (Smith, 1996) lends well to assessing posttraumatic growth, given its focus on understanding how individuals make sense and find meaning from a personally significant event, such as being diagnosed with cancer. The posttraumatic changes documented in qualitative research may be further expanded upon in quantitative research, increasing the validity of such findings. Therefore, in order to advance understanding of posttraumatic growth following cancer diagnosis and treatment, research should partially rely on qualitative approaches to theoretically advance knowledge, and quantitative research to provide empirical validation.

6.8 Concluding statement

Given the increased prevalence and reduced mortality of cancer, there are now more individuals who have been diagnosed, undergone treatment, and are dealing with cancer survivorship than ever before (Bray, Ren, Masuyer, & Ferlay, 2013; Ferlay et al., 2013). Therefore, understanding the psychological adjustment among individuals diagnosed with cancer is critical. The present program of research highlighted the influence of stigmatisation as a social factor leading to increased distress among cancer patients, with high levels already a concern within this population (Bultz & Carlson, 2006).

A cancer diagnosis can bring with it unique psychosocial difficulties, and as a result, those affected are at risk for stigmatising reactions from others (Sontag, 1991; Stahly, 1989). Blameworthy attributions were found
to consistently evoke negative reactions from the public, suggesting that some cancers are prone to increased discrimination, based on their association with risk factors associated with lifestyle. These findings may explain the discrepancy of government funding and grant allocation between cancers (Gritz et al., 2007). Unfortunately, this cancer stigmatisation appears to form a vicious cycle, as stigmatisation of ‘blaming the victim’ appears to lead to reduced support, resources and funding, which in turn leads to poor research gains to improve prognosis; subsequently, there are fewer individuals to advocate for increased support and resources, leading to increased stigmatisation (Conlon et al., 2010).

In addition to community stigmatisation, cancer patients also reported being stigmatised as a result of cancer. Findings supported the detrimental impact stigma can have by increasing distress, and reducing psychological well-being. In line with posttraumatic growth theory, this increased distress, however, was found to lead to psychological growth, in some (Tedeschi & Calhoun, 1995). In particular, posttraumatic growth was experienced among participants with and without strong support networks, and individuals were able to find meaning from acquiring their stigmatising attributes by being more understanding, empathetic and altruistic towards others.

The present findings uncovered a small piece of a cancer patient’s experience that may increase suffering and hardship. Yet there are still a breadth of issues and concerns involved in understanding and subsequently treating the psychosocial needs of cancer patients. The field of psycho-oncology is relatively new, with many avenues for future research and development. The present program of research contributes to this
burgeoning research area by highlighting how cancer-related stigma increases the psychological distress associated with the cancer experience.
References


predictors of benefit finding in patients with head and neck cancer.
*Psycho-Oncology, 22, 97-105. doi: 10.1002/pon.2065*


Page intentionally left blank
Appendix 1

Study 1: The Impact of Blameworthy Attributions, Physical Disfigurement, and Poor Prognosis on Cancer-related Stigma

Study 2: A Test of Attribution Theory in Understanding Stigma in Cancers Perceived to be Blameworthy Versus Non-Blameworthy

Human Research Ethics Approval ........................................................264
Advertisement .......................................................................................265
Online Participant Consent Form............................................................266
Online Survey .........................................................................................268
  Social Desirability Scale (short form) ..............................................270
  Social Distance Scale ........................................................................272
  Emotional Reaction to Mental Illness Scale .................................273
  Social Distance Scale (2nd presentation) .......................................277
  Emotional Reaction to Mental Illness Scale (2nd presentation) ...278
Online Debriefing form .....................................................................289
Dear Ms Jennifer Threader,

Protocol: Beliefs and Attitudes about Different Cancer Groups

I am pleased to advise you that your Human Ethics application received approval by the Chair of the HREC on 22 April 2013.

For your information:

1. Under the NHMRC/AVCC National Statement on Ethical Conduct in Human Research we are required to follow up research that we have approved. Once a year (or sooner for short projects) we shall request a brief report on any ethical issues which may have arisen during your research or whether it proceeded according to the plan outlined in the above protocol.

2. Please notify the committee of any changes to your protocol in the course of your research, and when you complete or cease working on the project.

3. Please notify the Committee immediately if any unforeseen events occur that might affect continued ethical acceptability of the research work.

4. Please advise the HREC if you receive any complaints about the research work.

5. The validity of the current approval is five years' maximum from the date shown approved. For longer projects you are required to seek renewed approval from the Committee.

All the best with your research,

Kim

Ms Kim Tiffen
Human Ethics Manager
Office of Research Integrity,
Research Services,
Ground Floor, Chancelry 10B
Ellery Crescent,
The Australian National University
ACTON ACT 0200
T: +61 6125 3427
F: +61 2 6125 4807
Kim.Tiffen@anu.edu.au or
human.ethics.officer@anu.edu.au
We are looking to understand **YOUR** attitudes and beliefs regarding different types of cancers, as well as the associated risk and treatment factors.

**AND** for every survey completed, $1 will be donated to the *Australian Cancer Council* to support cancer research, prevention, treatments, as well as patient support.

**Who’s eligible?** Everyone!

**How long does the study take?** 15-25 minutes online.

**How can I participate?** Take a tab below and either follow the link or email Jenn Threader (jennifer.threader@anu.edu.au)

*This research has been approved by the ANU Human Ethics Committee (Protocol 2013/023)*
in a study entitled “Beliefs and Attitudes about Different Cancer Groups” which aims to investigate how people feel about different cancer types, as well as the associated factors (e.g., treatment factors, risk factors etc.). The research will utilise vignettes that will require you to make some judgments about fictional people, and answer questions that will look to investigate your understanding about different cancer types as well as your attitudes about them. Please be aware that there are no right or wrong answers in this study; we are just interested in your opinions and knowledge.

It is expected that the study will take about 15-25 minutes to complete.

Your participation in this study is completely voluntary and you are free to withdraw at any time without giving any reason and without experiencing any negative personal repercussions. Your data will only be saved upon clicking the ‘submit’ button at the conclusion of the study, at which point it will not be possible to identify and delete your data. You must be 18 years or older to participate in this study.

There is no incentive for you to participate in this research. However, for every survey that is completed, $1 will be donated to Cancer Council Australia to support cancer research, prevention, treatments, as well as patient support.

Any information or personal details gathered in the course of the study are confidential. All data will be completely anonymous, and you are not required to enter your name, or any other identifiable information, at any point throughout the study. The data collected will be stored in a secure locked office at the Australian National University and electronic information will be password protected. Only the investigators on this project will have access to this data. By Australian National University requirements, all data is to be stored for a minimum of 5 years; following this period all data will be securely destroyed. A report of this study will be submitted for publication but individual participants will not be identifiable in such a report.

If you have any questions while you are completing, or after completion of, the questionnaire please feel free to email Jennifer Threader at (jennifer.threader@anu.edu.au) or the supervisor of this research, Professor Don Byrne (don.byrne@anu.edu.au)

The risk of psychological harm associated with this study is minimal. Reading about individuals experiencing medical conditions and making judgments about them may be inherently distressing for some people but it should be no more upsetting than reading a psychology or medical textbook.

However, if you experience any discomfort or distress during, or after completion of, the questionnaire please inform myself immediately. You
may also visit http://www.iasp.info/resources/Crisis_Centres for a list of crisis centres and the contact details of telephone counselling centres in your country.

This project has been approved by the Human Research Ethics Committee of the Australian National University (Protocol Number 2013-023).

Any other concerns about the conduct of this research may be directed to the Human Research Ethics Committee:

Human Ethics Officer
Research Services
Chancelry 10B, Lower Ground Floor
East Road
The Australian National University
Acton ACT 0200
AUSTRALIA
Email: human.ethics.officer@anu.edu.au
Telephone: +61 2 61253427

Thank you again for your time, your participation is greatly appreciated.

Jennifer Threader

I am over 18 years of age AND consent to participate in this study, as described above:

☐ Yes
☐ No
Q1 What is your gender?
○ Male
○ Female
○ Other

Q2 Please identify your smoking history:
○ Never Smoked
○ Current Smoker
○ Past Smoker (quit more than 3 months ago)

Q3 How old are you (in years)? ____

Q4 Do you drink alcoholic beverages?
○ Yes
○ No

Q5 On average, how often do you consume alcohol?
○ Everyday
○ 3-5 times a week
○ 1-2 times a week
○ Only on the weekends
○ Only on special occasions

Q6 What is your highest level of education achieved?
○ Year/Grade 10 or below (i.e. junior high, intermediate or school certificate)
○ Year/Grade 12 or Higher School Certificate (i.e. high school diploma or leaving certificate)
○ Trade certificate or diploma
○ University or college degree
○ Higher degree (i.e. postgraduate degree, e.g. Masters or PhD)

Q7 What is your occupation (if you are a student, what is your area of study)? __________

Q8 Have you ever been diagnosed with cancer?
○ Yes
○ No

Q9 Which type of cancer were you diagnosed with? ______

Q10 Do you know anyone (friends, relatives, colleagues) that has been diagnosed with cancer?
○ Yes
○ No
Q11 Which type of cancer were they diagnosed with? If you know more than one person diagnosed with cancer or, that one person was diagnosed with multiple types of cancer, please tick all that apply:

☐ Breast Cancer
☐ Brain Cancer
☐ Bowel Cancer
☐ Colon Cancer
☐ Rectal Cancer
☐ Cervical Cancer
☐ Leukemia
☐ Lung Cancer
☐ Lymphoma (non-Hodgkin & Hodgkin)
☐ Skin Cancer
☐ Head and Neck Cancer
☐ Oesophageal Cancer
☐ Ovarian cancer
☐ Stomach Cancer
☐ Other ___________________
☐ Other ___________________
☐ Other ___________________

Q12 Social Desirability Scale (short form)
Listed below are a number of statements concerning personal attitudes and traits. Read each item and decide whether the statement is true or false as it pertains to you personally.
It is sometimes hard for me to go on with my work if I am not encouraged.

I sometimes feel resentful when I don’t get my way.

On a few occasions, I have given up doing something because I thought too little of my ability.

There have been times when I felt like rebelling against people in authority even though I knew they were right.

No matter who I’m talking to, I’m always a good listener.

There have been occasions when I took advantage of someone.

I’m always willing to admit it when I make a mistake.

I sometimes try to get even rather than forgive and forget.

I am always courteous, even to people who are disagreeable.

I have never been irked when people expressed ideas very different from my own.

There have been times when I was quite jealous of the good fortune of others.

I am sometimes irritated by people who ask favors of me.

I have never deliberately said something that hurt someone’s feelings.

<table>
<thead>
<tr>
<th>True</th>
<th>False</th>
</tr>
</thead>
</table>

Q13 PLEASE READ THIS INFORMATION VERY CAREFULLY. YOU WILL BE ASKED QUESTIONS ABOUT IT IN A FEW MOMENTS.

Justin is employed as a secondary school teacher. Friends describe him as an active, hard-working and out-going individual. Likely as a result of his busy schedule, his symptoms of fatigue, weight loss and recurring headaches went unnoticed. But once he began having difficulty swallowing, he thought something may be wrong and booked an appointment to see his doctor. After the appointment and following several medical scans, Justin found out that he had been diagnosed with mouth cancer.

After 20 seconds you will be able to move on to the next page.
Q14 How much do you blame Justin for his illness?
- Not at all to blame
- Slightly to blame
- Moderately to blame
- Very much to blame
- Totally blame

Q15 How responsible do you think Justin is for his illness?
- Not at all responsible
- Slightly responsible
- Moderately responsible
- Very much responsible
- Totally responsible

Q17 How much sympathy do you have for Justin?
- Not sympathetic
- A little sympathetic
- Moderately sympathetic
- Very sympathetic
- Extremely sympathetic

Q18 If medical resources became scarce and priority had to be given to certain people to receive cancer treatment, do you think Justin should be given priority to receive treatment?
- Yes
- No
Q19 Social Distance Scale
Based on the brief description of Justin that you were provided, rate the statements using the scale provided.

<table>
<thead>
<tr>
<th></th>
<th>Definitely Willing</th>
<th>Probably Willing</th>
<th>Probably Unwilling</th>
<th>Definitely Unwilling</th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you feel about having someone like Justin as a neighbour?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How would you feel having someone like Justin as a co-worker?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How would you feel about having someone like Justin as a member of a group assignment for university or a project at work?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How would you feel about having someone like Justin as a Facebook friend?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How would you feel about recommending someone like Justin for a job to your employer?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How would you feel about exchanging mobile/cell numbers with someone like Justin?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How would you feel about living in a share house with someone like Justin?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How would you feel about having someone like Justin as a close personal friend?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q15 Emotional Reaction to Mental Illness Scale
After reading about Justin, please identify how you would react. Please identify how each item on the list applies to you.

<table>
<thead>
<tr>
<th>Item</th>
<th>Applies completely</th>
<th>Applies partially</th>
<th>Doesn't apply at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>The person scares me.</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>I feel uncomfortable.</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>I feel angry.</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>I feel compassionate towards him.</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>The person makes me feel insecure.</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>I feel amused by something like that.</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>I feel for him.</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>I feel annoyed by him.</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>I feel the need to help the person.</td>
<td>☐</td>
<td>☐</td>
<td>☑</td>
</tr>
</tbody>
</table>

Q16 PLEASE READ THIS INFORMATION VERY CAREFULLY. THIS IS ADDITIONAL INFORMATION ABOUT JUSTIN. YOU WILL BE ASKED ADDITIONAL QUESTIONS RELATING TO THIS NEW INFORMATION IN A FEW MOMENTS

VERSION 1 Vignette: During the medical examination, Justin's doctor noted a history of cancer in Justin's family. His cousin was recently diagnosed with cancer, and his mother was also diagnosed with cancer 20 years ago. Justin's doctor explained that cancer can be caused by many factors, but in Justin's case, it was likely influenced by genetics. Due to the type of mouth cancer diagnosed, Justin was advised to undergo surgical treatment. He underwent surgical treatment, with no resulting facial scarring or changes to his physical appearance. After surgery, Justin was provided with test results indicating the severity of his cancer. It was determined that his cancer was in an early stage of development and as a result, he has a good prognosis (95% chance of survival).

VERSION 2 Vignette: During the medical examination, Justin's doctor noted a history of cancer in Justin's family. His cousin was recently diagnosed with cancer, and his mother was also diagnosed with cancer 20 years ago. Justin's doctor explained that cancer can be caused by many factors, but in Justin's case, it was likely influenced by genetics. Due to the type of mouth cancer diagnosed, Justin was advised to undergo surgical treatment. He underwent surgical treatment, with no resulting facial scarring or changes to his physical appearance. After surgery, Justin was provided with test results indicating the severity of his cancer. It was determined that his cancer was in the very advanced stage and, as a result, he has a poor prognosis (30% chance of survival).
VERSION 3 Vignette: During the medical examination, Justin’s doctor noted a history of cancer in Justin’s family. His cousin was recently diagnosed with cancer, and his mother was also diagnosed with cancer 20 years ago. Justin’s doctor explained that cancer can be caused by many factors, but in Justin’s case, it was likely influenced by genetics. Due to the type of mouth cancer diagnosed, Justin was advised to undergo surgical treatment. He underwent surgical treatment, with significant facial scarring and changes to his physical appearance. That is, the shape of Justin’s face is now unequal on both sides. The side of his face most affected by surgery has lost most of the previous bone structure, and as a result slightly droops on one side. Justin also now has significant indentation and discolouration on his face from the scars. After surgery, Justin was provided with test results indicating the severity of his cancer. It was determined that his cancer was in the very advanced stage and, as a result he has a poor prognosis (30% chance of survival).

VERSION 4 Vignette: During the medical examination, Justin’s doctor noted a history of cancer in Justin’s family. His cousin was recently diagnosed with cancer, and his mother was also diagnosed with cancer 20 years ago. Justin’s doctor explained that cancer can be caused by many factors, but in Justin’s case, it was likely influenced by genetics. Due to the type of mouth cancer diagnosed, Justin was advised to undergo surgical treatment. He underwent surgical treatment, with significant facial scarring and changes to his physical appearance. That is, the shape of Justin’s face is now unequal on both sides. The side of his face most affected by surgery has lost most of the previous bone structure, and as a result slightly droops on one side. Justin also now has significant indentation and discolouration on his face from the scars. After surgery, Justin was provided with test results indicating the severity of his cancer. It was determined that his cancer was in an early stage of development and as a result, he has a good prognosis (95% chance of survival).

VERSION 5 Vignette: Before being diagnosed with mouth cancer, Justin’s friends reported that they all “worked hard but played hard too”. Justin reported that despite past recommendations from his doctor to reduce his alcohol consumption and smoking, Justin continued on with his lifestyle. Justin’s doctor believes that his past history of heavy drinking and smoking may have caused the cancer. Due to the type of mouth cancer diagnosed, Justin was advised to undergo surgical treatment. He underwent surgical treatment, with no resulting facial scarring or changes to his physical appearance. After surgery, Justin was provided with test results indicating the severity of his cancer. It was determined that his cancer was in an early stage of development and as a result, he has a good prognosis (95% chance of survival).

VERSION 6 Vignette: Before being diagnosed with mouth cancer, Justin’s friends reported that they all “worked hard but played hard too”. Justin reported that despite past recommendations from his doctor to reduce his alcohol consumption and smoking, Justin continued on with his lifestyle. Justin’s doctor believes that his past history of heavy drinking and smoking may have caused the cancer. Due to the type of mouth cancer diagnosed, Justin was advised to undergo surgical treatment. He underwent surgical
treatment, with no resulting facial scarring or changes to his physical appearance. After surgery, Justin was provided with test results indicating the severity of his cancer. It was determined that his cancer was in the very advanced stage and, as a result he has a poor prognosis (30% chance of survival).

VERSION 7 Vignette: Before being diagnosed with mouth cancer, Justin’s friends reported that they all “worked hard but played hard too”. Justin reported that despite past recommendations from his doctor to reduce his alcohol consumption and smoking, Justin continued on with his lifestyle. Justin’s doctor believes that his past history of heavy drinking and smoking may have caused the cancer. Due to the type of mouth cancer diagnosed, Justin was advised to undergo surgical treatment. He underwent surgical treatment, with significant facial scarring and changes to his physical appearance. That is, the shape of Justin's face is now unequal on both sides. The side of his face most affected by surgery has lost most of the previous bone structure, and as a result slightly droops on one side. Justin also now has significant indentation and discolouration on his face from the scars. After surgery, Justin was provided with test results indicating the severity of his cancer. It was determined that his cancer was in an early stage of development and as a result, he has a good prognosis (95% chance of survival).

VERSION 8 Vignette: Before being diagnosed with mouth cancer, Justin’s friends reported that they all “worked hard but played hard too”. Justin reported that despite past recommendations from his doctor to reduce his alcohol consumption and smoking, Justin continued on with his lifestyle. Justin’s doctor believes that his past history of heavy drinking and smoking may have caused the cancer. Due to the type of mouth cancer diagnosed, Justin was advised to undergo surgical treatment. He underwent surgical treatment, with significant facial scarring and changes to his physical appearance. That is, the shape of Justin's face is now unequal on both sides. The side of his face most affected by surgery has lost most of the previous bone structure, and as a result slightly droops on one side. Justin also now has significant indentation and discolouration on his face from the scars. After surgery, Justin was provided with test results indicating the severity of his cancer. It was determined that his cancer was in the very advanced stage and, as a result he has a poor prognosis (30% chance of survival).

Q17 How much do you blame Justin for his illness?
☐ Not at all to blame
☐ Slightly to blame
☐ Moderately to blame
☐ Very much to blame
☐ Totally blame
Q18 How responsible do you think Justin is for his illness?
- Not at all responsible
- Slightly responsible
- Moderately responsible
- Very much responsible
- Totally responsible

Q19 How much sympathy do you have for Justin?
- Not sympathetic
- A little sympathetic
- Moderately sympathetic
- Very sympathetic
- Extremely sympathetic

Q20 If medical resources became scarce and priority had to be given to certain people to receive treatment, do you think Justin should be given priority to receive treatment?
- Yes
- No

Q21 Why do you think that Justin should given priority treatment? ______

Q22 Why do you think that Justin should not be given priority treatment? ___
Q23 Social Distance Scale (2\textsuperscript{nd} presentation)

Based on the brief description of Justin that you were provided, rate the statements using the scale provided.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Definitely Willing</th>
<th>Probably Willing</th>
<th>Probably Unwilling</th>
<th>Definitely Unwilling</th>
</tr>
</thead>
<tbody>
<tr>
<td>How would you feel about having someone like Justin as a neighbour?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>How would you feel having someone like Justin as a co-worker?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>How would you feel about having someone like Justin as a member of a group assignment for university or a project at work?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>How would you feel about having someone like Justin as a Facebook friend?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>How would you feel about recommending someone like Justin for a job to your employer?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>How would you feel about exchanging mobile/cell numbers with someone like Justin?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>How would you feel about living in a share house with someone like Justin?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>How would you feel about having someone like Justin as a close personal friend?</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q24 Emotional Reaction to Mental Illness Scale (2nd presentation)
Please identify the type of emotional reactions you experienced after reading about Justin

<table>
<thead>
<tr>
<th>Emotional Reaction</th>
<th>Applies completely</th>
<th>Doesn't apply at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>The person scares me.</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel uncomfortable.</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel angry.</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel compassionate towards him.</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>The person makes me feel insecure.</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel amused by something like that.</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel for him.</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel annoyed by him.</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel the need to help the person.</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>

MANIPULATION CHECKS (next three questions)
Q25 In relation to the additional information that you read about Justin, did he have a GOOD or POOR (BAD) prognosis?
○ Good
○ Poor (bad)
○ I cannot remember

Q26 In relation to the additional information you read about Justin, did he have significant changes to his face (including facial scarring) following his surgery?
○ Yes
○ No
○ I cannot remember

Q27 In relation to the additional information you read about Justin, what did Justin's doctor believe caused Justin's mouth cancer? ________________

Thank you so much for your input! The rest of the survey will only take approximately 5 more minutes to complete!

Now you are going to be asked a few questions about four different cancer types. Please pay attention to the type of cancer type you are being asked to base your questions on. It is important for you to know that there are no right or wrong answers; we are just interested in your opinions and knowledge.
Group A (Participants split into 2 Groups)

Now you are going to be asked a few questions about PROSTATE CANCER. Please continue below:

Q28A What do you think causes prostate cancer? Give your best guess!! There are no right or wrong answers!!!

Q29A How much personal control do you think people with prostate cancer have over the prevention of their condition (i.e., personal behaviours versus genetic or environmental causes)?
- No control whatsoever
- A little control
- A moderate amount of control
- A lot of control
- Total control

Q30A How much do you blame prostate cancer patients for their diagnosis?
- Not at all to blame
- Slightly to blame
- Moderately to blame
- Very much to blame
- Totally blame

Q31A How much responsibility do you think prostate cancer patients have for their diagnosis?
- Not at all responsible
- Slightly responsible
- Moderately responsible
- Very much responsible
- Totally responsible

Q32A How much sympathy do you have for prostate cancer patients?
- Not sympathetic
- A little sympathetic
- Moderately sympathetic
- Very sympathetic
- Extremely sympathetic

Q33A If medical resources became scarce and priority had to be given to certain cancer groups to receive cancer treatment, do you think prostate cancer patients should be given priority to treatment?
- Yes
- No
Q34A Why do you think that prostate cancer patients should be given priority treatment? ________________

Q35A Why do you think that prostate cancer patients should not be given priority treatment? ________________

Now you are going to be asked a few questions about LUNG CANCER. Please continue below:

Q36A What do you think causes lung cancer? Give your best guess!! There are no right or wrong answers!!! ________________

Q37A How much personal control do you think people with lung cancer have over the prevention of their condition (i.e., personal behaviours versus genetic or environmental causes)?
   O No control whatsoever
   O A little control
   O A moderate amount of control
   O A lot of control
   O Total control

Q38A How much do you blame lung cancer patients for their diagnosis?
   O Not at all to blame
   O Slightly to blame
   O Moderately to blame
   O Very much to blame
   O Totally blame

Q39A How much responsibility do you think lung cancer patients have for their diagnosis?
   O Not at all responsible
   O Slightly responsible
   O Moderately responsible
   O Very much responsible
   O Totally responsible

Q40A How much sympathy do you have for lung cancer patients?
   O Not sympathetic
   O A little sympathetic
   O Moderately sympathetic
   O Very sympathetic
   O Extremely sympathetic

Q41A If medical resources became scarce and priority had to be given to certain cancer groups to receive cancer treatment, do you think lung cancer patients should be given priority to treatment?
   O Yes
   O No
Q42A Why do you think that lung cancer patients should be given priority treatment? _______________

Q43A Why do you think that lung cancer patients should not be given priority treatment? _______________

Now you are going to be asked a few questions about LYMPHOMA CANCER (non-Hodgkin & Hodgkin). Please continue below:

Q44A What do you think causes lymphoma (non-Hodgkin & Hodgkin)?
Give your best guess!! There are no right or wrong answers!!! __________

Q45A How much personal control do you think people with lymphoma (non-Hodgkin & Hodgkin) have over the prevention of their condition (i.e., personal behaviours versus genetic or environmental causes)?
- No control whatsoever
- A little control
- A moderate amount of control
- A lot of control
- Total control

Q46A How much do you blame lymphoma (non-Hodgkin & Hodgkin) patients for their diagnosis?
- Not at all to blame
- Slightly to blame
- Moderately to blame
- Very much to blame
- Totally blame

Q47A How much responsibility do you think lymphoma (non-Hodgkin & Hodgkin) patients have for their diagnosis?
- Not at all responsible
- Slightly responsible
- Moderately responsible
- Very much responsible
- Totally responsible

Q48A How much sympathy do you have for lymphoma (non-Hodgkin & Hodgkin) patients?
- Not sympathetic
- A little sympathetic
- Moderately sympathetic
- Very sympathetic
- Extremely sympathetic
Q49A If medical resources became scarce and priority had to be given to certain cancer groups to receive cancer treatment, do you think lymphoma (non-Hodgkin & Hodgkin) patients should be given priority to treatment?
   ○ Yes
   ○ No

Q50A Why do you think that lymphoma (non-Hodgkin & Hodgkin) patients should be given priority treatment?

Q51A Why do you think that lymphoma (non-Hodgkin & Hodgkin) patients should not be given priority treatment?

Now you are going to be asked a few questions about THROAT CANCER. Please continue below:

Q52A What do you think causes throat cancer? Give your best guess!! There are no right or wrong answers!! ______________

Q53A How much personal control do you think people with throat cancer have over the prevention of their condition (i.e., personal behaviours versus genetic or environmental causes)?
   ○ No control whatsoever
   ○ A little control
   ○ A moderate amount of control
   ○ A lot of control
   ○ Total control

Q54A How much do you blame throat cancer patients for their diagnosis?
   ○ Not at all to blame
   ○ Slightly to blame
   ○ Moderately to blame
   ○ Very much to blame
   ○ Totally blame

Q55A How much responsibility do you think throat cancer patients have for their diagnosis?
   ○ Not at all responsible
   ○ Slightly responsible
   ○ Moderately responsible
   ○ Very much responsible
   ○ Totally responsible
Q56A How much sympathy do you have for throat cancer patients?
○ Not sympathetic
○ A little sympathetic
○ Moderately sympathetic
○ Very sympathetic
○ Extremely sympathetic

Q57A If medical resources became scarce and priority had to be given to certain cancer groups to receive cancer treatment, do you think throat cancer patients should be given priority to treatment?
○ Yes
○ No

Q58A Why do you think that throat cancer patients should be given priority treatment? ________________________

Q59A Why do you think that throat cancer patients should not be given priority treatment?

Q60A If you could volunteer for a charity event (e.g., a Fun Run or Gala) and help in the organization of the event, which supports cancer research and treatment, out of the options below, which cancer type would you wish to support.
○ Prostate Cancer
○ Lung Cancer
○ Lymphoma (non-Hodgkin & Hodgkin)
○ Throat Cancer

Q 61A Why did you choose this cancer group? _______________

Q62A If you had $100.00 to donate to cancer research and support groups, which cancer group(s), of the ones listed below, would you wish to donate your money (you can give separate amounts to different groups)? Please only put number value in the box and exclude the $ sign.
____ Prostate Cancer
____ Lung Cancer
____ Lymphoma (non-Hodgkin & Hodgkin)
____ Throat Cancer

Q63A Why did you make the decision to divvy up your donation this way? ______________

Group B (Participants split into 2 Groups)

Now you are going to be asked a few questions about BREAST CANCER. Please continue below:

Q28B What do you think causes breast cancer? Give your best guess!! There are no right or wrong answers!! ______________
Q29B How much personal control do you think people with breast cancer have over the prevention of their condition (i.e., personal behaviours versus genetic or environmental causes)?
- No control whatsoever
- A little control
- A moderate amount of control
- A lot of control
- Total control

Q30B How much do you blame breast cancer patients for their diagnosis?
- Not at all to blame
- Slightly to blame
- Moderately to blame
- Very much to blame
- Totally blame

Q31B How much responsibility do you think breast cancer patients have for their diagnosis?
- Not at all responsible
- Slightly responsible
- Moderately responsible
- Very much responsible
- Totally responsible

Q32B How much sympathy do you have for breast cancer patients?
- Not sympathetic
- A little sympathetic
- Moderately sympathetic
- Very sympathetic
- Extremely sympathetic

Q33B If medical resources became scarce and priority had to be given to certain cancer groups to receive cancer treatment, do you think breast cancer patients should be given priority to treatment?
- Yes
- No

Q34B Why do you think that breast cancer patients should be given priority treatment? ______________

Q35B Why do you think that breast cancer patients should not be given priority treatment? ______________

Now you are going to be asked a few questions about SKIN CANCER. Please continue below:

Q36B What do you think causes skin cancer? Give your best guess!! There are no right or wrong answers!!! ______________
Q37B How much personal control do you think people with skin cancer have over the prevention of their condition (i.e., personal behaviours versus genetic or environmental causes)?
- No control whatsoever
- A little control
- A moderate amount of control
- A lot of control
- Total control

Q38B How much do you blame skin cancer patients for their diagnosis?
- Not at all to blame
- Slightly to blame
- Moderately to blame
- Very much to blame
- Totally blame

Q39B How much responsibility do you think skin cancer patients have for their diagnosis?
- Not at all responsible
- Slightly responsible
- Moderately responsible
- Very much responsible
- Totally responsible

Q40B How much sympathy do you have for skin cancer patients?
- Not sympathetic
- A little sympathetic
- Moderately sympathetic
- Very sympathetic
- Extremely sympathetic

Q41B If medical resources became scarce and priority had to be given to certain cancer groups to receive cancer treatment, do you think skin cancer patients should be given priority to treatment?
- Yes
- No

Q42B Why do you think that skin cancer patients should given priority treatment? ____________

Q43B Why do you think that skin cancer patients should not be given priority treatment? ____________
Now you are going to be asked a few questions about LEUKEMIA. Please continue below:

Q44B What do you think causes Leukemia? Give your best guess!! There are no right or wrong answers!!

Q45B How much personal control do you think people with Leukemia have over the prevention of their condition (i.e., personal behaviours versus genetic or environmental causes)?
- No control whatsoever
- A little control
- A moderate amount of control
- A lot of control
- Total control

Q46B How much do you blame Leukemia patients for their diagnosis?
- Not at all to blame
- Slightly to blame
- Moderately to blame
- Very much to blame
- Totally blame

Q47B How much responsibility do you think Leukemia patients have for their diagnosis?
- Not at all responsible
- Slightly responsible
- Moderately responsible
- Very much responsible
- Totally responsible

Q48B How much sympathy do you have for Leukemia patients?
- Not sympathetic
- A little sympathetic
- Moderately sympathetic
- Very sympathetic
- Extremely sympathetic

Q49B If medical resources became scarce and priority had to be given to certain cancer groups to receive cancer treatment, do you think Leukemia patients should be given priority to treatment?
- Yes
- No

Q50B Why do you think that Leukemia patients should be given priority treatment?

Q51B Why do you think that Leukemia patients should not be given priority treatment?
Now you are going to be asked a few questions about CERVICAL CANCER. Please continue below:

Q52B What do you think causes cervical cancer? Give your best guess!! There are no right or wrong answers!!! ______________

Q53B How much personal control do you think people with cervical cancer have over the prevention of their condition (i.e., personal behaviours versus genetic or environmental causes)?
- No control whatsoever
- A little control
- A moderate amount of control
- A lot of control
- Total control

Q54B How much do you blame cervical cancer patients for their diagnosis?
- Not at all to blame
- Slightly to blame
- Moderately to blame
- Very much to blame
- Totally blame

Q55B How much responsibility do you think cervical cancer patients have for their diagnosis?
- Not at all responsible
- Slightly responsible
- Moderately responsible
- Very much responsible
- Totally responsible

Q56B How much sympathy do you have for cervical cancer patients?
- Not sympathetic
- A little sympathetic
- Moderately sympathetic
- Very sympathetic
- Extremely sympathetic

Q57B If medical resources became scarce and priority had to be given to certain cancer groups to receive cancer treatment, do you think cervical cancer patients should be given priority to treatment?
- Yes
- No

Q58B Why do you think that cervical cancer patients should given priority treatment? ______________

Q59B Why do you think that cervical cancer patients should not be given priority treatment? ______________
Q60B If you could volunteer for a charity event (e.g., a Fun Run or Gala) and help in the organization of the event, which supports cancer research and treatment, out of the options below, which cancer type would you wish to support:

- Breast Cancer
- Skin Cancer
- Leukemia
- Cervical Cancer

Q61B Why did you choose this cancer group? ________________

Q62B If you had $100.00 to donate to cancer research and support groups, which cancer group(s), of the ones listed below, would you wish to donate your money (you can give separate amounts to different groups)? Please only put number value in the box and exclude $ sign.

- Breast Cancer
- Skin Cancer
- Leukemia
- Cervical Cancer

Q63B Why did you choose to divvy up your money this way? ____________
Online Debriefing Form

This study looked to understand people's attitudes and beliefs about different cancer types. In this survey, this question was assessed in two ways. This debriefing form is split in half explaining the two different aspects of the research.

Part 1: Vignettes (part of the survey where you read and answered questions about a fictional character named Justin). This part of the study investigated people's perceptions to several stigmatizing conditions: facial changes, attributional factors (i.e. lifestyle factors associated with increased risk of diseases/illnesses) and fear of death. Our aim was to identify if certain stigmatizing aspects impact more on people’s attitudes and prejudice levels.

As a participant you were provided with a vignette about "Justin" who was diagnosed with mouth cancer. Everyone in the study read this initial vignette. You were then randomly allocated to one of eight conditions, which manipulated the stigmatizing conditions mentioned above. That is, the vignettes varied as to whether there were attributive factors that could lead to perceptions that the individual was to blame or not to blame for their illness; whether the individual had facial scaring or no facial changes from surgery; and whether the individual had a good cancer prognosis (high risk of survival) or bad cancer prognosis (low risk of survival). We predicted that if you read a vignette that emphasized that Justin was not to blame you would feel sorry and sympathetic for him, and hence report less prejudicial attitudes towards him. In contrast, if you were allocated the vignette where Justin was to blame for his illness, you would blame Justin more for his condition, and hence show less sympathy and more prejudice towards him. We also hypothesized that if Justin had facial scaring and a bad prognosis (low risk of survival) you would show more prejudice towards them and less apt to engage with Justin socially (e.g., willing to have Justin as a co-worker or neighbour).

In some conditions we may have provided you with misleading information suggesting that Justin had a high degree of control over his illness. We
would like to take this opportunity to ensure you are aware that the information you received may have been misleading. Mouth cancer can occur in individuals of varying socio-economic status, gender, education and race. In addition, mouth cancer has biological, social and psychological underpinnings that are no fault of the individual. It should also be noted that not all individuals with mouth cancer receive surgery, and not all surgeries result in changes in facial appearance. Mouth cancer also has different prognosis rates depending on the progression of the tumor and when it is identified (through medical check-ups and scans). If you would like further information on mouth cancer, you may visit the following websites: http://www.cancer.gov/cancertopics/types/head-and-neck, or http://www.betterhealth.vic.gov.au/bhcv2/bharticles.nsf/pages/Mouth_cancer.

Part 2: Different Cancer Types (your understanding, attitudes and beliefs)

This part of the study investigated your knowledge about the causes of different cancer types, and how this knowledge may affect your beliefs about personal control, blame and responsibility the person has over their illness.

As a participant you were randomly allocated to answer questions about four of eight chosen cancer groups to study in this research. Included in the eight different cancer types were cancers that have associated lifestyle risk factors (i.e., lung cancer, skin cancer, cervical cancer and throat cancer) as well as cancers that do not have as well known lifestyle risk factors (i.e., breast cancer, prostate cancer, leukemia, and lymphoma). This research was based on attribution theory which addresses the processes by which individuals explain the causes of behaviour and events. Therefore, conditions (including cancers) that are considered ‘onset-controllable’ (i.e., caused by voluntary behavior, such as smoking, obesity or other lifestyle factors), tend to cause negative reactions in observers; whereas conditions that are considered uncontrollable tend to cause more sympathetic responses in observers.

Based on this theory, it was hypothesized that cancers thought to be caused by specific individual behaviours (e.g., smoking, drinking or unhealthy
lifestyle), versus environmental or genetic factors, would elicit more prejudice. In addition, cancers associated with certain lifestyle factors (e.g., smoking, drinking), and hence believed to be onset controllable, would have minimal inclinations to help, in terms of volunteering time and money.

As mentioned before, cancer can be diagnosed in individuals of varying socio-economic status, gender, education and race. Often cancers have many different types of biological, social and psychological underpinnings that are no fault of the individual. If you would like additional information on different types of cancer, please visit the Cancer Council Australia website at http://www.cancer.org.au/.

Final points:

Your data will only be saved upon clicking the ‘submit’ button at the bottom of this page. Once you have clicked “submit” it will not be possible to identify and delete your data. You may withdraw from the study by not clicking on the “submit” button and closing this internet window.

If participation in this study has upset you or made you uncomfortable in any way, please contact Jennifer Thredter (jennifer.thredter@anu.edu.au) immediately. You may also visit http://www.iasp.info/resources/Crisis_Centres for a list of crisis centres and the contact details of telephone counselling centres in your country.

Finally, if you have any complaints or questions regarding the manner in which this research was conducted, please contact Jennifer Thredter (jennifer.thredter@anu.edu.au) or the supervisor of this research, Don Byrne (don.byrne@anu.edu.au). If an independent person is preferred, please contact the Human Ethics Officer (contact details below)

Human Ethics Officer
Research Services
Chancery 10B, Lower Ground Floor
East Road
The Australian National University
Acton ACT 0200
AUSTRALIA
Thank you again for your participation. As mentioned in the consent form, $1 from every completed survey will be donated to Cancer Council Australia to support cancer research, prevention and treatment along with patient support! :)

Jennifer Threader

I have finished the questionnaire and would like to submit my responses! SUBMIT! to donate $1 to the Australian Cancer Council and submit your responses!!!

Submit!
Appendix 2

Study 3: The Impact of Stigma, Social Support and Core Belief Examination on Psychological Well-being among Cancer Patients

Human Research Ethics Approval (ANU) ...........................................294
Human Research Ethics Approval (The Canberra Hospital [TCH]) .....296
Dear Patient Letter .................................................................298
Online Participant Consent Form...........................................299
Online Survey .................................................................302
    Unsupportive Interactions Inventory.................................308
    Social Impact Scale ..................................................310
    Impact of Event Scale ...............................................313
    Distress Thermometer ...............................................315
    Core Beliefs Inventory ...............................................315
    Changes in Outlook Questionnaire (Short Version) ........318
    Psychological Well-Being - Post-Traumatic Change Questionnaire ...............................................319
Online Debriefing Form..................................................321
Dear Ms Jennifer Threader,

Protocol: 2012/366
Investigating factors that influence growth and adaptation following cancer diagnosis

I am pleased to advise you that your Human Ethics protocol received approval by the Chair of the HREC on 13 June 2012.

For your information:

1. Under the NHMRC/AVCC National Statement on Ethical Conduct in Human Research we are required to follow up research that we have approved. Once a year (or sooner for short projects) we shall request a brief report on any ethical issues which may have arisen during your research or whether it proceeded according to the plan outlined in the above protocol.

2. Please notify the committee of any changes to your protocol in the course of your research, and when you complete or cease working on the project.

3. Please notify the Committee immediately if any unforeseen events occur that might affect continued ethical acceptability of the research work.

4. Please advise the HREC if you receive any complaints about the research work.

5. The validity of the current approval is five years' maximum from the date shown approved. For longer projects you are required to seek renewed approval from the Committee.

All the best with your research,

Kim

Ms Kim Tiffen
Ethics Manager
Office of Research Integrity,
Research Services,
Ground Floor, Chancelry 10B
Ellery Road
The Australian National University
ACTON ACT 0200
T: +61 6125 3427
F: +61 2 6125 4807
Kim.Tiffen@anu.edu.au or
human.ethics.officer@anu.edu.au

Ms Jennifer Threader  
Research Centre for Nursing and Midwifery Practice  
Building 6, Level 3 (East Wing)  
The Canberra Hospital  
Garran ACT 2605

Dear Ms Jennifer Threader

Re: ETHLR.12.073

The ACT Health Human Research Ethics Committee’s Low Risk Sub-Committee received notification of the proposed study:

Investigating factors that influence growth and adaption following cancer diagnosis at its meeting of 28 March 2012.

I am pleased to inform you that, following further correspondence, your application has been approved out of session.

The Sub-Committee agreed that the application is for low risk research and determined that the research meets the requirements of the National Statement on Ethical Conduct in Human Research and is ethically acceptable.

I attach for your records an Outcome of Consideration of Protocol form.

I confirm that the ACT Health Human Research Ethics Committee is constituted according to the National Health and Medical Research Council Guidelines and operates in compliance with applicable regulatory requirements and the International Conference on Harmonization Guidelines on Good Clinical Practice.

Yours sincerely

[Signature]

Professor John SG Biggs MA MD
FRCOG FRANZCOG DHMSA
Chairman
ACT Health Human Research Ethics Committee
Low Risk Sub Committee
2 May 2012
Submission No: ETHLR.12.073 Date of Approval: 2 May 2012

Project Title: Investigating factors that influence growth and adaption following cancer diagnosis

Submitted by: Ms Jennifer Threader

Your project was considered by the ACT Health Human Research Ethics Committee and Approved for a period of 3 years.

First Annual Review due: April 2013

The Ethics Committee require as part of the review process that:

- At regular periods, and not less frequently than annually, Principal Investigators are to provide reports on matters including:
  - security of records
  - compliance with approved consent procedures and documentation
  - compliance with other approved procedures.
  - as a condition of approval of the protocol, that Investigators report immediately:
    - adverse affects on subjects
    - proposed changes in the protocol
    - unforeseen events that might affect continued ethical acceptability of the project.
- All published reports to carry an acknowledgement stating:
  - approved on 2 May 2012 by the ACT Health Human Research Ethics Committee.

Professor John SG Biggs, Chairman 2 May 2012
Dear [name]

I am contacting you on behalf of Ms Jennifer Threader, Provisional Psychologist and Clinical PhD Candidate at the Australian National University.

Ms Threader is conducting a research study titled: **Investigating Factors That Influence Growth and Adaption Following Cancer Diagnosis** and has permission to contact you to determine your interest in participating in the study.

Participation in the study is entirely voluntary and any decision not to participate will not affect your treatment or relationships with your treating team.

Please indicate below if you are happy for Ms Threader to send you information on the study. I encourage you to return this form, whatever your response.

Sincerely

Dr Sayed Ali

☐ Yes, I am happy to be contacted regarding participation in the above mentioned research project

☐ No, please **do not** contact me regarding the above mentioned research project

Name__________________________________________

Signature________________________________________

Date__________________________________________
Online Participant Consent Form

Invitation:
You are invited to participate in a research study into the factors that influence growth and positive adaptation following cancer diagnosis. Growth and positive adaptation are words used to describe how people cope and adjust after a difficult or tragic event. Some examples of this include your own feelings of distress and your well-being, as well as external factors such as how others in your life assist and support you. This research is looking to understand how this may be experienced differently among different cancer types, including breast, lung, prostate and skin cancer.

1. What is the purpose of this study?

The purpose of the study is to examine the impact various personal, social and environmental factors on developing growth and positive adaptation following cancer diagnosis.

2. Why have I been invited to participate in this study?

You are invited to participate in this study as you have been diagnosed with breast, lung, skin, or prostate cancer. You are encouraged to discuss this project and your potential participation with family and/or community members prior to agreeing to take part.

3. What if I don’t want to take part in this study, or if I want to withdraw later?

This study is completely voluntary, which means that it is up to you whether you participate or not. You can refuse to take part in this project or withdraw from it at any time without this affecting your medical care. To withdraw from the study, close the internet browser at any point when completing the survey. Your data would then be withdrawn from the study. This data will be kept in locked cabinets, in a secure locked office within the Australian National University for a period of seven years, and then will be shredded. Your withdrawn data will not be used in the final study analyses.

4. What does this study involve?

The procedure will involve answering a series of questionnaires and a demographic survey sheet.

The survey questions will ask you about your social support, thoughts and feelings about cancer, as well as assess how you are coping following diagnosis. Due to the comprehensive nature of the research, the survey will take about 15 minutes to complete.

5. Will I benefit from the study?

The results from the study may or may not be of direct benefit to your medical management. However, by participating in this study you will be
helping to advance our understanding as to what elements influence growth and positive adaptation following cancer diagnosis and treatment. We hope the information learned from this study will help other patients with cancer in the future.

6. **Are there risks to me in taking part in this study?**

There is a small chance that some people participating in this survey may experience distress. If you experience distress or require any supportive care during this study you can contact your cancer nurse coordinator.

You may also contact these services:

1) Lifeline (telephone: 13 11 14) is a 24-hour confidential counseling telephone service. Telephone Crisis Supporters can listen to your situation and concerns, and provide support and assistance. They are also able to provide you with referral information for other services in your local area.

2) The Canberra Counselling Service is also available to provide psychological assistance. To book an appointment, you may call (02) 6281 2625, Monday to Friday 9am to 6pm.

7. **How will my confidentiality be protected?**

Your responses in this survey cannot be linked back to you. The survey does not ask any specific identifying information, and is anonymous. The data collected will be stored in a secure locked office at the Australian National University and electronic information will be password protected. Only the investigators on this project will have access to this data. The electronic data will be kept for at least 7 years, to meet the requirements of the academic journals to which this work will be submitted for publication. Research from this study will also be included in a PhD research project, undertaken in Clinical Psychology at the Australian National University.

8. **What happens with the results?**

The results of the research may be published in medical or nursing journals and may be presented at medical or psychological conferences. Research from this study will also be included in a PhD research project, undertaken in Clinical Psychology at the Australian National University. Your identity will not be revealed in any publications or presentations.

9. **What happens if I suffer harm, injury or complications as a result of the study?**

Should you develop a problem which you suspect may have resulted from involvement in this research you can contact – the Project Leader: Jenn Threader, telephone (02) 6125 5585. You can also document whether this project will cause further distress and report this to the Project Leader.

10. **How is this study being paid for?**
The study is being undertaken as part of a PhD requirement at the Australian National University. It is not being funded by any other source

11. Will taking part in this study cost my anything, and will I be paid?

Participation in this study will not cost you anything, nor will you be paid for your participation.

12. What should I do if I want to discuss this study further before I decide?

You may contact the Project Leader: Jenn Threader, telephone (02) 6125 5585. You may also contact the supervisor of this project, Professor Don Byrne: (02) 6125 3974 by telephone or don.byrne@anu.edu.eu by email or Dr. Sayed Ali.

13. Who should I contact if I have concerns about the conduct of this study?

Approval has been given by the ACT Health Human Research Ethics Committee and the Australian National University Human Research Ethics Committee.

If you have any problems or queries about the way in which this study has been carried out and you do not feel comfortable communicating with the staff conducting this survey, please contact the committee secretariat via ACT Health Human Research Ethics Office, Level 6 Building 10 Telephone (02) 6205 0846, or by emailing acthealth-hrec@act.gov.au.

Dr Sayed Ali, MB BS, FRACP
Staff Specialist in Medical Oncology
Lecturer, ANU Medical School

Jennifer Threader, BSc (Hons)
Provisional Psychologist/Clinical PhD Candidate

By ticking the "I Agree" box below, I acknowledge that I have read the study information and agree to participate in this research study, with the knowledge that I am free to withdraw at any time.

☐ I agree
☐ I don't agree
Q1 What is your age (in years)?

Q2 What is your gender?
○ Male
○ Female
○ Other

Q3 What is your relationship status?
○ Single
○ In a relationship
○ Married/long-term de facto relationship
○ Separated
○ Widow

Q4 What is your current living arrangement?
○ I live alone
○ I live with others/in a share house
○ I live with my partner

Q5 What is your highest level of education achieved?
○ Year 10 or below (i.e., junior high, intermediate or school certificate)
○ Year 12/Higher School Certificate (i.e., high school diploma or leaving certificate)
○ Trade certificate or diploma
○ University or College Degree
○ Higher degree (i.e., postgraduate degree, e.g., Masters or PhD)

Q6 How would you describe your main employment situation at the moment?
○ Employed (full-time)
○ Employed (part-time/casual)
○ Unemployed
○ Retired
○ Student (full-time or part-time)
○ Ill/permanently unable to work
○ Home duties
○ Other, please specify: __________________________

Q7 What is your smoking history?
○ Never smoked
○ Current smoker
○ Past smoker (quit more than 3 months ago)
Q8 Which primary type of cancer were you diagnosed with (or which cancer were you diagnosed with in 2013, if you have had more than one cancer diagnosis)?
- breast cancer
- lung cancer
- prostate cancer
- skin cancer

Q9 In what month were you diagnosed in 2013? ______________

Q10 What stage of cancer were you diagnosed with (e.g., Stage I)? ______

Q11 Please identify below which type of treatment(s) you received or are currently receiving to treat your Breast/Lung/Prostate/Skin cancer. Tick all that apply.
- Surgery
- Chemotherapy
- Radiotherapy (Radiation)
- I have not received any treatment
- Other ___________________
- Other ___________________

Q12 Please identify if your Breast/Lung/Prostate/Skin cancer is ....
- Currently being treated (or plan to be treated)
- In remission/stable
- Other: ___________________

Q13 Have you ever been diagnosed with any other type of cancer?
- Yes
- No
Q14 Which type(s) of cancer were you diagnosed with (please select all that apply):
- Breast Cancer
- Brain cancer
- Bowel cancer
- Colon Cancer
- Rectal Cancer
- Cervical Cancer
- Leukemia
- Lung Cancer
- Lymphoma (non-Hodgkin and Hodgkin)
- Skin Cancer
- Head and Neck Cancer
- Oesophageal Cancer
- Ovarian Cancer
- Stomach Cancer
- Other ______________________
- Other ______________________

Q15 Have you volunteered or participated in charity events (e.g., a Fun Run or Gala) to support cancer awareness, research and/or treatment? For instance, Mother's day classic or Shine light on lung cancer.
- Yes
- No

Q16 Please identify which charity events you have participated in:

Q17 Have you participated in any cancer support groups (e.g., Bosom Buddies, Melanoma Patients Australia Canberra Support Group, Lung Cancer and Mesothelioma Support Group and Prostate Cancer Support Group – ACT Region)?
- Yes
- No

Q18 Please identify which support groups you have participated in:

Q19 Do you participate in any online cancer support groups or chat forums?
- Yes
- No

Q20 Below are some questions about the support that is available to you.
Q21 A) Whom can you really count on to be dependable when you need help? Please put initials and relationship below indicating these people you can trust e.g., B.H. (Brother)
1)  
2)  
3)  
4)  
5)  
6)  
7)  
8)  
9)  

Q22 1 B) How satisfied are you with this type of support from these people?
○ Very satisfied
○ Fairly satisfied
○ A little satisfied
○ A little dissatisfied
○ Fairly dissatisfied
○ Very dissatisfied

Q23 2 A) Whom can you really count on to help you feel more relaxed when you are under pressure or tense? Please put initials and relationship below indicating these people you can trust e.g., B.H. (Brother)
1)  
2)  
3)  
4)  
5)  
6)  
7)  
8)  
9)  

Q24 2 B) How satisfied are you with this type of support from these people?
○ Very satisfied
○ Fairly satisfied
○ A little satisfied
○ A little dissatisfied
○ Fairly dissatisfied
○ Very dissatisfied
Q25 3 A) Who accepts you totally, including both your worst and your best points? Please put initials and relationship below indicating these people you can trust e.g., B.H. (Brother)

1)
2)
3)
4)
5)
6)
7)
8)
9)

Q26 3 B) How satisfied are you with this type of support from these people?
○ Very satisfied
○ Fairly satisfied
○ A little satisfied
○ A little dissatisfied
○ Fairly dissatisfied
○ Very dissatisfied

Q27 4 A) Whom can you really count on to care about you, regardless of what is happening to you? Please put initials and relationship below indicating these people you can trust e.g., B.H. (Brother)

1)
2)
3)
4)
5)
6)
7)
8)
9)

Q28 4 B) How satisfied are you with this type of support from these people?
○ Very satisfied
○ Fairly satisfied
○ A little satisfied
○ A little dissatisfied
○ Fairly dissatisfied
○ Very dissatisfied
Q29 5 A) Whom can you really count on to help you feel better when you are feeling generally down-in-the-dumps? Please put initials and relationship below indicating these people you can trust e.g., B.H. (Brother)

1) 
2) 
3) 
4) 
5) 
6) 
7) 
8) 
9) 

Q30 5 B) How satisfied are you with this type of support from these people?

☐ Very satisfied
☐ Fairly satisfied
☐ A little satisfied
☐ A little dissatisfied
☐ Fairly dissatisfied
☐ Very dissatisfied

Q31 6 A) Whom can you count on to console you when you are very upset? Please put initials and relationship below indicating these people you can trust e.g., B.H. (Brother)

1) 
2) 
3) 
4) 
5) 
6) 
7) 
8) 
9) 

Q32 6 B) How satisfied are you with this type of support from these people?

☐ Very satisfied
☐ Fairly satisfied
☐ A little satisfied
☐ A little dissatisfied
☐ Fairly dissatisfied
☐ Very dissatisfied
Q33 Unsupportive Interactions Inventory
Directions: When someone is diagnosed with a serious illness such as cancer, those around them may not know how to best support them and react. Please rate below how often your family and friends have responded to you in these specific ways.
Please begin each sentence with “My closest family and friends…”

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>A Little</th>
<th>Sometimes</th>
<th>Often</th>
<th>A lot</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not seem to want to hear about it.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did not seem to know what to say, or seemed afraid of saying or doing the &quot;wrong&quot; thing.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Felt that I should stop worrying about my cancer.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asked &quot;why&quot; questions about my role in my diagnosis.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refused to take me seriously.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seemed to be telling me what they thought I wanted to hear.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Told me to be strong or keep my chin up.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Used &quot;should or shouldn't have&quot; comments about my role in being diagnosed with cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changed the subject before I wanted to.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>From voice tone, expression or body language, I got the feeling that they were uncomfortable talking about it.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Felt that I should focus on the present or the future and that I should forget about what has happened and get on with my life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Action</td>
<td>Circle</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>--------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Told me that I had gotten myself into the situation in the first place, and now I must deal with the consequences.</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Refused to provide the type of help or support I was asking for.</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tried to cheer me up when I was not ready to.</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Felt that it could have been worse or was not as bad as I thought.</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blamed me and tried to make me feel responsible for having cancer</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When talking about it, they didn't give me much time, or made me feel I should hurry.</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Responded with uninvited physical touching (e.g., hugging).</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Said I should look on the bright side.</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Said &quot;I told you so&quot; or a similar comment.</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discouraged me from expressing feelings such as anger, hurt or sadness.</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did things for me that I wanted to do or could have done for myself.</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Felt I was overreacting.</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Seemed disappointed in me.</td>
<td>☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q26 Social Impact Scale
Serious illness, such as cancer, can affect many areas of a person's life. Please identify how each item best describes your recent experiences (within the past 3-4 weeks).

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have experienced financial hardship that has affected how I feel about myself</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>My job security has been affected by my illness</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>My employer/co-workers have discriminated against me</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I have experienced financial hardship that has affected my relationships with others</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>It bothers me when I have to depend on others</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Some people act as though I am less competent than usual</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I feel I have been treated with less respect than usual by others</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I feel set apart from others who are well</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I feel others are concerned they could &quot;catch&quot; my illness through contact like a handshake or eating food I prepared</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I feel others avoid me because of my illness</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Some family members have rejected me because of my illness</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>I feel others think I am to blame for my</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
<td>o</td>
</tr>
<tr>
<td>Illness</td>
<td>Column 1</td>
<td>Column 2</td>
<td>Column 3</td>
<td>Column 4</td>
<td>Column 5</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
<td>----------</td>
</tr>
<tr>
<td>I do not feel others understand the problems that I am experiencing as a result of my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not feel I can be open with others about my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I fear someone telling others about my illness without my permission</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel the need to keep my illness a secret</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel some friends have rejected me because of my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have a greater need than usual for reassurance that others care about me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel lonely more than usual</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Due to my illness I have a sense of being unequal in my relationships with others</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel I am at least partially to blame for my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel less competent than I did before my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I encounter embarrassing situations as a result of my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Due to my illness others seem to feel awkward and tense when they are around me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is nobody with whom I can fully discuss concerns</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>related to my illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Others close to me have trouble accepting that sometimes I feel down in the dumps</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(sad, depressed)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Due to my illness I sometimes feel useless</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My illness has disrupted my sexual life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changes in my appearance have affected my social life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feelings of fatigue/tiredness have interfered with my social life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Q73 Impact of Event Scale
Below is a list of difficulties people sometimes have after stressful life events. Please respond to how things have been DURING THE PAST SEVEN DAYS with respect to dealing and thinking about your cancer experience (diagnosis and treatment). How much were you distressed by or bothered by these difficulties?

<table>
<thead>
<tr>
<th>Difficulty Description</th>
<th>None at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any reminder brought back feelings about it</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I had trouble staying asleep</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other things keep making me think about it</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I felt irritable and angry</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I avoided letting myself get upset when I thought about it or was reminded of it</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I thought about it when I didn't mean to</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I felt as if it didn't happen or wasn't real</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I stayed away from reminders about it</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Pictures of it popped into my mind</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I was jumpy and easily startled</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I tried not to think about it</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>I was aware that I still had a lot of feelings about it, but I didn't deal with them</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
</tr>
<tr>
<td>My feelings were kind of numb</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
</tr>
<tr>
<td>I found myself acting or feeling like I was back at the time when I was told I had cancer</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
</tr>
<tr>
<td>I had trouble falling asleep</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
</tr>
<tr>
<td>I had waves of strong feelings about it</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
</tr>
<tr>
<td>I tried to remove it from my memory</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
</tr>
<tr>
<td>I had trouble concentrating</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
</tr>
<tr>
<td>Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, or pounding heart.</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
</tr>
<tr>
<td>I had dreams about it</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
</tr>
<tr>
<td>I felt watchful and on-guard</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
</tr>
<tr>
<td>I tried not to talk about it</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
<td>〇</td>
</tr>
</tbody>
</table>
Q63 Distress thermometer:

From the thermometer above, please indicate the number (0-10) that best describes how much distress you have been experiencing in the past week including today: ________________________

Q28 Core Beliefs Inventory
Some events that people experience are so powerful that they "shake their world" and lead them to seriously examine beliefs about the world, other people, themselves and their future. Please reflect upon dealing with your cancer diagnosis and indicate the extent to which it led you to seriously examine each of the following beliefs.
<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>To a very small degree</th>
<th>To a small degree</th>
<th>To a moderate degree</th>
<th>To a great degree</th>
<th>To a very great degree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Because of the event, I</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>seriously examined the degree</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to which I believe things that</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>happen to people are</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>fair</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of the event, I</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>seriously examined the degree</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>to which I believe things that</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>happen to people are</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>controllable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of the event, I</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>seriously examined</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>my assumptions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>concerning why other people</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>think and behave the way that</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>they do</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of the event, I</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>seriously examined</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>my beliefs about my</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>relationships with other</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>people</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of the event, I</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>seriously examined</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>my beliefs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>About my own abilities, strengths and weaknesses</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>---------</td>
<td>---------</td>
<td>---------</td>
<td>---------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>Because of the event, I seriously examined my beliefs about my expectations for my future</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of the event, I seriously examined my beliefs about the meaning of my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of the event, I seriously examined my spiritual or religious beliefs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Because of the event, I seriously examined my beliefs about my own value or worth as a person</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Statement</td>
<td>Strongly disagree</td>
<td>Disagree</td>
<td>Disagree a little</td>
<td>Agree a little</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------------------</td>
<td>----------</td>
<td>-------------------</td>
<td>---------------</td>
<td>-------</td>
<td>----------------</td>
</tr>
<tr>
<td>I don't look forward to the future anymore</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>My life has no meaning anymore</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I don't take life for granted anymore</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I value my relationships much more now</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I'm a more understanding and tolerant person now</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I no longer take people or things for granted</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I have very little trust in other people now</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel very much as if I'm in limbo</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I have very little trust in myself now</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I value other people more now</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
</tbody>
</table>
Q31 Psychological Well-Being - Post-Traumatic Change Questionnaire

Think about how you feel about yourself at the present time. Please read each of the following statements and rate how you have changed as a result of dealing with cancer.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Much less now</th>
<th>A bit less now</th>
<th>I feel the same about this as before</th>
<th>A bit more now</th>
<th>Much more now</th>
</tr>
</thead>
<tbody>
<tr>
<td>I like myself</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I have confidence in my opinions</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I have a sense of purpose in life</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I have strong and close relationships in my life</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel I am in control of my life</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I am open to new experiences that challenge me</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I accept who I am, both my strengths and limitations.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I don't worry what other people will think of me</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>My life has meaning</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I am a compassionate and giving person.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I handle my responsibilities in life well.</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I am always seeking to learn about myself</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I respect myself</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I know what is important to me and will stand my ground, even if others disagree</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>I feel that my life is worthwhile and that I play a valuable role in life</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
<td>○</td>
</tr>
<tr>
<td>things</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>I am grateful to have people in my life who care for me.</td>
<td>⭕</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am able to cope with what life throws at me.</td>
<td></td>
<td>⭕</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am hopeful about my future and look forward to new possibilities.</td>
<td></td>
<td></td>
<td>⭕</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Online Debriefing Form

Thank you for your time in completing this survey. The information you have provided will be used to help further our understanding, and improve the treatment of those affected by cancer. Without individuals like you who participate in research projects, we would not be able to improve our knowledge and care of cancer patients.

Some of the questions that were asked in this survey may have brought up upsetting feelings. Should you feel any overwhelming feelings of distress, you should contact your doctor or cancer nurse coordinator. You may also contact these support services:

1) Lifeline (telephone: 13 11 14) is a 24-hour confidential counseling telephone service. Telephone Crisis Support Workers can listen to your situation and concerns, and provide support and assistance. They are also able to provide you with referral information for other services in your local area.
2) The Canberra Counselling Service is also available to provide psychological assistance. To book an appointment, you may call (02) 6281 2625, Monday to Friday 9am to 6pm.

Thank you again for your participation.

Should you have any questions about the study, please do not hesitate to contact us.

Best regards,

Dr Sayed Ali, MB BS, FRACP
Staff Specialist in Medical Oncology
Lecturer, ANU Medical School

Jennifer Threader, BSc (Hons)
Provisional Psychologist/Clinical PhD Candidate
(t): 02 6125 4582
(email): jennifer.threader@anu.edu.au
Appendix 3

Study 4: The ‘Lived’ Experience of Stigma, Distress and Psychological Growth on the Journey with Head and Neck Cancer

Human Ethics Approval (ANU) .............................................................. 324
Human Ethics Approval (The Canberra Hospital) .............................. 325
Participant Information Sheet ............................................................... 327
Participant Consent Form ................................................................. 331
Interview Schedule ........................................................................... 333
Dear Ms Jennifer Threader,

Protocol: 2012/407
Understanding the lived experience of developing adversarial growth following diagnosis among head and neck cancer patients

I am pleased to advise you that your Human Ethics protocol received approval by the Chair of the HREC on 10 July 2012.

For your information:

1. Under the NHMRC/AVCC National Statement on Ethical Conduct in Human Research we are required to follow up research that we have approved. Once a year (or sooner for short projects) we shall request a brief report on any ethical issues which may have arisen during your research or whether it proceeded according to the plan outlined in the above protocol.

2. Please notify the committee of any changes to your protocol in the course of your research, and when you complete or cease working on the project.

3. Please notify the Committee immediately if any unforeseen events occur that might affect continued ethical acceptability of the research work.

4. Please advise the HREC if you receive any complaints about the research work.

5. The validity of the current approval is five years' maximum from the date shown approved. For longer projects you are required to seek renewed approval from the Committee.

All the best with your research,

Kim

Ms Kim Tiffen
Ethics Manager
Office of Research Integrity,
Research Services,
Ground Floor, Chancelry 10B
Ellery Road
The Australian National University
ACTON ACT 0200
T: +61 6125 3427
F: +61 2 6125 4807
Kim.Tiffen@anu.edu.au or
human.ethics.officer@anu.edu.au
Ms Jennifer Threader
Research Centre for Nursing and Midwifery Practice
Building 6, Level 3 (East Wing)
The Canberra Hospital
Garran ACT 2605

Dear Ms Jennifer Threader

Re: ETHLR.12.073

The ACT Health Human Research Ethics Committee’s Low Risk Sub-Committee received notification of the proposed study:

Investigating factors that influence growth and adaption following cancer diagnosis at its meeting of 28 March 2012.

I am pleased to inform you that, following further correspondence, your application has been approved out of session.

The Sub-Committee agreed that the application is for low risk research and determined that the research meets the requirements of the National Statement on Ethical Conduct in Human Research and is ethically acceptable.

I attach for your records an Outcome of Consideration of Protocol form.

I confirm that the ACT Health Human Research Ethics Committee is constituted according to the National Health and Medical Research Council Guidelines and operates in compliance with applicable regulatory requirements and the International Conference on Harmonization Guidelines on Good Clinical Practice.

Yours sincerely

[Signature]

Professor John SG Biggs MA MD
FRCOG FRANZCOG DHMSA
Chairman
ACT Health Human Research Ethics Committee
Low Risk Sub Committee
2 May 2012
ACT HEALTH HUMAN RESEARCH ETHICS COMMITTEE

Outcome of Consideration of Protocol

Submission No: ETHLR.12.073 Date of Approval: 2 May 2012

Project Title: Investigating factors that influence growth and adaption following cancer diagnosis

Submitted by: Ms Jennifer Threader

Your project was considered by the ACT Health Human Research Ethics Committee and Approved for a period of 3 years.

First Annual Review due: April 2013

The Ethics Committee require as part of the review process that:

- At regular periods, and not less frequently than annually, Principal Investigators are to provide reports on matters including:
  - security of records
  - compliance with approved consent procedures and documentation
  - compliance with other approved procedures.
  - as a condition of approval of the protocol, that Investigators report immediately:
    - adverse affects on subjects
    - proposed changes in the protocol
    - unforeseen events that might affect continued ethical acceptability of the project.

- All published reports to carry an acknowledgement stating:
  - approved on 2 May 2012 by the ACT Health Human Research Ethics Committee.

Professor John SG Biggs, Chairman 2 May 2012
PARTICIPANT INFORMATION SHEET

‘Understanding the ‘lived’ experience of developing adversarial growth following diagnosis among head and neck cancer patients’

Invitation:
You are invited to participate in a research study that looks into your experience of dealing with head and neck cancer and how it has positively and/or negatively impacted on your life.

1. What is the purpose of this study?
The purpose of the study is to examine how head and neck cancer either positively or negatively affects those who are diagnosed. Specifically, this study aims to understand how social support and societal influences affect how head and neck cancer patients cope after diagnosis. As there is currently not a lot of information about this topic, this study involves being interviewed in order to understand your unique experiences.

2. Why have I been invited to participate in this study?
You are invited to participate in this study as you were diagnosed with cancer and you have received surgical treatment. You are encouraged to discuss this project and your potential participation with family and/or community members prior to agreeing to take part.

3. What if I don’t want to take part in this study, or if I want to withdraw later?
You can refuse to take part in this project or withdraw from it at any time without this affecting your medical care. Should you decide to withdraw from the study, please contact the Project Leader (Jenn Threader, telephone (02) 6125 5585) to inform of your decision. Your data (interview recordings and scripts) would then be withdrawn from the study. This data will be kept in locked cabinets, in a secure locked office within the Department of Psychology and Research at the Australian National University for a period of seven years. After seven years, your scripts will be securely shredded and your recordings deleted. Your withdrawn data will not be used in the final study analyses.

4. What does this study involve?
The procedure will involve being interviewed by the project leader (Jenn Threader), who is also a provisional psychologist at the Australian National University. The interview will ask you questions about your experience of dealing with head and neck cancer in terms of how you feel you have been treated by society and by significant others, as well as both the positive and/or negative ways it was influenced your life.
The interview will take approximately 1½ – 2 hours of your time. The interview will be audio recorded. This means that only what you say will be recorded.

In order to fully analyse the interviews, the conversation with the project leader (Jenn Threader) will be subsequently written up verbatim. This written script will be completed only by Jenn Threader and will be stored in a locked cabinet in Jenn’s office at the Australian National University.

If you consent to participate, Jenn will review your medical records to obtain your demographic information, pathological results and diagnosis, stage of disease, and treatment received. We will only review your medical record for episodes of care that relate to your diagnosis of cancer and any treatment for your cancer. If you do not consent to participate we will not access your medical record.

5. Will I benefit from the study?
The results from the study may or may not be of direct benefit to your medical management. However, by participating in this study you will be helping to advance our understanding as to what elements (e.g., social support) influence both positive and negative changes after diagnosis. We hope the information learned from this study will help other patients with cancer in the future.

6. Are there risks to me in taking part in this study?
There is a small chance that some people participating in this survey may experience distress. If you experience distress or require any supportive care during this study you can contact your cancer nurse coordinator.

You may also contact these services:
1) Lifeline (telephone: 13 11 14) is a 24-hour confidential counseling telephone service. Telephone Crisis Supporters can listen to your situation and concerns, and provide support and assistance. They are also able to provide you with referral information for other services in your local area.
2) The Canberra Counselling Service is also available to provide psychological assistance. To book an appointment, you may call (02) 6281 2625, Monday to Friday 9am to 6pm.

7. How will my confidentiality be protected?
All information collected about you will be coded and de-identified. That is, all of your data, including scripts and video tapes, will include the same specific code that has been assigned to you. Only your consent form will contain your contact information. Your consent form will be stored in another locked cabinet, separate from your scripts and video tapes.

Only the research team will have access to your data. All data and consent forms will be kept stored and locked in cabinets, in a secure
locked office within the Department of Psychology and Research, at the Australian National University. All data stored in the computer (including interview scripts) will be password protected and all data will be destroyed by appropriate means after seven years at the end of data collection. That is, all paper documents will be shredded; all password-protected computer files will be deleted; and audio tapes will be securely deleted.

8. What happens with the results?
The results of the research may be published in medical or nursing journals and may be presented at medical or psychological conferences. Research from this study will also be included in a PhD research project, undertaken in Clinical Psychology at the Australian National University. Your identity will not be revealed in any publications or presentations.

9. What happens if I suffer harm, injury or complications as a result of the study?
Should you develop a problem which you suspect may have resulted from involvement in this research you can contact – the Project Leader: Jenn Threader, telephone (02) 6125 5585. You can also document whether this project will cause further distress and report this to the Project Leader.

10. How is this study being paid for?
This study has been supported by the Australian National University, as a part of PhD requirement in Clinical Psychology. No external funding has been received for the conduct of this study.

11. Will taking part in this study cost my anything, and will I be paid?
Participation in this study will not cost you anything, nor will you be paid for your participation. However as a small token of appreciation for your time to share your experience, you will be provided with a $25 gift certificate from Westfield shopping centre.

12. What should I do if I want to discuss this study further before I decide?
You may contact the Project Leader: Jenn Threader, telephone (02) 6125 5585.

13. Who should I contact if I have concerns about the conduct of this study?
Approval has been given by the ACT Health Human Research Ethics Committee and the Australian National University Human Research Ethics Committee.

If you have any problems or queries about the way in which this study has been carried out and you do not feel comfortable communicating with the staff conducting this survey, please contact the committee secretariat via ACT Health Human Research Ethics Office, Level 6
Building 10 Telephone (02) 6205 0846, or by emailing acthealth-hrec@act.gov.au.
Consent Form to Participate in a Research Project

I, ________________________________ (name of participant) of
__________________ (street)  ____________________ (suburb)  __________________ (state & post code)
Telephone number ___________ Preferred time to call ___________

Have been asked to consent to participate in a research project entitled:
'Understanding the 'lived' experience of developing adversarial growth following diagnosis among head and neck cancer patients'

In relation to this project I have been informed in the following points:

1. Approval has been given by the ACT Health Human Research Ethics Committee and the Australian National University Human Research Ethics committee.

2. The aim of the project is to examine how head and neck cancer either positively or negatively affects those who are diagnosed. Specifically, through an interview format, this study aims to understand how social support and societal influences affect how head and neck cancer patients cope after diagnosis.

3. The results obtained from the study may or may not be of direct benefit to my medical management.

4. The procedure involves participating in an interview (of approximately 1½ to 2 hours) that can be completed at a time and located best suited for me. I understand the interview will be audio recorded and will assess my experience of dealing with head and neck cancer in terms of how I feel and have been treated by society and by significant others, as well as both the positive and/or negative ways it was influenced my life. My medical records will also be reviewed regarding my demographic information, pathological results and diagnosis, and the type of treatment I received.

5. There are no adverse effects or risk related to this project. If however, I experience distress or require supportive care needs during this study, I can contact my cancer nurse coordinator. I may also contact the services (Lifeline and The Canberra Counselling Service) which were indicated on the Patient Information Sheet. I can also document whether this project will cause me further distress and report this to the Project Leader.

6. Should I develop a problem which I suspect may have resulted from my involvement in this project, I am aware that I may contact – the Project Leader: Jenn Threader, telephone (02) 6125 5585.
7. Should I have any problems or queries about the way in which this study was conducted, and I do not feel comfortable contacting the research staff, I am aware that I may contact the ACT Health Human Research Ethics Secretary, telephone (02) 6205 0846.

8. I understand that I can refuse to take part in this project or withdraw from it at any time without affecting my medical care. I also understand that if I decide to no longer participate in the research, although my withdrawn data and information will be kept in secure locked cabinets and shredded (scripts) and deleted (audio tapes) after a period of seven years, it will not be used in study analyses.

9. Participation in this project will not result in any extra medical and hospital costs to me.

10. I understand the results of the research may be published in medical or psychological journals and may be presented at medical or psychological conferences. I also understand that research from this study will also be included in a PhD research project, undertaken in Clinical Psychology at the Australian National University. I am assured that my involvement and my identity will not be revealed.

After considering these points, I accept the invitation to participate in this project.

Signature: ______________________  ______________________
            (of participant)               (of witness)

Date:       (dd/mm/yyyy)          (dd/mm/yyyy)
Interview Schedule

1) The personal experience of cancer impacts differently on people. Some people have reported both negative and positive outcomes in their lives as a result of experiencing cancer. I am interested in how you have made meaning of (or, tried to understand the) changes to your body following surgery for cancer, and how this has impacted positively or negatively in your life?

2) What is it about your experience of dealing with head and neck cancer in particular that has impacted on you either positively or negatively?

3) Some people, who have experienced external changes to their body, have reported feeling stigmatized (or, negatively evaluated/ discriminated against) from others. Could you talk about your experience of other’s responses to you following head and neck cancer?

4) One of the risk factors for head and neck cancer is heavy smoking and drinking behaviour. Can you comment on whether you have had any negative reactions from others as a result of your lifestyle choices and how you interpret their responses?

5) Support can be regarded as positive or negative during times of distress. Could you talk about the type of support you received as a result of being diagnosed with head and neck cancer?

6) How did you make sense of this distressing event in your life?

7) Recently it has been found that psychological growth (or increased feelings of accomplishment and inner fulfilment) can follow terrible adversity such as dealing with a cancer diagnosis. How do you perceive you have changed psychologically, philosophically (or world view), or existentially (sense of reality or belonging – a sense of why are we here? What is our purpose?) as a result of dealing with cancer?

8) Similarly have you experienced different ways of thinking, either positively or negatively about yourself, your relationships, or your values and beliefs since being diagnosed?