

# THE EXPERIENCE OF POSTTRAUMATIC GROWTH BY IRISH FEMALE CANCER SURVIVORS

Thesis submitted for the degree of  
Doctor of Social Science at  
the University of Leicester

by  
Marie Walsh  
School of Management  
University of Leicester

May 2020

**Title:** The experience of PostTraumatic Growth by Irish female cancer survivors.

Marie Walsh

## Abstract

This thesis explores how 67 Irish female cancer survivors experienced positive growth from cancer. With better treatment and improvements in early detection, the cancer survivor population is growing exponentially. Survivors have unmet needs and there is a need for and a shortage of psycho social supports available. We need to understand the lived experience of cancer survivors to be able to provide supports appropriate to their needs.

The literature review positions this project within the research fields of survivorship and psycho-oncology. It examines the development and debates of the Model of PostTraumatic Growth which is a key framework used in this research.

There are three key research questions: What is PostTraumatic Growth (PTG) in the context of female cancer recovery? To what extent does the PostTraumatic Growth Inventory effectively capture Irish women's experience of cancer recovery? And how does the PostTraumatic Growth Inventory compare to semi-structured interviews in understanding women's experiences of cancer recovery?

The research employs a mixed-methods approach. The qualitative data consists of semi structured interviews and the quantitative data is derived from the PostTraumatic Growth Inventory-42. Thematic Analysis (Braun & Clarke, 2006) was used to analyse the qualitative data and Statistical Package for Social Science (SPSS) software used to analyse the quantitative data with an emphasis on descriptive statistics, correlations and Principal Components Analysis.

The findings highlight the importance of quality 'social support' especially from close friends as a significant driver of cancer recovery. Participants experienced the greatest degree of growth in the Relate to Others Factor. The findings suggest two new areas of positive growth: Proactive Mindset and Self Worth. Participants with children experienced greater positive growth compared to those who did not have children. Age, marital status and cancer stage were not predictors of growth.

This research recommends maximising social support as a key recovery driver and highlights the need to develop a new PostTraumatic Growth Inventory to ensure its validity as a measurement tool of positive growth for the cancer survivor population.

## Acknowledgments

Completing a doctoral project of this size really is a mammoth task and is not something I achieved alone. Firstly, I would like to thank my supervisors, Dr Jenna Ward, Dr Diana Pinto and Dr Daniela Rudloff. Your guidance and patience were genuinely appreciated. I would like to especially mention Dr Ward for believing in me and for keeping me on the right track.

I thank my colleagues at Limerick Institute of Technology – Mathew and Caitriona for the many walks to get coffee and for putting up with my rants along the way! I want to acknowledge the sparkly butterfly energy sent by Dee from time to time that kept me going. I must also credit here the powerful ‘beady eye’ of my sister in law Liz who I am proud to call friend. This research could not have happened without the support of my family – my husband Ger and my two lovelies – Holly and Tom. Thank you for allowing me the time and space to follow this dream.

The research would not have been possible at all without the support of the Cancer Support Centres in Ireland and the generosity of the amazing 67 women who took part. I thank each one of you and hope that this project will help voice some of your remarkable life stories. I would like to especially mention Noeleen, the incredible woman who threw two diaries at me and by doing so inspired the Dear Diary project.

I feel both proud and humble to say that I come from a long line of strong Brien women. My ‘little nanny Brien’ was fierce and determined and I would like to think she passed a little of this to me. I would also like to thank my Mother for my strength, perseverance and hardworking attitude, all of which helped me to complete this research. In 2008 a bright light went out when my Mother passed away from lung cancer and so I must credit her too for inspiring my desire to understand how women live with, cope with and sometimes overcome the cancer experience.

On my wedding day my lovely aunt Breda said she would be my mammy for the day. Then, in 2017, Breda too passed away from lung cancer. And so, my Mother and Breda have both silently walked this research journey alongside me. Though my research focuses on recovery and positive growth from cancer, I would like to dedicate this work to all whose time was cut short. May they all rest in true peace. Amen.

# Contents

Abstract	
Acknowledgments	
Contents	i
List of Tables	vi
List of Figures	vii
List of Abbreviations	viii
1. Introduction	1
1.1 Rising rates of cancer incidence and mortality	2
1.2 Cancer Survivor population growth and need for services	4
1.3 Research gaps in our understanding of cancer survivorship	5
1.4 Research Contribution	7
1.5 Thesis Overview	9
2. Literature Review	12
2.1 Introduction	12
2.2 Cancer Survivorship	13
• Cancer Survivor Population: growth, unmet survivor needs, and late effects	13
• Developments in Cancer Research	16
• Changes in survivor research from stress to growth	18
2.3 Psycho-oncology	20
• The field of Psycho-oncology	21
• Psycho-oncology and the Irish context	25
2.4 PostTraumatic Growth	27
• The PostTraumatic Growth Model	28
• Key Debates	31
3. Methodology	39
3.1 Introduction and Research Questions	39
3.2 Methodological approach	41
3.3 Researcher Stance	45
3.4 The Research Plan, Recruitment, Selection and Participant Profile	47
• The Research Plan	47
• Participant Profile	51
3.5 Interviews and PTGI-42	56
• Interviews	56
• PTGI-42	58
3.6 Data Analysis	59
• Phase 1: Familiarising myself with the Data	60
• Phase 2: Generating Initial Codes	61
• Phase 3: Generating Themes	62

• Phase 4: Reviewing Themes	63
• Phase 5: Defining and Naming Themes	66
• Phase 6: Producing the Report	66
3.7 Ethics	66
• Informed Consent	67
• Privacy, Confidentiality and Anonymity	68
3.8 Limitations	69
• Multiple difficulties in accessing participants	69
• Type of cancer determines treatment and therefore recovery experience	70
• Low racial representation	71
• Personal and cognitive skill level needed by participants to take part	71
• Potential for demand characteristics bias	71
4. Findings: Research Question One: What is PostTraumatic Growth (PTG) in the context of female cancer recovery?	73
• Relating to Others is the most significant PostTraumatic Growth area	75
• Significant impact of social support on survivor recovery	78
• Significant growth in New Possibilities were local and social	80
• Increased Personal Strength with more self-awareness and greater confidence	81
• Spiritual Change dichotomy from no growth to considerable change	82
• New Appreciation of Life means new priorities and a desire to ‘make the best out of life’	84
• Proactive Mindset is the new Sixth Growth Factor	85
5. Findings: Research Question Two: To what extent does the PostTraumatic Growth Inventory effectively capture Irish women’s experience of cancer recovery?	89
• Reasonably good internal reliability with a high Cronbach’s alpha ( $\alpha = .85$ )	89
• High mean PTG level at 77 for cancer survivors	89
• Analysis of each of the 5 Factors	91
• Appreciation of Life:	92
• Relating to Others	93
• Personal Strength	94
• New Possibilities	96
• Spiritual Change	97
• No positive PTG between those with breast cancer compared with other cancers	98
• Positive growth can happen in any cancer stage	100
• No correlation between positive growth levels and age	100
• No significant relationship between marital status and PTG	100
• Having children means higher positive growth in New Possibilities and Appreciation of Life	101

• Issues with PostTraumatic Growth Inventory - 42	101
• PostTraumatic Growth Inventory does not address the physicality of cancer	104
6. Findings: Research Question Three: How does the PostTraumatic Growth Inventory compare to semi structured interviews in understanding women’s experience of cancer recovery?	106
6.1 Introduction to Principal Components Analysis	106
• Component 1: Relate to Others	108
• Component 2: New Possibilities	110
• Component 3: Spiritual Connection	111
• Component 4: Self Worth	113
• Component 5: Personal Strength	114
• Component 6: Proactive Mindset	116
• Convergence and Divergence of findings	117
6.2 Significant qualitative findings not captured by quantitative data	120
• Cancer experience is a linear, chronological narrative marked by the 3 major transitions of diagnosis, treatment and recovery	120
• The diagnosis experience is the blueprint for recovery	125
• Participants attribute major negative life events as the cause of their cancer	125
• Cancer recovery is a socially embedded and collaborative process	126
• Key behaviours/attitudes that drive and hinder the dynamic of the recovery process	127
• Cancer Support Centres as a recovery driver for peer survivors to connect and to expand social networks	129
• Cancer is an emotional roller-coaster	130
• Anxiety, fear and depression perceived as ‘negative emotions’ that hinder recovery	131
• Participants facing cancer maintenance, or a high risk of cancer recurrence have higher needs and lower PTG	133
7. Discussion and Conclusion	135
7.1 Answering the three research questions	135
• Question One: What is PostTraumatic Growth (PTG) in the context of female cancer recovery?	135
• Question Two: To what extent does the PostTraumatic Growth Inventory effectively capture Irish women’s experience of cancer recovery?	139
• Question Three: How does the PostTraumatic Growth Inventory compare to semi-structured interviews in understanding women’s experiences of cancer recovery?	142
7.2 Contribution to Research	145
• Understanding the dynamics that drive the growth in how survivors ‘Relate to Others’.	145
• Know your tribe and take your (social) medicine, it’s good for you!	146
• Cancer is an emotional roller-coaster	147

• Cancer experience revolves around 3 major transitions of diagnosis, treatment and recovery	148
• Predictors of PostTraumatic Growth	148
• Redefining positive areas of growth	149
• Refining the PostTraumatic Growth Inventory as a research instrument	150
7.3 Study Limitations	151
• Sample and Recall Bias	151
• Limits of demographic information:	152
• Low access of cancer support centres by working class and non- Irish nationals:	153
7.4 Considerations for Further Research	154
• Research in ‘real time’ over several time points	154
• Identify if cancer was experienced as a trauma and if other traumas occurred	154
• ‘Positivity’ and the experience of positive growth by cancer survivors	154
• Interview the investigator	155
• The importance of researcher reflexivity and self-care	155
• Research as a potential therapeutic intervention	156
7.5 Future Recommendations	157
• Maximise ‘social support’ as a resource to drive positive growth	157
• Cancer survivors suffer late effects and need tailored initiatives/interventions	158
• Survivorship programmes needed that promote PostTraumatic Growth	159
• Improve the transition from hospital care to community and self-management	160
• Recommended changes to the PTGI to increase its validity as a measurement of positive growth for the survivor population	163
• Call for further research and support into recovery for survivors with a difficult prognosis	164
• Further research needed to investigate how come those from disadvantaged areas and different ethnic backgrounds are not accessing cancer services	165
Appendices	166
Appendix 1: Dear Diary Project	167
Appendix 2: Workshop Flyer for CARE	170
Appendix 3: List of Cancer Support Centres across the Southern Region of Ireland	171
Appendix 4: PTGI-42	172
Appendix 5: Questions for meeting with Care Cancer Centre	175
Appendix 6: Organization Information Sheet	176
Appendix 7: Organization Informed Consent Form	178
Appendix 8: Poster used by Recovery Haven Cancer Support Centre	179
Appendix 9: Participant Information Sheet	180
Appendix 10: Participant Informed Consent Form	182
Appendix 11: Interview Questions	184
Appendix 12: Demographic Questions	185

Appendix 13: Long Answer Questions	186
Appendix 14: Key organisations and the Irish Cancer Strategy	188
Appendix 15: Thematic Analysis Phase 2 Open Coding (346 codes)	190
Appendix 16: Statistics Percentiles where N= 66	198
Appendix 17: Findings of Core Beliefs Inventory and Frequencies	199
Appendix 18: Summary of the 4 Major Qualitative Themes	203
Appendix 19: Quantitative Findings: Post Traumatic Growth Inventory (PTGI-42)	259
Appendix 20: Quantitative Findings: Spearman Analysis and Principal Components Analysis	297
References	299
Bibliography	314



## List of Tables

Table 1:	Qualitative Mixed Methods Data Collection Type Applied	40
Table 2:	13 Steps for Mixing and Merging Methodologies, Schoonenboon (2018) applied	44
Table 3:	Study Participants' Age Range	51
Table 4:	Type of Cancer Experienced by Study Participants, as % of study population	52
Table 5:	Number of times that Study Participants indicated they had been treated for cancer	52
Table 6:	Stage of Cancer Experienced by Study Participants	53
Table 7:	Study Participants' Marital Status	53
Table 8:	Study Participants' Overall Data Table	54
Table 9:	Six Phases of Thematic Analysis Applied (Braun & Clarke, 2006)	60
Table 10:	Phase 3 Generating Themes	63
Table 11:	Positive Growth from Cancer from qualitative data.	88
Table 12:	List of PTG Research Projects undertaken in Recent Years, and their Mean PTGI scores	91
Table 13:	Study Participants' Statistics for each of the 5 Factors of growth	91
Table 14:	'I changed my priorities about what is important about life' and cumulative frequency	93
Table 15:	'I more clearly see that I can count on people in times of trouble'	94
Table 16:	I am better able to accept the way things work out'	95
Table 17:	'I developed new interests'	97
Table 18:	'I have a better understanding of spiritual matters'	98
Table 19:	Principal Components Analysis Total Variance Explained	107
Table 20:	Principal Components Analysis of PTGI Component 1, Relate to Others	109
Table 21:	Principal Components Analysis of PTGI Component 2, New Possibilities	111
Table 22:	Principal Components Analysis of PTGI Component 3, Spiritual Connection	113
Table 23:	Principal Components Analysis of PTGI Component 4, Self Worth	114
Table 24:	Principal Components Analysis of PTGI Component 5, Personal Strength	115
Table 25:	Principal Components Analysis of PTGI Component 6, Proactive Mindset	117
Table 26:	Summary of findings; interview, PTGI Items and 6 Components	119
Table 27:	Major themes of what helps Recovery	128
Table 28:	Study Participants' Statistics for each of the 5 Factors of growth	141

## List of Figures

Figure 1:	5 Year Survival Rates for Ireland and OECD Average	2
Figure 2:	Chart of 5-Year Cancer Survival Rates in Ireland, 1994-2014	4
Figure 3:	Model of PostTraumatic Growth (Tedeschi & Calhoun, 2004)	30
Figure 4:	Graphic Representation of Participants' Age Range (from 40 to 78 years)	51
Figure 5:	Study Participants' Marital Status (Percentage of Population)	54
Figure 6:	Thematic Map for T2 and Positive Growth from Cancer	65
Figure 7:	Thematic Map, Positive Growth from Cancer and 5 Factors	74
Figure 8:	Dear Diary: The importance of a phone call	78
Figure 9:	Dear Diary: Support from Others	80
Figure 10:	Thematic Map for Positive Growth from Cancer and 6th Factor Proactive Mindset	85
Figure 11:	Histogram of the Individual Mean PostTraumatic Growth Scores	90
Figure 12:	5 Factors of Growth: Study Participants' Responses – Appreciation of Life	92
Figure 13:	5 Factors of Growth: Study Participants' Responses – Relate to Others	93
Figure 14:	5 Factors of Growth: Study Participants' Responses – Personal Strength	95
Figure 15:	5 Factors of Growth: Study Participants' Responses – New Possibilities	96
Figure 16:	5 Factors of Growth: Study Participants' Responses – Spiritual Change	97
Figure 17:	Relating to Others Mean, for Breast and Other Cancer Types	99
Figure 18:	The Scree Plot of the Principal Components Analysis of the PTGI	108
Figure 19:	PTGI Component 1: Relate to Others – a full list of inventory items	109
Figure 20:	PTGI Component 2: New Possibilities – a full list of inventory items	110
Figure 21:	PTGI Component 3: Spiritual Connection – a full list of inventory items	112
Figure 22:	PTGI Component 4: Self Worth – a full list of inventory items	113
Figure 23:	PTGI Component 5: Personal Strength – a full list of inventory items	115
Figure 24:	PTGI Component 6: Proactive Mindset – a full list of inventory items	116
Figure 25:	Thematic Map for 4 Main Qualitative Themes	120
Figure 26:	Thematic Map of The Cancer Journey and Positive Growth from Cancer	121
Figure 27:	Dear Diary: Finding a lump	122
Figure 28:	Dear Diary: Dead Eyes – Mask on Mirror	124
Figure 29:	Thematic Map Support and Survival Strategies	127
Figure 30:	Interdependence of emotional, physical and relational hindrances to recovery	129
Figure 31:	'Negative Emotions' fed by Internal and External Stressors	133

## List of Abbreviations

APOS	American Psychosocial Oncology Society
CANCON	European Guide on Quality Improvement in Comprehensive Cancer Control
CARE	Cancer Aftercare Relaxation and Education
CS	Cancer Survivor
CSO	Central Statistics Office
DSM-IV	Diagnostic Statistical Manual IV
DSM-V	Diagnostic Statistical Manual V
EPAAC	European Commission Joint Action European Partnership for Action Against Cancer
EU	European Union
HSE	Health Services Executive
IARC	International Agency for Research on Cancer
IACR	Irish Association for Cancer Research
ICS	Irish Cancer Society
IPOS	International Psycho Oncology Society
IPSON	Irish Psycho Social Oncology Network
LIT	Limerick Institute of Technology
NCCP	National Cancer Control Programme
NCD	Non-Communicable Disease
NCRI	National Cancer Registry Ireland
OECD	Organisation for Economic Cooperation and Development
PCA	Principal Components Analysis
PE	Personal Empowerment
PRO	Patient Reported Outcomes
PSI	Psychology Society of Ireland
PTG	PostTraumatic Growth
PTGI	PostTraumatic Growth Inventory
PTSD	Post Traumatic Stress Disorder
PTSS	Post Traumatic Stress Syndrome
QOL	Quality of Life
SPSS	Statistical Package for Social Sciences
TA	Thematic Analysis
UK	United Kingdom
WHO	World Health Organisation

# 1. Introduction

With rising rates of both cancer incidence and mortality, cancer is a problem (National Cancer Registry, 2018). More people are being diagnosed with cancer and, while death rates as a result of cancer are rising, the size of the cancer survivor population is increasing rapidly (Department of Health, 2017a; van den Berg *et al.*, 2013; Hoffman *et al.*, 2012). This increase is attributed to better prevention strategies, early screening, and improved treatment. While this is a very welcome development, it means that we have a sizable and growing population of cancer survivors and we need to understand the survivor experience to be best able to provide support and services to address their needs (van der Spek *et al.*, 2013; Maher *et al.*, 2018).

The cost of cancer is high (Pearce & Bradley, 2016). Cancer is a chronic lifelong condition, and survivors experience a significant personal, social and financial burden. This cost is often due to late effects from cancer itself and even from treatment (Irish Cancer Society, 2015). Survivors need a range of medical and psychological services to help manage the medium to long term negative effects of cancer (Meade *et al.*, 2017; Keane *et al.*, 2018). These late effects therefore involve not just a personal cost but also high economic costs for national health services, due to medical appointments and hospital stays.

There are research gaps in our understanding of survivorship. Early cancer research focused on diagnosis and treatment (Bloom *et al.*, 2007). Survivorship research has only developed in the last 30 years. In fact, it was only in 1985 when the term ‘cancer survivorship’ was used in a medical journal for the first time (Takahashi, 2016). Much of the work in cancer survivorship has explored the negative impact and distress caused by the cancer experience. And methodologically, much of the research is quantitative rather than qualitative.

An important issue in survivorship research is the existing lack of, and recognised need for, patient reported outcomes (PRO) data (Thong *et al.*, 2018; Wehrle *et al.*, 2016). There are real gaps in our understanding of recovery drivers and positive growth from cancer (Fox *et al.*, 2014). There is a need and call for mixed methods research in cancer survivorship, to expand our understanding of the PostTraumatic Growth (PTG) construct (Hasson-Ohayon, 2016; Scignaro *et al.*, 2016). This mixed methods doctoral study will contribute to the understanding of how to evaluate PTG in cancer survivors

by providing a comparative analysis of how growth is studied using both interviews and the PTGI-42.

## 1.1 Rising rates of cancer incidence and mortality

With 41,080 people in Ireland being diagnosed with cancer each year and 8,875 people dying from it annually, cancer is most definitely a national and international health problem (National Cancer Registry, 2018). The reality of these numbers is that, in Ireland, one person is diagnosed with cancer every 3 minutes and one person dies from it every hour (Irish Cancer Society, 2018a). Within an international context, as can be seen Figure 1 below, Ireland is below the OECD average survival rates for breast, cervical and colon cancer, with rectal cancer being the exception (Department of Health, 2017a).

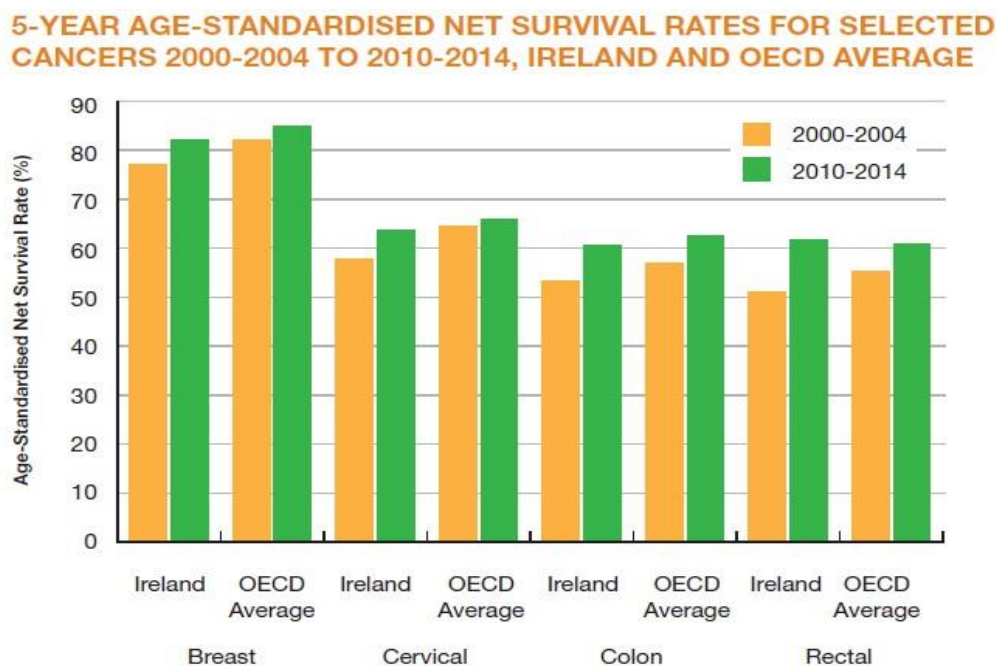


Figure 1: 5 Year Survival Rates for Ireland and OECD Average from [health.gov.ie/publications-research/statistics/statistics-by-topic/cancer](http://health.gov.ie/publications-research/statistics/statistics-by-topic/cancer). [Accessed Dec 11, 2018 at 11am]

Cancer incidence has increased approximately 3% per year in Ireland since 1994 and is estimated to increase to 42,000 by 2020 (National Cancer Registry, 2018). Several factors continue to drive this increase – including, a growing and aging population,

negative lifestyle factors (obesity, smoking and alcohol consumption), and better screening. Another contributing demographic factor is that life expectancy in Ireland is now at 81.5 years and is increasing at a faster rate than the European average (OECD, 2019) which means a growing late-adulthood population.

In its latest annual report, the National Cancer Registry (2018) used population statistics to estimate that the incidence of all cancers will double by 2045. In terms of mortality, cancer is the second most common cause of death (after circulatory system diseases) in Ireland, and an average of 8,875 people died from cancer each year from 2013-2015 (National Cancer Registry, 2018).

Breast cancer is the most common invasive cancer diagnosed for women, followed by lung and colorectal cancer. For both genders, lung cancer is the most common cause of death – 19% of deaths in women and 23% of male deaths. The lifetime risk for developing cancer for men is 1 in 3, and for women 1 in 4 in Ireland (National Cancer Registry, 2018). Cancer was attributed to 20% of deaths in Ireland in the 1980s– this has more recently risen to 30% (Department of Health, 2017a).

One of the larger societal costs of cancer, and cancer mortality, is the loss of productivity. The recent post-doctoral work of Pearce and Bradley (2016), at the National Cancer Registry of Ireland, sought to estimate the extent of Irish productivity loss due to cancer when people temporarily or permanently cannot work. They found that

“The 233,000 projected deaths from all invasive cancers in Ireland between 2011 and 2030 will result in lost productivity valued at €73 billion...an annual 1% reduction in mortality reduced productivity losses due to all invasive cancers by €8.5 billion over 20 years” (Pearce & Bradley, 2016, p. 1).

Both the incidence and mortality rates of cancer are increasing, which makes ‘cancer’ a significant national and international problem that needs to be addressed and therefore an important area of research.

## 1.2 Cancer Survivor population growth and need for services

The cancer survivor population is growing exponentially. Although internationally cancer is a leading cause of death, “About half of the cancer patients in developed countries recover from cancer and become long-term survivors” (van der Spek *et al.*, 2013, p. 1). In the UK alone, it is estimated that three quarters of people who were diagnosed with cancer are now living as survivors (Maher *et al.*, 2018). Therefore, there are increasing numbers of cancer survivors with cancer seen as a chronic disease rather than a death sentence (van den Berg *et al.*, 2013; Hoffman *et al.*, 2012).

In Ireland, the latest figure of cancer survivor prevalence is estimated at 173,050 people in December 2016 (National Cancer Registry, 2018) which is 4% of the population in that year (these are the latest figures available). One in seven of cancer survivors in Ireland are over 50 years of age (National Cancer Registry, 2018). Since the 1990s, as shown in Figure 2, below, the five-year survival rates of several cancers have improved and is currently at 61% (Department of Health, 2017b; National Cancer Registry, 2018).

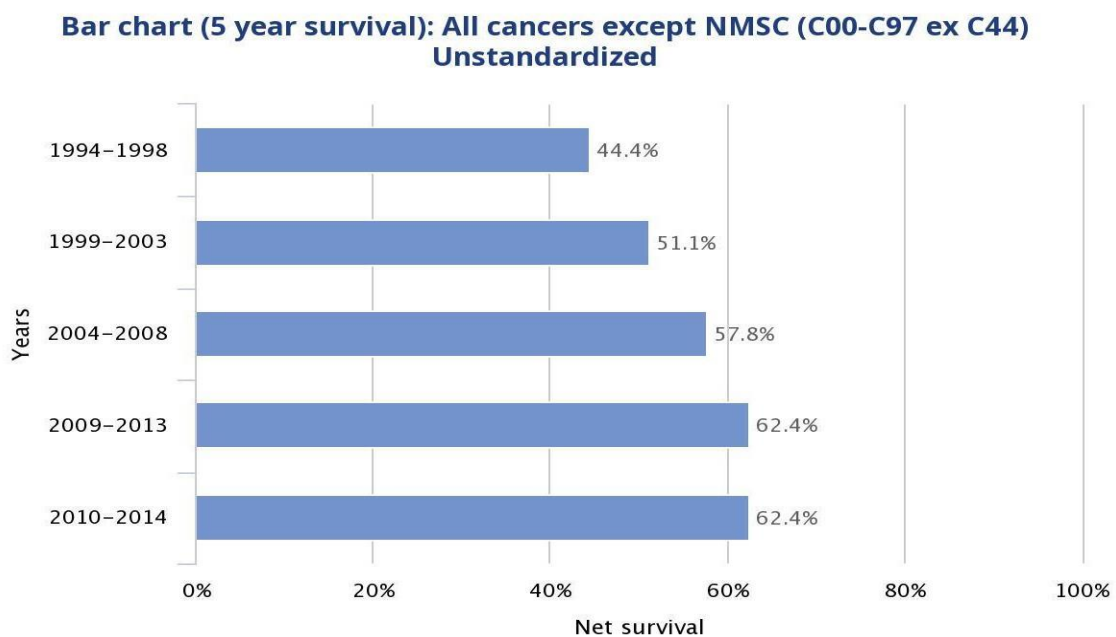


Figure 2: Chart of 5-Year Cancer Survival Rates in Ireland, 1994-2014 from <https://www.ncri.ie/data/survival-statistics/year?theme=accessible> [Accessed 11 Dec 2018, at 5pm].

Five-year survival rates can vary greatly depending on the cancer type and at what stage the patient is diagnosed. In fact, it is estimated that by 2020, 1 person in 20 in Ireland will be a cancer survivor (Department of Health, 2017). Given the current exponential growth of the cancer survivor population, the National Cancer Registry of Ireland in their latest annual report reinforced the importance of understanding the patient experience and their long-term needs (2018).

Cancer survivors experience negative late effects over their lifetime and need a range of health and psychological services to manage their recovery long term. One quarter of cancer survivors experience physical/psychological effects such as heart disease, chronic fatigue and cognitive impairment (Department of Health, 2017) so cancer has a social and financial cost for survivors and is a significant financial cost for health service providers.

In 2006, the Irish Government made a commitment to develop Psycho-oncology services throughout Ireland. However, by 2017 the National Cancer Strategy notes that only two Psycho-oncology services were in operation out of 8 cancer centres. The need to provide services for a life after cancer via survivorship initiatives, programmes and care pathways in Ireland is reinforced by the National Cancer Strategy 2017-2026 (Department of Health, 2017b).

A recent piece of research with Irish GPs, by Maher *et al.* (2018), also specifically highlights the need to develop survivorship services. However, before these services are developed further, we need research to identify who the cancer survivors are, what are their experiences and what their needs are. We need to answer these questions before we can know what services will best address survivor needs.

### **1.3 Research gaps in our understanding of cancer survivorship**

The name *cancer survivorship* was first used by Dr Fitzhugh Mullan who described his own experience of having cancer which he wrote an essay about and was published in the New England Journal of Medicine in 1985 (Takahashi, 2016). He wrote about his own cancer from a patient perspective which highlighted the differences between how patients and medical professionals viewed the disease at the time.

There is consensus that, historically, cancer research focused primarily on diagnosis and treatment (Bloom *et al.*, 2007). With the growth of survivor populations and the



recognition of cancer as a chronic lifelong condition, emphasis has moved to focus on the cancer survivor as a person. At the National Cancer Survivorship Conference in Dublin in September 2015, Professor John Fitzpatrick, Head of Research for the Irish Cancer Society, repeated that “research is moving away from the tumour to the person behind or with the tumour”. In doing so, he was recognising the growing trend towards studying the cancer survivor as a person, which also paves the way for more qualitative research in this area.

Another change in survivorship research is the move from an emphasis on risk assessments of late effects to more of a focus on patient reported measures e.g. quality of life (Wehrle *et al.*, 2016). Survivorship research uses data from clinicians as well as patient reported outcomes. PRO data is information obtained from the patient/client themselves. PRO covers data on symptoms, functioning, health status, psychological distress/wellbeing and quality of life (Thong *et al.*, 2018). Traditionally, collection of patient data was the domain of psychological research.

Wehrle *et al.* (2016) highlight the growing demand for PRO data in the medical field – up to 30% of medical trials now include this data to support their claims. In fact, in the UK, it is now a requirement of funding that research must involve patients and include PRO data (Absolom *et al.*, 2014). This awareness and prioritising of PRO data can be traced back to 1996, when the UK National Health Service set up an organisation called INVOLVE to promote patient involvement. It is recognised that there is limited data on the patient experience of cancer and cancer treatment (Department of Health, 2017b) and this doctoral research will help to address that gap.

Another significant development in survivorship research is the call for survivorship care plans, and for these plans to not just record diagnosis and treatment, but to also outline side effects as well as symptoms of recurrence and guidelines to manage late effects and health promotion (Meade *et al.*, 2017). The European Commission’s Joint Action on Cancer Control (CanCon) is working on creating EU Survivorship Care Plan Guidelines and they advocate for more survivorship research, the importance of multidisciplinary team care, and follow-up care that includes the patient, whilst focusing on prevention and effect management (Lorenzo *et al.*, 2018).

The positive effects of cancer have not received much attention by researchers (Fox *et al.*, 2014) as opposed to more ‘negative’ areas including: distress, depression, reduced

self-esteem, etc. This proposed research contributes to knowledge in terms of understanding what PostTraumatic Growth is and how this growth is experienced by this research cohort of 67 female cancer survivors in Ireland. Since it is a mixed methods study, it also highlights the strengths and challenges of measuring PTG using an inventory versus an interview leading to recommendations as to ways we can improve how we evaluate PTG.

Within the PTG research community there is a clear call for further research that explores PostTraumatic Growth from a mixed methods approach (Hasson-Ohayon, 2016; Scrignaro *et al.*, 2016) so that qualitative research can bring greater depth to our understanding of the PTG construct.

## **1.4 Research Contribution**

This research took 4 years to complete and comprised of a mixed methods study of 67 Irish female cancer survivors in Ireland. The study is primarily qualitative. The primary data which is qualitative consists of 30 semi-structured one-to-one interviews and 37 long answer questions. The quantitative data of 67 PostTraumatic Growth Inventories was used mainly for descriptive statistical purposes.

At the core of this research project are 3 key research questions;

1. What is PostTraumatic Growth (PTG) in the context of female cancer recovery?
2. To what extent does the PostTraumatic Growth Inventory effectively capture Irish women's experiences of cancer recovery?
3. How does the PostTraumatic Growth Inventory compare to semi-structured interviews in understanding women's experiences of cancer recovery?

This project positively contributes to survivorship research by enhancing our understanding of the lived experience of women as they go through cancer and recovery. There is a lack of PRO data in survivorship and this project provides PRO data on a sample of 67 women in the Munster region of Ireland. This project also tests the PTG construct – what effect did cancer have on these women, what are the key drivers of recovery, and did they experience positive growth? In addition, the comparative analysis of self-perceived positive growth outcomes, via both the interviews and the PTGI-42, provides insights to help further refine and develop the PTGI as a research instrument. The findings contribute to our understanding of the

needs of Irish female cancer survivors which helps to inform and refine the Psycho oncology services and survivorship programmes designed for this target group.

On a national level this could help reduce health care costs as it is accepted that if we can provide better psycho social support to survivors then there will be less of a demand (return visits) on the hospital services (Garrett *et al.*, 2013). In Garrett *et al.*'s (2013) study of a phone counselling service for survivors, the participants reported less stress, improved diet, and increased physical activity.

This doctoral project has effected a positive impact in several ways outside of the research. For me personally, it has helped to solidify my competence as a social researcher and to open further research opportunities in my career. For the research participant, the research process has acted as a reflective tool for them to review their cancer journey.

An executive summary will be fed back to the 8 cancer support centres involved, upon thesis submission, and therefore the findings could potentially inform future service provision in Ireland. If we better understand the psychosocial health of cancer survivors, then we can better target interventions (Roland *et al.*, 2013).

More broadly, this research contributes to better understanding psychosocial services in oncology and will inform services and supports that promote growth. In August 2018, I spoke with Dr Mairead O'Connor, a researcher at the National Cancer Registry in Cork, who is charged with designing and implementing a National Cancer Survivor Needs Assessment in Ireland (by Dec 2018). In our discussion, I shared some of my experience of researching this target group and I emphasised the need for qualitative research in this area as well as the potential use of the PTG model.

I wanted to do a Doctorate that would have real and practical impact. I see this research project as translational – moving knowledge from research into action – “moving from basic research (“the bench”) to applied research (“the bedside”) to routine clinical use (“the trench”) via the processes of diffusion, dissemination, and implementation” (Nicholas, 2013, p. 193). To this end, I envisage the project being disseminated via a number of channels nationally and internationally. Over the last two years, I have presented posters and papers of my preliminary work at annual conferences run by the [Psychology Society of Ireland](#), the [Irish Cancer Society](#) and the [International Psycho-Oncology Society](#).

## 1.5 Thesis Overview

This thesis is divided into 7 chapters.

Chapter 2 – the Literature Review positions this research project within: Survivorship, Psycho-oncology and PostTraumatic Growth literatures. To have a solid context for this research, it is essential to understand the research, key debates, and developments in the survivorship research field. The research is best situated in Psycho-oncology, which examines the behavioural, psychological and social supports for cancer survivors, and this doctoral project is located in a sub domain of Psycho-oncology known as psychosocial health. The literature review chapter provides an important mapping of the background and development of the PostTraumatic Growth model. It outlines the key features and dynamics of the PTG model and reviews the criticism and debates that surround it.

Chapter 3 – the Methodology section begins by outlining the research questions. To clarify my use of mixed methods, I applied the 13 steps of Mixing and Merging Methodologies, developed by Schoonenboom (2018), to my research process. This chapter also addresses my researcher stance as well as detailing the research plan (the participant profile as well as how they were recruited and selected). I demonstrate how I applied the six steps of Thematic Analysis by Braun and Clarke (2006) to analyse the data. This chapter concludes by examining how this project adhered to ethical procedures as well as a description of project limitations.

Chapter 4 is the first of 3 Findings chapters. It draws from the qualitative data/findings to address research question one: What is PostTraumatic Growth in the context of female cancer recovery? It shows how the qualitative findings map onto the 5 areas of positive growth as defined by Tedeschi and Calhoun (2006). Survivors from this research study experience the greatest degree of positive growth in how they Relate to Others. From the analysis of the qualitative findings, an additional new 6<sup>th</sup> area of growth is also proposed – Proactive Mindset.

Chapter 5 concerns the second research question: To what extent does the PostTraumatic Growth Inventory effectively capture Irish women's experience of cancer recovery? It is the analysis of the quantitative data - the 67 completed PTGI-42 inventories which examines positive growth levels in the five Factors: Relate to Others, New Possibilities, Appreciation of Life, Personal Strength and Spiritual Change.

Participants of this study generally experienced high levels of positive growth with the greatest growth in Appreciation of Life.

Neither age nor marital status were predictors of growth. Positive growth could happen at any stage of the disease (i.e. did not significantly vary if it was at an early or more advanced disease stage). However, having children did mean higher growth in the areas of New Possibilities and Appreciation of Life. This chapter also outlines some of the difficulties with using the PTGI-42 with a cancer survivor population including the issue of the inventory not capturing the physicality of the cancer experience.

Chapter 6 is the third and final Findings chapter. It integrates both the qualitative and the quantitative findings to address research question 3: How does the PostTraumatic Growth Inventory compare to semi-structured interviews in understanding women's experiences of cancer recovery? A statistical data reduction technique, known as Principal Components Analysis, was used that identified 6 key components (or Factors) from the inventory data. It provides further support for the significant growth for survivors in this study regarding how they Relate to Others and support for a Proactive Mindset Factor. In addition, this analysis also identified another new Factor entitled Self Worth. Chapter 6 also highlights the key qualitative findings that provide insights into how survivors experience cancer recovery/positive growth such as the importance of the diagnosis meeting and how cancer recovery is a socially embedded and collaborative experience.

The thesis ends with Chapter 7: Discussion and Conclusion, which examines what this research study contributes to research. This chapter identifies the study limitations of sample and recall bias, the limits of the demographic information and the bigger cancer service issue of low access of services by working class and non-Irish national survivors. Several considerations for future research are proposed including the need to isolate and specify the trauma as well as the value of doing research in real time which would reduce recall bias. This chapter concludes with an outline of six key recommendations, including the importance of maximising 'social support' as a resource to drive positive growth as well as highlighting the need to create a new PTGI specifically for cancer survivors.

Cancer survivors need tailored initiatives/interventions that promote growth, develop self-managed care and address their specific needs e.g. the identification and expression

of thoughts and feelings. Improvements are needed to help survivors transition from hospital care to community care and care plans is one tool that could be developed to address this. Further research is needed for survivors who are 'living with' cancer and to investigate how come survivors from working class or ethnic minority groups are not accessing cancer support centres.

Appendices – the appended documents contain the supplementary documentation and provide further information on how the research was conducted including a full summary of the qualitative data as well as an outline of the quantitative findings.

Throughout this thesis, there are several images used from the Dear Diary project where appropriate. Dear Diary was an unexpected outcome of this research and involves an art exhibition based on two diaries that one of the interviewees donated to the research process during one of the semi structured interviews. For an overview of this art initiative please see Appendix 1: Dear Diary Project.

## 2. Literature Review

### 2.1 Introduction

To situate this research project, this chapter begins with an exploration of *Cancer Survivorship* which is where this doctoral research is positioned. As outlined in section 1.1 earlier, recent years have seen an exponential growth of the survivor population as cancer incidence continues to rise and survivors are living longer (Department of Health, 2017a; Maher *et al.*, 2018; van der Spek *et al.*, 2013; Bloom *et al.*, 2017).

In this chapter, section 2.2 will highlight the key phases of the cancer illness continuum (Keane *et al.*, 2018; Meade *et al.*, 2017), and explore some of the significant late effects that survivors experience (Carroll *et al.*, 2018; Sharp *et al.*, 2014; Shi *et al.*, 2011). In cancer research, emphasis has moved from diagnosis and treatment to survivorship (Bloom *et al.*, 2007), with survivorship seen as a distinct phase (Meade *et al.*, 2017). Therefore, I will also outline some of the latest developments and debates in cancer survivorship research and show how this research is responding to a call for more research on survivorship, driven by Patient Reported Outcomes (Thong *et al.*, 2018). My research will provide data that could help to further understand the emerging new ideology of self-managed care.

Section 2.3 defines and outlines the development of Psycho-oncology. This field is dedicated to research and evidence-based services for cancer survivors at all stages from prevention to survivorship (Holland, 2018; Dunn *et al.*, 2015; Nicholas, 2013). There is a recognised need for these services in Ireland (Department of Health, 2017b; O'Shea & Collins, 2018), and a strong commitment by the Government to develop them, evidenced by the specific targets of the National Cancer Strategy for Ireland 2017-2026. This focus makes this doctoral research all the timelier and more relevant. This research contributes new knowledge to our understanding of the lived experience of cancer survivors.

The final section (2.4) of this Literature Review chapter provides a detailed overview of PostTraumatic Growth (Tedeschi & Calhoun, 1996) which is the model most frequently used in understanding growth in trauma research and is the core model used to study survivor growth in this doctoral research. The dynamics of the model is explained as well as an overview of the Five Factors or areas of growth that the PTGI measures;

Relating to Others, New Possibilities, Personal Strength, Spiritual Existential Change and Appreciation of Life. I clarify some of the key conflicting debates in the field as to the predictors of growth. As a mixed methods study, this doctoral research will include a comparative analysis of how PTG was studied by both an inventory and an interview. Before I proceed with the three core sections of the chapter, it is important to clarify two key terms; cancer and cancer survivor.

There are over 200 types of cancer (malignant or benign) but what they all have in common is lack of normal cell growth (Irish Cancer Society, 2018b). Cancer is seen as a disease that mainly affects older people and statistics support this. From 1994 until 2014, of those diagnosed with cancer, 62% of men and 53% of women were aged 65 years and older (Department of Health, 2017).

Cancer treatment follows a typical series of stages including screening, diagnosis, treatment, remission/follow up, potential relapse or death. There are various forms and combinations of treatment, and it may involve surgery, chemotherapy, radiation or hormonal treatment. As part of diagnosis, the cancer can be categorised in terms of Stages (from I to IV). Staging is essentially an indicator of how much cancer a person has and where it is located.

As a point of clarification, the term Cancer Survivor (CS) can be understood as “individuals with cancer from the point of diagnosis including individuals undergoing curative treatment until death and individuals who have been disease free for at least 5 years including family members” (Treanor *et al.*, 2013, p. 2428). This definition has broad acceptance and is also accepted by the Department of Health in Ireland (2017). The term survivorship is also sometimes used, not just for the person who has/had cancer, but also may include their families/carers.

## **2.2 Cancer Survivorship**

- **Cancer Survivor Population: growth, unmet survivor needs, and late effects**

Survivorship is a relatively new term – it was only in 2005 that the Institute of Medicine in the US recognised survivorship care as a distinct phase of the cancer care continuum (Meade *et al.*, 2017). However, it is now generally accepted that it is a distinct stage and that supporting survivors is vital (Keane *et al.*, 2018).



As explored in the Introduction Chapter, internationally, survival rates are increasing so the cancer survivor population is growing exponentially. In Ireland, in December 2016, cancer survivor prevalence was estimated at 173,050 people (National Cancer Registry, 2018) i.e. 4% of the population. Since the 1990s, the five-year survival rate for several cancers has improved.

Survival rates vary depending on the age of the person, the type of cancer, and the stage at which the person is diagnosed. The overall 5-year survival rate is on the increase and is currently at 61% (Department of Health, 2017). For those who have survived, breast (24%) and prostate (20%) were the most common cancers experienced. By 2020, it is estimated that 1 in 20 will be a cancer survivor in Ireland (Department of Health, 2017).

Though increasingly more people are surviving, it is not about life as usual but rather an adjustment to a ‘new normal’ as many survivors face complex health issues as a result of cancer and treatment (Sharp *et al.*, 2014). This means that survivors have ongoing medical and non-medical support needs, long after diagnosis and treatment. Discussions of unmet survivor needs are driving the conversations around developing more comprehensive survivorship care (Meade *et al.*, 2017).

In the study by Willems *et al.* (2016), they found that 63% of survivors in their first year post treatment had at least one unmet need with the most common needs concerning “emotional and social support, help to deal with fear of recurrence, management of healthcare and complications and up-to-date information” (p. 54). In addition, those with more unmet needs had greater anxiety. In the UK, the health system recognizes the potential for late effects to remain long term and is moving to a chronic care model with cancer survivors (Treanor & Donnelly, 2016).

To further understand the life of a cancer survivor, it is important to understand negative late effects and the significant burden that this can be for an individual. A late effect is simply a side effect from cancer or cancer treatment that materialises at a later stage. The risk for symptom burden is high during the first 12 months after diagnosis and 1 in 4 cancer survivors, during this time, experience severe symptoms (Shi *et al.*, 2011). This is also supported by Irish research where it is estimated that one quarter of cancer survivors experience physical/psychological effects (Department of Health, 2017) and cancer can also have a social and financial cost.

Late effects from treatment alone can be quite debilitating and can be anywhere from short to long term including osteoporosis, heart disease, nausea, sexual dysfunction, cognitive impairment, chronic fatigue, distress and, for some, cancer recurrence. Cognitive decline is a particularly important area of research in survivorship as this can lead to a loss of function and independence, especially for older survivors (Ahles & Hurria, 2017). Several late effect symptoms are as a result of the treatment rather than the cancer itself as treatment can “increase the risk of long-term and late toxicities, including persistent fatigue, pain, and cognitive dysfunction” (Carroll *et al.*, 2018, p. 1). Late effects may also be compounded with comorbidity issues e.g. diabetes or heart disease. Cancer survivors may suffer from depression or anxiety disorders and in fact they have “a higher prevalence of mental disorders than the general population across various tumor types” (Zimmermann-Schlegel *et al.*, 2017, p. 719).

A report issued by the International Federation of Psycho-oncology Societies states that “at least 30% of cancer patients report psycho social distress and mental disorders and even a higher percentage report unrecognized psycho social needs or untreated psycho social disorders as a consequence of cancer” (Grassi *et al.*, 2016, p. 1127). In the research on late effects by Treanor and Donnelly (2016), they found effects that lasted up to 20 years and were a constant reminder of cancer.

Survivorship is now seen as more than just a health issue and holistic needs must be considered e.g. economic impact and psychological needs. In 2015, for example, the Irish Cancer Society commissioned a report – The Real Cost of Cancer – which highlighted the decrease in income and the increased costs for medicine, consultant fees, hospital visits and higher household bills.

It is understood that survivors have different needs at different phases of survivorship. For example, during the first year of recovery, survivors may benefit from rehabilitation supports, psychological supports in the medium term (especially anxiety management) and help with managing long term late effects for survivors 10 years + post diagnosis (Sharp *et al.*, 2014). In addition, ‘age’ may also have an impact as issues and concerns of a younger versus an older survivor may differ e.g. fertility or career stage.

In terms of issues with survivorship care, it is recognised that a lower socio-economic status has a negative impact on the experience of cancer. In fact, “For all cancer types, patients resident in the most deprived areas were more likely to present emergently”

(National Cancer Registry, 2018, p. 7) i.e. in the emergency room as an urgent case. In addition, they also presented with a more advanced stage of cancer and therefore less treatment options with a poorer chance of survival. Other issues facing survivorship care are communication obstacles and lack of coordination of care (Tevaarwerk *et al.*, 2018). Attempts to address this include; the development of Survivorship Care Plans (which will be discussed further on) and psychosocial services provided in the community.

- **Developments in Cancer Research**

In oncology, cancer is now seen as a lifelong condition and as a trauma. This change in perception relates to changes in how Post Traumatic Stress Disorder (PTSD) is defined and how that initiated an interest in studying cancer as a stressful trauma. In 1994, the Diagnostic Statistical Manual of Mental Disorders (DSM-IV, 1994) expanded its definition of PTSD which meant that a traumatic event now included being diagnosed with a life-threatening illness (Jaehee & Min, 2014). This was a catalyst that led to considerable research of cancer as a stress/trauma and, therefore, as a lifelong condition.

In 2013, the DSM included further changes to the criteria of PTSD which means that cancer may not automatically be categorised as a traumatic event, as any psychological dysfunction must not be attributed to another medical condition. According to DSM-V a medical illness can only be classed as a trauma if it is both catastrophic and sudden (Faretta, 2018), however, it still refers to exposure to actual or threatened death or serious injury or sexual violence (Tedeschi *et al.*, 2018).

The narrowing of the PTSD definition reduced the number of cancer patients being diagnosed with this disorder (Shand *et al.*, 2015). None the less, research still supports that cancer is a traumatic experience (Faretta, 2018; Lang-Rollin & Berberich, 2018), that diagnosis may be traumatic, and that the trauma of cancer is not a discrete singular event, but rather a series of experiences over time e.g. from diagnosis to treatment, side effects to impairment of functioning. Trauma is thought of as having an external source, and as a major negative event i.e. something that happens to you like war or drought. However, the cancer trauma is a repetitive, cumulative experience with an internal source – from within the body (Rodin, 2018).

A second significant development concerns the stage of cancer being studied which has moved from diagnosis and treatment to survivorship. There is consensus that

historically, cancer research focused primarily on diagnosis and treatment (Bloom *et al.*, 2007). With better screening, increased awareness of healthy lifestyle and improved treatment, there is huge growth in survivor populations, resulting in a great need for survivorship research, which is still a relatively new field especially given that it was only in 1998 that funding for survivorship was first introduced in the United States of America. Focus on survivorship has only really developed in the last 10 years. In the UK, a crucial longitudinal study which highlighted survivor issues was only completed in 2009 (Maher *et al.*, 2018).

Thirdly, as outlined earlier, within Survivorship research there is a requirement for more patient reported data (PRO) so that we can better understand the cancer experience from their perspective (Thong *et al.*, 2018). PRO data is the focus of this doctoral work.

One of the latest developments in survivorship is the drive to promote survivor responsibility – for them to manage their own care. This is evidenced by the growth of self-management interventions which “represents an ideological shift in healthcare from viewing patients as passive recipients of care to empowered partners in managing their own health” (Coffey *et al.*, 2016, p. 1012).

To promote self-management, training and supports are provided to improve the ability and confidence of survivors, so they can manage their own care. One way that this self-management ideology has manifested is in the global call for survivorship care plans, and for these plans to not just record diagnosis/treatment but to also outline side effects, symptoms of recurrence and guidelines to manage late effects and health promotion (Meade *et al.*, 2017).

The European Commission’s Joint Action on Cancer Control (CanCon) is working on creating EU Survivorship Care plan guidelines and they advocate for more survivorship research, the importance of multidisciplinary team care and follow up care that includes the patient whilst focusing on prevention and effect management (Lorenzo *et al.*, 2018). As a result of the work by the Commission it is expected that we will see Cancer Survivor Care Plans implemented via the hospital services in European member states.

In Ireland, currently, care plans are hospital and physician led. In a recent piece of research on all the 8 cancer centres in Ireland, Keane *et al.* (2018) found differences in how and when these care plans were used. Despite 91% seeing the value of these plans, only 77% of the cancer centres considered using them. Keane *et al.* (2018) also found

that cancer centres were calling for this follow up care to move out of oncology and into nurse-based clinics in the community. The development of these care plans – by interdisciplinary teams who aim to promote self-management in the community – reflect important changes to priorities in how we work with cancer patients and how we expect them to take ownership of their own health.

As for future trends, the call for self-managed care has also led to growth in home-based programmes. Cheng *et al.* (2017) completed a review of 26 studies of home-based multidimensional survivorship programmes. Each programme addressed two of the following health areas; physical, psychological or educational. They found short term benefits which involved a higher quality of life and specific decreases in fatigue, insomnia and anxiety. Home-based programmes are a recent trend that needs further research and piloting to test impact.

- **Changes in survivor research from stress to growth**

Survivorship research studies how a person experiences, manages, and makes sense of their cancer experience. Much of the early research on psychosocial development focused on distress, anxiety and depression, so much so that there is a movement in Canada to name ‘distress screening’ as the 6<sup>th</sup> vital sign (after body temperature, pulse rate, blood pressure, respiration, and pain) (Nicholas, 2013, p. 204). For a cancer survivor, the diagnosis meeting is the initial stressor that is more of an ongoing process rather than a single event (influenced by the prognosis).

As stated earlier, the inclusion of a life-threatening illness as a trauma that could lead to PTSD by the DSM IV was a catalyst in the rapid increase in research of cancer as a major stress or trauma. Goodhart and Atkins (2013) in *The Cancer Survivor’s Companion* cite worry, depression and anger as key emotions that must be managed in the path to recovery. These emotions can seem even more difficult to deal with when compounded with the common occurrence of fatigue and issues with sleep whilst in recovery. Depression and post-traumatic stress have negative impact on psychological quality of life with long term survivors (Bloom *et al.*, 2007, p. 698).

In addition to the study of cancer as a major stress is a parallel stream of research on ‘coping’ which was originally investigating how to reduce stress. However, according to Frydenberg (2014, p. 82) “coping has made an important contribution to our understanding of human endeavour and achievement, and the theoretical insights have

enabled both researchers and practitioners to advance well-being and striving, thus going beyond the original goals of coping research”. Coping research has contributed to the development of interventions across the lifespan and our understanding of quality of life. Developments in coping research, seeks to investigate coping in real time and a focus on positive psychology with an emphasis on “positive emotions, health, and wellbeing and issues around being proactive rather than reactive” (Frydenberg, 2014).

In the study of stress and coping, there are two key theoretical models. The first is the Transactional Theory by Lazarus and Folkman (1984), where coping is a transactional process between the person and their environment. It involves managing the perceived demands of the internal or external environment by using cognitive or behavioural means (Frydenberg, 2014). It is a dynamic process that changes overtime.

The second theoretical model is the Conservation of Resources Theory by Hobfoll (2010). From this perspective “individuals strive to obtain, retain, and protect that which they value” (Frydenberg, 2014, p. 84) and therefore stress is when these become threatened or lost. It is a proactive process where people continuously invest in resources whether that is physical, money, relationships, or status, etc. They are building resources to protect from potential future losses.

Today, it is associated with Positive Psychology and the notion of flourishing and building resilience where a loss event can be experienced as a challenge and therefore less traumatic. People can cope with cancer in a myriad of ways including; problem focused (managing the stressor), emotion focused (managing the internal landscape – distancing, distracting or viewing the stressor differently), or meaning making coping strategies (Frydenberg, 2014).

Survivors can and do face significant distress concerning fear of the future, anxiety and a changing identity but they may also experience psychological well-being (van der Spek *et al.*, 2013). Survivors can “derive meaning from the cancer experience, feel more resilient, experience life fuller in the present or reprioritize their lives” (van der Spek *et al.*, 2013, p. 1). Finding this sense of meaning can bring about decreased stress, greater social adaptability and general well-being. In their focus group of 23 cancer survivors, they had greater meaning after cancer through their relationships, and by living more ‘consciously’. Roland *et al.* (2013) also found that spirituality helped survivors make sense of cancer, to integrate the experience and to have hope.

Researchers also view the experience of cancer as a time of great intrapersonal change. Kumar and Schapira (2013) carried out a qualitative study looking at people make sense of their cancer. The loss of physical control was significant where patients had to deal with changes with their hair, appetite and physical appearance. They found that “the quest for normalcy – fulfilling societal expectations for appearances, education, or career pursuits – influences their personal expectations and goals” (Kumar & Schapira, 2013, p. 1755) and influenced how they dealt with cancer. Another study by Morrison (2009) also emphasised the physical loss/difficulties and how expectations from self and others impacts on how this loss is experienced. Other intrapersonal factors are highlighted by Goodhart and Atkins (2013) who stress the importance of rebuilding self-esteem and renegotiating relationships in recovery.

In survivor research, researchers also investigate how personality impacts on the cancer experience especially; optimism, affect and generalised self-efficacy (Hoffman *et al.*, 2012). Higher optimism levels mean greater adjustment, whereas lower levels are correlated with depression. The importance of optimism is highlighted by Roland *et al.* (2013) who found it was positively associated with higher health related quality of life.

In terms of affect, Hoffman *et al.* found that “positive changes such as positive reappraisal and goal reengagement were related to greater positive affect, whereas negative changes (e.g. avoidant coping) were related to both greater negative affect and less positive affect” (2012, p. 253). Cancer patients with generalised self-efficacy were found to have better emotional well-being, less depressive symptoms and an adaptive coping style.

## **2.3 Psycho-oncology**

This section defines the field of Psycho-oncology and highlights significant developments that both positions and demonstrates the need for this doctoral study. With the growth of the survivor population and the change in perception of cancer as a chronic disease (rather than a terminal illness), these highlight the needs and lack of understanding of survivor care (Holland, 2018; Lang-Rollin & Berberich, 2018).

The International Psycho Oncology Society (IPOS) advocates for psychosocial care as a human rights issue (Travado *et al.*, 2016) and aims to advance our understanding of how psychological and behavioural factors impact on the cancer experience (Holland,

2018). Within Psycho-oncology, this research study is positioned within the ‘psychosocial’ strand that investigates the impact of psychological, social and behavioural factors on the survival experience (IPOS, 2019). It is an exciting area of research goes beyond looking at survivor quality of life to examining how psychosocial factors can extend life expectancy (Lang-Rollin & Berberich, 2018; Spiegel, 2012). In Ireland, the National Cancer Strategy for Ireland 2017-2026 is a significant public document that recognised the shortage of Psycho-oncological services and details specific recommendations to develop same (Department of Health, 2017b).

- **The field of Psycho-oncology**

Psycho-oncology as a field has grown out of changes to both cancer treatment and to how cancer is perceived and has emerged as a subspecialty of oncology (Holland, 2018). By the 1960s, with improved treatment and better survival rates, cancer was not seen as an automatic death sentence and interest grew in the psychological and supportive care of cancer patients (Holland, 2018; Lang-Rollin & Berberich, 2018).

In 1984, the International Psycho Oncology Society (IPOS) was established to advance psychosocial cancer care and establish it as a discipline. By 1992, psychosocial oncology was recognised as a sub speciality in the field of oncology. At this point, the core objectives were outlined, and activities were involved in four key areas; clinical programmes (psychosocial support located within oncology services), education and training, conferences, and training programmes.

Psycho-oncology has “played a key role in reducing cancer risk, improving cancer survivorship, and influencing social and cultural change to eliminate disease-related stigma” (Dunn *et al.*, 2015, p. 2). It is concerned with improving quality of life for survivors and increasing treatment effectiveness via understanding how psychological and behavioural factors impact on treatment outcomes (Holland, 2018).

IPOS advocates for psychosocial care as a human rights issue and that all cancer patients have a right to these services (Travado *et al.*, 2016). IPOS has traditionally positioned Psycho-oncology within a patient focus/context but in recent years they have been working on establishing relations with both the United Nations and the World Health Organisation to play a stronger role in policy and strategy at state level. There is a global movement to address the issue of Non-Communicable Disease (NCD) – this



can be attributed partly to community-based cancer control organisations and the NCD Alliance, which was set up in 2010.

In 2011, at a high-level UN meeting on NCD, Member States adopted a Political Declaration which demonstrated a commitment to a coordinated global response to NCDs. By doing this they agreed to provide the finance and develop national strategies with one of the key targets to reduce NCD deaths by 25% by 2025 (Dunn *et al.*, 2015, p. 3).

In a bid to increase international collaboration, the International Cancer Control Partnership (ICCP), where organisations work together on priority issues and share resources ([iccp-portal.org](http://iccp-portal.org)), was established in 2012. One of its key aims is to assist individual countries to develop National Cancer Control Plans.

By 2013, the NCD Global Action Plan was released which focused on cancer planning/monitoring, access to services, and early detection. That same year the World Cancer Declaration was announced which called on governments internationally to take specific actions to reduce the global cancer burden in 9 target areas.

Psycho-oncology is defined as “a subspecialty within professional psychology and is a multidisciplinary field emphasizing the psychological and social aspects of cancer” (Nicholas, 2013, p. 186). The foci of Psycho-oncology include; behavioural, psychological, social and lifestyle factors that impact on the cancer illness continuum.

This definition has expanded to include other factors such as culture and ethics. Traditionally Psycho-oncology focused on the survivor experience from cancer detection onwards. However, Rosberger *et al.* (2015) advocate for an expansion of Psycho-oncology to investigate how our understanding of psychosocial variables can help with cancer prevention strategies e.g. the uptake of cancer screening programmes. This view is supported by the American Psychosocial Oncology Society (APOS) which advocates for Psycho-oncology to research behavioural variables that impact cancer risk (2019).

Within Psycho-oncology there are two main strands. The first of these is psychosocial which explores the emotional response of patients (including families and carers) at every stage of cancer. This is typically post diagnosis and is often concerned with factors that impact on coping and adaptation. This has recently changed to include not

just survivors and their families but also staff. This is reflected in the definition of Psycho-oncology proposed by the International Psycho Oncology Society (2019) “Response of patients, families and staff to cancer and its treatment at all stages...psychological, social and behavioral factors that influence tumor progression and survival”. The second strand is known as psychobiological which is concerned with the psychological, social and behavioural aspects that influence morbidity and mortality.

The field is underpinned by holism and the focus is on comprehensive cancer care that is evidence based. Within Psycho-oncology, importance is placed on the integration of science and practice where “the most immediately important task of Psycho-oncology is to close the yawning gap between current knowledge and actual clinical care of patients” (Nicholas, 2013, p. 192), and is driven by the growing demand of evidence-based practice.

Obstacles to the Psycho-oncology field, as outlined by Holland (2018), include the need for more professionals – clinicians and researchers, the need for valid assessment instruments, and the need to develop research methods appropriate and effective for this field. Despite the growing recognition of the contribution of this field, it continues to be under-funded and there is a lack of a global agreed standard of Psycho-oncological services (Rodin, 2018). Psycho-oncology can offer counselling services as well as social and behavioural interventions to cancer patients. This field can offer training to cancer staff and its growing body of research is helping to mark its territory in oncology.

The research within Psycho-oncology can be quite varied from understanding distress to the role of meaning and mindfulness. The field has contributed ‘clinical practice guidelines for distress management’ which test for the level of psychosocial distress that could be a barrier to coping with cancer. Three key factors impact on positive psychosocial adaptation: developmental stage, intrapersonal style, and interpersonal resources. There is considerable development in research on meaning and mindfulness, where survivors with a higher sense of meaning and wellbeing, report lower distress, adapt well and, overall, have a higher quality of life than those with low meaning (Lang-Rollin & Berberich, 2018).

As the name suggests, ‘*Psycho-oncology*’ is concerned with understanding the relationship between the psychology of a person and cancer. Interventions that increase

emotional support reduce stress – this not only improves the quality of life of the cancer survivor but can also extend life by reducing the tumour growth response and improve response to healing (Spiegel, 2012).

Cancer leads to an individual experiencing several psychosocial changes and challenges from fatigue, depression, side effects from treatment, and relationship changes. It is estimated that up to 40% of survivors experience distress at a level that requires Psycho-oncological care (Senf *et al.*, 2018). There is a recent and growing stream of research that explores psychosocial interventions with cancer patients that not only relieves their symptoms but may also increase survival rates (Lang-Rollin & Berberich, 2018). It is shown that psychosocial interventions that “improve stress management at the end of life might have a positive impact on physiological stress response systems that affect survival” (Spiegel, 2012, p. 591) thereby increasing survival length. Another study, by Monti *et al.* (2013), examined the use of mindfulness-based art therapy programmes with breast cancer patients and found they had decreased psychosocial stress and improved quality of life. There is evidence of a growing recognition of the importance of psychosocial interventions.

From a global perspective, the level and development of Psycho-oncology services is more advanced for high-income countries as compared to low-income and middle-income countries (Travado *et al.*, 2017). Despite the recognised benefit and need for Psycho-oncology services, there are several issues that impact its delivery. Research by Zimmermann-Schlegel *et al.* (2017, p. 719) found that, in rural areas, “community-based physicians providing survivorship care for cancer patients regard Psycho-oncology services as a highly reasonable and beneficial addition to medical care”. However, there is still a shortage of coverage, and issues with referrals, which means that survivor needs are unmet. The reality was that 98% of physicians saw the benefit of these services, but only 56% of them were providing it.

This doctoral research is therefore in the realm of Psycho-oncology, within the sub domain of psychosocial health. Roland *et al.* (2013) subdivides the psycho social life of cancer survivors into 6 aspects; “quality of life (QOL), social support and relationships, self-image and sexual functioning, psychological distress and functioning, fear of death/recurrence, and personal growth and coping” (Roland *et al.*, 2013, p. 2408). This

doctoral research studies two of these aspects: social support and relationships and personal growth.

- **Psycho-oncology and the Irish context**

In Ireland, the importance of Psycho-oncology has grown significantly in the last 10 years and its development in the next 5 years will be fuelled by recommendations from the National Cancer Strategy for Ireland 2017-2026. Currently, there is a lack of Psycho-oncology services in Ireland despite the significant need for them by cancer survivors (Department of Health, 2017; Maher *et al.*, 2018). The National Cancer Registry of Ireland is presently conducting a needs assessment of cancer survivors, which will then help inform the Government of what type of survivorship programmes/initiatives to develop.

The Strategy for Cancer Control in Ireland (2006) outlined the importance of Psycho-oncology services and its development. However, by 2017 the National Cancer Strategy notes that only two Psycho-oncology services were in operation out of 8 cancer centres and stated that multi-disciplinary Psycho-oncology teams are needed in all centres. This under resourced service will come under increasing pressure as cancer incidence rates rise and further development in hereditary cancers emerge, as well as the need for new survivorship programmes. There is a new model of care that will involve cross working with voluntary, primary and acute services.

At the International Psycho-oncology Congress in Dublin, in 2016, a new Irish group was launched – the Irish Psycho Social Oncology Network (IPSON). This organisation is committed to promoting and advancing psychosocial care for cancer patients in Ireland. The central vision of IPSON is “to make psychosocial care an integral part of Cancer Care by 2020” (IPSON, 2018).

Psychologically, cancer patients experience ‘distress’ from mild to severe (5 levels) and the new Psycho-oncology care model proposes that patient intervention is based on their level of distress e.g. moderate stress would warrant support from medical social workers, mental health or group therapy. Up to 30% of cancer patients develop psychological distress and Psycho-oncology services are needed throughout the care continuum, including survivorship (Department of Health, 2017b). The need for these services was also supported by a recent study of GPs in Ireland, which highlights the significant gaps in supports for GPs in providing survivorship care, and notes the need

for: “Extended access to services (such as psycho social, Psycho-oncological and counselling for genetic cancers, sexual and fertility counselling) to support the management of cancer patients in general practice” (O’Shea & Collins, 2018, p. 77).

The National Cancer Strategy 2017-2026 also states that psycho-oncology services should also provide education on the psychosocial needs of patients for all cancer care workers, especially when communicating diagnosis and prognosis. The report recommends that the National Cancer Control Programme appoints a clinical lead to develop the Psycho-oncology services in Ireland.

The cancer care continuum begins with prevention followed by detection, diagnosis and treatment. Then this pathway moves to either end-of-life care or survivorship. As mentioned earlier, cancer survivorship is recognised as a distinct stage of the cancer care trajectory. The focus in survivorship is not just to ‘survive’ but to maximise quality of life.

The need for survivorship initiatives, programmes, and care pathways in Ireland is reinforced by the National Cancer Strategy (Department of Health, 2017b). The difficulty of the transition from treatment was highlighted and the suggestion is that survivors have access to hospital supports for reassurance. The report also emphasised the need to recognise and provide support for a life after cancer e.g. returning to work and managing late effects. Recommendation 41 of the report directly relates to survivorship:

“The NCCP, in conjunction with the ICGP, cancer centres, the Irish Cancer Society and cancer support centres, will conduct a Cancer Survivorship Needs Assessment to ascertain the most suitable model of survivorship healthcare. The Needs Assessment will be completed by the end of 2018” (Department of Health, 2017, p. 110).

A second key piece that will impact on Psycho-oncology services in Ireland is recommendation 43 which states that:

“Designated cancer centres working with the NCCP, the ICGP, primary care services, patients and voluntary organisations will develop and implement survivorship programmes. These programmes will emphasise physical, psychological and social factors that affect health and wellbeing, while being

adaptable to patients with specific survivorship needs following their treatment”  
(Department of Health, 2017, p. 114).

The above quote highlights that psychosocial services and supports are not just about alleviating distress but rather the emphasis is on positive adaption, growth and resilience.

With early detection, better screening and treatment and improved survival rates, cancer is no longer the death sentence it once was, and it is increasingly seen as a chronic disease. Cancer may even be a psychosocial transition that has both negative and positive changes. Many of the negative effects were outlined in the Cancer Survivorship section of this thesis. The positive changes may be understood in terms of benefit finding and PostTraumatic Growth (PTG).

Before outlining the PTG model, it is important to differentiate and clarify the boundaries between PostTraumatic Growth and benefit finding. The terms PTG and benefit finding are often used interchangeably but are quite different. Benefit finding refers to perceived positivity in a traumatic event in the perception of benefits e.g. positive lifestyle changes like increased exercise or smoking cessation. In contrast, PTG tends to refer to changes in cognition and affect as a result of the cognitive struggle with trauma. PTG is also sometimes confused with Post Traumatic Stress Disorder and their differences will be clarified in the next section.

## **2.4 PostTraumatic Growth**

Within Psycho-oncology “theoretical models of well-being that account for the complexity of survivorship issues are needed” (Hoffman *et al.*, 2012, p. 240). They also note the lack of studies on the positive impact of cancer and further research using the PTG model could address this gap. It is only in the last 30 years that positive growth from trauma has been studied in a systematic way (Lindstrom *et al.*, 2013). Joseph (2014) believes that interest in positive changes only began to develop in the 1980s.

Research on positive change has been noted in various experiences of trauma including cancer, sexual assault, combat, and natural disasters. Trauma is often associated with one-off, major and distressing events outside of our control. However, it also includes what may be termed as “lower level repeated incidents” (Akhtar, 2017, p. 25) which comprises of experiences such as domestic abuse. The word ‘trauma’ comes from the

Greek word meaning ‘wound’. The DSM-V “defines trauma as an aversive event involving actual or threatened death that must be violent or accidental, whereas we define trauma as a highly stressful and challenging life-altering event” (Tedeschi *et al.*, 2018b, p. 4).

For the purpose of this section it is important to give an overview of the model of PostTraumatic Growth and to highlight some of the key debates in this field. In the interest of transparency, I will also identify some of the criticisms and questions that surround the PTG construct.

- **The PostTraumatic Growth Model**

The PostTraumatic Growth Model, as developed by Tedeschi and Calhoun (1996), is a strengths-based approach that acknowledges the resilience and strength of a human being to not only overcome, but to potentially experience positive gains from a traumatic life event. Positive growth is not about happiness but instead is concerned with an increase in psychological well-being (Joseph, 2014). PTG is located within the developing field of Positive Psychology which focuses on developing personal strengths and virtues for optimal wellbeing (Casellas-Grau, 2014).

According to the PTG model, a trauma is a perception of a life threat that is usually sudden, unexpected and outside of their control (Tedeschi *et al.*, 2018). There are several key features of the model. According to this framework, the trauma that an individual may experience causes a breakdown in major assumptions about life and the world – causing the assumptive world to become unstable and uncontrollable. For the individual it may cause them to question their beliefs about the world and their place in it.

This initial struggle may not be about growth but rather is typically about survival or coping (Tedeschi *et al.*, 2018b), and can lead to rumination, of which there are 2 types. The first is passive, uncontrollable, distressing and involves repetitive intrusive thoughts - this can be quite a negative experience for the individual as they deal with these thoughts. The second is deliberate or instrumental rumination where the person is consciously thinking about the event to understand it and give it meaning and at the same time reconfiguring core beliefs. This process is reflective, deliberate and with a purpose. One aspect of this deliberate rumination is when the person considers how the trauma may have had a positive impact on them or their lives.

PTG is, therefore, as a result of cognitive processing via this second type of deliberate rumination. Therefore the “degree of challenge to core beliefs and deliberate rumination are strong predictors of PTG” (Ramos *et al.*, 2017, p. 259). In fact, Lindstrom *et al.* (2013, p. 54) argues that “Significant challenge to the assumptive world appears to be an important correlate of, and perhaps causal antecedent to PTG”.

Instrumental rumination is positively associated with all 5 growth areas of the PTG model (Soo & Sherman, 2015). To manage this distress and re-appraise the trauma, a person can use cognitive strategies such as coping strategies, seeking social support, and cognitive processing to make sense of and give meaning to the trauma. Some people adopt an adaptive coping style e.g. positive reappraisal where the rumination may develop into a narrative and the search for meaning. According to this model, ‘self-analysis’ and ‘self-disclosure’ are two very important channels by which a person can process and integrate a traumatic event thereby leading to personal growth. It is thought that ‘self-disclosure’ may be related to the amount of growth a person experiences (Lindstrom *et al.*, 2013) i.e. that the more the person is willing to share about themselves the greater the chance of growth. The type of content that is shared may also have an impact on growth levels. In their research, Lindstrom *et al.* (2013, p. 54) found that people who self-disclosed the positive impact of their trauma “reported more deliberate rumination soon after the event, and less current stress related to the event”.

Social support can help the development of this meaning and growth by encouraging and supporting the processing of this trauma. PTG may happen as individuals rethink and reshape their new view of life and the world. It is not the actual trauma that causes change but rather the struggle and aftermath of that experience. Spirituality and religious coping are important factors in PTG. Prayer and religion can help a person make sense of and find meaning in a trauma.

Figure 3, overleaf, describes PTG as a process which may be experienced over a short or extended timeframe. However, PTG is also an outcome – which is the “cluster of positive changes that result from a complex combination of cognitive, emotional, and social processes” (Tedeschi *et al.*, 2018b, p. 25).



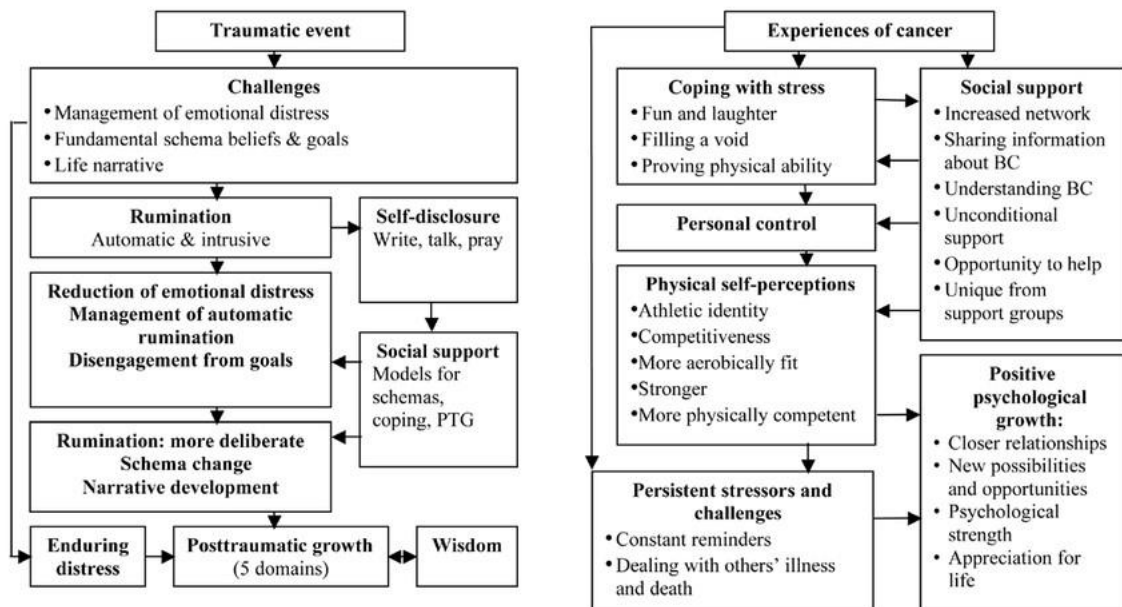


Figure 3: Model of Posttraumatic Growth (Tedeschi & Calhoun, 2004)

*Left panel: model of posttraumatic growth (Tedeschi, from Tedeschi, R.G. and Calhoun, L.G. (2004: Fig 1). Posttraumatic growth: Conceptual foundations and empirical evidence. Psychological Inquiry, 15, 1-18. Right panel: model of positive psychological growth.*

Tedeschi and Calhoun (1996) highlight 3 broad ways that people can experience perceived benefits and changes from trauma, these are; Self Perception (feeling vulnerable yet stronger), Relationships (closeness and greater compassion) and Life Philosophy (view of life and new possibilities).

According to the PTG Model, there are five Factors or potential growth areas that the PostTraumatic Growth Inventory measures. They each have high levels of internal consistency (Taku *et al.*, 2008). Construct validity of these 5 Factors is supported by several studies (Shakespeare-Finch *et al.*, 2013; Zamora *et al.*, 2017).

- Factor I is ‘Relating to others’ and refers to connecting to others differently and with greater compassion, especially if the other person has experienced a trauma.
- A person may also experience growth in Factor II ‘New Possibilities’ by establishing new goals or ways of living.
- With Factor III, ‘Personal Strength’, a person may feel greater self-reliance and that they can handle difficulties better.
- In terms of Factor IV, ‘Spiritual Change’, a person might experience a greater spiritual understanding and increased religious faith.

- Factor V concerns ‘Appreciation of Life’ and includes; an increased valuing of one’s own life and the everyday.

One way of looking at PTG is that instead of ‘bouncing back’ people who experience PTG are bouncing forward to a new way of life (Tedeschi *et al.*, 2018). The study of posttraumatic growth challenges us to rethink recovery from trauma as a nonlinear experience – where a person might well be dealing with the negative impacts as well as the potential positive impact at the same time (Grace *et al.*, 2015).

PostTraumatic Growth is most commonly measured using the PostTraumatic Growth Inventory (PTGI-21). This is a series of 21 pairs of statements where participants indicate on a Likert scale (from 0 to 5) the degree to which they experienced this change. There is also a short form, a form for children and the PTGI-42 which measures both growth and negative depreciation.

The latest version of the inventory is the PTGI-X which consists of 25 items. The model is recognised as being reliable and having internal consistency. According to Shakespeare-Finch *et al.* (2013) “the internal consistency of the PTGI is strong ( $\alpha = .90$ ), a is .71” (p. 575). Koutrouli *et al.* (2016) found high internal reliability with the PTGI with a Cronbach’s alpha of 0.95. There has been some development in recent years of certain subscales including compassion (Morris *et al.*, 2013). In 2017, Tedeschi and Calhoun renamed Spiritual Change to Spiritual-Existential Change and added an additional 4 items to better measure this Factor. The PTGI-21 is the most common instrument used to measure positive growth from cancer (Morris *et al.*, 2013; Joseph *et al.*, 2012).

#### • Key Debates

One of the key debates in the PTG field of research is the relationship between PTG and Post Traumatic Stress Syndrome (PTSS). In a meta-analysis of articles on PTSS and PTG by Shand *et al.* (2015), the evidence supported that PostTraumatic Growth and Post Traumatic Stress Syndrome are independent constructs with a complex relationship and not opposite ends of the same construct. They found that PTG may act as a buffer for psychological distress. PTG and stress can co-occur and so are therefore not mutually exclusive. The research by Romeo *et al.* (2017) also found that severe depression negatively impacted on PTG levels.

One debate is that PTG could be an illusion – i.e. a way of coping, of wanting to believe that some good can come of a trauma. One response to this is that illusory PTG is a self-deceptive way of avoiding a painful reality that is maladaptive in the long term (Tedeschi *et al.*, 2018b, p. 37). On the other hand, constructive PTG involves real change i.e. transformative growth as a result of the processing of a trauma.

There are several studies on the role and impact of stress on PTG. In a recent longitudinal piece of research on Irish breast cancer patients, high cancer specific stress is correlated with higher PTG levels (Groake *et al.*, 2017). Research on head and neck cancer survivors in Ireland also supports this finding (Sharp *et al.*, 2018) and the idea that stress triggers the individual to find a way to cope with and make sense of the experience. However, they also found that global stress was correlated to lower PTG levels. In addition, over time, PTG was also linked to lower levels of both stressor types which suggest that PTG might help an individual deal with future stress. In another Irish study higher cancer specific stress (cancer worry/fear of recurrence) in carers of those with head and neck cancers was associated with higher PTG scores (Balfe *et al.*, 2016).

Cancer survivors can experience growth in several different ways; spiritually regarding a renewed sense of meaning, personal relationships and a new way of perceiving life (Roland *et al.*, 2013). In 2014, Jaehee and Min also highlighted several positive changes for cancer survivors in their research including “better social relationships, greater personal resources such as religious satisfaction, and better coping skills” (Jaehee & Min, 2014 p. 461). There are some who would even argue that PTG is correlated with reduced death rates and morbidity in serious illnesses (Fox *et al.*, 2014).

Much of the research into PostTraumatic Growth focuses on identifying the predictors of PTG levels and attempts to understand how PTG levels vary across individuals. This research is recent and ongoing. There is some consensus that PTG levels are higher for women than for men. In 2004, Stanton *et al.* reviewed the literature from 1960 until 2004 on PTG and cancer survivors. They found that women reported higher PTG than men especially in the areas of Relating to Others, Spiritual Change and Appreciation of Life (but not Personal Growth or New Possibilities).

Several studies also support this finding that PTG is higher for women (Jaehee & Min, 2014; Jin *et al.*, 2014; Yi *et al.*, 2015; Sharp *et al.*, 2018 and Shand *et al.*, 2018). One suggestion to explain this is that women “are more likely to engage in event rumination

– a precursor to PTG- more frequently than men, receive emotional relief and support from others by revealing themselves more, and attempt more frequently to find the event’s meaning in their lives” (Joel *et al.*, 2015, p. 872). Higher PTG scores for women due to the tendency for females to engage in more rumination than men, and to use more emotion focused coping (Yuchang *et al.*, 2014; Sharp *et al.*, 2018). Emotion focused coping involves “positive reappraisal, rumination and positive self-talk” (Sharp *et al.*, 2018, p. 8).

There also seems to be consensus on the *importance of social support* in increasing PTG levels (Balfe *et al.*, 2016; Sharp *et al.*, 2018). However, there is some debate as to agent (i.e. if it is a spouse, friend, family member, etc.) and type of support needed. Romeo *et al.* (2017), working with 108 Breast Cancer Survivors, found that “women with a partner tend to show greater growth and tend to have major changes in the dimension of relationships, enjoying their life and future projects more” (p. 318). This is also supported by Harding and Moss (2018) who found that being married was positively correlated with higher PTG levels. Being married is not just potentially associated with greater growth but also potentially increased survival rates.

Research by Ibrahim and Pinheiro (2017) stated that, in the US, married women were diagnosed with cervical cancer earlier and therefore had a better prognosis than those who were unmarried. Their partners had encouraged them to seek a medical appointment and being married typically meant that they were in a financially better position than those who were not. In contrast, Hasson-Ohayon *et al.* (2016) found that friends rather than family or spouses were much better predictors of higher PTG levels. In this study, the spouses were dealing with the experience themselves and so the main support was from close friends/family.

Romeo *et al.* (2017) also highlight another area of agreement in the PTG literature – that higher PTG levels are associated with higher distress. In their study, they found that those who experienced combined therapy rather than hormone only, had higher levels of distress and experienced greater PTG. Another area of consensus concerns psychological aspects associated with higher PTG levels – concerning positive cognitive reconstruction and problem focused coping (Joel *et al.*, 2015). This is supported by an Irish study of PTG and Acquired Brain Injury, where higher PTG

levels were associated with greater use of adaptive coping strategies (Rogan *et al.*, 2013).

Jaehee and Min (2014) found higher PTG rates for: higher earners, those with more severe treatment, and the longer the time since diagnosis. In 2015, Yi *et al.* found that optimism and social support are positively related to PTG. They analysed 602 adult survivors of childhood cancer in Utah. In their study, they also found that PTG levels were higher if you were older at time of diagnosis, had greater disease severity and were non-white (Yi *et al.*, 2015). They also suggest that the greater the trauma, the more pronounced the positive and negative impact of cancer will be.

Even more recently, the research by Cao *et al.* (2018) found that adaptive coping (acceptance, use of religion, positive reframing and planning) positively predicts PTG. In fact, higher levels of social support (family, friends and doctors) predict higher levels of adaptive coping. Social support was found to be a necessary condition for PTG to occur. Social support impacts on adaptive coping which in turn impacts on the level of PTG experienced by the individual. Adaptive coping is also affected by the level of uncontrollability appraisal which again in turn impacts on PTG levels.

When individuals felt that their disease was highly uncontrollable (and accept fatalism), they are less likely to actively cope. Cao *et al.* (2018) showed that PTG is complex and that several both internal (positive appraisal and adaptive coping) and external variables (social support) are needed for growth to occur. They argue that adaptive coping is a mediator and that without this, neither positive appraisal nor social support are enough for PTG to occur.

There are several studies investigating the impact of groupwork on levels of PTG. Psychosocial peer group interventions may increase PTG by encouraging disclosure, cognitive processing and the positive appraisal of the trauma. It is also argued that “the supportive group environment may also enhance an intrinsic motivation towards growth” (Ramos *et al.*, 2017:259) so that PTG may increase in group interventions not even focused on PTG. This research by Ramos *et al.* was a longitudinal study on 205 women with breast cancer and showed that open sharing in groups leads to changes in both core beliefs and rumination thereby leading to increased PTG.

In their research on personal growth of ovarian cancer survivors, Roland *et al.* found that

“Supporting other OvCa survivors, participating in OvCa advocacy, maintaining a positive attitude, disregarding statistics, living for the moment, as well as focusing on the future, and journaling are important adaptive and coping techniques”

(Roland *et al.*, 2013, p. 2414).

Shand *et al.* found that “optimism, positive reappraisal, spirituality and religious coping were moderately related to PTG” and social support was positively related (2015, p. 630). The research by Joen *et al.* (2015) found higher PTG with participants who had more frequent religious activities. In their original research, Tedeschi and Calhoun (1996) found correlations between the areas of growth and the personality trait of extraversion which is being open to internal experience and optimism. This suggests that personality might influence the perception of positive changes.

One recent debate in the PTG literature concerns the call for the model to include physical trauma and its related constructs especially as a physical trauma can bring with it its own unique experience. The physical trauma is an internal transgressor as opposed to an external one (where the trauma is from an outside source e.g. war or famine). For example, with cancer, a person experiences a physical trauma and the treatment/side effects are experienced intensely on a physical level.

The research by Walsh *et al.* (2018) with male prostate cancer survivors highlights that

“Physical trauma can facilitate a ‘reconnection to the body’ with specific positive outcomes including (1) enhanced appreciation for the body, (2) increased care toward the body (listening to the body; treating it better) and (3) increased health behaviour changes” (Walsh *et al.*, 2018, p. 2).

There is far more debate than consensus in the PTG literature. Though debate is inherently healthy, there seems to be conflicting research results which adds to the questions and sometimes confusion in this field. An example of this concerns age as a predictor of PTG. There are dissenting voices in research with some suggesting that younger cancer patients report higher PTG levels.

Sharp *et al.* (2018) for example, found higher growth in younger survivors which could be attributed to the fact that they have more time and more to accomplish, or perhaps

less comorbidities or linked to employment status than older survivors. Other research points to retirees as having higher levels, with more time to make sense of their experience (Romero *et al.*, 2017; Joen *et al.*, 2015; Grace *et al.*, 2015). This doctoral research could potentially contribute to this – by examining the quantitative data to see whether age is a predictor of PTG levels.

- Criticisms and Questions

There are several criticisms of the PostTraumatic Growth model. Its construct may reflect and bias towards socially desirable responses and the prevalence of PTG is difficult to establish (Scrignaro *et al.*, 2016). The PTG construct was developed initially from researcher theories/experiences rather than participants and is typically studied quantitatively. Another issue concerns the fact that the PTGI asks the research participant to retrospectively think back to when they experienced a positive change which could result in defensive PTG to “an identity safeguard, a coping strategy to reduce the distress, and to maintain one’s self-esteem and perception of control” (Scrignaro *et al.*, 2016, p. 2). In this way the life narrative could influence a person to see the cancer experience as a series of redemptive sequences with ultimately a positive outcome. This reporting of growth may not represent real changes but instead be an ‘illusory coping strategy’ (Grace *et al.*, 2015).

Though the PostTraumatic Growth Inventory is a reliable scale, and has strong internal validity, there are questions as to the content validity. The qualitative study of the 21 inventory items by Shakespeare-Finch *et al.* (2013) showed that participants consistently understood the items and that positive growth correlated to each of the 5 factors of the PTG model. Construct validity is also supported by Zamora *et al.* (2017). However, the work of Yi *et al.* (2015) highlights the need to clarify the PTG construct and questions if PTG happens or if it is a coping mechanism by the survivor – wanting to believe there are positives/meaning from the experience as a way of dealing with it. They emphasise the need to “examine whether PTG is an outcome or a process” (Yi *et al.*, 2015, p. 7). There are also arguments that PTG could also be “a subjective perception of reality or a way of coping with a traumatic experience, in which no real growth takes place” (Holtmaat *et al.*, 2016, p. 5). This supports the importance of tracking PTG longitudinally.

Another criticism raised by Harding (2017) is the focus of the PTG model (Calhoun & Tedeschi, 2006) on coping as a form of primarily cognitive processing rather than affective responses. Inventories require a certain degree of self-awareness and skill by the respondent. They need to consider how they were pre-trauma and post trauma, and then work out the degree of change. There is, therefore, an argument that inventories could be examining positive attitude or more global growth (Harding, 2017) and not growth specific to the trauma.

For this doctoral research, PostTraumatic Growth is studied using a mixed methods approach. The primary data is from 30 semi structured interviews to investigate if, and to what extent, Irish female survivors experience positive growth from cancer. By studying the lived experience of cancer survivors, this research provides insights into the dynamics and drivers of the recovery process.

The quantitative data from the PTGI-42 is analysed using descriptive statistics to measure growth. Specifically, it assesses the 5 areas of growth as defined by the PTG model as well as investigating if there are any significant relationships with the demographic data.

With the release of the National Cancer Strategy for Ireland 2017-2026 in December 2018, this doctoral research could not be timelier (Department of Health, 2017b). This government document recognises that Ireland has a growing survivor population who are challenged with late effects. It acknowledges that current Psycho-oncological services are insufficient and that survivors have unmet needs. We need to understand survivor needs and develop services that address them (National Cancer Registry, 2018; Maher *et al.*, 2018). This lack of understanding of survivor needs/care in research is not just an Irish issue but a global one (Holland, 2018; Lang-Rollin & Berberich, 2018).

This doctoral study contributes to our understanding of the lived experience of survivors and explores what and how they experience growth. If we better understand their needs, and what helps them to recover then we can design programmes/initiatives that have a greater likelihood of addressing these needs. It is not just about having needs met or even quality of life as psychosocial supports can extend life (Spiegel, 2012; Lang-Rollin & Berberich, 2018). This project answers the call for greater patient reported outcomes (Thong *et al.*, 2018). The research is positioned in the psychosocial strand of Psycho-



oncology which is concerned with the psychological, social and behavioural factors that impact on the survivor experience (IPOS, 2019).

My research focuses on three key research questions:

1. What is PostTraumatic Growth (PTG) in the context of female cancer recovery?
2. To what extent does the PostTraumatic Growth Inventory effectively capture Irish women's experience of cancer recovery?
3. How does the PostTraumatic Growth Inventory compare to semi-structured interviews in understanding women's experiences of cancer recovery?

### **3. Methodology**

#### **3.1 Introduction and Research Questions**

The general aim of this research is to understand how Irish women experience cancer recovery and the dynamics of their recovery process. I wanted to know whether they experienced growth and, if they did, what was growth, and what were the factors that helped or hindered positive growth? I was also very interested to see how the PostTraumatic Growth Inventory captured this experience. I recognised the potential of this research project to contribute to our understanding of how PTG is assessed by including a comparison of interview and inventory data. Alvesson and Sandberg identify ‘gap spotting’ as the main way in which researchers generate research questions and do so by “adding something to existing literature, not identifying and challenging its underlying assumptions, and, based on that, formulating new and original research questions” (2011, 249).

My research focuses on three key research questions:

1. What is PostTraumatic Growth (PTG) in the context of female cancer recovery?
2. To what extent does the PostTraumatic Growth Inventory effectively capture Irish women’s experience of cancer recovery?
3. How does the PostTraumatic Growth Inventory compare to semi-structured interviews in understanding women’s experiences of cancer recovery?

PostTraumatic Growth is measured predominantly with the use of the PTG-21 or PTG-42 inventories (Tedeschi *et al.*, 2018). One of the ‘gaps’ in PTG research is in understanding this type of growth using qualitative methods. The first research question is an analysis of growth from the interview data. The second research question analyses growth from the quantitative/inventory data. The third and final question is a comparative analysis of the data from the PTGI-42 and interviews. A mixed methods study provides the opportunity to analyse the content validity of the PTG inventory. The comparative analysis could potentially inform and provide guidelines as to how the PTGI could be developed.

The research employs a qualitative mixed methods approach. The qualitative data, as outlined in Table 1, is derived from 30 one-to-one semi-structured interviews and 37 long answer questions derived from the interview questions. The quantitative data is

generated from the PostTraumatic Growth Inventory-42 which 67 participants completed. The sampling criteria consists of; female cancer survivors, 21 years or older, 2 or more years after their last treatment, living in Ireland and are/were clients of a cancer support centre.

Table 1: Qualitative Mixed Methods Data Collection Type Applied

<b>Sample Size = 67</b>	<b>Data Collection Tool Used</b>
30 Participants	One-to-one interview PostTraumatic Growth Inventory-42 Demographic Questions
37 Participants	PostTraumatic Growth Inventory-42 Demographic Questions Long Answer Questions

The semi-structured interview questions and long answer questionnaires (as presented in Appendices 10 and 12, respectively) explored the following:

- What was the respondents' experience of cancer?
- What was the main impact of having had cancer? (and they were then prompted into answering 'negative' or 'positive' depending on what their initial answer was i.e. if they spoke of the negative impact then they were prompted to consider the positive and vice versa.
- What helped and what hindered the recovery process?

The PostTraumatic Growth Inventory-42 is a series of 21 pairs of statements developed by Calhoun and Tedeschi (2006). For each statement, the participant is asked to self-select the degree to which they experienced a change from 0 to 5 (reference Appendix 4 for a list of PTGI-42). Each statement corresponds to 5 Factors or areas of positive growth that a person may experience as the result of a major life trauma such as cancer.

## 3.2 Methodological approach

This doctoral research project views theory through the lens of applied practice. To provide further transparency to the research design, I will apply the 13 steps of Mixing and Merging Methodologies developed by Schoonenboom (2018) to my research process.

This project has findings which “apply to (and therefore could be replicated with) other persons, situations or contexts, treatments, observations or measures, study methods or designs, and times” (Krathwohl & Smith, 2005, p. 26), as would be expected of a pre-specified study. As a researcher I have attempted to be as transparent as possible in my process so that this type of study could be replicated. The research is also empirical in nature (studying people).

*Theory* in this project is seen as ‘in relation to practice’ which concerns “ideas about how an activity of a particular type ought to be carried out, why, what its value is and so on” (Hammersley, 2012, p. 394). The focus of this research is on understanding the cancer recovery process and the significant factors that impact it. The research uses ‘explanatory language’, “capturing the basic principles of causal systems, these being hidden from ordinary forms of perception and cognition” (Hammersley, 2012, p. 396). In a traditional view of theory, “social theories offer ways of seeing that provide an interpretation of aspects of the world and make descriptive, explanatory and predictive statements about them” (Trowler, 2012, p. 274).

For this doctoral research a mixed methods approach was employed as it best fit the research questions – where the interview would provide insights into the lived experience of having cancer and the inventory (quantitative) data would assess the 5 growth areas as defined by PTG. A mixed methods research approach “includes any research with different types of data, approaches to analysis, or research conducted on two different populations or groups, whether it is qualitative or quantitative” (Morse, 2010, p. 340). As a researcher I recognise the ‘divide’ and differences that can exist between qualitative and quantitative research.

With qualitative research there are multiple realities/knowledge that must be understood in terms of its context both in terms of data generation (interview setting) and the wider socio/political culture (Braun & Clarke, 2013). Other features include: ‘words’ as data, natural data collection methods, the use of inductive theories, the role of the researcher

and a focus on meaning. Quantitative research uses numbers as data, takes an experimental approach, uses deductive theories, sees the researcher as objective/neutral and seeks data that is observable, controllable that has proven validity and reliability.

However, despite these differences and to use Bryman's terminology, I take a 'particularistic' view that sees "mixed methods research only appropriate when relevant to the research questions being asked" (Bryman, 2006, p. 270).

In order to understand how Irish women experience PostTraumatic Growth, I deemed it necessary to take a mixed methods approach where the interviews provided depth on the lived experience of women in recovery. This qualitative approach it could be argued can provide a more complete picture of the experience of growth as participants are not limited to the specific areas measured using a quantitative method such as the inventory in this instance.

Qualitative exploration has the potential to generate data that might contribute to the understanding of underlying mechanisms of PTG and contribute to theory generation. In addition, the use of neutral questions e.g. 'what was the main impact of cancer on you?' may encourage a more spontaneous or natural description of growth rather than working within the confines of the 5 growth areas measured by the PTGI (Tedeschi *et al.*, 2018b). Using a qualitative approach (semi-structured interviews) also has the potential to analyse Factor content validity – i.e. to see how the growth described in the interviews compares or corresponds with the Factors in the inventory. A qualitative analysis may yield insights into the process of PTG whereas the inventory is a measure of growth outcomes only.

Tedeschi and Calhoun support a mixed methods approach using qualitative and quantitative ways to understand and measure PTG (Calhoun & Tedeschi, 2014; Tedeschi *et al.*, 2018b). By taking a qualitative approach, this naturally lends itself to an inductive research view where the data and findings are participant-led.

The results of the PTGI-42 would measure any growth on the 5 factors pre-specified by Tedeschi and Calhoun (2006). The inventories are completed sequentially immediately after the interviews and are analysed using descriptive statistics. Integrating the findings from both the inventory and the interviews provides a more complete and richer account of the positive growth experience of cancer survivors than one method could provide alone. A comparative analysis of both methods will potentially yield insights into the

construct validity of the PTGI as well as highlighting changes that are needed so that the inventory better captures the growth experienced by cancer survivors. I agree with Braun and Clarke (2014) when they say that qualitative research may be different but can be complementary to what we can learn from quantitative research.

There are various forms of mixed methods research designs and this doctoral project uses a convergent parallel design (Bryman, 2006). This essentially means that the qualitative and the quantitative data was collected and analysed separately but at the same time (in the same session) and therefore it uses an identical sampling design. This type of convergent design is appropriate to explore and provide a rich description of a process (Hashemi & Babaii, 2013). Results are triangulated and integrated during interpretation of the findings in Chapter 6.

Within mixed methods, there is a growing call to clarify the purpose of mixing (Hasemi & Babaii, 2013; Schoonenboom, 2018) i.e. outlining the rationale for mixing methodologies and explaining how this will be done. To further elucidate my use of mixed methods in this research project, I applied the 13 steps of Mixing and Merging Methodologies developed by Schoonenboom (2018) to my research process, as outlined in Table 2, overleaf. In addition, the Principal Components Analysis (Chapter 6) was used as a data reduction technique on the inventory data to investigate and identify the key components/Factors that were significant for this research sample. These components were then compared with both the existing 5 Factors from the original PTG model (Tedeschi and Calhoun, 2006) as well as the qualitative findings.

Table 2: 13 Steps for Mixing and Merging Methodologies, Schoonenboon (2018) applied

REMOTE	
<b>1. REMOTE PURPOSE</b>	contribute to our understanding of growth and resilience of women in cancer recovery
<b>2. REMOTE PURPOSE TYPE</b>	explore, understand and assess the experience of cancer recovery for women
THIS STUDY	
<b>3. IMMEDIATE PURPOSE</b>	better understand how Irish women recover from cancer and their experience of PostTraumatic Growth
<b>4. IMMEDIATE PURPOSE TYPE</b>	Explore, understand and assess
<b>5. RESEARCH QUESTION</b>	<ol style="list-style-type: none"> <li>1. What is PostTraumatic Growth (PTG) in the context of female cancer recovery?</li> <li>2. To what extent does the PostTraumatic Growth Inventory effectively capture the Irish women's experience of cancer recovery?</li> <li>3. How does the PostTraumatic Growth Inventory compare to semi-structured interviews in understanding women's experiences of cancer recovery?</li> </ol>
<b>6. SCOPE OF STUDY</b>	Irish Female cancer survivors
RESEARCH STRANDS	
<b>7. PURPOSE TYPE OF EACH RESEARCH STRAND</b>	A: Semi-Structured Interviews (30) and long answer questionnaire (37) Explore and understand how women experience recovery and PTG B: PTGI-42 Assess PostTraumatic Growth
<b>8. SCOPE OF EACH RESEARCH STRAND</b>	A: Semi-Structured Interviews (30) and long answer questionnaire (37) 30 female cancer survivors B: PTGI-42 67 female cancer survivors
<b>9. METHODOLOGIES FOR EACH RESEARCH STRAND</b>	A: semi-structured Interviews and long answer questionnaire Thematic Analysis (Braun & Clarke, 2006) Underpinned by Phenomenology B: PTGI-42 Statistical Analysis including Principal Components Analysis, using SPSS (Ver 24.0)
STRAND COMBINATION	
<b>10. PURPOSE OF MIXING</b>	Use different methods to address the same research questions and compare the results
<b>11. ADAPTATIONS FOR MIXING</b>	30 interviewees needed to represent a diverse population of female cancer survivors. The interview data on the experience of recovery must include PTG to compare the data from the inventories in research strand B.
<b>12. ASSIGN LABEL</b>	II mixed methods (Interview, Inventory)
<b>13. ITERATION</b>	Consistent reviewing of steps for consistency

It is also important to note as part of the methodological approach that this doctoral research is underpinned by phenomenology which as an integrated paradigm naturally lends itself to mixed methods research (Feldon & Tofel-Grehl, 2018). Phenomenology recognises the link between and the importance of both qualitative and quantitative data. It “emphasizes personal conceptions as a necessary construct to understand the relationship between the physical events that people experience and the personal meanings that they derive from those experiences” (Feldon & Tofel-Grehl, 2018, p. 887).

Phenomenology highlights the importance of understanding personal conceptions as the construct through which we can understand the physical experience of a situation and the way in which a person derives meaning from it (and the relationship between both the experience and the meaning). According to Feldon and Tofel-Grehl (2018), conceptions may be distinct or related, they can change over time and are hierarchically organised. Phenomenology would argue the necessity of studying both the physical phenomena/experience as well as how the person derived meaning in order to ascertain the conceptions involved. Phenomenology is constructively aligned with the epistemology, ontology and methodology of this research.

### **3.3 Researcher Stance**

As a researcher, I believe it is important to accept, acknowledge and address researcher bias. I came to this research project influenced by a very personal experience with cancer and I was also influenced by my epistemological and ontological stance.

The concept of a researcher being an objective, neutral person with no bias is long challenged. If we look for example at the work of Code (1993) in her paper on subjectivity, she highlighted how the personality and experience of the researcher impacts on their researcher role/process. She said that the researcher role is shaped by the “nature of inquirers: upon their interests in the inquiry, their emotional involvement and background assumptions and their character; upon their material, historical, and cultural circumstances” (p. 26). I believe that any researcher brings who they are to their role and cannot be devoid of personal bias.

Code points to potential influences from significant and current social movements, institutions, funders as well as personal bias so that despite scientific rigour, “the scope



of epistemological investigation has to expand to merge with moral-political inquiry, acknowledging that ‘facts’ are always infused with values and that both facts and values are open to on-going critical debate” (Code, 1993:30).

Rather than repressing or ignoring researcher bias, I would argue that researchers need to evaluate and account for their subjective experience whilst carrying out research if it is to have any chance of being objective. This view is supported by Bryman (2012, p. 39) who states “research cannot be value free but to ensure that there is no untrammelled incursion of values in the research process and to be self-reflective and so exhibit reflexivity about the part played by such factors”.

Concerns about researcher bias have led to the recent rise in pre-registered studies – where a researcher clearly outlines what they will study and detail the proposed methodology (Kupferschmidt, 2018). Even the choice of topic or the aspect of that topic you wish to study has the potential for bias i.e. what you want to study and how. In addition, the use of semi-structured interviews itself can be potentially biased as the researcher is in fact the instrument – designing typically open questions to encourage disclosure (Chenail, 2009). Therefore, I believe it is vital for a researcher to have a certain degree of self-awareness and be familiar with their own bias.

A significant personal bias for me stems from the fact that my mother was diagnosed with lung cancer in November 2007 and passed away in April the following year. In my opinion having been a caregiver, and family member of someone who died from cancer, I think I had great empathy and could connect easily with someone who had faced this disease. It also fuelled my desire to understand how someone experienced cancer and recovery. However, I was also very aware of the fact that my personal experience could also lead me to stereotyping of the medical or even the interviewee experience through the lens of my mother’s experiences.

I spoke with a colleague at work who became a regular ‘sounding board’ to provide an objective stance and someone with whom I could discuss the research progress in the interest of researcher self-care. I also investigated counselling options for myself in case the research experience triggered any emotions that I might need to process. This research caused me to look at potential bias in a very personal way, however, it is also important to outline here the influence of my epistemological and ontological stance.

My ontological and epistemological stance influenced both the aspect of the topic to study and how it is to be studied. As a researcher in training, I see myself as a pragmatist aiming to open ‘social enquiry’ (Brannen, 2005) and seek findings that have practical applications. The research design is also driven by the desire to be relevant and useful to policy makers, cancer centres, cancer survivors themselves, and those who work with these clients.

Brannen (2005) highlights the importance for researchers to highlight their rationale behind decisions. He would argue that choice of method is driven by the ontological and epistemological stance of the researcher. In accordance with this aspect, qualitative and quantitative research have very different philosophical foundations. “In the paradigmatic vision of the world the former is more interested in ideas and their origins, in the ideas which drive the research and the ideals upon which research should be founded” (Brannen, 2005, p. 10). Although this research is mixed methods it is primarily qualitative with the quantitative data analysed via a qualitative lens.

As a researcher I am aligned to an interpretive stance where reality is seen as subjective, socially constructed and a key research aim is for an empathic understanding of the subjective experience of reality by cancer survivors. Qualitative methods are the norm with idiographic data where the themes/patterns and theory emerge over time and inductive reasoning is evident. As a researcher, I want to immerse myself in the experience with participants. Ontology is “the image of social reality upon which a theory is based” (Grix, 2002, p. 177) and for me this is social constructivist where the sense of meaning is ever changing and embedded in social interaction.

### **3.4 The Research Plan, Recruitment, Selection and Participant Profile**

#### **• The Research Plan**

In 2015, the plan for this research was to recruit 26 participants from Ireland to take part in a one-to-one interview and complete the PostTraumatic Growth Inventory-42. Thirty individuals volunteered and were interviewed. In addition, I met with groups of survivors (37 people) at the cancer support centres to complete the following; the PostTraumatic Growth Inventory, long answer questions (based on the interview questions), and demographic data. This data expanded and increased the validity of the quantitative data.

The intention of the research was to run a qualitative piece of research with the data from the inventories used primarily in a descriptive way. By accessing participants via the centres, it meant that research participants had had some opportunity to be aware of/process their experience and they could benefit from the counselling support of the centres if needed after taking part in the research.

As a researcher, one of the challenges is to decide how much data to gather - to define the size of the sample and determine how much data is enough to answer the research questions. For this study, 30 interviewees is sufficient because the research questions are quite specific (Morse, 2015) and the sample group is directly relevant and holds high 'information power' (Malterud, 2016). According to Morse (2015), 30-60 semi structured interviews are appropriate based on the analytic strategy. Morse argues that "the less clear the phenomena studies, the larger the sample required; the more interpretative, thematic the method, the larger the sample required" (Morse, 2015, p. 1318).

Malterud *et al.* (2016) would argue the use of 'information power' rather than saturation to guide adequate sample sizing in qualitative research which "indicated that the more information the sample holds, relevant for the actual study, the lower amount of participant is needed" (p. 1753). It is this estimation of information power that should guide the sample size. Factors that impact on this power include: study aim, how specific the sample is, how established is the theory being used, the dialogue quality, and analysis strategy. A smaller sample size is sufficient if the information power is high which happens when the study aims are narrow, the target sample is very specific to what you need to study, the theory is established, the dialogue is clear and focused, and the analysis is in-depth.

Since the research participants were accessed via Cancer Centres and most of their clients were women, I decided to work with a sample of female cancer survivors only. In over 5 years of working with various groups in the Clonmel CARE Centre, I personally never met even one male participant on a programme/workshop – or even met one male availing of the Centre's services. The Centre Directors confirmed that their clientele are predominantly female.

- Recruitment and Selection

I began by meeting the Director of each of the cancer support centres. The purpose of this meeting was to; introduce me, outline the research, find out more about the operation of the centre, establish the profile of their client group, and to establish their interest in being involved with this research project (see Appendix 5 for a full list of the meeting questions). Each Director was given a copy of the Organisation Information Sheet and an Organisation Consent form to sign if they were happy to take part. Each of the support centres met with their respective Boards of Management to seek approval before agreeing to take part.

Initially it was proposed that the project would be promoted via; word of mouth, poster, and the cancer support centre website (in that order). For the centres, this was how they typically communicated with their clients. The plan was that the potential research participants would then contact me directly. However, each of the four centre Directors that I met with first, specifically asked that they be the gatekeeper of the participants. This meant that each Director reviewed their database of current and former clients who fit the research criteria and then contacted them directly to introduce the research and establish if they were interested. One of the centres chose to create and display a poster to inform participants of the research (see Appendix 8).

The sample was purposive (non-probability sample) as each participant was a cancer survivor. To use Bryman's terminology, I used a generic purposive sampling approach with a priori fixed criteria (Bryman, 2012). To be eligible to take part in the research the participant had to meet the following criteria; be female, 21 years of age or over, had any type of cancer, are two years (and up to 10 years) after their last major treatment and either have used or currently use the services of a cancer support centre. This meant that the sample was made up of what I considered 'typical case sampling'. The fact that participants needed to be two years post primary treatment, meant that they had had time for physical recovery before taking part in the research. According to the Irish Cancer Society website remission is "A period of good health where there is no detectable evidence of cancer" [accessed from <http://www.cancer.ie/cancer-information/cancertypes/glossary-of-terms#r>, Tuesday September 23<sup>rd</sup> 2014]. Remission is also sometimes referred to as No Evidence of Disease (NED).

Each Director was asked to only contact clients who met the sample profile and in addition they were asked to consider variability in their selection (i.e. to seek diversity

in age profile, ethnicity, education level and economic background). If the potential participant was interested, the Director then set up the interview session at their centre and liaised with the client and with me to confirm logistics. Centre Directors were furnished with the Participant Information Sheet to distribute to the participants beforehand. Also, each centre agreed to provide their counselling service to anyone who took part in the research who felt they might need this service after they took part in the project. I was using convenience sampling in the sense that I was accessing survivors through a support centre I had previously volunteered for.

By using the support centres, I showed participant due diligence by negotiating with each of the centres to provide a free counselling service to research participants should they need it. From a methodological viewpoint, I also saw the advantage of running the interviews in the centres as these were familiar territories for the participants where I thought they would feel comfortable thereby helping them to open up and talk during the interview. A second important decision was to include participants who were a minimum of two years from the date of their last treatment and up to a maximum of 10 years.

With my personal cancer experience and having worked as a volunteer in a cancer support centre, I was very aware of the physical and emotional toll that treatment and the subsequent medical appointments can take. I was also aware of the impact of late effects which can happen at any time but are more likely within one year of the treatment finishing (Treanor *et al.*, 2013). Therefore, the potential participant needed to be a minimum of two years after their last major treatment (where major treatment is defined as surgery, chemotherapy or radiotherapy). This 2-year timeframe would allow time for physical recovery as well as potentially some time to reflect on their experience. PTG is usually experienced once treatment has ended (Romeo *et al.*, 2017).

The option of running a pilot study was comprehensively discussed with my supervisor. Due to concerns regarding access to this client group, I decided not to do a pilot study for practical reasons as I did not want to lose limited research participants. Instead, I chose to spend considerable time developing the content and flow of questions. It was also agreed that I would have a full debrief with my supervisor after the second recorded individual interview to discuss the perception of the questions and decide on any changes needed.

### • Participant Profile

67 female participants took part in this research project and all were resident in Ireland. All the participants were either current or past clients of cancer support centres. The age range, as outlined and depicted in Table 3 and Figure 4, below, was from 40 to 78 years, with a mean of 60 years.

Table 3: Study Participants' Age Range

Age of Study Participants	Number of Participants	Percentage of Participants
40-49 years	11	16.4
50-59 years	24	35.8
60-69 years	20	29.9
70+ years	12	17.9
Total	67	100.0

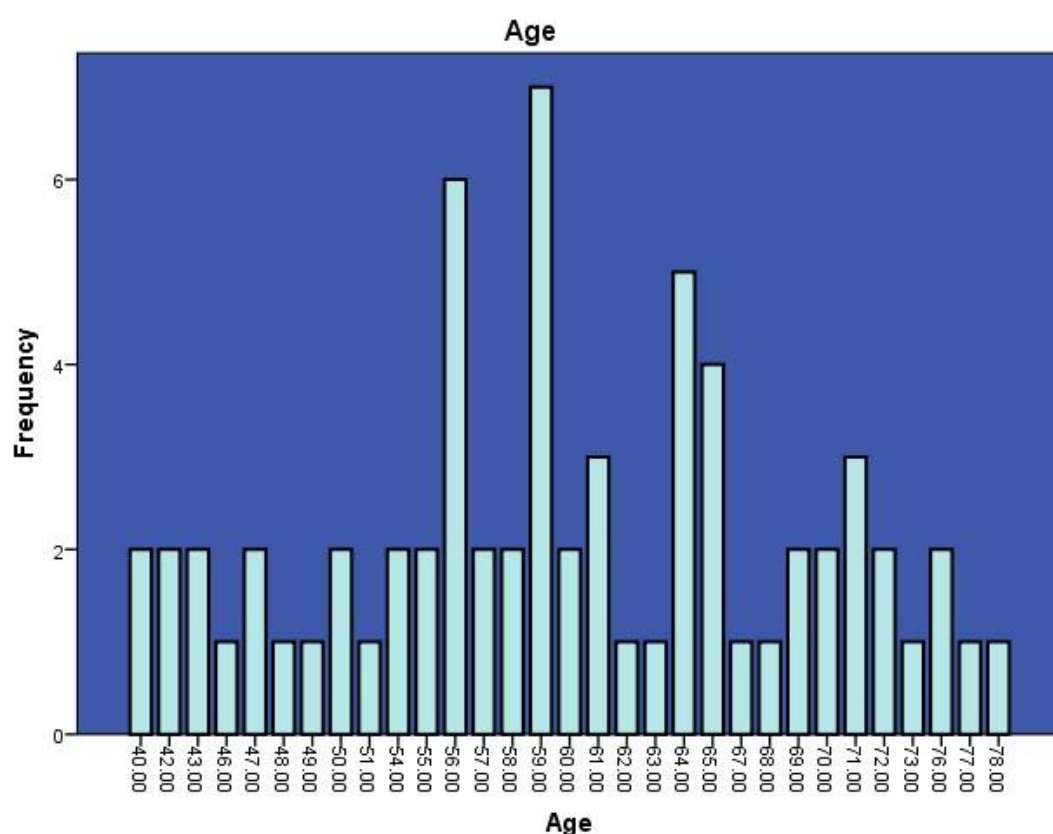


Figure 4: Graphic Representation of Participants' Age Range (from 40 to 78 years)

The 67 participants were diagnosed with 15 different types of cancer/cancer combinations, with the most commonly diagnosed cancer being breast cancer (70% of participants) see

Table 4 for a detailed breakdown.

Table 4: Type of Cancer Experienced by Study Participants, as % of study population

Study Participants' Type of Cancer	Number of Participants	Percentage of Participants
Breast	47	70.1
Lymph	2	3.0
Kidney	1	1.5
Thyroid	1	1.5
Lung	2	3.0
Colon	3	4.5
Uterine	1	1.5
non-Hodgkin's lymphoma	3	4.5
Malignant Melanoma	1	1.5
Ovarian and Sarcoma	1	1.5
Hormonal	1	1.5
Carcinoma	1	1.5
Multiple Myeloma (Bone Marrow)	1	1.5
Melanoma Breast Lung	1	1.5
NET (Neuroendocrine Tumours)	1	1.5
<b>Total</b>	<b>67</b>	<b>100.0</b>

As indicated in Table 5, below, 88% participants were treated for one cancer with 12% being treated for more than one cancer. The maximum number of times that a person had cancer was five.

Table 5: Number of times that Study Participants indicated they had been treated for cancer

How many times have you had cancer?	Number of Participants	Percentage of Participants
1	59	88.1
2	4	6.0
3	3	4.5
4		0.0
5	1	1.5
<b>Total</b>	<b>67</b>	<b>100.0</b>

In terms of the stage of the disease, 31% participants did not know what stage of cancer they had and of those who did know, the most common was stage III which accounts for 24% of the sample. Cancer staging is a classification system which indicates how much the disease has spread. The stages are from I to IV. With stage III, cancer has spread to surrounding tissue/organs and stage IV is usually considered terminal (Detterbeck, 2017). See Table 6, below for study participant cancer stage breakdown.

Table 6: Stage of Cancer Experienced by Study Participants

Age of Study Participants	Number of Participants	Percentage of Participants
Stage I	12	17.9
Stage II	12	17.9
Stage III	19	28.4
Stage IV	3	4.5
Don't Know	21	31.3
<b>Total</b>	<b>67</b>	<b>100.0</b>

With regards to treatment plans, 29 different ones were identified. 97% of participants were Irish Nationals with only 3% who identified as a Non-Irish Nationals (both from the UK). The majority of participants (72%) were married (see

Table 7 and Figure 5, below, for more information).

Table 7: Study Participants' Marital Status

Marital Status of Study Participants	Number of Participants	Percentage of Participants
Single	11	16.4
Married	48	71.6
Separated	2	3.0
Divorced	2	3.0
Widow	3	4.5
Common in law	1	1.5
<b>Total</b>	<b>67</b>	<b>100.0</b>



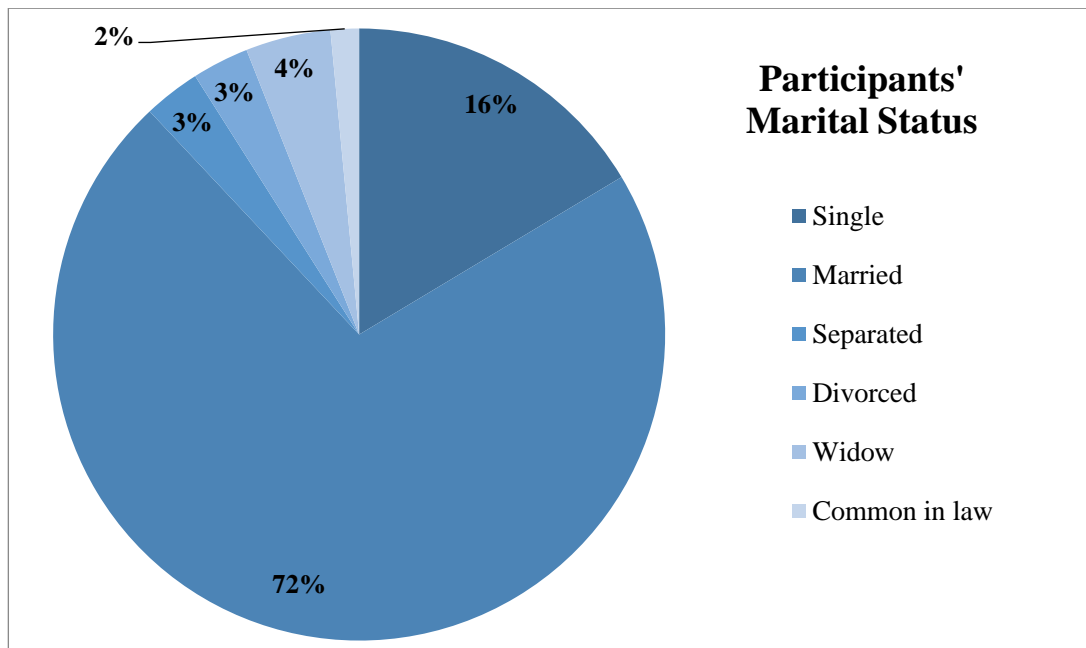


Figure 5: Study Participants' Marital Status (Percentage of Population)

In terms of children, 70% of participants had children and 30% did not. For those who did have children, the mean average for number of children was 2.25. All the participants were Caucasian and were female. For a full list of Study Participants' Overall Data see Table 8.

Table 8: Study Participants' Overall Data Table

Partici pant	Rel to Others	New Poss	Personal Strength	Spiritual Change	App Life	Total	Age	Cancer	Children
1	29	24	20	0	9	82	50	Thyroid	yes
2	31	19	19	0	11	80	40	Lung	no
3	31	19	17	6	13	86	42	Breast	no
4	32	23	11	10	11	87	57	Lung	no
5	29	19	13	0	15	76	65	Colon	yes
6	28	17	17	10	11	83	46	Breast	no
7	34	19	18	10	14	95	56	Breast	yes
8	33	19	17	0	15	84	65	Uterine	yes
9	29	17	16	0	13	75	56	Breast	yes
10	35	24	19	10	15	103	48	Breast	yes
11	30		15	5	13	63	71	Colon	yes
12	35	20	17	10	15	97	61	Breast	yes
13						0	65	Breast	yes
14	35	25	20	5	15	100	59	Breast	yes
15	28	11	14	2	11	66	64	Breast	no
16	9	5	6	2	3	25	71	Breast	no
17	25	3	20	10	10	68	56	Breast	yes
18	25	8	14	4	12	63	40	Non-Hodgkin's	yes
19	15	17	10	3	6	51	56	Melanoma	yes
20	22	11	16	3	15	67	69	Breast	yes
21	20	20	7	0	13	60	55	Breast	yes
22		5	7	3	11	26	65	Breast	yes
23	29	13	19	9	8	78	69	Non-Hodgkin's	no
24	28	7	13	7	11	66	42	Breast	yes
25	22	17	12	5	6	62	61	Breast	yes
26	35	22	13	10	15	95	58	Breast	yes
27	31	12	16	8	13	80	51	Breast	yes
28	32	18	15	7	15	87	49	Breast	no
29	27	20	15	5	8	75	57	Breast	no
30	35	24	20	10	15	104	64	Breast	yes
31	25	15	14	8	13	75	73	Breast	yes
32	26	25	20	3	15	89	72	Colon	yes
33	29	17	7	0	14	67	55	Kidney	yes
34	18	17	19	5	6	65	43	Lymph	no
35	18	19	17	9	11	74	64	Breast	yes
36	24	9	16	1	14	64	71	Ovarian	yes
37	10	12	16	0	9	47	72	Breast	yes
38	21	17	16	7	8	69	62	Breast	yes
39	29	12	10	9	9	69	50	Breast	yes
40	31	15	17	3	15	81	59	Breast	yes
41	31	14	18	9	14	86	60	Hormonal	yes
42	32	22	18	4	14	90	59	Breast	yes
43	24	16	13	7	8	68	76	Non-Hodgkin's	yes
44	21	4	20	5	8	58	63	Breast	yes

Participant	Rel to Others	New Poss	Personal Strength	Spiritual Change	App Life	Total	Age	Cancer	Children
45	27	18	17	0	13	75	47	Breast	yes
46	25	11	16	7	7	66	70	Breast	no
47	26	8	11	3	12	60	54	Breast	no
48	31	24	18	2	15	90	59	Breast	yes
49	35	25	15	0	14	89	70	Breast	yes
50	35	21	18	5	13	92	68	Breast	no
51	28	23	17	0	15	83	59	Breast	yes
52	35	22	17	8	14	96	54	Breast	yes
53	24	15	9	3	13	64	58	Breast	no
54	35	21	17	9	15	97	61	Lymph	yes
55	30	21	18	7	13	89	78	Carcinoma	no
56	29	14	15	7	8	73	77	Breast	yes
57	31	23	20	10	13	97	64	Bone	yes
58	22	10	16	0	6	54	60	Melanoma	yes
59	29	11	14	5	14	73	76	Breast	no
60	30	22	15	8	15	90	59	Breast	yes
61	35	16	19	5	15	90	43	Breast	yes
62	17	18	14	0	10	59	64	Breast	no
63	24	21	17	4	14	80	56	Breast	no
64	24	16	12	0	14	66	56	Breast	no
65	24	20	16	7	11	78	67	Breast	no
66	29	19	16	6	15	85	47	Brain	yes
67	26	17	10	0	11	64	59	Breast	yes

### 3.5 Interviews and PTGI-42

#### • Interviews

Each participant was told that the session could take up to 2 hours. This would start with 10 minutes for introductions, to read the information sheet and to sign the consent form (see Appendices 9 and 10). Up to 60 minutes was allocated for the interview, with the final 30 minutes for completion of the PTGI-42 as well as the demographic questions. The additional 20 minutes facilitated if there was a problem with the technology or a participant was late etc. In terms of a break, the researcher either made tea and it was brought into the interview from the start or it was made for the participant when they started the inventory.

The interviews all took place at the cancer support centre used by the participant, so it was within their familiar territory. I wanted them to feel comfortable. In line with the culture and current physical set up of each of the centres, I planned to only use a small table and kept this to the side to keep the space relaxed (rather than a table between me

and the interviewee). I had water and glasses in the room for the interview and made sure it was uncluttered and an appropriate temperature. In all cases it was in the room that the therapist usually used so I made sure to enquire as to where the therapist sat and was deliberate in ensuring that this is where the interviewee sat. Since it was the room used by the therapist there was usually a box of tissues on the side table and I would put this away in a press before starting interviews. Having worked as a case worker previously, I was very comfortable dealing with a wide range of emotions but felt that this box would be a prompt to feel sad and I did not want to 'set them up' to feel this way.

The interviews were semi-structured, and I went through several iterations of questions with my supervisor. Following the guidelines of Morse (2015), the questions were asked in a logical order with probing where necessary. Having worked as a volunteer with cancer survivors before, I knew how important their personal story of cancer could be and so decided to begin the interview asking them to tell of their experience of cancer, wherever they would like to start. In this way they could disclose whatever they had been thinking about/came in with and it might help them relax. The interview questions (Appendix 11), focused on areas such as; what the main effects were, if their beliefs had changed, if they as a person had changed, and what helped or hindered their recovery.

The first 2 interviews were thoroughly reviewed and debriefed with my supervisor to assess how the interviews were going and if any changes needed to be made. One change was to focus on the interview as a conversation which meant keeping the content areas, that I needed to know about, clear in my mind, but to allow the flow of the interview to be a conversation rather than a question and response. In this way it was thought that there would be greater ease and perhaps more in-depth sharing.

All interviews were recorded with a small hand-held device that was left on the side table during the interview. The interviews were transcribed later. No notes were taken during the actual interview but at times some notes were made about the interview when the interviewee left and before the next interview began. I completed an average of three interviews in one sitting. The shortest interview was 30 minutes and the longest one was 2.5 hours in length. The average interview time was one hour.

- PTGI-42

I used the PostTraumatic Growth Inventory (PTGI-42) (see Appendix 4). I used the latest version of this inventory and obtained it by contacting the Post Traumatic Growth Research Group in June 2015 which is in the Psychology Department of the University of North Carolina Charlotte. This research group is run by Dr Tedeschi and Dr Calhoun who are the original researchers/developers of the PostTraumatic Growth Model. Researchers have permission to use this inventory if it is for a not-for-profit purpose.

The PostTraumatic Growth Inventory is the most common measure used to assess psychological growth from trauma. All 67 participants completed the PTGI-42. It was Baker *et al.* (2008) who expanded the PTGI to look at both positive and negative changes in growth and developed the PTGI-42 (Cann *et al.*, 2010). This is a list of 21 pairs of statements and in each pairing, one of the statements is written in the positive and the other is written in the negative form. For example: '*8a. I have a greater sense of closeness with others and 8b. I have a greater sense of distance from others.* Each pair of statements relates to one of five potential areas of growth. The items are measured using a 6-point Likert scale from 0 (I did not experience this change as a result of my crisis) to 5 (I experienced this change to a very great degree as a result of my crisis). Scores range from 0-20 to 0-70 for subscales. Scores also range 0-210 for the total PTG score and the higher the score, the higher the person perceives PTG. The constructs used in PTGI are robust with good construct validity (Yi *et al.*, 2015). The PTG model "refers to positive psychological change conferred after a major life event or traumatic experience" (Fox *et al.*, 2014, p. 385).

The PTGI-42 is organised into 5 Factors or potential areas of growth: Relating to Others (14 items), New Possibilities (10 items), Personal Strength (8 items), Spiritual Change (4 items) and Appreciation of Life (6 items). The data from the PTG inventories was verified by manually comparing 20% of the original inventories with the scores in SPSS to ensure that the data was correctly entered. The inventory data is interval which means that the findings can be analysed using central tendency (Mean, Mode and Median) as well as Standard Deviation.

In terms of the sequence, participants always completed the interview first and then the PTGI and demographic questions (see Appendix 12). For the participants who did not

complete an interview, they were asked to complete a series of long answer questions based on the interview questions (see Appendix 13).

A core framework of this research is the PostTraumatic Growth model. According to this model ‘self-analysis’ and ‘self-disclosure’ are two very important channels by which a person can process and integrate a traumatic event thereby leading to personal growth. The interview process and the inventory are an opportunity to reflect, articulate and indeed process their experiences. As a researcher I had hoped that the experience for the participant would be a time to reflect and an acknowledgement of what they have gained as a result of managing this personal process of dealing with cancer.

### **3.6 Data Analysis**

The qualitative analysis of interview and long question data followed the 6-step thematic analysis (TA) by Braun and Clarke (2006). In this approach to TA, “coding and theme development processes are organic, exploratory, and inherently subjective, involving active, creative and reflexive researcher engagement” (Braun & Clarke, 2016, p. 741). It is essentially the exploration of data to establish patterns of meaning. I wanted to stay as close to the data as possible and to be as open as I could be to the type of codes and themes I created. Braun and Clarke recommend using TA if you want to “focus more on patterned meaning across the data-set” (2018) which is what I wanted to do.

Braun and Clarke (2006, p. 6) argue that thematic analysis is not a generic tool but rather “a method for identifying, analysing, and reporting patterns (themes) within data”. Since it is independent of theory, its ‘theoretical freedom’ brings great flexibility. Thematic Analysis can be used with a wide range of epistemological and ontological bases and can address a wide range of research questions (Clarke & Braun, 2017). There is no specific sampling requirement and as a method can analyse most sources of qualitative data.

Within thematic analysis, when exploring the full data corpus, I used a constructionist approach looking for latent themes and found that the themes typically clustered together. This search for latent themes is in line with my epistemological constructivist stance as I was searching for socially constructed patterns of meaning.

As stated earlier, I followed the guidelines for 6 phases of thematic analysis outlined by Braun and Clarke (2006) and these are discussed and applied to this research project in greater detail below (see Table 9, below). Although the steps are sequential, they are not completely linear or separate as I agree with Braun and Clarke's suggestion that coding is in fact recursive and develops over time (Braun & Clarke, 2014). Coding involves going back and forward over the data. The six phases are more of a recipe and starting point rather than a fixed series of steps. I found coding to be an active and reflexive process, and I was very aware of researcher influence/bias especially not just in identifying a theme but even in selecting a code and just trying to make sense of what someone was saying.

Table 9: Six Phases of Thematic Analysis Applied (Braun & Clarke, 2006)

1. Familiarising Myself with Data	<ul style="list-style-type: none"> <li>•Immersion in data, transcription</li> <li>•Re reading data and noting ideas</li> </ul>
2. Generating Initial codes	<ul style="list-style-type: none"> <li>•Initial coding of data extracts</li> <li>•Collating data to each code</li> </ul>
3. Generating Themes	<ul style="list-style-type: none"> <li>•Collating codes into themes</li> <li>•Gathering data relevant to each theme</li> </ul>
4. Reviewing Themes	<ul style="list-style-type: none"> <li>•Check if themes work with specific codes</li> <li>•Check if themes work with data corpus</li> <li>•Review data to look for other themes</li> <li>•Generate thematic map</li> </ul>
5. Defining and Naming Themes	<ul style="list-style-type: none"> <li>•Ongoing analysis to refine specifics of themes and the overall story</li> <li>•Generate definitions and names for themes</li> </ul>
6. Producing the Report	<ul style="list-style-type: none"> <li>•Select vivid extract examples</li> <li>•Tell the story and analysis of themes</li> <li>•Analytic narrative related to research question and literature review</li> </ul>

• Phase 1: Familiarising myself with the Data

I collected all the data myself. I transcribed the interviews verbatim and I also typed the long answer questions, reading and re reading the data. I also re-listened to the audio of

the 30 interviews. I took notes when an interview finished and before the next one began.

- Phase 2: Generating Initial Codes

Codes were identified by reading the full data corpus (interviews and long answer questions) line by line, segment by segment and selecting data extracts. Quite literally, I systematically read a line of data and then selected and copied a segment that I thought was making a point. Using NVivo (Version 12.0), I then pasted this segment into a coding tree and gave it a name e.g. ‘diagnosis experience’. I decided to use NVivo to manage the qualitative data as the use of the software made my analysis transparent and allows complex searches. However, I was also aware of the potential danger of software that could lead to the “use of frequency as an indicator of the salience of analytic themes” (Bryman & Beardsworth, 2006, p. 10).

One data extract could be coded in several sections if appropriate e.g.

‘a different outlook you know life is for livin and I don’t get bothered over little niggly, niggly things anymore’ Noreen.

This was coded as both a positive recovery driver and change in mindset. Codes of a similar theme were put in a group together e.g. anything that concerned coping with cancer was put under the broader name of Coping and then put in a subgroup under this in the appropriate section e.g. Coping – Anger. According to Braun and Clarke (2006), they suggest the actual themes are developed in Phase 3 but for my research I created some of the themes (broader categories) as I was also identifying the initial extracts to code. During this phase, I discarded one theme – that of Cancer Type, as I already had this information from the Demographic Question Sheet, so the information was already accounted for in the quantitative data.

With thematic analysis there is a debate as to when to engage with the literature (Braun & Clarke, 2006). Although I did some prior preliminary reading into cancer research and PostTraumatic Growth, this was very much in the background as I read through the qualitative data. Instead I took an inductive approach and created data driven codes and looked for as many different codes as possible. By using NVivo I could also include additional data before and after the extract selected to ensure I kept the context.



Unlike Hennink *et al.* (2017) who found that 50% of the core codes were established from the very first interview, I found that core codes only gained some stability after interview #4. After reviewing the researcher memos/notes I would estimate codebook saturation at interview #10. By interview #22, I met with my supervisor to discuss the fact that no new information/understanding was coming from the interviews. Hennink *et al.* (2017, p. 594) defines this as meaning saturation “the point when we fully understand issues, and when no further dimensions, nuances, or insights of issues can be found”.

By the end of Phase 2, I had 42 categories containing 346 codes (see Appendix 15: Thematic Analysis Phase 2 Open Coding (346 codes)).

#### • Phase 3: Generating Themes

A code is a building block for a theme. Similar codes are collated together. A theme is when the researcher names a pattern of meaning and it is unified by a central organising concept (Clarke & Braun, 2017). This stage is primarily about focusing on generating broader themes and sorting the codes into same. Its aim is to identify the key themes/sub themes and identify any thematic relationships.

I methodically read through each code individually to ensure that the data it contained fit the name. At times I needed to discard a quote if it did not fit or even move a quote to a different code where it had a better fit. By grouping similar codes together into categories, the data began to take shape or form. For example, any codes relating to beliefs were categorised together under the name ‘changes in beliefs’. I was very conscious and concerned that I wanted to develop themes and not domain summaries, so I kept asking myself ‘what is this data telling me?’ In this way, it gave me the freedom to put a code in several different categories if that was relevant.

As I was coding, I felt the weight of responsibility –I wanted to do the data justice. For me, this meant being thorough and inclusive of all data as well as checking and rechecking if I was capturing the essence of what the women had shared with me. By the end of Phase 3, I had identified 16 broad categories containing 497 nodes (see Table 10, overleaf).

For my research project I took an inductive approach to thematic analysis. The coding of the data line by line led to the creation of themes. Although I was aware of the model of PostTraumatic Growth and indeed the inventory, I wanted the themes to come from

the stories, the lived experience of the cancer survivors themselves and therefore the themes were data driven.

Table 10: Phase 3 Generating Themes

	Name	Files	References
1	Positive Recovery Driver	67	1150
2	Positive growth from cancer	66	986
3	Coping with cancer	64	791
4	Negative impact of cancer	62	518
5	Hindrance to recovery	63	427
6	Changes in Beliefs	57	323
7	Cancer View	35	200
8	Diagnosis	43	199
9	Advice for someone newly diagnosed	62	110
10	Treatment	34	100
11	Cancer cause	26	87
12	Self	24	41
13	Cancer support centre	18	29
14	Stories	19	29
15	Neutral Impact of having had cancer	9	16
16	Requests and Observations	7	10

#### • Phase 4: Reviewing Themes

As mentioned earlier, coding within a thematic analysis framework is an iterative and cyclical process. It needs to be both systematic and comprehensive. I again ‘cleaned up’ the data i.e. continued to group similar codes together and work on creating sub levels of codes e.g. Positive Recovery Driver – Proactive Behaviour – Dreams and Plans. As the categories developed, I was conscious that I wanted to create internal coherence and yet the category needed to be distinct from others (Braun & Clarke, 2013).

In Phases 2, 3 and 4, I generated semantic codes (also sometimes known as manifest codes). Within thematic analysis, (Braun & Clarke, 2006), there are semantic and latent codes, and these are on a continuum (rather than an either-or approach). Semantic codes capture the surface meaning of the participants experience and are derived from what the participant literally says. It was only in Phase 4 that I began searching for latent themes. These identify underlying ideas and assumptions under the codes and are

researcher led. It makes the researcher a cultural commentator. An example of latent codes is under the 'positive growth from cancer section', where any codes related to growth were categorised using the 5 Factors from the model of PTG. I was looking for shared concepts/meaning and was very aware that frequency did not mean importance i.e. that something could have saliency analysis (Braun & Clarke, 2018). This states that a code could be quite significant but appear very little in the data. An example of this from the research project is that only 3 people spoke of a loss of sex drive from having had cancer, but it was shared with such intensity and I do question if this is a topic that a participant may find difficult to share without being asked about it directly. Another example of a latent code is the theme of 'Cancer is an emotional roller-coaster' which looks at the dynamic of emotions freezing and unfreezing and how this impacted on how a participant experienced cancer and recovery.

Again, since thematic coding is an iterative process, I was still refining the themes – looking specifically at the codes to decide what needed to be discarded, reduced, increased or subdivided etc.

It was also during this phase that I created a series of thematic maps to create a full and complete image of the data. Initially I used NVivo as this kept the data behind the code names. However due to the high number of codes, it looked like a dense, overpopulated map that was difficult to read and impossible to print. In addition, there is limited scope in NVivo maps to add colour and design etc. Therefore, I switched to paper and marker versions using plain art paper that was approximately 6ft by 6ft in size.

The use of different coloured markers on the thematic map denotes different levels. This form of mapping was extremely useful in helping to get a great overview of the complete data set and to see the potential relationships between different codes. For example, for the theme of 'The Cancer Journey', I had originally identified 3 stages from the data – Diagnosis, Treatment and Recovery. However, when I created the large paper map, I then saw that 'Cancer Cause' was potentially a pre-stage for this theme.

Themes were established from patterning across the data and not frequency. The themes took time and reflection to develop and I found that I could only work on a theme for a short period and then move to another section of the thesis for a while before coming back again to the theme. I did not want to rush or force this process and believed that themes took time to develop/refine. Figure 6, below, is an example of a section of the

map that visually represents the different aspects of Positive Growth from Cancer. You can see below that red ink is used for the primary level and minor points on the next sub-level are in blue.

I used thematic analysis with critical realism (between essentialism and constructionism) “which acknowledge the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material and other limits of ‘reality’” (Braun & Clarke, 2006, p. 9).

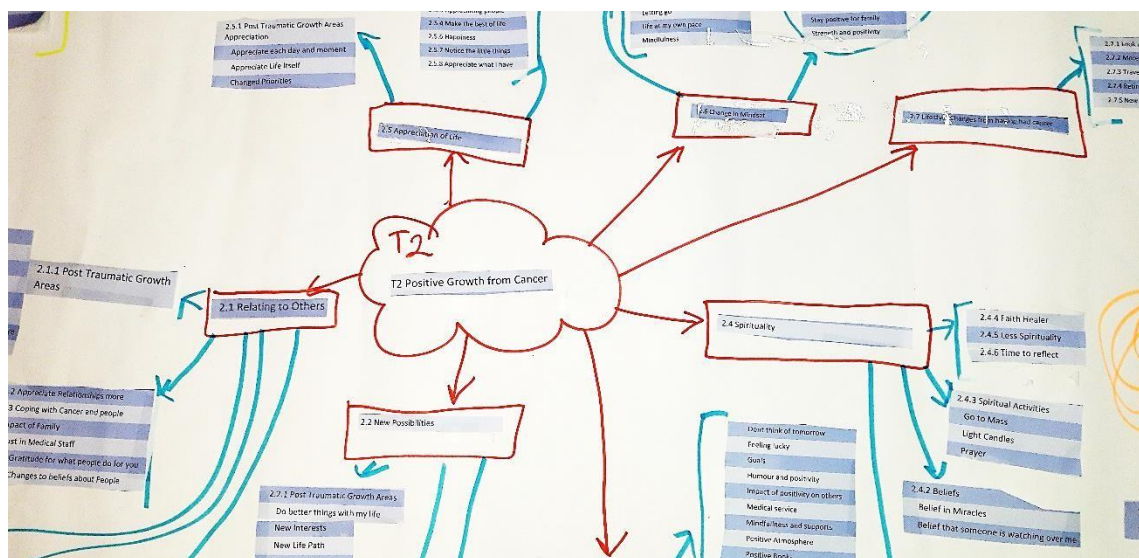


Figure 6: Thematic Map for T2 and Positive Growth from Cancer

At this phase, I went back to the literature to do a thorough exploration of thematic coding processes to ensure I was on the right track. I was especially concerned about creating themes (meaning pattern) and *not* domain summaries (all the data from a particular question). Also, at this point I was asking myself how the themes related to the full data set. I questioned how comprehensive the themes were in capturing the participants' experience of recovery. At this stage I had developed 4 key themes from the qualitative data which were; The Cancer Journey, Positive Growth from Cancer, Cancer Recovery as a socially embedded and collaborative experience and Cancer is an emotional roller-coaster. In addition, I was exploring how each of these themes fit or linked with each other.

#### • Phase 5: Defining and Naming Themes

At this phase of data analysis, I was again checking and refining the themes to ensure the data fit the theme. I also wanted to ensure that the name of the theme gave the central idea and boundary of that particular theme. At this point I was looking at sub themes for each of the 4 major themes to see if I could establish their structure and to see if there were any inter sub theme dynamics e.g. if there was any hierarchy. I wanted to see if there was anything interesting in the data and to understand if there was any consistency/inconsistency in the narrative of the theme i.e. how it all fit together. This was phase was a reminder that “The aim of TA is not simply to summarize the data content, but to identify, and interpret, key, but not necessarily all, features of the data, guided by the research question” (Braun & Clarke, 2017, p. 297).

#### • Phase 6: Producing the Report

In terms of using the data extracts, I wanted to ensure that I drew from a wide range of participants and not just a select few. I also wanted to include a few longer extracts or stories that give a more comprehensive insight into not just the lived experience of the participant but also acted as a window into the interview discussion/process and the kind of conversation/dynamic between the interviewee and myself. To ensure that the analysis was driven by my research questions, I structured the findings into 3 different chapters – each addressing a different research question.

For the quantitative data, descriptive analyses were conducted to examine the demographic characteristics of the sample (Age, location, cancer type/stage and if they had children etc). Descriptive statistical analysis as well as Principal Components Analysis was also used to examine the PTGI-42 data. IBM SPSS Version 24.0 was the software used to analyse the quantitative data.

### 3.7 Ethics

This research project was approved by the Ethics Committee of University of Leicester in August 2015. No other ethical approval process was required though I did explore several channels including; the Irish Cancer Society (ICS) and Limerick Institute of Technology, and I also investigated if there was an ethical procedural requirement from the Irish Government. From emails and a phone meeting with researcher Dr Sinéad Burke at the Irish Cancer Society, which would be the largest body involved in cancer research in Ireland, it was clear that they only seek to approve projects which they

themselves fund. Other cancer research studies are typically approved by the hospital or university in which it takes place. In terms of Limerick Institute of Technology, where I work, the ethics committee said that it only offered the ethical approval process primarily for students engaged in research and only for staff if such staff were doing research on the Institute's own student/staff body.

Surprisingly in Ireland there is still no national, governmental group that oversees cancer research but there are plans to address this in the medium to long term as outlined in the National Cancer Strategy 2017-2026.

- **Informed Consent**

Each of the cancer support centres who took part in the research project was given an Organisation Information Sheet which outlined the background and design of the research (see Appendix3). This sheet also explained how the data would be used, the steps taken to assure privacy, confidentiality and anonymity as well as a request for the Centre to provide counselling to the participant after they took part in the research if they requested it. The Organisation Information Sheet also clarified that an executive summary of the collated data from all the Support Centres would be given to each Centre if requested when the research process is complete.

In my meeting with each of the Centre Directors, I was very clear that they would not have access to the original data or even data that was specific to their Centre. This is to protect the anonymity of both the participants and the Centres as well. Each Centre was also given a copy of the interview questions and the PTGI-42. They then had an opportunity to seek further clarification on any aspect of the research and only then and if satisfied to take part, they were asked to read and sign the Organisation Informed Consent Form (see Appendix 5). By signing this form, they were agreeing to share information about the research to potential participants, provide the physical space to hold the interviews and to provide counselling to participants post research if needed. Even if an organisation signed the consent form, the consent form stated that they could still change their mind and withdraw at any time. I should also state here that each support centre was governed by a Board of Directors. The Director of each centre had to bring this research project to a Board meeting for approval before the Director could sign the Organisational Consent Form.

The Participant Information Sheet was distributed to participants by the Director of the cancer support centre one week before the interview/research session took place (see Participant Information Sheet, Appendix 9). This Information Sheet was also distributed again at the start of the actual research session and they were given time to read this and to ask questions. This sheet gave the research background, clarified what was being asked of them, let them know how their data would be used and that counselling support was available.

Participants were then given additional time to read and sign the consent form before taking part in the research (see Participant Informed Consent Form, Appendix 10). The documentation was very clear in terms of acknowledging the right of the participant to withdraw at any time and specifically stated in the Information Sheet that ‘You can still withdraw from the research after signing the form’. The Participant Informed Consent Form used tick boxes for clarity.

- **Privacy, Confidentiality and Anonymity**

The Consent Form for both the Organisation and the individual Participant gave assurances that all data would be kept private and confidential. All identifying information was removed and the data coded using a numerical label to anonymise it thereby protecting participants’ identity. The primary data were only seen by the principal researcher and potentially the 2 key supervisors. Any raw data used in the thesis or other publications are not attributable to a specific participant or cancer support centre. Hammersley and Traianou (2012) note the importance of publishing work, of publicity and of being accountable which creates a tension with the need to protect the privacy of participants/sources.

As stated earlier, identifiers were removed and as stated in the Information Sheets, even ‘Where a verbatim quote is used, it will be unattributable to an individual’. All soft copies of the data are kept in a secure folder that is password protected on my personal computer. Information stored on an external hard drive is also kept in a locked cabinet. Any interview audio recordings are also kept in this secure computer folder and were removed from the hand-held recording device within 6 hours of the interview taking place. In addition, the paper copies of the inventory and any other documentation is kept in a secure locked cabinet. The audio recordings and the

original inventory will be destroyed at the completion of the Doctoral process when the final thesis is approved.

The need to clarify the researcher role, and to provide a counselling option for participants, is particular to this research project and need to be outlined. The ethical approval process at the University of Leicester highlighted the importance of clarifying the relationship between the researcher and the cancer support centre. To address this, the Participant Information Sheet and the Participant Informed Consent Form both specifically stated that ‘The researcher is neither a volunteer nor a staff member of any cancer support centre and is not affiliated to them in any way.’ This clarification was also reiterated verbally at the beginning of the research session by the researcher.

Another significant ethical issue was the need to provide a counselling service to research participants. This was especially important for interview participants who were taking part in the one-to-one session. At the initial meeting with the Centre Directors, it was agreed that each Centre would provide counselling sessions to any research participant who requested it. There are a variety of counsellors who work with each of the cancer support centres on a voluntary basis, so the counselling would be free of charge to participants. These counsellors already have established relationships with the centres and have been vetted by them.

### **3.8 Limitations**

- **Multiple difficulties in accessing participants**

Perhaps the biggest limitation facing this research project is the challenge of accessing participants. It is well documented that there are people who have had cancer and who do not identify themselves as survivors (Kumar & Schapira, 2013). There may be difficulty in connecting with participants who have moved on and away from cancer. Within the cancer support centre sector, there seems to be an implicit norm that participants will use their services less (and are sometimes encouraged to do so) at 2 to 3 years after treatment which may be a barrier for recruitment. However, to offset this negative, after two years they may only have a minimal medical schedule and the goodwill that is typically evident between the cancer survivor and the support centre is a positive factor that would encourage someone to take part in the research.



A practical access issue is that cancer support centres typically open Mon-Fri, from 10am until 2pm. This creates potential difficulties for timetabling data collection. It also means that there are fewer cancer survivors who are back to work who can take part in the research.

The centre Director is the gatekeeper to the research participants, which was not part of the original research proposal. However, each centre Director requested this in the interest of protecting their clients. They also felt that some participants might have a willingness but not the emotional readiness to take part in the research. To reduce potential bias, the researcher needed to be clear as to the sample profile and the need for diversity i.e. with regards to age and socioeconomic status. Considerable time was spent in building relationships with the centres to establish their trust to ensure access to participants. In addition, there is also a concern that those survivors who are more active and in better health will take part (Jaehae & Min, 2014).

To account for the issue with access, one practical step I took was to completely open up my work timetable so that I was available to meet with the survivors any day or time and I had replacement cover at work. This meant that the centres set the timetable, not me. For any of the centres who did open in the evening, I was available to meet survivors who were back in employment. There is a possibility that some potential participants did not take part because they no longer see themselves as survivors, or perhaps were not well enough, but this is difficult to accurately measure.

- **Type of cancer determines treatment and therefore recovery experience**

Cancer is the term given to a category of illnesses which involves a lack of normal cell growth and in fact an overgrowth in cells that leads to tumours. There are over 200 types of cancer (malignant or benign) with various treatments ranging from radiotherapy, chemotherapy and hormonal treatment. Cancer patients can expect relapses and changes to the treatment programme over time (Irish Cancer Society, 2018c). The cancer type will impact on the type of treatment which will in turn impact on the experience of the recovery process. ‘Cancer type’ is not a factor in the participant profile but as a researcher I am aware that a potential overdominance of one type of cancer could skew results.

For this doctoral research, there was no restriction as to the type of cancer in terms of sampling criteria. For this sample of 67 female survivors, the participants had 15

different types of cancers. However, 70% of the women had had breast cancer. This dominance does mean that there is a likelihood that the findings may apply more to breast cancer survivors than other cancer groups.

- **Low racial representation**

Participants were recruited from 8 different cancer support centres. However, only one of these centres is in a city, so there is potential for the research to not fully represent different minority groups. This will need to be investigated as part of the research to ascertain the representativeness of the sample group to the wider population of Ireland. Another important consideration here is the profile of the client users for each of the Centres and how representative their users are in terms of different non-national backgrounds.

To increase the diversity of participants, each centre Director was asked to use 'diversity' as a criterion for identifying potential participants – i.e. to create a broad range of; ages, economic and ethnic backgrounds etc. The participant profile of this sample however showed that all of them were Irish Nationals except for two participants who were from the UK. Each of the centre Directors was asked if the research participants were representative of their client group and each responded 'yes'. Therefore, there are potential limitations with applying the findings of this study to other ethnic groups. However, this indicates a much larger issue of ethnic groups not accessing services.

- **Personal and cognitive skill level needed by participants to take part**

This type of research demands that participants have a certain degree of self-awareness to be able to reflect on how they have changed and how their experience of cancer has impacted on their lives. The research is based on the self-reporting by cancer survivors which could potentially result in misclassification bias in cancer and mental health status. Any data generated by self-reporting can lead to recall bias (Treanor *et al.*, 2013), however, this is an even more limiting factor given the cognitive impairment associated with cancer treatment such as chemotherapy.

- **Potential for demand characteristics bias**

In order to reduce the potential for bias in terms of demand characteristics, participants were informed (verbally and via the Participant Information Sheet – see Appendix 9) that the research was to explore their experience of cancer and recovery. During data

collection, the participants were not aware that a key research area was the study of positive growth from cancer. They were only informed that this was the research focus at the very end of the interview or group session.

The interview questions were also developed with an awareness of the potential for demand characteristics bias. The questions were exploratory in nature e.g. 'Tell me about your experience of cancer, wherever you would like to start' or 'How would you describe your recovery?' – I wanted to see if they would start with the positives or the negative aspects of their experience.

As the researcher, I was very aware of the potential for me to guide or influence how the participants might answer. I reassured the participants that they were the expert in their own story and that I just wanted to understand what they had experienced. In addition, I entered this research project with a genuine curiosity about what cancer recovery was really like. I did not set out to prove or disprove that positive growth happened nor to assess the PostTraumatic Growth Inventory as an instrument, but instead saw myself as a researcher explorer.

#### **4. Findings: Research Question One: What is PostTraumatic Growth (PTG) in the context of female cancer recovery?**

Based on the qualitative data, the cancer survivors of this doctoral research did experience positive growth in 6 key areas. Five of these areas correspond to each of the existing PTG Factors of Relating to Others, New Possibilities, Personal Strength, Spiritual Change and Appreciation of Life. The sixth and final new area of positive growth proposed from the qualitative data is a Proactive Mindset. The presentation and analysis of findings in this chapter is based on the qualitative data (30 interviews and 37 long answer questions).

From the qualitative data, there are 4 main themes and as examined in Chapter 3: Methodology, they were created inductively from the data using the 6 steps of Thematic Analysis (Braun and Clarke, 2006). The four main themes are;

- The cancer journey
- Positive growth from cancer
- Cancer recovery as a socially embedded and collaborative experience
- Cancer is an emotional roller-coaster.

The answer to research question one: *What is PostTraumatic Growth (PTG) in the context of female cancer recovery?* draws mainly from the major qualitative theme of 'Positive growth from cancer'. Please see Figure 7, below, for a thematic map of the main theme of Positive Growth and the 5 growth areas from the PTGI (Tedeschi & Calhoun, 2006).

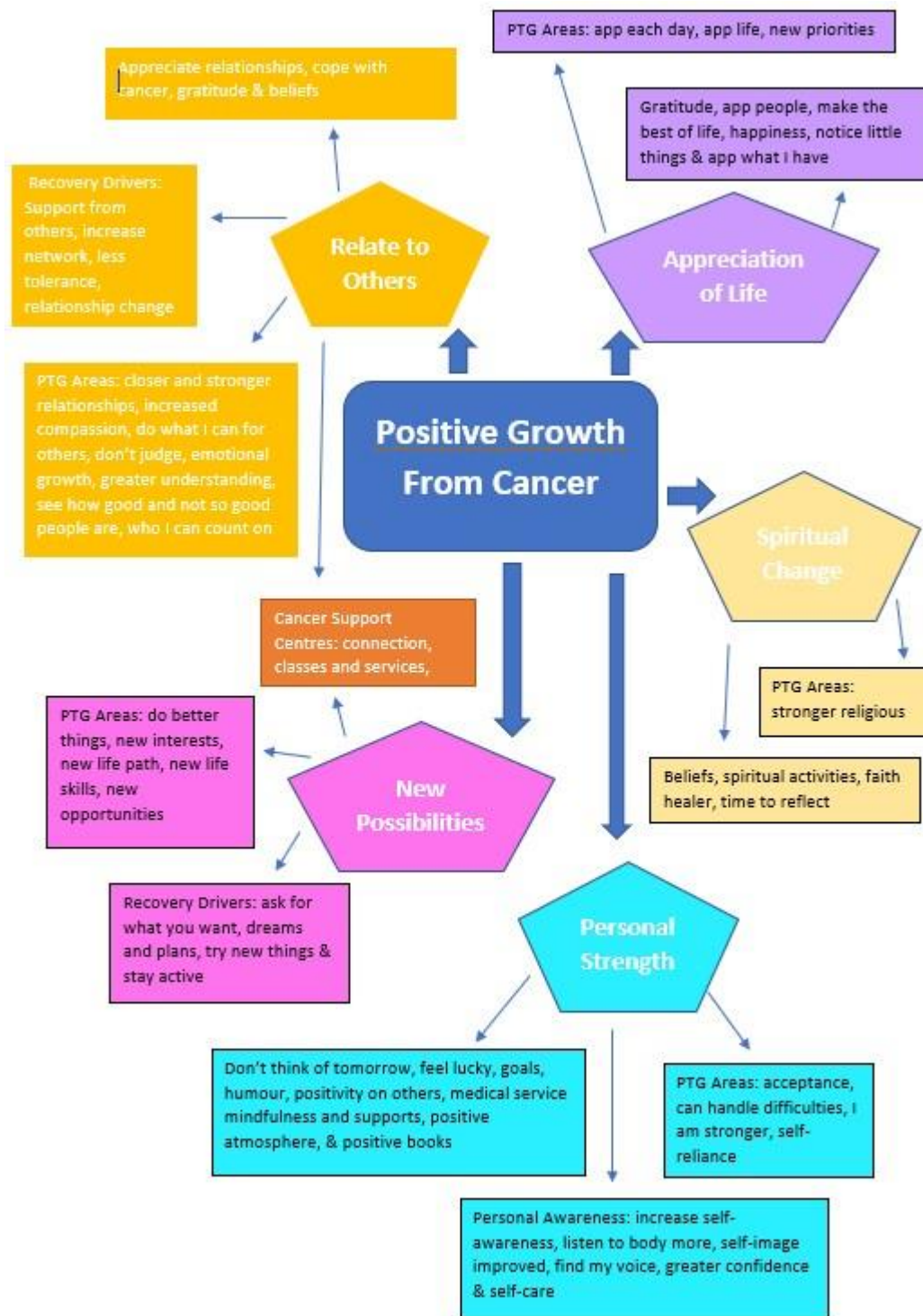


Figure 7: Thematic Map, Positive Growth from Cancer and 5 Factors

The other three qualitative themes will be addressed later in the Findings chapter 6. A complete summary of the four main qualitative themes is provided in Appendix 18. A thematic map for the 6<sup>th</sup> proposed new Factor of Proactive Mindset is included later in this chapter.

- Relating to Others is the most significant PostTraumatic Growth area

From the qualitative data, the most significant positive growth experienced by participants is in how they relate to others. This is consistent with the findings of Holtmaat *et al.* (2016), whose research with 74 head and neck cancer survivors also found the highest PTG levels in the ‘relating to others’ subscale, and several other studies found significant growth in Relating to Others (Balfe *et al.*, 2016; Shand *et al.*, 2015; Sharp *et al.*, 2018; Yi *et al.*, 2015).

For this doctoral research, survivors’ relationships were typically closer and stronger after having had cancer, and their social network underwent considerable change. This is supported by Shakespeare-Finch *et al.* (2013) who also found that relationships were stronger. The experience of having had cancer changed how participants viewed and related to other people by seeing relationships as important, and by talking more. This is supported by van der Spek *et al.* (2013) who found that survivors found a greater sense of meaning in their relationships. Iris speaks of the increased closeness with her husband since having had cancer because she feels she can be open and talk with him more now.

“he’s been a rock, he has been through everything with me, an we’ve survived d’you know we’ve come out of it stronger, stronger cause I can talk to him now about anything mm I don’t have to hold things back anymore, I can be more open with him mm if I feel unwell then he understands” Iris.

Many reported having greater empathy towards others – especially in terms of health-related matters. This increase in empathy and compassion was driven in part by their perceived greater understanding of other people. They also noted emotional growth; they now find they do not judge others, and they do what they can for other people. At the same time there was a significant reporting of less tolerance of others especially if the other person was being particularly ‘negative’ or complaining about something that the survivor no longer thinks is important. For Lucy, below as for other participants less tolerance in part comes from facing mortality and the realisation that life is short.

“Ye I have changed mm there is no doubt at all about that I, I take very little nonsense from people aha... aha I’m not as tolerant as I was mm because to me life is too short now... that has that what it taught me is that I’m, the shock is realising that you’re not here forever because we all think we’re here forever” Lucy.

For many of the participants, having cancer helped them to see who their friends really were and who they needed to let go of. They were more selective about who they spent time with. The change in their social network was driven by two underlying mechanisms regarding how they now saw people as ‘good’ and ‘not so good’ as well as the increase in compassion coupled with less tolerance. Sarah below describes the change to her social network quite clearly:

“It made me found out like about people a, about how, how, how can I say... the good people in my life that were really supportive of me, it weeded them all out, that the good people that, that were in my life an they were good an the others that weren’t. So I kinda dropped the people that weren’t” Sarah.

Participants reported much greater compassion, especially if the other person was going through a difficult time or illness. This compassion was driven by a perceived greater understanding of other people as well as increased emotional growth with less judgement of others. Bree speaks of knowing how others feel now by just looking at them:

“ye’d have a little bit more understanding though of what people is going through... what way they’re feelin an all, you’d have a bit more understandin like that when you’d see people sick and.. you’d know exactly what they’re, how they’re feelin, you’d nearly know by lookin at them” Bree.

The changing nature of the survivor relationships is echoed by Goodhart and Atkins (2013) who emphasize the importance of renegotiating relationships in recovery. Participants experienced significant expansion of their social network especially with regards to meeting and connecting with other survivors or support groups and this was driven by the support centres. By connecting with these groups, they felt a strong connection that they were understood and, for some people like Iris, it gave them hope that they would get better.

“I had saw people here that I could talk too, who’d been through it maybe nine or ten years past, I could see some people that were a survivor of it so it kind of gave me the hope that I would hopefully get through the next few months” Iris.

As survivors experienced their health improving, they wanted to ‘give back’ and support other survivors thereby becoming role models for others (Tedeschi *et al.*, 2018b; Threader & McCormack, 2015). In fact, the participants of this research cited

Helping Others as one of the key positive drivers of their own recovery – that giving back to others (one-to-one listening or fundraising etc.) gave them an emotional lift and sense of purpose. Shakespeare-Finch *et al.* in their research cited how participants were now “being more giving of themselves” and that this was an area of growth not captured by the inventory (2013, p. 585). Threader and McCormack (2015) found that this desire to help others was borne from being helped by others themselves as well as increased compassion. Shakespeare-Finch *et al.* (2013) also found that participants were more giving of themselves and recognised this as an area of growth not captured by the PTGI.

‘Friends’ were the main source of social support for participants. This finding is consistent with the research by Hasson-Ohayon *et al.* (2016) which highlights the importance of friends and the “lack of association between spousal support and all PTG dimensions” (p. 390). They suggest that perhaps the spouse is experiencing their own stress or perhaps they just do not have that kind of discussion that promotes PTG. This doctoral research supports that view. This finding contrasts with other research which supports the importance of spousal support (Romeo *et al.*, 2017; Moss & Harding, 2018). However, for this doctoral research, participants turned to close friends, then peer survivors followed by medical staff and family for social support (in that order). The research by Fox *et al.* (2014) also found higher PTG levels with participants who had a strong friend network.

The importance of relationships with others is reinforced by the fact that participants identified ‘support from others’ as the main positive recovery driver. Its importance is also underscored by the fact that social isolation/lack of support was also identified by participants as one of the major hindrances to their recovery. From the PTG literature social support is essential for PTG but there is a call for further studies to better understand the complexity of the relationship between social support and PTG (Joseph, 2014).

Figure 8, overleaf, is an image from the Dear Diary project which illustrates how important it was for a survivor to get a call from someone asking how they were rather than a text. The Dear Diary project is an art installation which emerged from this doctoral research (Reference Appendix 1: Dear Diary, for an overview of this project).





Figure 8: Dear Diary: The importance of a phone call

- Significant impact of social support on survivor recovery

There is considerable evidence in the literature that the higher the social support a person has, then the higher PTG they will experience (Balfe *et al.*, 2016; Holtmaat *et al.*, 2016; Sharp *et al.*, 2018; Yi *et al.*, 2015). People around the cancer survivor can motivate and encourage growth by providing comfort and a safe place to discuss and therefore process the trauma. This support facilitates cognitive processing and deliberate rumination which is necessary for PTG to occur (Joseph, 2014; Koutrouli *et al.*, 2016; Nelson *et al.*, 2014).

Self-disclosure/sharing also helps the development of social support. In fact, “Social support may affect PTG as a pre-trauma factor or predictor variable” (Tedeschi *et al.*, 2018b, p. 51). This suggests that having or even perceiving a strong social network prior to the trauma will help people cope and may increase the level of PTG.

Frydenberg (2014) also emphasises the importance of the social system as a resource to help the person proactively cope. High social support means better self-esteem, less depression and better general health for survivors (Roland *et al.*, 2013). In fact, because of the importance of social support, if it is low then Roland *et al.* (2013) suggest that the survivor is provided with professional supports like counselling etc.

The research by Svetina and Nastran (2012) found that not just the presence of social support alone that increased PTG but rather the quality/communication and extent of emotional support that they provided. Their research explored whether “family processes and outcomes such as family flexibility, cohesion, communication and satisfaction predict PTG” (p. 299).

Communication contributed positively to PTG but satisfaction contributed negatively. It suggests that the presence of family members is not enough, but we need to take account of the quality of communication i.e. emotional support rather than instrumental support that impacts on PTG levels. It is this perceived quality of the social environment if positive then contributes to better adjustment but likewise if there are social constraints then this is detrimental to their health and well-being (Green *et al.*, 2013). For the participants of this research, they highlighted the importance of accessing and accepting all help as well as asking for what you want which Stella reinforces:

“Ask for help, accept all offers of help, talk to someone outside your family and friends circle, it’s so important to be emotionally supported” Stella.

Hasson-Ohayon *et al.* (2016) suggest that ‘cognitive support’ (information provision) as opposed to emotional or instrumental support is an important contributor to PTG. They found that this new knowledge may help in the cognitive reappraisal that is necessary for growth to take place. The support centres provide this type of support in the form of information sessions regarding stress management etc. but for this doctoral research emotional support/connection was of much greater significance.

The more a survivor engages in positive cognitive reconstruction and adaptive coping, the greater the level of PTG they will experience (Cao *et al.*, 2018; Joen *et al.*, 2015; Rogan *et al.*, 2013; Shand *et al.*, 2015). Relationships help the survivor to positively appraise the situation and to develop a positive identity, both of which impact on PTG levels (Grace *et al.*, 2015, Cao *et al.*, 2018).

For this doctoral research, support from others impacted on the type of recovery strategies that participants used e.g. the emphasis on ‘positivity’ led to a focus on thinking positively and surrounding yourself with positive people. Joseph (2014) highlights how higher levels of social support predict high levels of adaptive coping including how the emphasis on positivity by survivors encourages this positivity with their peers. Nelson *et al.* (2014) also found that “Increasing cancer survivors’ self-efficacies in accepting cancer/maintaining a positive attitude, affective regulation, and seeking support may improve cancer survivors’ QoL” (p. 629). Self-efficacy helps a person to adjust to having cancer.

For many of the participants, they noted that several channels of different social support positively impacted their recovery. The framed image from the Dear Diary project

below (Figure 9) illustrates this point. It is a visual portrayal of specific people and events that helped Laura to recover. It highlights spiritual help in the form of holy water, a visit from a friar, and people in heaven looking out for her. It was a friend who had arranged for the friar to visit and give a blessing. She specifically mentions medical support in the form of surgery. The image of the rose at the centre of this piece was created by the artist Sheila Wood who noticed that when you looked at a microscopic view of a breast cancer cell it had a striking resemblance to a rose. The rose/cancer is very prominent in this art piece – both in size and position to illustrate how several channels of support helped Laura to recover from cancer.

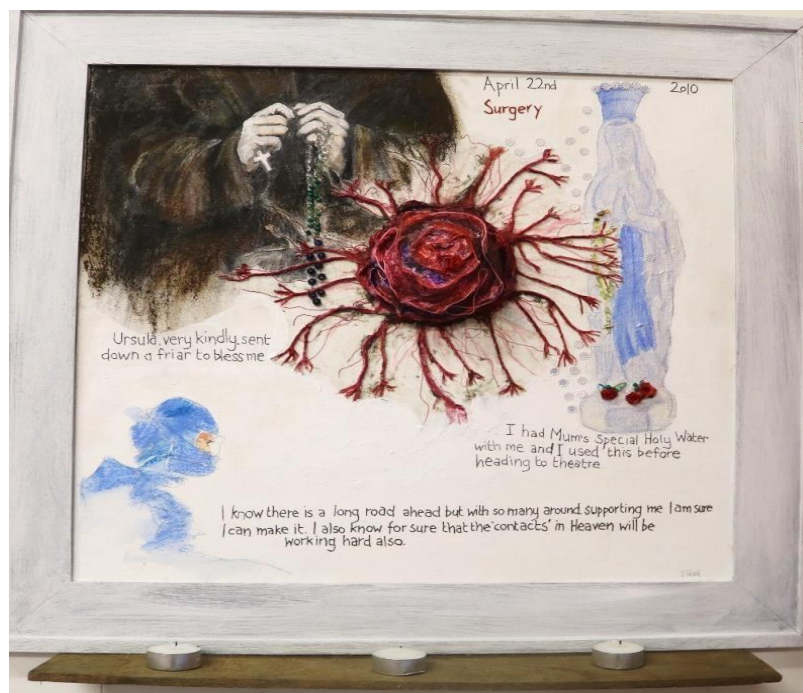


Figure 9: Dear Diary: Support from Others

- Significant growth in New Possibilities were local and social

New interests were typically local, social and enjoyable. They took the form of hobbies, classes and travel including; art classes, meditation and hill walking. This contrasts with the stereotype of survivors making radical life changes e.g. complete change of lifestyle or starting a 'new' life. Instead, it was about developing hobbies and habits that made them feel good e.g. gardening. Many participants like Jessica below now travel more and think of themselves as doing better things with their lives.

“An we definitely go on foreign holidays now, far more breaks you know. We were in... mm... Austria our X anniversary an we went to Austria with another couple in June, we went away, did part of the Camino in July, that’s our third time doin that so since that happened” Jessica.

The new interests were facilitated and encouraged by the free services provided by the support centres. It was also driven by the recovery strategies of ‘stay active’ and ‘dreams and plans’ where being busy and setting goals encouraged participants to try something new. Participants noted the importance of setting and focusing on positive goals that you want to achieve as a recovery strategy. Mira experienced cancer as a threat to her life that now acts as a force for her to set and achieve goals.

“like I did a bucket test before I was fifty, all the things I wanted to do. So I’m getting another lot together now before I’m sixty, an they’re goin to be a hell of a lot different than the six, the ten things that I wanted ta do then to the ten things that I want to do now, and I think that those two life threatening illnesses has definitely put a whole new gloss or glow” Mira.

Goals were often ‘small’ such as making dinner or attending a child’s football match and were as Kumar and Schapira (2013) described it – a quest for normalcy.

- **Increased Personal Strength with more self-awareness and greater confidence**

Participants felt stronger from having survived cancer and the cancer treatment. The phrase ‘I feel stronger’ was frequently used. This is consistent with the PTG Model which states that *strength* is achieved through suffering (Tedeschi *et al.*, 2018). By crediting themselves for their recovery, they feel greater self-reliance – that they can better handle any future difficulties especially since any future problems seem smaller and more manageable than dealing with cancer. Ingrid sums this up quite well.

“of course I’ve been hurt people have hurt me an they will hurt me into the future... but oh I’ll get over it you know and I just think of really you would think of all you’ve been through an you’d say, how big a deal is this anyway... and ye I suppose if anything the cancer taught me that, that nothing is a big deal anymore” Ingrid.

This new-found personal strength is positively correlated with greater confidence. For example, by feeling stronger, there is more confidence to speak up, care less about what others think and try new things. Some participants described this as ‘finding their

voice’. Iris talks about how before cancer, she would not have been confident enough to talk with someone on a one to one basis and would have put her own ideas down, but this has now changed.

“my confidence has come out, I wouldn’t be able to do this before... I wouldn’t be able to talk to somebody on a one to one... I’d be too shy. I’d be the one that stood back and let everybody else kind of talk in front of me, and if I thought I had an idea I’d think it might be a silly idea and if you say it you, you’d look stupid so don’t say it at all” Iris.

Shakespeare-Finch *et al.* (2013) also noted that survivors expressed themselves more. In addition, participants highlighted that they are more self-aware in terms of being able to know and name how they feel/think/behave. Along with self-awareness, participants also spoke of how they now prioritise themselves more with several survivors (like Sarah) using the phrase of ‘put myself first’.

“I think of just myself in a sense that I do think of my children like. And I’d be good and kind to them but I put myself first as well... kinda thing, always used to put myself last, sometimes do now, but I check myself” Sarah.

- **Spiritual Change dichotomy from no growth to considerable change**

For the participants of this doctoral research there was a split between those who had no spiritual change compared with those who had a great deal of change. For participants who did experience significant spiritual change, it was borne from the struggle with their faith caused by having cancer e.g. from being angry with and questioning God and some like Emma below, even saying that they lost and then found their faith again.

“when I got the diagnosis first, I was saying oh my god why is this happening to me... And why is the man above doing it, whatever, I was always trying to live my life used to go to mass, we most of the time got the children to mass. Always and ever up to the time they got up to a certain age and beliefs were strong. And then when I got the diagnosis you know is there any god there?” Emma.

Tedeschi *et al.* (2018b) and Shand *et al.* (2015) state that PTG levels are higher for those who participate in religion. This is because having cancer could challenge your beliefs and therefore trigger the cognitive processing needed for PTG to occur. In addition, a strong religious belief can help with coping, finding meaning and increasing the social network (Roland *et al.*, 2013).

For Linley and Joseph (2011) it is the presence of meaning which is associated with higher levels of positive growth from trauma. From this doctoral research, the experience of cancer did cause participants to question their beliefs and for some it provided a way to make sense and cope with the experience. Some studies do not identify any PTG in spiritual change such as Shakespeare-Finch *et al.* (2013).

Considering the dichotomy of participant results in spiritual change, I do not believe that it was religiosity that led to the generally high levels of PTG but would point more to a value change and increase in social network via the cancer support centres.

Spirituality found physical expression in prayer, going to mass and lighting candles. ‘Prayer’ was the most important activity and Bree even credits her recovery to prayer.

“I do believe because the prognosis wouldn’t have been good... so ye I do believe prayer got me through. Really if I was ta ask you what cure aha, I’d say prayer... Prayer got me through” Bree.

Vonarx and Hyppolite (2014) interviewed cancer patients to explore the impact of their religion/spirituality. They found that spirituality provided a role in individual empowerment – that spiritual activity provided a channel through which they sought hope, self-mastery and individual empowerment. The importance of rituals in this study also took on this function. By actively taking part in spiritual rituals e.g. lighting candles, they were actively doing something to get well (Vonarx & Hyppolite, 2014).

Many took comfort from the sense that ‘someone’ was watching over them – be it God, or a higher power, a deceased relative or an angel. Some participants reported feeling or sensing this other presence as is evident in the story below of Iris who describes meeting her personal angel.

“I seriously believe in them, (Angels) I seriously... mm have thought in myself that they are all around me, they are constantly guiding and protecting me an I swear I was seeing something mm... don’t know what it was but I’ve seen something mm... during the time I’ve been at home an I’ve been laying in bed an then feeling really sorry for myself an feeling really upset an thinking about mm... the Angels, thinking about prayer an... it was really strange because I have this lamp in my in the middle of my room, mm an all the curtains were closed... It was really strange it was all closed an it was dark, but there was a, a glow very strange but there was a glow an I saw yellows and purples an I could see these flashes of yellows and

purples all over the place. An to me that was that was my Angels... I thought, oh ye they've come to help" Iris.

Though there was a dichotomy in terms of how much spiritual change participants experienced, what they did have in common was that the majority preferred the term 'spiritual' rather than 'religion'. Vachon (2008) identifies the difficulty in defining spirituality and religion. Spirituality was a sense of connectedness with God or nature etc. (Vachon, 2008; Shakespeare-Finch *et al.*, 2013), whereas religion is concerned with values, beliefs and rituals.

- **New Appreciation of Life means new priorities and a desire to 'make the best out of life'**

The experience of cancer meant that participants reflected on the meaning and the way in which they live their lives. This led them to re-evaluate and re prioritise what is important which is consistent with the study by Shakespeare-Finch *et al.* (2013) that cited this change in values as a major shift. Participants reported 'I realise what is important' and spoke of a change in values which meant less stress and appreciating their health and other people more. Rose echoes what many participants referred to which was about learning what really matters.

"It has been an interesting journey. An experience I wouldn't swap, and I wouldn't wish on anyone. Because of the experience, I learned a lot about myself and the meaning of life, put value on what really matters" Rose.

Participants feel a new sense of gratitude and Joseph (2014) comments that further research is needed to investigate if this is a personality predictor of growth. This new appreciation is about noticing 'the little things', feeling grateful for and making the best of life. For some, it has led to a lasting feeling of happiness. Ingrid exemplifies this awareness of and enjoyment of the little things in life which is underpinned by a desire to live in the present.

"My family life was happy you know the usual up and downs but mm now I am at the happiest I ever was in my life, hand on my heart... I sat out today in the sunshine an I just ah... you could thank God for the sunshine, the beautiful day and the simple things make me very happy" Ingrid.

The growth in appreciation of life is in part due to facing mortality and acknowledging how short life really is. As Sally succinctly describes:



“Life is for living and I have more of a sense of how precious life is” Sally

- **Proactive Mindset is the new Sixth Growth Factor**

The discussion thus far has highlighted the findings which mapped quite easily to the 5 areas of growth that are predefined by the PTG model. In my opinion there is a sixth and highly significant growth area which is a Proactive Mindset, as depicted in Figure 10, below. This factor consists of positive attitudinal and cognitive changes as a result from having had cancer.

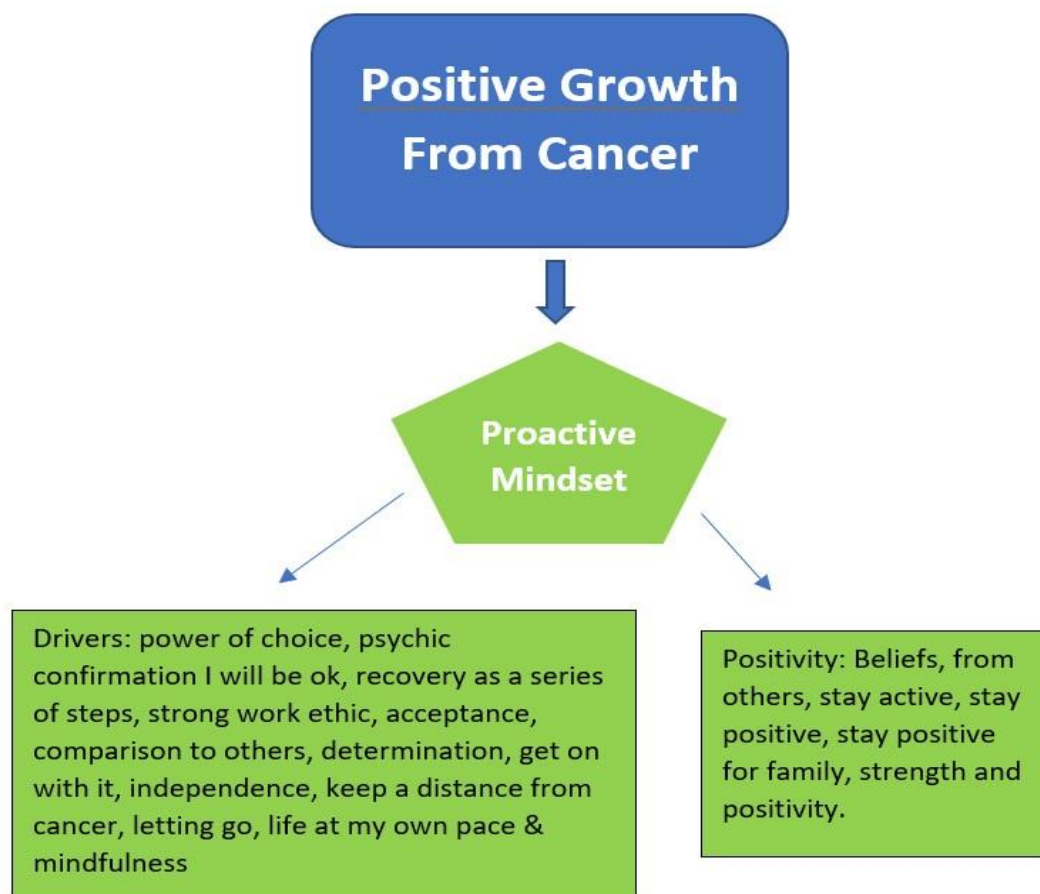


Figure 10: Thematic Map for Positive Growth from Cancer and 6th Factor Proactive Mindset

Participants repeatedly used the phrase ‘get on with it’ when referring to how they dealt with cancer, managed fears of recurrence and general approach to life. For Orla, and many others, it was about doing what you need to do and moving on as a way of coping with the experience.



“Do what needs to be done, surgery, treatment. Move on and get a better life for yourself. Don’t let it define you and your future” Orla.

For other participants like Sandra, getting on with it was motivated by the quest for normalcy (Kumar & Schapira, 2013), driven by a desire to make things normal for others.

“I just kept pluggin away and try to make things as normal as possible for everyone round me” Sandra.

‘Stay positive’ was the mantra for wellness and seen as an important recovery driver by participants. Positivity was fuelled by setting goals and feeling lucky to be alive.

Participants spoke at length of goals that they had – whether that was making the dinner each day, going to a family wedding or even reaching a mountain top. These goals gave them something positive to focus on/aim for. At times, the drive to achieve these goals came from the determination to beat cancer, as Josie explains below.

“...never left you know the treatment, anything stand in my way you know... I just said I’ll do this now for the year an I’ll just, at the beginning I said listen it’s goin to take a year here an this is my year you know... an nobody else’s” Josie.

Positivity was both a consequence from having dealt with cancer and a way of dealing with it. Treanor and Donnelly (2016) found that participants who had a positive outlook managed late effects better and so they suggest initiatives to encourage positive thinking. In fact, higher optimism levels mean greater adjustment whereas lower levels are correlated with depression (Hoffman *et al.*, 2012). When asked what advice you would give to someone recently diagnosed one of the top two most common answers was to ‘stay positive’. For Rose, it was not just about staying positive but also about looking ahead.

“Stay positive, don’t panic, there is a life after cancer” Rose.

Dunne *et al.* (2017) advocate for inclusion of positive appraisal and seeking normality as a self-management strategy to aid recovery which is consistent with the findings of this research project. They found that maintaining a positive outlook was a significant strategy that participants used to help them manage their experience. Positive self-talk contributes to PTG (Sharp *et al.*, 2018). Hoffman *et al.* (2013, p. 253) also found that “positive changes such as positive reappraisal and goal reengagement were related to

greater positive affect, whereas negative changes (e.g. avoidant coping) were related to both greater negative affect and less positive affect”.

Participants positively positioned their cancer experience by using downward social comparison to compare themselves to others who were considered ‘worse off’. For example, by comparing themselves to those who had died, or who had worse treatment side effects, more severe treatment or who were much younger or who had children/young children or who had a ‘worse’ cancer etc. (and in that order).

Treanor and Donnelly (2016) noted the downward comparison that survivors made which had a positive effect on their emotions in that they felt lucky or thankful. Shakespeare-Finch *et al.* (2013) also highlighted that participants compared themselves to others which helped them increase appreciation for what they do have. This downward comparison is a way to make sense of and ‘draw value’ from the cancer experience (Grace *et al.*, 2015). Jessica felt she had ‘nothing’ compared to those who died from cancer.

“different women here had died like you people that were here an people die...an you think say to yourself, Jesus it could be me. An then you think well what I had was nothing compared to what they had” Jessica.

The high prevalence of the focus on positivity by participants does suggest a need to explore optimism levels to establish if personality is impacting on PTG levels. In 2015, Yi *et al.* and Shand *et al.* found that optimism is positively related to PTG. In fact, Yi *et al.* (2015) also stated it was a protective cognitive strategy. Hoffman *et al.* (2012) showed that higher optimism meant greater adjustment to the trauma. This warrants further investigation in future research and it would be interesting to measure optimism levels to better understand if there is a correlation/relationship with PTG results.

Table 11 overleaf, provides an overview of ‘Positive Growth from Cancer’ from the qualitative data.

Table 11: Positive Growth from Cancer from qualitative data.

<b>Positive Growth from Cancer</b> <b>(5 Factors of growth from the PTG model, plus sixth is a Change in Mindset) and all its sub themes</b>	
Relating to Others	Relationships are closer and stronger Support is the most significant recovery driver Learning how 'good' or 'not so good' people are Increased compassion and less tolerance
New Possibilities	Significant increase in new interests driven by Support Centres Survival strategies of 'stay active' and 'dreams and plans' as motivation to try something new
Personal Strength	I am stronger Increased self-reliance and can better handle difficulties Increased strength positively correlated with increased confidence Increase in self-awareness and 'put myself first'
Spiritual Change	'Spiritual' rather than religious change Spiritual growth borne of struggle with faith Spirituality expressed in prayer, going to mass and lighting candles Comfort from someone watching over me
Appreciation of Life	I realise what is important I value less stress, my health and other people more Increased awareness and enjoyment of the 'little things' Appreciate each day and life itself Make the best out of life I am grateful
Change in Mindset	Get on with it Stay Positive Positive Positioning of cancer

## **5. Findings: Research Question Two: To what extent does the PostTraumatic Growth Inventory effectively capture Irish women's experience of cancer recovery?**

The purpose of this chapter is to open up and explore the PostTraumatic Growth Inventory data. The quantitative data consists of the 66 completed PostTraumatic Growth Inventories – 67 participants completed the inventory, but 1 inventory was incomplete and therefore not included. This chapter concludes with a discussion of some of the key issues from using the PTGI as a research instrument with the cancer survivor population.

- **Reasonably good internal reliability with a high Cronbach's alpha ( $\alpha = .85$ )**

For Shakespeare-Finch *et al.* (2013, p. 575), “the internal consistency of the PTGI is strong ( $\alpha = .90$ )”.

This doctoral study showed reasonably good internal reliability (21 items,  $\alpha = .85$ ). This score remained relatively consistent when the Cronbach's alpha with each item deleted was tested. For a list of the Cronbach's alpha for each of the 5 areas of growth, reference Table 13, containing the study participant's statistics for each of the 5 Factors of growth, located in the next section.

The reasonably good internal reliability for this study is also consistent with other studies such as; Cann *et al.* (2010) who found  $\alpha = .94$ , and Koutrouli *et al.* (2016) where  $\alpha = .95$ .

- **High mean PTG level at 77 for cancer survivors**

From a sample of 66 participants, the mean PTG level was 77. This score was calculated by adding each of the individual responses of participants (5021) and dividing it by 66. Since there were 21 items with a maximum of 5 points each, the potential maximum score is 105. Reference Figure 11, below, for a histogram of the individual mean PostTraumatic Growth scores.

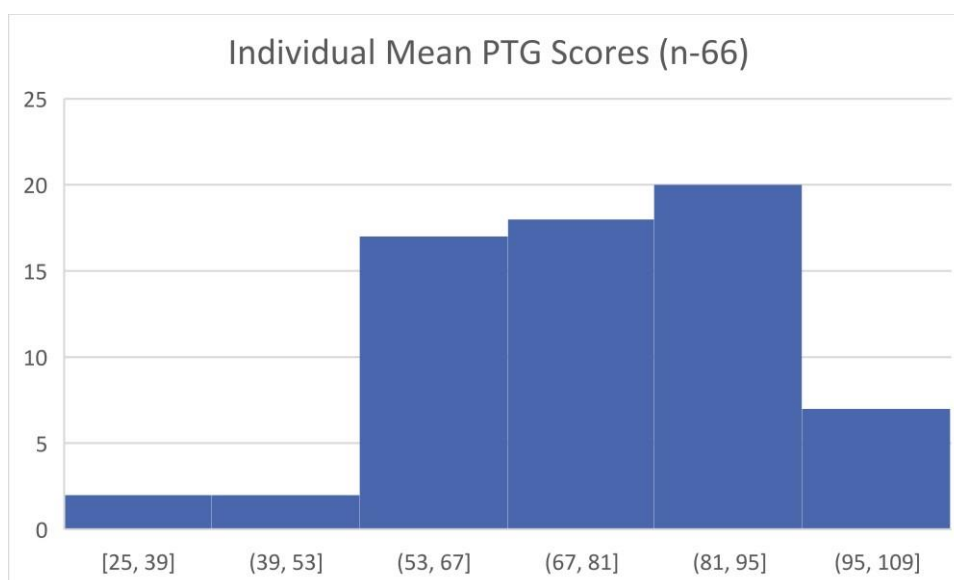


Figure 11: Histogram of the Individual Mean PostTraumatic Growth Scores

The mean PTG level at 77 is relatively high given that other research like, for example, Joen *et al.* (2015), determine a high score to be 64+. To put this mean growth score in context, please see Table 12 below for a list of PTG research projects in recent years and their mean PTGI scores. For some researchers, PTG was established using methods other than mean scores. For example, for Jin *et al.* (2014), anything above the 75<sup>th</sup> percentile was considered to indicate the existence of positive growth. In a recent study by Sharp *et al.* (2018), they used tertiles, where PTG levels were classed as low <49, intermediate as 49-70 and a high PTG score is >70.

It is important to note here that this research sample is atypical. All of the participants are current or former clients of a Cancer Centre. One of the core functions of these Centres is to provide a safe space where participants can discuss and be supported in their recovery. The fact that the research participants have availed of the Centre supports may have contributed to higher Mean PTGI scores.

Table 12: List of PTG Research Projects undertaken in Recent Years, and their Mean PTGI scores

Research	Year	PTG Mean
Sharp <i>et al.</i>	2018	56
Romeo <i>et al.</i>	2017	54
Koutrouli <i>et al.</i>	2016	67
Jaehee and Min	2014	63
Shakespeare-Finch <i>et al.</i>	2013	57
Cann <i>et al.</i>	2010	52

- Analysis of each of the 5 Factors

If we look at Table 13, below, and the statistics for each of the 5 Factors of growth, Factor V: Appreciation of Life has the highest growth level. The next area of growth is Factor I: Relating to Others which is closely followed by Factor III: Personal Strength. The fourth area of growth is Factor II: New Possibilities and the least area of growth is in Factor IV: Spiritual Change.

Table 13: Study Participants' Statistics for each of the 5 Factors of growth

		5 Factors of Growth				
Statistics		Relate to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation of Life
N	Valid	65	65	66	66	66
	Missing	2	2	1	1	1
Mean		27.45	16.74	15.36	4.85	11.97
Median		29.00	17.00	16.00	5.00	13.00
Mode		35.00	17.00	17.00	0.00	15.00
Cronbach's Alpha		.79	.79	.56	.71	.59
Std. Deviation		5.93	5.62	3.53	3.56	3.02
Possible Minimum		0	0	0	0	0
Possible Maximum		35.00	25.00	20.00	10.00	15.00
Actual Minimum		9.00	3.00	6.00	0.00	3.00
Actual Maximum		35.00	25.00	20.00	10.00	15.00
Percentiles	25	24.00	12.50	13.75	1.75	10.00
	50	29.00	17.00	16.00	5.00	13.00
	75	31.00	21.00	18.00	8.00	15.00

The data for each of the 5 Factors are all negatively skewed and are now examined individually:

- **Appreciation of Life:**

Of the 5 Factors or areas of growth, the highest reported growth for this sample of cancer survivors is Appreciation of Life where  $m=12$  which is relatively high given the possible maximum score is 15. The data is negatively skewed, the median = 13 and the IQR(10,15), as depicted in Figure 12, below. It contains 3 items with a maximum score of 15.

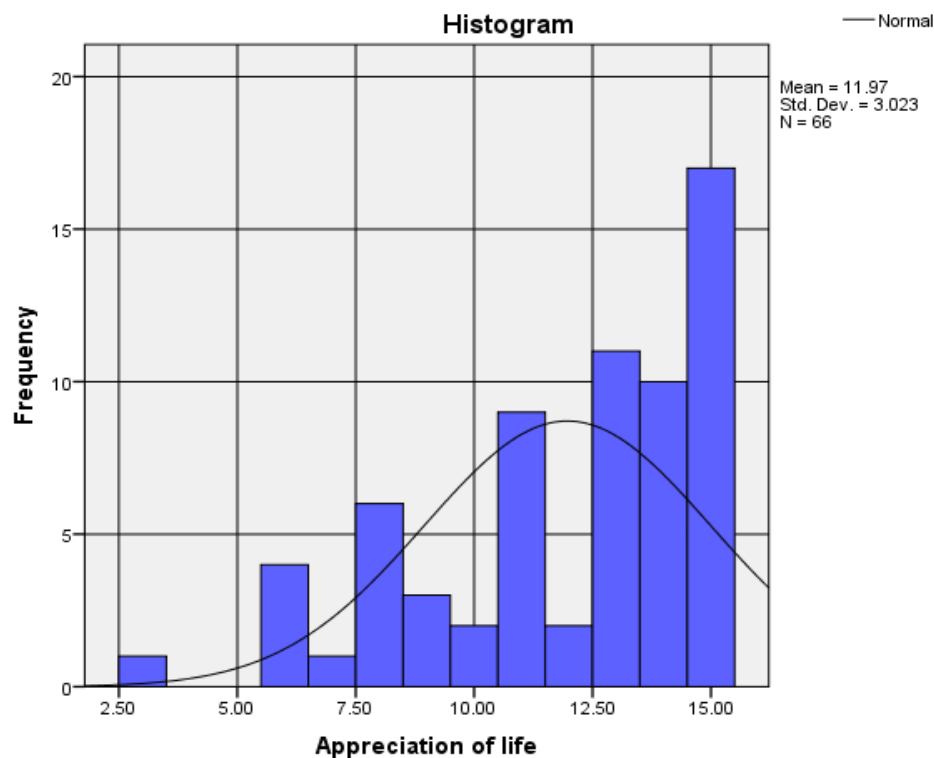


Figure 12: 5 Factors of Growth: Study Participants' Responses – Appreciation of Life

The most significant growth in this section concerns the high number of participants who now better appreciate each day since having had cancer (91%). They had a greater appreciation/value of their own life (87%). In addition, 81% of participants said that they had now changed their priorities about what is important in life, as can be seen in Table 14, overleaf.

Table 14: 'I changed my priorities about what is important about life' and cumulative frequency

<b>I changed my priorities about what is important about life (n=66)</b>	<b>Responses – Percent</b>
I did not experience this change as a result of my crisis	4.5
I experienced this change to a very small degree as a result of my crisis	7.5
I experienced this change to a moderate degree as a result of my crisis	6.0
I experienced this change to a great degree as a result of my crisis.	17.9
I experienced this change to a very great degree as a result of my crisis.	20.9
Total	41.8
Missing	1.0
<b>TOTAL</b>	<b>100.0</b>

- Relating to Others

As can be seen by the histogram for Relating to Others (see Figure 13 overleaf), the data is negatively skewed. The median= 29 and the IQR(24,31). It contains 7 items with a maximum score of 35. M= 27 with a possible maximum score of 35.

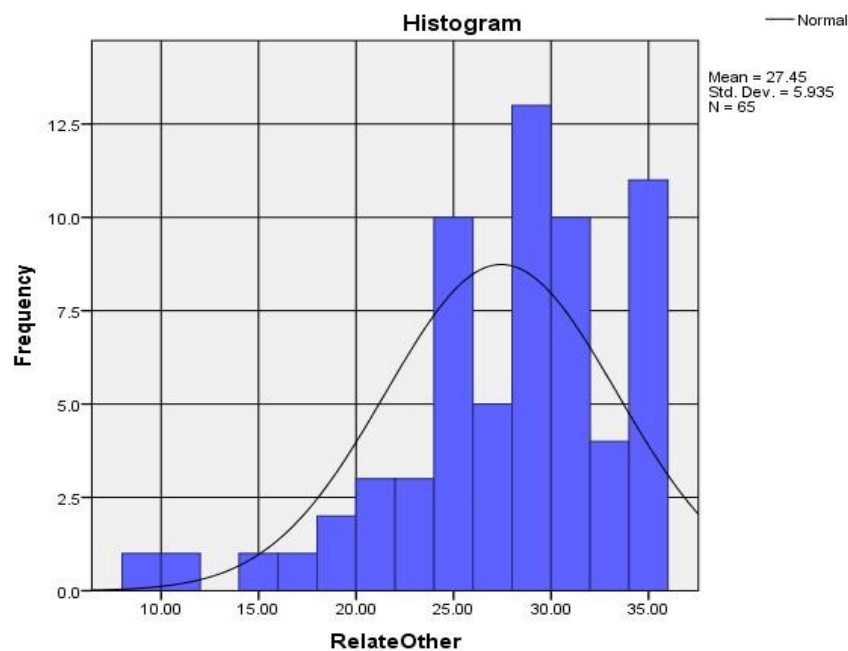


Figure 13: 5 Factors of Growth: Study Participants' Responses – Relate to Others

In terms of the specific items, 93% of participants clearly felt they could count on others (see Table 15, below) and felt closer to people (85%). In addition, 88% of participants stated that they learned how wonderful people are. At the same time, 18% of



participants felt they could not count on others *and* 18% experienced a greater sense of distance from others too. As well as this, 25% of participants said they learned how disappointing people are. This could be explained by the change in social network that survivors experience as cancer ‘shows you who your real friends are’. What is clear is that 91% said they had increased compassion for others and in general, participants put more effort into their relationships (82%) with many participants finding that they better accepted needing others (79%). In terms of emotions, 70% are more willing to express them whereas 22% said they were less willing to do so.

Table 15: ‘I more clearly see that I can count on people in times of trouble’

<b>I more clearly see that I can count on people in times of trouble (n=66)</b>	<b>Responses – Percent</b>
I did not experience this change as a result of my crisis	3.0
I experienced this change to a very small degree as a result of my crisis	3.0
I experienced this change to a moderate degree as a result of my crisis	10.4
I experienced this change to a great degree as a result of my crisis.	17.9
I experienced this change to a very great degree as a result of my crisis.	64.2
Total	98.5
Missing	1.0
<b>TOTAL</b>	<b>100.0</b>

- **Personal Strength**

As can be seen by the histogram for Personal Strength (see Figure 14, below), the data is negatively skewed. The median= 16 and the IQR(13.75,18). It contains 5 items and has a maximum score of 25. M=15 with a possible maximum score of 20.

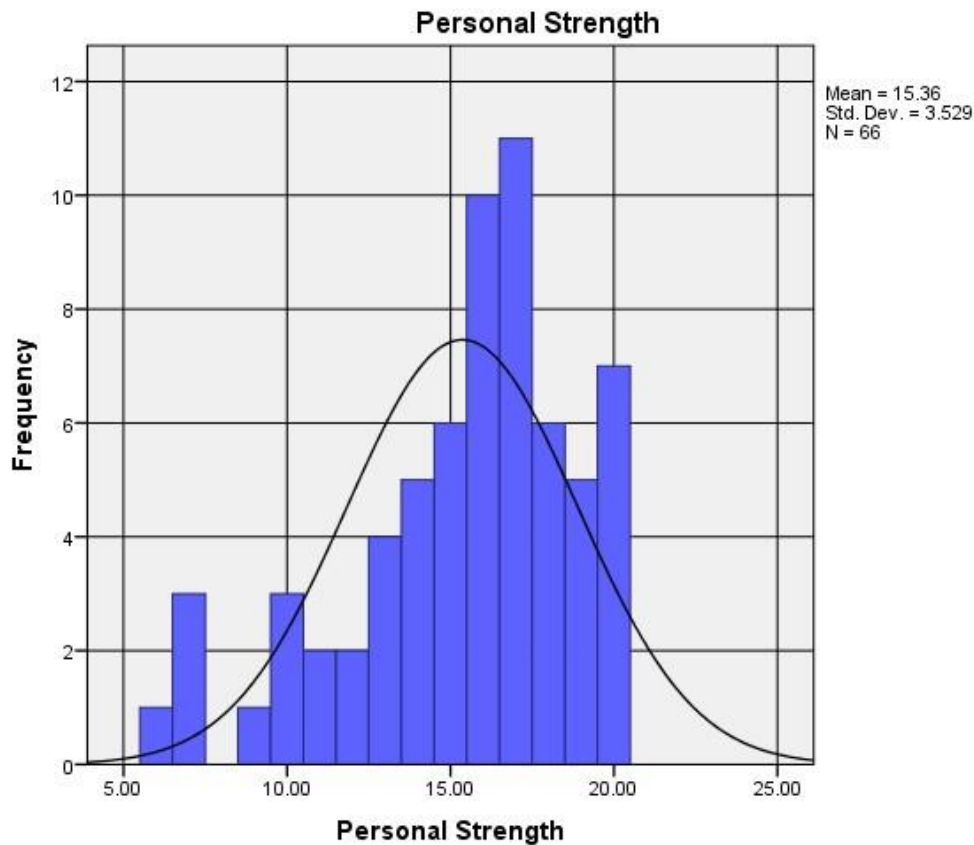


Figure 14: 5 Factors of Growth: Study Participants' Responses – Personal Strength

The greatest change in this factor is how 87% of participants said they were stronger than they thought they were and that they could better handle difficulties (88%). Many of them stated that they had a greater feeling of self-reliance (85%). 82% of participants now felt that they are better able to accept the way things work out (see Table 16, which follows).

Table 16: I am better able to accept the way things work out'

<b>I am better able to accept the way things work out n= 66</b>	<b>Responses – Percent</b>
I did not experience this change as a result of my crisis	6.0
I experienced this change to a very small degree as a result of my crisis	4.5
I experienced this change to a small degree as a result of my crisis.	6.0
I experienced this change to a moderate degree as a result of my crisis	23.9
I experienced this change to a great degree as a result of my crisis.	28.4
I experienced this change to a very great degree as a result of my crisis.	29.9
Total	98.5
Missing	1.5

<b>TOTAL</b>	<b>100.0</b>
--------------	--------------

- **New Possibilities**

As can be seen by the histogram for New Possibilities (see Figure 15 below), the data is negatively skewed. The median = 17 and the IQR(12.5, 21). It contains 5 items with a maximum score of 25. M=17 with a possible maximum score of 25.

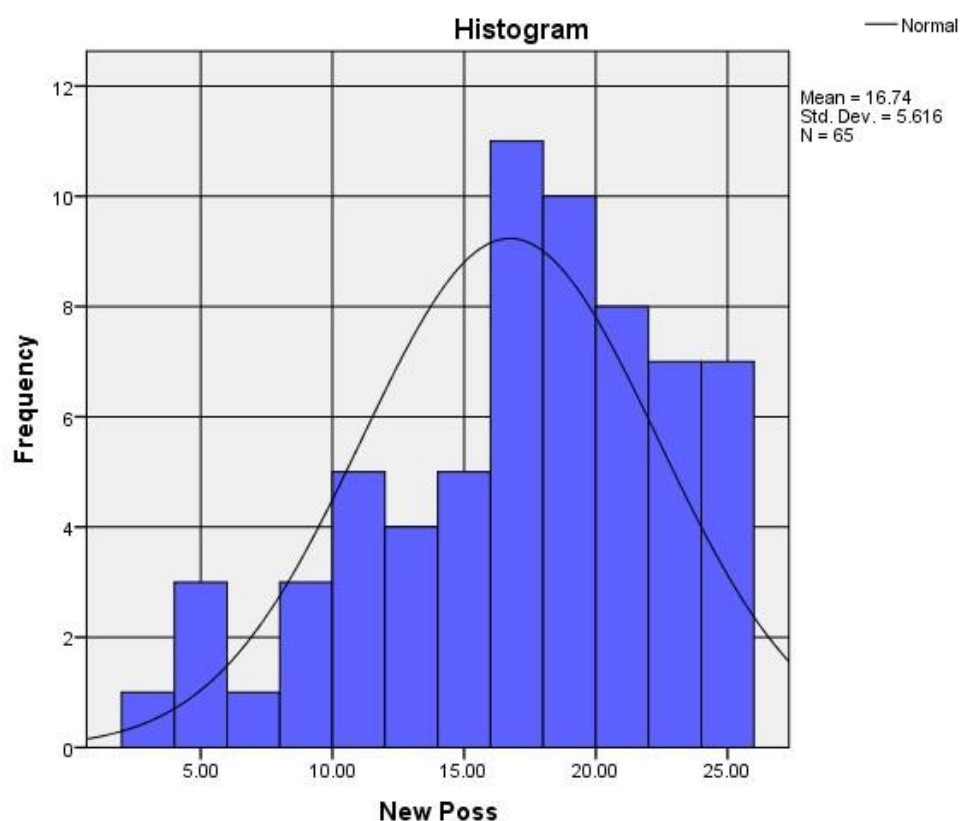


Figure 15: 5 Factors of Growth: Study Participants' Responses – New Possibilities

Most participants felt that they were doing better things with their lives (82%), saw newer opportunities that they would not have seen otherwise (75%) and in fact 78% had developed new interests (see Table 17, below). 66% of people said that the experience of having had cancer led them to establish a new path for their life and that they now try to change the things that need changing. Some studies, such as that by Jaehee and Min (2014), found the highest mean growth levels in New Possibilities.

Table 17: 'I developed new interests'

<b>I developed new interests n= (66)</b>	<b>Responses – Percent</b>
I did not experience this change as a result of my crisis	6.0
I experienced this change to a very small degree as a result of my crisis	6.0
I experienced this change to a small degree as a result of my crisis.	9.0
I experienced this change to a moderate degree as a result of my crisis	23.9
I experienced this change to a great degree as a result of my crisis.	20.9
I experienced this change to a very great degree as a result of my crisis.	32.8
Total	98.5
Missing	1.5
<b>TOTAL</b>	<b>100.0</b>

- **Spiritual Change**

From the histogram for Spiritual Change (see Figure 16, below), the data is negatively skewed. The median = 5, and the IQR(1.75, 8). It contains 2 items with a maximum score of 10. M=5 with a possible maximum score of 10.

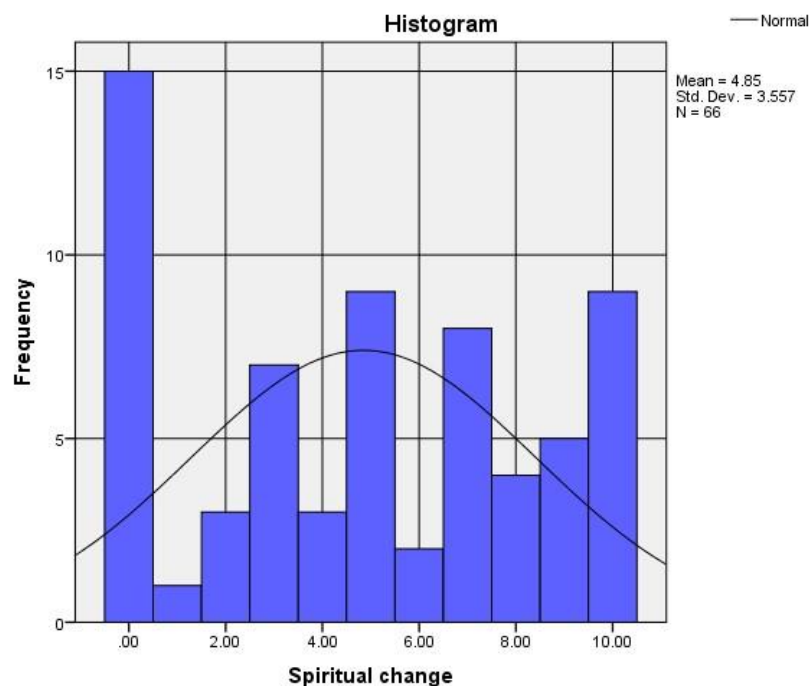


Figure 16: 5 Factors of Growth: Study Participants' Responses – Spiritual Change

This factor had the lowest recorded level of growth. There was a dichotomy in responses between those who did experience a better understanding of spiritual matters to a very great degree (23%) as compared to those who did not experience

this at all (29%). Figure 16 above visually represents quite clearly the spread of responses.

Table 18: 'I have a better understanding of spiritual matters'

<b>I have a better understanding of spiritual matters n = 66</b>	<b>Responses – Percent</b>
I did not experience this change as a result of my crisis	28.4
I experienced this change to a very small degree as a result of my crisis	10.4
I experienced this change to a small degree as a result of my crisis.	7.5
I experienced this change to a moderate degree as a result of my crisis	14.9
I experienced this change to a great degree as a result of my crisis.	14.9
I experienced this change to a very great degree as a result of my crisis.	22.4
Total	98.5
Missing	1.5
<b>TOTAL</b>	<b>100.0</b>

In terms of having a stronger religious faith, there was another dichotomy with 34% not experiencing this change at all versus 38% of participants who did experience this from a moderate to a very great degree. Frost *et al.* (2013) found that spiritual well-being is very much an individualistic experience that changes considerably over time and so to better understand this factor it must be studied longitudinally.

One key issue in measuring spiritual change using the PTGI is that there are only two statements used to assess this area; better understanding of spiritual matters and increased religious faith. This makes it psychometrically weak. Also, the statements refer to a religious context but there is a need to recognise and include existential changes. To address this, in 2017, Tedeschi and Calhoun revised the Spiritual Change scale to include 4 additional items and it is now renamed 'Spiritual-Existential Change'.

Romeo *et al.* (2017) researched 108 Italian cancer survivors and found the highest level of PTG in Appreciation of Life and the lowest levels in Spiritual Change. This is consistent with my findings on both counts. In terms of the PTG literature, there are several studies that have identified Spiritual Change as the least area of growth (Fox *et al.*, 2014; Jaehee & Min, 2014; Bloom *et al.*, 2007). Frost *et al.* (2013) found that spirituality was very individualistic and fluctuated greatly over time.

- No positive PTG between those with breast cancer compared with other cancers

Higher PTG levels are typically reported for breast cancer survivors than other cancer

survivors (Joen *et al.*, 2015). However, the comparison of the mean PTG scores of breast cancer survivors to other cancers shows only a marginal difference (where mean is 74 for breast cancer and 76 for other cancers), as indicated in Figure 17, overleaf, which shows similar mean scores for Relating to Others.

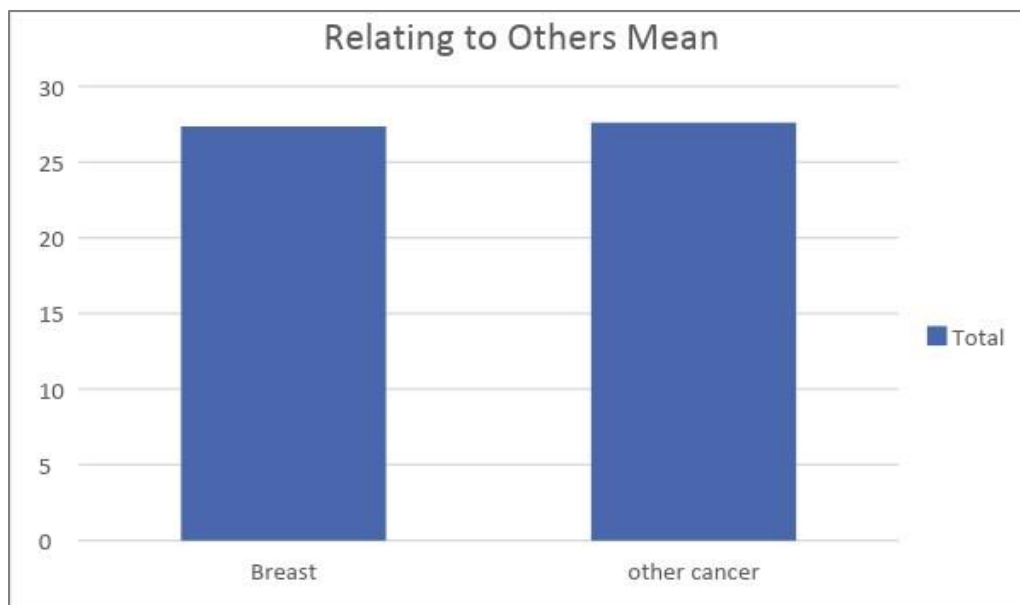


Figure 17: Relating to Others Mean, for Breast and Other Cancer Types

In a T test to analyse the mean growth between Breast Cancer and Other Cancers, no significant difference was found. The mean growth for Breast Cancer and Other Cancers was analysed for each of the 5 Factors or areas of growth and again, no significant difference was found. What this suggests is that positive growth levels were relatively the same whether the person had breast cancer or another cancer. This contrasts with other studies who found higher PTG for survivors who had breast cancer (Joen *et al.*, 2015, Tedeschi *et al.*, 2018b).

I would also like to note here that of the 66 participants, breast cancer was the most common cancer experienced – 71% (47 participants). A further comparison of PTG by cancer type in this research is needed.

There is a significant difference between negative depreciation for those with breast cancer versus other cancers in terms of one of the Factors – Relating to Others. The results show that survivors of Breast Cancer had lower negative changes in terms of

how they Relate to Others compared to survivors of other cancers. This could potentially be linked to the fact that Breast Cancer survivorship has its own distinct identity and established support network. Tedeschi *et al.* (2018b), suggest that those with breast cancer have a higher mean PTG due to well know survivor personalities associated with it.

- Positive growth can happen in any cancer stage

A Spearman's correlation was conducted to examine the relationship between stage of cancer and the five factors of growth. Findings show that there was no significant relation between stage of cancer and any of the five Factors  $p > .05$  (see Table A-19.01 in Appendix 20). This means that growth can happen at any stage. In contrast, Yi *et al.* (2015) found higher levels of PTG the greater the severity of the disease. This contrasts with the research by Harding (2017), who found greater positive psychological consequences for cancer patients with lower stage tumour and less treatment interventions.

- No correlation between positive growth levels and age

A Spearman's correlation was conducted to examine the relationship between age and the five factors of growth. Findings show that there was no significant relation between age and any of the five Factors  $p > .05$  (see Table A-19.02 in Appendix 20). Other studies did find a correlation between age and growth. Balfe and al (2016) also found that the older age group had lower PTG levels. However, Harding (2017) proposes that the greatest growth is in early recovery and that growth levels stabilise over time. Several studies report that PTG levels are higher the older you are (Romero *et al.*, 2017; Joen *et al.*, 2015; Grace *et al.*, 2015). Svetina and Nastran (2012) on the other hand found age did not predict PTG levels.

It warrants further research as a larger sample may prove significant. To contextualise this further I would like to note that the age range for this sample was from 40 to 78 years, with a mean of 60 years.

- No significant relationship between marital status and PTG

A Spearman's correlation was conducted to examine the relationship between marital status and the five factors of growth. Findings show that there was no significant relation between marital status and any of the five Factors  $p > .05$  (see Table A-19.03 in Appendix 20).

However, upon closer examination of marital status, and the individual inventory items, there was borderline significance with two statements which could warrant further research with a larger sample size for ‘I am more likely to try to change things that need changing’ as well as ‘I can better appreciate each day’. Other PTG studies suggest greater PTG levels for married participants (Grace *et al.*, 2015) whereas Svetina and Nastran (2012) found marital status did not predict PTG levels.

- **Having children means higher positive growth in New Possibilities and Appreciation of Life**

A Spearman’s correlation was conducted to examine the relationship between those with/without children and the five factors of growth. Findings show that there was no significant relation between having children and any of the five Factors  $p > .05$  (see Table A-19.04 in Appendix 20). However, Appreciation of Life is approaching significance  $p = .023$ , so a potentially larger sample could show significance.

When the individual items of the PTGI-42 were analysed in terms of whether participants had children or not, there were three significant findings. Two of the findings concerns Factor II: New Possibilities. If participants had children, then they experienced change to a much greater degree in ‘establishing a new life path’ and ‘doing better things with my life’ than participants without children.

The third significant finding concerns Factor V: Appreciation of Life. For participants who had children, they self-reported a greater degree of change in ‘I changed my priorities about what is important in life’ compared to those without children. In an Irish study of carers of head and neck cancer survivors, having children was associated with higher PTG levels (Balfe *et al.*, 2016).

The first half of this chapter focused on providing a detailed overview of the quantitative findings. However, it is also important here to outline some of the issues that emerged in using this inventory with the cancer survivor population.

- **Issues with PostTraumatic Growth Inventory - 42**

The use of the PostTraumatic Growth Inventory - 42 in this doctoral research highlighted several issues with it as a research tool and which warrant consideration in future research. These issues concern; order effect, social desirability bias, wording accessibility, cognitive dysfunction and cultural pragmatics, each of them are explored here.



The 42-item inventory was used to offset criticisms of the original 21-item scale which examined areas of growth only. The 42 items, in comparison, is a series of 21 pairs of statements where, within each pair, one statement is written in the positive and the other negative. The participants circle their response in terms of the degree to which they experienced this change – from 0 (not at all) to 5 (a very great degree). From the research interviews the issue of order effect was quite apparent since when participants grew in confidence so too did the frequencies of 0 and 5. In addition, although participants were told that change could happen in both, in one or in none of the statements, they seemed to still identify each of the statements in the particular pairing as a dichotomy of *yes* or *no*. As well as this, the positive statement was always listed first and then it was followed by a negative statement which again could have contributed to a bias in answering more positively to the first statement which was by its nature, positive.

I believe that there was a social desirability bias – that the socially correct answer was to answer *yes* to the positively phrased statement, but this then leads to questioning the accuracy of the responses. One clear example of this concerns statements 8a - ‘I have a greater sense of closeness with others’ and 8b - ‘I have a greater sense of distance from others’. Many participants questioned if it was ‘ok’ to score high on both statements and were concerned that they were contradicting themselves.

There was a high level of support/concern regarding completing the inventory by participants. Five participants asked the researcher to read out the statements and two thirds asked questions regarding the meaning of the statements – particularly the ones which were stated in the negative. An example of this is statement 1b - ‘I find it difficult to clarify priorities about what is important in life’ which required participants to reread, think about and sometimes ask questions to understand what it was asking.

I believe that some of the difficulty for participants in completing the inventory comes from the actual wording not being accessible. This cognitive burden (Bowling, 2005) may constitute a source of error and can impact on the quality of data collected. Another factor that would have had a negative impact on how cancer survivors understood what was being asked of them is commonly known as ‘chemo brain’. Issues with memory and cognitive functioning are a well-accepted, and well researched, side effect of cancer treatment, and it can take up to 5 years for most of this cognitive functioning to return

(Carroll *et al.*, 2018; Ahles & Hurria, 2017). This accounts for the issues participants faced when completing the inventory.

In my experience, the completion of the inventory was more difficult for participants 2-4 years after treatment as opposed to those 6+ years in recovery. In the research by Treanor *et al.* (2012), one of the criteria to take part was that the participant needed to not have any cognitive impairment since this would have hindered them in completing a postal questionnaire. I think that for the PTGI to be used with cancer survivors that cognitive functioning must be measured and a qualification criterion to take part.

Recent studies by the Acquired Brain Injury Association of Ireland into brain injury and PTG also raised the issue of pragmatics and how the statements used in the PTG inventory may not always translate well into the Irish Culture (Rogan *et al.*, 2013). An example of this is statement 20a - 'I learned a great deal about how wonderful people are' which may work in the United States more than in Ireland. Participants of this research study definitely had an issue with the wording of 'wonderful' and found it difficult to assess/relate to if they 'find I better accept needing others'.

In the Australian PTG research by Soo and Sherman (2015), they noticed differences between their PTG findings versus other research studies in terms of their mean PTG scores being quite low, and suggest that these differences reflect "cultural differences related to growth that may not be adequately assessed by the post-traumatic growth inventory" (p. 75). Furthermore, the factor structure of the PTG model is different across different countries e.g. Latino and Japanese studies favour a four-factor subscale (Morris *et al.*, 2013). Jin *et al.* (2014) did not use the 2 statements referring to Spiritual Change, when they used the PTGI, as they felt it did not apply to local cultural values in China.

The PTGI-42 was used in the study by Cann *et al.* (2010) who suggest that, by using paired statements, participants can measure both growth and depreciation at the same time. Both growth and depreciation items showed good internal reliability (where growth = alpha 0.94 and depreciation = alpha 0.92).

Though Cann *et al.* (2010) used the PTGI-42, they found that the "opportunity to report depreciation does not result in a major gain of information" (p. 162). They also found

that the use of depreciation measures in the same pairing as the positive led to participants reporting low depreciation levels.

- **PostTraumatic Growth Inventory does not address the physicality of cancer**

Cancer is a very physical experience and it is on a very personal level as it is experienced and sourced from inside the body (as opposed to a trauma that is an external event such as flooding or war). It involves a series of stressors, fears about the future, and it is difficult to determine the end of the trauma (Jaehee & Min, 2014). In addition, cancer treatment and the ensuing side effects are also quite physical. For participants of this doctoral research, the main negative impact of cancer was the physical effects and especially the tiredness, physical limitations, treatment side effects and hair loss. In fact, participants cited ‘treatment side effects’ as one of the hindrances to their recovery. They related to a loss of physical control of their bodies which is consistent with the findings of Kumar and Schapira (2013).

Due to the physicality of cancer, “the shock of a trauma such as a cancer diagnosis can reconnect us with the physical and prompt us to take better care of our bodies” (Akhtar, 2017, p. 68). There is a new awareness of the body (Morris *et al.*, 2013). Walsh *et al.* (2018) reported that cancer survivors may appreciate their body and care for it more thereby leading to health behaviour changes. For some participants in this doctoral research, they did indeed make positive lifestyle changes and took care of their health more by improving their diet, increasing exercise and reducing or eliminating alcohol/cigarettes.

Participants like Deirdre, below, made more time for themselves.

“Also nutrition, exercise and ‘me’ time very important now, where previously would have been less”. Deirdre

“...different phase of my life you know givin up workin was a great, I mean I go to the Gym you know the mm... the Leisure Centres now you know that kinda thing. I go walkin different thing, I have a different life an I’d say that all helped it because I was ploddin along you know”. Josie

Tedeschi and Calhoun (2014) acknowledge that the inventory does not include the health-related behaviour change experienced by cancer survivors.

Akhtar (2017) proposes a form of corporeal posttraumatic growth which is how people may experience PTG related to the body. This can take the form of an improved relationship with the body (taking better physical care), increased health related behaviour (e.g. might eat better and give up smoking etc) and finally they may be stronger in mind (feel more alert and optimistic).

## **6. Findings: Research Question Three: How does the PostTraumatic Growth Inventory compare to semi structured interviews in understanding women's experience of cancer recovery?**

One of the key challenges of a mixed methods study is the integration and consolidation of mixed data findings (Hashemi & Babaii, 2013) which for this study is the quantitative inventory data from the PTGI-42 as well as the qualitative findings from the interviews/long answer questions.

To address this challenge, Principal Components Analysis (PCA) is used as the mechanism to reduce the quantitative data. Each component identified from PCA, is then analysed in terms of how it complements/supports or diverges from the original 5 Factors of the PTGI as well as the qualitative findings from the interviews.

### **6.1 Introduction to Principal Components Analysis**

Principal Components Analysis (PCA) is a Factor Analysis method. It is a data reduction technique where it takes a large data set and reduces it to a smaller number of components whilst at the same time keeping the maximum variation of the original data set. The 21 positive PostTraumatic Growth Inventory Items were subjected to a Principal Components Analysis using SPSS version 24. Prior to performing PCA the suitability for data factor analysis was assessed. The correlation matrix showed the presence of many coefficients of .3 and above. In addition, Bartlett's Test of Sphericity is significant (where  $p < .05$ ) and the Kaiser-Meyer-Olkin measure is above the .6 minimum (Pallant, 2010) – see Table A-19-05 in Appendix 20.

The decision to do the Principal Components Analysis on the positive inventory statements only was mainly based on the fact that the key focus of this research project was the exploration of potential positive growth from cancer. In addition, I believe due to order bias and social desirability bias that some of the scores of the negative statements were invalid. The inventory statements were presented in pairs – a positive statement followed by its corresponding negative statement. The instructions at the start of PTGI-42 explicitly state that you may experience change in one *or* both *or* none of the paired statements. However, participants expressed two issues. The first was that when they scored high on the positive statement, several participants verbalised 'oh it must be low for this one then' (referring to the negative statement). This indicated

potential order bias. In addition, the second statement (which was negative) was written in a way that was at times difficult or took time for the participant to understand. This was evidenced in that several participants asked about the wording or meaning of the negatively worded statements. As a researcher I did not have confidence in the validity of the scoring of the negative statements and so did not include them in the PCA.

From the Principal Components Analysis, the 21 positive inventory items can be reduced to six components. An orthogonal rotation was used along with the Varimax technique to run the PCA.

Table 19, below, identify that only six components have an Eigenvalue above 1 and these six components account for a total of 67.13% of the variance of the total data set. Each of the 21 items does load at a cut off of .4 on at least one of these components i.e. there are no components that are not represented in each of the six components.

Table 19: Principal Components Analysis Total Variance Explained

<b>PRINCIPAL COMPONENTS ANALYSIS TOTAL VARIANCE EXPLAINED</b>			
<b>Component</b>	<b>Initial Eigenvalues</b>		
	<b>Total</b>	<b>% of Variance</b>	<b>Cumulative %</b>
<b>1</b>	5.490	26.142	26.142
<b>2</b>	2.297	10.936	37.078
<b>3</b>	2.167	10.318	47.396
<b>4</b>	1.620	7.714	55.109
<b>5</b>	1.436	6.838	61.948
<b>6</b>	1.088	5.179	67.127

The Scree plot (Figure 18, below) also supports the 6-component reduction as the line tapers off, significantly, from component 7 onwards.

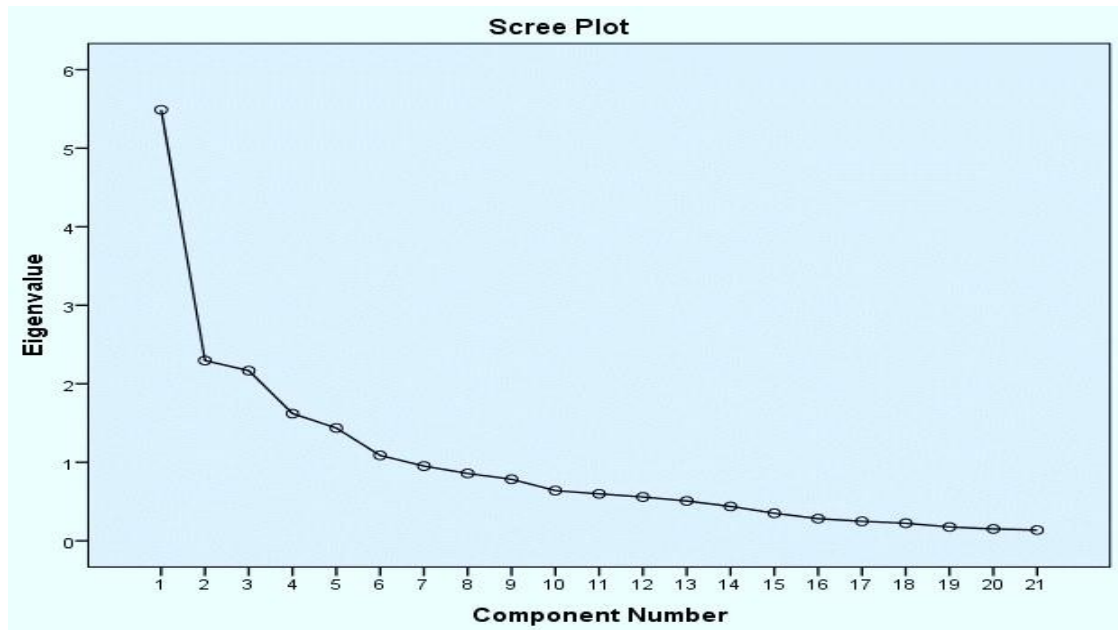


Figure 18: The Scree Plot of the Principal Components Analysis of the PTGI

- **Component 1: Relate to Others**

Component 1: Relate to Others, is quite significant as it accounts for 26% of the variance. For a full list of inventory items for component 1, see Figure 19. The five items marked with an asterix denote those items that are in the original Relate to Others factor as per the PTGI. The items without an asterix are loaded to this component at a cut-off of .4 or above but are not in the original inventory item list for this area of growth as defined by Tedeschi and Calhoun (2006) and are therefore specific and derived from this dataset.

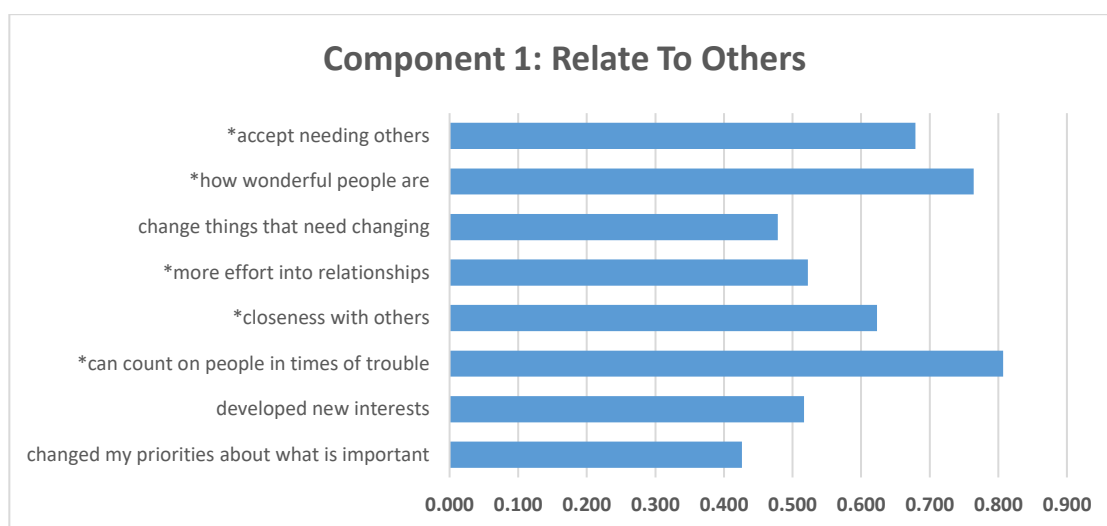


Figure 19: PTGI Component 1: Relate to Others - a full list of inventory items

Table 20: Principal Components Analysis of PTGI Component 1, Relate to Others

PRINCIPAL COMPONENTS ANALYSIS: COMPONENT 1, RELATE TO OTHERS	
Rotated Component Matrix <sup>a</sup>	Loading
changed my priorities about what is important	0.426
developed new interests	0.517
*can count on people in times of trouble	0.807
*closeness with others	0.623
*more effort into relationships	0.522
change things that need changing	0.479
*how wonderful people are	0.764
*accept needing others	0.679
Extraction Method: Principal Component Analysis.	
Rotation Method: Varimax with Kaiser Normalization.	
a. Rotation converged in 8 iterations.	
% Total	100.00%

Table 20, above, identifies the 3 inventory items with the highest loading which are driving this component; that participants ‘can count on people in times of trouble’ (.8 loading), are learning ‘how wonderful people are’ (.8 loading) and that they better ‘accept needing others’ (.7 loading). The significance of these items from the inventory is also very similar to what was found in the qualitative data in that participants did express an increased closeness and it very much impacted their perception of others – but instead of ‘wonderful’, it was how ‘good/not so good’ people were. Both data sets also supported the idea that survivors experienced greater compassion for others.



What is also interesting to note here is that component 1 also includes a ‘change in priorities’ and a development of ‘new interests’. This was also supported by the qualitative findings since, from the experience of cancer, survivors realised and reprioritized the importance of relationships.

In addition, the new interests i.e. hobbies, travel etc really drove the increase in social networks. From both the inventory and the interview findings, ‘Relating to Others’ was where participants experienced the greatest degree of growth.

In terms of differences between the two data sets, the qualitative data highlighted that participants felt less tolerance for others which was not found in the inventory data.

#### • Component 2: New Possibilities

Component 2: New Possibilities accounts for 11% of the total variance. For the full list of inventory items for this component reference Figure 20, below. Again, any item with an Asterisk denotes that it is in the original Factor as defined by Tedeschi and Calhoun (2006). 4 of the 5 items maps onto the original inventory listing for this Factor.

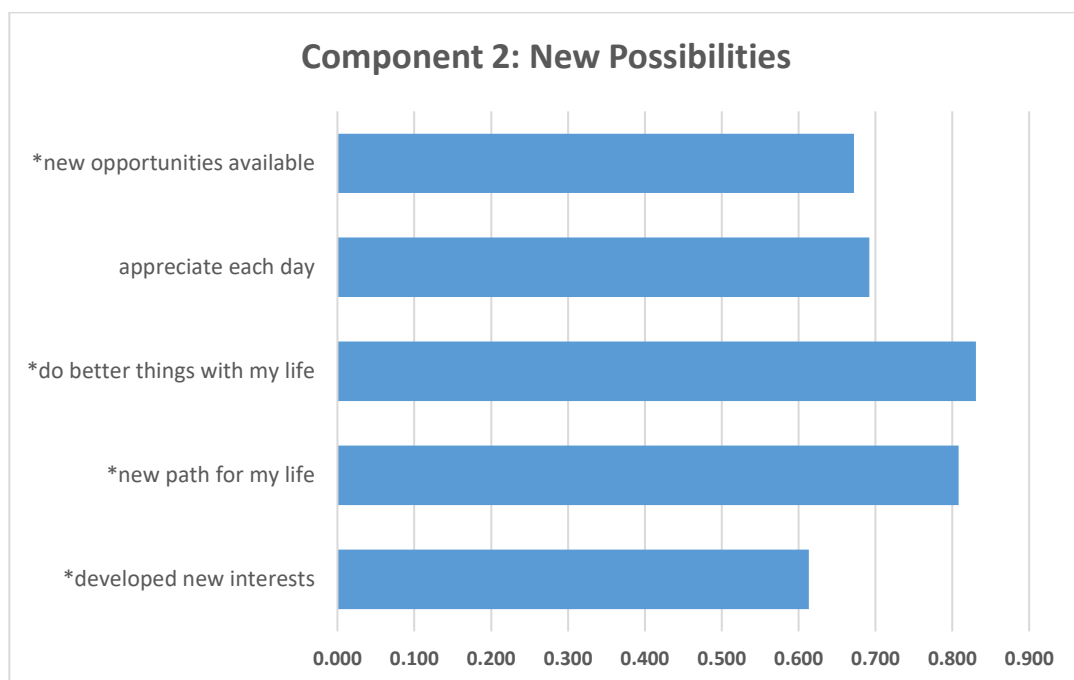


Figure 20: PTGI Component 2: New Possibilities - a full list of inventory items

From Table 21 below, the 2 items that have the highest loading and are driving New Possibilities are that I can ‘do better things with my life’ (.8 loading) and having a ‘new

path for my life' (.8 loading). Again, this is supported by the qualitative data where participants expressed that their lives were more enjoyable and that they were doing more of what they wanted to do than before cancer.

For New Possibilities, both the quantitative and the qualitative data highlighted that survivors do better things with their lives and noted a significant increase in new interests. Any life changes expressed by the interviewees were small, personal and social. What is interesting to note here is that this component also includes 'appreciate each day' but in the original inventory listing this is in the Factor 'Appreciation of Life'. However, it is appropriate for this doctoral research that it is in New Possibilities as many of the change's survivors made concerned seeing/experiencing the 'little things' differently.

In terms of differences, 66% of participants said that they have established a new life path for themselves via the inventory data. However, as stated above, the interview data shows survivors making changes involving changes of perception, of who they spend their time with etc rather than radical changes of moving to a new house or changing careers etc.

In the interview data, participants highlighted the importance of staying busy and of setting goals/reaching for dreams, but this was not accounted for in the PTGI.

Table 21: Principal Components Analysis of PTGI Component 2, New Possibilities

<b>PRINCIPAL COMPONENTS ANALYSIS: COMPONENT 2, NEW POSSIBILITIES</b>	
<b>Rotated Component Matrix<sup>a</sup></b>	<b>Loading</b>
*developed new interests	0.613
*new path for my life	0.808
*do better things with my life	0.831
appreciate each day	0.692
*new opportunities available	0.672
<b>Extraction Method: Principal Component Analysis.</b>	
<b>Rotation Method: Varimax with Kaiser Normalization.</b>	
<b>a. Rotation converged in 8 iterations.</b>	

#### • Component 3: Spiritual Connection

Component 3: Spiritual Connection accounts for 11% of the total variance. For the full list of inventory items for this component please see Figure 21 overleaf. Again, the two

items with an Asterix denotes that it is in the original Factor as defined by Tedeschi and Calhoun (2006).

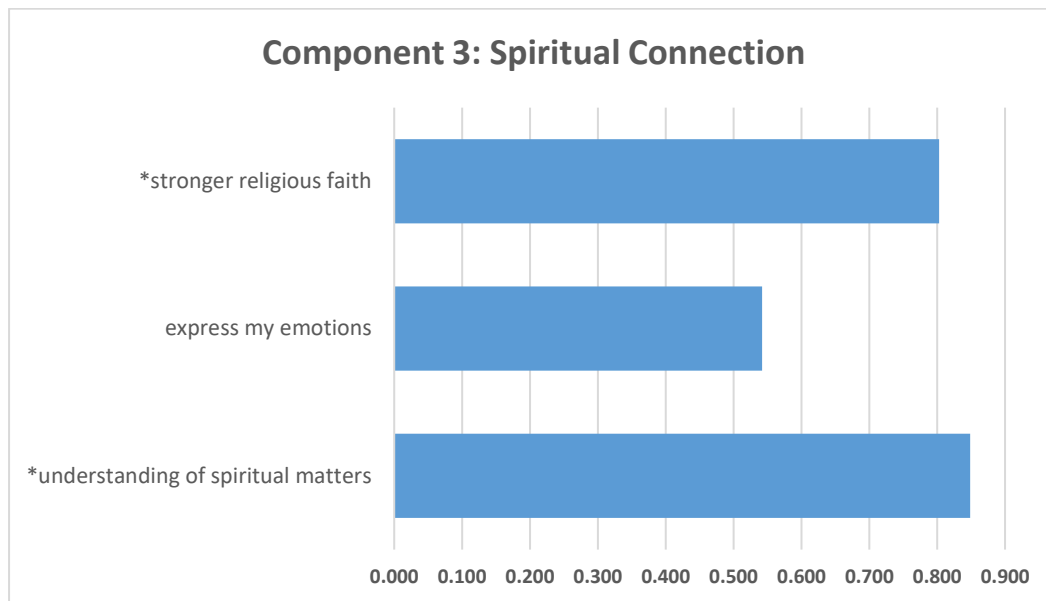


Figure 21: PTGI Component 3: Spiritual Connection - a full list of inventory items

From Table 22 below, both ‘understanding of spiritual matters’ (.8 loading) and ‘stronger religious faith’ (.8 loading) have the highest loading and are driving this component. The original Spiritual Change Factor from the PTGI includes only these 2 items. What is interesting to note with this component is the inclusion of ‘express my emotions’.

From the qualitative data, for those participants who did experience growth in Spiritual Change, this was rooted in their personal relationship with God/Spirit and the physical expression of rituals (lighting candles and prayer) which were very important for survivors. It is worth considering that the enactment of these rituals served as a vehicle for participants to express their emotions. This expression constitutes self-disclosure which is one of the mechanisms needed for positive growth to occur.

The interview data also emphasises the comfort that participants felt in being ‘watched over’ by a deceased relative/God/angel etc. Though the original factor is called ‘Spiritual Change’, the addition of the third inventory item and the importance of the relationship with God/Spirit, the title of ‘Spiritual Connection’ would be a more appropriate name.

In terms of Spiritual Change, the limitations of the inventory, in only looking at spiritual understanding and religious faith, was discussed earlier. Spiritual Change had the least positive growth of all the factors for both quantitative and qualitative data.

Table 22: Principal Components Analysis of PTGI Component 3, Spiritual Connection

<b>PRINCIPAL COMPONENTS ANALYSIS: COMPONENT 3, SPIRITUAL CONNECTION</b>	
<b>Rotated Component Matrix<sup>a</sup></b>	<b>Loading</b>
*understanding of spiritual matters	0.848
express my emotions	0.542
*stronger religious faith	0.803
<b>Extraction Method: Principal Component Analysis.</b>	
<b>Rotation Method: Varimax with Kaiser Normalization.</b>	
<b>a. Rotation converged in 8 iterations.</b>	

- **Component 4: Self Worth**

Component 4: Self Worth accounts for 5% of the total variance. For the full list of inventory items for this component please see Figure 22, below.

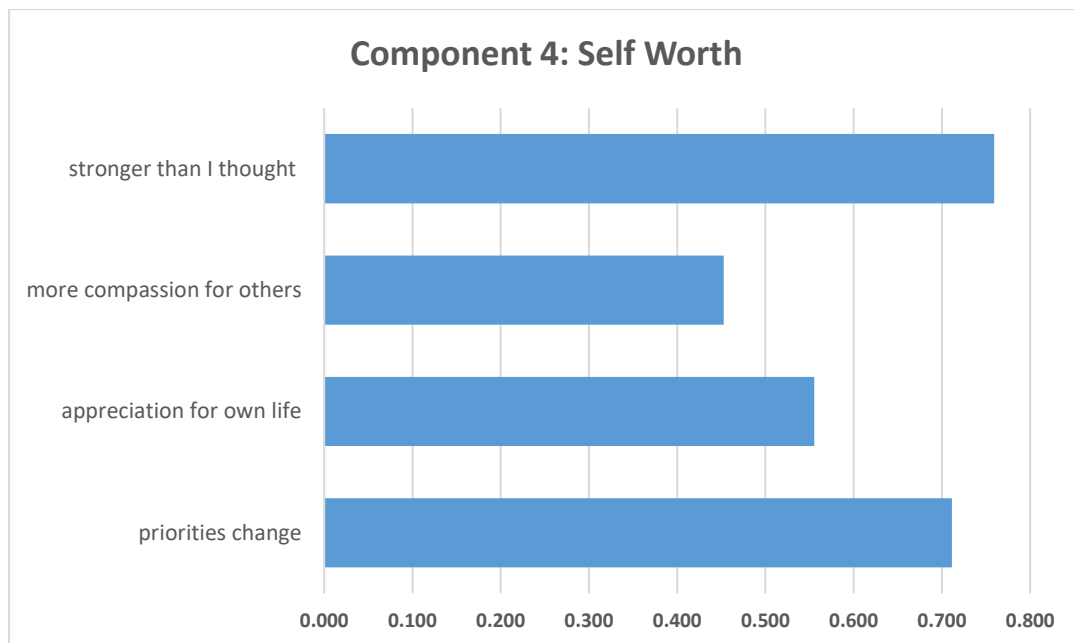


Figure 22: PTGI Component 4: Self Worth - a full list of inventory items

This component contains 4 inventory items (see Table 23 below for a breakdown of item loadings). It is a new area of growth and contains items from different Factors. The item with the greatest loading is originally from the Personal Strength Factor and is when the survivor now sees themselves as ‘stronger than I thought’ (with a .8 loading). In terms of loading weight, the next 2 items are originally from the Appreciation of Life Factor; ‘priorities change’ (.7 loading) and ‘appreciation of own life’ (.6 loading). The fourth item is from Relate to Others and is ‘more compassion for others’ with a .5 loading.

Both the quantitative and the qualitative data support the finding that participants perceived themselves as stronger. When survivors were asked about how they would describe the impact of cancer, many of them responded with ‘I am stronger’. The priorities change and increased value of own life are both consistent with the interview data in that several of the survivors spoke of having learned to put themselves first and of appreciating how precious their life is. Another significant change in priorities is how relationships with others are valued more. This new awareness, and understanding of the self, leads to an increase in compassion/understanding of others.

Table 23: Principal Components Analysis of PTGI Component 4, Self Worth

<b>PRINCIPAL COMPONENTS ANALYSIS: COMPONENT 4, SELF WORTH</b>	
<b>Rotated Component Matrix<sup>a</sup></b>	<b>Loading</b>
priorities change	0.711
appreciation for own life	0.556
more compassion for others	0.453
stronger than I thought	0.759
<b>Extraction Method: Principal Component Analysis.</b>	
<b>Rotation Method: Varimax with Kaiser Normalization.</b>	
<b>a. Rotation converged in 8 iterations.</b>	

- **Component 5: Personal Strength**

Component 5: Personal Strength accounts for 7% of the total variance and consists of 3 items in Figure 23.

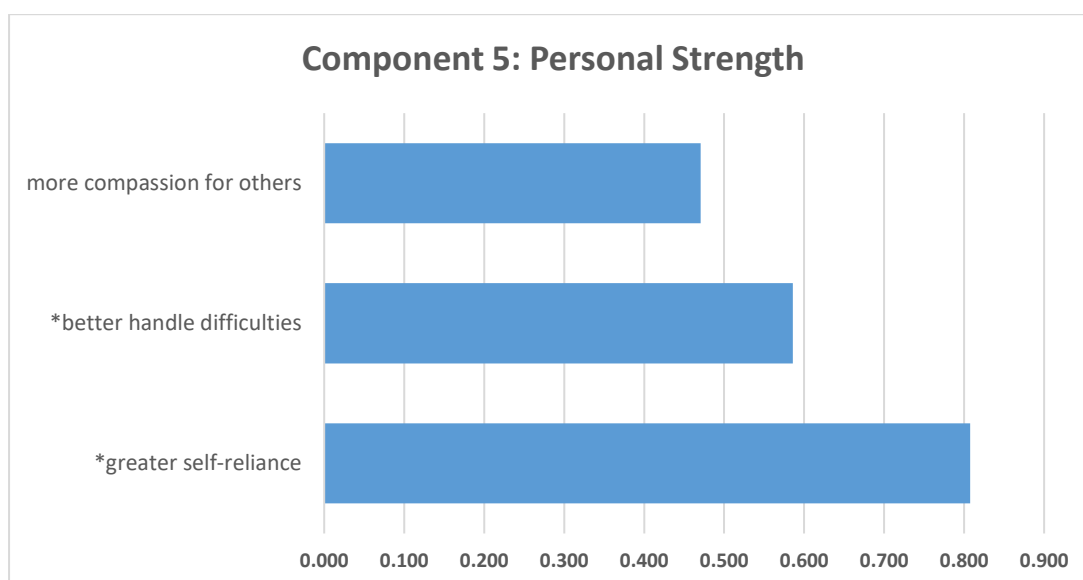


Figure 23: PTGI Component 5: Personal Strength - a full list of inventory items

The item regarding ‘greater self-reliance’ has the highest loading (.8) followed by being better able to ‘handle difficulties’ (.6) – see Table 24 below. Both correspond with the items in the original Factor and were also found in the qualitative findings for this area of growth where participants felt that having dealt with cancer that they could handle whatever life sent their way and they did not stress over the little things anymore.

Table 24: Principal Components Analysis of PTGI Component 5, Personal Strength

PRINCIPAL COMPONENTS ANALYSIS: COMPONENT 5, PERSONAL STRENGTH	
Rotated Component Matrix <sup>a</sup>	Loading
*greater self-reliance	0.808
*better handle difficulties	0.586
more compassion for others	0.470
Extraction Method: Principal Component Analysis.	
Rotation Method: Varimax with Kaiser Normalization.	
a. Rotation converged in 8 iterations.	

What is interesting to note is the inclusion of ‘more compassion for others’ and how this might relate to Personal Strength. From the qualitative interviews, survivors did recognise that they had increased understanding/empathy towards others especially if they were going through an illness. By having experienced the difficulty of having cancer, they had increased coping skills and increased understanding of others.

Component 5: Personal Strength also diverges from the inventory data. The original Factor includes items such as; ‘I am stronger than before’ and an ‘acceptance of how things work out’ which is not loaded to component 5. This component is also not consistent with the qualitative findings where ‘I am stronger’ was frequently used by survivors and they perceived it as a very significant area of growth. The qualitative data also highlighted other important aspects not addressed by the inventory at all including; an increase in self-awareness, improved self-confidence and a re-prioritising of putting self first. Shakespeare-Finch and al (2013) note that the inventory does not effectively capture the increase in cognitive awareness that participants experience.

- **Component 6: Proactive Mindset**

Component 6: Proactive Mindset accounts for 5% of the total variance and consists of 3 items in Figure 24 overleaf.

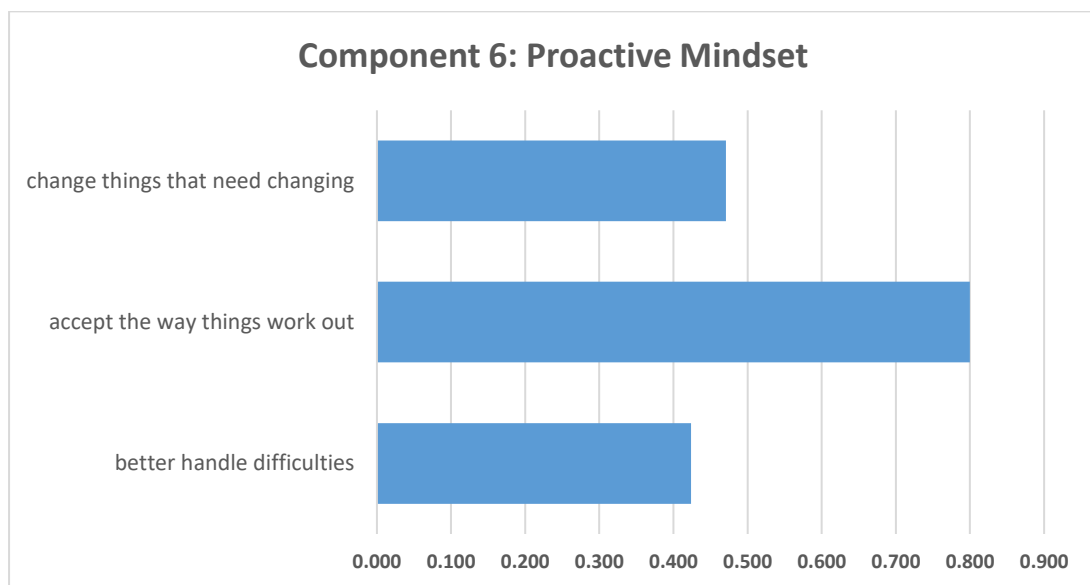


Figure 24: PTGI Component 6: Proactive Mindset - a full list of inventory items

Of the 3 items in Proactive Mindset, ‘accept the way things work out’ is the item with the greatest loading at .8 so this item is therefore driving this component (see Table 25 below). This is consistent with the qualitative data especially in terms of the recovery strategy of ‘get on with it’ which focused on moving on with the diagnosis to focus on the practical business of treatment and recovery. The other two items are; ‘change the things that need changing’ (with a .5 loading), followed closely by ‘better handle

difficulties’ (with a .4 loading). The 3 items of this component together are reminiscent of the Serenity Prayer – God grant me the serenity to accept the things I cannot change, courage to change the things I can and the wisdom to know the difference.

From this doctoral project I am proposing a sixth new area of growth – that of a Proactive Mindset identified from the qualitative data and which is not measured by the PTGI. This concerns cognitive and attitudinal changes where participants approach life with a ‘get on with it’ frame of mind whilst at the same time staying positive.

Table 25: Principal Components Analysis of PTGI Component 6, Proactive Mindset

<b>PRINCIPAL COMPONENTS ANALYSIS: COMPONENT 6, PROACTIVE MINDSET</b>	
<b>Rotated Component Matrix<sup>a</sup></b>	<b>Loading</b>
better handle difficulties	0.424
accept the way things work out	0.800
change things that need changing	0.471
<b>Extraction Method: Principal Component Analysis.</b>	
<b>Rotation Method: Varimax with Kaiser Normalization.</b>	
<b>a. Rotation converged in 8 iterations.</b>	

- **Convergence and Divergence of findings**

By comparing the findings from the two data sets, it is clear where the findings converge and diverge. The convergence confirms and complements the findings. The divergence provides an opportunity to explore new insights into positive growth.

Table 26, overleaf, provides a complete outline of the qualitative findings regarding the 7 areas of positive growth. It also highlights the aspects of each of the growth areas that are measured by the PTGI. For the most part, the aspects identified in the first two Factors of Relating to Others and New Possibilities are quite similar in content. However, as outlined in the previous section, there are significant differences in the other areas of growth.

As is shown in Table 26, ‘Appreciation of Life’ is an original area of growth from the PTGI and is supported by the qualitative data. In fact, the interview data outlines specific details of what this appreciation means e.g. valuing less stress and enjoying the little things. However, this Factor was not a standalone component of the Principal



Components Analysis, but rather individual items of this Factor were incorporated into 3 components; Appreciation of Life, New Possibilities, and Self-Worth.

Table 26: Summary of findings; interview, PTGI Items and 6 Components

Growth	Qualitative Data	PTGI Items	6 Components
<b>Relating to Others</b>	Relationships are closer and stronger Support is the most significant recovery driver Learning how 'good' or 'not so good' people are Increased compassion and less tolerance	Count on others Feel close or distant to others Express emotions Compassion Effort into relationships Wonderful or disappointing others are Accept needing others	Count on others How wonderful people are Accept needing others Closeness with others More effort Developed new interests Change things that need changing Changed priorities
<b>New Possibilities</b>	Significant increase in new interests driven by support centres Survival strategies of 'stay active' and 'dreams and plans' as motivation to try something new	New interests New life path Doing better things with my life See new opportunities Try to change what needs changing	Do better things with my life New path Appreciate each day New opportunities Developed new interests
<b>Personal Strength</b>	I am stronger Increased self-reliance and can better handle difficulties Increased strength positively correlated with increased confidence Increase in self-awareness and 'put myself first'	Self-reliance Handle difficulties Accept the way things work out Strength and Weakness	Greater self-reliance Better handle difficulties Compassion for Others
<b>Spiritual Change</b>	'Spiritual' rather than religious change Spiritual growth borne of struggle with faith Spirituality expressed in prayer, going to mass and lighting candles Comfort from someone watching over me	Spiritual Understanding Religious Faith	Title: Spiritual Connection Spiritual understanding Religious faith Express my emotions
<b>Appreciation of Life</b>	I realise what is important I value less stress, my health and other people more Increased awareness and enjoyment of the 'little things' Appreciate each day and life itself Make the best out of life I am grateful	Priorities change Value own life Appreciate each day	
<b>Proactive Mindset</b>	Get on with it Stay Positive Positive Positioning of cancer		Accept the way things work out Change things that need changing Better handle difficulties
<b>Self-Worth</b>			Stronger than I thought Priorities change Appreciation of own life Compassion for others

## 6.2 Significant qualitative findings not captured by quantitative data

From the qualitative findings, only one theme directly relates to PostTraumatic Growth and that is ‘Positive growth from cancer’ and this data was analysed in Chapter 4 to answer to research question 1. However, three further qualitative themes were also identified which provide wholistic, rich and in-depth insight into the lived experience of cancer and recovery (reference Appendix 18 for a complete summary of all 4 qualitative themes).

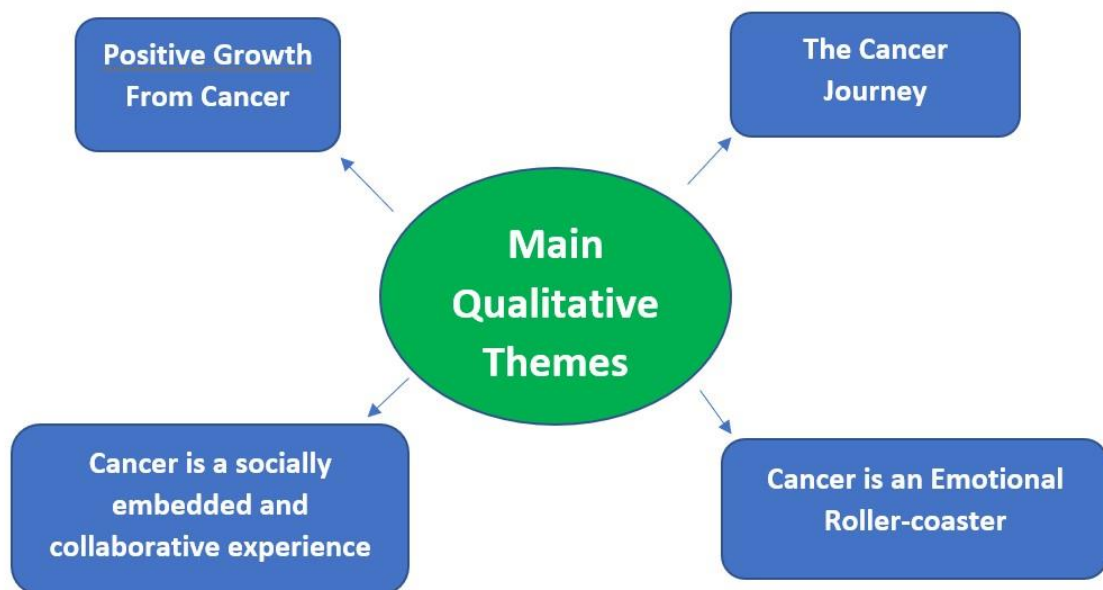


Figure 25: Thematic Map for 4 Main Qualitative Themes

The additional 3 themes are:

- The cancer journey
  - Cancer recovery as a socially embedded and collaborative experience
  - Cancer is an emotional rollercoaster
- 
- Cancer experience is a linear, chronological narrative marked by the 3 major transitions of diagnosis, treatment and recovery

‘The cancer journey’, presents a comprehensive overview of what a person goes through from stage one: cancer diagnosis to stage two: treatment and then to stage three: recovery (see Figure 26, which follows, for the thematic map developed during the research). Each participant recounted their ‘story’ in a linear, chronological fashion

punctuated by the dates of medical appointments, important events and reaching recovery milestones. However, any growth experienced was not a linear development but rather where survivors were dealing with growth and the negative impact of cancer at the same time (Grace *et al.*, 2015).



Figure 26: Thematic Map of The Cancer Journey and Positive Growth from Cancer

Cancer is not one singular trauma as the diagnosis, treatment, treatment effects, and/or fear of recurrence are multiple traumas that a cancer patient may face (Harding & Moss, 2018). In terms of diagnosis, most participants were diagnosed via the national free breast check programme and did not have any noticeable signs or symptoms though some did find a lump. This is borne out in the literature as there is a significant decline in breast cancer incidence in Ireland since 2008, and this is attributed to increased mammography (National Cancer Registry, 2018).

The national breast screening programme 'Breast Check' was set up in 2000 and offers free mammograms to eligible women every two years. According to the Breast Check website, by 2021, the programme will be extended to include women from 50 to 69 years old (2018). The image provided in Figure 27, below, from the Dear Diary project depicts a survivor finding a lump in their breast in the shower. It is a dark image that captures the shock that a person feels when they find a lump and consider it might be cancer.

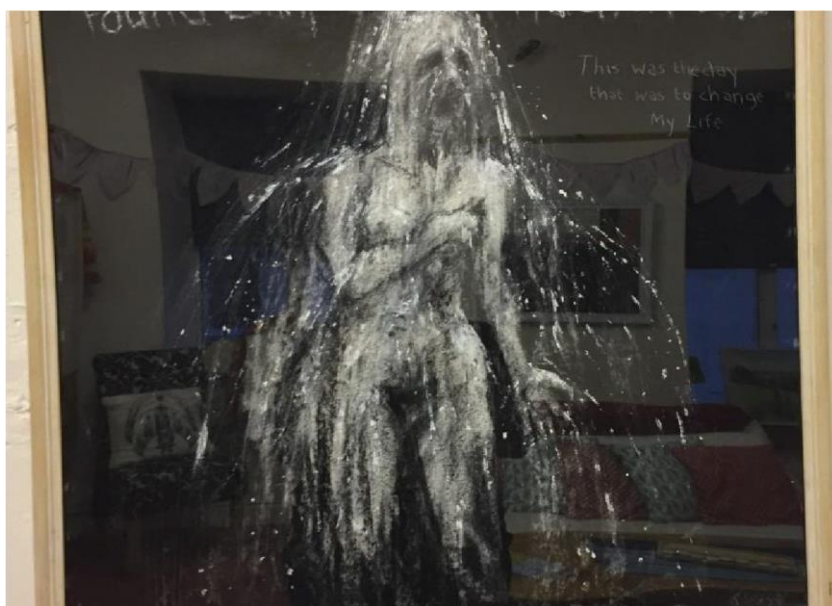


Figure 27: Dear Diary: Finding a lump

When a cancer patient is first diagnosed the main response is that of ‘freeze’ when not just talking about but even thinking about cancer can be quite difficult. The diagnosis experience was greatly impacted by the way in which the diagnosis was given by medical staff as well as the degree of social support felt by the individual. “The communication of an oncological diagnosis triggers a major emotional impact that makes the patient feel confused, numbed and vulnerable” (Faretta, 2018, p. 207). Farah was reassured by the direct and clear diagnosis she was given as well as the assurance that the cancer was contained.

“I met the first Consultant in Cork because I was transferred to Cork at that stage and I eventually got told this... you have cancer, and the good news is that it’s contained in the centre of the kidney and more than likely you’ll be mm... the thing that will have to be done with you is that you will have to have the kidney removed” Farah.

The second major transition/trauma concerns treatment where participants reported getting caught up in the busyness of appointments and scans. There was security in this ‘bubble’ of being closely monitored which was then burst by the end of treatment when they were discharged from hospital and medical monitoring is reduced. There is a significant decrease in the quantity of social support post treatment (Fong *et al.*, 2017).

At this stage participants often felt emotionally overwhelmed, lost, scared and exhausted as it was typically only at this point that they stopped to process what was happening to them. Shi *et al.* (2011, p. 2785), found that “the transition from active cancer therapy to follow-up has been identified as a period of disrupted adjustment during survivorship” as symptoms are not monitored. They argue that the symptom burden that survivors face at this time are worsened by the lack of medical monitoring.

The National Cancer Strategy 2017-2026 recognises the issue of end of treatment and highlights the need to have greater integration with primary care and local services to ensure seamless patient pathways before, during and after treatment” (Department of Health, 2017:6). Treanor & Donnelly, (2016) also advocate the use of care plans to assist with the transition from primary care (hospitals) to secondary care (GPs).

The third and final major transition was that of recovery. Participants felt they were treated differently by medical staff. Survivors can feel disconnected from the medical system after treatment as frequency of contact radically diminishes (Fong *et al.*, 2017). In terms of what helped recovery, the key driver was receiving and giving support. This came from asking for what you want, accessing services and helping others. Participants spoke of developing a survival mindset with a ‘get on with it’, ‘stay positive’ attitude. Positive positioning helped participants cope. Emphasis was placed on being proactive in your own recovery by talking with others (especially other survivors) and making plans. Normality was welcomed and reaching temporal milestones was celebrated.

On the other hand, participants also identified 3 specific dynamics that hindered their recovery. The first and main hindrance was the emotions of anxiety and fear. This primarily concerned the fear of recurrence and just living with the shock of cancer. As Faretta (2018) points out, this fear can be an adaptive reaction but when it is very high it leads to considerable distress for survivors. This fear can be triggered by aches and pains as well as review meetings and repeat scans (Rodin, 2018), which can be “anxiety provoking, time-consuming, and frustrating” (Foster *et al.*, 2018:93).

Laura recounts how she sees death in her own eyes, even years after having cancer. It illustrates the depth of darkness that a person can feel from having had cancer as well as the fear of death.

For Laura, she carries death in her eyes.

**Laura:** an I hate photographs an negatives, mm I felt like I look at some photographs of me ...I think I see death in my eyes. D'you know I said that to one sister recently don't show me the photographs I can see death in my eyes, but she said I don't know what you're talkin about.

But it's something you see d'you know, Ye not every photograph but lots of them.

**R:** Just around that time.

**Laura:** No, see it now.

**R:**No it's even still now?

**Laura:** Ye oh the photographs then they... funny enough they... it wasn't in the photographs then but it's now I've seen it.

**R:** An what's the difference, hope you don't mind me asking you – what do you see now that wasn't there six years ago?

**Laura:** I don't know I think my eyes were, were happier back then. **R:** Okay.

**Laura:** An they just look, they look dead but that's silly me cause I look in the mirror an they're not dead aha aha, mm I don't know how to explain that one perhaps even after years far away you can be goin back aha aha.

As part of the Dear Diary project, the artist Sheila Wood used a mirror and mask to evoke this concept of the dead eyes, see Figure 28 below.



Figure 28: Dear Diary: Dead Eyes – Mask on Mirror



- The diagnosis experience is the blueprint for recovery

The experience of 'diagnosis' was greatly influenced by how the medical staff treated participants. For those who had a relatively positive diagnosis experience, they spoke of the trust in the medical staff, acts of kindness (e.g. being given a cup of tea or looked at compassionately) and reassurance from the idea that the doctor had a plan. However, if the patients did not feel they were treated well by staff in that diagnosis meeting then the experience was highly negative. Participants cited reasons such as delayed diagnosis, unavailability of staff and felt they were being dismissed or treated coldly. Mairead below shook with anger and cried with anguish as she re told the story of her lengthy diagnosis stage.

“well he said (the Dr) since I saw the last one you’ve multiple tumours but he said I can’t say now until I aa do some surgery, but he said as I explained to you before I’ll do the keyhole cause I wouldn’t open you. So he said my secretary will be in touch with you. I’m going on holidays for six weeks he said so you’ll get a phone call, an he turned on his heel an he walked away....I just was just left with everybody listening (sob, sob) and I was so frightened (sob) and ...I look back on it now (sob). It’s so abusive (sob), an it’s so horrible” Mairead.

- Participants attribute major negative life events as the cause of their cancer

Participants identified a pre-stage where the cause of cancer was attributed to a major life event such as bereavement or significant stress. Both of these are driven by difficult and intense emotions including grief and anxiety. Nancy experienced a trauma as a child when her Dad died, and this marked an important transition of instantly growing up and facing mortality.

“even at a very young age it’s one of my boys said ‘Mummy you grew up when you were ten’, because I saw my Dad die. I know how temporary life is” Nancy.

Mairead below talks about the stress of her life and the struggle to let it go.

“it’s all stress, I’m a ball of stress with... am you surprised I’m stressed after all my story? ... I’m tryin to handle all this... I’m tryin to write it out of me. I’m tryin to, I’m tryin to cope with you know the story of life – that’s the crippler an it shouldn’t be. I must let it go, I can’t change the past God don’t I know but it’s easier said than done” Mairead.



According to Lang-Rollin and Berberich (2018 p. 14), “retrospective studies show a statistically relevant correlation between major life events and cancer incidence”. In addition, the number of stressors prior to illness can be a predictor of not just the quality of life, but also the late distress experienced by the cancer survivor (Faretta, 2018). Beliefs about the cause of cancer impacts on the quality and the approach to recovery. In an extreme example, in Iran, lack of understanding about cancer causes and religious beliefs can lead to isolation and loneliness of cancer survivors especially when they think that God gave them cancer as a form of punishment (Tabrizi *et al.*, 2016).

Many of the women in this study perceived the cause of their cancer as stress. Andersen *et al.* completed a study of the cause of cancer with a sample of 552 participants (2017). They found that 31% of participants attributed their cancer to stress/stressful life events and suggest that if you believe stress is the cause then it may increase the use of complementary medicine as this reduces stress (2017).

- **Cancer recovery is a socially embedded and collaborative process**

‘Support’ is the most significant recovery driver for participants in this doctoral research and this support not only impacts on the quality of their recovery but also on the survival strategies that participants used. If participants felt supported by others, they had a more positive experience whereas lack of support and loneliness was a hindrance which made recovery more difficult. For participants who had a positive relationship with staff i.e. found them relatable and kind as well as reassured from the idea that the doctor had a clear treatment plan, they had a positive recovery experience. This is supported by Rodin who found that “perceived support of health care providers at the time of trauma protects patients from traumatic stress” (2018, p. 2312). Therefore, for the cancer survivor, recovery is a socially embedded experience where external support influences their internal experience of recovery. Dunn *et al.* advocates that we need to “develop new understandings of cancer as not only a disease but also a context linked to individual, community, and society health and well-being” (2015, p. 3).

‘Support’ shaped the survival strategies participants used. For example, survivors positioned themselves positively in a downward comparison to their peers e.g. that their cancer type or treatment was somehow easier. This was a cognitive strategy to minimise and manage their experience. ‘Stay Positive’ was a prominent cultural survivor norm that was a key recovery driver. This led to a change in relationships (more positive

people and move away from negative ones) as well as internally thinking more positively. Dreams and plans is another strategy that survivors used to get well. Other people may participate in or even be the object of these dreams and plans. Depicted in Figure 29, below, is a thematic map showing how support impacts on cancer survival strategies. For example, the perceived negative emotions (of anxiety and fear etc) are a 'bomb' waiting to explode under the internal strategies used. This 'bomb' is fed by family stress, loss of mobility and lack of support etc.

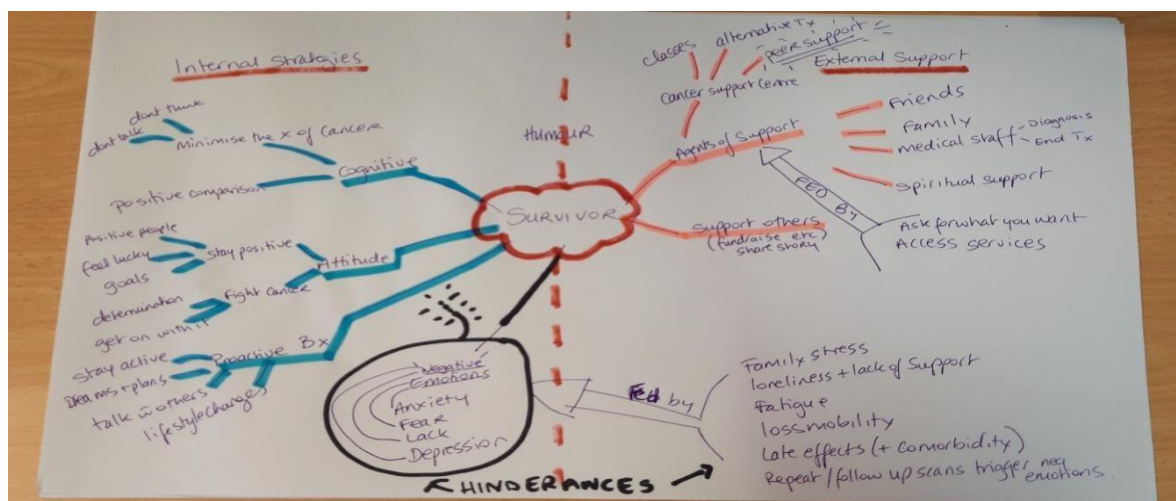


Figure 29: Thematic Map Support and Survival Strategies

- Key behaviours/attitudes that drive and hinder the dynamic of the recovery process

The qualitative interview data provides rich insights into the dynamics of how survivors recovered which indicate the movement/flow of recovery. Four specific strategies/approaches were used by survivors that helped them to recover. Table 27, provides an outline of these 4 areas with the most significant driving force as the receiving and giving of support. The example of Jessie below demonstrates proactive behaviour that helped her recovery. She was determined to get better. Jessie spoke of taking a year out to deal with her cancer and shows how important setting temporal milestones can be.

“...never left you know the treatment, anything stand in my way you know... I just said I’ll do this now for the year an I’ll just, at the beginning I said listen it’s goin to take a year here an this is my year you know... an nobody else’s” Jessie.

Table 27: Major themes of what helps Recovery

Recovery Major Themes	Recovery Sub theme
<b>Receiving and giving Support is the main driver of Recovery</b>	Access/accept help and specify what you want/need Connection with Survivor Peers who really understood me and gave me a lift Medical staff who are kind and relatable Strength from prayer and a spirit looking after me Alternative therapies and classes reduced treatment side effects and increased self-care Helping Others gives meaning and increases self-esteem
<b>Develop a ‘Survival Mindset’</b>	‘Get on with it’ attitude helps survivors to cope ‘Stay Positive’ as the mantra to wellness Positive Positioning makes cancer manageable Humour is a coping strategy that relieves tension
<b>Implement Proactive Strategies</b>	Be proactive by staying active, talk with others and make plans
<b>Pay Attention to Wellness Markers</b>	Celebrate normality and reaching temporal milestones

Whilst there were 4 strategies/behaviours driving recovery in a positive way, at the same time, there were three key factors which hindered and at times even blocked recovery (see Figure 30, below). These three themes also correspond to three different realms of experience namely; emotional (with the main feelings of anxiety and fear), physical (side effects and comorbidity issues) and relational (lack of support and family stress). This points to the complexity of understanding the different domains of life that impact on recovery.

These three facets are interdependent – a change in one, impacts on the other areas. For example, high family stress can increase anxiety and potentially make it more difficult to manage treatment side-effects i.e. less able to cope with pain, etc. A complete summary of all the qualitative themes are provided in Appendix 18.

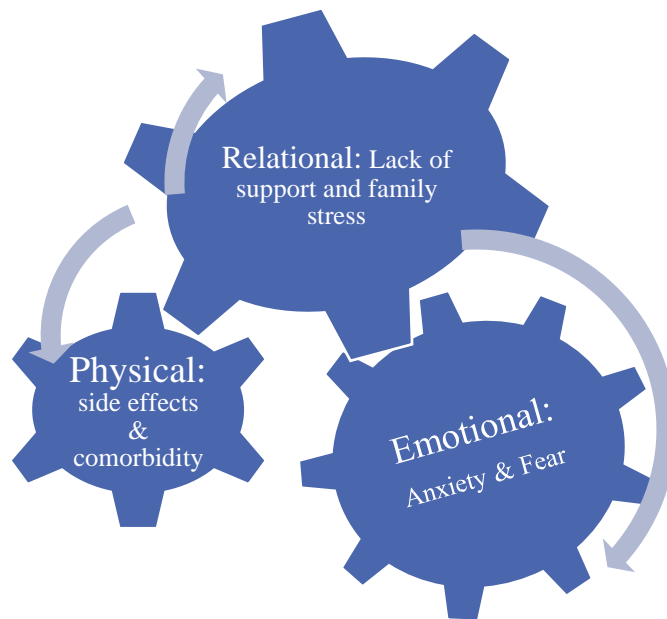


Figure 30: Interdependence of emotional, physical and relational hindrances to recovery

- Cancer Support Centres as a recovery driver for peer survivors to connect and to expand social networks

According to survivors, ‘peer support’ was the most important form of social support that helped their recovery where they felt connected and were really understood. The side effects from cancer and the treatment can leave a survivor with severe fatigue, weight gain and pain. This can lead to increased distance from their social network and yet it is this network that can help them make the lifestyle changes needed to deal with these negative late effects e.g. going for walks (Fong *et al.*, 2017). Participants typically accessed the cancer support centres when treatment ended. Cancer support centres play an important role in providing the physical space, services and opportunities for peer survivors to interact e.g. via social events, yoga or jewellery making classes etc. As Leah below expressed, even the physical environment of these centres felt safe and welcoming.

“Tis a great thing to have these Centres, you know because it does lift your soul. An if I was really havin a really bad day often came down, they put me on the chair an throw a blanket over me an I’d have a rest an d’ you know I know I feel the security of the house here” Leah.

Cancer support centres also provided alternative treatments and counselling which helped recovery in practical ways including; reduced nausea, improved bowel

movement, better sleep, feeling calmer and meeting new people. Ingrid below spoke of how she knew herself better because of the treatments and classes. Counselling sessions were also a great support to participants who at times did not want to burden their family and needed a safe space to express and make sense of their feelings.

“I’m happy. I think I’ve learned to know myself, I don’t think I knew myself in 2009. I don’t think I did but all the, the Mindfulness an all the mm classes that I did, art classes and whatever, they all helped me to bring me out of myself” Ingrid.

- **Cancer is an emotional roller-coaster**

‘Cancer’ is a highly emotive word and some participants spoke of their difficulty in just hearing or saying the word ‘cancer’. For others, cancer was associated with ‘the big C’ which made it even more ominous and dangerous. Cancer can lead a person to face and question their own mortality which is a very emotional (rollercoaster) experience.

During the one-to-one interview, each person was asked to describe their experience from diagnosis until the end of treatment by using an image, metaphor or saying. Participants used words and images that depicted the terror, the fear of the unknown, the lack of control and the intense emotionality. The term ‘roller coaster’ was used several times suggesting that their experience was intense, overwhelming and out of their control. Lorraine described recovery as that post wedding feeling – when the treatment is done, and you are dealing with all the emotions and the fear afterwards.

“It’s like panic you know when you’re getting’ ready for a wedding ... t’is afterwards when you’re married an’ the honeymoon is over you realise oh...right an you’ll never be the same with the cancer. ...The mental pain an’ the physical pain. ...Physical pain an’ mental pain. Mental pain you know was mm... I would say it was the nearest I came to probably a breakdown” Lorraine.

For most participants, emotions were typically frozen at the diagnosis stage with the key emotions being shock and fear. Participants coped by dealing with cancer at all i.e. to specifically not talk about it, not think about it, to minimise the experience and to focus on other people. The key emotions that underpinned how people coped were of anxiety (fear of recurrence and living with the shock of cancer) and of loneliness (dealing with cancer on your own, feeling misunderstood and physical distance from others). Jessica just refused to talk about cancer. Once cancer was diagnosed, most participants began a

very busy time of hospital care involving a combination of bloods, scans, surgery, radiation and hormonal treatments. The ‘busyness’ of dealing with treatments and side effects kept emotions at bay. The focus was on *doing* and not *feeling* as Lola states;

“Once you get used to the treatments life revolves around Hospitals” Lola.

However, at the end of treatment, participants felt lost, frightened and alone when they finished treatment as they left the ‘bubble’ and security of close monitoring by the hospital system. The unfreezing of emotions is at times overwhelming as survivors suddenly have the time to stop and emotionally process what has been happening.

“Reality only began to dawn towards the end of my treatment. While having treatment I just dealt with each day as it came” Haley.

Iris (below) speaks of the sheer fear of losing the hospital ‘lifeline’ and the huge uncertainty she is left with.

“It’s very frightening and you feel as though you can’t let go of me because if you let go of me now it will come back again... It’s like your lifeline is gone mm very nervous I was very nervous for her to say, that’s it you’re not coming back anymore. ...I have to come back ...you need to be told that you’re still alright. ... I didn’t like it at all. I wasn’t looking forward to it one little bit because I, I thought I, you can’t you can’t just leave me now”. Iris.

- **Anxiety, fear and depression perceived as ‘negative emotions’ that hinder recovery**

When participants were asked about what they thought hindered recovery, they noted they felt a ‘lack’ (support and finances etc) as well as the negative impact of treatment side effects – including; cognitive loss, lack of finances and medication issues. Perhaps the most significant hindrance was that of Anxiety, Fear (of recurrence and generalized anxiety) and Depression. These 3 ‘negative emotions’ were intensified further by several issues that participants identified as hindering their recovery; family stress (issues and friend loss), fatigue, loss of mobility and late effects (compounded by comorbidity). Participants also highlighted loneliness (physical and emotional distance from others) as well as lack of support as negatively affecting their recovery. Repeat/follow up scans triggered their anxiety. Rodin (2018) in his study of women undergoing mammography found that those with a history of breast cancer were much more distressed at the time of the scan than those with no history.

For some, like Iris below, they did not need a trigger for anxiety, they live with it all the time and as her description depicts, it is as if she is trapped in circle of fear;

“There’s always that feeling in the back of your head that it’s gona show itself again...though you’re watching, you’re continually say you’ve got a time bomb going off inside you that could go off at any time... in the back of my head it’s always gona be there... that feeling is never gona go away that’s like the scar that aha never heal even though you’re told you’re fine, you are in remission even though you’re told all those things you still don’t believe an I wish I could” Iris.

In my opinion, the three ‘negative emotions’ and the hindrances that feed them, can be viewed systemically – co existing and interdependent to each other. For example, the insomnia and muscle aches due to cancer/treatment might also lead to feeling tired and depressed etc. Further research is needed to investigate these areas in terms of what their relationships might be, the power dynamics and if there are other causal factors. In Figure 31, overleaf, you can see how these ‘negative emotions’ are fed by internal and external stressors. It is a two-way relationship and that the experience of the stressors is also fed by/influenced by the negative emotions that participants face.

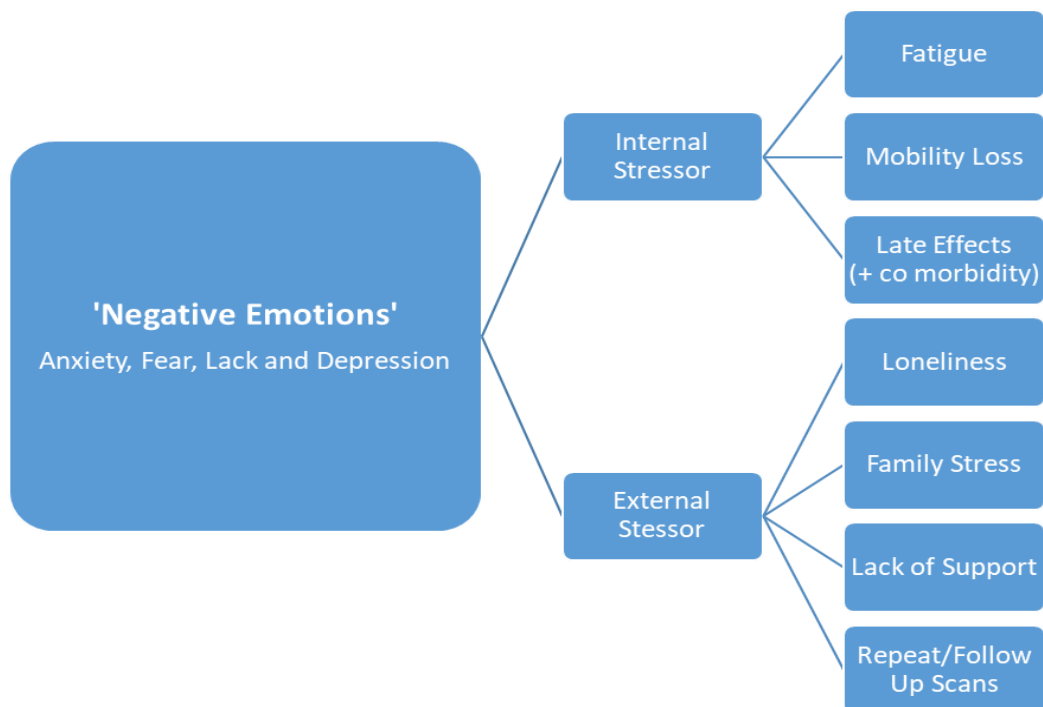


Figure 31: 'Negative Emotions' fed by Internal and External Stressors

'Get on with it', 'Stay Positive' and 'Stay Active' – positive recovery strategies but they negatively confine emotions. At times these strategies meant that survivors had a practical/move on attitude and minimised their experience. Another strategy that participants used to help them recover was to 'Stay Busy' via hobbies, lifestyle changes and/or by spending time with family. This helped Laura and others to keep moving forward and not to dwell on the cancer experience.

"Fine ye I think what I felt was keepin busy cause just you know keepin your mind off things... you didn't get time to worry too much you kept busy" Laura.

For the three strategies (*Get on with it*, *Stay Positive* and *Stay Active*), the emphasis is on thinking and doing and can potentially lead to a type of containment of emotions (rather than feeling). Detaching from and minimising emotions is a very useful survival strategy in the short term. In terms of the main negative impact from cancer, participants spoke of the anxiety and fear of recurrence that they live with. Therefore, for full health and quality of life there needs to be the right space at the right time in the recovery trajectory for participant to safely share and process their emotions to build emotional resilience. One criticism of the PTG model (Calhoun & Tedeschi, 2006), which was raised by Harding (2017), is the focus on coping as a primarily cognitive process rather than an affective response. This doctoral research highlights the survivor pattern of detaching/minimising emotions to deal with diagnosis and treatment. However, during the transition at the end of treatment the survivors then feel overwhelmed and that they cannot emotionally cope.

- Participants facing cancer maintenance, or a high risk of cancer recurrence have higher needs and lower PTG

The qualitative experience of recovery is affected by the severity of the cancer and the treatment. For those participants who had a positive prognosis, experienced straightforward treatment and were given hormonal treatment, their recovery was relatively positive. There is considerable variability in the distress response of patients which is linked to the seriousness of their prognosis (Frydenberg, 2014).

For participants who faced cancer maintenance (i.e. the cancer could be maintained but not 'cured' e.g. blood cancer), complicated treatment (i.e. infection setbacks or



additional surgery) with no hormonal treatment, recovery was hindered and experienced more negatively. This contrasts with the findings of Sharp *et al.* (2014) who studied cancer prevalence in Ireland over a 17-year period – to 2011 and found unmarried survivors and older survivors (especially those living alone and frailer) had higher supportive care needs.

For this research, whether the person was married or not did not impact on the extent of their needs. If a participant felt more isolated due to having recently moved, little to no social support or physical isolation required by treatment then this did negatively impact on the recovery experience. However, the other three factors that I mentioned had a greater impact (cancer maintenance, complicated treatment and absence of hormonal treatment). Romeo *et al.* (2017) found higher distress for participants who experienced combined therapy. However, I found that for those who had a poor prognosis and less treatment, they felt more distress as if little could be done for them.

## 7. Discussion and Conclusion

### 7.1 Answering the three research questions

At the core of this research project are 3 key research questions which will be explicitly addressed here;

1. What is PostTraumatic Growth (PTG) in the context of female cancer recovery?
2. To what extent does the PostTraumatic Growth Inventory effectively capture Irish women's experiences of cancer recovery?
3. How does the PostTraumatic Growth Inventory compare to semi-structured interviews in understanding women's experiences of cancer recovery?

- **Question One: What is PostTraumatic Growth (PTG) in the context of female cancer recovery?**

This answer is derived from the qualitative data and in particular from one of the four key qualitative themes – 'Positive growth from cancer'. The cancer survivors of this doctoral research did experience positive growth in 6 key areas. Five of these areas correspond to each of the existing PTG Factors of Relating to Others, New Possibilities, Personal Strength, Spiritual Change and Appreciation of Life. The sixth and final new area of positive growth proposed from the qualitative data is a Proactive Mindset. Table 11, below, provides an overview of 'Positive Growth from Cancer' from the qualitative data.

Table 11: Positive Growth from Cancer from qualitative data.

<b>Positive Growth from Cancer (5 Factors of growth from the PTG model, plus sixth is a Change in Mindset) and all its sub themes</b>	
Relating to Others	Relationships are closer and stronger Support is the most significant recovery driver Learning how 'good' or 'not so good' people are Increased compassion and less tolerance
New Possibilities	Significant increase in new interests driven by Support Centres Survival strategies of 'stay active' and 'dreams and plans' as motivation to try something new
Personal Strength	I am stronger Increased self-reliance and can better handle difficulties Increased strength positively correlated with increased confidence Increase in self-awareness and 'put myself first'
Spiritual Change	'Spiritual' rather than religious change Spiritual growth borne of struggle with faith Spirituality expressed in prayer, going to mass and lighting candles Comfort from someone watching over me
Appreciation of Life	I realise what is important I value less stress, my health and other people more Increased awareness and enjoyment of the 'little things' Appreciate each day and life itself Make the best out of life I am grateful
Proactive Mindset	Get on with it Stay Positive Positive Positioning of cancer

*Relating to Others* is the most significant area of PostTraumatic Growth. This is consistent with various studies (Balfe *et al.*, 2016; Shand *et al.*, 2015; Sharp *et al.*, 2018; Yi *et al.*, 2015). Survivor relationships were closer and stronger after having had cancer, and their social network underwent considerable change. The change in their social network was driven by two underlying mechanisms regarding how they now saw people as 'good' and 'not so good' as well as the increase in compassion coupled with less tolerance. The expansion of the social network was in part due to the social networking via the cancer centres.

Relationships were prioritised as more important and participants noticed they now talked more. They noted increased empathy, emotional growth and that they do not judge others. As survivors experienced their health improving, they wanted to 'give back' and support other survivors thereby becoming role models for others (Tedeschi *et al.*, 2018b; Threader & McCormack, 2015). In fact, the participants of this research

cited Helping Others as one of the key positive drivers of their own recovery – gave them an emotional lift and sense of purpose. ‘Friends’ were the main source of social support for participants. This finding is consistent with the research by Hasson-Ohayon *et al.* (2016).

The importance of relationships with others is reinforced by the fact that participants identified ‘support from others’ as the main positive recovery driver. Its importance is also underscored by the fact that social isolation/lack of support was also identified by participants as one of the major hindrances to their recovery. There is considerable evidence in the literature that the higher the social support a person has, then the higher PTG they will experience (Balfe *et al.*, 2016; Holtmaat *et al.*, 2016; Sharp *et al.*, 2018; Yi *et al.*, 2015). For the participants of this research, they highlighted the importance of accessing and accepting all help as well as asking for what you want.

The cancer centres provide cognitive support in the form of information sessions regarding stress management etc. but for this doctoral research the emotional support/connection from the centres and their friends was of much greater significance.

For this doctoral research, support from others impacted on the type of recovery strategies that participants used e.g. the emphasis on ‘positivity’ led to a focus on thinking positively and surrounding yourself with positive people. Joseph (2014) highlights how higher levels of social support predict high levels of adaptive coping including how the emphasis on positivity by survivors encourages this positivity with their peers.

The *New Possibilities* that participants experienced were local, social and enjoyable (rather than radical life changes). They took the form of hobbies, classes and travel. It was about developing hobbies and habits that made them feel good e.g. gardening. The new interests were facilitated and encouraged by the free services provided by the cancer centres. It was also driven by the recovery strategies of ‘stay active’ and ‘dreams and plans’ where being busy and setting goals encouraged participants to try something new. Participants noted the importance of setting and focusing on positive goals that you want to achieve as a recovery strategy. Goals were often ‘small’ such as making dinner or attending a child’s football match and were as Kumar and Schapira (2013) described it – a quest for normalcy.

Participants experienced increased *Personal Strength* with the phrase ‘I feel stronger’ frequently used. This is consistent with the PTG Model which states that *strength* is achieved through suffering (Tedeschi *et al.*, 2018). By crediting themselves for their recovery, they feel greater self-reliance – that they can better handle any future difficulties especially since any future problems seem smaller and more manageable than dealing with cancer. This new-found personal strength is positively correlated with greater confidence. For example, by feeling stronger, there is more confidence to speak up, care less about what others think and try new things. Some participants described this as ‘finding their voice’. Participants highlighted that they are more self-aware in terms of being able to know and name how they feel/think/behave. Along with self-awareness, participants also spoke of how they now prioritise themselves more.

In terms of *Spiritual Change*, there was a dichotomy from no growth to considerable change. For participants who did experience significant spiritual change, it was borne from the struggle with their faith caused by having cancer e.g. from being angry with and questioning God to finding faith again. From this doctoral research, the experience of cancer did cause participants to question their beliefs and for some it provided a way to make sense and cope with the experience. Spirituality found physical expression in prayer, going to mass and lighting candles with ‘prayer’ being the most significant activity. By actively taking part in spiritual rituals, they were actively doing something to get well (Vonarx & Hyppolite, 2014). Many took comfort from the sense that ‘someone’ was watching over them – be it God, or a higher power, a deceased relative or an angel. Though there was a dichotomy in terms of how much spiritual change participants experienced, what they did have in common was that the majority preferred the term ‘spiritual’ rather than ‘religion’.

Participants highlighted a *New Appreciation* of life with new priorities and a desire to ‘make the best out of life’. Participants had reflected, re-evaluated and re prioritised the way in which they live their lives. Participants reported ‘I realise what is important’ and spoke of a change in values which meant less stress and appreciating their health and other people more. They had a new sense of gratitude and appreciated ‘the little things’. The growth in appreciation of life is in part due to facing mortality and acknowledging how short life really is.

The qualitative data easily mapped to the 5 areas of growth that are predefined by the PTG model. However, there is also a sixth and highly significant growth area which is Proactive Mindset. This factor consists of positive attitudinal and cognitive changes as a result from having had cancer and the main features include; get on with it, stay positive and the positive positioning of cancer. Participants repeatedly used the phrase ‘get on with it’ when referring to how they dealt with cancer, managed fears of recurrence and general approach to life. Getting on with it was motivated by the quest for normalcy (Kumar & Schapira, 2013), driven by a desire to make things normal for themselves or others. ‘Stay positive’ was the mantra for wellness and seen as an important recovery driver by participants.

Positivity was fuelled by setting goals to focus on and feeling lucky to be alive. Positivity was both a consequence from having dealt with cancer and a way of dealing with it. When asked what advice you would give to someone recently diagnosed one of the top two most common answers was to ‘stay positive’. Dunne *et al.* (2017) advocate for inclusion of positive appraisal and seeking normality as a self-management strategy to aid recovery which is consistent with the findings of this research project. Positive self-talk contributes to PTG (Sharp *et al.*, 2018).

Participants positively positioned their cancer experience by using downward social comparison to compare themselves to others who were considered ‘worse off’ e.g. if someone had died or had more severe treatment. This downward comparison is a way to make sense of and ‘draw value’ from the cancer experience (Grace *et al.*, 2015).

- **Question Two: To what extent does the PostTraumatic Growth Inventory effectively capture Irish women’s experience of cancer recovery?**

In my opinion, the PostTraumatic Growth Inventory-42 does not effectively capture Irish women’s experience of cancer recovery. I think the PTGI would need to be significantly modified in order for it to be a valid research instrument and effectively measure the positive growth experienced by cancer survivors. The PTGI is a quantitative tool that measures the 5 Factors or areas of growth as defined by the PostTraumatic Growth Model (Tedeschi and Calhoun, 1996). I do think that the PTGI provides a way to numerically analyse and compare the results not just of the 5 growth Factors but also on a more granular level – the analysis of the specific inventory statements. This analysis especially coupled with the demographic data

provides insights into the experience of positive growth by survivors. However, in the main, I do not think that the PTGI-42 is an effective research tool with cancer survivors.

In my opinion, the PTGI-42 is adequate in assessing 4 of the 5 Factors namely; Relating to Others, New Possibilities, Personal Strength and Appreciation of Life. However, I do think there are issues in terms of how the PTGI measures Spiritual Change. In addition, there is a 6<sup>th</sup> Factor of growth for survivors derived from the qualitative data – Proactive Mindset which is not assessed by the PTGI (see answer to research question one in previous section). Lastly, the use of the PostTraumatic Growth Inventory - 42 in this doctoral research highlighted several issues with it as a research tool which would need to be addressed including; order effect, social desirability bias, wording accessibility, cognitive dysfunction and cultural pragmatics. Lastly, the PTGI does not address the physicality of cancer.

I want to begin with an overview of how the PostTraumatic Growth Inventory did capture women's experience of cancer recovery in this doctoral study. The PTGI as a quantitative tool, provides a way to numerically analyse and compare the data for each of the 5 growth areas. If we look at Table 28 overleaf, and the statistics for each of the 5 Factors of growth, Factor V: Appreciation of Life has the highest growth level where  $m=12$  which is relatively high given that the maximum potential score is 15. The most significant growth in this section concerns the high number of participants who now better appreciate each day since having had cancer (91%). The next area of growth is Factor I: Relating to Others which is closely followed by Factor III: Personal Strength. The fourth area of growth is Factor II: New Possibilities and the least area of growth is in Factor IV: Spiritual Change.

The analysis of quantitative data provided the opportunity to highlight small but significant insights. For example, the comparison of the mean PTG scores of breast cancer survivors to other cancers shows only a marginal difference (where mean is 74 for breast cancer and 76 for other cancers). This contrasts with other studies who report that breast cancer survivors have higher PTG levels (Joen *et al.*, 2015; Tedeschi *et al.*, 2018b). Using Spearman's correlation, findings show that there was no significant relation between PTG levels and either cancer stage or age or marital status which suggests that for this study, these 3 areas are not predictors of growth.

Table 28: Study Participants' Statistics for each of the 5 Factors of growth

Statistics		5 Factors of Growth				
		Relate to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation of Life
N	Valid	65	65	66	66	66
	Missing	2	2	1	1	1
Mean		27.45	16.74	15.36	4.85	11.97
Median		29.00	17.00	16.00	5.00	13.00
Mode		35.00	17.00	17.00	0.00	15.00
Cronbach's Alpha		.79	.79	.56	.71	.59
Std. Deviation		5.93	5.62	3.53	3.56	3.02
Possible Minimum		0	0	0	0	0
Possible Maximum		35.00	25.00	20.00	10.00	15.00
Actual Minimum		9.00	3.00	6.00	0.00	3.00
Actual Maximum		35.00	25.00	20.00	10.00	15.00
Percentiles	25	24.00	12.50	13.75	1.75	10.00
	50	29.00	17.00	16.00	5.00	13.00
	75	31.00	21.00	18.00	8.00	15.00

In the quantitative analysis of the individual statements and PTG levels, there was a significant difference between those who did and did not have children. More specifically, those who had children had higher growth levels in the areas of New Possibilities and Appreciation of Life. The statistics for each of the 5 Factors as well as the analysis of the PTGI coupled with the demographic data, did provide interesting insights and further understanding of growth and cancer recovery. However, the following issues detailed in the next section outweigh these benefits.

One key issue in measuring Spiritual Change using the PTGI is that there are only two statements used to assess this Factor; better understanding of spiritual matters and increased religious faith. This makes it psychometrically weak. Also, the statements refer to a religious context but there is a need to recognise and include existential changes. The participants of this study questioned the wording of 'religious' and more readily identified with 'spiritual'. To address some of these issues, in 2017, Tedeschi and Calhoun revised the Spiritual Change scale to include 4 additional items and it is now renamed 'Spiritual-Existential Change'.



There are several issues with the PTGI-42 as a research tool that were outlined in detail in Chapter 5 so I will only refer to them here. These issues concern; order effect, social desirability bias, wording accessibility, cognitive dysfunction, and cultural pragmatics. Each of the 21 paired statements began with a positive statement first and then followed by a negative one which resulted in order effect. If participants scored high on the first statement, they felt they needed to score lower on the second.

I believe that social desirability bias led to some participants thinking that they should answer the positive statement higher than the negative one. Another issue concerned the accessibility of the wording – particularly of the negatively worded statements which for some participants meant that they needed to take time to think through what the statement meant. This led to a cognitive burden (Bowling, 2005). It is well documented that cancer survivors experience issues with cognitive functioning after cancer/cancer treatment that can last up to 5 years (Carroll *et al.*, 2018; Ahles & Hurria, 2017) so the wording/phrasing needs to be accessible. Another issue is that of pragmatics and how the statements used in the PTG inventory may not always translate well into the Irish Culture (Rogan *et al.*, 2013). One such example of this is statement 20a - ‘I learned a great deal about how wonderful people are’ which may work in the United States more than in Ireland.

For the PTGI to more effectively capture women’s experience of cancer, it would need to be modified to incorporate the physicality of the cancer recovery experience. Cancer, cancer treatment and the resulting side effects are all a physical type of experience. Tedeschi and Calhoun (2014) acknowledge that the inventory does not include the health-related behaviour change experienced by cancer survivors. The PTGI would need to be modified to include an area of growth that takes into account not just the health-related behaviours but also the changes in their relationship to their body or cognitive ability (Akhtar, 2017).

- **Question Three: How does the PostTraumatic Growth Inventory compare to semi-structured interviews in understanding women’s experiences of cancer recovery?**

As outlined in the previous question, I do think that the PTGI does contribute to our understanding of women’s experiences of cancer recovery. It provides a way to measure and statistically analyse as well as compare each of the 5 Factors of growth. The participants of this study did identify with and express growth in all 5 Factors that the inventory measures. As outlined in Chapter 5, the analysis of the PTGI coupled with the

demographic information yielded some interesting insights regarding higher PTG in New Possibilities and Appreciation of Life if you had children. The Principal Components Analysis which was performed on the inventory data also provided useful insights on the areas of growth experienced by the participants in this study (the PCA is fully outlined in Chapter 6). This is a data reduction technique which provides further support for the significant growth for survivors in how they Relate to Others and support for a new Proactive Mindset Factor. In addition, this analysis also identified another new Factor entitled Self Worth.

From the qualitative data 4 key themes were identified; Positive growth from cancer (see Chapter 4), The cancer journey, Cancer as a socially embedded and collaborative experience and Cancer is an emotional roller-coaster. Though the primary focus of this research is on the experience of positive growth from cancer, the 30 semi structured interviews resulted in quite a substantial amount of data that painted a very comprehensive picture of what both cancer and recovery is like for a survivor. 'The cancer journey' was very much a chronological story of their experience from diagnosis to treatment and then to recovery (and even included a pre stage where participants traced back what they believed was the cause of their cancer).

'Cancer as a socially embedded and collaborative experience' highlighted the importance of social support as a key recovery driver that even influenced the type of recovery strategies that survivors used. When participants were asked what image or word they would use to describe their experience they frequently used 'roller-coaster', hence the theme of 'Cancer is an emotional roller-coaster'. It speaks to the intense emotional journey they experienced from the freezing of emotions at the diagnosis meeting to the unfreezing of them at the end of treatment and the transition to the 'new normal'.

Anxiety, fear and depression were seen as intense emotions that hindered recovery. The qualitative data was a window into the flow/dynamics of the recovery experience. There were 4 key drivers of recovery; receiving and giving support, develop a survival mindset, implement proactive strategies and pay attention to wellness markers. During recovery, the participants felt they were hindered by;

Physical side effects and comorbidity, lack of support and family stress and lastly dealing with the emotions of anxiety and fear.

The qualitative exploration provided a very comprehensive perspective on the cancer recovery experience and generated data that contributes to our understanding of underlying mechanisms of PTG e.g. the role of social support. The use of neutral questions e.g. ‘what was the main impact of cancer on you?’ encouraged a more spontaneous or natural description of growth rather than working within the confines of the 5 growth areas measured by the PTGI (Tedeschi *et al.*, 2018b).

When I first began to devise this research project, I was very interested in not just understanding cancer recovery and growth, but I also wanted to better understand how the PTGI and interviews would capture the participant experience. As previously discussed, the PTGI does an adequate job of assessing the 5 Factors and further statistical analysis generated interesting insights. However, major revisions are needed to the inventory for it to be more effective in assessing the experience of cancer survivors.

The interview data provided a much more comprehensive picture of the cancer recovery experience – not just the positive growth areas but also the key drivers that impact on this process. The qualitative analysis yielded insights into the process of PTG whereas the inventory is a measure of growth outcomes only. However, what I was really surprised by was the huge research value in combining the data.

Integrating the findings from both the inventory and the interviews provides a more complete and richer account of the positive growth experience of cancer survivors than one method could have provided alone.

The qualitative approach contributed to the understanding of Factor content validity. Participants did identify with all 5 areas of growth but the qualitative data highlights other areas that could be incorporated into future versions of the PTGI. One such example is the importance of ‘helping others’ as a key recovery driver which could be included in the ‘relate to others’ Factor. The convergence of findings from both sets serves to support and complement the findings.

The key aspects of the first two Factors of Relating to Others and New Possibilities are quite similar in content from both the inventory and interview data. The other three Factors of Personal Strength, Spiritual Change and Appreciation of Life are

much more detailed from the qualitative data than the quantitative. Another key difference is that the qualitative data highlights another new key area of growth – of Proactive Mindset that is not in the PTGI but is a significant area for cancer survivors.

## 7.2 Contribution to Research

- Understanding the dynamics that drive the growth in how survivors ‘Relate to Others’. The greatest degree of positive growth was in how survivors ‘Relate to Others’. This is a consistent finding in several studies (Balfe *et al.*, 2016; Holtmaat *et al.*, 2016; Shand *et al.*, 2015; Sharp *et al.*, 2015). From having had cancer, relationships were stronger and closer than before and generally were now prioritised more. Again, this is also consistent with the research literature (Shakespeare-Finch *et al.*, 2013; van de Spek *et al.*, 2013).

There is considerable evidence in the literature that the higher the social support a person has then the higher the PTG they will experience (Balfe *et al.*, 2016; Holtmaat *et al.*, 2016; Sharp *et al.*, 2018; Yi *et al.*, 2015). The relationship between social support and PTG is complex (Joseph, 2014). However, it is essential to understand the dynamics of the social system so that researchers, professionals and survivors themselves can harness their social systems to ensure the best recovery possible.

Survivors experienced radical changes to their social network and their relationships (Goodhart and Atkins, 2013). Both the qualitative and the quantitative data highlighted the significance of how they now saw people as ‘good’ and ‘not so good’ as well as the increase in compassion coupled with less tolerance. In my opinion it is this change in perception and increase in compassion/less tolerance that drove the expansion and change to their social networks. They were selective with who their friends were, and though their social network increased with new interests/cancer support centres, some friendships did dissipate.

From the quantitative data, 85% of survivors said they felt closer to others whilst 18% experienced greater distance. Though 91% had increased compassion for others, 25% said they learned how disappointing people are. On a practical level, the development of ‘new interests’ was a catalyst of the expansion of the survivors’ social network i.e. the new hobbies were not just about trying something new/learning a skill but provided the

opportunity to connect with new people. The importance of ‘new interests’ is also reinforced by the Principal Components Analysis where Component 1: Relate to Others included this item.

Most participants highlight the importance of asking for, and being specific about, what you want. Shakespeare-Finch (2013) noted that survivors express themselves more but, for this research, it is not just about speaking up more but rather about survivors being more self-aware (knowing and naming what they think/feel). It also concerns prioritising themselves more as is evident from the quantitative data where 87% of participants said that they valued their lives more.

From the qualitative data, Relate to Others was the Factor where survivors experienced the greatest degree of growth. However, in the quantitative data this Factor was secondary to Appreciation of Life. This at first appears like a contradiction, but on closer inspection it is the overall change in priorities, and the prioritization of relationships, that drives the relationship change. This prioritization is also confirmed by the item ‘new priorities’ which loads onto Component 1: Relate to Others using the PCA.

The importance of relationships as a positive recovery driver is also evident in Component 3: Spiritual Connection. Participants drew great comfort from their personal relationship with God/Spirit and the belief that someone was watching over them. In the research by Vonarx *et al.* (2014), their participants also turned to God or angels, etc, but it was about asking or bargaining for help, and participants performed religious rituals to obtain healing. For this study, it was about developing a relationship with spirit and drawing comfort from that. The physical expression of rituals (lighting candles and prayer) was a way to express emotions and the act of lighting a candle was a proactive action to manage their cancer.

- **Know your tribe and take your (social) medicine, it’s good for you!**

Close friends were the main source of social support which contrasts with other research that highlights the importance of spousal support (Romeo *et al.*, 2017; Moss and Harding, 2018). Survivors with a strong friend network (and even the perception of having one), experience higher PTG (Joseph, 2014; Fox *et al.*, 2014; Tedeschi *et al.*, 2018b). The people around the survivor provide an outlet to discuss and process the trauma which facilitates deliberate rumination that is necessary for PTG to occur

(Joseph, 2014; Koutrouli *et al.*, 2016; Nelson *et al.*, 2014). This means that a strong social network is crucial for PTG to occur.

It is not just the extent of social support that is important but also the quality of the relationships. Svetina and Nastran (2012) found that ‘communication’ and the extent of the emotional support available were positively correlated with PTG levels. For participants, ‘communication’ was a key driver of positive growth in terms of not just talking about/processing the trauma but also in being able to ask for what you want/need (and be specific about it). Some studies point to the importance of the cognitive support to help the survivor reappraise the trauma (Hasson-Ohayon *et al.*, 2016). However, for this research project, emotional support was far more important as a recovery driver.

Support from others influenced the type of recovery strategies that participants used e.g. the emphasis on ‘positivity’ led to a focus on thinking positively and surrounding themselves with positive people (which is supported by Joseph, 2014). This research also highlights the importance of having support from diverse channels e.g. friends, medical community, family or support from a deceased loved one etc.

‘Helping Others’ is a key positive driver of recovery which gave survivors an emotional lift and sense of purpose. Shakespeare-Finch *et al.* (2013) recognise the importance of this action and note that it is not accounted for in the PTGI.

- **Cancer is an emotional roller-coaster**

Survivors described cancer as an emotional roller-coaster – which depicts the intensity, out of control and overwhelming nature of the experience. At diagnosis, emotions were frozen as survivors felt mainly shock and fear. The ‘busyness’ of treatments and side effects kept emotions at bay. Harding (2017) criticises the PTG model (Calhoun & Tedeschi, 2006) for focusing on coping as a primarily cognitive rather than an emotional process. During the transition at the end of treatment, survivors began to emotionally process their experiences and this unfreezing of emotions was overwhelming.

Emotions were perceived negatively with anxiety, depression and fear specifically named as a hindrance to their recovery. These emotions are fed by stressors that are internal (fatigue, mobility loss and late effects) as well as external (loneliness, family stress, lack of support and repeat scans). Even the 3 key recovery strategies that

survivors identified as using potentially lead to a containment of emotions.

Participants sought to ‘Get on with it’, ‘Stay Positive’ and ‘Stay Active’ – all practical and proactive approaches but they do minimise emotion and focus on moving forward.

- **Cancer experience revolves around 3 major transitions of diagnosis, treatment and recovery**

Cancer is not a singular event but rather a series of multiple traumas (Harding and Moss, 2018). For the participants of this study, the experience of cancer revolved around the 3 major transitions beginning with diagnosis, treatment and then recovery. Broom *et al.* (2018) note that these are not 3 neat and distinct categories. For this study there was a degree of overlap, but they did occur in this order. The diagnosis meeting was pivotal in setting the expectations, the tone and the approach to treatment with the participants greatly influenced by the attitude and care of the medical staff i.e. if they were positive then so too were survivors (Rodin, 2018), the diagnosis meeting became the blueprint for recovery.

Survivors expressed their difficulty with the transition at the end of treatment when the busyness of appointments reduced, and the hospital reduced patient monitoring/contact. Participants experienced this as their ‘security bubble’ being burst and were lost and feeling overwhelmed with the emotions (Fong *et al.*, 2017; Shi *et al.*, 2011). During the third stage of recovery, participants were dealing with the side effects of treatment and living with the fear of recurrence that was sometimes triggered by repeat scans/review appointments (Rodin, 2018). They were treated differently by medical staff (Fong *et al.*, 2017) and looked to social support and developing a survival mindset to recover.

- **Predictors of PostTraumatic Growth**

Much of the research literature attempts to identify predictors of growth be it age, marital status or severity of disease etc. A recent piece of Irish research by Sharp *et al.* (2018) advocates the need for qualitative research to better understand what the factors are that lead to positive growth.

From the quantitative data of this research there was no significant relationship between age or cancer stage and PTG levels. This means that positive growth can happen at any age and at any stage of cancer. There was no significant relationship between PTG and marital status so whether the person was single or in a relationship did not predict a change in growth levels. Some studies suggest that PTG is higher for breast cancer

survivors than other cancers, but for this research study there was no significant difference.

However, the quantitative findings do indicate that having children means higher positive growth in Appreciation of Life and New Possibilities. In an Irish study of carers of head and neck cancer survivors, having children was associated with higher PTG levels (Balfe *et al.*, 2016). In the analysis of the 5 growth areas of this research and whether the participants had children, no significance was found. However, when the individual items of the PTGI were analysed in terms of whether participants had children or not, there were three significant findings.

Two of the findings concerns Factor II: New Possibilities. If participants had children, then they experienced change to a much greater degree in ‘establishing a new life path’ and ‘doing better things with my life’ than participants without children. The third significant finding concerns Factor V: Appreciation of Life. For participants who had children, they self-reported a greater degree of change in ‘I changed my priorities about what is important in life’ compared to those without children.

- [Redefining positive areas of growth](#)

The work of Yi *et al.* (2015) highlights the need to clarify the PTG construct and that using a mixed methods study incorporating quantitative and qualitative data is one way of doing this. The integration of qualitative and quantitative data from this doctoral work in chapter 6 has identified 2 new Factors or areas of positive growth; Proactive Mindset and Self-Worth.

Survivors in this research had a Proactive Mindset involving a ‘get on with it’ attitude to not only how they dealt with cancer but generalised to how they live their lives now. A ‘stay positive’ attitude was fuelled by setting goals and feeling lucky to be alive. This positivity was a consequence from having had cancer and a way of dealing with it.

Participants used downward social comparison with those who had a ‘worse’ cancer or treatment where they perceived themselves as ‘better off’ than those with a ‘worse’ cancer or more difficult treatment. Grace *et al.* (2015) suggests that this comparison helps them to make sense of the cancer experience. However, for this research, the comparison helped survivors feel lucky and appreciate what they have which was more in line with Treanor and Donnelly (2016) and Shakespeare-Finch (2013).



This new Factor of a Proactive Mindset developed initially from the qualitative data but was also a component identified from the Principal Components Analysis. The PCA attributes 3 inventory items to this area of growth including; accepting how things work out, changing what needs changing and better able to handle difficulties. The second new Factor or area of growth called Self-Worth emerged from the Principal Components Analysis. It is driven primarily by survivors feeling stronger than they were before and experiencing a change of priorities. It also concerns having a greater appreciation for their own lives and increased compassion for others.

- Refining the PostTraumatic Growth Inventory as a research instrument

Cancer survivors experience cognitive difficulties due to their cancer/treatment (Carroll *et al.*, 2018; Ahles & Hurria, 2017). The format of the PTGI-42 (with paired statements where the positive is followed by the negative), creates a cognitive burden (Bowling, 2005) which can make it difficult for survivors to understand the wording. Participants had difficulty in understanding the negatively worded statements e.g. 1b 'I find it difficult to clarify priorities about what is important in life'.

As stated earlier, in my opinion this contributed to social desirability bias (where it is socially 'right' to answer yes to the positive) and order effect (given that the negative was sequentially after the positive, it increases the likelihood of scoring lower on the negative statement). Given my experience with PTGI-42, and to offset the issues, I would suggest using a version of PTGI of 21 statements with a depreciation scale i.e. from -5 to +5. This was one of the suggestions made by Shakespeare-Finch *et al.* (2013) who in their qualitative research on the inventory noted the request from participants to have a negatively valanced scale so that depreciation can be accounted for. This would eliminate the issue of order effects and of trying to understand the negatively written statement.

'Culture' is an important contextual factor which must be accounted for when using the PTGI (Ho *et al.*, 2013; Scarinci *et al.*, 2012; Soo & Sherman, 2015). Revisiting the wording of the statements in terms of their pragmatics and fit for Irish culture (or whichever culture PTG is being used) would make it easier for participants to use.

For Spiritual Change, there is a clear dichotomy between those who did experience a significant degree of change in terms of a stronger religious faith (38%) compared with those who experienced no change at all (34%). With only 2 inventory items, it is psychometrically weak. Consistent with other studies, the findings of this study showed the lowest degree in growth in Spiritual Change from all 5 Factors (Fox *et al.*, 2014; Jaehee & Min, 2014; Bloom *et al.*, 2007; Romeo *et al.*, 2017).

Since 2017, Tedeschi and Calhoun revised this Factor to include four additional items and it is renamed to Spiritual-Existential Change (Tedeschi *et al.*, 2017). From my research I did not think there were enough inventory items to capture this Factor so the expansion of inventory statements may improve its validity. In addition, study participants consistently used the word ‘spirituality’ rather than religion, as the word ‘religion’ was associated negatively with rules and dogma.

### 7.3 Study Limitations

- Sample and Recall Bias

This research sample may be biased in terms of not including those who do not see themselves as cancer survivors, the potential of attracting ‘healthy’ participants, the impact of Centre Directors as gatekeepers and indeed the size of the sample. It is well documented that there are people who have had cancer and who do not identify themselves as survivors (Kumar & Schapira, 2013). Indeed, the very first participant interviewed as part of this research was quite angry that ‘women in remission’ was in the research question because for this person they were quite adamant that the cancer was now gone, and she was neither waiting nor expecting it to come back! This group would be less likely to use the services of the cancer centres (which is where this sample came from) and so may not be well represented in the sample.

The last piece to consider regarding potential sample bias is that the cancer survivors are volunteers and so there is the potential that those who are more active and in better health will take part (Yeahee & Min, 2014). I was very aware of the danger of sampling bias. This concern was even greater given that each of the cancer support centres wanted to act as the gatekeeper to the participants – they would share information about the project and set up interview/group sessions. To counteract this, I communicated clearly by email and in person the sample profile and as mentioned earlier, specifically asked them to consider diversity in their selection of potential participants.

In terms of the sample, I also want to raise the question of size and specifically what sample size is enough? In consultation with my supervisor, we estimated that 26 interviews would provide enough data to answer the research questions. In the end, 30 interviews were completed, and I can say with confidence that by interview 22 there was no additional new data. There is an argument to be made that data collection could have stopped here. If this research project had been commissioned and had defined resources and set deadlines etc then it would have been appropriate to do this. However, I only recognised data saturation via hindsight – finishing interview 26 and then looking back and recognising that there was no new data since interview 22.

As a novice researcher, I perhaps did not have the confidence to stop the interviews at this point. As a result, I had quite a substantial amount of data to transcribe and work with. This took considerable time and energy to process and highlights a lack of self-care on my part. However, I was also quite aware of how the interviews were a form of positive reflection for participants, so when 30 participants agreed to be interviewed, I felt a responsibility to follow through and conduct the interviews.

With only 67 completed inventories, it was appropriate to do a statistical analysis that was primarily descriptive. Since this project is designed as a piece of qualitative research, this level of quantitative analysis is appropriate. However, if this study was to be replicated and if there was a desire for a more detailed statistical review then a larger sample size is needed.

This research focuses on the self-reporting of cancer survivors and their own perspective of their wellbeing which can lead to recall bias (Treanor *et al.*, 2013). This could even be further hampered by the cognitive impairment/difficulties that cancer survivors experience especially in the first 5 years after treatment (Ahles & Hurria, 2017). Joseph (2012) questions how much actual growth takes place versus perceived growth.

- **Limits of demographic information:**

If this research was to be carried out again, further extension of the demographic questions is needed to enable a more detailed comparative analysis of the content of what people said by the profile of who said it. These additional questions could address socio economic status, employment status/profession, educational level and religious affiliation.

- **Low access of cancer support centres by working class and non- Irish nationals:**

A startling realization was the low level of access by non-nationals. Of the 67 participants, 65 were Irish nationals with only 2 participants being non-nationals (from the UK) and they were all Caucasian. This is even more surprising given the remit that was given to the centre directors in terms of having specifically asked them to seek diversity amongst participants (in terms of age, socio economic status and nationality etc). When the lack of representativeness was raised with the 4 cancer support centre directors, they confirmed that it was representative of the clients who use the centres at large, though not of the general population.

‘Language’ was cited as the barrier as the centres are predominantly English speaking and counselling is provided in English.

The services were provided free of charge, so they did not envisage a financial obstacle.

‘Culture’ was a potential second barrier that was named in terms of perhaps people of different norms/perceptions who do not expect that such a service exists. Each of the four cancer support centres are also located in towns which could impact the predominance of Irish nationals as there would be greater diversity in cities. The sample was predominantly middle class with a minority of three participants who were working class. Again, the directors confirmed that this was a norm for the centres.

People in more disadvantaged areas are diagnosed later, have poorer chances of survival, and have poorer diets with high incidence of smoking. A recent report on emergency presentation of cancer at Irish hospitals indicated that this happens to 3,000 people per year, and that 77% of those are diagnosed with an advanced cancer. It is also noted that people from “the poorest communities, and those over 65, are far more likely to have their cancer diagnosed as an emergency, and therefore at a late stage” (Irish Cancer Society, 2018, p. 5). The reality is that cancer incidence in deprived populations in Ireland are higher by 10% for males and 4% for females (Department of Health, 2017). This means that those individuals have an even greater need for cancer support services, but they are not accessing them.

The low access of services by the working class and non-Irish nationals is a major issue that warrants further investigation.

## 7.4 Considerations for Further Research

If this research project was to be replicated there are several recommendations in terms of the research process that would be worthwhile for the potential researcher to consider:

- Research in ‘real time’ over several time points

If time and finance allowed, this research would benefit from being carried out in ‘real time’ at different time points i.e. at diagnosis, during treatment, and in the recovery stage of the participants. This would reduce recall bias and help to track the experience of both the cancer and recovery over time. Research completed over several time points would also involve a risk of incompleteness by some participants.

For PTG, further research is needed on how it is impacted by time. PTG is potentially a coping response, and real growth takes place over a period of time. Therefore, further study on how PTG levels change over time is needed (Holtmaat *et al.*, 2016).

- Identify if cancer was experienced as a trauma and if other traumas occurred

According to the model of PostTraumatic Growth, for growth to occur, the survivor needs to experience cancer as a trauma and not all cancer survivors do – especially if they are diagnosed at Stage 1 and have less arduous treatment (Harding, 2017). The research did not ask the participants about if they perceived cancer as a trauma. In addition, participants may have experienced other traumas, which were not controlled in this study. If this research was repeated a query for the participant that asks if they see cancer as a trauma, and would enquire about other past traumas, would be of benefit.

- ‘Positivity’ and the experience of positive growth by cancer survivors

A key focus of this study is the exploration of how female cancer survivors experience positive growth. The participants of this study experienced significant positive growth. They reinforced the importance for them of staying and thinking positively as a key driver of their recovery. One potential avenue for future research in this area, is that the researcher could measure and explore positive attitude and the potential impact of this attitude (or lack thereof) on the experience of positive growth. In addition, another research direction is for the researcher to consider participants who either are not able to or do not wish to be ‘positive’. What is their experience of positive growth from cancer

and how does it compare to this current study of an atypical sample where Cancer Centres culturally value and promote ‘positivity’?

- Interview the investigator

Due to the difficulty in accessing cancer survivors, it was decided not to do a pilot study which would reduce the sample even further, choosing instead to do a detailed review after the first 2 interviews. If this study was replicated, the ‘Interviewing the Investigator’ technique could be useful. This approach involves the researcher taking on the interviewer and/or the interviewee role(s) for a recorded interview which provides an opportunity to test the questions and assess the kind of responses they elicit (Chenail, 2009). Then the interview questions can be refined before commencement of the research proper. This approach helps to further reduce instrumentation bias.

- The importance of researcher reflexivity and self-care

Given that my mother died from cancer in 2008, I had an acute awareness of potential researcher bias which could negatively impact any stage of the research process. To counteract this, I put provisions in place to minimize the risk of bias.

- A colleague at work was an effective ‘sounding board’, providing an objective voice, throughout the research.
- A series of memos were written up to track any comments, ideas or responses to the data.
- Great attention was paid to the type of literature I was reading.
- In order to reduce the chance of the bandwagon effect and authority bias, divergent sources of information were sought.

By being aware of and actively trying to minimize bias, I gained an increased awareness of and respect for the role of researcher reflexivity. Several researchers all advocate the importance of researcher reflexivity and reflective research (Hammersley, 2012; Trowler, 2012; Alvesson & Skolberg, 2007).

Reflective research requires first and foremost ‘careful interpretation’ where there is an explicitness and understanding of theoretical underpinnings and language. It also requires ‘reflection’ in terms of the researcher who needs to be aware of ‘the interpretation of the interpretation’ (Alvesson & Skolberg, 2007). I wanted to use personal life experience to help connect with, and hopefully really understand, the cancer survivors yet, at the same time, I wanted to minimise any potential research bias

especially in terms of interpreting the data. It is easy to argue that researcher reflexivity is important for any research. However, reflexivity is even more important for research that deals with traumatic and at times highly emotional experiences (which in this case is the experience of cancer).

*Self-care* is also of importance for any researcher but again even more crucial when the research involves working with participants and data that is highly personal, emotional and that deals with trauma. Prior to data collection, I made contact with a counsellor to discuss how the research was impacting personally and met with them a number of times during the research process. A core recommendation to any researcher working with participants that have had intense experiences, is to ensure they have a professional support structure in place whether that is counselling or coaching or another form of support.

- **Research as a potential therapeutic intervention**

Having worked as a case worker with vulnerable women and now in education for the last 20 years, I carefully considered what the role of researcher is e.g. in terms of how I related with/spoke with participants. In my Participant Information Sheet (Appendix 9), and at the start of the interviews, I took the time to clearly outline what my role as researcher was and I saw my job as connecting with people to gather/record their stories/data. However, over time, I realised that for many of the participants taking part in the research was experienced as a form of therapeutic intervention. It was an opportunity for survivors to reflect on and share their recovery experiences and one participant joking said at the end that I should put a sign up on the door to say ‘confessions taken here’. This self-disclosure/processing is a necessary ingredient for PTG to take place so the act of taking part in the research was also a chance for them to experience growth.

Shakespeare-Finch *et al.* (2013) noted how filling out the inventory helped participants with the rumination process. Several participants from this study thanked me for the opportunity to look back on their experience and see how far they came. During one data gathering session, a participant recounted how she was not getting on with her sister at the time but that when she thought back on her time when she had cancer that she remembered her sister used to bake her bread every day. This was something she

had forgotten about and she appreciated the reminder and of how she was going to thank her sister for that small act of kindness and explain what it meant.

## 7.5 Future Recommendations

The conclusion of this research has potential implications for professionals working with cancer survivors, for cancer support centre workers and for policy makers. The results of this study could inform; the kind of services provided and ways of working with cancer survivors. An underlying aim of this research project is that it would take the form of translational research i.e. moving knowledge from research into action (Nicholas, 2013, p. 193).

- **Maximise ‘social support’ as a resource to drive positive growth**

From this doctoral research ‘social support’ is the main driver of positive growth for cancer recovery. From the research literature, studies have repeatedly found that participants with greater social support have higher PTG levels (Balfe *et al.*, 2016; Holtmaat *et al.*, 2016; Sharp *et al.*, 2018). Strong social support provides an opportunity for the survivor to share their feelings, make sense of their experience and seek advice (Sharp *et al.*, 2018). Social support systems post-treatment improve emotional wellbeing (Fong *et al.*, 2017). Therefore, the support system of a survivor needs to be assessed in recovery (Roland *et al.*, 2013), and if it is low, then we need to provide professional services as a resource for the survivor.

Many participants from this study highlighted how peer-support groups, and helping fellow survivors, really helped their recovery. Tabrizi *et al.* (2016) studied the effect of supportive-expressive discussion groups for cancer survivors and found that they “played a protective role and had a significant effect on reducing loneliness, promoting their hope and enhancing the QoL” (p. 1060). Participants benefited from emotional support and Tabrizi *et al.* (2016) advocate for programmes and initiatives that promote this ‘companionship’ with people who understand what they are going through.

Based on the findings from this research, I would recommend formalising peer support as part of the survivor journey. This would mean legitimising, funding and training peer mentors. This would not only sustain survivors receiving this support,



but legitimise a peer-support role to recognise the person giving the support, and help them through recognising and giving meaning to their contribution.

- **Cancer survivors suffer late effects and need tailored initiatives/interventions**

Cancer survivors can potentially suffer a wide range of physical, emotional and cognitive late effects that last for years. In a research study on chronic cancer care patients, Frick *et al.* (2017, p. 4268) emphasised the many challenges faced by this survivor group including “difficulty in coping with the physical and psychosocial effects of treatment”. As a specific example, anxiety and adjustment disorders, as well as depressive episodes, are common in individuals who have experienced cancer. “Point prevalence’s are about 11% for depression and dysthymia, 10.2% for anxiety disorders” (Lang-Rollin & Berberich, 2018).

In Ireland, there are limited psychosocial oncological services, which was highlighted by the recent survey of Irish GPs O’Shea and Collins (2018) who emphasised the importance of extending these services.

To design these interventions for survivors several design considerations need to be accounted for including: the diversity of the population, the benefits of groupwork and that programmes are specific to survivor needs (cancer type and stage of survivorship). There are ongoing challenges for psychosocial oncology in terms of the diversity of clients it supports. In addition to supporting those who will recover from cancer and get back to a ‘normal’ life, there are others who will live with chronic conditions, live with an incurable cancer, face a second diagnosis and of course others who do not recover and die from cancer. Much more research is needed with each of these groups to establish the size of the populations and their specific needs if we are to develop policies and services to best serve them (Maher *et al.*, 2018).

Sharp *et al.* (2018) highlight that though PTG interventions have been developed, they are not used with cancer survivors and may need to be designed to suit specific groups. Support for psychosocial programmes to incorporate groupwork to facilitate PTG. The open sharing in groupwork can facilitate PTG as survivors can process their experience by deliberate rumination (Calhoun & Tedeschi, 2006; Ramos *et al.*, 2017).

Keane *et al.* (2018) also propose that initiatives need to be specific to cancer type and survivorship phase. Another important consideration is that survivors cope with cancer differently and so accounting for ‘coping style’ could better inform how a professional

could work with the survivor and the most appropriate recovery strategies to recommend. One such way to understand the different styles is to consider ‘monitors’ or ‘blunters’ (Rooij *et al.*, 2018). Monitors seek out detailed information but may experience more treatment anxiety. However medical information for blunters before a procedure could result in depression and anxiety (Rooij *et al.*, 2018). Therefore programmes need to be tailored to not only the cancer type and survivorship phase but also coping style.

- **Survivorship programmes needed that promote PostTraumatic Growth**

The model of PostTraumatic Growth lends itself to the clinical question of how do we promote growth? (Joseph, 2014). It calls for a focus on client centred approaches, relationship therapies as well as a recognition that growth comes from cognitive processing (deliberate rumination) as well as emotion focused coping.

Programmes are needed that increase and improve emotional and social support. Psychosocial interventions are not just about coping with or even living well with cancer but rather “psychosocial treatment for patients with a variety of cancers enhanced both psychological and survival outcome” (Spiegel, 2012, p. 589). These interventions not only decrease stress but can also change the physiological response to the tumour and improve healing (Spiegel, 2012). The programmes/initiatives need to be developed for both the survivor and their close family/friends (Buchman *et al.*, 2018; Roland *et al.*, 2013; Svetina & Nastran, 2012) – a systemic approach is needed as they are all experiencing a trauma, and all have the potential to experience PTG.

In developing these programmes/initiatives a key area of content is the inclusion of self-management techniques as well as programmes that assist the survivor in expressing feelings and thoughts. A programme could contribute to enhancing “sources of self-management support (i.e. healthcare workers, family and friends, accessing information, networking with other cancer survivors) and personal strategies for self-managing psychological, physical and social difficulties facilitate the resolution of problems associated with cancer survivorship thereby enhancing wellbeing” (Keane *et al.*, 2016, p. 1030).

Dunne *et al.* (2017, p. 2198) suggest specific self-management strategies that concern “proactive problem solving, goal and action setting, creating a healthy environment, reasoned decision making, self-motivating, self-sustaining, and activity-based coping”.

Cancer patients with generalized self-efficacy were found to have better emotional wellbeing, less depressive symptoms and an adaptive coping style (Hoffman *et al.*, 2012). By providing programmes that help participants to express their emotions, this will help them to process the cancer experience and reduce stress (Koutrouli *et al.*, 2016). In addition, survivors need to access interpersonal resources and their social network for support to help cope with cancer (Nelson *et al.*, 2014). Therefore, survivors need self-efficacy and to be able to ask for what they want need for them to seek and request social support. Positive thinking, positive appraisal and seeking normalcy are also beneficial self-management strategies that aid recovery (Dunne *et al.*, 2017).

In the last 5 years, a more recent trend is the growth in home-based programmes which stemmed from the call for self-managed care. Cheng *et al.* (2017) completed a review of 26 studies of home-based multidimensional survivorship programmes and found benefits including; a higher quality of life and specific improvements in fatigue, insomnia and anxiety. Further piloting/research is needed but this trend could gain momentum.

Tedeschi and Calhoun have developed the model of ‘Expert Companion’ as a therapeutic approach for professionals to work with trauma survivors and this could be modified for cancer survivors. It is an integrative approach drawing upon constructivism, existentialism and the narrative approach. It is essentially about taking on a companion role with someone who has experienced a trauma, listening and learning from the client and respects their knowledge base. The professional helps to dispel trauma myths and helps the client to understand/integrate their experience, develop a future focus and help them see the growth from loss. Some of the key tenants of the Expert Companion approach are expressed in the Posttraumatic Growth Workbook (Tedeschi & Moore, 2016). It is a self-help book which encourages the reader to tell the story of the trauma, explore the impact, manage emotions/thoughts and then to reframe the story by reflecting on the positive impact of the experience.

- [Improve the transition from hospital care to community and self-management](#)

The outlook for cancer research in Ireland looks very positive with the extensive work and recommendations coming forward from the National Cancer Strategy 2017-2026. New initiatives are being developed as a result. Take for example the ‘Delivering Bad News Well’ training by the National Cancer Control programme that is now provided

for doctors and staff in hospitals to address the issues with communicating diagnosis and prognosis. There is a shortage of health and social care professionals (which includes psychologists) to make the multi-disciplinary Psycho-oncology teams envisioned by the National Cancer Strategy a reality (Department of Health, 2017). Other researchers including Frick *et al.* (2017) in their study of chronic cancer care patients have identified the lack of integration between treatment services as an issue for survivors.

However, there are specific changes that could be made to improve the transition of cancer survivors from hospital care to community and self-managed care and one such change is the use of a care plan (Meade *et al.*, 2017; Treanor and Donnelly, 2016). Frick *et al.* (2017) recognise the need for Survivorship Care Plans to help increase communication between the patient and the cancer care team as well as highlighting the responsibility of the patient to self-manage their own health.

The need for a care plan is recognised at a European level. The Europeans Commission Joint Action on Cancer Control (Can Con) advocates personalized survivorship care plans which details care summary and outlines follow up care after acute treatment. It provides a check list of interventions for follow up care that will help smooth the transition from acute to follow up care (Lorenzo *et al.*, 2018).

A recent qualitative study by Meade *et al.* (2017) highlighted several key changes that could improve the transition from the hospital setting that involved having a consistent hospital contact person. Research participants wanted to meet the same health care worker at each review visit and to have a contact person between visits (and preferably the same person).

In the transition from hospital care, another change that would help this process is the adoption of a team-based approach to care and the use of multiple interventions. Buchman *et al.* (2018) report on the 3-year pilot INTEGRATE – a comprehensive cancer care programme in Canada. They found that multiple interventions with several stakeholders were more effective than a single intervention. In the US, a recent study recommended a “personalized approach to care in which survivors are triaged or risk-stratified to distinct care pathways based on the complexity of their needs and the types of providers their care requires” (Mayer and Alfano, 2019, p. 8). By creating a specific

care pathway, it would lead to improved/more focused individual care and reduce the demand on primary care providers.

To improve the transition from hospital care, there needs to be a formal transition/referral process to the cancer support centres. This could be achieved by the primary care providers informing survivors of the support centres and setting up their first appointment in the centres. The National Cancer Strategy 2017-2026 recognises the essential role that cancer support centres provide outside of the acute services.

However, it also notes that there is no official referral procedure to these centres from primary care and so cancer patients/survivors may not be aware of these services (Department of Health, 2017).

There is a significant decrease in the quantity of social support post treatment (Fong *et al.*, 2017) and poorer support contributes to survivors experiencing greater stress, depression and negative affect. The cancer support centres are places that help to foster and significantly expand the survivor's social network via their peer groups, classes and services.

Most participants in this research study identified the important role of the cancer support centres in terms of their recovery. Cancer support centres by their very nature are promoting PTG. The research participants emphasised the importance of connection, of support, of how much it meant to be with peers. This open sharing lends itself to people sharing their cancer stories, to open disclosure that will open the opportunity to reshape core beliefs and promote deliberate rumination thereby leading to PTG (Ramos *et al.*, 2017).

The centres therefore provide the environment where participants can positively appraise the trauma and benefit from modelling coping behaviour. Most participants accessed these centres only after treatment had ended. Many spoke of the difficulty of entering through the door that first time – afraid that as a centre is might be 'gloomy' and there would be talk of death and dying. There was also a hesitation re the initial visit in terms of it meaning that they really were cancer victims/survivors. The main support/benefits identified were meeting peers they could talk to, the general welcoming atmosphere, the individual counselling and the treatments – reflexology, massage and angel readings (in order of importance). Others did note the group activities such as art classes, mindfulness, yoga and tai chi though these were typically not accessed right

away citing needed confidence as an issue. It is also important to point out that the support centres typically reduce support to individuals between 2-3 years after treatment as they re-integrate into 'normal' life.

- Recommended changes to the PTGI to increase its validity as a measurement of positive growth for the survivor population

From working with this sample of 67 survivors, the mechanisms of the PostTraumatic Growth model were relevant and applied to their experience. Cancer was experienced as a trauma that shook their assumptive world (Tedeschi and Calhoun, 2006). Survivors advocated the importance of talking (self-disclosure) in driving their own recovery. The participants cited intrusive thoughts regarding fears around death or cancer recurrence especially in the early stage of recovery (automatic rumination). They also emphasised cognitive ways of managing the cancer recovery experience such as: think positive as well as making plans/goals (deliberate rumination).

However, there was one aspect of the model that did not quite fit with the survivor population concerning the emotional process that survivors experience (see the qualitative theme of 'cancer is an emotional roller-coaster' in 7.2). The PTG model does not capture nor account for the emotional intensity and the phases of same (e.g. the overwhelming emotions at the end of treatment) that a survivor experiences. The PTG model needs to be revised to incorporate emotional processing as a mechanism of growth as well as taking account of the phases of the emotional process.

The PostTraumatic Growth Inventory needs to be significantly modified for it to be a valid measurement tool of growth for cancer survivors. To better account for the experience of the cancer population, 'Proactive Mindset' and 'Self Worth' need to be added as 2 new growth Factors if replicated with a larger and more representative sample. The 'Appreciation of Life' needs to be removed as a stand-alone Factor. As evidenced in the qualitative findings and the Principal Components Analysis, individual inventory statements from this Factor drives the growth in other areas. For example, an increase in the 'value of my own life' drives the growth of Self Worth, 'appreciate each day' is part of New Possibilities and 'new priorities' is a significant element of Relate to Others as well as Proactive Mindset. 'Spiritual Change' needs to be modified to 'Spiritual Connection' to better represent the importance of the spiritual relationship. Figure 31, overleaf, provides a visual mapping of the original

PTGI to the recommended new Factors. This new PTGI would need to incorporate more aspects of the physicality of cancer including health related changes.

As stated earlier, I would also recommend a 21-item inventory with a valanced scale that also includes depreciation (Shakespeare-Finch, 2013) which would resolve order bias and social desirability bias. The inventory also needs to be revised to account for linguistic pragmatics to ensure it has the best cultural fit.



Figure 31: Map of PTGI Original Factors to Recommended Factors

- Call for further research and support into recovery for survivors with a difficult prognosis

We need more research with cancer survivors who live with/manage their cancer (certain blood cancers) or live with a high likelihood of it returning (triple negative breast cancer). This difficult prognosis negatively impacts their recovery experience and quality of life. In a conversation with one of the participants after they took part in the research, they felt that since it was so hard for them to find someone with their cancer and since there is more known about other cancers than theirs (in their opinion), that they felt forgotten about, less supported and more scared.

Broom *et al.* (2018) recognises those also ‘living with’ cancer – the incurable survivors who feel their life is about ‘waiting’ and managing symptoms and the fact that their needs as survivors are often overlooked.

From this study, 10% of participants had triple negative breast cancer and they were all told that it had a high percentage of reoccurrence, which made their fear of the future much greater. In addition, once chemotherapy and/or radiation had finished there was no other hormonal medication to take which heightened their insecurity about the future (as opposed to several other cancers where the person can take Tamoxifen or other such drug for 5 years to reduce the likelihood of reoccurrence).

- Further research needed to investigate how come those from disadvantaged areas and different ethnic backgrounds are not accessing cancer services

An unexpected surprise from this research project was the realization that typically people from disadvantaged backgrounds are not accessing the services of the cancer support centres. This was evident on completion of the 30 interviews when the demographics clearly showed that 28 participants were Irish nationals and only two were non-nationals – from the UK. All participants were Caucasian. When I met with each of the centre directors, they each agreed that the research sample was representative of their service users.

The reality is that cancer incidence in deprived populations in Ireland is higher by 10% for males and 4% for females. Behavioural risk factors are higher in disadvantaged areas where 35% are likely to smoke, and there is a greater incidence of obesity and binge drinking. These behavioural risks of people with low income/education leads to health inequalities (OECD, 2017). In addition, those with low income/education are not accessing services (Department of Health, 2017). Most support centres offer their services free of charge yet those from disadvantaged areas are not accessing them and further research is needed to identify and understand these access barriers.



## Appendices

- Appendix 1: Dear Diary Project
- Appendix 2: Workshop Flyer for CARE
- Appendix 3: List of Cancer Support Centres across the Southern Region of Ireland
- Appendix 4: PTGI-42
- Appendix 5: Questions for meeting with Care Cancer Centre
- Appendix 6: Organization Information Sheet
- Appendix 7: Organization Informed Consent Form
- Appendix 8: Poster used by Recovery Haven Cancer Support Centre
- Appendix 9: Participant Information Sheet
- Appendix 10: Participant Informed Consent Form
- Appendix 11: Interview Questions
- Appendix 12: Demographic Questions
- Appendix 13: Long Answer Questions
- Appendix 14: Key organisations and the Irish Cancer Strategy
- Appendix 15: Thematic Analysis Phase 2 Open Coding (346 codes)
- Appendix 16: Statistics Percentiles where N= 66
- Appendix 17: Findings of Core Beliefs Inventory and frequencies
- Appendix 18: Summary of the 4 Major Qualitative Themes
- Appendix 19: Quantitative Findings: Post Traumatic Growth Inventory (PTGI-42)
- Appendix 20: Quantitative Findings: Spearman Analysis and Principal Components Analysis

## Appendix 1: Dear Diary Project

This research project has taught me to ‘expect the unexpected’ and that sometimes you need to go off the plan to fully immerse yourself in what you find, and this is where Dear Diary came from. One of the interviewees arrived unexpectedly with 2 diaries. She said she had found them in a drawer that she was sorting out the previous week and that her instinct was to burn them but then she remembered she was going to meet me, and she literally threw them in my lap at the start of the research interview.

Though she had never written a diary before, the interviewee had decided to write down her thoughts and feelings everyday as she went through breast cancer and recovery for a year and a half. Though I was grateful that she had thought of me, I was initially unsure of what to do with them but knew I wanted to honour and include them somehow.

One year later, I contacted the artist Sheila Wood who was very interested in venturing into ‘trauma art’ – i.e. capturing the difficult and intimate moments of life like childbirth, or war or illness. I explained that I had an idea, 2 diaries and no funding but Sheila was delighted to get the diaries and the original plan was to create one art piece that would be shown as part of an upcoming festival. In June 2018, I visited Sheila Wood’s studio and found that she had created 27 art pieces depicting the experiences of this participant over one year of her life. It was clear that it had become an exhibition in its own right.

October is breast cancer awareness month. For the first 2 weeks of October 2018, the Dear Diary project was exhibited at the Tudor Artisan Hub in Carrick on Suir, Tipperary (<https://www.facebook.com/tudorartisanhub/>). For the last 2 weeks of October, the Dear Diary project was installed in the South Tipperary Arts Centre in Clonmel Tipperary (<http://www.southtippartscentre.ie/>).

Attendees could spend time with the art pieces and a 25 min audio background depicted sounds that the participant would have heard over that year e.g. radio programmes, the noise of hospital equipment, and getting the bus to treatment etc. Attendees could also listen to QR codes that would give the background to the project and an opportunity to hear the participant herself reading from her own diaries. The aim was to promote awareness of what a person goes through when

faced with cancer and recovery as well as starting conversations that would help lift the taboo of talking about cancer.

Figure A-1-01, below, shows the artist Sheila Wood as she set up the installation in Carrick on Suir, and Figure A-1-02 is a photo taken on the launch night of the exhibition.



Figure A-1-01: Dear Diary: Installation in Carrick on Suir, Oct 2018  
(with artist ,Sheila Wood)



Figure A-1-02: Photo of the Dear Diary Launch, Carrick on Suir, Oct 2018  
L-R: Noleen Doherty, Linda Fahy, Marie Walsh and Sheila Wood

Over 60 people attended the launch nights and 300 people in total went to see the exhibition. Attendees found it very real, very moving and as one of the attendees who was a cancer survivor said ‘it was like experiencing echoes from the past’. I had discussed with the diarist if she wanted to retain anonymity and that the project would be about any survivor’s journey and not just hers. Upon consideration, Noeleen chose to be a visible and vocal part of the project. Audio recordings were made of her reading from her own diaries and she read from her diary at both launch nights. In accordance with ethical requirements, Noeleen did sign an additional consent form to agree in writing that her name and image would be used and that she was giving up her anonymity.

The Dear Diary project was an unplanned but highly positive outcome from this doctoral research and as I mentioned earlier it taught me that with research you need to ‘expect the unexpected’!



## Appendix 2: Workshop Flyer for CARE

# Playshops!


Leap into 2012 this Spring with a series of playshops at the CARE Centre in Clonmel

All of the playshops are designed especially for **you!**  
They are an opportunity to reflect, explore and 'play' with like minded people in such areas as;

- **what life do I really want,**
- **who am I now**
- **how do I create change in my life?**

They are at an introductory level and all are most welcome.  
We will use a combination of discussions, creative activities and relaxation. The playshops are hosted by Marie Walsh and/or Marion Carroll from Limerick Institute of Technology.

All of the sessions are **free** and while you will get the most from taking part in all three, you can sign up for 1, 2 or all 3 playshops. Please speak to Ann or Eileen if you would like to attend or if you would like more information. **Go on - come play with us!**



### Playshop 1

#### **Visioning the life you really want.**

Friday March 9th, 10.30am - 12.30pm

February 1st is Imbolc which brings with it the Celtic tradition that celebrates the beginning of Spring and new growth.

This playshop is the perfect opportunity for you to reflect and envision the life you really want to live.

- What are your dreams?
- What kind of relationships do you really want?
- How about money and health?

Energy follows intention and now is exactly the right time to focus on what you truly want.

Hosted by Marie Walsh.

### Playshop 2

#### **Celebrating who I am right now**

Friday March 30th, 10.30am - 12.30pm

So who are you right now? As human beings we are ever changing ever moving in the flow of life. It might seem a total luxury at times to just take time out and create some 'me' space but that is exactly what this playshop offers.

It is the chance for you to stop and look at who you are celebrating your uniqueness.

Hosted by Marie Walsh and Marion Carroll.

### Playshop 3

#### **Empowering yourself**

Friday 20th April, 10.30am - 12.30pm

This playshop is a very practical session where you will identify concrete changes that you want to make in your life. We will explore how personal change happens and help you come up with specific steps that you can take to create the life you truly want.

Hosted by Marie Walsh and Marion Carroll.

**C.A.R.E.**  
CANCER SUPPORT CENTRE  
14 WELLINGTON STREET, CLONMEL  
052-6182667  
Email: [caresupport@eircom.net](mailto:caresupport@eircom.net)

### Appendix 3: List of Cancer Support Centres across the Southern Region of Ireland

<b><u>Cancer Information &amp; Support Centre</u></b>	University Hospital Limerick, Dooradoyle, LIMERICK Tel: 061 485163
<b>CARE Cancer Support Centre</b>	14 Wellington Street, CLONMEL, Co Tipperary Tel: 052 6182667 Email: <a href="mailto:caresupport@eircom.net">caresupport@eircom.net</a>
<b><u>CoisNore – Kilkenny Cancer Support Centre</u></b>	8 Walkin Street, KILKENNY Tel: 056 775 2222 Email: <a href="mailto:coisnorekilkenny@gmail.com">coisnorekilkenny@gmail.com</a>
<b><u>Cork ARC Cancer Support House</u></b>	Cliffdale, 5 O'Donovan Rossa Road, CORK Tel: 021 4276688 Email: <a href="mailto:ellen@corkcancersupport.ie">ellen@corkcancersupport.ie</a>
<b><u>Cork Brain Tumour Support Group</u></b>	Chemotherapy Day Unit, Cork University Hospital Wilton, CORK Tel: 087 146 5742
<b>Eist, Carlow Cancer Support Group</b>	The Waterfront, Mill Lane, CARLOW Tel: 059 913 8684 Email: <a href="mailto:info@eistcarlowcancersupport.ie">info@eistcarlowcancersupport.ie</a>
<b>Hope Cancer Support Centre</b>	22 Upper Weafer Street, ENNISCORTHY, Co Wexford Tel: 053 9238555 Email: <a href="mailto:mary@hopesupportcentre.ie">mary@hopesupportcentre.ie</a>
<b><u>Kerry Cancer Support Group</u></b>	Acorn Centre, Apartment 124, Tralee Town Centre Apartments, Main Street, TRALEE, Kerry Tel: 066 7195560 Email: <a href="mailto:kerrycancersupportgroup@eircom.net">kerrycancersupportgroup@eircom.net</a>
<b><u>Recovery Haven</u></b>	5 Haig's Terrace, TRALEE, Kerry Tel: 066 7192122 Email: <a href="mailto:recoveryhaven@gmail.com">recoveryhaven@gmail.com</a>
<b>South Eastern Cancer Foundation</b>	The Solas Centre, Williamstown, WATERFORD Tel: 051 304604 Email: <a href="mailto:info@solascentre.ie">info@solascentre.ie</a>
<b><u>South Eastern Cancer Foundation/The Solas Centre</u></b>	Williamstown, WATERFORD Tel: 051 304604 Email: <a href="mailto:info@solascentre.ie">info@solascentre.ie</a>
<b>Suaimhneas Cancer Support Centre</b>	2 Clonaslee, Gortland Roe, NENAGH, Co Tipperary Tel: 067 37403 Email: <a href="mailto:suaimhneascancersupport@eircom.net">suaimhneascancersupport@eircom.net</a>
<b>Suir Haven Cancer Support Centre</b>	Clongour Road, Clongour, THURLES, Co Tipperary Tel: 0504 21197 Email: <a href="mailto:suirhaven@gmail.com">suirhaven@gmail.com</a>

## Appendix 4: PTGI-42

### **PTGI – 42 (Growth & Depreciation)**

For each of the statements below, **use the scale provided below** the instructions to indicate the **degree to which this change occurred** in your life **as result of the stressful situation you identified** as having happened on the Life Events Report. The statements are arranged in pairs representing different types of change you might have experienced.

Within each pair ,

- you might **not have experienced either** change
- you might have experienced **both** changes to some degree, or
- you might **only have experienced one type** of change.

Consider both statements in each pair, then rate the degree to which, if any, you experienced each type of change using the scale below

- 0= I did not experience this change as a result of my crisis.
- 1= I experienced this change to a very small degree as a result of my crisis.
- 2= I experienced this change to a small degree as a result of my crisis.
- 3= I experienced this change to a moderate degree as a result of my crisis.
- 4= I experienced this change to a great degree as a result of my crisis.
- 5= I experienced this change to a very great degree as a result of my crisis.

Please **rate each item below** by placing the number from the scale above that reflects your choice in the space provided to the left of the item.

- \_\_\_\_ 1a.I changed my priorities about what is important in life.
- \_\_\_\_ 1b.I find it difficult to clarify priorities about what is important in life.
- 
- \_\_\_\_ 2a.I have a greater appreciation for the value of my own life.
- \_\_\_\_ 2b.I have less of an appreciation for the value of my own life.
- 
- \_\_\_\_ 3a.I developed new interests.
- \_\_\_\_ 3b.I have fewer interests than before.
- 
- \_\_\_\_ 4a.I have a greater feeling of self-reliance.
- \_\_\_\_ 4b.I have a diminished feeling of self-reliance
-

- 0= I did not experience this change as a result of my crisis.
- 1= I experienced this change to a very small degree as a result of my crisis.
- 2= I experienced this change to a small degree as a result of my crisis.
- 3= I experienced this change to a moderate degree as a result of my crisis.
- 4= I experienced this change to a great degree as a result of my crisis.
- 5= I experienced this change to a very great degree as a result of my crisis.

\_\_\_\_5a.I have a better understanding of spiritual matters.

\_\_\_\_5b.I have a poorer understanding of spiritual matters.

-----

\_\_\_\_6a. I more clearly see that I can count on people in times of trouble.

\_\_\_\_6b. I more clearly see that I cannot count on people in times of trouble.

-----

\_\_\_\_7a. I established a new path for my life.

\_\_\_\_7b. I have a less clear path for my life.

-----

\_\_\_\_8a. I have a greater sense of closeness with others.

\_\_\_\_8b. I have a greater sense of distance from others.

-----

\_\_\_\_9a. I am more willing to express my emotions.

\_\_\_\_9b. I am less willing to express my emotions

-----

\_\_\_\_10a. I know better that I can handle difficulties.

\_\_\_\_10b. I am less certain that I can handle difficulties

-----

\_\_\_\_11a. I am able to do better things with my life.

\_\_\_\_11b. I am less capable of doing better things with my life

-----

\_\_\_\_12a. I am better able to accept the way things work out.

\_\_\_\_12b.I am less able to accept the way things work out.

-----

\_\_\_\_13a. I can better appreciate each day.

\_\_\_\_13b. I appreciate each day less than I did before

-----



- 0= I did not experience this change as a result of my crisis.
- 1= I experienced this change to a very small degree as a result of my crisis.
- 2= I experienced this change to a small degree as a result of my crisis.
- 3= I experienced this change to a moderate degree as a result of my crisis.
- 4= I experienced this change to a great degree as a result of my crisis.
- 5= I experienced this change to a very great degree as a result of my crisis.

\_\_\_\_14a. New opportunities are available which wouldn't have been otherwise.

\_\_\_\_14b. Fewer opportunities are available than would have been before.

\_\_\_\_15a. I have more compassion for others.

\_\_\_\_15b. I have less compassion for others.

\_\_\_\_16a. I put more effort into my relationships.

\_\_\_\_16b. I put less effort into my relationships.

\_\_\_\_17a. I am more likely to try to change things that need changing.

\_\_\_\_17b. I am less likely to try to change things that need changing.

\_\_\_\_18a. I have a stronger religious faith.

\_\_\_\_18b. I have a weaker religious faith.

\_\_\_\_19a. I discovered that I'm stronger than I thought I was.

\_\_\_\_19b. I discovered that I'm weaker than I thought I was.

\_\_\_\_20a. I learned a great deal about how wonderful people are.

\_\_\_\_20b. I learned a great deal about how disappointing people are.

\_\_\_\_21a. I better accept needing others.

\_\_\_\_21b. I find it harder to accept needing others

Baker, J. M., Kelly, C., Calhoun, L. G., Cann, A., & Tedeschi, R. G. (2008) An examination of posttraumatic growth and posttraumatic depreciation: Two exploratory studies. *Journal of Loss and Trauma*, 13(5), 450-465.

## **Appendix 5: Questions for meeting with Care Cancer Centre**

Tuesday Sept 23<sup>rd</sup> 2014

Meeting with the Director:

After a general outline of the research proposal to ask the following questions;

1. General thoughts or feedback on my research outline?
2. What intrapersonal aspects do they work with in working with the clients? (self-efficacy, attitude, mental well-being, self-esteem, motivation, confidence etc)
3. What are the models/frameworks/theories of well-being do they work from in CARE?
4. Does CARE work with or provide a service to cancer survivors in remission?
5. When is someone classed as in remission or recovered? (how many years and is it different for different cancers?)
6. What instruments is the Centre aware of (or do they use) in assessing the wellness of clients? E.g. QoL measures, sense of meaning, positive attitude etc
7. Is CARE interested in being part of this research?
8. What other people in CARE's network would they suggest I talk with?
9. Any other comments?

## **Appendix 6: Organization Information Sheet**

### ***Post Traumatic Growth in women in remission from cancer***

**Marie Walsh, University of Leicester**

Thank you very much for your interest in this research on post traumatic growth in women in remission from cancer. I greatly appreciate you giving up your time in order to help me. I am undertaking this project as a part of a Doctorate in Social Science which I am studying with the University of Leicester. I work full time as a Lecturer with Limerick Institute of Technology and am a 3<sup>rd</sup> year Doctoral student in Leicester.

The project I am working on is about personal growth in women in remission from cancer. I am very interested in the concept of ‘post traumatic growth’ and how an individual despite a traumatic life experience such as cancer may still experience significant positive effects.

I approached your organization to take part in this research project because my target sample is participants who have/had accessed a cancer support centre in Tipperary. Other criteria for participants include; they are women, aged 21 years of age or older and are 2-8 years in remission from cancer. 26 participants are needed for this research project.

In this research study, each participant will take part in 1 session which will take approximately 1 hour and 30 minutes in length. This will consist of a 1 hour interview and 30 minutes to complete questionnaires. The focus of the session is on personal growth. The individual session will need to take place in an office at the cancer support centre.

In addition to providing an office space for the individual sessions, I am also asking for the support of the cancer support centre in disseminating information about the research. This could include any of the following; displaying a poster about the research at your Centre, uploading a brief description of the research on your website, informing your staff/volunteers of the research and letting your clients know via word of mouth. If an individual wishes to take part in the study they will contact the researcher directly.

As an organization, you can withdraw from the study at any time if you feel that is necessary. If you are happy to take part in the research, however, I will ask you to sign

a consent form giving your agreement. Your organization can still withdraw from the research after signing the form.

I would like to reassure you that the information which is obtained in this research project will be treated in the strictest of confidence. The research will be conducted in accordance with the Research Ethics Code of Practice of the University of Leicester. In addition, none of the data will be attributed to individuals or to your specific cancer support centre.

The data gathered during the research will only be used for my Doctorate thesis and my publications. As a researcher, my hope is that this study will provide an insight into the personal growth process experienced by women in remission from cancer.

Once again, thank you very much for your participation. If you have any questions at any stage of the project please do not hesitate to contact me.

Yours Sincerely,

Marie Walsh

Researcher

*(Email)*

*(Telephone Number)*

## Appendix 7: Organization Informed Consent Form

### *PostTraumatic Growth in women in remission from cancer*

**Marie Walsh, University of Leicester**

I \_\_\_\_\_, on behalf of the cancer support centre called  
\_\_\_\_\_, give consent for the Centre to take part in the above named project.

The research has been clearly explained to me and I have read and understand the organization information sheet. I understand that by signing this consent form I am consenting to the cancer support centre to participate in this research and that the organization can withdraw from the research at any time.

By consenting to participate, this means that the Centre will

a; offer support in disseminating the research description to both staff and client users  
and

b; provide an office space to carry out the individual interview sessions.

I understand that any data generated by the study is confidential and will not be used for any purpose other than the research project outlined above and any subsequent publications. The raw data will not be shared with any other organizations.

Name of organization: .....

Organization Representative Name: (please print) .....

Signature: ..... Date: .....

Researcher Name: Marie Walsh

Signature: ..... Date: .....

## Appendix 8: Poster used by Recovery Haven Cancer Support Centre

### Have your say!!!

How?

Have your say by taking part in a research project that explores women's experiences of cancer and recovery.

What?

To take part you need to be...

- ✓ Female
- ✓ 21 years+
- ✓ Have attended or currently attend a Cancer Support Centre
- ✓ Between 2 and 10 years in remission (i.e. at least two years since your last treatment)



This research project is being rolled out all over the Munster region and is run by Marie Walsh (a Lecturer at Limerick Institute of Technology) as part of her Doctorate in Social Science at Leicester University in the UK.

Where?

The research is a one-off session at Recovery Haven in Tralee on ***Tuesday September 6<sup>th</sup> from 12pm until 1.30pm*** You will be asked to complete questionnaires which contain questions about what your experience was like and what helped/hindered your recovery.

Why?

This research will help us better understand how women experience cancer and recovery. It is hoped these findings will help cancer support centres, policy makers and anyone who works with people affected by cancer.

Next Step?

If you would like to take part or find out more information, please contact (*Centre Director*) at (*email address*) or (*telephone number*).

## **Appendix 9: Participant Information Sheet**

### **Participant INFORMATION SHEET Phase 2: *Personal Growth in women in remission from cancer***

**Marie Walsh, University of Leicester**

#### ***Who is the researcher and what is the research project?***

Thank you very much for your interest in this research project on personal growth for women in remission from cancer. I greatly appreciate you giving up your time in order to help me. My name is Marie Walsh and I am undertaking this project as a part of a Doctorate in Social Science which I am studying with the University of Leicester in the UK. The project I am working on is about personal growth in recovery from cancer. Phase 1 is complete and involved gathering stories and opinions from 26 women who are in remission from cancer via interviews and questionnaires. Phase 2 began in July 2016 and is the collection of information from women all across the Munster area who have experienced cancer. This information will be used to help better understand how we grow and change as a result of a major life event such as cancer. If you are taking part in this research it is because you chose to answer the research call for participants and you fit the criteria; are a woman, are 21 years of age or older, are 2-8 years in remission from cancer and have accessed one of the cancer support centres in the Munster region. It is important to note that the researcher is neither a volunteer nor a staff member of any cancer support centre and is not affiliated to them in any way.

#### ***Consent Form***

You can withdraw from the study at any time if you feel that is necessary. If you are happy to take part in the research, however, I will ask you to sign a consent form giving your agreement and this is to be signed at the start of the interview. You can still withdraw from the research after signing the form.

By taking part in this research you are agreeing to meet me, the researcher for 1 group session which will involve the completion of a series of questionnaires. The session will last for approximately 1.5 hours. The questions will focus on your experience of cancer, remission and the changes that you have experienced and you will have the opportunity to ask me any questions you may have. This session will take place at the cancer support centre.

### ***Privacy, Confidentiality and Anonymity***

I would like to assure you that your personal details are kept private and confidential. The information which you provide in the questionnaires will be anonymized so as to protect your identity. This means that all identifying information will be removed and the information will be coded to protect your identity. Your answers will be not only unattributable to you but also to any of the cancer support centre (s) you may have/had contact with. In addition, where a verbatim quote is used, it will be unattributable to an individual. Only the researcher and her supervisors will have access to the research data.

In the write up of the research data an individual label will be assigned to each person so that no personal details are used. The audio recordings and the original questionnaires will be destroyed at the completion of the PhD process when the final thesis is approved.

The research project will be conducted in accordance with the Research Ethics Code of Practice of the University of Leicester.

### ***How will the research data be used?***

The data gathered will be used for my Doctoral thesis and any subsequent academic conferences and journal articles, academic blogs and in interviews where I am consulted as an academic expert on this topic.

At the end of this research project, an executive summary using the combined data of all the participants will be given to each of the participating cancer support centres.

### ***Additional support***

The questionnaires are an opportunity for you to reflect on your experiences. Should you wish to further explore anything that came up for you from the research session then you are encouraged to access the support services available to you at your cancer support centre. The researcher cannot offer any counselling or medical advice.

Once again, thank you very much for your participation in this project. If you have any questions at any stage of the project please do not hesitate to contact me, Marie Walsh at (*telephone number*) or at (*email address*).

If you wish to connect with a Leicester University contact regarding this research project than you can contact my Supervisor (*name/office address*), (*telephone number*) or at (*email address*)



## **Appendix 10: Participant Informed Consent Form**

### ***Personal Growth in women in remission from cancer***

**Marie Walsh, University of Leicester**

This is the Participant Informed Consent Form for the doctoral research project of Marie Walsh. This form must be signed before the research session can commence. It is important that you read the information below carefully and feel free to ask any questions that may arise.

#### ***What is the research project?***

The topic of this research project is on personal growth for women in remission from cancer which involves 2 phases. In phase 1, it concerns gathering stories and opinions from a sample of 26 women via interviews and questionnaires and this phase is complete. Phase 2 began in July 2016 and is the administration of questionnaires to women in the Munster region. This information will be used to help better understand how we grow and change as a result of a major life event such as cancer. This research is undertaken by Marie Walsh as a student of the Doctorate in Social Science at the University of Leicester in the UK. The researcher is neither a volunteer nor a staff member of any cancer support centre and is not affiliated to them in any way.

#### ***Privacy, Confidentiality and Anonymity***

I would like to assure you that your personal details are kept private and confidential. The information which you provide will be anonymized so as to protect your identity. This means that all identifying information will be removed and the information will be coded to protect your identity. Your answers will be not only be unattributable to you but also to any of the cancer support centre (s) you may have/had contact with. Only the researcher and her supervisors will have access to the research data.

#### ***Additional Support***

In phase 2, the questionnaires are distributed in a group session. The research is envisaged as an opportunity to reflect on what you have experienced. Should you wish to further explore anything that came up for you from the research session then you are encouraged to access the support services available to you at your cancer support centre. The researcher cannot offer any counselling or medical advice.

***Please read each of the following statements carefully and tick the box if you agree.***

The research has been clearly explained to me and I have read and understand the participant information sheet. ☐

I understand that by signing this consent form I am agreeing to participate in this research and that I can withdraw from the research at any time. ☐

I agree to complete the series of questionnaires as part of the above named project. ☐

I agree that the information gathered during the interview will be studied as part of the larger research data set and that this anonymized data will be used for the Doctoral thesis and any subsequent academic conferences and journal articles, academic blogs and in interviews where the researcher is consulted as an academic expert on this top ☐

I agree that at the end of this research project, an executive summary using the combined data of all the participants will be given to each of the participating cancer support centres. ☐

Participant Name: (please print) .....

Participant Signature: ..... Date:  
.....

Researcher Name: Marie Walsh

Researcher Signature: ..... Date:  
.....

## Appendix 11: Interview Questions

1. What was your experience of having had cancer?  
(date of diagnosis, cancer type, treatment and date of last treatment)
2. From your personal experience, what are the main effects of having had cancer? (prompt positive or negative)
3. When you think of the person you are now, how have you changed since having had cancer?
4. How did your experience of having cancer challenge your beliefs?  
What key beliefs were challenged? (the world, other people, themselves – beliefs about your abilities, strengths and weaknesses, future) In what way?(changed, dropped, new, re prioritised)
5. In terms of your recovery, what specifically has helped?
6. In terms of your recovery, what specifically has hindered?
7. What image, saying or metaphor would you use to describe from diagnosis to treatment?
8. What image, saying or metaphor would you use to describe recovery?
9. What advice would you like to give to someone who has just finished treatment?
10. Anything else you would like to add?

## **Appendix 12: Demographic Questions**

**Research Project:**    **How does ‘meaning making’ contribute to post traumatic growth in women in remission from cancer?**

**Researcher:**            **Marie Walsh**

**Date:**                    **August 2015**

Demographic Questions:

1. What is your nationality?
2. How old are you?
3. What type of cancer did you have?
4. What stage of cancer did you have?
5. Type of Treatment
6. Marital status
7. No. of Children

## **Appendix 13: Long Answer Questions**

### **Research Project Phase 2 by Marie Walsh,**

#### **Long Questions**

11. How would you describe your experience of having had cancer?

12. From your personal experience, what are the main effects on you of having had cancer?

13. Please describe if you have had any positive effects from having had cancer.

14. When you think of the person you are now, how have you changed since having had cancer?

15. How did your experience of having cancer challenge your beliefs?  
(e.g. spirituality, the world, other people, the future, yourself...)

16. In terms of your own recovery, what specifically has helped?

17. In terms of your own recovery, what specifically has hindered you?

18. What advice would you like to give to someone who has just been diagnosed with cancer?

19. Anything else you would like to add?

## Appendix 14: Key organisations and the Irish Cancer Strategy

To understand the landscape of cancer research it is important to note some of the key cancer organisations worldwide, in the EU and in Ireland. Within the World Health Organisation, there is an International Agency for Research on Cancer (IARC) which focuses on research for prevention and control. Another important body is the European Commission Joint Action European Partnership for Action Against Cancer (EPAAC) which has helped nearly all member states at this point to develop cancer strategies and cancer control programmes. This Commission has created a *European Guide on Quality Improvement in Comprehensive Cancer Control* and has made policy suggestions for all EU member states on the provision of survivorship care plans. The European Cancer Patient Coalition is also working towards creating an EU Survivorship Care Plan to map out the care and services needed for a life with and beyond cancer.

Within Ireland, cancer research is a growing sector. The Irish state funds cancer research up to €30m per year which is 20% of the health research budget. Much of the research in Ireland takes place in Universities and the cancer centres. The Health Research Board was set up in 1986 and their mission is to improve people's health and healthcare delivery via advancing health research and cancer research is under their remit. Another key player in cancer research and monitoring in Ireland is the National Cancer Control Programme run by the Health Services Executive (HSE) which aims to prevent and treat cancer as well as improving the quality of life for those with cancer and for survivors. Its role is to promote, influence and coordinate cancer research in Ireland. Other important groups worth noting are the Clinical Research Facilities and the HRB Trials Methodology Research Network as well as the National Centre for Pharmacoeconomics which assesses the cost effectiveness of drugs in Ireland. In terms of non-profit organisations, the Irish Association for Cancer Research (IARC) aims to encourage researchers from multiple disciplines in the biomedical field to share data and work collaboratively to ultimately reduce the cancer burden. On a national scale, the Central Statistics Office (CSO) publishes mortality data and the National Cancer Registry (NCR) collects data on the incidence and treatment of cancer.

In terms of Irish national policy on cancer, there are 3 important documents of note. The very first cancer strategy in Ireland was published in 1996 – Cancer Services Ireland: A

National Strategy. This was a seminal piece of policy which led to improvements in services, more specialists and a decrease in premature cancer mortality. The second major cancer policy change occurred in 2006 with the Strategy for Cancer Control in Ireland. This resulted in the development of cancer centres, changes to how cancer is diagnosed/treated, developments in cancer screening and reduced smoking. The following year, the National Cancer Control Programme (NCCP) led to changes in cancer services including faster access and more specialised services. The third and most recent policy change concerns the National Cancer Strategy 2017-2026 which recognises that “There is now and increased awareness and demand for additional support for cancer patients after diagnosis, including survivorship programmes and psycho social services” (Department of Health, 2017, p. 6). This new strategy is underpinned by a commitment to prevention, a focus on continuum care and patients are cared for by multidisciplinary teams. This new government strategy proposes to establish a National Cancer Research Group for the first time ever which will coordinate and encourage cancer research activities. In response to this strategy, the Irish Cancer Society recently began a new initiative to set up 5 Collaborative cancer research centres. The first of these is called Breast Predict which was launched in October 2013 and includes researchers from academia as well as clinical trial information and the aim is to better understand breast cancer disease and treatment and develop new approaches to dealing with it.

There are 4 key goals outlined in the National Cancer Strategy 2017-2026 and the one that specifically relates to cancer survivors is to ‘Maximise Patient Involvement and the Quality of Life of those living with and beyond cancer’. It emphasises the importance of psycho social care of cancer survivors and proposes to develop survivorship programmes that will “emphasise physical, psychological and social factors that affect health and wellbeing, while being adaptable to people with more specific survivorship needs following their treatment” (Department of Health, 2017, p. 9). Survivors will be given treatment summaries and care plans with a view to encouraging self-management and to assist with quality of life. The National Strategy points to the importance of individualised care and the significance of psychological and social needs of cancer survivors after treatment.



## Appendix 15: Thematic Analysis Phase 2 Open Coding (346 codes)

Name	Files	References
Positive Recovery Driver	69	835
Intuition trust	2	2
Surgery	1	1
Access support	11	14
Read self help	1	1
Support from survivor peers	20	29
Mindset	54	234
Positivity	50	127
Get on with it	23	63
Letting go	7	10
Life at my own pace	7	9
Mindfulness	7	8
Power of choice	4	5
Keeping a distance from cancer	4	5
Understanding transience	2	2
Acceptance	2	2
Strong work ethic	1	1
New coping skills	1	1
Recovery as a series of steps	1	1
Alternative Treatments	25	36
Increasing confidence	4	6
Self awareness	2	2
Music	3	5
Putting yourself first	4	8
Independence	3	4
Hobbies	13	17
Early Diagnosis	1	1
Counselling	12	20
Physical Health returning	2	3
Increased distance from cancer	8	11
Helping Others	17	31
Social Connections	19	42
Social Support	50	117
Writing feelings	4	5
Determination	18	26
Lifestyle changes	8	10
Proactive behaviour	10	21
Medical support	35	77
Free mammogram	1	1
Spiritual Comfort	33	70
Personal Strength	12	15
Self belief will be ok	1	1
Psychic confirmation	1	1
Humour	15	33
Asking for what you want	11	12

Name	Files	References
Staying busy	11	20
Dreams and plans	6	7
Work being flexible	4	4
Pet	2	2
Talking	13	20
Story of breast reconstruction	1	1
Prosthetic	1	1
Get back to normal	3	4
5 year marker	3	3
Comparison to others	8	13
Deep breathing	1	1
Travel	2	2
Reconstructive surgery	1	1
Stay active	1	1
Looked after myself	3	3
Family motivation	3	5
Distractions	2	2
Try new things	2	2
Being fit when diagnosed	1	1
Cognitive behaviour programme	2	3
Go with your feelings	1	1
Positive impact from cancer	65	606
Retired early	1	1
Self image improved	2	4
Finding my voice	16	30
Change in mindset	41	123
Cope more now with stress	6	7
Increased social network	19	27
Personal Strength	30	61
Increased confidence	17	35
Stronger religious faith	25	55
Relationship change	33	60
Appreciation of Life	38	79
Family positive impact	4	6
Increased compassion	26	41
Learn new skills	6	8
New Opportunities	25	48
Listen to my body more	4	6
Time to reflect	2	2
Look after my health	14	14
Time for myself and others	4	4
Joy of recovery	2	2
Negative Impact of Cancer	66	545
Guilt	1	2
challenging	1	1
Friend loss	4	5
Spirituality loss	4	6

Name	Files	References
Friends	4	7
Vulnerability	2	3
Loss of independence	1	3
Medication Limitations	6	7
Treatment Pain	5	7
Loss of Sex Drive	3	4
Loneliness	10	15
Hair Loss	19	29
Further surgery needed	3	5
Physical Difficulties	24	40
Body image	11	16
Family Strain	19	34
Sleep disruption	2	6
Tiredness	29	43
Self view	6	6
Anxiety	43	125
Limitations of where you can go	5	6
Nausea	6	7
Side effects of treatment	21	47
Job Loss	2	2
Mastectomy	9	16
Taste poor	3	4
Weight gain	2	2
Weight Gain	2	2
Weight	1	1
Weight loss	1	2
Weight Gain	1	1
Repeat Scans	11	26
Scans	4	4
what I can wear	1	1
Travel	1	1
Depression	7	9
Financial cost	4	4
Go out less	2	2
Concentration loss	1	1
Don't want to go to Dr	1	1
Cope less with stress	2	3
Insurance changes	1	1
Aged me	2	3
Emotional pain	2	3
Identity loss	1	1
Infertility	2	4
Menopause	1	1
Hysterectomy	1	1
Feeling misunderstood	3	5
Back pain	2	2
Work Retirement	8	12

Name	Files	References
Dealing with medical system	1	1
Motivation low	1	1
Move from carer to patient	1	2
Could not do what I wanted to	6	6
Loss of control	1	1
Less confidence	1	1
Coping with cancer	62	541
Shock	4	6
Felt overwhelmed	2	2
Acceptance	9	10
Got on with it	21	66
Lonely	10	14
Fight	10	15
Go away	1	1
Self punishment	2	2
Tips and tricks	4	5
Culture and minding the sick	1	1
Anger	6	9
Self belief	4	5
Put up a front	2	5
Determination	6	9
Acupuncture	2	2
Focus on others	3	6
Emotional recovery	4	4
Minimise cancer	18	38
Don't think about it	9	14
Humour	11	21
Worry after cancer	15	22
Positivity	24	52
Trust in medical staff	6	11
Staying in the now	3	4
Don't talk about it	9	19
culture Irish and worry	2	2
Spirituality	27	59
Less spirituality	3	3
Impact of family	19	38
Anxiety	27	58
Hobbies	2	2
Not knowing where it was going	1	1
Stay busy	2	3
Felt devastated	2	2
Frightening	8	9
Hindrance to recovery	55	326
Stress	2	2
Fear	4	4
Friend loss	2	2
Spirituality Loss	2	3

Name	Files	References
Loneliness	2	3
Work	1	1
Comparison to others	1	1
Weight gain	1	1
Could have been diagnosed earlier	2	4
Delay in treatment start	5	7
Lack of exercise	1	1
Misperception of treatment	3	4
Lack of support	18	49
Lack of Finances	6	6
Feeling down	10	19
Problems with reconstructive surgery	3	5
Side Effects from Treatment	22	38
2nd diagnosis	4	5
Family Stress	14	22
Fatigue	10	14
Not having a break	1	1
Physical Isolation	2	2
BCRA Gene diagnosis	1	3
Worry	30	54
Comorbidity Issues	10	18
Major negative life events during cancer	9	17
Medical Staff	1	3
Negative relationship with medical staff	4	15
Waiting for test results	3	4
Located between hospitals	3	3
Medical relationship after treatment	1	3
Delays with treatment	3	3
Change in oncologist	2	2
Being given the diagnosis	1	2
File lost	1	2
Appointments cancelled	2	2
Not enough explanation of diagnosis	2	2
Medication hormone	2	2
Communication poor	1	1
Story of prolonged diagnosis	1	1
Self belief and esteem	4	4
Physical contact from others	1	1
Sex life	2	3
Triple X and no hormone therapy	1	2
Use of internet	3	4
Not talking	2	2
Me	5	5
Fertility adjustment	2	2
physical changes	3	3
Need to be more positive	2	2
Hard to accept help	1	1

Name	Files	References
Slow recovery	2	2
Lack of knowledge	3	4
Changes in Beliefs	59	314
Spiritual Beliefs	44	88
People	25	41
Cancer recurrence	23	38
Life	19	31
Self	10	25
Self doubt	5	6
Facing mortality	11	24
The future and money	13	20
No Changes to Beliefs	15	18
Values change	7	11
Powerlessness	4	5
Belief in the body	3	5
Belief I would be ok	3	4
Emotion	2	2
Care varies	2	2
Diagnosis	45	176
Initial reaction to diagnosis	43	115
shock	34	42
Fear	11	13
Denial	7	9
Fight	6	9
Why me	7	9
Proactive	6	7
worry	4	6
Acceptance	3	5
Resentment towards Dr	2	3
Surprise	3	3
Anger	2	3
Guilt	3	3
Positive	1	1
The diagnosis experience	28	61
Advice for someone newly diagnosed	63	111
Self View after cancer	53	90
Major life events before cancer diagnosis	25	69
Image Metaphor or Saying	29	68
Image or Metaphor of part 1 experience	29	64
words	17	24
Image	11	21
Metaphor	5	5
whirlwind	1	1
Image or Metaphor of part 2 experience	2	4
words	25	33
image	10	10
Treatment Experience	25	58

Name	Files	References
Conceptions of cancer	21	53
View of cancer now	19	37
View of cancer before	10	16
Emotive power of cancer terminology	12	35
hearing or saying cancer	8	16
Fear of the Big C	5	8
Perception of cancer after recovery	5	5
Cancer as death	2	2
Cancer as a serious illness	2	2
Prosthesis	2	2
Initial Symptoms	23	29
Cancer Support Centre	18	29
Request for more opening hours	2	4
Barriers to attending	4	6
When cancer support centre is accessed	11	14
1 year after diagnosis	5	6
At diagnosis	3	3
After treatment	1	3
During Treatment	2	2
Positive impact of cancer support centre	4	4
Connection	39	76
Therapies	21	37
Classes	17	26
Specialist Information	2	2
Writing	1	1
Energy	1	1
New coping skills	1	1
Medical staff to recommend support centres	1	1
Transition at the end of treatment	21	29
Lifestyle changes from having had cancer	22	27
lifestyle changes for family from having had a person with cancer	2	2
Cancer Cause	11	17
Neutral Impact of having had cancer	9	16
Major negative life events after cancer	7	13
Self view before cancer	6	11
Requests and Observations	7	10
More research on rare cancers	1	1
Preparation needed for return to work	1	1
Nutrition Advice	1	1
Mammogram Cut off	1	1
Banks	1	1
Counsellors	1	1
Care varies	2	4
Cancer Type	9	9
Ovarian cancer	1	1
Colon cancer	1	1
Kidney cancer	1	1

Name	Files	References
Breast cancer	6	6
Story of cancer experience	6	6
Story of Mary McPhillip	1	2
Don't lose your identity	2	2
Story of hair loss	1	2
Story of someone looking out for me	1	1
Story of singing during 1st blood transfusion	1	1
Story of being your own advocate	1	1
Story of dead eyes	1	1
Story of having a human being to talk to	1	1
Story of cancer description	1	1
Story of cancer short description	1	1
Story of diagnosis	1	1
Story of weight gain	1	1
Story of changing the chair	1	1
Story of transition at end of treatment	1	1
Story of Majella O Donnell on TV	1	1
Story of going to a counsellor	1	1
Story of party and wig	1	1



## Appendix 16: Statistics Percentiles where N= 66

Statistics Percentiles (n=66)						
		Relate Other	New Poss	Personal Strength	Spiritual change	Appreciation of life
N	Valid	65	65	66	66	66
	Missing	2	2	1	1	1
Mean		27.4462	16.7385	15.3636	4.8485	11.9697
Std. Deviation		5.93462	5.61604	3.52851	3.55719	3.02283
Minimum		9.00	3.00	6.00	.00	3.00
Maximum		35.00	25.00	20.00	10.00	15.00
Percentiles	25	24.0000	12.5000	13.7500	1.7500	10.0000
	50	29.0000	17.0000	16.0000	5.0000	13.0000
	75	31.0000	21.0000	18.0000	8.0000	15.0000

## Appendix 17: Findings of Core Beliefs Inventory and Frequencies

### • Relationships with others

In terms of relationships with others, as shown in Table A-17.1, 37 participants said that the experience of cancer led them to examine their assumptions about why people think and behave the way they do from a moderate to a very great degree. In addition, 50 participants said that they examined their beliefs about their relationships with others from a moderate to a very great degree.

Table A-17.1 'I seriously examined my beliefs about my relationships with other people' and cumulative frequency

Because of the event, I seriously examined my beliefs about my relationships with other people					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	not at all	6	9.0	9.0	9.0
	to a very small degree	4	6.0	6.0	14.9
	to a small degree	7	10.4	10.4	25.4
	to a moderate degree	17	25.4	25.4	50.7
	to a great degree	19	28.4	28.4	79.1
	to a very great degree	14	20.9	20.9	100.0
	Total	67	100.0	100.0	

### • Self: personal strengths and self-worth

55 participants said that the experience of cancer led them to seriously examine their beliefs about their own abilities, strengths and weaknesses (from a moderate to a very great degree), as depicted in Figure A-16.1 below.

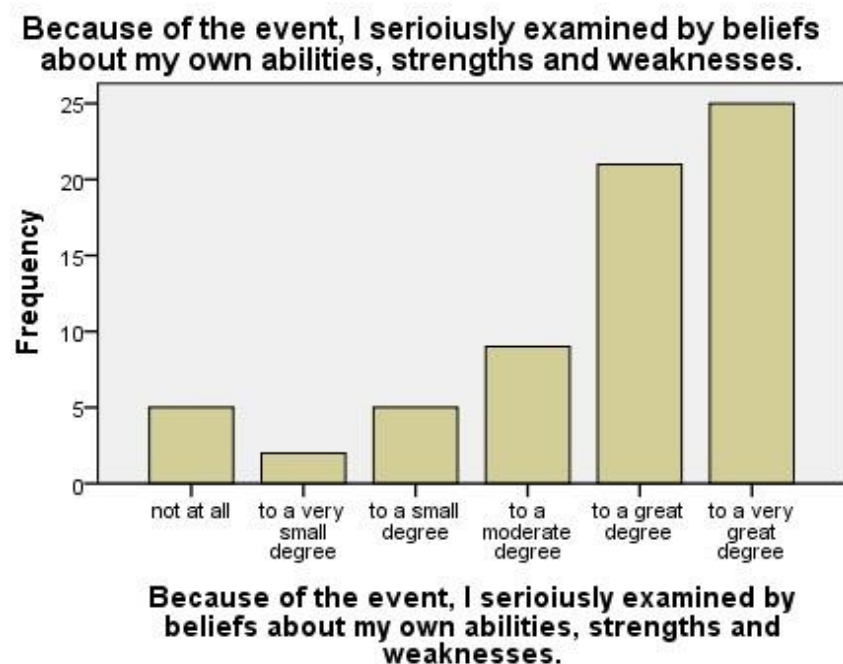


Figure A-17.1: 'I seriously examined my beliefs about my own abilities, strengths and weaknesses'

48 participants stated that they seriously examined their beliefs about their own value or worth as a person with 37 people experiencing this to a great/very great degree – as detailed in Table A-17.2.

Table A-17.2: ‘I seriously examined my own beliefs about my own value or worth as a person’ and cumulative frequency

<b>I seriously examined my own beliefs about my own value or worth as a person</b>					
		<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	not at all	8	11.9	11.9	11.9
	to a very small degree	4	6.0	6.0	17.9
	to a small degree	7	10.4	10.4	28.4
	to a moderate degree	11	16.4	16.4	44.8
	to a great degree	18	26.9	26.9	71.6
	to a very great degree	19	28.4	28.4	100.0
	Total	67	100.0	100.0	

• **Expectations for the future and meaning of life:**

50 participants stated that the experience of cancer led them to seriously examine their beliefs about the meaning of life (from a moderate to a very great degree). This is elaborated in Table A-17.3 below.

Table A-17.3: ‘I seriously examined my beliefs about the meaning of my life’ and cumulative frequency

<b>I seriously examined my beliefs about the meaning of my life</b>					
		<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	not at all	6	9.0	9.1	9.1
	to a very small degree	4	6.0	6.1	15.2
	to a small degree	6	9.0	9.1	24.2
	to a moderate degree	15	22.4	22.7	47.0
	to a great degree	17	25.4	25.8	72.7
	to a very great degree	18	26.9	27.3	100.0
	Total	66	98.5	100.0	
Missing	Missing	1	1.5		
System	Total	67	100.0		

Beliefs about expectations for the future were identified by 41 participants to a great degree/very great degree – reference Figure A-17.4 for more details.

Table A-17.4: 'I seriously examined my beliefs about my expectations for my future' and cumulative frequency

<b>I seriously examined my beliefs about my expectations for my future</b>					
		<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	not at all	4	6.0	6.1	6.1
	to a very small degree	4	6.0	6.1	12.1
	to a small degree	4	6.0	6.1	18.2
	to a moderate degree	13	19.4	19.7	37.9
	to a great degree	16	23.9	24.2	62.1
	to a very great degree	25	37.3	37.9	100.0
	Total	66	98.5	100.0	
Missing	Missing	1	1.5		
System	Total	67	100.0		

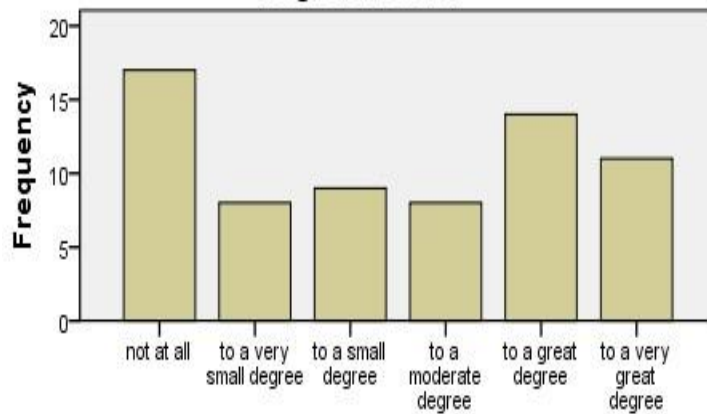
### • Spiritual or religious beliefs

25 participants said that they examined these beliefs either not at all or to a very small degree which accounts for 37.31% of the sample. In contrast to this, 25 participants also said that they examined their spiritual or religious beliefs to a great degree or very great degree which also accounts for 37.31% of the sample. Reference Table A-17.5 for more information and Figure A-17.2 for a graphic representation of these responses.

Table A-17.5: 'I seriously examined my spiritual or religious beliefs' and cumulative frequency

<b>I seriously examined my spiritual or religious beliefs</b>					
		<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	not at all	17	25.4	25.4	25.4
	to a very small degree	8	11.9	11.9	37.3
	to a small degree	9	13.4	13.4	50.7
	to a moderate degree	8	11.9	11.9	62.7
	to a great degree	14	20.9	20.9	83.6
	to a very great degree	11	16.4	16.4	100.0
	Total	67	100.0	100.0	

**Because of the event, I seriously examined my spiritual or religious beliefs.**



**Because of the event, I seriously examined my spiritual or religious beliefs.**

Figure A-17.2: 'I seriously examined my spiritual or religious beliefs'

- **Fairness and Controllability**

An examination of beliefs concerning how things happen to people and how fair or controllable they are is not significant as for both cases 40 participants rated it from not at all to a small degree.

## Appendix 18: Summary of the 4 Major Qualitative Themes

The qualitative data consists of 30 semi-structured one-to-one interviews and 37 long answer questionnaires. The 4 key themes are:

- The cancer journey
- Positive growth from cancer
- Cancer recovery as a socially embedded and collaborative experience
- Cancer as an emotional roller-coaster

*The Cancer Journey* provides a comprehensive overview of the experiences of the survivor experience. It begins with a pre-stage where participants identified the cause of their cancer to major negative life events such as bereavement. This theme also highlights some of the key aspects of the following 3 stages of Diagnosis, Treatment and then Recovery. Figure A-18.1 below shows the thematic map for T1 and T2.

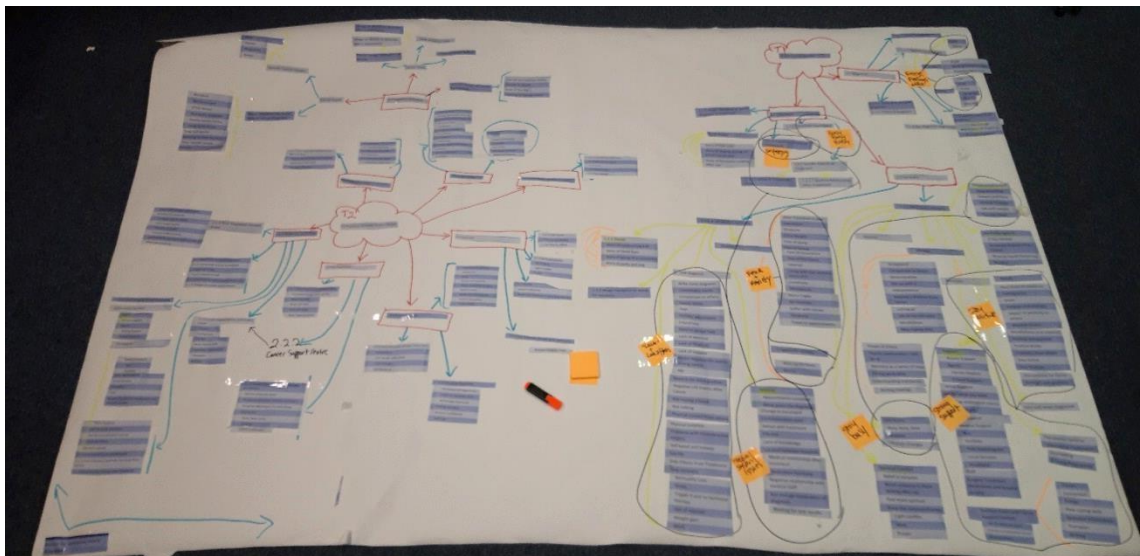


Figure A-18.1: Thematic Map of The Cancer Journey and Positive Growth from cancer

*Positive growth from cancer*, highlights 6 key areas of positive growth that participants said they experienced from having had cancer. 5 of these areas correspond to the PTG areas of growth; Relating to Others, New Possibilities, Personal Strength, Spiritual Change and Appreciation of Life. One additional area of positive growth is also highlighted – that of a Change in Mindset.

*Cancer Recovery as a socially embedded and collaborative experience* explores ‘support’ as the main recovery driver and how this support helps recovery not just in practical ways but also impacts on the kind of recovery strategies that survivors use.

*Cancer as an emotional roller-coaster*, focuses on how participants experience emotions and how they impact on recovery. It traces the freezing of emotions in Diagnosis as an initial survival strategy which is then fuelled by the coping strategies of minimising cancer and focusing on the positive. These emotions unfreeze and become overwhelming at the end of treatment and participants then perceive emotions (of fear, lack and anxiety) as a major hindrance to recovery.

Each of the key qualitative themes will now be examined further.

- **The Cancer Journey**

Though this theme is quite descriptive in nature, I believe it provides a holistic overview of what a cancer survivor experiences from diagnosis through recovery and highlights some of the key dynamics of this experience.

Theme one consists of 1 pre-stage and 3 core stages:

- Pre-Stage Cancer Cause
- Stage One Diagnosis
- Stage Two Treatment
- Stage Three Recovery

Table A-18.1, which follows, provides a complete view of all themes for The Cancer Journey.

Table A-18.1: T1, The Cancer Journey and all themes

Pre-Stage Cancer Cause	Participants believe major negative life events cause cancer
Stage One Diagnosis	<p>No initial symptoms and diagnosis was via mammogram</p> <p>Frozen in diagnosis with shock and disbelief</p> <p>Diagnosis Stage focused on triple assessment, diagnosis appointment and transition to treatment</p>
Stage Two Treatment	<p>Treatment is a physical and practical experience</p> <p>Diagnosis delay or 2<sup>nd</sup> diagnosis increased anxiety and complications</p> <p>End of treatment is the end of the security bubble and the start of intense emotions</p> <p>Perceptions of diagnosis to treatment depicted terror, the unknown, fear and lack of control</p> <p>Objects become treatment signifiers</p>
Stage Three Recovery	<ol style="list-style-type: none"> <li>1. Receiving and giving support is the main driver of cancer recovery</li> </ol>
What helps recovery?	<p>Access/accept help and specify what you want/need</p> <p>Medical staff who are kind and relatable</p> <p>Strength from prayer and a spirit looking after me</p> <p>Alternative therapies and classes reduced treatment side effects and increased self-care</p> <p>Helping Others gives meaning and increases self-esteem</p> <ol style="list-style-type: none"> <li>2. Develop a ‘survival mindset’</li> </ol> <p>‘Get on with it’ attitude helps survivors to cope</p> <p>Stay Positive’ as the mantra to wellness</p> <p>Positive Positioning makes cancer manageable</p> <p>Humour is a coping strategy that relieves tension</p> <ol style="list-style-type: none"> <li>3. Implement Proactive Strategies</li> </ol> <p>Be proactive by staying active, talk with others and make plans</p> <ol style="list-style-type: none"> <li>4. Pay attention to wellness markers</li> </ol> <p>Celebrate normality and reaching temporal milestones</p>
What hinders recovery?	<p>‘Anxiety’ and ‘Fear’ are the main emotional hindrances to recovery</p> <p>Treatment side effects hamper recovery and comorbidity causes complications</p> <p>Lack of support and family stress slow down recovery</p>



## **Pre-Stage Cancer Cause**

### ***Participants believe major negative life events cause cancer***

Although neither the interview nor long answer questions asked the participants about what they believed caused their cancer, 26 people made 87 references as to what they believed caused their illness. The first interview question asks the participant to tell of their experience of cancer. Typically, the participant began telling the diagnosis experience and then would stop and say that they needed to go back to an earlier time. This earlier time was usually a major negative life event which they believed was the cause of their cancer. These life events included; bereavement of family members, abuse, health issues and by far the most significant event was stress – both long term and family stress (from dealing with family issues). Sarah identifies specific family stress such as suicide that she believes caused her cancer. For Sandra, it was a family death and she alludes to the ‘stuff’ going on in her house.

“I wonder was it, was it stress that gave it to me, stress that gave me cancer because in 2008 my son in law committed suicide an I had the trauma of that that’s a terrible effect on your family... my daughter cause she had six children an the youngest was only three. ... An tha had devastating effect on us all... an I often wonder was it stem from there then I said no that was 2008, an two years later ye you know” Sarah.

“Well for me it was it was a bad year because as I said my daughter was gettin married, my sister in law died, I had to defer my, my treatment the first few weeks because she was in a coma. ...an there was a lot of stuff goin on in my house” Sandra.

12 participants were very specific about the cause of their cancer as stemming from stress, diet or genes.

“I wonder is tha... an I firmly believe now that stress is the thing that sends all your cancer cells multiplying and God knows wha in your body that breaks down an all your little DNA inside ya, an then they all start clicking out of sync” Sarah.

“...re-educated myself on food as well, because that was another big thing, it was changing my diet, thinking about what I was actually putting into my body that might of even kind of caused some of the cancer” Iris.

## **Stage One Diagnosis**

### ***No initial symptoms and diagnosis was via mammogram***

For many of the participants there were no symptoms at all, and the cancer was diagnosed via a routine mammogram. It must be noted here that 47 out of 67 participants had breast cancer which would have increased the likelihood for mammogram being the main vehicle for diagnosis. For those who did have symptoms, the main initial symptom was finding a lump. Figure A-18.2 below from the Dear Diary Project illustrates a participant finding a lump in the shower and highlights the terror that some participants feel. Other symptoms included; extreme fatigue, nipple change and issues with mobility.

“...by accident I just rubbed me hand an I just found it... I made nothin of it...d’ you know an I just couldn’t believe it like you know because I wasn’t sick or anything you know...” Joan.

“when I went for the Mammogram... wasn’t expectin to be told anythin but they decided there an then to do a Ultra sound and a Biopsy, sure I mean I knew comin out of there that had to be somethin wrong you know” Elaine.

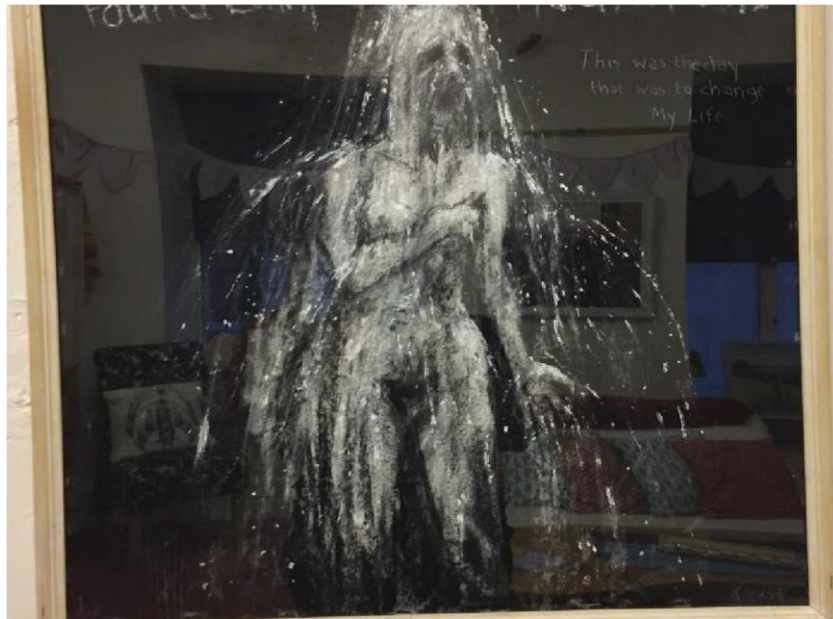


Figure A-18.2: Dear Diary: Finding a lump

### *Frozen in diagnosis with shock and disbelief*

The reaction to diagnosis can be viewed as freeze, fight and flight. ‘Freeze’ was the most significant category. The main response here was shock and participants experienced disbelief – they could not take in the diagnosis. Participants also identified feeling fear and there was an element of ‘why me?’.

“an they took the four samples an then they told me to go back up to the Consultant an sure I’m thinking, oh it’s only a bit of fatty tissue an you know totally your mind just... doesn’t kind of take this in and I went back upstairs and eventually an the Nurse came out an she took me in an she gave me tea an I thought, gosh this is a lovely hospital still never dawned on me. Never dawned on me, an the next thing the Consultant came in and she said, I’m sorry to tell you tis cancer. Well it was like been hit on top of the head with a ton of bricks” Imelda.

“I was concerned about telling my husband and family and friends that I was diagnosed with cancer. I think I felt it was some kind of a weakness or shame. I was scared myself because I didn’t know how serious this diagnosis was as I had never really discussed breast cancer before with anyone” Doris.

In terms of fight, participants spoke of ‘battling’ with cancer, the anger they felt and how some moved into action mode e.g. asking questions and seeking immediate treatment.

“when I was kinda hit with words cancer, it’s a shock to the system but it’s also kind of wakeup call and say, okay let’s deal with it lets deal with it the best way we can we can in a positive manner.” Iris

Flight was expressed as denial – by minimising or not believing they had cancer.

“...you just think that it’s not... they’re after making a mistake they’ve the wrong person... it’s not going to happen to me and anger.” Paula

### ***Diagnosis stage focused on triple assessment, diagnosis appointment and transition to treatment***

With the general experience of diagnosis, participants spoke of the triple assessment used to diagnose cancer and the fast transition into treatment. They also spoke of the importance of that diagnosis meeting i.e. what and how they were told and the impact that this had on them.

“Well it started really I suppose on the 2nd January 20XX an I was diagnosed today or tomorrow eight years ago... an that was nine months of tryin to be diagnosed, it’s very very, very difficult” Farah.

“...the day he told me I was diagnosed I mean I just heard I had cancer an I just heard him say, if you do everything that we’ll ask you to do we’ll cure ya an that’s all I heard. So I said that’s fine I’ll do my bit” Josie.

The story of diagnosis below captures some of the feeling of uncertainty that some participants feel and the type of assessments that they experience as well as highlighting the need for a person to trust themselves.

Interviewee Norah and her story of diagnosis:

**Norah:** So I went to see her and she requested a triple assessment in Waterford for me. So I was called down to the Breast Clinic in Waterford and mm to cut a long story short I, I met the Doctor but she sent me for a Mammogram and an Ultra Sound, and when I finished with the Ultra Sound the Doctor said that everythin was okay that t’ was only a cluster cyst, so I said fine. So I left there. I wasn’t really that happy been honest but...

**R:** Mm

**Norah:** I left there and there was still something in my head tellin me that it's not over, so I kinda pondered on it for a few days and I went to work and my supervisor said to me look Josephine you're gonna have to get something done even just for your own peace of mind, so I rang every hospital in around my area...

**Norah:** Mm mm

**Norah:** I explained everythin to them on the phone and mm they said no problem. They sent me a date to go to see a Miss X in the X Clinic, but mm I went up to see her anyway and she done her examination. She requested another Mammogram there so I had that done and then I went into Dr Y and he done the Ultra Sound. He mm... knew, I knew there was somethin there. He said to me you're not silly Mary he said you know. So I said no, I said I really feel that there is something there. So he went around the lump and I knew when he was goin around it that you know. Basically, I said to myself I'm shagged, I just got that feelin.

**R:** Mm

**Norah:** So he finished the Ultra Sound and he said to me I will have to do a Biopsy and when I heard that, then comin after I know now how long he was at the lump.

**R:** Ye

**Norah:** with the Ultra Sound that definitely something there, I think a woman knows her own body as well”.

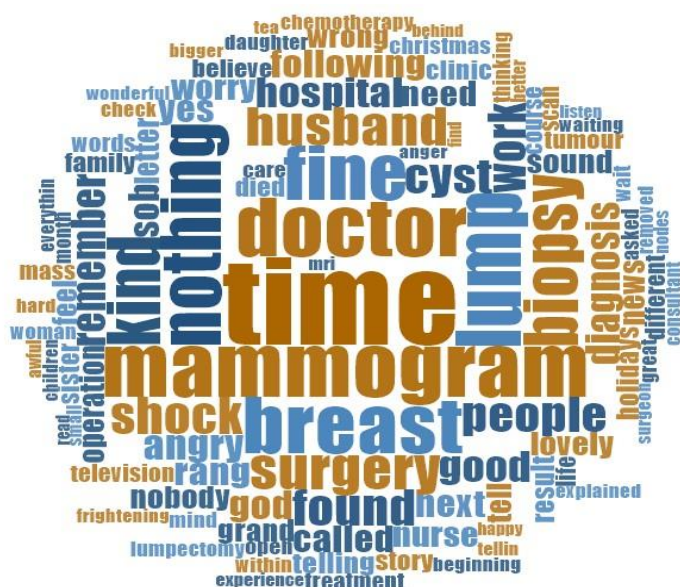


Figure A-18.3: Word Cloud Diagnosis

The Word Cloud for Diagnosis, as depicted in Figure A-18.3 above, is based on the 1000 most frequent words of the node 'diagnosis'. The most common words to

describe diagnosis by participants are; breast, mammogram, time, lump, doctor, biopsy and surgery. Other words speak to the waiting, the tests, the people in their lives, the communication and the experience of fear/worry.

## **Stage Two Treatment**

### ***Treatment is a physical and practical experience***

When participants spoke of their treatment experience, they mentioned the specific treatment, number of sessions and side effects. Life became medicalised and was about the next appointment, the next scan. Emphasis was on the medication/treatments and the physical impact on the body. Comorbidity issues caused further complications. Bree's account of treatment illustrates how life was punctuated by treatment.

"...so they decided that I'd be better to have chemotherapy first and reduce the lump, an then have the surgery an then have radium therapy, so that's where I went I had eight sessions of Chemotherapy... an because I have rheumatoid arthritis as well I had to come off an injection. I was on but the chemotherapy worked as good as the injection, but I came off chemotherapy, I just locked completely, so I wasn't able to move. So then I had to postpone surgery for a week until they pumped me with steroids to get me loosened up again... Had my surgery and then I was down for 33 sessions of radiotherapy" Bree.

### ***Diagnosis delay or 2<sup>nd</sup> diagnosis increased anxiety and complications***

Some participants spoke of their concern and worry about delayed diagnosis from the tests not picking up the cancer or delays in testing.

"But it took a long while to be diagnosed, I knew there was something wrong for about eighteen months and went in for a test in X hospital an I got fed up of them so I went to Y" Laura.

"...then a Biopsy an she came back up and she said, I'm very sorry but mm I'm 70% to 80% sure that tis back but we can't give a fine detail for eleven days now... which I think is a disaster having to wait eleven days, I really do" Leah.

Some participants felt a 2<sup>nd</sup> or subsequent diagnosis and treatment was more difficult because with a 1<sup>st</sup> diagnosis you do not know what is really happening.

“I think you go in the first time you’ve no idea... So mm... you don’t know what to expect or you don’t know how bad, an I must say the first time wasn’t so bad you know I got through it. It wasn’t nice but you’d get through it... because it’s, it’s new to you so you really things happen very quickly... But the second time it just floored me, they told me if I continued the chemo it would be the chemo that would have killed me not the cancer” Lucy.

*End of treatment is the end of the security bubble and the start of intense emotions*

Participants felt lost, frightened and alone when they finished treatment as they left the

‘bubble’ and security of close monitoring by the hospital system. Mary names the treatment experience as a bubble and Leah points to the importance of a follow up.

“I didn’t avail of Services of any of the mm cancer support centres during my treatment...because I was concentrating on just doing it an it’s like as if you’re in a little bubble... And there’s no other outside world an you’re doing this and you’re so protected. The Doctors are there, the Nurses are there. They reassure you an they’re so nice... so it’s, it’s easy kind of to cope during the treatment, but tis afterwards I found the real need for support an help, because the minute you’re finished an it’s goodbye, suddenly you’re, you’re by yourself an you haven’t got this this bubble anymore” Mary.

“... go away, gone now mm next thing you’re at home an you’re lookin around an you’re not goin into the Nurses an you’re not goin mm the next thing, what do I do? ...An you just don’t know what to do. ...I know people say ah sure you get on with your life but it’s, you know there should be a follow up I think” Leah.

Participants also noticed that they were treated differently by medical staff after treatment ended.

“That’s the unfortunate part of it you know... when it’s all done, an you’re in this big room an it’s almost like a normal Doctor’s Surgery an people are acting normal d’ you know that way ... You’re just in an out ye, just a number” Jessica.

Participants spoke of finding it hard to see others acting ‘normal’ while you do not feel the same way. Jessica referred to this to a game of musical chairs, but she had no seat.

This may point to a feeling of not knowing where you fit anymore.

“an you think to yourself, how could everything be the same when everything is different? I used to feel like I was in musical chairs an the music stopped an I had no seat” Jessica.

This transition at the end of treatment is also marked by feeling overwhelmed by emotions. Many participants remarked on how when the busyness of treatments stopped, then they felt intense emotions. Lorraine describes it as a mental pain and for Emma she felt quite sad and low.

“I feel horrible I feel rotten and mm it was just everything had caught up with me... but what had caught up with me more so was the mental pain of having had the cancer, it you see t’ was all over then” Lorraine.

“your next appointment, your next session, going up and down to Waterford and that was all was all going and I didn’t, I didn’t stop and think. ...But I did stop and think after the radio, after the sessions were over... and that’s when I got to a low point” Emma.

### ***Perceptions of diagnosis to treatment depicted terror, the unknown, fear and lack of control***

During the one-to-one interview, each person was asked to describe their experience from Diagnosis to the end of Treatment using an image, metaphor or saying. They depicted the terror, the fear of the unknown, the lack of control and the intense emotionality. The term ‘roller coaster’ was used several times. Others spoke of a dark place or a black hole. The whole experience was described by several participants as a long or great journey. Still others spoke of treatment as being wrapped in ‘cotton wool’ or as a wave. Some felt ‘at sea’ or in the centre of cancer. For several participants who came up with words rather than visuals to describe the overall experience, the common words were: terrifying, fear and horror. Noreen describes it as a whirlwind whereas for Mairead it was a dark place.



“...a whirlwind doesn’t go there... the walls were closing in all around me”

Noreen.

“t’ was the day the sun went in an never came out again an then I can understand it, it was lovely it was a sad image to before but it’s a dark place” Mairead.

### *Objects become treatment signifiers*

During treatment, objects can take on another significance. Leah spoke in detail about how much time she had spent in bed and the tree that she used to look at from her bedroom window and, when she started to feel better, what she wanted to do to it (see her quite below). When asked for an image, Joan described the loss of her hair and how this was confirmation that she really had cancer.

“...someone go over and cut that fuckin tree I said across the road aha cause my bedroom is facing the tree ...nothing else comes into my head only that tree lookin out the bedroom winda an cryin like a baby I was” Leah.

“when I lost the hair I think... now it didn’t bother me but just I, I suppose just when I the hair was goin I said was d’ you know this is it...now I really definitely have it like you know” Joan.

## **Stage Three Recovery**

How the cancer survivors experienced recovery can be understood in terms of what helped and what hindered this experience.

### ***What helps Recovery?***

Before I outline what participants said helped their recovery, I would like to first explore how they perceived recovery – after their last treatment to the day of the research interview.

### *Recovery perceived as a Journey, a bridge, a wall, a whirlwind and full of emotions*

During the one-to-one interview, each person was asked to describe their experience of recovery using an image, metaphor or saying. Participants described it as a whirlwind, a journey, a bridge, to get over a solid wall and that post wedding feeling – when the treatment is done, and you are dealing with all the emotions and the fear

afterwards. For Paula, she remembered a card that she had received and on the front was the picture of a flower all closed up and the other person said:

“watch that grow and that can be you, you’ll be watching all new things, your new hair growing, all that kind of thing, your spirit lifting and your eyelashes come back all that so I do remember that group, it’s like it’s a flower closed” Paula.

Several participants described recovery with words rather than coming up with an image or saying. They used words like; impatient, anxiety, gratitude, keep going, thank God, fear, life is tough, and endurance. For Paula, recovery was rebirth and for Breda it was a home coming.

“It’s rebirth, it’s all rebirth. Everything is re growing again once the Chemo is gone out everything is growing again...So it was time to breathe that and not go back” Paula.

“Hip hooray...I’m home free.” Breda.

In my opinion there are key themes which capture the various strategies and approaches that participants identified as driving their recovery. These themes are outlined in Table A-18.2 below, with the most significant theme as receiving and giving support.

Table A-18.2: Major themes of what helps Recovery

Recovery Major Themes	Recovery Sub theme
<b>Receiving and giving Support is the main driver of Recovery</b>	Access/accept help and specify what you want/need Connection with Survivor Peers who really understood me and gave me a lift Medical staff who are kind and relatable Strength from prayer and a spirit looking after me Alternative therapies and classes reduced treatment side effects and increased self-care Helping Others gives meaning and increases self-esteem
<b>Develop a ‘Survival Mindset’</b>	‘Get on with it’ attitude helps survivors to cope ‘Stay Positive’ as the mantra to wellness Positive Positioning makes cancer manageable Humour is a coping strategy that relieves tension
<b>Implement Proactive Strategies</b>	Be proactive by staying active, talk with others and make plans
<b>Pay Attention to Wellness Markers</b>	Celebrate normality and reaching temporal milestones

### ***Receiving and giving support is the main driver of cancer recovery***

Participants emphasised the importance of accessing, accepting and asking for help. They really connected with peer survivors and identified the positive impact from medical staff and alternative treatments/classes. Participants drew comfort from prayer and the belief that spiritually someone was looking after them. Survivors also recognised the positive benefit to recovery of helping others.

### ***Access/accept help and specify what you want/need***

The most important recovery driver that 62 out of 67 participants identified was 'support'. Participants, like Una and Doris below, highlighted the importance of accessing support (from personal and professional networks) and of accepting all offers of help.

“Utilise all the Support Systems available, don’t isolate yourself” Una.

“Be positive, be curious and reach out for help as soon as possible. Do not get worked up or let your mind run wild. There are plenty of Centres and Help Lines available free of charge and make use of them, they are wonderful and are there to help you. Make that phone call. Talk to family and friends and especially new friends and the experts at the cancer support centres who will put you on the right path” Doris.

For participants, it was not just about asking for help, but it was important to be specific about what you want or need. For example, to ask for what you need from your family, to ask the doctor questions and find out as much information as you can which is what Pauline recommends.

“To constantly ask questions and to know your own body. Do not be afraid to speak your mind to Doctors or Consultants. To ask for help” Pauline.

### ***Connection with Survivor Peers who really understood me and gave me a lift***

In terms of agents of support, people mainly turned to friends, then survivor peers, followed by medical staff and family. Participants like Bree felt quite supported by survivor peers as they sometimes did not want to 'burden' their family and felt that a survivor would really understand what they were thinking and feeling. By speaking with survivors, they felt it gave them a 'lift'.

“It’s hard kinda to, it’s hard to explain it to people that hasn’t gone through the full treatment or gone through the cancer thing...they (family) can’t understand it as the same as someone that has gone through it” Bree.

### ***Medical staff who are kind and relatable***

Participants spoke of the medical staff typically in a very positive light – that they were kind, they were there for them, they created a positive atmosphere and they could relate to them also. Participants, such as Elaine, also felt supported by the hospital service in terms of getting treatment quite quickly, medication to help with side effects and the quality of service in general:

“...the care and the speed of everything was wonderful, absolutely wonderful you know, my Consultant Mr X lovely, lovely man very down to earth you know”  
Elaine.

### ***Strength from prayer and a spirit looking after me***

Approximately half of participants said that spiritual comfort and strength helped them to recover. Participants spoke of their belief in a spirit looking out for them (an angel, God or a deceased relative) how prayer got them through and some people, such as Carol below, now felt more spiritual.

“mm I also called big time on the angels...and I do think that mm my Mum an my brother were my minders... because I couldn’t have just sat back an never went for second opinion mm but I think there was someone pushin me. An I think that t’was my Mum and my brother because both of them passed away with cancer” Chrissie.

“Mm I was always religious, I was never a huge Mass goer but I always prayed, an prayed like a demon when I was sick” Carol.

### ***Alternative therapies and classes reduced treatment side effects and increased self-care***

Another key recovery driver concerned accessing therapeutic services i.e. alternative therapies (reflexology, Indian head massage, or acupuncture), classes such as art, mindfulness or yoga and counselling. They provided a place to relax, were an opportunity to try something new, helped with treatment side effects and a facility to connect with other survivors. For Iris, it helped her feel less nauseous.

“I used to come here an have a Reflexology after all of my Chemo’s because it would help me get the Chemo out. It would help me feel not so nauseas an help me feel better” Iris.

### ***Helping others gives meaning and increases self-esteem***

Participants highlighted ‘helping others’ as an important recovery driver. This help took the form of sharing their story, fundraising, using humour to lift the atmosphere during treatment or practical support. Participants like Bree felt good in being able to help someone else.

“but I’m just more tuned into people who are unwell in general say... I don’t go round lookin for sick people, but you know when you know somebody says I’m not feelin the best, ...say well come on what can we do about it? How do you feel? Do you need d’you need washin done? Will I take the kids out?” Bree.

### ***Develop a ‘survival mindset’***

Many participants developed a ‘Get on with it’ attitude and were determined to get well. ‘Stay Positive’ was a mantra to wellness that was underpinned by setting goals and reminding themselves how ‘lucky’ they were. Participants positively positioned themselves compared to other cancer survivors. In addition, humour was used as a way to reduce tension and lift the atmosphere.

### ***‘Get on with it’ attitude helps survivors to cope***

Over one third of participants repeatedly used the phrase ‘get on with it’ when referring to how they coped with cancer, how they deal with the anxiety of recurrence and also their attitude to life. Bree just got on with things and Sandra tried to keep everything normal.

“I’m fairly, I’m positive myself I had to think I, I, I never even contemplated dyin. I just mm... just, I just it has to be done go an do it an get on wit it, that’s the way I look at things I have to say” Bree.

“I just kept pluggin away and try to make things as normal as possible for everyone round me” Sandra.

Participants referred to being determined to beat cancer and to accomplishing goals.

“...never left you know the treatment, anything stand in my way you know... I just said I’ll do this now for the year an I’ll just, at the beginning I said listen it’s goin to take a year here an this is my year you know... an nobody else’s” Jessie.

### ***‘Stay Positive’ as the mantra to wellness***

The significant change in mindset also included a change in attitude with emphasis on positivity. Three key features underpinned positivity and these are ‘stay positive’, goals and feeling lucky. A recurring phrase used by participants was ‘stay positive’ and this was commonly used when asked what advice they might give to someone newly faced with a diagnosis.

“I would stay positive I just I suppose I just have that attitude that... you just get on with things an you know mm you can sit in the corner an feel sorry for yourself” Bree.

“Stay positive, don’t panic, there is a life after cancer” Rose.

When talking about positivity, participants spoke of goals that they had – whether that was going to a family wedding, reaching a mountain top like the example below or even being focused on putting the dinner on the table each day.

“I kinda said this year now I didn’t do the second mountain last year, it’s a bit lower... but I kinda said go an right June you forget about the big mount aha do the second mount this year then...” Bree.

“I think He, lookout now you owe me you owe me, I need to be here you know. You can’t take me yet, I have to be here for the daughter’s weddin first of all... I’d be here seein my son playin in the County” Sandra.

Participants referred to feeling lucky in terms of being alive, their health, getting diagnosed early and for the people in their lives.

“I was angry mm an then mm I suppose I kinda had got to the stage now that I, I would say, I’m, I’m lucky I’m well an I feel well fingers crossed all going well please God” Lorraine.

### ***Positive Positioning of cancer***

Another way that positivity played an important role is in the way participants saw themselves in a positive position when comparing themselves to others. People spoke of being in a better position compared to those who; had died, those who experienced more severe side effects from treatment or more severe treatment. They also thought they were in a more positive position compared to those who had a

‘worse’ cancer (e.g. were diagnosed at a later stage or who had what was considered a more difficult cancer).

“...different women here had died like you people that were here an people die...an you think say to yourself, Jesus it could be me. An then you think well what I had was nothing compared to what they had” Jessica.

“I was lucky enough not to have treatment, didn’t have to have Chemo etc., and I know from my friends who have had cancer, the treatment is almost worse than the illness” Hilda.

### ***Humour is a coping strategy that relieves tension***

Participants used humour during treatment, as a way to cope with the treatment/side effects and to help others. Humour helped to release tension, lighten the atmosphere and connect with others. The role of humour is captured in the story of Mairead and how she sang with medical staff during treatment:

“there was laughter on my first blood transfusion, aha. Jane is a Italian Nurse an Sarah was an Irish girl aha. An they came in, I couldn’t keep the eyelids open the blood was so low aha. An they said sing us a song. I said where am I goin to get the energy to sing a song ah. Oh they said you have a Choir come on, come on. An they were riggin me up an all the rest of it... but I said I can’t sing I said somebody would hear you outside there you know. I said we’ll close the door. ‘Mairead what are you going to sing?’ God I said, me party piece – Every Time we say Goodbye I said but with this blood I hope I’m not goin to say goodbye aha ahaaha” Mairead.

Iris below found discussions about how a breast prosthesis falls out gave them comfort.

“so I was always trying to cover it up with different clothes so that again kind of brought me down in myself, but then coming here (Support Centre) after I had the Mastectomy was brilliant because they were the people that had Mastectomies and ...we were talking about funny things, about the Prosthesis an how it could fall out (laughter). An it fell out you know, in several several places (laughter) an people would laugh it off, an not even think about it ...that was that was a comforter” Iris.

## **Implement Proactive Strategies**

### ***Be proactive by staying active, talk with others and make plans***

Proactive behaviour helped participants recover from cancer. ‘Staying Active’ was an attitude and practice that drove recovery. Part of this was simply staying busy. Participants enjoyed their ‘Hobbies’ or new interests and welcomed it as a way to meet new people. Another aspect included specific lifestyle changes that people made such as walking, changes to diet and giving up cigarettes.

“I found my two things I love in life besides my family of course is the Gospel Choir

Tipperary Gospel Choir an my Genealogy they’re the two things that make me function.

So that’s what keeps me goin an my Genealogy and I go up an I have, I have my attic converted into a little office. An I got all my Genealogy up there, an I go up there an I lose myself up there an that’s what I do” Sandra.

“I have become more determined to look after my well-being – i.e. diet, exercise and stress levels. I have taken on a hobby which involves exercise and made some new and wonderful friends” Una.

Another proactive behaviour was talking with others and how dreams and plans motivated participants to get well.

“Go with your feelings whatever they are. Talk, talk, talk”. Participant 53. “I did a bucket test before I was fifty all the things I wanted to do. So I’m getting another lot together now before I’m sixty an their goin to be a hell of a lot different...I think that those two life threatening illnesses... has definitely put a whole new gloss or glow” Mira.

## **Pay attention to wellness markers**

### ***Celebrate normality and reaching temporal milestones***

Participants noted and celebrated the signs of normality returning e.g. energy levels returning and being able to do things they did before. Reaching temporal milestones like finishing treatment or reaching the 5- year recovery marker helped participants feel more positive as if increasing the distance between them and cancer.



“it was just a dream come true, that I could put on a normal bra. I was wearing a sports bra it was just, it was I, I’d forgotten about the cancer, it, it gave me that kind of feeling... that never happened that it passed” Iris.

“they say everything is a stage and the first stage is gettin over the Surgery and the Treatment. An then I don’t know what the second phase is but you kind of, you’re goin to Year 5 you know you’re always aiming towards Year 5” Ingrid.

***Story of Louise and the wig at the party:***

This story exemplifies how humour and a positive mindset can help a person deal with cancer. For Nuala, she used both of these to help her cope with hair loss, to thank people who were there for her and also to acknowledge others who did not lend their support.

**Louise:** And they had a party for... I was 60 at the time, down at something – the place at the end of the town. And they were all ‘a aa song Louise, a song Louise, ye know the way they go on.

**R** Yeah

**Louise:** Crowds there, young and old and the eldest grandson was there. I said I can’t sing. It’s no good asking me to sing, I can’t sing. I just thank ye all for coming I can’t sing. Ah a song, a song, any kind of a song so the young fella said to me I’ll sing it with you nanny. So I saw the face a him, what could I do? I don’t know what I even sang. And I sang it at the end of it what did I do. I can’t thank everybody who came to see me, who brought books or brought whatever.

**R:** Mm

**Louise:** Em and it was good to have ye, it helped me through.

**R:** Yeah

**Louise:** And this and fuck the begrudgers and I put my hand up like this on the wig and threw it. (laughter) And on the video... **R:** Right

**Louise:** Here here’s loads of them (makes a shocked face), they didn’t know... **R:** They weren’t expecting that!

**Louise:** No, not the, the they didn’t know

**R:** And that just came out

**Louise:** it just came out

**R:** it wasn’t planned

**Louise:** No just came out. Just took off the wig and...

**R:** Yeah

**Louise:** cause there was little bits of hair. I was like someone from .... On the video (laughter). The little, small little bits of hair (laughter)

**R:** Mm

**Louise:** But like that’s I suppose the way I felt

**R:** Yeah

**Louise:** You know and it just came out itself but twas as comical to see the video

**R:** I’m sure

**Louise:** Ye know people got a shock I suppose



Figure A-18.4: Word Cloud What helps recovery

The Word Cloud for what helps recovery, in the preceding Figure A-18.4, is based on the 1000 most frequent words in this section. As you can see from the image ‘People’ is an important driving force of recovery, not just as the most prominent word but also if you take into account the various relationships identified including; husband, sister, daughter, friends, family and brother. Also significant are staying positive, support, treatment and talk.

The 4 major themes of what helps recovery are a collective driving force towards wellbeing. At the same time, participants also identified key hindrances that slow down, block or even complicate recovery.

### ***What hinders Recovery?***

In my opinion, there are 3 key themes which address what participants identified as hindering their recovery. These 3 themes also correspond to 3 different realms of experience namely; emotional (with the main feelings of anxiety and fear), physical (side effects and comorbidity issues) and relational (lack of support and family stress). I believe that these 3 facets are interdependent where a change in one impacts on the other areas. For example, high family stress can increase anxiety and

potentially make it more difficult to manage treatment side effects e.g. less able to cope with pain etc. This interdependence is illustrated in Figure A-18.5 below.

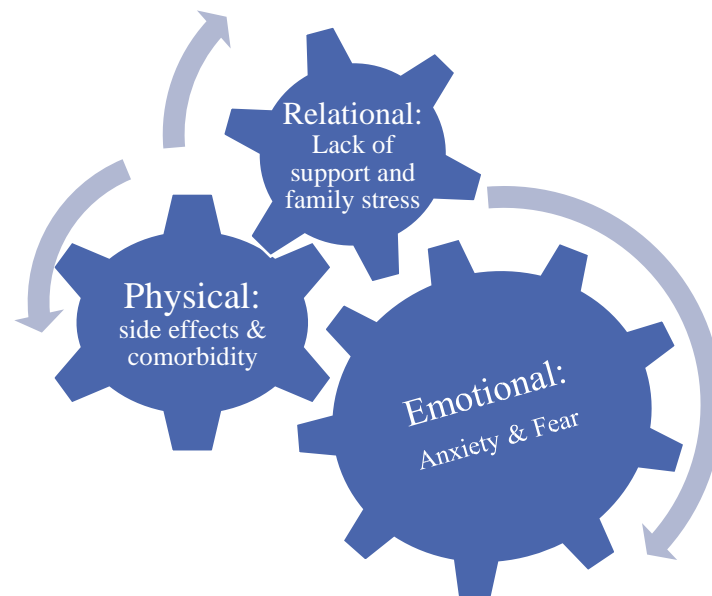


Figure A-18.5: Interdependence of emotional, physical and relational hindrances to recovery

***‘Anxiety’ and ‘Fear’ are the main emotional hindrances to recovery***

The main hindrance to recovery experienced by participants are the perceived negative emotions of anxiety and fear. The fear is primarily about the fear of recurrence that participants live with and living with the fear and shock of cancer itself. Some like Norah, spoke of the struggle of trying to push anxiety and fear down or to the back of their mind and that it is always there.

“you’re kinda constantly thinkin back to when... you were first diagnosed... now yesterday I was quite concerned because my ankles were fairly swollen and you know it will always come into your head when things like that happen. So you were always kinda conscious of it... but at the same time tryin to put it back to the back of your head” Norah.

The experience of anxiety and fear is further intensified by fatigue, depression, lack of support and loneliness. Participants also spoke of the anxiety triggers that they face from revisiting places associated with treatment, dealing with follow up scans or having an ache or pain that might signal that something is wrong.

### ***Treatment side effects hamper recovery and comorbidity causes complications***

Participants felt that recovery was hampered by side effects from treatment often lasting between 2 and 5 years and this was further complicated by comorbidity issues leading to higher monitoring and longer stays in hospital. Side effects included; not sleeping (due to steroids), the menopause, panic attacks, issues with veins, infections, nausea and aches/pains.

“the reason they had to do such a strong treatment on me was because I have a lot of health issues and like they had to keep an eye on me as well. The main effects on me were I was very very sick... I was in hospital for a majority of those months, mm because of my other illnesses I’ve quite a few” Chrissie.

### ***Lack of support and family stress slow down recovery***

Lack of support and family stress are also cited as issues which can slow down recovery. Lack of support was expressed in terms of feeling misunderstood by others, that family was not there for them and feeling unsupported once treatment ended. Leah spoke of so many people telling her how ‘lucky’ she was but that it just left her misunderstood and annoyed.

“...an yet they’d come to me an they’d go, aren’t you lucky oh God please don’t keep remindin you know, why, why keep sayin that to me like? I can’t understand why” Leah.

This lack of support was heightened depending on where the person lived – some participants like Trisha below recently moved and did not know anyone, and others lived rurally and felt physically cut off from others.

“and this is a very lonely country. I lived in the centre of London – I have friends. I live in a village now, I have no friends. ...life in itself has changed but people haven’t, they’re still a clan an you can’t break into ...as I always say mm they have their own little families. An it’s like a cocoon an you cannot break through that cocoon” Trisha.

The family stress that some participants experienced concerned difficult relationships with their husbands, their children were dealing with issues (depression, health or drugs etc) or major family life events like death in the family.

### ***Story of Laura and Dead Eyes:***

This story illustrates the darkness that a person can feel and the fear of death which for this participant they can see in their own eyes, even years after having cancer.

**Laura:** an I hate photographs an negatives, mm I felt like I look at some photographs of me ...I think I see death in my eyes. D'you know I said that to one sister recently don't show me the photographs I can see death in my eyes, but she said I don't know what you're talkin about.

But it's something you see d'you know, Ye not every photograph but lots of them.

**R:** Just around that time.

**Laura:** No, see it now.

**R:** No it's even still now?

**Laura:** Ye oh the photographs then they... funny enough they... it wasn't in the photographs then but it's now I've seen it.

**R:** An what's the difference, hope you don't mind me asking you – what do you see now that wasn't there six years ago?

**Laura:** I don't know I think my eyes were, were happier back then. **R:** Okay.

**Laura:** An they just look, they look dead but that's silly me cause I look in the mirror an they're not dead aha aha, mm I don't know how to explain that one perhaps even after years far away you can be goin back aha aha.

As part of the Dear Diary project, the artist Sheila Wood used a mirror and mask to evoke this concept of the dead eyes, see Figure A-18.6 below.



Figure A-18.6: Dear Diary: Dead Eyes – Mask on Mirror

### ***Positive Growth from Cancer***

The data for this theme is derived from two sources. The first is the 30 interviews and especially the question concerning ‘what is the main impact from having had cancer?’ where participants were then prompted to answer negative and positive

impacts e.g. if they mentioned the negative impact then they were prompted to answer the positive and vice versa (see Appendix 8.10 for the list of interview questions). The second source of data is the 37 long answer questions which were completed by those who did not do an interview (see Appendix 8.12). Again, participants were asked to write about the 'main effects of having had cancer' as well as describing any positive effects.

There are 6 Key Areas of Positive Growth, which are:

- Relating to Others
- New Possibilities
- Personal Strength
- Spiritual Change
- Appreciation of Life
- Change in Mindset

The first 5 areas of growth correspond directly to the 5 Factors of growth from the PTG model. The sixth is a Change in Mindset which in my opinion is a distinct and significant category of positive growth. Table A-18.3 which follows provides a complete view of Positive Growth from Cancer and all its sub themes.

Table A-18.3: Positive Growth from Cancer and all themes

<b>Positive Growth from Cancer (5 Factors of growth from the PTG model, plus sixth is a Change in Mindset) and all its sub themes</b>	
Relating to Others	Relationships are closer and stronger Support is the most significant recovery driver Learning how 'good' or 'not so good' people are Increased compassion and less tolerance
New Possibilities	Significant increase in new interests driven by Support Centres Survival strategies of 'stay active' and 'dreams and plans' as motivation to try something new
Personal Strength	I am stronger Increased self-reliance and can better handle difficulties Increased strength positively correlated with increased confidence Increase in self-awareness and 'put myself first'
Spiritual Change	'Spiritual' rather than religious change Spiritual growth borne of struggle with faith Spirituality expressed in prayer, going to mass and lighting candles Comfort from someone watching over me
Appreciation of Life	I realise what is important I value less stress, my health and other people more Increased awareness and enjoyment of the 'little things' Appreciate each day and life itself Make the best out of life I am grateful
Change in Mindset	Get on with it Stay Positive Positive Positioning of cancer

#### • **Relating to Others:**

From the experience of having had cancer, participants found that their relationships were now generally closer and stronger. Participants recognised the important role that relationships/support played in helping them to recover. Their social circle underwent considerable change (in terms of increasing in size and who was in/who was now out) Two underlying mechanisms drive this change. The first is that survivors now saw people differently by differentiating between those they now saw as 'good' and others as 'not so good'. The second is a personal change of increased compassion and less tolerance.

Some of the general features of Relating to Others are highlighted in the Word Cloud (Figure A-18.7) below which is based on the top 1000 most frequent words in this theme. As expected, the largest and most central word is 'people'. Other high frequency words include; family, time, support, positive and friends.





“I had saw people here that I could talk too, who’d been through it maybe nine or ten years past, I could see some people that were a survivor of it so it kind of gave me the hope that I would hopefully get through the next few months” Iris.

Figure A-18.8, below, is an image from the Dear Diary project which illustrates how important it was for this survivor to get a call from someone asking how they were rather than a text (also Figure 7 within the body of the report).



Figure A-18.8: Dear Diary: The importance of a phone call

### ***Learning how ‘good’ or ‘not so good’ people are***

Participants stated that they see people differently in terms of how good or not so good people are. They expressed gratitude for what others had done for them. They found that their social circles had changed greatly with an increase in their social networks and the cancer support centres (with their peer groups, supports and classes) are key drivers of this change. There was considerable movement in their social circles with some people who they thought were friends were now not anymore and new friendships emerging.

Sarah below describes this quite clearly:

“It made me found out like about people a, about how, how, how can I say... the good people in my life that were really supportive of me, it weeded them all out, that the good people that, that were in my life an they were good an the others that weren’t. So I kinda dropped the people that weren’t” Sarah.

### ***Increased compassion and less tolerance***

Participants reported a significant increase in compassion especially if the other person was experiencing a difficult time or illness. This increase was primarily driven by a perceived greater understanding of other people. They also noted emotional growth; they now find they do not judge others, and they do what they can for other people.

“ye’d have a little bit more understandin though of what people is goin through... what way they’re feelin an all, you’d have a bit more understandin like that when you’d see people sick and... you’d know exactly what they’re, how they’re feelin, you’d nearly know by lookin at them” Bree.

Though participants highlighted increased compassion, they also recognised that they also had less tolerance of others, especially if they were being negative or if what the other person is concerned about is not seen as important by the participant (due to priorities/values change).

“Ye I have changed mm there is no doubt at all about that I, I take very little nonsense from people aha... aha I’m not as tolerant as I was mm because to me life is too short now... that has that what it taught me is that I’m, the shock is realising that you’re not here forever because we all think we’re here forever” Lucy.

This increase in compassion and reduction in tolerance meant that participants found they had less patience with some people and were more selective with who they spent time with.

### **• New Possibilities**

Survivors experienced a significant increase in new interests including; hobbies and travel. This increase was primarily driven by the classes and services provided by the cancer support centres. The survival strategies of ‘stay active’ and ‘dreams and plans’ motivated participants to try something new.

### ***Significant increase in new interests driven by Support Centres***

Participants highlighted their willingness and delight in developing new interests since cancer which includes; art classes, meditation, music, dancing, hill walking and

yoga. In addition to new interests/hobbies, participants now travel more and think of themselves as doing better things with their lives.

“An we definitely go on foreign holidays now, far more breaks you know. We were in... mm... Austria our X anniversary an we went to Austria with another couple in June, we went away, did part of the Camino in July, that’s our third time doin that so since that happened” Jessica.

For most participants, the new possibilities focused on trying something that was local, social and enjoyable such as hobbies or classes. However, a few participants did make major changes to their life path in terms of leaving work, getting a new job, starting a business or early retirement (though these were in the minority).

“Now whereas before t’ was always an achievement when you have to have targets, you had to have this done you had to have that done, you were always working against something. Whereas now I’m working for something, I’m working for myself. I’m working for... I’m doing what I love” Ingrid.

A key driver for new interests is fuelled by the classes, supports and services offered by the cancer support centres. These Centres provide free classes, groups and individual sessions/treatments.

“I am more active and have taken up new interests, hobbies such as weekly meditation group attendance and daily meditation on my own as I appreciate life much more now. I have a curiosity about the benefits of alternative treatments, support groups, energy and spiritual healings” Doris.

### ***Survival strategies of ‘stay active’ and ‘dreams and plans’ as motivation to try something new***

Many participants highlighted ‘stay active’ as a strategy to help them recover. This led to *hobbies* and *staying busy* as important recovery drivers.

“I am an I always was determined, look I mean you’re not goin to get anywhere sittin down an just sayin I’m so sick you’re not goin to get anywhere tha way. You know get up and get out an fight this thing. Go to the shops when you want to go to

the shops. Okay you'll be tired like, but you know make yourself do somethin"  
Chrissie.

'Dreams and plans' is another recovery driver that feeds into New Possibilities. Participants noted the importance of setting and focusing on positive goals that you want to achieve.

"like I did a bucket test before I was fifty, all the things I wanted to do. So I'm getting another lot together now before I'm sixty, an they're goin to be a hell of a lot different than the six, the ten things that I wanted ta do then to the ten things that I want to do now, and I think that those two life threatening illnesses has definitely put a whole new gloss or glow" Mira.

In my opinion, the Word Cloud of New Possibilities (Figure A-18.9) captures the main themes of this area of growth quite well and so is a good way of summing up this section. The word 'People' is at the centre of the image and has the highest frequency. This makes sense given that this area focuses on trying something new and typically involves other people. Other words that capture this data include; time, life, well, great, support, help and different. This connects with the fact that given survivors have changed priorities, they spend their time differently and have a greater focus on doing things that make them feel good/well.



Figure A-18.9: New Possibilities - Word Cloud

- **Personal Strength:**

In my opinion it is clear from the qualitative data that survivors feel stronger from having recovered from cancer. The phrase ‘I feel stronger’ was frequently used. Participants reported an increased self-reliance and that they could better handle difficulties. For survivors, increased strength was positively correlated with greater confidence. An example of this is the way in which participants stated that they could speak up more now and cared less about what others thought. Survivors highlighted a new-found increase in self-awareness and said that they now ‘put myself first’.

The Word Cloud for Personal Strength (Figure A-18.10) is based on the 1000 most frequent words. The most common words include; people, life, person, stronger, able and time. Changed, better, different are also listed. What is interesting to note is that it also highlights *confidence* and *want* as well as *hurt* and *fight*. This suggests that the process of increasing personal strength involves getting clear on what you want as well as courage as it is a challenging process.



Figure A-18.10: Word Cloud Personal Strength

### ***I am stronger***

Participants identified with feeling stronger from the experience of cancer and recovery. Some of this strength comes from having gone through the challenge of cancer and treatment.

“Maybe I’m a better person since I got cancer (laughter) honestly. Maybe it’s made me a better person (laughter)... you know what I mean. It has because honestly before that I would have been so negative about things, life in general... And I’ve got the strength somewhere to get through it and to mentally and physically and try and keep myself physically well as best I can” Emma.

### ***Increased self-reliance and can better handle difficulties***

From having recovered from cancer, participants felt greater self-reliance and they credited themselves for having survived the experience.

“Mm but I sort of had to get on, on my own... an do my own thing and mm so consequently I’m here today... you know but I done it for me... nobody else done it”. Trisha.

Participants also felt that they could handle difficulties better in that having faced cancer, all other problems seemed less, and they felt better able to cope.

“...of course I’ve been hurt people have hurt me an they will hurt me into the future... but oh I’ll get over it you know and I just think of really you would think of all you’ve been through an you’d say, how big a deal is this anyway... and ye I suppose if anything the cancer taught me that, that nothing is a big deal anymore” Ingrid.

### ***Increased strength positively correlated with increased confidence***

Participants associated increased strength with greater confidence. One clear way that this manifested was in the way that survivors noted that they had found their voice and can now speak up for themselves. As Sarah explains below, they saw themselves as a people pleaser before but now do not care as much about what others think. This confidence was also evident in the way participants enjoyed travelling and trying something new. Sarah explains this well.

“...oh God Jesus a much stronger person, I’m much stronger person I’m a person in the sense tha mm I don’t care wha the people think of me it’s what I think of myself as more important, I always used to wonder about other people an I was always a please, people pleaser I found out, always pleasing other people bar myself” Sarah.

### ***Increase in self-awareness and ‘put myself first’***

Participants stated that they were more aware of themselves now in terms of what they thought, felt and what they did. Carol below talks about how she can see and name what she is doing whereas before she would not have been conscious of it. In addition to this increase in self-awareness, participants also spoke of how they now prioritise themselves more with several survivors (like Sarah) using the phrase of ‘put myself first’.

“...I think of just myself in a sense that I do think of my children like. An I’d be good an kind to them but I put myself first as well... kinda thing, always used to put myself last, sometimes do now, but I check myself” Sarah.

### **• Spiritual Change:**

As a researcher, having met these 67 women, I found a dichotomy when it came to spiritual change, between a large portion of women experiencing no growth at all in this area and yet quite a large group who did experience considerable change. What they all had in common was that participants overwhelmingly preferred the term ‘spirituality’ rather than religion. For those who did experience spiritual growth, it was borne out of a personal struggle with their faith and the change itself was a change in their own personal relationship with God or a higher power. Spirituality was expressed via prayer, going to mass and lighting candles. Participants got great comfort from the belief that someone was watching over them/minding them be it God or for some a deceased relative.

### ***‘Spiritual’ rather than religious change***

Many of the women said that there was no change at all and yet another major group of women experienced significant growth in this area. What they did have in common is that most participants preferred to use the term ‘spirituality’ rather than religion.

“Cancer gave me a greater curiosity about spirituality, and I think it strengthened my faith in God” Doris.

### ***Spiritual growth borne of struggle with faith***

For those who did experience a greater religious/spiritual faith, this was borne of struggle – being initially angry with God and some even saying that they lost and then found their faith again.

“when I got the diagnosis first I was saying oh my god why is this happening to me... And why is the man above doing it, whatever, I was always trying to live my life used to go to mass, we most of the time got the children to mass. Always and ever up to the time they got up to a certain age and beliefs were strong. And then when I got the diagnosis you know is there any god there?” Emma.

### ***Spirituality expressed in prayer, going to mass and lighting candles***

In terms of specific religious/spiritual activities, participants spoke of prayer, going to mass and lighting candles. ‘Prayer’ was the most important activity and Farah wrote a poem about how so many people were praying for her. Bree even credits her recovery to the power of prayer.

“God has been very good to me, people kept me alive. I have a poem written on the river of prayer, everyone prayed for me in Tipperary” Farah.

“I do believe because the prognosis wouldn’t have been good... so ye I do believe prayer got me through. Really if I was ta ask you what cure aha, I’d say prayer... Prayer got me through” Bree.

### ***Comfort from someone watching over me***

Many participants believed that there was someone watching over them and this took the form of God or a higher power, a deceased relative or an angel. This gave the participant great comfort. Some participants reported feeling or sensing this other



presence as is evident in the story below of one participant who described meeting her personal angel.

“I seriously believe in them, (Angels) I seriously... mm have thought in myself that they are all around me, they are constantly guiding and protecting me an I swear I was seeing something mm... don't know what it was but I've seen something mm... during the time I've been at home an I've been laying in bed an then feeling really sorry for myself an feeling really upset an thinking about mm... the Angels, thinking about prayer an... it was really strange because I have this lamp in my in the middle of my room, mm an all the curtains were closed... It was really strange it was all closed an it was dark, but there was a, a glow very strange but there was a glow an I saw yellows and purples an I could see these flashes of yellows and purples all over the place. An to me that was that was my Angels... I thought, oh ye they've come to help” Iris.

#### • **Appreciation of Life:**

For the majority of participants, the experience of cancer resulted in a reflection on the meaning and the way in which they live their lives. Many reported ‘I realise what is important’ and spoke of a change in values which meant less stress and valuing their health and other people more. There was general increase in awareness and a new-found appreciation of ‘the little things’ of life. Participants reported they appreciated each day and even life itself more. There was a shift in attitude in terms of how they lived – by ‘making the best out of life’ and feeling grateful.

#### ***I realise what is important***

Participants reported that their values had changed – that they look at life and themselves differently and now realise what is important. Sandra speaks about how material things are just not important anymore and Rose echoes what many participants referred to which was about learning what really matters.

“I mean we're very much taken up with, with material things, how we look an this an that, an keepin up you know appearances an all that mm... you know they're so unimportant” Sandra.

“It has been an interesting journey. An experience I wouldn’t swap, and I wouldn’t wish on anyone. Because of the experience, I learned a lot about myself and the meaning of life, put value on what really matters” Rose.

### ***I value less stress, my health and other people more***

In terms of the change in values, people gave examples of not getting stressed over little things, valuing their health and appreciating other people more.

“...a different outlook you know life is for livin, and I don’t get bothered over little niggly, niggly things anymore” Noreen.

“I try an enjoy life as much as I can an I appreciate people now... I appreciate what’s done for me” Lucy.

### ***Increased awareness and enjoyment of the ‘little things’***

Participants noticed and enjoyed the little things more now since having had cancer.

“My family life was happy you know the usual up and downs but mm now I am at the happiest I ever was in my life, hand on my heart... I sat out today in the sunshine an I just ah... you could thank God for the sunshine, the beautiful day and the simple things make me very happy” Ingrid.

### ***Appreciate each day and life itself***

Participants appreciated each day, each moment more.

“A wide awakening to what life was all about. It has given me a greater appreciation of life and to take each day as it comes” Lorna.

Participants specifically mentioned appreciating life itself.

“Life is for living and I have more of a sense of how precious life is” Sally.

Participants expressed a change in attitude where they admitted they try to ‘make the best out of life’ and to feel grateful for the life they do have.



The Word Cloud for Appreciation of Life (Figure A-18.11, above) is based on the 1000 most frequent words and is a good reflection of the key points of this growth area. 'Life' is at the centre of this image and reflects the general appreciation of life. Other important words include; people, good, person, live, great, time, different, enjoy, aha and love.

### • **Change in Mindset**

Participants who recovered from cancer reported a considerable change in mindset. Many repeated the phrase 'get on with it' which reflected not only how they coped with cancer but also their attitude to life now. Survivors emphasised the importance of positivity with the mantra of 'stay positive'. This positivity was fuelled by focussing on goals and reminding themselves of how 'lucky' they are to have survived. Social comparison was also used by participants to positively position themselves as a way to manage their experience – i.e. that they were better off compared to others who had a worse prognosis or 'worse' cancer etc.

#### ***Get on with it***

Over one third of participants repeatedly used the phrase 'get on with it' when referring to how they coped with cancer, how they deal with the anxiety of recurrence and their attitude to life. Bree coped by just focusing on what needs to be done and for some, like Sandra, the motivation to get on with it was driven by a desire to make things normal for others.

"I'm fairly, I'm positive myself I had to think I, I, I never even contemplated dyin. I just mm... just, I just it has to be done go an do it an get on wit it, that's the way I look at things I have to say" Bree.

"I just kept pluggin away and try to make things as normal as possible for everyone round me" Sandra.

#### ***Stay Positive***

The significant change in mindset also included a considerable emphasis on positivity. A recurring phrase used by participants was 'stay positive' and this was

commonly used when asked what advice they might give to someone newly faced with a diagnosis.

“I would stay positive I just I suppose I just have that attitude that... you just get on with things an you know mm you can sit in the corner an feel sorry for yourself” Bree.

Two key features underpinned positivity and these are; goals and feeling lucky. Participants spoke at length of goals that they had – whether that was going to a family wedding, reaching a mountain top (like Bree below) or even being focused on putting the dinner on the table each day. These goals gave them something positive to focus on/aim for.

“I kinda said this year now I didn’t do the second mountain last year, it’s a bit lower... but I kinda said go an right June you forget about the big mount aha do the second mount this year then...” Bree.

“I think He, lookout now you owe me, you owe me, I need to be here you know. You can’t take me yet, I have to be here for the daughter’s weddin first of all... I’d be here seein my son playin in the County” Sandra.

At times the drive to achieve these goals came from the determination to beat cancer.

“...never left you know the treatment, anything stand in my way you know... I just said I’ll do this now for the year an I’ll just, at the beginning I said listen it’s goin to take a year here an this is my year you know... an nobody else’s” Josie.

Participants also referred to feeling lucky in terms of being alive, their health, getting diagnosed early and for the people in their lives.

“I was angry mm an then mm I suppose I kinda had got to the stage now that I, I would say, I’m, I’m lucky I’m well an I feel well fingers crossed all going well please God” Lorraine.

### ***Positive Positioning of cancer***

Another way that positivity played an important role is in the way participants saw themselves in a positive position when comparing themselves to others (social comparison). People spoke of being in a better position compared to those who; had died, those who experienced more severe side effects from treatment or more severe

treatment. They also thought they were in a more positive position compared to those who had a ‘worse’ cancer (e.g. were diagnosed at a later stage or who had what was considered a more difficult cancer).

“...different women here had died like you people that were here an people die...an you think say to yourself, Jesus it could be me. An then you think well what I had was nothing compared to what they had” Jessica.

“I was lucky enough not to have treatment, didn’t have to have Chemo etc., and I know from my friends who have had cancer, the treatment is almost worse than the illness” Hilda.

### ***Cancer Recovery as a socially embedded and collaborative process***

Table A-18.4, below, gives a complete overview of all the sub themes for T3 Cancer Recovery as a socially embedded and collaborative process.

Table A-18.4: T3, Cancer Recovery as a socially embedded and collaborative process and all themes

<b>Overview of the Sub Themes for T3 – Cancer Recovery as a Socially Embedded and Collaborative Process</b>
<p>Support from others and especially peer survivors, is the most significant driver of recovery The Diagnosis experience is greatly impacted by how medical staff treat patients cancer support centres play an important role in creating connection and the provision of therapies and classes</p> <p>Alternative Treatments, classes and counselling helped recovery in practical ways Helping Others drives recovery</p> <p>Support from others directly impacts on the survival/recovery strategies that participants used</p> <ul style="list-style-type: none"> <li>- Positive positioning of self via social comparison</li> <li>- Stay Positive with positive people and positive thinking</li> <li>- Dreams and plans involve others and motivate survivors to get well</li> </ul>

In my opinion, it is clear from the data that ‘Support’ is the most significant recovery driver for participants in this research project and that this support not only impacts on the quality of their recovery but also impacts on the survival strategies that participants used.

How the participant felt supported by others impacted on the quality of their recovery with those who perceived themselves as supported, having a more positive

experience. Other participants highlighted lack of support and loneliness as a hindrance which made recovery more difficult. The thematic map below (Figure A-18.12) highlights 5 key agents of support with peer survivors being the most important. The cancer support centres play an important role in providing the physical space, services and opportunities to meet peers. They provide alternative treatments and classes for survivors which aid recovery. The positive benefits of support also apply to survivors who, when they feel well enough, then seek to help others by sharing their story and fundraising etc.

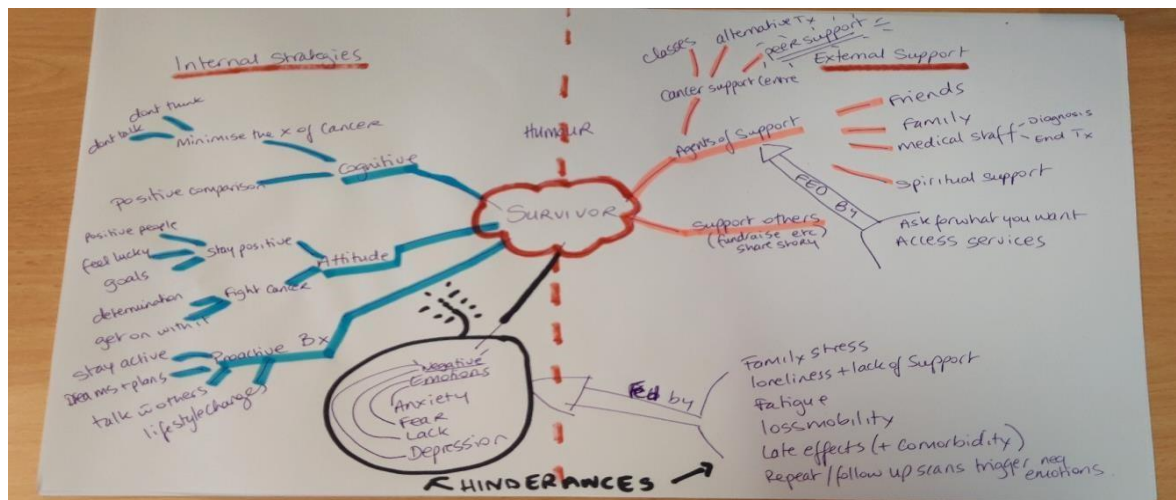


Figure A-18.12: Thematic Map Support and Survival Strategies

***Support from others and especially peer survivors, is the most significant driver of recovery***

The most significant positive recovery driver as identified by participants was *Support*. As mentioned in the theme of The Cancer Journey, participants emphasised the importance of seeking and accepting appropriate help when needed. One of the suggestions was to seek information/ask questions but Lucy also warned of the danger of using the internet:

“ask as much and get as much information without going on the Internet as that just frightens the life out of everybody...get as much as you can but ask all the questions... you need to know what you’re dealing with” Lucy.

In terms of agents of support, this took the form of peer survivors, medical staff, friend, family, spiritual and to a lesser extent work and pet support. With fellow

peers' participants felt they could open up with how they were feeling and felt both connected and understood (see Bree below). The cancer support centres provide the space for peer groups to meet and for peer survivors to interact during activities e.g. jewellery making or yoga. The support of medical staff was also noted as quite an important recovery driver again in terms of the connection and Iris (below) describes the happy atmosphere during treatment where she felt part of a family.

“and cause you don’t like burdeninkinda your family, I wouldn’t say bits, tell the women an awful lot or me husband...I just get on with it but here you can come in an talk to people an they know if you’re feelinkinda this way wan day. Well they know exactly how you’re feelin cause they’ve gone through the same thing themselves... It’s hard to explain it to people that hasn’t gone through the full treatment or gone through the cancer” Bree.

“absolutely brilliant, an they always kind of brought a smile on me face it was, you go in there and you’d be like a little family sittin around all having your Treatments done, and we kind of edged each other on, and it was the happy atmosphere that you had where you’re having your Treatment done that kind of lifted me along” Iris.

The framed image from the Dear Diary project below (Figure A-18.13, and Figure 8 within the main report) provides a clear example of support. It is a visual portrayal of specific people and events that helped Laura to recover. It highlights spiritual help in the form of holy water, a visit from a friar and people in heaven looking out for her. It was a friend who had arranged for the friar to visit and give a blessing. She specifically mentions medical support in the form of surgery. The image of the rose at the centre of this piece was created by the artist Sheila Wood who noticed that when you looked at a microscopic view of a breast cancer cell it had a striking resemblance to a rose. The rose/cancer is very prominent in this art piece – both in size and position to illustrate how several channels of support helped Laura to recover from cancer.



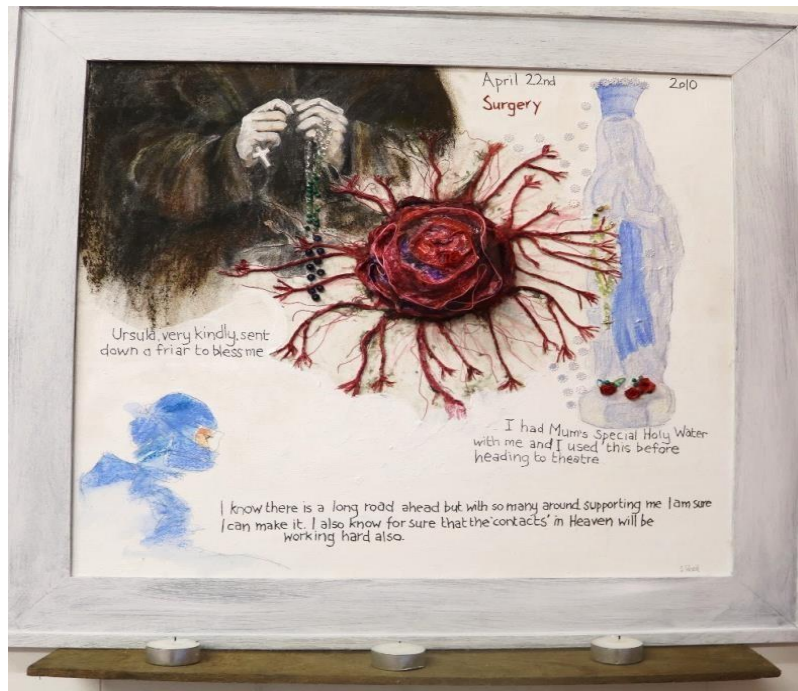


Figure A-18.13: Dear Diary: Support from others

*The Diagnosis experience is greatly impacted by how medical staff treat patients* A clear example of how support from others impacts the recovery experience is the way in which the experience of Diagnosis was greatly influenced by how the medical staff treated participants. For those who had a relatively positive diagnosis experience, they spoke of the trust in the medical staff, acts of kindness (e.g. being given a cup of tea or looked at compassionately) and reassurance from the idea that the doctor had a plan (see Josie below). However, if the patients did not feel they were treated well by staff in that diagnosis meeting then the experience was highly negative. Participants cited reasons such as delayed diagnosis, unavailability of staff and felt they were being dismissed or treated coldly. Mairead below shook with anger and cried with anguish as she re told the story of her lengthy diagnosis stage.

“all that Mr Jones (Dr) said to me the day he told me I was diagnosed, I mean I just heard I had cancer an I just heard him say ‘if you do everything that we’ll ask you to do we’ll cure ya’an that’s all I heard. So I said that’s fine, I’ll do my bit” Josie.

“well he said (the Dr) since I saw the last one you’ve multiple tumours but he said I can’t say now until I aa do some surgery, but he said as I explained to you before I’ll do the keyhole cause I wouldn’t open you. So he said my secretary will be in touch with you. I’m going on holidays for six weeks he said so you’ll get a phone

call, an he turned on his heel an he walked away....I just was just left with everybody listening (sob,sob)and I was so frightened (sob) and ...I look back on it now (sob). It's so abusive (sob), an it's so horrible" Mairead.

***Cancer support centres play an important role in creating connection and the provision of therapies and classes***

All of the participants for this doctoral research were accessed via the cancer support centres and both the Interviews and group sessions took part in the centres. In addition, participants expressed a high degree of gratitude and goodwill towards the centres for the support that they received in the past. Though I never asked specifically about what the centres offer or what they might have attended in the centres, it was natural to assume that they would cite centre services that they had availed of as helping their recovery. I am highlighting this point here as a note of caution that participants may have potentially over reported the positive impact of the centres.

Participants typically accessed the cancer support centres when treatment ended. Alternative treatments, classes and counselling were usually provided free of charge and were cited by participants like Emma below as a positive force in their recovery. The main positive impact of the centre was the important sense of connection that participants felt. As Leah below expressed, even the physical environment felt safe and welcoming.

"Tis a great thing to have these Centres, you know because it does lift your soul.An if I was really havin a really bad day often came down, they put me on the chair an throw a blanket over me an I'd have a rest an d' you know I know I feel the security of the house here" Leah.

"oh my god they are fantastic down here.And I had counselling sessions and to do with other things going on in my life and I did other em, I did mindfulness course, I did I did yoga, meditation courses, lots of courses here which I found fantastic.And only for the support centre here I don't think I'd have got through it" Emma.

***Alternative Treatments, classes and counselling helped recovery in practical ways***

As highlighted in T1, participants noted the positive benefits from alternative treatments and classes. This included; reduced nausea, improved bowel movement, better sleep, feeling calmer and meeting new people. For many, it was the first time

that they had tried alternative treatments and several continued with the sessions/classes even years later. Ingrid below spoke of how she knew herself better because of the treatments and classes. Counselling sessions were also a great support to participants who at times did not want to burden their family and needed a safe space to express and make sense of their feelings.

“I’m happy. I think I’ve learned to know myself, I don’t think I knew myself in 2009. I don’t think I did but all the, the Mindfulness an all the mm classes that I did, art classes and whatever, they all helped me to bring me out of myself” Ingrid.

“Tai chi helped definitely, I mean you know the Chemo and everything... it’s all very advanced and that, but I think what helped with it was the healthy treatments mm – they did, the combination of the two” Paula.

“And I felt that by coming here and opening up and the support that I got here (cancer support centre) ...And the counselling sessions ...really made me strong” Emma.

Talking with others is an important proactive behaviour that helps survivors recover. The act of talking helps the person connect to others and helps them make sense of and even release themselves from the cancer experience. As Trisha says so clearly:

“Talk, talk, talk to everyone that will listen to you, cause it’s the only way you’re goin to get it out of your system” Trisha.

“she said ‘I can’t tell anybody’, I said you’ve told me (pause) it’s so important to allow others to be with you I told her, (pause) you’re not alone” Mairead.

### ***Helping Others drives recovery***

Many participants highlighted how helping others then helped them to recover. This help was at times for their families (if their child or grandchild needed them) but was mainly in the form of helping other cancer patients/survivors. Participants spoke of fundraising, volunteering, using humour to lift the mood and practical support. The main way of helping was to just be there for the other person; to listen, to share their own story, offer reassurance and be physically available for the other person. This helping behaviour manifested at a time when the cancer survivor was starting to feel well, at a time when confidence and strength was returning.

“I do a lot more for cancer charities now ...I was never goin ta get cancer but once you have it like you realise that, that, that people that were there for you, that perhaps you can give something back” Laura.

“I’m just more tuned into people who are unwell ...havin said that I don’t go around lookin for sick people, but you know when you know somebody says ‘I’m not feelin the best’...what can we do about it? How do you feel?D’you need washindone?Will I take the kids out?” Mira.

For some participants, they felt they had to survive so that they could look after their family.

“I felt as a Mother I had to be alive for my husband and my children” Susan.

***Support from others directly impacts on the survival/recovery strategies that participants used***

As I noted at the beginning of this theme, support from others not only impacts on the quality of the recovery experience but it also directly impacts on the recovery strategies that participants used to get well. One such example is the way in which survivors positioned themselves positively in comparison to their peers e.g. that their cancer or the treatment was somehow easier. This was a cognitive strategy to minimise and manage their experience. ‘Stay Positive’ was a prominent cultural survivor norm that was a key recovery driver. This led to a change in relationships (more positive people and move away from negative ones) as well as internally thinking more positively. Dreams and plans is another strategy that survivors used to get well. Other people may participate in or even be the object of these dreams and plans.

***Positive positioning of self via social comparison***

Again, as highlighted in T1, participants saw themselves in a positive position when comparing themselves to others. People spoke of being in a better position compared to those who; had died, those who experienced more severe side effects from treatment or more severe treatment. They also thought they were in a more positive position compared to those who had a ‘worse’ cancer (e.g. were diagnosed at a later stage or who had what was considered a more difficult cancer).

“you know and mm... you know there are younger people than me who’ve got cancer, had Chemotherapy – it hasn’t worked for them an they’ve died quite young. So I just consider myself to be very fortunate” Imelda.

“there was a woman like that near me in in the village that had cancer she’s had it twice. She used to have to put her duvet into the bathroom you know that’s how sick she was you know. So I mean I’ve been lucky all the way long you know” Elaine.

### ***Stay Positive with positive people and positive thinking***

When asked about what helped them recover from cancer, participants highlighted a change in mindset. One of these changes was to Stay Positive which involved surrounding yourself with positive people and staying away from people who are negative or causing stress. Bree spoke of a relative who was diagnosed but not dealing with it so well and so she walked away:

“she’s diagnosed with Lung cancer mm fourteen weeks ago, terrible negative absolutely brutal. She had herself dead an buried. ...I had to stay away from her in the end cause I thought I probably would have throttled her. ...I know tis the shock an everyone deals with it in a different way but I kinda said to her, you’re feedin this bloody cancer so, you’re so negative you’re actually feedin it, you’re makin it worse” Bree.

Stay Positive is an important survivor cultural norm that encouraged participants to think positively. When Anna was asked what was the best advice she would give to someone who is just diagnosed she replied:

“I would say straight away be positive ...be as positive an be absolutely sure an certain you are goin to beat it no matter how bad t’is ...you’re the winner” Anna.

### ***Dreams and plans involve others and motivate survivors to get well***

As mentioned in T1, having goals and plans gives survivors something to aim for and increases positivity. These goals can be small (making the dinner) or large (climbing mountains). They often involve others who may take part or even be the object of the dream/plan e.g. travel or aiming to attend and enjoy family events. These ‘dreams and plans’ also feed into the ‘stay active’ which participants

identified as a positive recovery driver. This involved just staying busy, new hobbies and lifestyle changes.

“Plan little events during Chemo treatment that you can look forward to doing between Chemo cycles, so you are looking forward to that event and not post dreading the next Chemo cycle” Abigail.

***‘Cancer’ is an emotive word and the experience is a roller-coaster i.e. intense emotions, terror and lack of control***

‘Cancer’ is a highly emotive word. Some participants spoke of their difficulty in just hearing or saying the word cancer. For others, cancer was associated with ‘the big C’ which made it even more ominous and dangerous.

Cancer can lead a person to face and question their own mortality which is a very emotional (rollercoaster) experience. After the cancer experience some participants, like Mira below, found they were not afraid of the word anymore and there was some acceptance of cancer as a chronic illness rather than the death sentence that it historically once was.

“I’ve said this the Big C... that is one thing that I would love to see gone. Move it in there with serious illnesses, stop givin it this unmighty thing that it’s cancer... sentence deadgone forever, stop doin that. But I have to be honest and also I’m not afraid of cancer anymore, tha was, I wouldn’t even watch a programme about before, because I thought ...it meant death to me too, whereas now I’m happy to talk about if somebody asks me I don’t think about it all the time, I haven’t talked about it in months except now to you, but I’m not afraid of it anymore I watch a programme about it, I want to help people” Mira.

During the one-to-one interview, each person was asked to describe their experience from *diagnosis until the end of treatment* by using an image, metaphor or saying. As highlighted earlier in T1 The Cancer Journey, participants used words and images that depicted the terror, the fear of the unknown, the lack of control and the intense emotionality. The term ‘roller coaster’ was used several times. In my opinion, the participants used this term to infer that their experience was intense, overwhelming and out of their control (reference Table A-18,5 below). Others spoke of a dark place or a black hole. The whole experience was described by several participants as a

long or great journey. Still others spoke of treatment as being wrapped in ‘cotton wool’ or as a wave. Some felt ‘at sea’ or in the centre of cancer.

“...so it’s been a roller coaster you know ...it’s been an a long journey you know, and I still I would be fit for the skip at nine o’clock half nine at night, go to bed”

Sandra.

Table A-18.5: Cancer as an emotional roller-coaster and all themes

Cancer as an Emotional Roller-Coaster
<p>‘Cancer’ is an emotive word and the experience is a roller-coaster i.e. intense emotions, terror and lack of control</p> <p>Perception of cancer is fuelled by prior negative experience</p> <p>Emotions frozen in diagnosis stage</p> <p>‘Busyness’ of treatments keeps emotions at bay</p> <p>Unfreezing of emotions at end of treatment is overwhelming</p> <p>Anxiety, Fear and Depression as ‘negative emotions’ which hinder recovery</p> <p>‘Get on with it’, ‘Stay Positive’ and ‘Stay Active’ – positive recovery strategies but they negatively confine emotions</p> <p>Peer Support – the unregulated channel of emotional sharing</p>

Participants were also asked to describe their experience of *recovery* in terms of an image, metaphor or saying. Participants described it as a whirlwind, a journey, a bridge to get over, and a solid wall and the emotions were of fear and joy. Lorraine described recovery as that post wedding feeling – when the treatment is done, and you are dealing with all the emotions and the fear afterwards.

“It’s like panic you know when you’re gettin ready for a wedding, ...t’is afterwards when you’re married an the honeymoon is over you realise oh...right an you’ll never be the same with the cancer. ...The mental pain an the physical pain. ...Physical pain an mental pain. Mental pain you know was mm... I would say it was the nearest I came to probably a breakdown” Lorraine.

#### *Perception of cancer is fuelled by prior negative experience*

The participants view of cancer was greatly influenced by their prior experience of it – if family or friends had had cancer and what kind of experience they had. If they

had seen someone have a difficult time or hard death, then this led to a negative perception. If there was no family history of cancer, then this added to the shock of a diagnosis. The participants saw cancer differently having gone through recovery – it did not have the same power or fear over them and was ‘just another illness’. For many, they were left with a resolve to deal with it. For Sarah this resolve was driven by fear whereas for others like Sandra it was sheer determination.

“an the thing I dread was, oh I didn’t want to die like my sister, Jesus Christ I didn’t want to die like her, I really didn’t” Sarah.

“It’s... you’re never done with cancer. Mm I’m not the type, I am a worrier but I don’t worry about gettin cancer again, been there done that an if I have to I’ll do it again” Sandra.

As discussed earlier, participants traced the cause of their cancer to a major negative life event/experience. The main two that were identified were bereavement and stress (family and long-term). Both of these are driven by difficult and intense emotions including grief and anxiety.

“even at a very young age it’s one of my boys said Mummy you grew up when you were ten because I saw my Dad die, I know how temporary life is” Nancy.

### ***Emotions frozen in diagnosis stage***

As discussed in T1 The Cancer Journey, the main response from participants during diagnosis was to ‘freeze’ with the key emotions being shock and fear. Some did move into ‘fight’ – ready to do battle and move into action and still there were others who were in denial by refusing to believe or minimise the cancer experience. Despite there being a select view who channelled emotions into proactive behaviour (seeking treatment and asking questions), most participants detached from and froze out their emotions. If we take a closer look at the research data and how participants coped, one strategy was to not deal with cancer at all i.e. to specifically not talk about it, not think about it, to minimise the experience and to focus on other people. The key emotions that underpinned how people coped were of anxiety (fear of recurrence and living with the shock of cancer) and of loneliness (dealing with cancer on your own, feeling misunderstood and physical distance from others). Jessica just refused to talk about cancer.



“...that’s what I used to often think, I had I don’t know where to go with this I don’t know what to do. D’you know who could you talk to? And there was a woman at work actually who had breast cancer about two years before me an she sent me a lovely note but I never made contact with her because I didn’t want to talk about it. ...An I never talk about it in work... an if anybody ask me anything I cut them off” Jessica.

***‘Busyness’ of treatments keeps emotions at bay***

Once cancer was diagnosed, most participants began a very busy time of hospital care involving a combination of bloods, scans, surgery, radiation and hormonal treatments (for 67 participants, 29 different treatment programmes were used). Participants were also busy dealing with treatment side effects. Overall, the focus was on *doing* and not *feeling*. Both Lola and Haley speak to the day to day appointments becoming the centre of their world.

“Once you get used to the treatments life revolves around Hospitals” Lola.

“Reality only began to dawn towards the end of my treatment. While having treatment I just dealt with each day as it came” Haley.

***Unfreezing of emotions at end of treatment is overwhelming***

As highlighted in T1 The Cancer Journey, participants felt lost, frightened and alone when they finished treatment as they left the ‘bubble’ and security of close monitoring by the hospital system. The Thematic Map for T1 and Treatment (Figure A-18.14), shows how the busyness of treatment is followed by a specific transition at the end of treatment where survivors suddenly have the time to stop and emotionally process what has been happening.

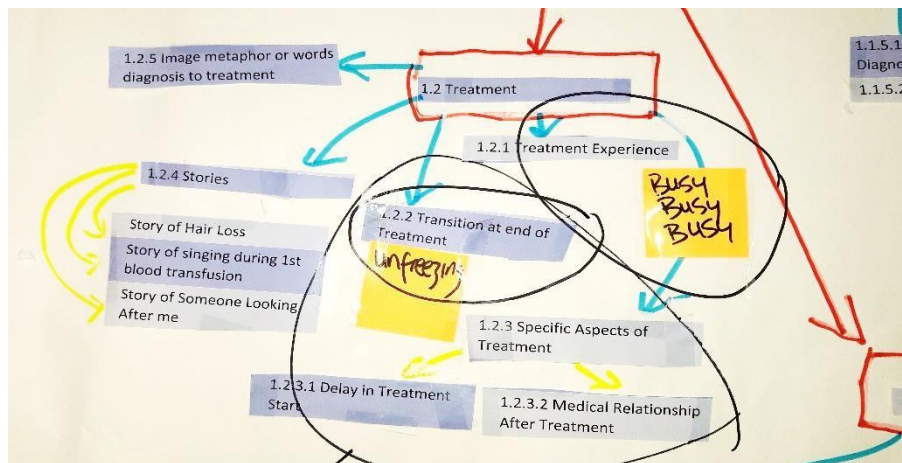


Figure A-18.14: Thematic Map for The Cancer Journey and Treatment

This transition at the end of treatment opened very intense emotions as if they were just experiencing cancer for the first time. Iris (below) speaks of the sheer fear of losing the hospital ‘lifeline’ and Carol describes what she sees as two separate sides of the cancer experience – the medical and the emotional.

“It’s very frightening and you feel as though you can’t let go of me because if you let go of me now it will come back again... It’s like your lifeline is gone mm very nervous I was very nervous for her to say, that’s it you’re not coming back anymore. ...I have to come back ...you need to be told that you’re still alright. ... I didn’t like it at all. I wasn’t looking forward to it one little bit because I, I thought I, you can’t you can’t just leave me now”. Iris.

“I see two different two very different sides...I see medical side...An I see the emotional side. Mmm the medical side was actually much easier than the emotional side, if that makes sense” Carol.

### ***Anxiety, Fear and Depression as ‘negative emotions’ which hinder recovery***

When participants were asked about what they thought hindered recovery, they noted they felt a ‘lack’ (support and finances etc) as well as the negative impact of treatment side effects – including; cognitive loss, lack of finances and medication issues. Perhaps the most significant hindrance was that of Anxiety, Fear (of recurrence and generalized anxiety) and Depression. These 3 ‘negative emotions’ were intensified further by several issues that participants identified as hindering their recovery; family stress (issues and friend loss), fatigue, loss of mobility and late

effects (compounded by comorbidity). Participants also highlighted loneliness (physical and emotional distance from others) as well as lack of support as negatively affecting their recovery. They also noted that repeat/follow up scans triggered their anxiety. For some, like Iris below, they did not need a trigger for anxiety, they lived with it all the time:

“There’s always that feeling in the back of your head that it’s gona show itself again...though you’re watching, you’re continually say you’ve got a time bomb going off inside you that could go off at any time... in the back of my head it’s always gona be there... that feeling is never gona go away that’s like the scar that aha never heal even though you’re told you’re fine, you are in remission even though you’re told all those things you still don’t believe an I wish I could” Iris.

In my opinion the 3 ‘negative emotions’ and the hindrances that feed them, can be viewed systemically – co existing and interdependent to each other. For example, if I have insomnia and muscle aches due to cancer/treatment then I might also feel tired and depressed etc. I think that further research is needed to investigate these areas in terms of what their relationships might be, the power dynamics and if there are other causal factors. In Figure A-18.15 below, you can see how these ‘negative emotions’ are fed by internal and external stressors. I would also go further and argue that it is a 2-way relationship and that the experience of the stressors is also fed by/influenced by the negative emotions that participants face.

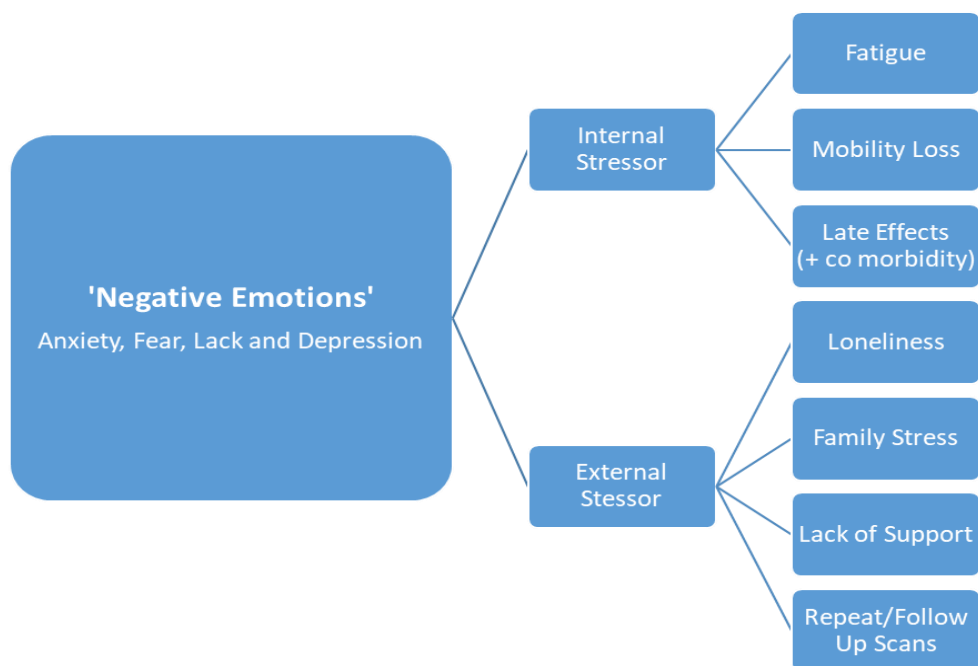


Figure A-18.15: ‘Negative Emotions’ fed by Internal and External Stressors

***‘Get on with it’, ‘Stay Positive’ and ‘Stay Active’ – positive recovery strategies but they negatively confine emotions***

When participants were asked what helped their recovery, they spoke of a ‘get on with it’ attitude which meant being practical – a ‘no nonsense’ approach to focus on one thing at a time. This is demonstrated by Orla below. ‘Stay Positive’ was also another crucial strategy in terms of how you think and surrounding yourself with positive people. As discussed in T1 The Cancer Journey, positivity played a key role in positioning the survivor in a ‘better’ position to others which could cognitively make their experience more manageable but at the same time perhaps negatively minimise their experience. Another strategy that participants used to help them recover was to

‘Stay Busy’ via hobbies, lifestyle changes and/or by spending time with family. This helped Laura and others to keep moving forward and not to dwell on the cancer experience.

“Do what needs to be done, surgery, treatment. Move on and get a better life for yourself. Don’t let it define you and your future” Orla.

“Fine ye I think what I felt was keepin busy cause just you know keepin your mind off things... you didn’t get time to worry too much you kept busy” Laura.

All 3 strategies (*Get on with it*, *Stay Positive* and *Stay Active*) can potentially lead to a type of containment of emotions – where the emphasis is on thinking and doing (rather than feeling).

***Peer Support – the unregulated channel of emotional sharing***

The most significant driver of recovery as identified by participants was that of support, especially from hospital staff and peer survivors. Participants emphasised the importance of accessing support and asking for what you need. What specifically helped was feeling monitored, taking part in peer survivor groups, activities and helping fellow survivors.

“...saw people here that I could talk to, who’d been through it maybe nine or ten years past. I could see some people that were a survivor of it so it kind of gave me the hope that I would hopefully get through the next few months” Iris.

In my opinion, relating with cancer survivors provided the opportunity to disclose and process how they experienced cancer, providing a safe place to share their

emotions. However, most of this sharing was with peers rather than counsellors or therapists. This supports the call to formalise peer support. We need to legitimise, formalise, fund and train peer mentors. This would not only support survivors receiving this support but legitimise a peer support role to recognise the person giving the support and thereby helping them by recognising and giving meaning to their contribution.

“you know now I have been on medication for depression, I have been on antirelaxants, I’m tryin to wean myself off of them but I do find myself that I slip but I know I’m slipping... at this stage I don’t need to go to Jane (counsellor), I’m able to lift myself out of it...but it does leave a legacy of fear” Ingrid.

According to the model of PostTraumatic Growth (Tedeschi & Calhoun, 1996), a person can process a trauma via self-disclosure and analysis and that this can lead to cognitive and emotional positive growth. From analysing the data from this particular doctoral research, participants experienced positive emotions/emotional development in 4 growth areas. In terms of Appreciation of Life, several participants reported feeling happy and a new sense of gratitude in the way they now appreciated life and other people (see Bree below). A positive mindset was underpinned by participants ‘feeling lucky’. With an increased personal strength, participants felt stronger and more confident. And finally, when it comes to how they relate to others, participants identified that they have grown emotionally and can recognise and deal with their emotions in a new way (as per Mairead’s quote below).

“Become a better person. Learned about the importance of gratitude, how precious life is” Bree.

“I’ve had a lot of emotion in the last couple of weeks and mm I’m allowing it to happen. I never did before, but I’m trying to be real an to not always be Miss Perfect” Mairead.

Detaching from and minimising emotions is a very useful survival strategy in the short term. In terms of the main negative impact from cancer, participants spoke of the anxiety and fear of recurrence that they live with. Therefore, for full health and quality of life we need to provide the right space at the right time in the recovery trajectory for participants to safely share and process their emotions to build emotional resilience.

## **Appendix 19: Quantitative Findings: Post Traumatic Growth Inventory (PTGI-42)**

Each participant completed the Post Traumatic Growth Inventory (42). The quantitative data set consists of 66 completed inventories (1 inventory was incomplete and therefore not included). This data was analysed in 2 ways. Firstly, I used descriptive stats to look at a general overview of how participants scored the inventory and analysed the frequencies of each of the statements. For clarity, I grouped the statements according to the Factor to which they belonged. These 5 Factors or areas of growth as specified by Calhoun and Tedeschi (2006) are: Relating to Others, New Possibilities, Personal Strength, Spiritual Change and Appreciation of Life. The second way I analysed the quantitative data was to use cross tabulation and Fishers Exact Test to see if there were any significant relations between either Marital Status or those with or without children and each of the PTGI-42 individual statements. Since I was looking at the quantitative data through a qualitative lens and since the inventory data is categorical, the most appropriate analyses was achieved via descriptive statistics and cross-tabulation. The data was analysed using SPSS Version 24.0.

### **Analysis 1: Descriptive Statistics**

In terms of the overall picture of PTGI scores, out of 66 participants, the average score was 77. This is relatively high given that other research like for example Joen *et al.* (2015) determine a high score to be 64+. The lowest score was 25 and the highest was 104 (where the highest potential score is 21 items X 5 i.e. 105). The median and mode are both 75. Table A-19.1 below contains a complete summary of the statistics for all 5 Factors.

Table A-19.1: A summary of the PTGI inventory statistics for the 5 Factors

Analysis	I Relating to Others	II New Possibilities	III Personal Strength	IV Spiritual Change	V Appreciation of Life
Factor Totals	1784	1088	1014	320	790
Mean	27	17	15	5	12
Max Individual Potential	35	25	20	10	15
Max Sample Potential	2310	1650	1320	660	990
Min Score Actual	9	3	6	0	3
Max Score Actual	35	25	20	10	15
IQR	7	8	4	6	4.5
Stddev	5.9	5.6	3.5	3.5	3.0

The participants self-reported the greatest degree of change in Factor V: Appreciation of Life with a total of 790 out of a sample maximum of 990. The average was 12 and the potential individual maximum score is 15. The frequency of scores for this factor are below in Figure A-19.1.

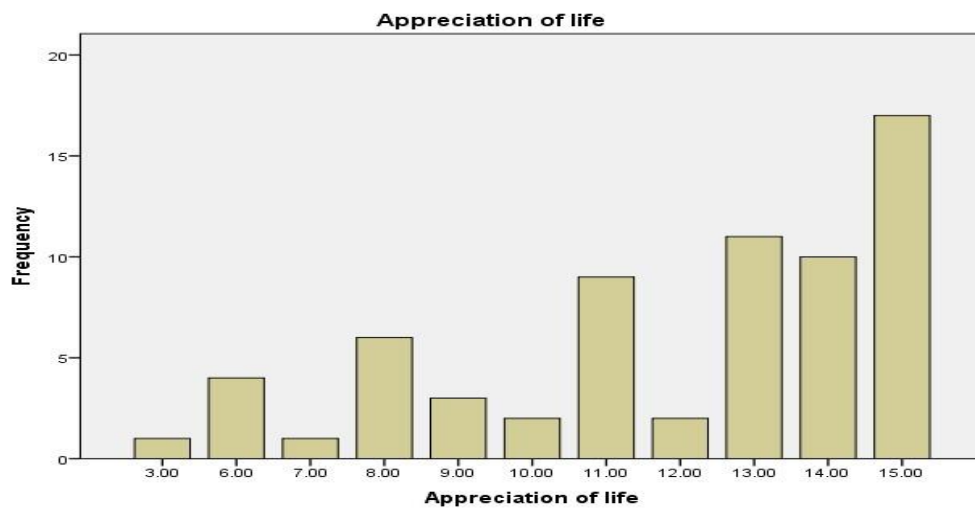


Figure A-19.1: Appreciation of Life and Frequency

The second highest recorded area of growth was in Factor 1: Relating to Others with a total score of 1784 out of a potential maximum of 2310 (as seen in Table A-19.1 above). The average was 27.

This factor contains 7 statements which means a maximum scoring per participant of 35 (which was the mode for this Factor). The median is 29. For a further breakdown of statistics percentiles where N = 66, see Appendix 19. Figure A-19.2 below highlights the frequency scores for this factor.

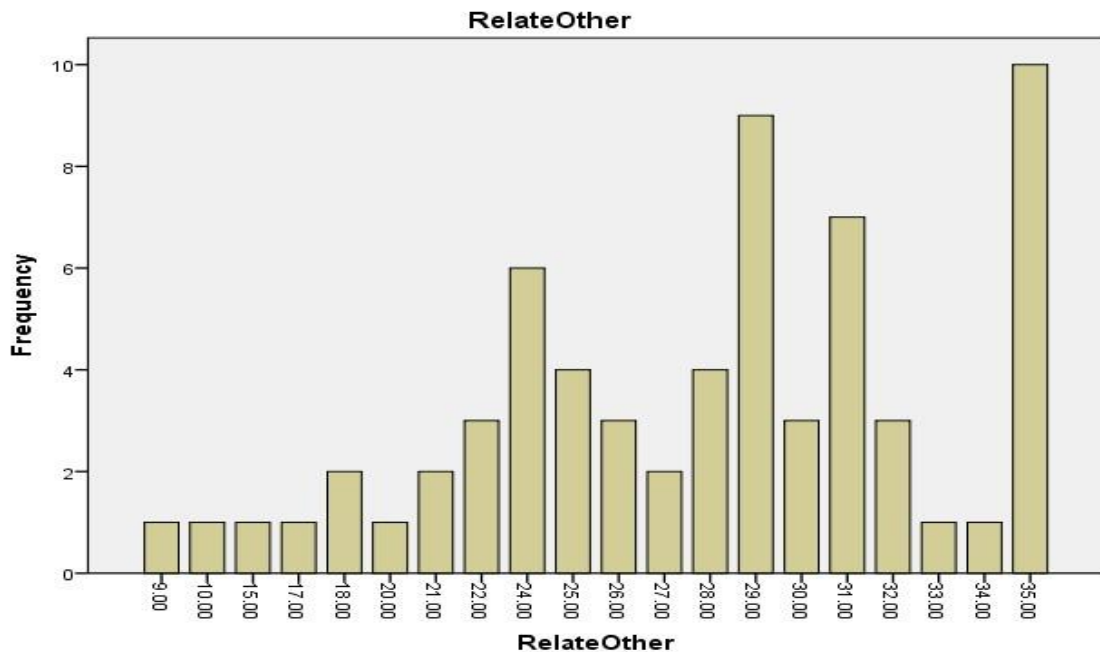


Figure A-19.2: Relate to Others and Frequency

The third highest area of growth was Factor III: Personal Strength with a total score of 1014. The maximum sample potential was 1320. The average score for this Factor is 15 and the potential individual maximum score is 20. Figure A-19.3 below illustrates the frequency of scores for this factor.



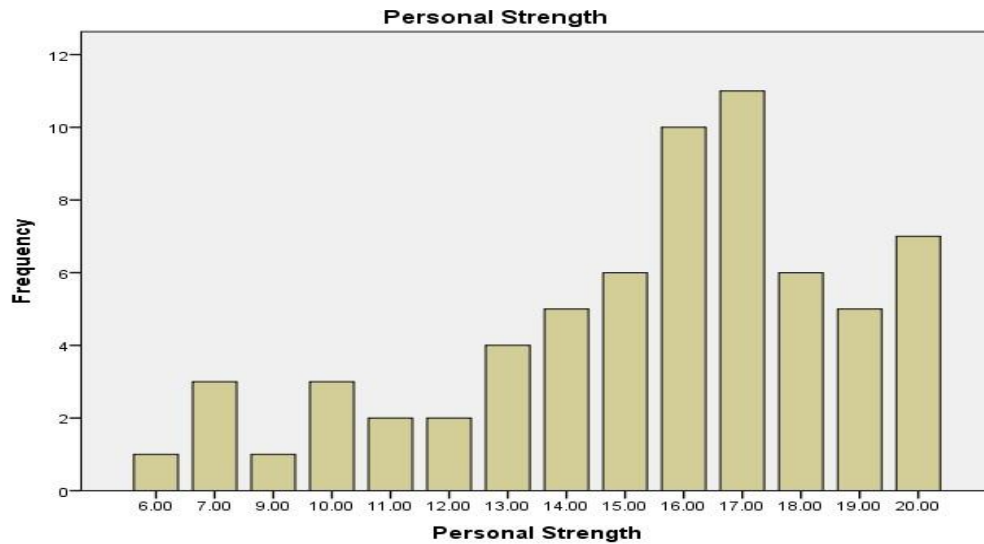


Figure A-19.3: Personal Strength and Frequency

The fourth highest degree of change was Factor II: New Possibilities with a total score of 1088 out of a potential maximum of 1650 for the full sample. The average was 17 and the potential individual maximum score was 25. Figure A-19.4 below illustrates the frequency of scores for this factor.

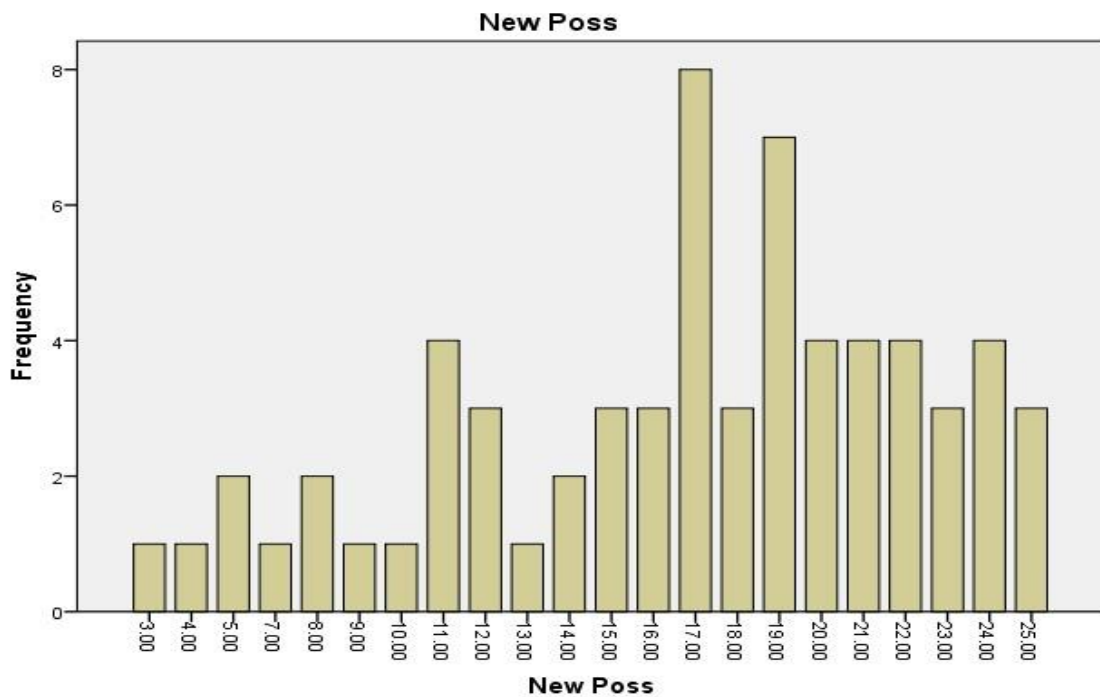


Figure A-19.4: New Possibilities and Frequency

Factor IV: Spiritual Change was the lowest self-reported degree of change of all the five Factors. The total score was 320 out of a sample maximum of 660. The average score is 5 and the potential individual maximum score is 10. The frequency of scores for this factor is illustrated in Figure A-19.5 below.

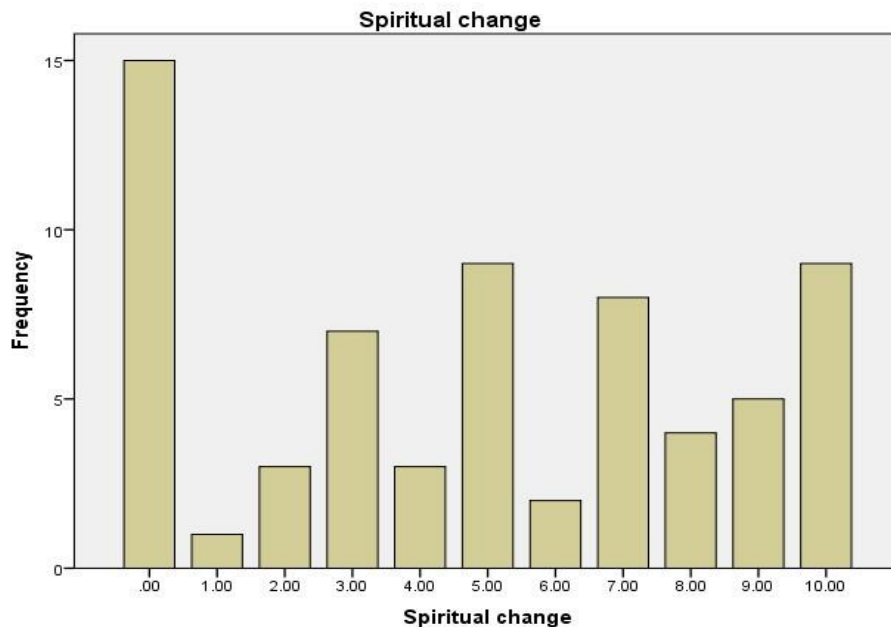


Figure A-19.5: Spiritual Change and Frequency

I will consider each of the 5 growth Factors in turn.

### **Factor I: Relating to Others**

This Factor comprises of 14 statements which measure how people feel they can count on and feel close to others, how willing they are to express emotions, have compassion for others and how much effort they are willing to put into relationships. It also measures how a person might perceive how wonderful or disappointing people are as well as how much they accept needing others.

#### **• Counting on people**

62 participants (92.5%) said that they could more clearly see that they could count on people in times of trouble (from a moderate to a very great degree – see Table A-19.2 below. The bar chart in Figure A-19.6 clearly shows that the most frequent response from participants was that ‘I more clearly see that I can count on people in times of trouble’ was experienced to a very great degree (by 43 participants). In terms of more clearly seeing that you cannot count on people, 37 participants did not

experience this at all. It is worth noting that 12 people noted this change on a moderate to a very great degree. This apparent incongruence of thinking ‘I can count on someone’ and ‘I cannot count on someone’ was noted by several participants who completed the inventory and reference was made to the experience of cancer ‘showing you who your real friends are’ and the change in who became a friend and who was once a friend but is not anymore.

Table A-19.2: ‘I more clearly see that I can count on people in times of trouble’ and cumulative frequency

I more clearly see that I can count on people in times of trouble		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I did not experience this change as a result of my crisis	2	3.0	3.0	3.0
	I experienced this change to a very small degree as a result of my crisis	2	3.0	3.0	6.1
	I experienced this change to a moderate degree as a result of my crisis	7	10.4	10.6	16.7
	I experienced this change to a great degree as a result of my crisis.	12	17.9	18.2	34.8
	I experienced this change to a very great degree as a result of my crisis.	43	64.2	65.2	100.0
	Total	66	98.5	100.0	
Missing	System	1	1.5		
Total		67	100.0		

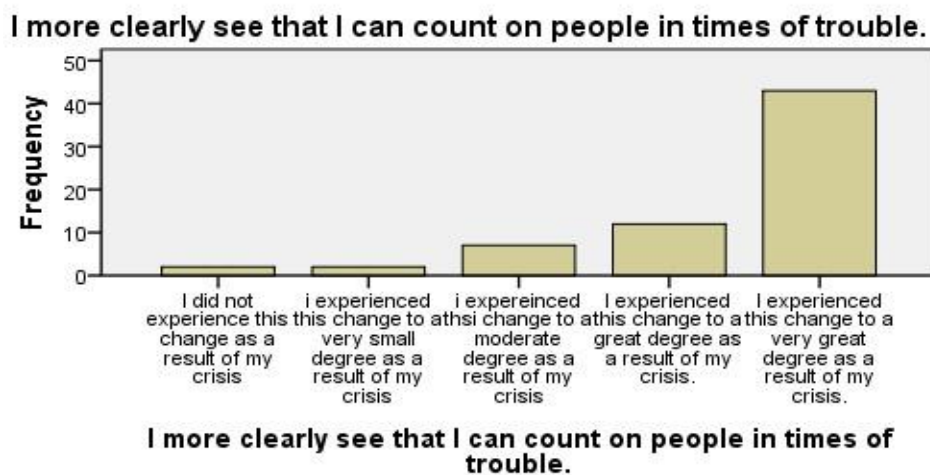


Figure A-19.6: Chart of ‘I can more clearly see that I can count on people in times of trouble’

• **Closeness with others:**

57 participants (85%) said that they experienced a greater sense of closeness to others (from a moderate to a very great degree). See the bar chart in Figure A-19.7 below. 36 participants (53.7%) said that they did not experience a greater sense of distance from others. 12 (17.9%) experienced an increase in distance (from a moderate to a very great degree).

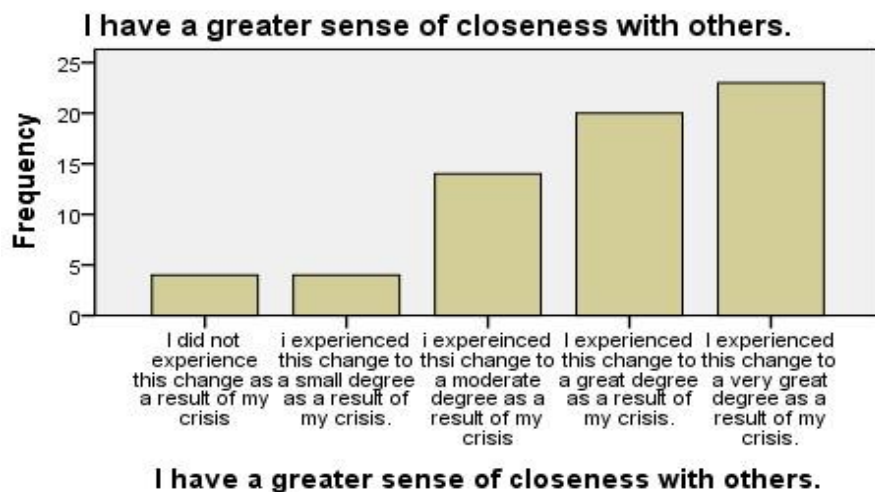


Figure A-19.7: 'I have a greater sense of closeness with others'

• **Expressing Emotions:**

47 participants (70%) said that they are more willing to express their emotions. 39 participants (58%) said that in terms of being less willing to express their emotions that they did not experience this at all. 15 people (22%) stated that they were less willing to express emotions (from a moderate to a very great degree). Further details are contained in Table A-19.3 overleaf.

Table A-19.3: ‘I am more willing to express my emotions’ and cumulative frequency

I am more willing to express my emotions		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I did not experience this change as a result of my crisis	5	7.5	7.6	7.6
	I experienced this change to a very small degree as a result of my crisis	4	6.0	6.1	13.6
	I experienced this change to a small degree as a result of my crisis.	10	14.9	15.2	28.8
	I experienced this change to a moderate degree as a result of my crisis	15	22.4	22.7	51.5
	I experienced this change to a great degree as a result of my crisis.	13	19.4	19.7	71.2
	I experienced this change to a very great degree as a result of my crisis.	19	28.4	28.8	100.0
	Total	66	98.5	100.0	
Missing	System	1	1.5		
Total		67	100.0		

- Compassion for others:

61 participants (91%) said they experienced increased compassion for others (from a moderate to a very great degree) with 40 of them (60%) experiencing this to a very great degree. With regards to having less compassion for others, 48 participants did not experience this at all (72%).Figure A-19.8 below clearly highlights that most of the participants experienced increased compassion for others.

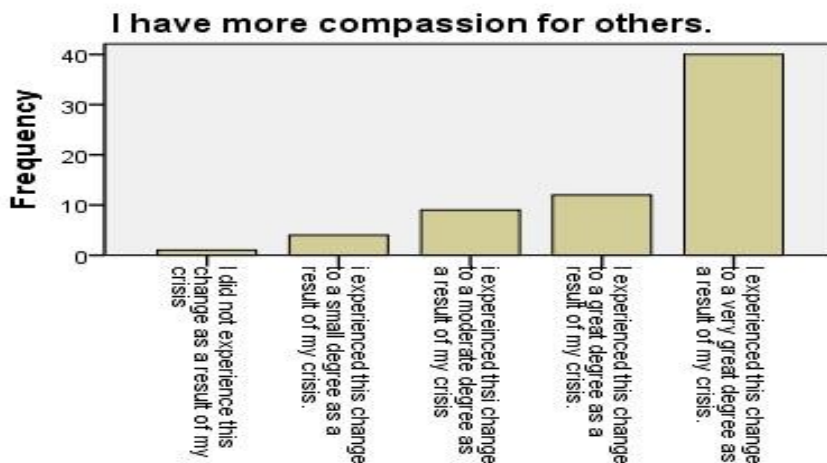


Figure A-19.8: Chart: ‘I have more compassion for others’

• **Effort into relationships:**

55 participants (82%) said that they put more effort into relationships (from a moderate to a very great degree) with 26 people (39%) saying that they experienced this to a very great degree. Please see Table A-19.4 below for the breakdown of cumulative frequency. As far as putting less effort into relationships is concerned, 46 participants (69%) did not experience this at all.

Table A-19.4: 'I put more effort into my relationships' and cumulative frequency

<b>I put more effort into my relationships</b>		<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	I did not experience this change as a result of my crisis	6	9.0	9.1	9.1
	I experienced this change to a small degree as a result of my crisis.	5	7.5	7.6	16.7
	I experienced this change to a moderate degree as a result of my crisis	14	20.9	21.2	37.9
	I experienced this change to a great degree as a result of my crisis.	15	22.4	22.7	60.6
	I experienced this change to a very great degree as a result of my crisis.	26	38.8	39.4	100.0
	Total	66	98.5	100.0	
Missing	System	1	1.5		
Total		67	100.0		

• **How wonderful or disappointing people are:**

59 participants (88%) stated that they learned how wonderful people are as a result from having had cancer to either a great or very great degree (see Figure A-19.9 below). In terms of learning how disappointing people are, 27 participants (40%) did not experience this at all and yet 17 people (25%) said that they learned how disappointing people are to a great and very great degree (see Table A-19.5 overleaf).

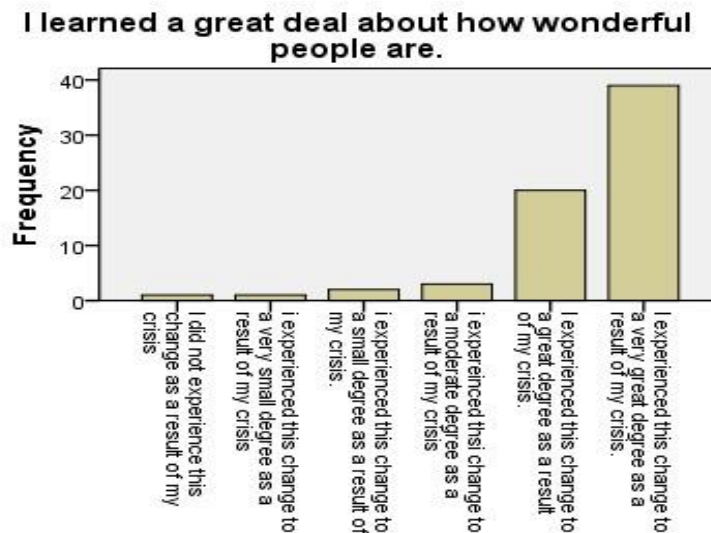


Figure A-19.9: 'I learned a great deal about how wonderful people are'

Table A-19.5: 'I learned a great deal about how disappointing people are' and cumulative frequency

I learned a great deal about how disappointing people are					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I did not experience this change as a result of my crisis	27	40.3	41.5	41.5
	I experienced this change to a very small degree as a result of my crisis	9	13.4	13.8	55.4
	I experienced this change to a small degree as a result of my crisis.	7	10.4	10.8	66.2
	I experienced this change to a moderate degree as a result of my crisis	5	7.5	7.7	73.8
	I experienced this change to a great degree as a result of my crisis.	2	3.0	3.1	76.9
	I experienced this change to a very great degree as a result of my crisis.	15	22.4	23.1	100.0
	Total	65	97.0	100.0	
Missing	System	2	3.0		
Total		67	100.0		

- **Acceptance of needing others:**

53 participants (79%) said they better accepted needing others (from a moderate to a very great degree). For 'I find it harder to accept needing others', 35 participants (52%) did not experience this at all but results were more spread than the previous statement (see Table A-19.6 overleaf).

Table A-19.6: 'I find it harder to accept needing others' and cumulative frequency

I find it harder to accept needing others					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I did not experience this change as a result of my crisis	35	52.2	53.0	53.0
	I experienced this change to a very small degree as a result of my crisis	4	6.0	6.1	59.1
	I experienced this change to a small degree as a result of my crisis.	8	11.9	12.1	71.2
	I experienced this change to a moderate degree as a result of my crisis	10	14.9	15.2	86.4
	I experienced this change to a great degree as a result of my crisis.	5	7.5	7.6	93.9
	I experienced this change to a very great degree as a result of my crisis.	4	6.0	6.1	100.0
	Total	66	98.5	100.0	
Missing	System	1	1.5		
Total		67	100.0		

## Factor II: New Possibilities

This Factor comprises of 10 statements and is a self-reporting measure of the degree to which participants experienced positive change in New Possibilities. It includes; new interests, a new life path, if I am doing better things with my life, if I have experienced new opportunities and also if I try to change what needs changing.

### • Interests

52 participants (77.6%) said that they developed new interests from a moderate to a very great degree (see Table A-19.7 below). This is supported by 46 participants who did not experience at all fewer interests than before.

Table A-19.7: 'I developed new interests' and cumulative frequency

I developed new interests					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I did not experience this change as a result of my crisis	4	6.0	6.1	6.1
	I experienced this change to a very small degree as a result of my crisis	4	6.0	6.1	12.1
	I experienced this change to a small degree as a result of my crisis.	6	9.0	9.1	21.2
	I experienced this change to a moderate degree as a result of my crisis	16	23.9	24.2	45.5
	I experienced this change to a great degree as a result of my crisis.	14	20.9	21.2	66.7
	I experienced this change to a very great degree as a result of my crisis.	22	32.8	33.3	100.0
	Total	66	98.5	100.0	
Missing	System	1	1.5		
Total		67	100.0		



• **Path for my life:**

44 participants (65.68%) stated that the experience of having had cancer led them to establish a new path for their life and 8 participants did not experience this change at all (see Table A-19.8 below). With regards to having a less clear path for my life, 39 participants (58.2%) did not experience this at all with 10 people (14.9%) experiencing this to a very small degree.

Table A-19.8: ‘I established a new path for my life’ and cumulative frequency

		<b>I established a new path for my life</b>			
		<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
Valid	I did not experience this change as a result of my crisis	8	11.9	12.3	12.3
	I experienced this change to a very small degree as a result of my crisis	7	10.4	10.8	23.1
	I experienced this change to a small degree as a result of my crisis.	6	9.0	9.2	32.3
	I experienced this change to a moderate degree as a result of my crisis	12	17.9	18.5	50.8
	I experienced this change to a great degree as a result of my crisis.	14	20.9	21.5	72.3
	I experienced this change to a very great degree as a result of my crisis.	18	26.9	27.7	100.0
	Total	66	98.5	100.0	
Missing	System	1	1.5		
Total		67	100.0		

• **Doing better things with my life:**

55 people (82%) said they were able to do better things with their life from a moderate to a very great degree (see Figure A-19.10 overleaf). In terms of being less capable to do better things with my life, 39 participants (58%) did not experience this at all and 9 people (13%) experienced it to a very small degree.

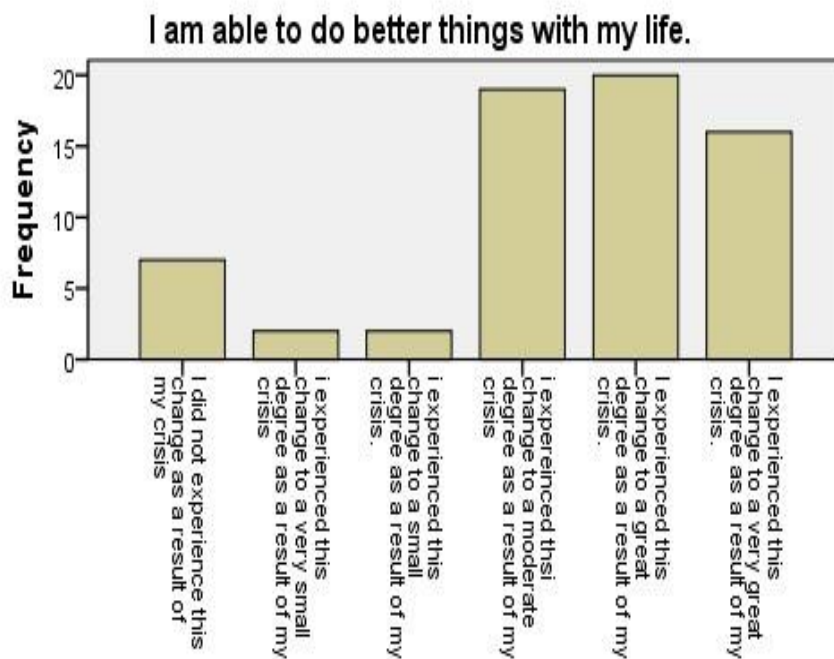


Figure A-19.10: 'I am able to do better things with my life'

• **Opportunities:**

50 participants (75%) said that since having had cancer that 'I now see newer opportunities that I would not have seen otherwise' (from a moderate to a very great degree), with 8 participants (12%) stating that they did not experience this at all. See Table A-19.9 below for a breakdown of the cumulative frequency of this statement. 14 participants (21%) saw fewer opportunities available now than before and 42 participants (63%) did not experience this at all.

Table A-19.9: ‘New Opportunities are available which wouldn’t have been otherwise’ and cumulative frequency

New Opportunities are available which wouldn’t have been otherwise				Valid	Cumulative
		Frequency	Percent	Percent	Percent
Valid	I did not experience this change as a result of my crisis	8	11.9	12.1	12.1
	I experienced this change to a very small degree as a result of my crisis	3	4.5	4.5	16.7
	I experienced this change to a small degree as a result of my crisis.	5	7.5	7.6	24.2
	I experienced this change to a moderate degree as a result of my crisis	15	22.4	22.7	47.0
	I experienced this change to a great degree as a result of my crisis.	17	25.4	25.8	72.7
	I experienced this change to a very great degree as a result of my crisis.	18	26.9	27.3	100.0
	Total	66	98.5	100.0	
Missing	System	1	1.5		
Total		67	100.0		

• **Try to change things that need changing:**

56 participants (84%) said that since having had cancer that they are more likely to try to change things that need changing from a moderate to a very great degree (see Figure A-19.11, overleaf). In fact, 40 participants (60%) stated that they experienced this change from a great to a very great degree. In terms of being less likely to change things that need changing, 41 participants (61%), did not experience this at all.

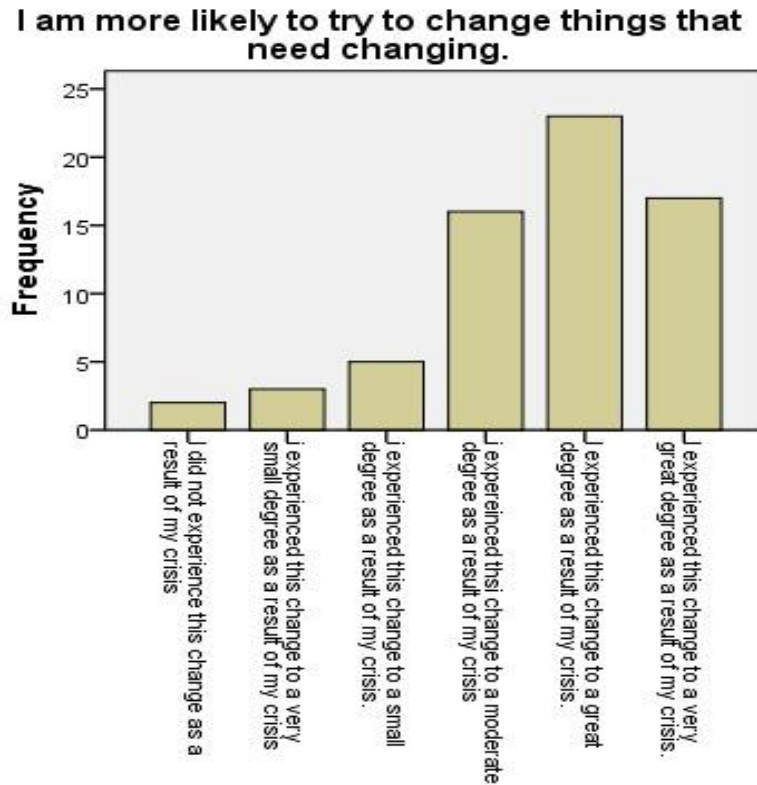


Figure A-19.11: 'I am more likely to try to change things that need changing'

### Factor III: Personal Strength

There are 8 statements that measure Personal Strength and include the following aspects; self-reliance, how they handle difficulties, the degree to which they accept the way things work out and how strong or weak they think they are.

- **Self-Reliance:**

57 participants (85%) said that they have a greater feeling of self-reliance from a moderate to a very great degree (see Figure A-19.12, overleaf), with 20 people experiencing it to a very great degree. 35 participants said that they did not experience a diminished feeling of self-reliance at all and in addition, 18 people stated that they only experienced this to a very small degree.

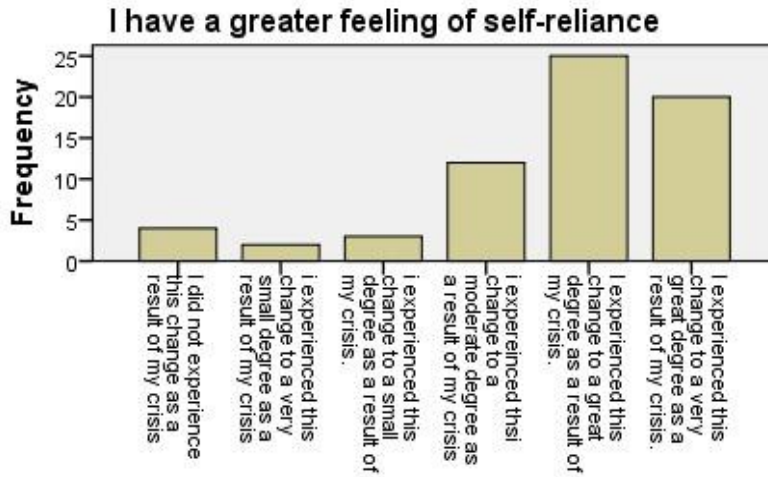


Figure A-19.12: Bar Chart: 'I have a greater feeling of self-reliance'

- **Handle Difficulties:**

59 participants (88%) said that as a result of having had cancer that they now know better that they can handle difficulties from a moderate to a very great degree (see Figure A-19.13 below). In terms of being less certain of handling difficulties, 34 people (50.7%) said that they did not experience this at all and 11 people (16.4%) experienced this to a very small degree.

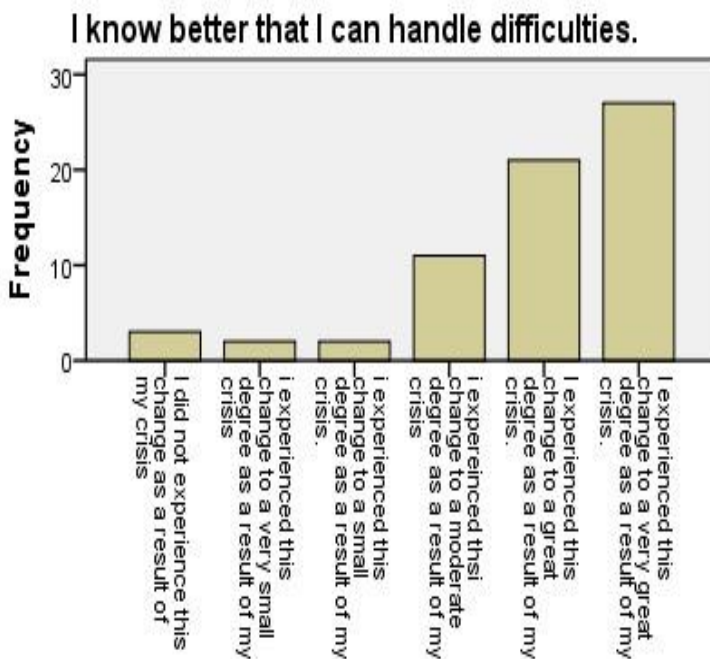


Figure A-19.13: Bar Chart: 'I know better that I can handle difficulties'

• **Accepting the way things work out:**

55 participants (82%) said that ‘I am better able to accept the way things work out’ from a moderate to a very great degree (see Table A-19.10below). 20 people (30%) stated that they experienced this to a very great degree. With regards to being less able to accept the way things work out, 36 participants (54%) did not experience this at all.

Table A-19.10: ‘I am better able to accept the way things work out’ and cumulative frequency

I am better able to accept the way things work out		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I did not experience this change as a result of my crisis	4	6.0	6.1	6.1
	I experienced this change to a very small degree as a result of my crisis	3	4.5	4.5	10.6
	I experienced this change to a small degree as a result of my crisis.	4	6.0	6.1	16.7
	I experienced this change to a moderate degree as a result of my crisis	16	23.9	24.2	40.9
	I experienced this change to a great degree as a result of my crisis.	19	28.4	28.8	69.7
	I experienced this change to a very great degree as a result of my crisis.	20	29.9	30.3	100.0
	Total	66	98.5	100.0	
Missing	System	1	1.5		
Total		67	100.0		

• **Personal Strength and Weakness:**

58 participants (87%) said that they discovered that they were stronger than they thought they were from a moderate to a very great degree (see Figure A-19.14below). This includes 37 people (55%) who said that they experienced this to a very great degree. In terms of discovering that I am weaker than I thought I was, 40 participants (60%) did not experience this at all.

#### I discovered that I am stronger than I thought I was.

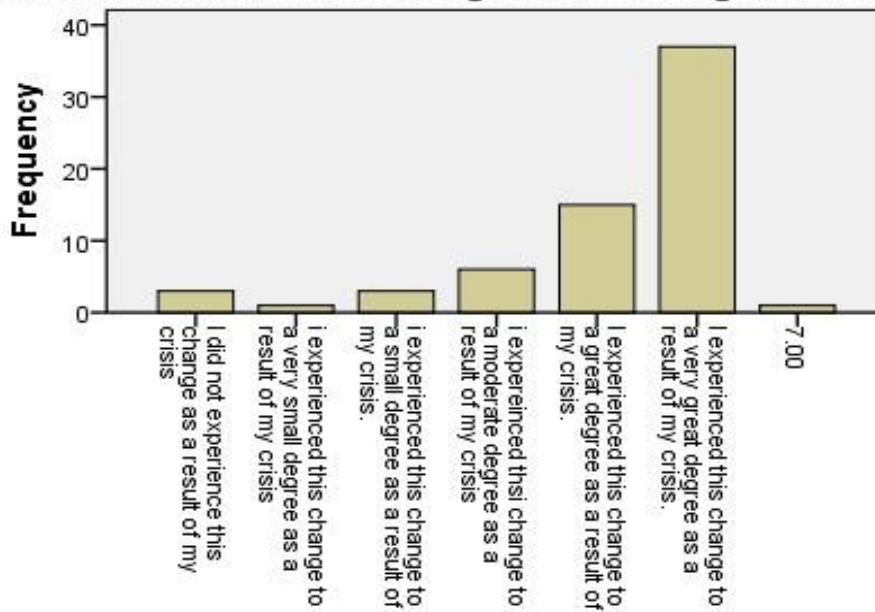


Figure A-19.14: Bar Chart: 'I discovered that I am stronger than I thought I was'

#### Factor IV: Spiritual Change

There are 4 statements which measure the degree to which participants experienced spiritual change as a result of having had cancer. These statements include; if they have a greater or lesser understanding of spiritual matters as well as if they have a stronger or weaker religious faith.

##### • Spiritual Understanding:

In terms of a better understanding of spiritual matters, 19 participants said that they did not experience this at all, and 12 participants experienced this to a very small or small degree (see Table A-19.11 below). 35 participants stated that they had a better understanding of spiritual matters from a moderate to a very great degree (52.2%). Figure A-19.15, overleaf, visually represents quite clearly the spread of responses in terms of a dichotomy between those who did experience a better understanding of spiritual matters to a very great degree (15 participants) as compared to those who did not experience this at all (19 participants).

Table A-19.11: I have a better understanding of spiritual matters' and cumulative frequency

I have a better understanding of spiritual matters					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I did not experience this change as a result of my crisis	19	28.4	28.8	28.8
	I experienced this change to a very small degree as a result of my crisis	7	10.4	10.6	39.4
	I experienced this change to a small degree as a result of my crisis.	5	7.5	7.6	47.0
	I experienced this change to a moderate degree as a result of my crisis	10	14.9	15.2	62.1
	I experienced this change to a great degree as a result of my crisis.	10	14.9	15.2	77.3
	I experienced this change to a very great degree as a result of my crisis.	15	22.4	22.7	100.0
	Total	66	98.5	100.0	
Missing	System	1	1.5		
Total		67	100.0		

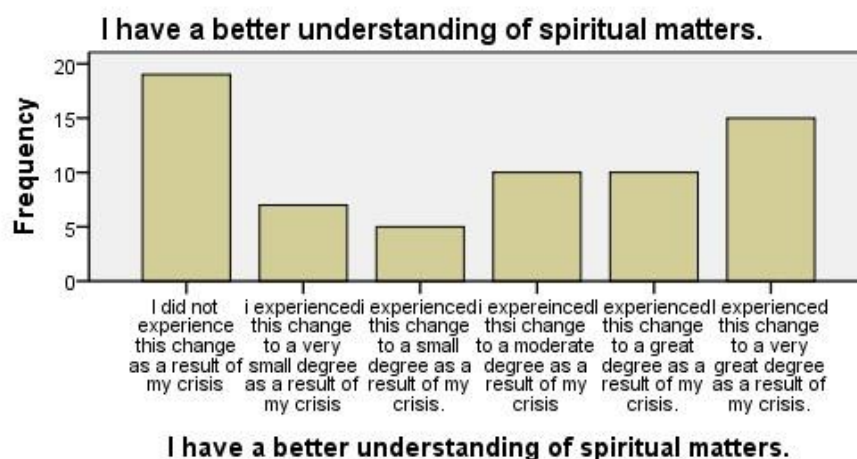


Figure A-19.15: 'I have a better understanding of spiritual matters'

#### • Religious Faith:

23 participants (34%) did not experience a stronger religious faith at all as a result from having cancer (see Table A-19.12 which follows). On the other hand, 9 participants did have a stronger faith to a great degree and 16 participants to a very great degree (to a combined total of 37%). 49 participants did not experience a weaker religious faith at all (73%). Again, the bar chart in Figure A-19.15 is a very good visual representation of the dichotomy of the 23 participants who did not



experience a stronger religious faith at all compared with 16 participants who experienced this change to a very great degree.

Table A-19.12: ‘I have a stronger religious faith’ and cumulative frequency

<b>‘I have a stronger religious faith’</b>					
		<b>Frequency</b>	<b>Percent</b>	<b>Valid Percent</b>	<b>Cumulative Percent</b>
<b>Valid</b>	I did not experience this change as a result of my crisis	23	34.3	34.8	34.8
	I experienced this change to a very small degree as a result of my crisis	2	3.0	3.0	37.9
	I experienced this change to a small degree as a result of my crisis.	8	11.9	12.1	50.0
	I experienced this change to a moderate degree as a result of my crisis	8	11.9	12.1	62.1
	I experienced this change to a great degree as a result of my crisis.	9	13.4	13.6	75.8
	I experienced this change to a very great degree as a result of my crisis.	16	23.9	24.2	100.0
	<b>Total</b>	<b>66</b>	<b>98.5</b>	<b>100.0</b>	
<b>Missing</b>	<b>System</b>	1	1.5		
<b>Total</b>		<b>67</b>	<b>100.0</b>		

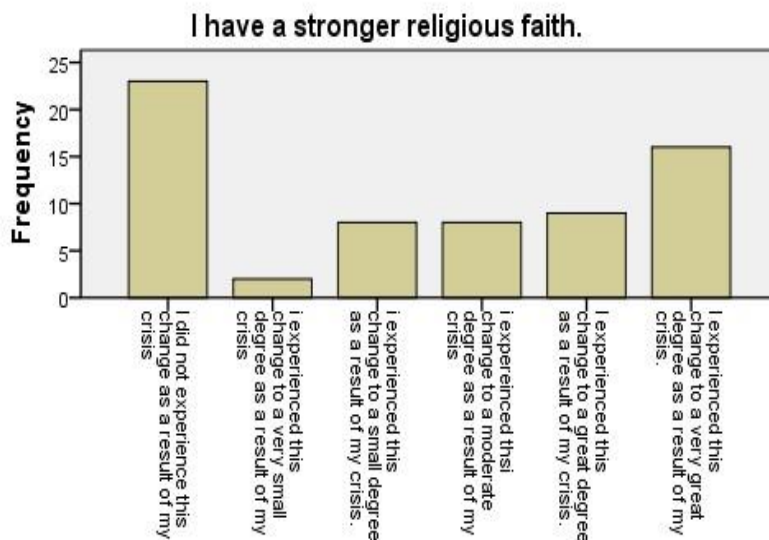


Figure A-19.15: ‘I have a stronger religious faith’

### Factor V: Appreciation of Life

There are 6 statements that measure the degree to which participants experienced positive change in terms of their Appreciation of Life. These statements measure change in the following areas; if their priorities have changed, the degree to which they value their own life, and if there was a change in how they appreciate each day.

• **Priorities about life**

54 participants said that they changed their priorities about what is important in life from a moderate to a very great degree which accounts for 80.6% of the sample (see Table A-19.13 below). 40% said that they did not find it difficult to clarify priorities about what is important in life. Figure A-19.16 illustrates the frequency of scores in the moderate to very great degree categories.

Table A-19.13: ‘I changed my priorities about what is important about life’ and cumulative frequency

I changed my priorities about what is important about life					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	I did not experience this change as a result of my crisis	3	4.5	4.5	4.5
	I experienced this change to a very small degree as a result of my crisis	5	7.5	7.6	12.1
	I experienced this change to a small degree as a result of my crisis.	4	6.0	6.1	18.2
	I experienced this change to a moderate degree as a result of my crisis	12	17.9	18.2	36.4
	I experienced this change to a great degree as a result of my crisis.	14	20.9	21.2	57.6
	I experienced this change to a very great degree as a result of my crisis.	28	41.8	42.4	100.0
	Total	66	98.5	100.0	
Missing	System	1	1.5		
Total		67	100.0		

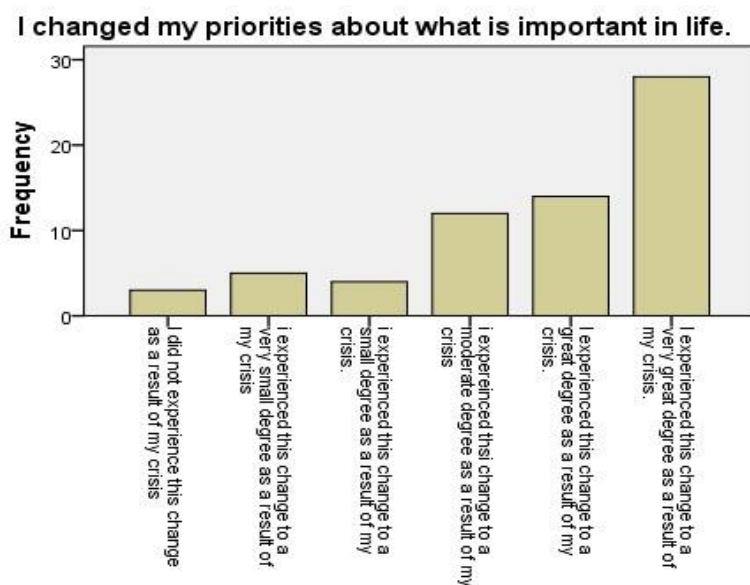


Figure A-19.16: Bar Chart: ‘I changed my priorities about what is important in life’

- **Value of my own life:**

58 participants stated that they have a great appreciation of their own life from a moderate to a very great degree which is 86.6% of sample. The high frequency of participants who experienced this change to a very great degree is illustrated in the bar chart of Figure A-19.17, below. In parallel, 48 participants said that they did not experience at all less of an appreciation for the value of their life.

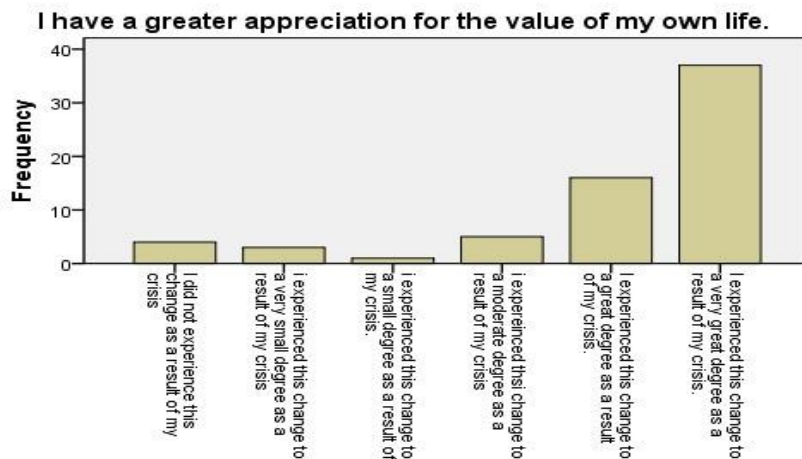


Figure A-19.17: Bar Chart: ‘I have a greater appreciation for the value of my own life’

- **Appreciation of each day:**

61 participants (91%) stated that they can better appreciate each day since having had cancer (from a moderate to a very great degree) with 35 participants experiencing it to a very great degree (see Figure A-19.18 which follows). In terms of appreciating each day less than before, 53 participants (79) said that they did not experience this at all.

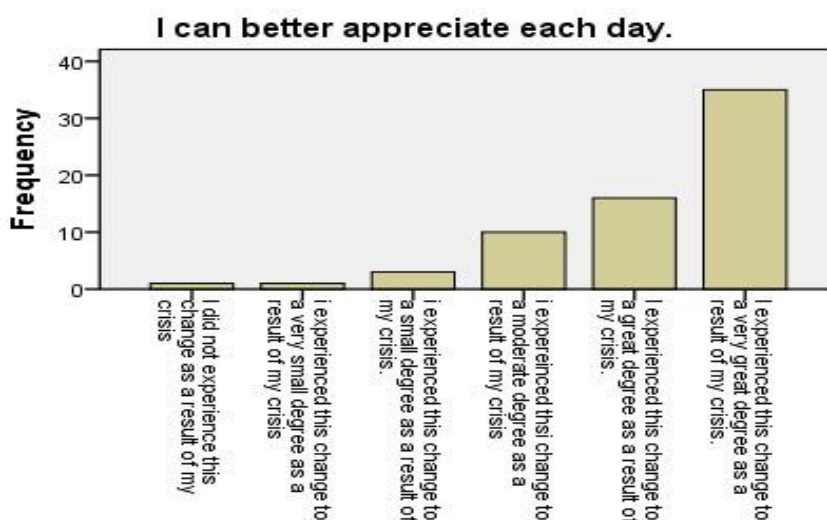


Figure A-19.18: ‘I can better appreciate each day’

## Analysis 2: Analysing the descriptive statistics

In addition to analysing the data using descriptive statistics (previous section), I also wanted to explore specific correlations and cross tabs to see if there were any important relationships. I looked at elements such as cancer type, cancer stage, age, marital status and with/without children.

### Cancer Type:

When I compared the mean for each of the 5 Factors with ‘breast cancer’ and then ‘other cancer’, there was little to marginal difference in all 5. Take for example FigureA-19.19 overleaf – Relating to Others, which diverges from the literature as some research suggests that PTGI scores are higher for breast cancer than for other cancers. The mean for the total PTGI scores (all 5 Factors) for ‘other cancers’, is 76. The mean for the total PTGI scores (all 5 Factors) for ‘breast cancer’ is 74.

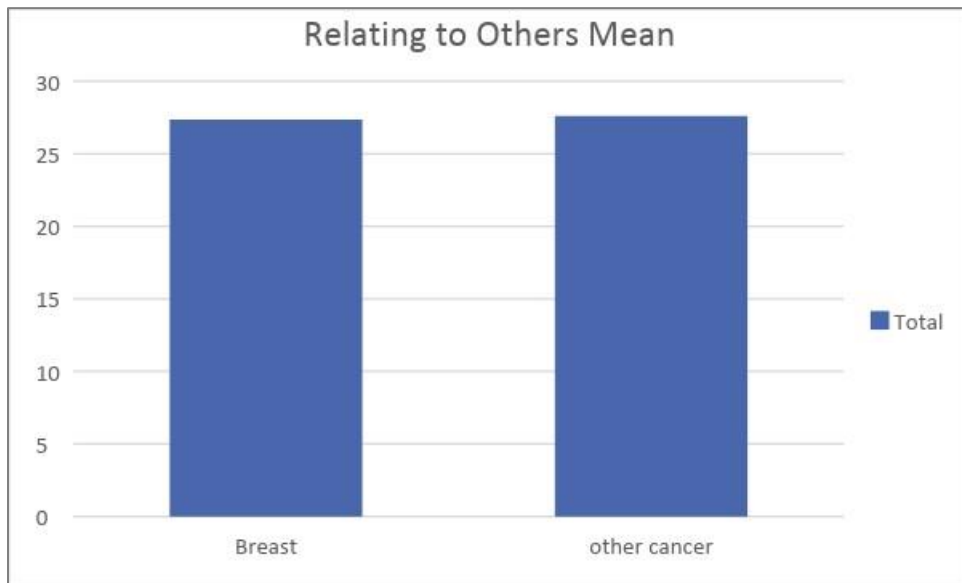


Figure A-19.19: Relating to others and mean for Breast and Other cancer

### Cancer Stage:

If I exclude those participants who did not know/remember their cancer stage (21), then Stage 3 cancer was the most frequent with a total of 19 participants (see Table A-19.14below).

Table A-19.14: Cancer Stage and Frequency

		Stage of cancer			Cumulative Percent
		Frequency	Percent	Valid Percent	
Valid	Stage I	12	17.9	17.9	17.9
	Stage II	12	17.9	17.9	35.8
	Stage III	19	28.4	28.4	64.2
	Stage IV	3	4.5	4.5	68.7
	don't know	21	31.3	31.3	100.0
	Total	67	100.0	100.0	

There is a slight increase in the mean growth scores for the more advanced cancer stages. If we take for example Relate to Others, the mean growth scores increase from stage 1 to stage 3: 26.5 to 26.25 to 29.11. This increase is even more prominent from stage 2 to stage 3 (see Tables A-19.15, A-19.16 and A-19.17, which follow overleaf).

Table A-19.15: Cancer Stage 1 and mean for each of the 5 Factors

<b>Descriptive Statistics</b>					
	<b>N</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>	<b>Std. Deviation</b>
Relate Other	12	9.00	32.00	26.5000	6.43146
New Poss.	12	5.00	24.00	15.5000	5.58407
Personal Strength	12	6.00	19.00	14.1667	3.85730
Spiritual change	12	.00	9.00	3.1667	3.40677
Appreciation of life	12	3.00	15.00	11.9167	4.05549
Valid N (list wise)	12				

Table A-19.16: Cancer Stage 2 and mean for each of the 5 Factors

<b>Descriptive Statistics</b>					
	<b>N</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>	<b>Std. Deviation</b>
Relate Other	12	17.00	35.00	26.2500	4.84534
New Poss.	12	3.00	24.00	16.9167	6.06717
Personal Strength	12	7.00	20.00	15.0000	3.93123
Spiritual change	12	.00	10.00	4.8333	4.13045
Appreciation of life	12	7.00	15.00	11.7500	2.49089
Valid N (list wise)	12				

Table A-19.17: Cancer Stage 3 and mean for each of the 5 Factors

<b>Descriptive Statistics</b>					
	<b>N</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>	<b>Std. Deviation</b>
Relate Other	18	15.00	35.00	29.1111	5.65570
New Poss.	18	5.00	25.00	16.2778	6.00789
Personal Strength	19	7.00	20.00	15.3158	3.60636
Spiritual change	19	.00	10.00	5.7368	3.10630
Appreciation of life	19	6.00	15.00	12.4737	2.96963
Valid N (list wise)	17				

I did not include a table for Stage 4 Cancer because N=3.

### **Age and each of the growth factors:**

I examined age and each of the 5 growth factors to see if there was any relationship.

I looked at potential correlations between age and each of the 5 growth factors and noticed a slight decreasing trendline in every instance with the greatest degree of change in Relating to Others (see Figure A-19.20 below for the decreasing trendline and Figure A-19.21 for the Relate to Others by age group mean scores). This relationship is not a significant finding but is worth noting as a larger sample size may prove significant.

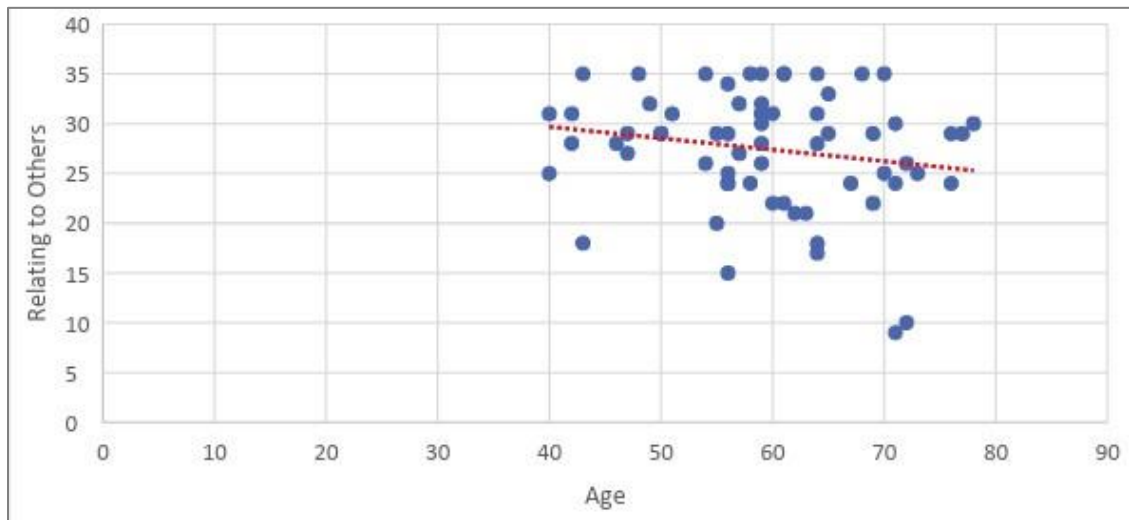
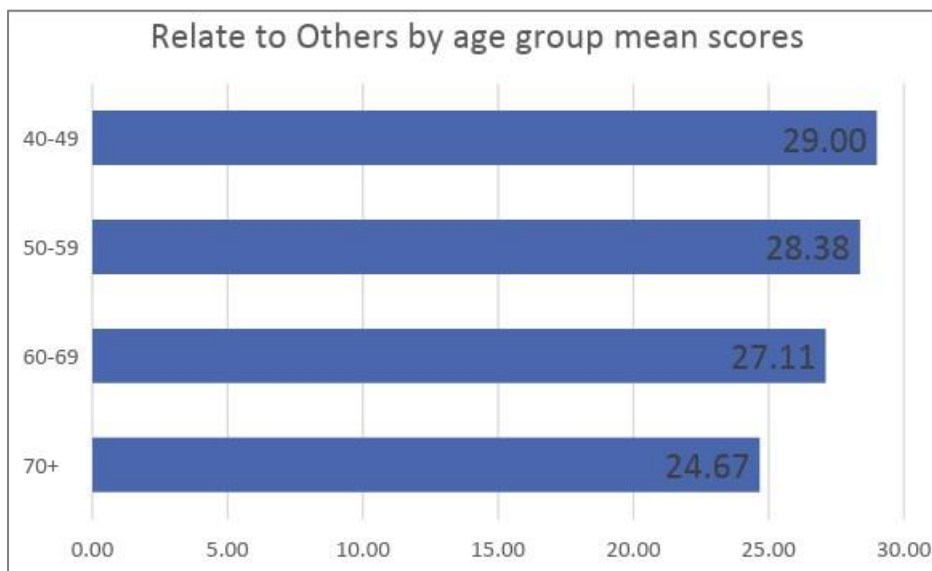


Figure A-19.20: Scatterplot: Relating to Others and Age



FigureA-19.21: Chart of Relate to Others and Age group mean scores

### Marital Status:

I used cross-tabulation of the PTGI-42 individual statements with Marital Status to test for significance using the Fishers Exact Test for accuracy ( $>.05$ ).

In terms of Marital Status, there were no significant findings. In the longitudinal research by Harding (2017) on head and neck cancer survivors, she also found no association between positive growth and marital status. However, there were several

borderline significant findings in my research which may warrant further research in the future as a larger sample size may increase significance. There was borderline significance with 'I am more likely to try to change things that need changing' and Marital Status, with a Fishers Exact Test of .062 (where Fishers value is 33.801). Borderline significance was also noted with 'I can better appreciate each day' and Marital Status with a Fishers Exact Test of .092 (Fishers value is 35.594).

#### **With or without children:**

Out of 67 participants, 47 had children and 20 did not. Of those who did have children it ranged from 1 to 7 children. I used crosstabulation of each of the 5 growth factors and with/without children using Fishers Exact test and found 4 borderline and 3 significant findings.

There are 4 borderline significant findings in terms of the PTGI-42 individual statements and whether the person had children or not. These were; 'I have a better understanding of spiritual matters' with a Fishers test of .081 (and a Fishers value of 9.280), 'I am more willing to express emotions' with a Fishers Test of .060 (and a Fisher value of 9.855), 'I developed new interests' with a Fishers Test of .092 (and a Fishers value of 8.726) and finally 'I can better appreciate each day' with a Fishers Test of .057 ( with a Fishers value 39.594). Again, these statements could merit additional research with a bigger sample.

However, I want to devote the most time in this section to the 3 significant findings in terms of the PTGI-42 individual statements and whether the participants had or did not have children. These 3 findings relate to New Possibilities and Appreciation of Life (see Table A-19.18, overleaf).



Table A-19.18: Mean for 3 significant findings and participants with or without children

Group Statistics					
	do you have children?	N	Mean	Std. Deviation	Std. Error Mean
I established a new path for my life.	no	20	3.1500	1.38697	.31014
	yes	45	3.0667	1.87568	.27961
I am able to do better things with my life.	no	20	3.3000	1.08094	.24170
	yes	46	3.4130	1.66768	.24589
I changed my priorities about what is important in life.	no	20	3.0500	1.53811	.34393
	yes	46	4.0000	1.38243	.20383

## Factor II: New Possibilities

2 of the significant findings concern Factor II: New Possibilities and are about establishing a new life path and doing better things with my life.

From a sample of 65 participants and a Fishers Exact Test of .030 (and a Fishers value of 11.549) there is a significant relation between if a person has children (or not) and if they established a new path for their life. 53.3% of people with children (24 participants) experienced a change (to a great and very great degree) in establishing a new life path. 40% of those without children (8 people) experienced this change to the same degree (see TablesA-19.19and A-19.20 below). The differences between this statement and if you have children are visually represented in the bar charts of Figures A-19.22and A-19.23below.

Table A-19.19: Chi-Square Test: 'I established a new life path' and 'if you have children'

Chi-Square Tests						
	Value	d f	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)	Point Probability
Pearson Chi-Square	12.355 <sup>a</sup>	5	.030	.026		
Likelihood Ratio	13.860	5	.017	.028		
Fisher's Exact Test	11.549			.030		
Linear-by-Linear Association	.032 <sup>b</sup>	1	.858	.878	.464	.061
N of Valid Cases	65					

a. 7 cells (58.3%) have expected count less than 5. The minimum expected count is 1.85.  
b. The standardized statistic is -.179.

Table A-19.20: Crosstabulation: 'I established a new life path' and 'if you have children'

<b>I established a new path for my life. * do you have children? Cross tabulation</b>					
			do you have children?		
			no	yes	Total
I established a new path for my life.	I did not experience this change as a result of my crisis	Count	2	6	8
		Expected Count	2.5	5.5	8.0
		% within do you have children?	10.0%	13.3%	12.3 %
	I experienced this change to a very small degree as a result of my crisis	Count	0	7	7
		Expected Count	2.2	4.8	7.0
		% within do you have children?	0.0%	15.6%	10.8 %
	I experienced this change to a small degree as a result of my crisis.	Count	2	4	6
		Expected Count	1.8	4.2	6.0
		% within do you have children?	10.0%	8.9%	9.2%
	I experienced this change to a moderate degree as a result of my crisis	Count	8	4	12
		Expected Count	3.7	8.3	12.0
		% within do you have children?	40.0%	8.9%	18.5 %
	I experienced this change to a great degree as a result of my crisis.	Count	5	9	14
		Expected Count	4.3	9.7	14.0
		% within do you have children?	25.0%	20.0%	21.5 %
	I experienced this change to a very great degree as a result of my crisis.	Count	3	15	18
		Expected Count	5.5	12.5	18.0
		% within do you have children?	15.0%	33.3%	27.7 %
Total		Count	20	45	65
		Expected Count	20.0	45.0	65.0
		% within do you have children?	100.0%	100.0%	100.0 %

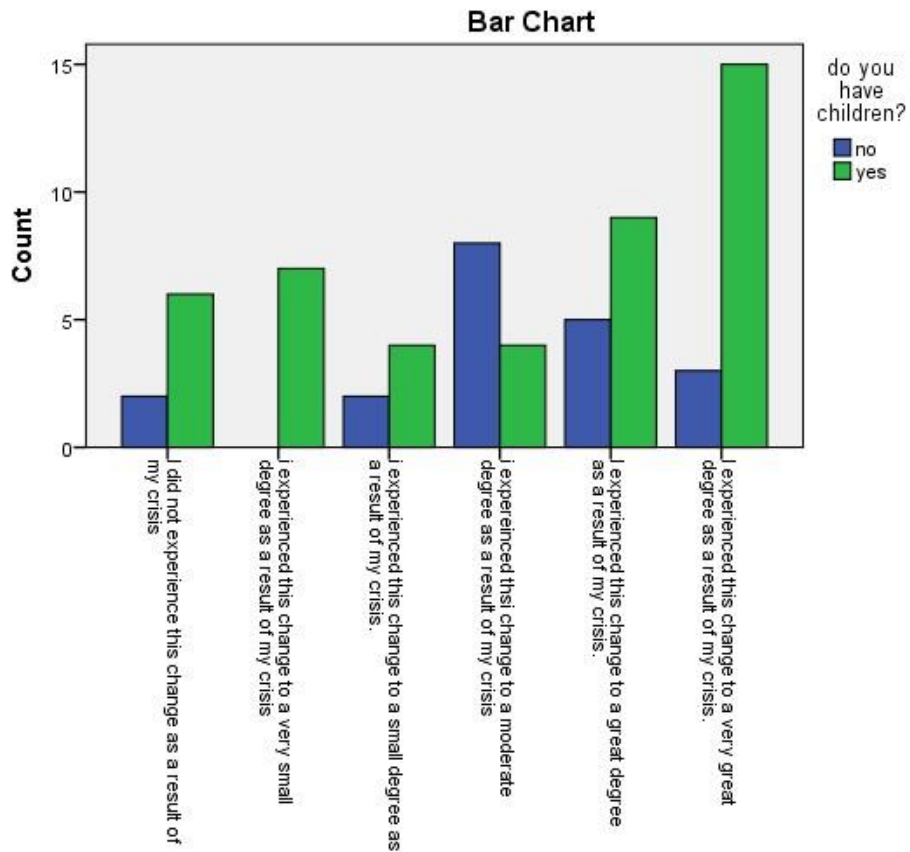


Figure A-19.22: Bar Chart: 'I established a new life path' and 'with or without children'

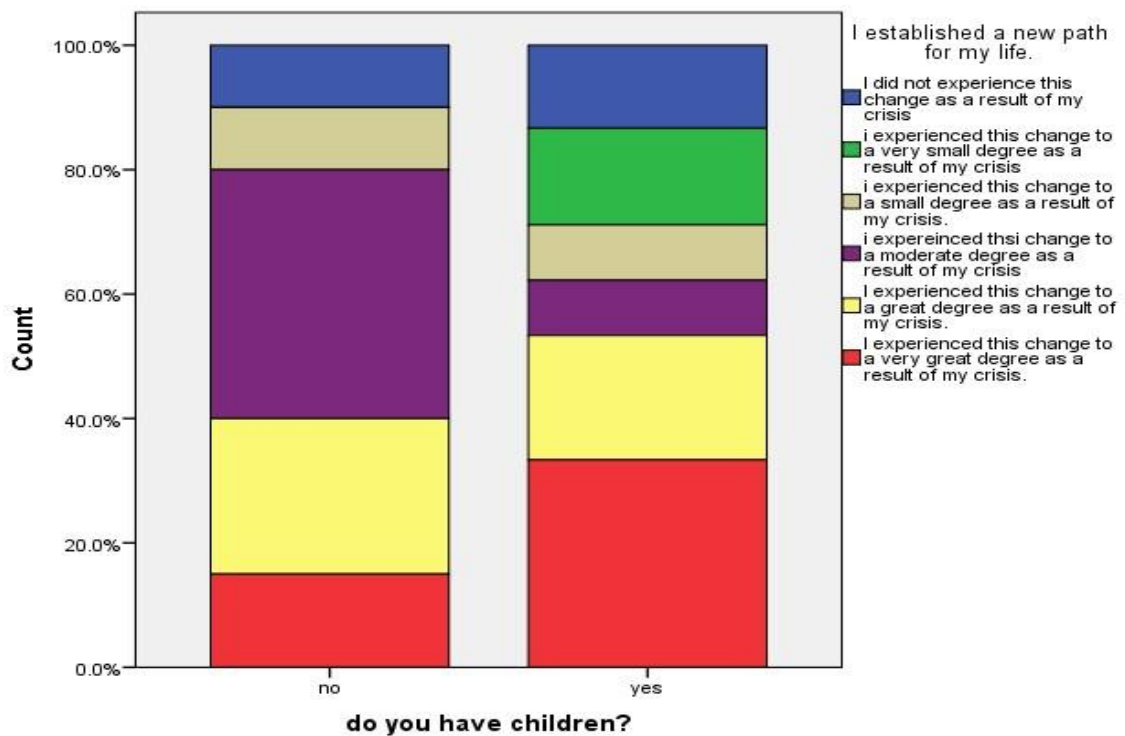


Figure A-19.23: Bar Chart: 'I established a new life path' and 'with or without children'

The second significant finding concerns ‘I am able to do better things with my life’ (see

Table A-19.21 and A-19.22 below). From a sample of 66 participants and a Fishers Exact Test of .025 (with a Fishers value of 11.274) there is a significant relation between if a person has children (or not) and whether they can do better things with their life after having experienced cancer. 58.7% of people (27 persons) with children experienced a change in this area of their lives (to a great and very great degree). Only 45% of those (9 people in total) without children experienced this change to the same degree. The responses for ‘I am able to do better things with my life’ and ‘with or without children’, are visually represented in Figures A-19.24 and A-19.25 below.

Table A-19.21: Chi Square Tests: ‘I am able to do better things with my life’ and ‘with or without children’

<b>Chi-Square Tests</b>						
	Value	df	Asymptotic Significance (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)	Point Probability
Pearson Chi-Square	11.874 <sup>a</sup>	5	.037	.028		
Likelihood Ratio	14.379	5	.013	.017		
Fisher's Exact Test	11.274			.025		
Linear-by-Linear Association	.078 <sup>b</sup>	1	.779	.792	.418	.066
N of Valid Cases	66					
a. 7 cells (58.3%) have expected count less than 5. The minimum expected count is .61.						
b. The standardized statistic is .280.						

Table A-19.22: Cross tabulation: ‘I am able to do better things with my life’ and ‘with or without children’

<b>I am able to do better things with my life. * do you have children? Cross tabulation</b>					
		do you have children?			
		no	yes	Total	
I am able to do better things with my life.	I did not experience this change as a result of my crisis	Count	0	7	7
		Expected Count	2.1	4.9	7.0
		% within do you have children?	0.0%	15.2%	10.6%
	I experienced this change to a very small degree as a result of my crisis	Count	2	0	2
		Expected Count	.6	1.4	2.0
		% within do you have children?	10.0%	0.0%	3.0%
	I experienced this change to a small degree as a result of my crisis.	Count	1	1	2
		Expected Count	.6	1.4	2.0
		% within do you have children?	5.0%	2.2%	3.0%
	I experienced this change to a moderate degree as a result of my crisis	Count	8	11	19
		Expected Count	5.8	13.2	19.0
		% within do you have children?	40.0%	23.9%	28.8%
	I experienced this change to a great degree as a result of my crisis.	Count	7	13	20
		Expected Count	6.1	13.9	20.0
		% within do you have children?	35.0%	28.3%	30.3%
	I experienced this change to a very great degree as a result of my crisis.	Count	2	14	16
		Expected Count	4.8	11.2	16.0
		% within do you have children?	10.0%	30.4%	24.2%
Total		Count	20	46	66
		Expected Count	20.0	46.0	66.0
		% within do you have children?	100.0%	100.0%	100.0%

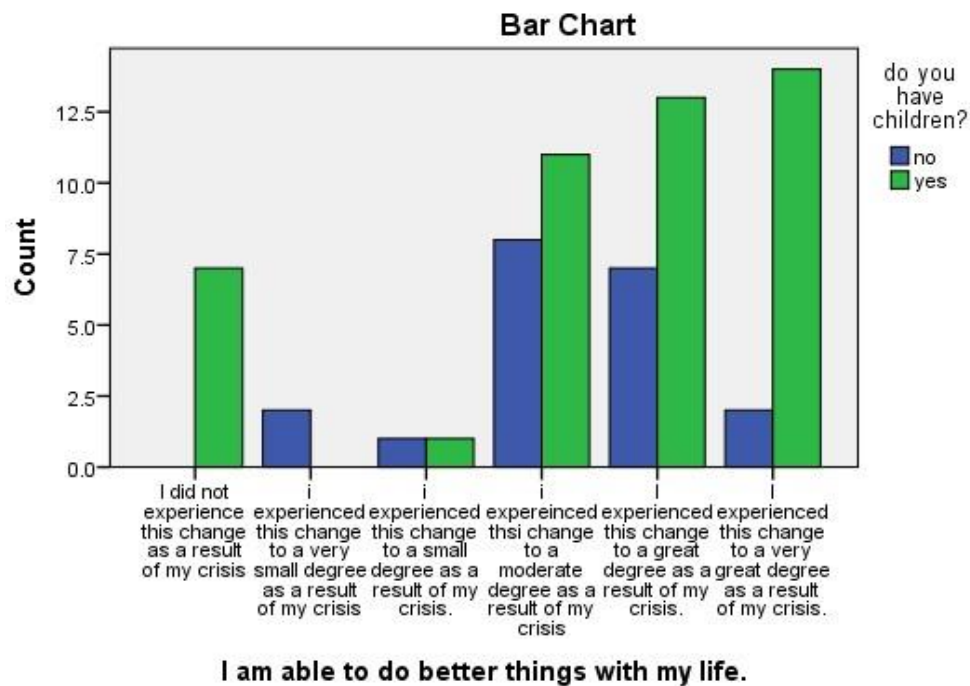


Figure A-19.24: 'I am able to do better things with my life' and 'with or without children'

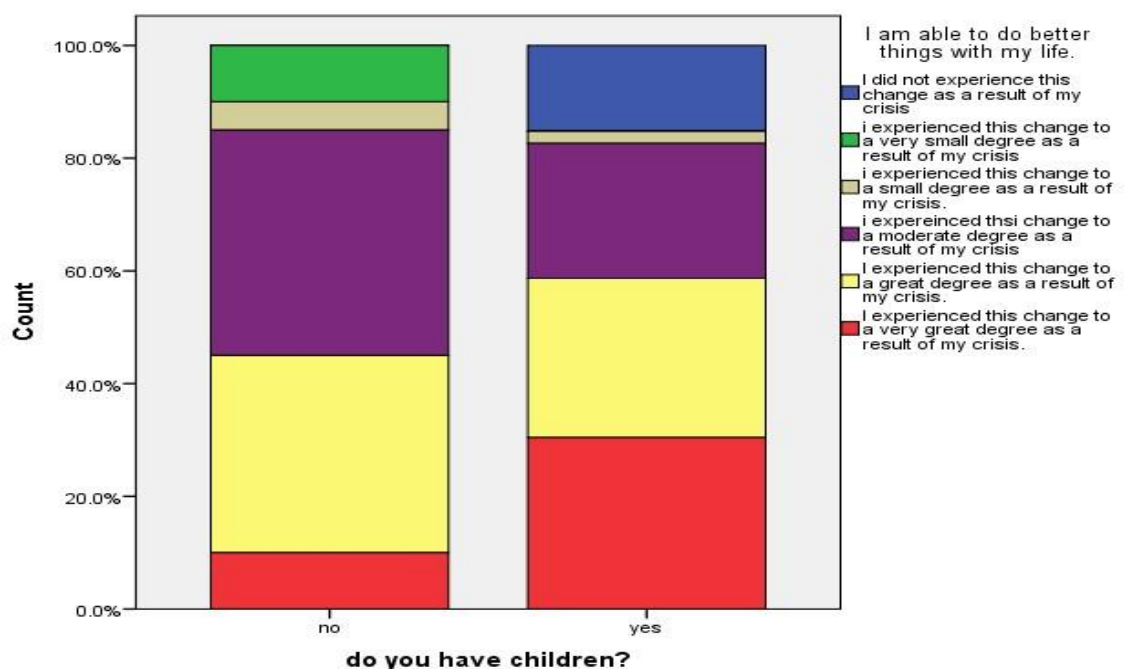


Figure A-19.25: 'I am able to do better things with my life' and 'with or without children'

The 3<sup>rd</sup> significant finding concerns Factor V: Appreciation of Life. With a sample of 66 and a Fishers Exact Test score of .032 (with a Fishers value of 10.965), there is a

significant relation between ‘I changed my priorities about what is important in life’ and whether or not the person has children. 63.6% of participants with children experienced a change in this area from a great to a very great degree (which is 42 people). Only 35% of those without children (i.e. 7 people) experienced it to the same degree (see Tables A-19.23 and A-19.24 below).

Figures A-19.26 and A-19.27 visually illustrates the differences in frequency.

Table A-19.23: Chi-Square Test: ‘I changed my priorities about what is important about life’ and ‘with or without children’

<b>Chi-Square Tests</b>						
	<b>Value</b>	<b>df</b>	<b>Asymptotic Significance (2-sided)</b>	<b>Exact Sig. (2- sided)</b>	<b>Exact Sig. (1- sided)</b>	<b>Point Probability</b>
Pearson Chi-Square	11.054 <sup>a</sup>	5	.050	.045		
Likelihood Ratio	10.816	5	.055	.084		
Fisher's Exact Test	10.965			.032		
Linear-by-Linear Association	5.697 <sup>b</sup>	1	.017	.018	.012	.005
N of Valid Cases	66					
a. 8 cells (66.7%) have expected count less than 5. The minimum expected count is .91.						
b. The standardized statistic is 2.387.						

Table A-19.24: Cross tabulation: 'I changed my priorities about what is important about life' and 'with or without children'

<b>I changed my priorities about what is important in life.</b> <b>* do you have children? Cross tabulation</b>					
			do you have children?		Total
			no	yes	
I changed my priorities about what is important in life.	I did not experience this change as a result of my crisis	Count	1	2	3
		Expected Count	.9	2.1	3.0
		% within do you have children?	5.0%	4.3%	4.5%
	I experienced this change to a very small degree as a result of my crisis	Count	3	2	5
		Expected Count	1.5	3.5	5.0
		% within do you have children?	15.0%	4.3%	7.6%
	I experienced this change to a small degree as a result of my crisis.	Count	2	2	4
		Expected Count	1.2	2.8	4.0
		% within do you have children?	10.0%	4.3%	6.1%
	I experienced this change to a moderate degree as a result of my crisis	Count	7	5	12
		Expected Count	3.6	8.4	12.0
		% within do you have children?	35.0%	10.9%	18.2%
	I experienced this change to a great degree as a result of my crisis.	Count	2	12	14
		Expected Count	4.2	9.8	14.0
		% within do you have children?	10.0%	26.1%	21.2%
	I experienced this change to a very great degree as a result of my crisis.	Count	5	23	28
		Expected Count	8.5	19.5	28.0
		% within do you have children?	25.0%	50.0%	42.4%
Total		Count	20	46	66
		Expected Count	20.0	46.0	66.0
		% within do you have children?	100.0%	100.0%	100.0%



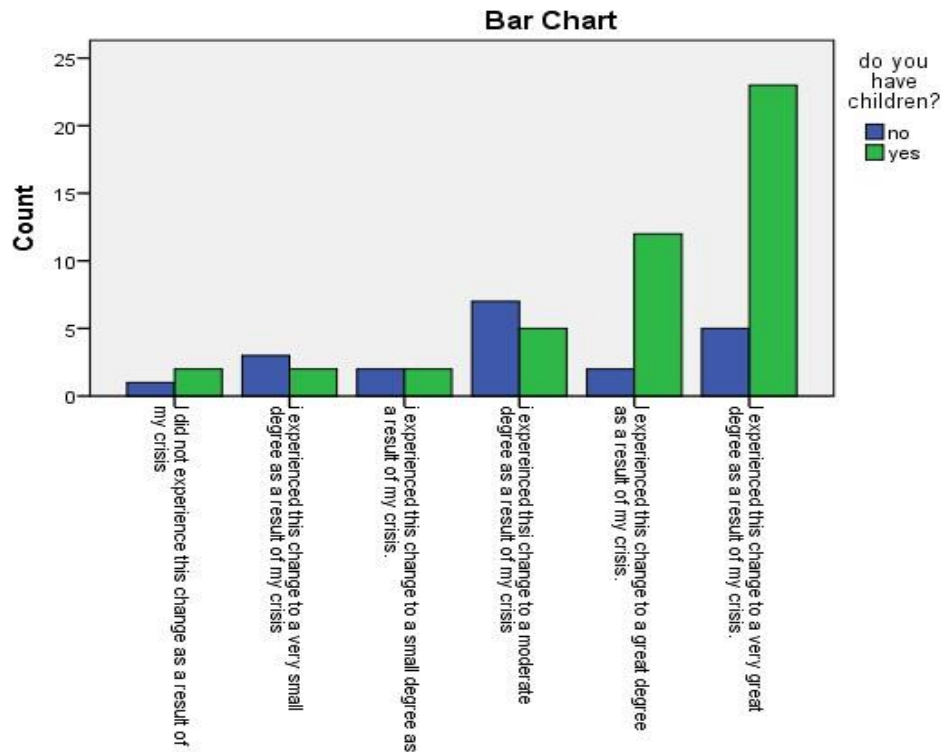


Figure A-19.26: ‘I changed my priorities about what is important about life’ and ‘with or without children’

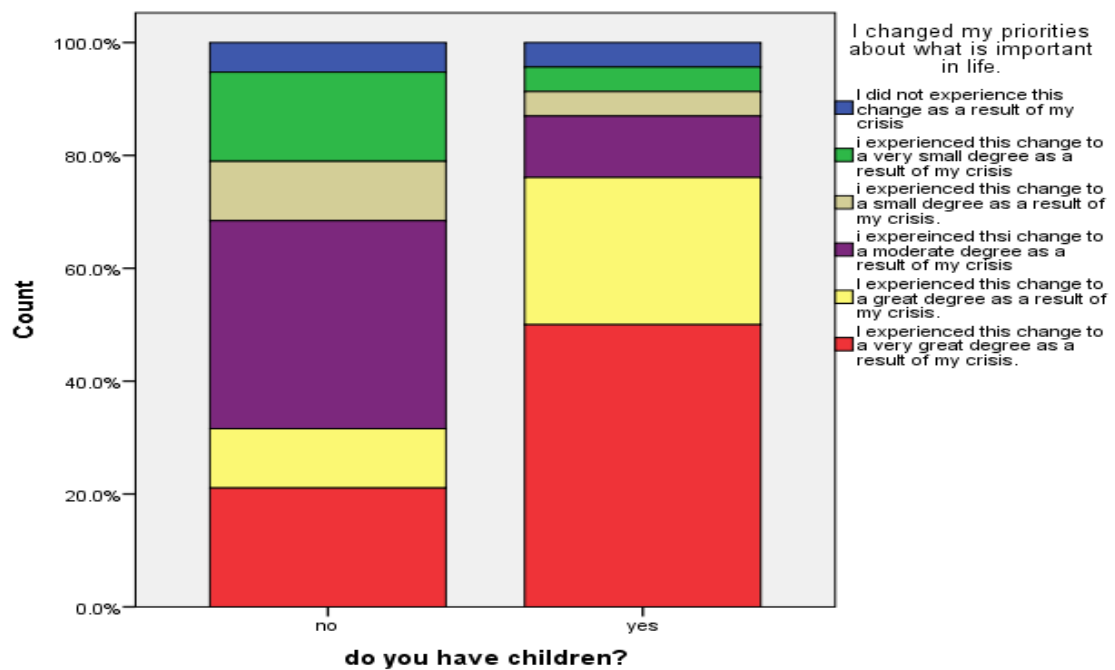


Figure A-19.27: ‘I changed my priorities about what is important about life’ and ‘with or without children’

Table A-19.25:

INDEPENDENT SAMPLES TEST										
		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2- tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Relate to Others	Equal variances assumed	0.026	0.871	-1.177	63	0.243	-1.87222	1.59009	-5.04976	1.30532
	Equal variances not assumed			-1.162	35.438	0.253	-1.87222	1.61094	-5.14116	1.39672
New Poss	Equal variances assumed	0.667	0.417	-0.512	63	0.610	-0.77778	1.51804	-3.81133	2.25578
	Equal variances not assumed			-0.553	44.046	0.583	-0.77778	1.40676	-3.61284	2.05728
Personal Strength	Equal variances assumed	0.021	0.886	-0.777	64	0.440	-0.73696	0.94797	-2.63074	1.15683
	Equal variances not assumed			-0.775	35.972	0.443	-0.73696	0.95085	-2.66542	1.19151
Spiritual Change	Equal variances assumed	2.972	0.090	0.002	64	0.998	0.00217	0.96018	-1.91600	1.92035
	Equal variances not assumed			0.002	43.388	0.998	0.00217	0.89098	-1.79419	1.79854
Appreciation of Life	Equal variances assumed	0.043	0.837	-1.935	64	0.057	-1.53478	0.79307	-3.11912	0.04955
	Equal variances not assumed			-1.881	33.981	0.069	-1.53478	0.81606	-3.19325	0.12369

### Independent Samples Test: Growth/Depreciation and Single/Married

		Levene's Test for Equality of Variances		t-test for Equality of Means						
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Postraumatic Growth Total	Equal variances assumed	.392	.534	-.1723	54	.091	-8.85657	5.14117	-19.16399	1.45086
	Equal variances not assumed			-.1463	13.011	.167	-8.85657	6.05266	-21.93146	4.21833
Negative Changes Total	Equal variances assumed	.829	.367	-.1721	52	.091	-8.84567	5.14043	-19.16070	1.46937
	Equal variances not assumed			-.1896	17.793	.074	-8.84567	4.66505	-18.65477	.96344

## Appendix 20: Quantitative Findings: Spearman Analysis and Principal Components Analysis

Table A-20.01: Correlation Data – Spearman Analysis – Profile Cancer Stage

CORRELATIONS									
			Stage of Cancer	Total ptgpos	Relate to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation of Life
<b>Spearman's rho</b>	Stage of cancer	Correlation Coefficient	1.000	0.127	0.089	0.132	0.188	0.138	-0.079
		Sig. (2-tailed)		0.309	0.482	0.293	0.130	0.268	0.526
		N	67	66	65	65	66	66	66
**. Correlation is significant at the 0.01 level (2-tailed)									
* Correlation is significant at the 0.05 level (2-tailed)									

Table A-20.02: Correlation Data – Spearman Analysis – Profile Age

CORRELATIONS								
			Age	Relate to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation of Life
<b>Spearman's rho</b>	Age	Correlation Coefficient	1.00	-0.16	-0.07	-0.05	-0.03	-0.07
		Sig. (2-tailed)		0.21	0.60	0.67	0.81	0.56
		N	67	65	65	66	66	66
**. Correlation is significant at the 0.01 level (2-tailed).								
*. Correlation is significant at the 0.05 level (2-tailed).								

Table A-20.03: Correlation Data – Spearman Analysis – Profile ‘Marital Status?’

CORRELATIONS								
			Marital Status	Relate to Others	New Possibilities	Pers- onal Strength	Spiritual Change	Appreciation of life
<b>Spearman's rho</b>	Marital Status	Correlation Coefficient	1.000	0.14	0.12	0.06	-0.01	0.17
		Sig. (2-tailed)		0.27	0.36	0.63	0.93	0.16
		N	67	65	65	66	66	66
**. Correlation is significant at the 0.01 level (2-tailed).								
*. Correlation is significant at the 0.05 level (2-tailed).								

Table A-20.04: Correlation Data – Spearman Analysis – Profile ‘do you have children?’

CORRELATIONS								
			do you have children ?	Relate to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation of Life
<b>Spearman's rho</b>	do you have children?	Correlation Coefficient	1.000	0.152	0.085	0.104	0.006	.279*
		Sig. (2-tailed)		0.228	0.498	0.408	0.961	0.023
		N	67.000	65.000	65.000	66.000	66.000	66.000
*. Correlation is significant at the 0.05 level (2-tailed).								
**. Correlation is significant at the 0.01 level (2-tailed).								

Table A-20.05: Bartlett’s Test of Sphericity and the Kaiser-Meyer-Olkin measure

KMO and Bartlett's Test		
Kaiser-Meyer-Olkin Measure of Sampling Adequacy.		0.689
Bartlett's Test of Sphericity	Approx. Chi-Square	555.922
	df	210
	Sig.	0.000

## References

- Absolom K., Holch P., Woroncow B., Wright E.P. and Velikova G (2014) Beyond lip service and box ticking: how effective patient engagement is integral to the development and delivery of patient-reported outcomes. *Qual Life Res* (2015) 24:1077-1085. Springer International Publishing.
- Ahles, T.A. and Hurria, A. (2017) New Challenges in Psycho-Oncology Research IV: Cognition and cancer: Conceptual and methodological issues and future directions. *Psycho-Oncology*, 2018; 27: 3-9. Wiley Online Library.
- Akhtar, M. (2017) #What is Post-Traumatic Growth? Germany. Watkin Publishing.
- Alveson, M. and Skolberg, K. (2007) Reflexive Methodology, New Vistas for Qualitative Research: 'Introduction: the intellectualization of method', pp. 1-44 London: Sage.
- Alvesson, M. and Sandberg, J. (2011) 'Generating Research Questions. Through Problematization', *Academy of Management Review* 36(2): 247-271
- American Psychosocial Oncology Society (2019) What is Psycho Oncology? [online] available: <https://apos-society.org/people-affected-by-cancer/what-is-psychosocialoncology/> [accessed 12 February 2019].
- Andersen, R.M., Afdem, K., Hager, S., Gaul, M., Sweet, E. and Standish, L.J. (2017) The 'cause' of my cancer, beliefs about cause among breast cancer patients and survivors who do and do not seek O care. *Psycho-Oncology*, Vo. 26: 248-254. Published online 9 November 2015 in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/pon.4028.
- Balfe, M., O'Brien, K., Timmons, A., Butow, P., O'Sullivan, E., Gooberman-Hill, R. and Sharp, L. (2015) What factors are associated with posttraumatic growth in head and neck cancer carers? *European Journal of Oncology Nursing*, 21 (2016), 31-37. DOI: 10.1016/j.ejon.2015.11.005
- Becker, H. (1986) Writing for Social Scientists. How to start and finish your thesis, book or article: 'Terrorized by the Literature' (Chapter 8). Chicago; London: The University of Chicago Press.
- Bloom, J., Peterson, D. and Kang, P. (2007) Multi-dimensional quality of life among long-term (5+ years) adult cancer survivors, *Psycho-Oncology* 16: 691-706 (2007), Published online 13 July 2007 in Wiley InterScience, John Wiley & Sons.
- Brannen, J. (2005) 'Mixed Methods of Research: A Discussion Paper' (NCRM/005), ESRC National Centre for Research Methods.
- Braun, B. and Clarke, V. (2014) What can "thematic analysis" offer health and wellbeing researchers? *International Journal of Qualitative Studies in Health and Well-being*. 2014; 9:10.3402/qhw.v9.26152, d.3402/qhw.v9.26152oi:10

- Braun, B. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2). pp. 77-101. ISSN1478-0887
- Braun, B. and Clarke, V. (2013) *Successful Qualitative Research*. London. Sage.
- Braun, B. and Clarke, V. (2016) (Mis)conceptualising themes, thematic analysis, and other problems with Fugard and Potts' (2015) sample-size tool for thematic analysis, *International Journal of Social Research Methodology*, 19:6, 739-743, DOI: 10.1080/13645579.2016.1195588
- Braun, B. and Clarke, V. (2018) Thematic analysis – an introduction. You Tube Video [video online], available: <http://youtube.com/watch?v=5zFcC10vOVY> [accessed 10 June 2018].
- Breast Check (2018) Breast Screening, [online], available: [https://www.breastcheck.ie/content/breast\\_screening](https://www.breastcheck.ie/content/breast_screening) [accessed 17 Dec 2018].
- Broom, A., Kenny, K. and Kirby, E. (2018) On waiting, hauntings and surviving: Chronicling life with cancer through solicited diaries. *The Sociological Review* 2018 Vol. 66(3) 682-699. DOI: 10.1177/0038026117719216. Sage
- Bryman, A. (2006). Integrating quantitative and qualitative research: how is it done? *Qualitative Research*, 6 (1), 97-113
- Bryman, A. (2012) *Social Research Methods* (4th ed.) New York, Oxford University Press
- Bryman, A. (2014) June 1989 and beyond: Julia Brannen's contribution to mixed methods research, *International Journal of Social Research Methodology*, 17:2, 1211310, DOI: 10.1080/13645579.2014.892653 Routledge
- Bryman, A. and Beardsworth, A. (2006) Is Qualitative Research Becoming McDonaldized? *Methodological Innovations Online* (2006) 1(1) 3-13. DOI: 10.4256/mio.2006.0002
- Bryman, A., Becker, S. and Sempik, J. (2008) 'Quality criteria for quantitative, qualitative and mixed methods research: A view from social policy', *International Journal of Social Research Methodology* 11(4): 261-276.
- Buchman, S., Evans, J.M., MacKinnon, M., Gradin, S. and Wright, F.C. (2018) Bridging silos: Delivering integrated care to patients with cancer in Ontario, Canada. *Psycho-Oncology*. 2018; 27: 2673–2676. Published online. doi.org/10.1002/pon.4858. Wiley & Sons.
- Calhoun, L.G. and Tedeschi, R.G. (2006) *Handbook of Posttraumatic Growth: Research and Practice*. New York. Psychology Press.
- Calhoun, L.G. and Tedeschi, R.G. (2014) *Handbook of Posttraumatic Growth: Research and Practice*. (2nd ed.). New York. Psychology Press.

- Cann, A., Calhoun, L.G., Tedeschi, R.G. and Solomon, D.T. (2010) Posttraumatic Growth and Depreciation as Independent Experiences and Predictors of Well-Being. *Journal of Loss and Trauma: International Perspectives on Stress & Coping*, 15:3, 151-166, DOI: 10.1080/15325020903375826. Taylor & Francis.
- Cao, W., Qu, X., Cai, D., and Han, X. (2017) Modelling posttraumatic growth among cancer patients: The roles of social support, appraisals, and adaptive coping. *Psycho-Oncology*, 2018; 27:2008-215. John Wiley & Sons Ltd.
- Carroll, J.E, van Dyk, K., Bower, J.E., Scuric, Z., Petersen, L., Schiesti, R., Irwin, M.R. and Ganz, P.A. (2018) Cognitive Performance in Survivors of Breast Cancer and Markers of Biological Aging. *Cancer* Published online 2018, in Wiley Online Library. DOI: 10.1002/cncr.31777.
- Casellas-Grau, A., Font, A. and Vives, J. (2014) Positive psychology interventions in breast cancer. A systematic review. *Psycho-Oncology* 23: 9-19 (2017) John Wiley & Sons Ltd.
- Chenail, R.J. (2009) Interviewing the Investigator: Strategies for Addressing Instrumentation and Researcher Bias Concerns in Qualitative Research. *The Qualitative Report*, 13 (4), 14-21.
- Cheng, K.K.F., Lim, Y.T.E., Koh, Z.M. and Tam, W.W.S. (2017) Home-based multidimensional survivorship programmes for breast cancer survivors (Review) *Cochrane Database of Systematic Reviews* 2017, Issue 8. Art. No: CD011152. DOI: 10.1002/14651858.CD011152.pub2.
- Clarke, V. and Braun, B. (2013) *Successful qualitative research: A practical guide for beginners*. London: Sage, ISBN 978184775815
- Clarke, V. and Braun, B. (2017) Thematic Analysis, *The Journal of Positive Psychology*, 12:3, 297-298, DOI: 10.1080/17439760.2016.1262613
- Code, L. (1993) "Taking Subjectivity into Account" from Alcoff, L. and Potter, E. *Feminist Epistemologies*. pp.15-48, New York: Routledge.
- Coffey, L., Mooney, O., Dunne, S., Sharp, L., Timmons, A., Desmond, D, O'Sullivan, E., Timon, C., Gooberman-Hill, R. and Gallagher, P. (2016) Cancer survivors' perspectives on adjustment-focused self-management interventions: a qualitative meta-synthesis. *Journal Cancer Survivor* (2016) 10:10121034. DOI: 10.1007/s11764-016-0546-3
- Coghlan, D. (2005) *Doing action research in your own organization: 'Preunderstanding, Role Duality and Access' (Chapter 5)*. London: Sage
- Coghlan, D. and Brannick, T. (2005) *Doing Action Research in Your Own Organization: 'Researching Your Own Organization' (Chapter 4)*. London: Sage.
- Cresswell, J. (2013) *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (4<sup>th</sup> edn.). 'Research Questions and Hypotheses' (Chapter 7). London: Sage.



- de Rooji, B.H., Exendam, N.P.M., Vos, M.C., Pijnenborg, J.M.A., Boll, D., Kruitwagen, R.F.P.M. and vande Poll-Franse, L.V (2018) Patients' information coping styles influence the benefit of a survivorship care plan in the ROGY Care Trial: New insights for tailored delivery. *Cancer*. [Published online, 2018] in Wiley Online Library. DOI: 10.1002/cncr.31844.
- Department of Health (2017a) *Health in Ireland Key Trends 2017*. Dublin, Ireland: Government Stationery Office.
- Department of Health (2017b) *National Cancer Strategy 2017-2026*. Dublin, Ireland: Government Stationery Office.
- Detterbeck, F.C. (2017) The eighth edition TNM stage classification for lung cancer: What does it mean on main street? *The Journal of Thoracic and Cardiovascular Surgery*, January 2018, USA, Elsevier.
- Diagnosing cancer in an emergency: Patterns of emergency presentation of cancer in Ireland 2002-2015. Irish Cancer Society, Dublin and National Cancer Registry, Cork.
- Dunn, J., Adams, C., Holland, J. and Watson, M. (2015) Reinforcing the role of psycho-social oncology in global cancer prevention: applying psycho-oncology research in programmes and practice. *Psycho-Oncology*, 2015: 24:1217-1221. Wiley Online Library.
- Dunne, S., Coffey, L., Sharp, L., Timmons, A., Desmond, D, Gooberman-Hill, R., O'Sullivan, E., Keogh, I., Timon, C. and Gallagher, P. (2018) Barriers to active self-management following treatment for head and neck cancer: survivors' perspectives. First published 29 June 2018. <https://doi.org/10.1002/pon.4835> [accessed July 16th at 10.32am]
- Dunne, S., Mooney, O., Coffey, L., Sharp, L., Timmons, A., Desmond, D, Gooberman-Hill, R., O'Sullivan, E., Keogh, I., Timon, C. and Gallagher, P. (2017) Self-management strategies used by head and neck cancer survivors following completion of primary treatment: A directed content analysis. *Psycho-Oncology*, 2017; 26: 2194-2200.
- Eichler, M. (1991) *Nonsexist Research Methods: A Practical Guide: 'Guidelines for Nonsexist research', (Chapter 7)*. London: Routledge.
- Eisenhardt, K. (1989) 'Building theories from case study research', *Academy of Management Review* 14(4): 532-550.
- Faretta, E. (2018) EMDR in Psycho oncology. *Clinical Neuropsychiatry* (2018) 15, 3, 206-221
- Feldon, D. and Tofel-Grehl, C. (2018) Phenomenography as a Foundation for Mixed Models Research, *American Behavioral Scientist* 2018, Vol. 62(7) 887-899. DOI: 10.1177/0002764218772640. Sage Publications.

- Fong, A.J., Scarapicchia, T.M.F., McDonough, M.H., Wrosch, C. and Sabiston, C.M. (2017) Changes in social support predict emotional wellbeing in breast cancer survivors. *Psycho-Oncology* 26: 664-671 (2017) Published online 28 January 2016 in Wiley Online Library (wileyonlinelibrary.com). DOI: 10.1002/pon.4064.
- Foster, C., Calman, L., Richardson, A., Pimerton, H and Nash, R. (2018) Improving the lives of people living with and beyond cancer: Generating the evidence needed to inform policy and practice. *Journal of Cancer Policy*, 15 (2018) 92-95  
<http://doi.org/10.1016/j.jcpo.2018.02.004>
- Fox, K., Posluszny, D.M., DiMartini, A.F., DeVito Dabbs, A.J., Rosenberger, E.M., Zomak, R.A., Bermudez, C. and Dew, M.A. (2014) Predictors of post-traumatic psychological growth in the late years after lung transplantation, *Clin Transplant* 2014: 28: 384-393, John Wiley & Sons.
- Frick, M.A, Vachani, C.C., Bach, C., Hampshire, M.K., Arnold-Korzeniowski, K., Metz, J.M. and Hill-Kayser, C. (2017) Survivorship and the Chronic Cancer Patient: Patterns in Treatment-Related Effects, Follow-Up Care, and Use of Survivorship Care Plans. *Cancer*. Published online: June 27, 2017 in Wiley Online Library.
- Fries, C.J. (2009) 'Bourdieu's reflexive sociology as a theoretical basis for mixed methods research', *Journal of Mixed Methods Research* 3(4): 326-348
- Frost, M., Novotury, P., Johnson, M., Clarke, M., Sloan, J. and Yang, P. (2013) Spiritual well-being in lung cancer survivors, *Support Care Cancer*, Vol 21: 1939-1946. Springer
- Frydenberg, E. (2014) Coping research: Historical background, links with emotion, and new research directions on adaptive processes, *Australian Journal of Psychology* 2014; 66: 82-92
- Garrett, K., Okuyama, S., Jones, W., Barnes, D., Tran, Z., Spencer, L., Lewis, K., Maroni, P., Chesney, M. and Marcus, A. (2013) Bridging the transition from cancer patient to survivor: Pilot study results of the Cancer Survivor Telephone Education and Personal Support (C-Steps) program. *Patient Education and Counselling* 92 (2013)266-272. SciVerse Science Direct.
- Geddes, B. (2003) *Paradigms and Sandcastles: Theory Building and the Research Design in Comparative Politics: 'Big questions, little answers. How the questions you choose affect the answers you get'*, (Chapter 2). Ann Arbor, MI: University of Michigan Press.
- Gerring, J. (2007b) 'Case study versus large-N cross-case analysis', pp. 37-63 in *ibid.*, *Case Study Research. Principles and Practices*. Cambridge: CUP.
- Goodhart, F. and Atkins, L. (2013) *The Cancer Survivor's Companion; Practical ways to cope with your feelings after cancer*, UK, Piatkus.
- Grace, J.J., Kinsella, E.L., Muldoon, O.T. and Fortune, D. (2015) Posttraumatic growth following acquired brain injury: a systematic review and metaanalysis. *Frontiers in Psychology*, Vol. 6:1162.

- Grassi, L., Fujisawa, D., Odyio, P., Asuzu, C., Ashley, L., Bultz, B., Travado, L. and Fielding, R. (2016) Disparities in psycho social cancer care: a report from the International Federation of Psycho-oncology Societies. *PsychoOncology* 2016; 25: 1127-1136. Wiley Online Library.
- Green H., Ferguson M., Shum D., and Chambers S. (2012) Prospective individual and social predictors of changes in adjustment for patients attending a regional cancer service, Published online, Springer Science & Business Media V.V. 2012.
- Grix, J. (2002) 'Introducing Students to the Generic Terminology of Social Research', *Politics* 22(3): 175-186.
- Groarke, A., Curtis, R., Groarke, J.M., Hogan, M.J., Gibbons, A. and Kerin, M. (2017) Post-traumatic growth in breast cancer: how and when do distress and stress contribute? *Psycho-Oncology*, 2017; 26: 967-974. Wiley Online Library. DOI: 10.1002/pon.4243
- Hammersley, M. (2012) 'Troubling theory in case study research', *Higher Education Research & Development* 31 (3): 393-405.
- Hammersley, M. and Traianou, A. (eds) (2012) *Ethics in Qualitative Research: Controversies and contexts: 'Privacy, confidentiality and anonymity'* (Chapter 5), pp. 99-132. London: Sage.
- Harding S. and Moss T.P. (2018) The impact of treatment for head and neck cancer on positive psychological change within a year of completing treatment. *International Journal of Oral Maxillofacial Surgery*. 2018; 47: 302-308. Published by Elsevier Ltd.
- Harding, S.A. (2017) Identification of longitudinal patterns of positive psychological change in people following treatment for Head and Neck Cancer. Faculty of Health and Applied Sciences, University of the West of England, Bristol, UK.
- Hart, C. (1998) *Doing a Literature Review: Releasing the Social Science Research Imagination: 'Writing the Review'* (Chapter 7). London: Sage.
- Hashemi, M.R. and Babaii, E. (2013) Mixed Methods Research: Toward new research designs in applied linguistics, *The Modern Language Journal*, Vol. 97, No. 4. Pp. 828-852. Wiley
- Hasson-Ohayon, I., Tuval-Mashiach, R., Goldzweig, G., Levi, R., Pizem, N. and Kaufman, B. (2016) The need for friendships and information: Dimensions of social support and posttraumatic growth among women with breast cancer. *Palliative and Supportive Care* (2016), 14, 387-392. DOI: 10.1017/S1478951515001042. Cambridge University Press.
- Hennink, M., Kaiser, B. and Marconi, V. (2017) Code Saturation Versus Meaning Saturation: How Many Interviews Are Enough? *Qualitative Health Research* 2017, Vol. 27(4) 591-608 DOI: 10.1177/1049732316665344. Sage Publications.

- Ho, S.M.Y., Law, L.S.C., Wang, G.-L., Shih, S.-M., Hse, S.H. and Hou, Y.-C. (2013) Psychometric analysis of the Chinese version of the Posttraumatic Growth Inventory with cancer patients in Hong Kong and Taiwan. *Psycho-Oncology*, Vol. 22: 715-719. John Wiley & Sons Ltd.
- Hobfall, S. (2010) Resource caravans and resource caravan passageways: a new paradigm for trauma responding. *Intervention* 2014, Vol. 12 (1) 21 – 32. War Trauma Foundation.
- Hoffman, M., Lent, R. and Raque-Bogdan, T. (2012) A Social Cognitive Perspective on Coping with Cancer: Theory, Research, and Intervention. *The Counselling Psychologist* 2013, 41: 240, published online 11 October. Sage Publications.
- Holbrook, A., Bourke, S., Fairbairn, H. And Loyal, T. (2007) ‘Examiner comment on the literature review in PhD theses’, *Studies in Higher Education* 32(3): 337-356.
- Holland J. (2018) Psycho-Oncology: overview, obstacles, and opportunities, *Psycho-Oncology*, Vol 27: 1364-1376
- Holtmaat, K., van der Spek, N., Cuijpers, P., Leemans, C.R. and Verdonck-de Leeuw, I.M. (2016) Posttraumatic growth among head and neck cancer survivors with psychological distress. *Psycho-Oncology* (2016) Wiley Online Library. DOI: 1.10.1002/pon.4106 [Http://www.cso.ie](http://www.cso.ie) [Accessed September 23, 2014, 11.30am]
- Ibrahimi, S.E. and Pinheiro, P.S. (2017) The effect of marriage on stage at diagnosis and survival in women with cervical cancer. *Psycho-Oncology* 26: 704-710 (2017) Published online 26 January 2016 in Wiley Online Library ([wileyonlinelibrary.com](http://wileyonlinelibrary.com)) DOI: 10.1002/pon.4070.
- International Psycho Oncology Society (2019) About IPOS. [online] available: <https://www.ipos-society.org/About> [accessed 12 February 2019].
- Irish Cancer Society (2015) Report on the Real Cost of Cancer, Millward Brown.
- Irish Cancer Society (2017) Establishing a Community Focused Approach to Cancer Prevention in Cork City North West. Dublin, Ireland. Irish Cancer Society.
- Irish Cancer Society (2018a) Cancer Information and Support, [online], available: <https://www.cancer.ie/about-us/media-centre/cancerstatistics#sthash.m8kH7cTl.dpbs> [accessed 10 Dec 2018].
- Irish Cancer Society (2018b) Cancer Information and Support, [online], available: <http://www.cancer.ie/cancer-information/cancer-types#sthash.gN123Bkg.dpbs> [accessed 23 July 2018].
- Irish Cancer Society (2018c) Cancer Information and Support, [online], available: <http://www.cancer.ie/cancer-information/treatments>, [accessed 28 Sept 2018].
- Irish Psycho Social Oncology Network (2018) 2020 Vision [online], available: <http://ipson.ie/about/2020-vision> [accessed: Dec 10 2018 at 11am]

- Jaehee, Y. and Min, A.K. (2014) Post cancer Experiences of childhood Cancer Survivors: How is Posttraumatic Stress Related to Posttraumatic Growth? *Journal of Traumatic Stress* August 2014, 27, 461-467
- Jin, Y., Su, J. and Liu, D. (2014) The relationship between post traumatic stress disorder and post traumatic growth: gender differences in PTG and PTSD subgroups. *Soc Psychiatry Psychiatry Epidemiol* (2014) 49: 1903-1910. DOI: 10.1007/s00127-014-0865-5
- Joen, M., Yoo, Y., Kim, S. and Lee, J. (2015) Post-traumatic growth in survivors of allogeneic hematopoietic stem cell transplantation. *Psycho-Oncology* 24: 871-877 (2015) 10 November 2014. Wiley Online Library. DOI: 10.1002/pon.374
- Joseph, S. (2014) Posttraumatic Growth a talk, 14 February, British Psychological Society Scottish Branch AGM, Limerick, Ireland.
- Joseph, S. and Linley, A.P. (2006) Growth following adversity: Theoretical perspectives and implications for clinical practice. *Clinical Psychology Review* 26 (2006) 1041-1053. DOI: 10.1016/j.cpr.2005.12.006
- Joseph, S., Murphy, D. and Regel, S. (2012) An Affective-Cognitive Processing Model of Post-Traumatic Growth. *Clinical Psychology and Psychotherapy*, Vol 19: 316-325. John Wiley & Sons Ltd.
- Keane, F., Greally, M., Power, D.G. and Leonard, G.D. (2018) A survey of colorectal cancer (CRC) survivorship practices in Ireland, and implementation of a survivorship care plan (SCP) pilot program. *Journal of Clinical Oncology* 36, no. 7\_suppl (March 2018) 60-60. DOI: 10.1200/jco.2018.36.7\_suppl.60
- Kenqay, J. and McLeod J. (2004) 'Bourdieu's reflexive sociology and 'spaces of points of view': Whose reflexivity, which perspective?', *British Journal of Sociology of Education* 25(4): 525-544.
- Koutrouli, N., Anagnostopoulos, F., Griva, F., Gouruonti, K., Kolokotroni, F., Efstathiou, V., Mellon, R., Papastylianou, D., Niakas, D. and Potamianos, G.(2016) Exploring the relationship between posttraumatic growth, cognitive processing, psychological distress, and social constraints in a sample of breast cancer patients. *Women & Health*. 56:6, 650-667, DOI: 10.1080/03630242.2015.1118725. Taylor & Francis.
- Kramer, J.M. (2010) Using Mixed Methods to Establish the Social Validity of a Self-Report Assessment: An Illustration Using the Child Occupational Self-Assessment (COSA), *Journal of Mixed Methods Research*, 2011, 5:52. <https://doi.org/10.1177/1558689810386376>
- Krathwohl, D. and Smith, N. (2005) How to prepare a dissertations proposal: 'Functions of a Dissertation Proposal' (Chapter 2). New York: Syracuse University Press.

- Kumar, A. and Schapira, L. (2013) The impact of intrapersonal, interpersonal, and community factors on the identity formation of young adults with cancer: a qualitative study, *Journal of Psycho-Oncology* 22: 1753-1758 (2013), Published online, Wiley Online Library.
- Kupfershmidt, K. (2018) A Recipe for Rigour. *Science* 361 (6408), 1192-1193. DOI: 10.1126/science.361.6408.1192
- Lang-Rollin, I. and Berberich, G. (2018) Psycho-oncology. *Dialogues in Clinical Neuroscience*. Vol 20. No. 1. 2018: 13-21. Servier Research Group
- Lazarus, R. and Folkman, S. (1984). *Stress, Appraisal, and Coping*. New York. Springer.
- Learmonth, M., Lockett, A. and Dowd, K. (2012) 'Promoting Scholarship that Matters: The Uselessness of Useful Research and the Usefulness of Useless Research', *British Journal of Management* 23 (1): 35-44.
- Lent, R.W. (2004) Toward a Unifying Theoretical and Practical Perspective on Well Being and Psycho social Adjustment. *Journal of Counselling Psychology*, Vol. 51, 2004, 4:482-509.
- Lindstrom, C., Cann, A., Calhoun, L.G. and Tedeschi, R.G. (2013) The relationship of core belief challenge, rumination, disclosure, and sociocultural elements to posttraumatic growth. *Psychological Trauma*, Vol 5 (1), Jan 2013: 50-55. DOI: 10.1037/a0022030
- Linley, A.P. and Joseph, S. (2004) Positive Change Following Trauma and Adversity: A Review. *International Society for Traumatic Stress Studies*, Vol. 17, No. 1, February 2001, pp. 11-21.
- Linley, A.P. and Joseph, S. (2011) Meaning in Life and Posttraumatic Growth, *Journal of Loss and Trauma*, 16:2, 150-159, DOI: 10.1080/15325024.2010.519287. Routledge.
- Lorenzo, F., Apolstolidis, K., Florindi, F. and Makaroff, L.E. (2018) Improving European policy to support cancer survivors. *Journal of Cancer Policy* 15 (2018) 72-75. <https://doi.org/10.1016/j.jcpo.2018.01.004>
- Maher, J., Petchey, L., Greenfield, D., Levitt, G. and Fraser, M. (2018) Implementation of nationwide cancer survivorship plans: Experience from the UK, *Journal of Cancer Policy* 15 (2018) 76-81. <https://doi.org/10.1016/j.jcpo.2018.01.002> accessed July 15th, 2018 at 11am.
- Malterud, K., Dirk Siersma, V. and Guassora, A.D. (2016) Sample Size in Qualitative Interview Studies: Guided by Information Power *Qualitative Health Research* 2016. Vol. 26(13) 1753-1760 DOI: 10.1177/1049732315617444. Sage Publications.
- Mayer, D.K. and Alfano, C.M. (2019) Personalized Risk-Stratified Cancer Follow-Up Care: Its Potential for Healthier Survivors, Happier Clinicians, and Lower Costs. *JNCI: Journal of the National Cancer Institute*, <https://doi.org/10.1093/jnci/djy232>

- Meade, E., McIlfatrick, S., Groarke, A.M., Butler, E. and Dowling, M. (2017) Survivorship care for postmenopausal breast cancer patients in Ireland: What do women want? *European Journal of Oncology Nursing* 28 (2017) 69-76  
<https://dx.doi.org/10.1016/j.ejon.2017.03.003> [accessed Dec 9th, 2018 at 11am]
- Monti, D., Kash, K., Kunkel, E., Moss, A., Mathews, M., Brainard, G., Anne, R., Leiby, B., Pequino, E., and Newberg, A. (2013) Psycho social benefits of a novel mindfulness intervention versus standard support in distressed women with breast cancer, *PsychoOncology* 22: 2565-2575 (2013) Published online 21 July 2013 in Wiley Online Library, John Wiley & Sons.
- Morris Bronwyn, A., Wilson, B. and Chambers, S.K. (2013) Newfound compassion after prostate cancer: a psychometric evaluation of additional items in the Posttraumatic Growth Inventory. *Support Care Cancer*, Vol. 21: 3371-3378. Springer.
- Morrison, S. (2009) *Even the eyebrows? A practical guide to managing cancer with your boxing gloves on*, US, Author house.
- Morse, J. (2010) 'Procedures and practice of mixed methods design. Maintaining control, rigor and complexity', pp. 339-352 in Takkashori, A. and Teddlie, C. (eds) *Sage Handbook of Mixed Methods in Social and Behavioural Research*. London: Sage.
- Morse, J. (2015) *Analytic Strategies and Sample Size, Qualitative Health Research* 2015. Vol. 25(10) 1317 – 1318 DOI: 10.1177/11049732315602867. Sage Publications.
- National Cancer Registry Ireland (2014) *Cancer in Ireland 1994-2011: Annual report of the National Cancer Registry 2014*, published May 2014, Cork Ireland.
- National Cancer Registry Ireland (2015) *Cancer in Ireland 1994-2015: with estimates from 2015-2017: Annual Report of the National Cancer Registry*. NCR, Cork, Ireland.
- National Cancer Registry Ireland (2018) *Cancer in Ireland 1994-2016 with estimates for 2016-2018: Annual report of the National Cancer Registry*. NCRI, Cork, Ireland.
- Nicholas, D. (2013) *On Being a Psycho-Oncologist: A counselling psychology perspective*, [Published Online 22 October 2012], Sage Publications
- O'Shea, M.T. and Collins, C. (2018) Cancer Survivorship in General Practice – Barriers Encountered by General Practitioners in Ireland, *Universal Journal of Public Health* 6(2): 73-78, 2018, Irish College of General Practitioners.  
<http://www.hrpub.orgdoi:10.13189/ujph.2018.060206>
- OECD/European Observatory on Health Systems and Policies (2017) *Ireland: Country Health Profile 2017, State of Health in the EU*. OECD Publishing, Paris/European Observatory on Health Systems and Policies, Brussels.  
<https://doi.org/10.1787/9789264283435-en>.

- Organisation for Economic Cooperation and Development (2019) OECD Health Statistics 2018 – Frequently Requested Data, [online], available: <http://www.oecd.org/els/health-systems/health-data.htm>, [accessed 6 Feb 2019].
- Pallant, J. (2010) *SPSS Survival Manual: A step by step guide to data analysis using SPSS* (4th ed.) Australia, McGraw Hill
- Pearce, A., Bradley, C., Hanly, P., O'Neill, C., Alforque, T.A., Molcho, M. and Sharp, L. (2016) Projecting productivity losses for cancer-related mortality 2011-2030. *Cancer* (2016) 16:804. DOI: 10.1186/s12885-016-2854-4
- Ragin, C. (2008) *Redesigning Social Inquiry: Fuzzy Sets and Beyond: 'Limited diversity and counterfactual cases'* (Chapter 8). Chicago: Chicago University Press.
- Ramos, C., Costa, P., Rudnicki, T., Maroco, A., Leal, I., Guimaraes, R., Fougho, J. and Tedeschi, R. (2017) The effectiveness of a group intervention to facilitate posttraumatic growth among women with breast cancer, *Psycho-Oncology*. 2018; 27:258-264. John Wiley & Sons Ltd.
- Richardson, L. (2003) 'Writing: A method of inquiry', pp. 499-541 in N. Denzin and Y. Lincoln (eds) *Collecting and Interpreting Qualitative Materials*. London: Sage.
- Rodin, G. (2018) From evidence to implementation: The global challenge for psychosocial oncology. *Psycho-Oncology*. 2018; 27: 2310–2316. DOI: 10.1002/pon.4837. Wiley & Sons.
- Rogan, C., Fortune, D.G. and Prentice, G. (2013) Post-traumatic growth, illness perceptions and coping in people with acquired brain injury, *Neuropsychological Rehabilitation*, 23:5, 639-657, DOI: 10.1080/09602011.2013.799076
- Roland, K., Rodriguez, J., Patterson, J. and Trivers, K. (2013) A literature review of the social and psychological needs of ovarian cancer survivors, *Psycho-Oncology* 22: 2408-2418, Published online 13 June 2013 in Wiley Online Library.
- Romeo, A., Ghiggia, A., Tesio, V., Di Tella, M., Torta, R. and Castelli, L. (2017) Post-traumatic growth, distress and attachment style among women with breast cancer, *Journal of Psycho social Oncology*, 35:3, 309-322, DOI: 10.1080/07347332.2017.1289291 Routledge.
- Rosberger, Z., Perezl, S., Bloom, J., Shapiro, G.K. and Fielding, R. (2015) The missing piece: cancer prevention within Psycho-oncology – a commentary. *Psycho-Oncology* 24: 1330-1337. DOI: 10.1002/pon.3916. Published online in Wiley Online Library.
- Rosenberg, A. (2007) "Chapter 4: Interpretation" from Rosenberg, Alexander, *Philosophy of Social Science*, pp.101-140, Boulder, Col.: Westview Press.
- Sabiston, C., McDonough, M. and Crocker, P. (2007) Psychosocial Experiences of Breast Cancer Survivors Involved in a Dragon Boat Program: Exploring Links to Positive Psychological Growth. *Journal of sport & exercise psychology*. 29. 419-38. 10.1123/jsep.29.4.419. [accessed 16 Nov, 2018]



- Scarcini, I., Bandura, L., Hidalgo, B. and Cherrington, A. (2012) Development of a Theory-Based (PEN-3 and Health Belief Model), Culturally Relevant Intervention on Cervical Cancer Prevention Among Latina Immigrants Using Intervention Mapping. *Health Promotion Practice*. Vol. 13, No. 1, 29-40. Society for Public Health Education.
- Schoonenboom, J. (2018) Designing Mixed Methods Research by Mixing and Merging Methodologies: A 13-Step Model. *American Behavioral Scientist* 208, Vol. 62(7) 998-1015. DOI: 10.1177/0002764218772674. Sage
- Scrignaro M., Marini E., Magrin M.E. and Borreani C. (2016) Emotive and cognitive processes in cancer patients: linguistic profiles of post-traumatic growth. *European Journal of Cancer Care*. 2018;27: e12620. DOI: 10.1111/ecc.12620 Wiley & Sons Ltd.
- Senf, B., Fettell, J., Demmerle, C. and Maiwurm, P. (2018) Physicians' attitudes towards psycho-oncology, perceived barriers, and psychosocial competencies: Indicators of successful implementation of adjunctive psycho-oncological care? *PsychoOncology* 2018;1–8. DOI: 10.1002/pon.4962. Wiley & Sons.
- Shakespeare-Finch, J., Martinek, E., Tedeschi, R.G. and Calhuon, L.G. (2013) A Qualitative Approach to Assessing the Validity of the Posttraumatic Growth Inventory, *Journal of Loss and Trauma*, 18:6, 572-591, DOI: 10.1080/15325024.2012.734207. Routledge.
- Shand, L., Cowlshaw, S., Brooker, J., Burney, S. and Ricciardelli, L. (2015) Correlates of post-traumatic stress symptoms and growth in cancer patients: a systematic review and meta-analysis. *Psycho-Oncology* 24: 624-634 (2015)
- Sharp, L., Deady, S., Gallagher, P., Molcho, M., Pearce, A., Thomas, A.A., Timmons, A. and Comber, H. (2014) The magnitude and characteristics of the population of cancer survivors: using population-based estimates of cancer prevalence to inform service planning for survivorship care. *BMC Cancer* 2014, 14:767. BioMed Central
- Sharp, L., Redfearn, D., Timmons, A., Balfe, M. and Patterson, J. (2018) Posttraumatic growth in head and neck cancer survivors: Is it possible and what are the correlates? *Psycho-oncology*, 2018; 27: 1517-1523. John Wiley & Sons Ltd.
- Shi, Q., Smith, T.G., Michonski, J., Stein, K.D., Kaw, C. and Cleeland, C.S. (2011) Symptom Burden in Cancer Survivors 1 Year After Diagnosis. *Cancer*. Published online April 14, 2011 in Wiley Online Library. DOI: 10.1002/cncr.26146.
- Soo, H. and Sherman, K.A. (2015) Rumination, psychological distress and posttraumatic growth in women diagnosed with breast cancer. *Psycho-Oncology* 24: 70-79 (2015) Published online 24 June 2014 in Wiley Online Library. DOI: 10.1002/pon.3596
- Spiegel, D. (2012) Mind matters in cancer survival, *Psycho-Oncology* 21: 588-593, Published online 21 March 2012 in Wiley Online Library, John Wiley & Sons.

- Svetina, M. and Nastran, K. (2012) Family Relationships and Post-Traumatic Growth in Breast Cancer patients. *Psychiatria Danubina*, Vol. 24, No 3:298-306.
- Tabrizi, F.M., Radfar, M. and Taei, Z. (2016) Effects of supportive-expressive discussion groups on loneliness, hope and quality of life in breast cancer survivors: a randomized control trial. *Psycho-Oncology* 25: 1057-1063. Published online 15 June 2016 in Wiley Online Library (wileyonline library.com) DOI: 10.1002/pon.4169.
- Takahashi, M. (2016) Cancer Survivorship: Current Status of Research, Care and Policy in Japan. *Japanese Journal of Clinical Oncology*, 2016, 46(7) 599–604. DOI: 10.1093/jjco/hyw057. Oxford.
- Taku, K., Cann, A., Calhoun, L.G. and Tedeschi, R.G. (2008) The Factor Structure of the Posttraumatic Growth Inventory: A Comparison of Five Models Using Confirmatory Factor Analysis. *Journal of Traumatic Stress*, Vol. 21, No. 2, April 2008, pp. 158-164. Wiley Interscience. DOI: 10.1002/jts.20305
- Tedeschi, R.G. and Calhoun, L.G. (1996) The Posttraumatic Growth Inventory: Measuring the Positive Legacy of Trauma. *Journal of Traumatic Stress*, Vol. 9, No. 3, 1996.
- Tedeschi, R.G. and Calhoun, L.G. (2004) Psycho social Experiences of Breast Cancer Survivors Involved in a Dragon Boat Program: Exploring Links to Positive Psychological Growth – Scientific Figure on ResearchGate. Available from: [https://www.researchgate.net/Left-panel-model-of-posttraumatic-growth-FromTedeschi-RG-Calhoun-LG-2004\\_fig1\\_5878311](https://www.researchgate.net/Left-panel-model-of-posttraumatic-growth-FromTedeschi-RG-Calhoun-LG-2004_fig1_5878311) [accessed 16 Nov, 2018].
- Tedeschi, R.G. and Moore, B.A. (2016) *The Posttraumatic Growth Workbook*. California.
- Tedeschi, R.G., Cann, A., Taku, K., Senol-Durak, E. and Calhoun, L. (2017) The Posttraumatic Growth Inventory: A Revision Integrating Existential and Spiritual Change. *Journal of Traumatic Stress*. February 2017, 30, 11-18. International Society for Traumatic Stress Studies. Wiley Online Library. DOI: 10.1002/jts.22155
- Tedeschi, R.G., Shakespeare-Finch, J., Taku, K. and Calhoun, L.G. (2018) *Posttraumatic Growth: Theory, Research, and Applications*. New York. Routledge.
- Tevaarwerk, A.J., Klemp, J.R., van Londen, G.J., Hesse, B.W. and Sesto, M.E. (2018) Moving Beyond Static Survivorship Care Plans: A Systems Engineering Approach to Population Health Management for Cancer Survivors. *Cancer*. Published online September 12, 2018 in Wiley Online Library. DOI: 10.1002/cncr.31546
- Thong, M., Mols, F., Doege, D., Poll-Franse, L. and Arndt, V. (2018). Population-based cancer survivorship research: Experiences from Germany and the Netherlands. *Journal of Cancer Policy* 15 (2018) 87-91.
- Threader, J. and McCormack, L. (2016) Cancer-related trauma, stigma and growth: the ‘lived’ experience of head and neck cancer. *European Journal of Cancer Care*., 2016, 25: 157-169. John Wiley & Sons Ltd.

- Travado, L., Breitbart, W., Grassi, L., Fujisawa, D., Patenaude, A., Baider, L., Connor, S. and Fingeret, M. (2016) 2015 President's Plenary International Psycho-oncology Society: psycho social care as a human rights issue – challenges and opportunities. *Psycho-Oncology*, 2017; 26: 563-569. Wiley Online Library.
- Travado, L., Bultz, B.D., Ullrich, A., Asuzu, C.C., Turner, J., Grassi, L. and Jacobsen, P. (2017) 2016 President's Plenary International Psycho Oncology Society: challenges and opportunities for growing and developing psycho social oncology programmes worldwide. *Psycho-Oncology*, 2017; 26: 1231-1238. Wiley Online Library.
- Treanor, C. and Donnelly, M. (2016) Late effects of cancer and cancer treatment – the perspective of the patient. *Support Care Cancer* (2016) 24: 337-346. DOI 10.1007/s00520-015-2796-4. Springer.
- Treanor, C., Santin, O., Mills, M. and Donnelly, M. (2013) Cancer survivors with selfreported late effects: their health status, care needs and service utilization, *PsychoOncology* 22: 2428-2435 (2013) Published online 16 May 2013 in Wiley Online Library.
- Trowler, P. (2012) 'Wicked issues in situating theory in close-up research', *Higher Education Research & Development* 31 (3): 273-284.
- Vachon, M. (2008) Meaning, Spirituality, and Wellness in Cancer Survivors. *Seminars in Oncology Nursing*, Vol. 24, No 3: 218-225. Elsevier.
- van den Berg, S, van Amstel, F., Ottevanger, P., Gielissen, M., and Prins, J. (2013) The Cancer Empowerment Questionnaire: Psychological Empowerment in Breast Cancer Survivors, *Journal of Psycho social Oncology*, 31: 565-583, Routledge.
- van der Spek, N., Vos, J., van Uden-Kraan, C.F., Breitbart, W., Tollenaar, R.A., Cuijpers, P. and Verdonck-de Leeuw, I.M. (2013) Meaning Making in Cancer Survivors: A Focus Group Study. *PloS ONE* 8(9)
- Vonarx, N. and Hyppolite, S.-R. (2014) Religion, Spirituality, and Cancer: The Question of Individual Empowerment. *Integrative Cancer Therapies*. Vol. 12 (1) 69-80. Sage.
- Wallace, M. and Wray, A. (2011) *Critical Reading and Writing for Postgraduates: 'Integrating Critical Literature Reviews into your Dissertation' (Chapter 13)*. London: Sage.
- Walsh, D., Morrison, T., Conway, R., Rogers, E., Sullivan, F. and Groarke, A.M. (2018) A Model to Predict Psychological and Health-Related Adjustment in Men with Prostate Cancer: The Role of Post Traumatic Growth, Physical Post Traumatic Growth, Resilience and Mindfulness. *Frontiers in Psychology* 9: 136. DOI: 10.3389/fpsyg.2018.00136
- Wehrlen, L., Krumlauf, M., Ness, E., Maloof, D. and Bevans, M. (2016) Systematic collection of patient reported outcome research data: A checklist for clinical research professionals. *Contemporary Clinical Trials* 48 (2016) 21–29. Elsevier.

Willems, R.A., Bolman, C.A.W., Mesters, I., Kanera, I.M., Beaulen, A.A.J.M. and Lechner, L. (2016) Cancer survivors in the first year after treatment: the prevalence and correlates of unmet needs in different domains. *PsychoOncology* 25: 51-57 (2016) Published online 25 June 2015 in Wiley Online Library (wileyonlinelibrary.com) DOI: 10.1002/pon.3870.

Williams, M., Snyder, D., Sloane, R. Levens, J., Flynn, K., Dombek, C., Wahnefried, W. and Weinfurt, K. (2013) A comparison of cancer survivors from the PROMIS study selecting telephone versus online questionnaires, *Psycho-Oncology Journal* 22: 2632-2635 (2013), Wiley Online Library.

Wright Mills, C. (1959) *The Sociological Imagination: 'Appendix: On Intellectual Craftmanship'*, pp. 195-226. Oxford: Oxford University Press.

Wright-Mills, C. (2000) "Chapter 1 – The Promise". from Wright Mills, C., *The Sociological imagination*, pp3-24. Oxford: Oxford University Press

Yeung, N.C., Lu, Q. and Lin, W. (2014) Specificity May Count: Not Every Aspect of Coping Self-Efficacy is Beneficial to Quality of Life Among Chinese Cancer Survivors in China. *International Journal Behaviour Medicine* Vol 21:629-627. Springer.

Yi, J., Zebrack, B., Kim, M. and Cousino, M. (2015) Posttraumatic Growth Outcomes and their Correlates Among Young Adult Survivors of Childhood Cancer. *Journal of Paediatric Psychology*, 2015, 1-11. Oxford University Press.

Zamora, E., Yi, J., Akter, J., Kim, J., Warner, E. and Kirchhoff, A. (2017) 'Having cancer was awful but also something good came out': Post-traumatic growth among adult survivors of paediatric and adolescent cancer. *European Journal of Oncology Nursing* 28 (2017) 21-27.

Zimmermann-Schlegel, V., Hartmann, M., Sklenarova, H., Herzog, W. and Haun, M.W. (2017) Accessibility, Availability, and Potential Benefits of Psycho-Oncology Services: The Perspective of Community-Based Physicians Providing Cancer Survivorship Care. *The Oncologist* 2017; 22: 719-727.

#### **Websites:**

[<https://www.psych.auckland.ac.nz/en/about/our-research/research-groups/thematicanalysis/frequently-asked-questions-8.html#dd355b01912d6a98deccacd260ec3e7a>. Accessed Saturday 13 October 2018 at 15.04]

#### **Videos:**

Richard Tedeschi – Posttraumatic Growth: Basic Concepts and Strategies for Facilitation. (2018). APA Division 56 [Online Video]. 11 September 2015. Available from: <https://www.youtube.com/watch?v=VcymghZcxBs> [Accessed: 2 November 2018]

## Bibliography

- Agustina, E., Dodd, R.H., Waller, J. and Vrinten, C. (2017) Understanding middle-aged and older adults' first associations with the word "cancer": A mixed methods study in England. *Psycho-Oncology*, 2018: 27: 309-315. Wiley Online Library. DOI: 10.1002/pon.4569
- Bazeley, P. (2016) Analysing qualitative data: More than 'identifying themes'. Published online, 01 November 2016 in ResearchGate. <https://www.researchgate.net/publication/237458922>.
- Belotto, M.J. (2018) Data Analysis Methods for Qualitative Research: Managing the Challenges of Coding, Interrater Reliability, and Thematic Analysis. *The Qualitative Report*, 23 (11), 26222-2633.
- Bray, P. (2013) Bereavement and Transformation: A Psycho-spiritual and Posttraumatic Growth Perspective. *Journal Religious Health* Vol. 52: 890-903. Springer.
- Calhoun, L.G. and Tedeschi, R.G. (2013) Post traumatic Growth in Clinical Practice. UK. Routledge. New Harbinger Publications Inc.
- Calhoun, L.G., Tedeschi, R.G., Cann, A. and Hanks, E.A (2010) Positive Outcomes Following Bereavement: Paths To PostTraumatic Growth. *Psychologica Belgica*. 2010, 50-1&2, 125-143. DOI: <http://dx.doi.org/10.5334/pb-50-12-125>
- Cann, A., Calhoun, L.G., Tedeschi, R.G., Taku, K., Vishnevsky, T., Triplett, K.N. and Danhauer, S.C. (2010) A short form of the Posttraumatic Growth Inventory. *Anxiety, Stress & Coping*. Vol. 23: 127-137. Routledge.
- Department of Health (2006) National Cancer Strategy 2006: A Strategy for Cancer Control in Ireland. National Cancer Forum. Dublin, Ireland: Government Stationery Office.
- Duffy, M.J. (2013) The war on cancer: are we winning? *Tumor Biology*. Vol. 34: 12751284. Springer.
- Hanley, J.A, Hannigan, A. and O'Brien, K.M. (2017) Mortality reductions due to mammography screening: Contemporary population-based data. *PloS One* 12 (12): e0188947. <https://doi.org/10.1371/journal.pone.0188947>
- Hunter, A.C. (2016) A Phenomenological Investigation of Women's Experience of Recovering from Childhood Trauma and Subsequent Substance Abuse, *Indo-Pacific Journal of Phenomenology*, 16: sup1, 1-21, DOI: 10.1080/20797222.2016.1164990
- Kashdan, T.B. and Kane, J.Q. (2011) Post-traumatic distress and the presence of post-traumatic growth and meaning in life: Experiential avoidance as a moderator. *Personality and individual differences*, 50(1), 84–89. <https://doi.org/10.1016/j.paid.2010.08.028>

- Lang, M., Giese-Davis, J., Patton, S.B. and Campbell, D.J.T. (2017) Does age matter? Comparing post-treatment psycho social outcomes in young adult and older adult cancer survivors with their cancer-free peers. *Psycho-Oncology*, 2018: 27: 1404-1411 <https://doi.org/10.1002/pon.4490> accessed July 16th, 2018 at 10.30am
- Lauterbach, A. (2018) Hermeneutic Phenomenological Interviewing: Going Beyond Semi-Structured Formats to Help Participants Revisit Experience, *The Qualitative Report*, 23(11), 2883-2898. Retrieved from <https://nsuworks.nova.edu/tqr/vol23/iss11/16>.
- Lebel, S., Ozakinci, G., Humphris, G., Thewes, B., Prins, J., Dinkey, A. and Butow, P. (2017) Current State and future prospects of research on fear of cancer recurrence. *Psycho-Oncology* 26: 424-427 (2017) Published online 18 February 2016 in Wiley Online Library ([wileyonlinelibrary.com](http://wileyonlinelibrary.com)). DOI: 10.1002/pon.4103.
- Lorgella, P. and Neri, M. (2018) Survivorship burden for individuals, households and society: Estimates and methodology. *Journal of Cancer Policy* 15 (2018) 113-117. <https://doi.org/10.1016/j.jpo.2018.02.005>
- McFarland, M.J., Pudrovskaya, T., Schieman, S., Ellison, C.G. and Bierman, A. (2013) Does a cancer diagnosis influence religiosity? Integrating a life course perspective. *Social Science Research* Vol 42: 311-320. Elsevier.
- Mystakidou, K., Tsilika, E., Parpa, E., Galanos, A. and Vlahos, L. (2008) Post-traumatic growth in advanced cancer patients receiving palliative care. *British Journal of Health Psychology*. Vol. 13: 633-646. The British Psychological Society.
- O'Shea, M.T. and Collins, C. (2016) A survey of GP experience with the work of the National Cancer Control Programme and their views in relation to service priorities, National Cancer Control Programme.
- Pudrovskaya, T. (2010) Cancer and mastery: Do age and cohort matter? *Social Science & Medicine*. Vol. 71: 1285-1291. Elsevier.
- Punch, K. (2006a) "Chapter 6 – Writing the Proposal" from Punch, Keith, *Developing effective research proposals* pp. 59-74, London: Sage
- Punch, K. (2006b) *Developing effective research proposals: 'A General Framework for Developing Proposals'* (Chapter 5) London: Sage
- Ruddy, K.J., Risendal, B.C., Garber, J.E. and Partridge. A.H (2016) Cancer survivorship care: An opportunity to revisit cancer genetics. *Journal of Clinical Oncology*, 34(6), 539-541. <https://doi.org/10.1200/JCO.2015.63.5375>