SOMEONE WHO UNDERSTANDS

A QUALITATIVE STUDY EXPLORING CANCER PATIENTS' EXPERIENCES OF PSYCHOTHERAPY IN CANCER CARE

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TABLE OF CONTENTS

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I dedicate this study to my mother, whose love and wisdom remains with me. Thank you.

DECLARATION

I would like to declare that all the information in this doctoral thesis is either my own original work or has been gathered from accepted sources and referenced accordingly.

Signed: **Date: 18th January 2019**

ABSTRACT

Emotional distress is now recognised as the sixth vital sign of cancer and as such is not unexpected at any stage along the disease trajectory. It has gradually become an aspect of the disease that is recognised, monitored, documented, and promptly treated in many healthcare systems worldwide. Psycho-oncology is the specialist field concerned with the emotional distress of cancer. It focuses on understanding and treating the psychological impact of the disease and providing effective psycho-social care to all those affected by it, including patients, their family and friends and indeed clinicians working in oncology. Psycho-oncology is fast becoming an integral part of cancer care as an active and valuable area of research and practice, thus providing more knowledge and support within this specific healthcare field.

This study explored cancer patients' experience of their psycho-oncological care via the qualitative methodology, Interpretative Phenomenological Analysis (IPA). Exploring what psycho-oncology means to them and how it has impacted the cancer coping process, the study aims to further inform and develop research and practice in this specialist field. Much of the research thus far (both quantitative and qualitative) has investigated outcome measures and/or benefits of psychotherapeutic interventions used in cancer care. Studies have tended to be randomised controlled trials adhering to strict parameters of practice, including specific settings, models of therapy and number of therapy sessions. In order to gain a more subjective and ecologically valid understanding of this phenomenon, in-depth interviews were conducted with six cancer patients who have accessed and availed of psycho-oncology via different pathways within a real-life setting (the Republic of Ireland).

Using IPA's analytic techniques, three master themes emerged from the data – Cancer Patient Needs; The Power of Talking and The Therapeutic Relationship (with each theme containing three corresponding sub-themes) - all of which capture the essence of this experience. Results of the data imply that therapist values, flexibility of care and relational processes are deemed most meaningful and of benefit to cancer patients. Someone who has a professional and personal understanding and experience of cancer and disease processes in addition to embodying humanistic core values emerged as key factors in affecting therapeutic experience and outcome. Implications for such findings suggest that training and practice for psychotherapists working in cancer care need to emphasise a “being with” rather than a “doing do” style of therapy, capacity to discuss existential concerns and have a strong knowledge and experience of cancer.

“*The heart has its reason which reason knows nothing of*”
- Blaise Pascal, Pensées

REFLEXIVE STATEMENT

Cancer is everywhere, it touches most of us either directly or indirectly. A family member, a close friend, a work colleague - safe to say, that it is a disease that moves amongst us all. Its occurrence can be unpredictable, aggressive, indiscriminate and often fatal. It poses life changing questions, can cause havoc to daily life and brings us face to face with our mortality. Born and raised in Ireland, I am the youngest child of two parents who have had cancer. It has been a strong and influential presence in my life for over twenty years. My father, who resembles the bionic man, was first diagnosed with lung cancer over twenty years ago and has survived it three times (lung, bowel and neck). Witness to this, I know treatment can work and the disease can be curable. My mother, who died four years ago after living with it for over three years, taught me that even with the most positive of attitudes and with the greatest of human spirits, treatment does not always work, and death can ensue. This experience was life changing for me and has been the catalyst to pursue this area of research and practice as part of my doctoral training in Counselling Psychology (CoP).

In the midst of surgeries, treatments, remission, survivorship, palliative and hospice care, certain profound changes occur within one’s life. It became increasingly evident to me that cancer is a disease of the body and the mind, a physical disease that often burdens the patient and their loved ones with a strong emotional affect. I was studying psychology at the time of my mother’s cancer diagnosis and during her treatment and so, I was becoming ever more aware and attentive to psycho-social processes in human life and particularly in healthcare. Quality of life and individual needs become paramount. I learned what matters most is understanding and caring for those needs as patients transition from one stage of the cancer trajectory to another. As I experienced cancer and cancer care via my mother, I often noticed the impact of medical staff who were gifted with a wonderful ‘bed-side’ manner, always seeming to ease the pain of receiving bad news and/or undergoing harsh cancer treatments. These experiences, steeped in humanity, were immensely powerful and often softened the suffering that can pervade life. As a disease that can be physically and emotionally challenging, I often wondered about the presence of a psychologist as part of cancer care. I had yet to encounter one within the oncology team. Does this role exist and if so, who, where, what and how? These were questions that lingered in the back of my mind as my mother’s health deteriorated and after she had died. As I emerged from my own grief and loss, and was pursuing my own personal and professional path, I learned the answers to those questions and discovered the specialist field of psycho-oncology. Unknown to be before, my curiosity and passion for this specialism was awakened and to this day has remained so.

Since I embarked on the doctorate in CoP, I have pursued my curiosity and passion in cancer care via both research and practice. I have spent a year of my clinical training in a psycho-oncology setting, working therapeutically with cancer patients and their families. I was immediately struck by the unique nature of psychotherapy in this specific context. The process was particularly challenging, at times overwhelming, but always, deeply rewarding. Navigating through it led me to explore, with curiosity, many facets of the therapeutic experience, including strengths and limitations of chosen models of therapy and my capacity or lack thereof to practice pluralistically and with flexibility. I have seen profound change in individuals as they live with the disease - physical, psychological, spiritual, emotional, relational change – all affecting and linking to who they are, what they need and how this is expressed. A lot of what I experienced was echoed in literature with much contributing to a deeper understanding of a very complex disease. However, nothing quite replaces lived experience to gain a profound understanding of life events, processes and transitions. My personal and professional experience of being with people who have died from, live with and survived cancer, as well as my own reading of literature in this area, has further stimulated me to explore this area in more depth. My interest in gaining insight into cancer patients’ experience of psychotherapy in cancer care is to understand what the subjective experience of it really entails.

I am aware that from my indirect experience of living with the disease, I hold the belief that psycho-oncology should be an integral part of cancer care, providing a whole person approach to care that addresses all aspects of the disease. Integrating psychological therapy into mainstream healthcare and adopting a more holistic approach can improve patient care, meet individual needs and furthermore reduce the stigma associated with psychological problems that still seems to exist today. Viewing the body as a whole, I believe a disease such as cancer can affect all of a person and therefore the provision of professional care for all aspects of the illness should be fully integrated into healthcare. This is my stance as an individual and as a Trainee Counselling Psychologist (TCP). My professional and personal stance will potentially affect the following research study via my own conscious and unconscious processes. It is crucial that I remain acutely aware of these by maintaining a strong level of reflexivity throughout and expressing this at various junctures of the study. In recognition of this, my research is first and foremost an opportunity to give voice to those who can provide rich and detailed information on their experience of psycho-oncology and thus generate new and valuable knowledge to further inform and develop practice in this ever-expanding specialist field.

CHAPTER 1: INTRODUCTION

"The doctor said that the physical pain must be dreadful which was true. But more dreadful than the physical pain was the suffering in spirit, his greatest agony"

- Leo Tolstoy, The Death of Ivan Ilyich

1.1 Overview of Research Topic

The above quote from Tolstoy's 1886 classic short story 'The Death of Ivan Ilyich' depicts his protagonist's suffering as his health deteriorates and he gradually approaches death. Tolstoy sensitively captures the psychological distress that ensues in times of great suffering and a man's need for compassion and empathy to acknowledge, understand and ease such distress. In 2018, modern medicine can prevent, treat and cure a myriad of diseases with the average human lifespan now reaching circa 80 years, double that of Tolstoy's time. Our life expectancy has evidently increased over time, with advances in medical research and practice being a key reason for this. Diseases like tuberculosis (TB), previously incurable and fatal, are now more easily treated and therefore no longer represent a death sentence. However, cancer remains to this day a highly complex, unpredictable and often fatal disease. While extraordinary medical advances have been made to prolong and indeed save the lives of people diagnosed with cancer, it remains a leading cause of death worldwide (Torre et al., 2015). Hence, it continues to be a global concern and a meaningful confrontation with mortality (Brennan & Moynihan, 2004).

Cancer tends to cause more psychological distress than other comparatively dangerous diseases. This distress is now officially recognised as the "sixth vital sign" after body temperature, blood pressure, pulse, breathing rate and pain (Bultz & Carlson, 2006). The National Comprehensive Cancer Network (NCCN) in conjunction with the American Cancer Society (ACS) have implemented measures "to ensure that no patient with distress goes unrecognised and untreated. Therefore, the first principle is that distress, like pain, should be recognised, monitored, documented, and promptly treated at all stages" (NCCN, 2007b, p. MIS-3). Leading international healthcare systems now emphasise and stipulate a whole person approach to cancer care, thereby attending to the physical and psycho-social needs of patients. With this movement towards holism, psycho-oncology or psycho-social oncology as it is often referred, has firmly established itself as a specialist field of research and practice in cancer care. It focuses on understanding and treating the psychological impact of the disease and to provide expert psycho-social care to all those affected by it, including patients, their family and friends and indeed clinicians working in oncology.

It seems the emotional distress associated with life-threatening illnesses, like cancer, is an aspect of the human condition that transcends time. Tolstoy captures a man's emotional response to illness and death which seems to echo much of what we still feel today. Arguably, this is the reason why the Russian author's timeless theme remains so poignant. However, times have changed since the 19th century. Today, the recognition and treatment of distress in cancer indicates a significant change in perspective towards human suffering. This recent shift in perspective has borne witness to the field of psycho-oncology, which is gradually becoming an integral part of cancer care. This doctoral thesis aims to contribute to the field of psycho-oncology and indeed all related fields via a unique exploration into cancer patients' experiences of psycho-oncological care. Prior to presenting the crux of the research itself, it is essential to provide the key stepping stones that formed the basis of pursuing this study. These will be presented in chapter two. A more detailed structure of the thesis follows herewith.

1.2 Structure of Thesis

After a brief introduction, the following chapters of this thesis will explore more deeply the chosen topic of research, cancer patients' subjective experiences of their cancer psychological care in a real-life setting, namely the Republic of Ireland. Before conducting the actual research itself, it is necessary to understand how I ended up funnelling down from my own personal experience and curiosity in the field to pursuing the aforementioned topic. Certain cancer related terms will be used frequently throughout the thesis and therefore a preliminary understanding of them is necessary. Therefore, I will present a brief background of cancer, of psycho-oncology and the position of Counselling Psychology in cancer care. Chapter Two will then present a cohesive literature review on the psychological impact of cancer and common psychotherapeutic interventions practiced in this domain. As my research study is conducted in the Republic of Ireland (RoI), I will also provide an overview of psycho-oncology in this setting. This should illustrate a clear foundation upon which the rationale of this doctoral research study is formed and thus presented. The thesis will then discuss in detail the chosen methodology and research procedure of the study, before finally presenting the analysis and discussion of the data results. As an integral component of the chosen methodology (interpretative phenomenological analysis) and indeed Counselling Psychology, a reflexive component exists throughout the entire thesis. This reflexivity appears explicitly at three junctures – at the beginning via my opening reflexive statement, at the end of Chapter Three via reflexivity, and Chapter Five via reflexive conclusion. This is to maintain researcher transparency and congruence, thus ensuring validity and rigour throughout this exploratory process.

1.3 Cancer

Cancer is a disease that has existed for centuries, with its first recorded case dating back to Ancient Egypt in 3000BC (Sudhakar, 2009). However, it wasn't until 400BC that the disease became known as cancer, a term devised by the Greek physician, Hippocrates, who called it *karkinos*, meaning crab, due to the shape of the tumours Hippocrates saw at that time (Sudhakar, 2009). Cancer and its treatments have gone through many changes and developments throughout the years with extraordinary advances made to further understand and treat the disease. Despite this, it is still one of the leading causes of death worldwide (Torre et al., 2015).

Physiologically, cancer is a genetic disease, caused by changes to genes either inherited from parents or by damages from environmental factors during one's lifetime such as excessive sun exposure, smoking, viral and bacterial infections ("Cancer", 2018). Cancer refers to a collection of related diseases which are all caused by the abnormal growth of cells in the body. In normal cell growth, the body regenerates itself in an orderly way with old or damaged cells dying away and new cells replacing them. However, with cancer, this orderly system breaks down ("What is Cancer?", 2017). The old or damaged cells fail to die away and new cells form without being needed. This uncontrollable cell division then forms malfunctional growths called tumours which can continue to spread (metastasise) via the blood and lymphatic system and invade surrounding and distant tissues and organs in the body ("What is Cancer?", 2017). Tumours can be malignant or benign. Cancerous tumours are malignant which means they spread, are dangerous and life-threatening. Benign tumours do not spread, rarely grow back after being removed and are not life-threatening unless located in the brain ("Cancer", 2018). People often refer to cancer as primary or secondary cancer. Primary cancer is when the malignant tumour has not yet spread and is therefore contained in its original or primary site. If the original or primary malignant cancer is sited in the breast and has spread to the lungs, this is termed metastatic breast cancer or secondary cancer (“What is Cancer?”, 2019). Metastatic cancer is less easily curable but with current treatments, can be cured and/or managed for years. This is one of the main reasons why cancer has become more prevalent. More people now live with the disease, often referred to by clinicians as a long-term or chronic illness in much of the developed world where up to date treatments are more readily available (Brennan & Moynihan, 2004).

Cancer is often referred to in stages ranging from Stage 1 to 4 with the seriousness of the disease graduating upwards. Stage 1 cancer means that the cancerous tumour is usually small and contained in the primary organ, while stage 4 means the cancer has spread to other organs, otherwise known as secondary or metastatic cancer and therefore is less easily treated (“What is Cancer”, 2017). The cancer trajectory is often divided into several stages – initial diagnosis, treatment, remission, palliative, survivorship and end of life. Most terms are self-explanatory apart from perhaps remission and palliative stage. Remission is further broken down into two stages – partial and complete remission (“About Cancer”, 2018). Partial remission refers to a time when patients can take a break from treatment due to a positive response to it and a reduction in the cancerous tumour(s) as indicated via scans/tests. Partial remission is based on the condition that the cancerous tumour remains stable and does not start to grow again. Complete remission refers to no signs of cancer in the body post treatment. In the event the patient remains in complete remission for five years, they transition into survivorship (“About Cancer”, 2018). However, there is no guarantee that cancer will never recur with the fear of recurrence being a common cause of distress in both the remission and survivorship stages (Muzzin, Anderson, Figueredo, & Gudelis, 1994). Palliative stage cancer is incurable, but can be successfully managed. Palliative care is concerned with managing the symptoms and side effects of cancer and its treatment, thereby minimising pain, improving quality of life and providing support for patients living with the disease (“Cancer”, 2018). Cancer patients can be in palliative care for years before transitioning to end of life or hospice care. This all depends on the nature of the cancer, its response to palliative treatment and subsequent decisions taken by the patient and healthcare team.

There have been an estimated 18 million newly diagnosed cancer cases worldwide in 2018 (Bray et al., 2018). Due to our increased lifespan, 47% (almost one in two people) of the population are likely to receive a cancer diagnosis during their lifetime (Ahmad, Ormiston-Smith, & Sasieni, 2015). Affecting us all either directly or indirectly, it continues to be an increasing global burden and therefore treatment and prevention of cancer is considered a priority in public health now and going forward (Fitzmaurice et al., 2015). Lifestyle changes, advanced early detection and treatments have reduced the mortality rate of cancer significantly over the last twenty years with many people avoiding it, surviving it and/or living with it for several years. Although preventative measures are in place, lung and breast cancers are the most common types and account for 12.3% of the total number of new cases (Bray et al., 2018). Lung cancer has the highest mortality rate and is found to be the most emotionally distressing (Zabora, BrintzenhofeScoc, Curbow, Hooker & Painadosi, 2001).

A time when we rely on health care professionals to diagnose, treat, manage and cure the disease and all its symptoms, each oncology healthcare professional, with their own specialism, is guided by their medical expertise to focus on treating specific aspects of the disease. Common physical cancer treatments include surgery, chemotherapy, radiation therapy, immunotherapy, stem cell transplants and hormone therapy (“About Cancer”, 2018). Cancer treatments can cause short and long-term side-effects (for example hair loss and mastectomy respectively) which can often feel worse than the disease itself and can have adverse bio-psycho-social effects on patients. Recognition of the emotional impact of cancer in addition to a global movement towards “cancer care for the whole patient” (Bultz et al., 2015) has seen the emergence and gradual growth of the sub-specialist field, psycho-oncology.

1.4 Psycho-oncology

Psycho-oncology is concerned with the psychological impact of cancer and the provision of appropriate care to adequately attend to this aspect of the disease. It is also concerned with the social, behavioural and psychological factors that influence cancer risk, treatment and survival (Breitbart & Alici, 2009). Psycho-oncology is a dynamic and valued area of research and practice in many healthcare systems and is fast becoming an integral part of cancer care worldwide (Bultz, 2016). Pioneered in the 1970s by American psychiatrist, Dr Jimmie Holland, psycho-oncology is a sub-speciality of psychiatry, psychology and psychosomatic medicine (Holland & Weiss, 2010). A multi-disciplinary field, it includes clinical, counselling and health psychologists, psychiatrists, oncology nurses, social workers, psychotherapists and pastoral care workers (Breitbart & Alici, 2009). Over the last four decades, it has firmly established itself as a specialism within cancer care and has generated its own professional journals, conferences and societies. Since its emergence, much light has been shed on the psychological impact of cancer and appropriate psycho-social interventions to help cope with the disease and its aftermath. Prevention of cancer, via behavioural and lifestyle changes, is also a key area of focus in the field (Breitbart & Alici, 2009). Psycho-oncology continues to contribute significantly to cancer research and practice, much of which will be demonstrated in more detail in Chapter Two. Firstly however, it is important to know its history and development over time.

Prior to the 1970s, the physical cure and treatment of cancer was the sole focus of medical research and practice with its psychological impact largely being ignored (Holland & Weiss, 2010). Cancer hospitals were historically built away from urban centres, viewing the disease as contagious, isolating patients and therefore stigmatising the disease. Clinicians preferred not to disclose a cancer diagnosis to patients, believing that such disclosure would negatively affect their ability to cope and retain a sense of hope. Such stigma and avoidance prevented psycho-social aspects of cancer to be openly studied, let alone recognised and/or cared for in healthcare settings (Holland & Weiss, 2010). However, in the USA during the mid '70s, perspectives within the field started to shift. Patients were informed of their diagnosis and more open and honest communication between doctor and patient started to occur. This change enabled patients to make more informed and collaborative decisions about their treatment plan (Novack et al., 1979). It also created an environment whereby the emotional impact of the disease could be more openly observed, acknowledged and hence studied. With the first national research conference in psycho-oncology occurring in 1975, it was deemed a pivotal moment in its history and thereafter began to establish itself as the specialist field devoted to cancer related psycho-social care (Holland & Weiss, 2015).

Psycho-oncology has contributed significantly to cancer care over the last four decades much of which came into meaningful effect in the last twenty years. In 1997, the National Comprehensive Cancer Network (NCCN) published the first clinical practice guidelines (Grassi & Watson, 2012), stipulating the provision of psychological therapies to play an integral role in cancer care. Following psycho-oncology related research findings, the Institute of Medicine (IOM) published a report in 2002 titled "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs". This aimed to apply research to practice and hence improve and provide quality holistic healthcare to cancer patients. This change in emphasis has seen psycho-oncology become an increasingly valued and recommended part of cancer care worldwide (WHO, 2002). The growing awareness and acceptance of cancer as a disease of the body and mind has contributed to national healthcare systems adhering to and adopting best practice guidelines. The governing bodies in the UK (NICE), USA (NCCN), Australia (NCCI) and Canada (CAPO) have all recognised and implemented measures to address the psychological impact of cancer with many other countries following suit. It is the role of psycho-oncology to adhere to these measures, provide professional support and care for this aspect of the disease and in collaboration with multidisciplinary teams provide quality whole person care.

Dr. Jimmie Holland died in 2017 after dedicating much of her life to cancer care. In an interview she conducted not long before her death, she emphasised the need to advocate for psycho-oncology as an integral role in cancer care, one that needs to gain more international recognition, especially in less developed countries where it rarely exists. She also advocated it as a meaningful, rewarding and exciting field to be involved in.

1.5 Counselling Psychology and Psycho-Oncology

Specialties in professional psychology, of which there are many, are defined by their parameters of practice. These include theoretical orientations, populations they work with, issues addressed, contexts and settings (Rodolfa et al., 2005). Such parameters of practice are also designed towards the specific fields that each specialism ends up working in. Counselling (originating from a vocational base) and clinical (originating from a medical base) psychologists share much in common and often perform similar work in professional settings (Orlans & Van Scoyoc, 2009) such as psycho-oncology. Differences between the two professions tend to be nuanced and are often based on philosophical underpinnings and emphases in training. Psycho-oncology is a sub-specialism of Clinical, Counselling and Health Psychology. In other words, psycho-oncology is an area of clinical health psychology that any of these three professional schools of psychology are qualified to work in. When considering the position of Counselling Psychology (CoP) in psycho-oncology, the congruence and compatibility that exists between these two specialist fields is evident. Both share similar values and parameters of practice.

Counselling Psychology is rooted in a humanistic and phenomenological philosophical ethos (Strawbridge & Woolfe, 2015). Like psycho-oncology, it has a holistic approach to care, emphasising personal strengths and resilience to help cope with inevitable suffering across the lifespan such as a cancer diagnosis. Its focus is on wellbeing in the here and now, taking into consideration a person's subjective experience within a specific context. CoP can veer away from diagnostic criteria or psychopathology as derived from the medical model and often holds the perspective that the potential to face psychological difficulties across the lifespan is a normal part of the human condition (Orlans & Van Scoyoc, 2009). Both specialisms value pluralism and subjectivity, with a range of psychotherapeutic modalities deemed appropriate to meet individual needs. Other commonalities include valuing positive relationships, (including the Therapeutic Relationship), as key mediums for change, inclusion of difference and diversity, integration of research and practice, social justice and advocacy (Nicholas, 2013).

As a Trainee Counselling Psychologist (TCP) who embarked on a research topic relating to cancer care, it appears CoP shares similar values and parameters of practice as those embedded in psycho-oncology, thus highlighting the congruence that evidently exists between both specialist fields. Such congruence helps to promote psycho-oncology as a meaningful, viable and rewarding specialism for counselling psychologists to pursue on training and post qualification. This goodness of fit between the two specialisms provides an opportune time for counselling psychologists to be more actively involved in psycho-oncology, play a dynamic role in what is gradually becoming an integral part of cancer care worldwide and pursue a career in an area of global concern.

"We are not ourselves when nature, being oppressed, commands the mind to suffer with the body"

\- William Shakespeare, King Lear

CHAPTER 2: LITERATURE REVIEW

2.1 Overview

Since the psychological impact of cancer began to be openly studied back in the 1970s, much knowledge and understanding of this aspect of the disease has been generated (Holland, 2003). The knowledge that currently exists stretches far wider than the following literature review could possibly contain. However, this review aims to illustrate the key areas pertaining to the specific topic under exploration. These include **psychological distress in cancer, psychotherapy in cancer care and a brief look at this domain in the Republic of Ireland** which together, hope to provide relevant context to formulate the rationale for pursuing this doctoral research study. As this research is an exploration into cancer patients' experiences of their individual psycho-oncology (psychotherapy in cancer), it is crucial to understand the psychological distress associated with the disease. This distress is the main reason why those affected by the disease need support and why psycho-oncology is becoming ever more embedded in cancer care.

2.2 Psychological Distress in Cancer

Cancer tends to cause more distress than other comparatively dangerous diseases, thereby adding a considerable psychological aspect to the disease, now known as the Sixth Vital Sign (Bultz & Carlson, 2006). Psychological difficulties experienced in medical illnesses such as cancer were stigmatised due to the entrenched stigma associated with mental health (Holland, 2003). The more accessible term "*distress*" was eventually used in the context of cancer to help make the psychological impact of the disease more easily understood and accepted by the lay person (Carlson, Waller & Mitchell, 2012). There has been a significant shift in the recent past to recognise and discuss the emotional distress as a normal response to cancer and not unexpected at any stage along the disease trajectory.

From Jimmie Holland’s (2003) extensive experience of working in the field of psycho-oncology, she found that at some point along the cancer journey, patients are faced with one or more of the “5Ds” - dependence, disfigurement, disability, disruption and death – with the most common symptoms of distress being pain, anxiety, depression, delirium and fatigue. The distress is of a social, spiritual and psychological (cognitive, behavioural and emotional) nature and can cause difficulties in coping effectively with the disease (NCCN, 2009). It impacts Quality of Life (QoL), adherence to treatment and survivorship, with *depressed* patients less likely to attend hospital appointments, seek and/or comply with oncology treatments, thus causing more complex issues further down the disease path (Goodwin, Zhang & Ostir, 2004).

Approximately one third of cancer patients suffer from clinical levels of psychological distress (Zabora et al., 2001). Zabora’s seminal study (1997) of a large sample (n = 4496) found the overall prevalence score to be 35.1% with clear variations due to the type of cancer, its prognosis and psycho-social factors. Lung cancer and its associated distress was highest at 43.4% with gynaecological cancer having a distress prevalence of 29.6% and other malignancies such as prostate (30.5%), breast (32.8%) and pancreatic (36.6%) falling in between. While distress associated with cancer can profoundly impact QoL and aspects of psychological behaviour, every experience is subjective and unique to the individual. The distress is multi-faceted and can present itself to varying degrees and at various points along the disease trajectory due to the illness itself, treatment and/or personal circumstances. It can affect daily functioning, view of self, adherence to treatment, relationships (including patient-doctor relationship) and physical and psychological wellbeing (Bor, Erikson & Stapelkamp, 2010).

2.2.1 Distress in Different Cancers

For each cancer patient, different symptoms occur and can vary with each cancer type. Factors contributing towards the heightened levels of distress among lung cancer patients include poor prognosis, high mortality rate, difficulty in managing physical symptoms (dyspnea, fatigue and pain) (Henoch, Bergman, Gustafsson, Gaston-Johansson, & Danielson, 2008) and associated stigma (Gonzalez & Jacobsen, 2012). Fatigue (55%) and pain (61%) have been reported as the most common problems amongst breast cancer patients with a sense of guilt and frustration associated with being unable to participate in day to day activities and fulfilling personal and professional roles in life (Mosher et al., 2013). In this same study, women suffering metastatic breast cancer described initial diagnosis as a time of shock and isolation with one female patient expressing her distress as “I have never gained back the feeling of utter laugh out loud happiness and freedom I once enjoyed”. Other findings have reported the change in body image, “as much as they rebuilt me, I look in the mirror and it’s absolutely awful”, returning to work and re-integrating back into ‘normal’ life as all contributing towards feeling psychologically vulnerable and distressed (McGarry, Ward, Garrod & Marsden, 2013). In those diagnosed with pancreatic cancer, research on this population has shown that they experience clinical levels of anxiety and/or depression at some stage along the cancer trajectory with males suffering significantly higher levels of depression than females (Clark, 2001). Research conducted on prostate cancer patients found that information and age were contributing factors to the levels of distress associated with diagnosis and treatment. The combination of younger age and loss of function post treatment are two factors that put younger men at higher levels of distress (Badger et al., 2013). For older cancer patients, issues such as patients' knowledge and beliefs about cancer, cognitive decline and sensory impairments all contribute to varying levels of distress for the patient, their family and the medical staff (Van Weert, Bolle, Van Dulmen & Jansen, 2013).

2.2.2 Distress at Different Stages

Initial diagnosis and palliative care are considered the most distressing stages whereby individuals are confronted in an intense and very meaningful sense with their mortality (Gao, Bennett, Stark, Murray & Higginson, 2010). Oncologists report an everyday question asked during consultations is "how long do I have to live?" with patients being fearful and uncertain of the road ahead (Saraiya, Beren-Bodnar, Leventhal & Leventhal, 2008). From initial diagnosis, a relationship with cancer starts and life can fundamentally change for patients, their family and friends. Following a cancer diagnosis, patients are often unable to adopt the roles that they derive their self-worth from which can cause a loss of confidence and ability to resume "life as normal", a common effect of the illness and treatment (Brennan, 2004). As patients undergo treatment, they can often feel at the mercy of those in authority. This loss of personal control can exacerbate distress, thereby causing patients to feel helpless and hopeless (Greer & Moorey, 1997). In most physical health conditions, treatment often makes the patient feel better and improves their health and wellbeing. However, cancer proves different. Treatments can often make patients feel worse with permanent (mastectomy) and temporary (nausea), visible (hair loss) and invisible (infertility) side-effects understandably causing significant levels of distress for patients. The differences in cancer diagnoses, prognoses, treatments and treatment side-effects demonstrate the complexity of the disease and how it manifests in a myriad of different ways. This variance and complexity gives rise to a constellation of both cancerous diseases and treatments, all of which contribute to its unpredictability and distressing experience.

The period following treatment when patients are no longer attending frequent hospital appointments and what the oncology team refer to as "remission" can be a lonely and frightening time (Brennan, 2004). Patients can feel physically and emotionally vulnerable, with stresses and uncertainties often proving overwhelming for the patient and family (Rolland, J. 2005). In remission and survivorship, a fear of recurrence is a common cause of distress. Patients' often expect to feel relief that treatment has ended and hopeful for the future, but in reality, they contend with adjusting to life and fear a cancer recurrence (Harvey, 2009). Psycho-social needs often go unattended due to internal and external expectations to feel relief and hope during this time. Such expectations can manifest in a loss of social support when in fact it is still very much required (Stanton et al. 2005; Wenzel et al., 2002). Ending cancer treatment is often likened to being on a rollercoaster, "strapped in and sent off into the terror, knowing that there is nothing you can do about it until you emerge, wobbly and battered at the other end" (Harvey, 2009). Patients need time for their body and mind to adjust to being on firm ground again. According to Harvey (2009), there are three stages of recovery – recuperation, growing strong and rehabilitation - which take time but are part of a gradual healing process to regain trust and confidence in both body and mind. Patients can struggle with fatigue and distress, thus needing time for their body and mind to adjust to being on firm ground again and resume life after a difficult transition.

2.2.3 Other Contributory Factors

Other challenging issues include accessing services easily, concerns about how loved ones are coping, financial issues related to being out of work, coping with side effects such as hair loss, pain, fatigue and a profound sense of vulnerability, experiencing tears at random moments in time (Knott, Turnbull, Olver & Winefield, 2012). Many of these psychological issues have been identified through research into the unmet needs of cancer patients. These unmet needs seem to be most prevalent during treatment. However, patients were more likely to report such unmet needs only after treatment was completed (Harrison, Young, Price, Butow & Solomon, 2009). One patient attending a London NHS hospital expressed her need for psychological support. She was only offered it once but declined it at the time. She felt that she would have availed of the support if it was offered again, but she was too self-conscious to request it initially (McGarry et al., 2013). Examples like this suggest that individuals are reluctant to ask for support even when they know or suspect they need it. The perception of successfully fighting the disease with a positive attitude can hide underlying distress and demonstrate the stigma that still exists in accessing psychological services. Such findings highlight the distance still to go in normalising psychological distress in cancer and for patients and healthcare professionals to communication more openly about a difficult yet normal response to the disease.

Clinician communication style is found to be an important factor in how patients respond to their cancer diagnosis with guidelines and recommendations now available to clinicians on how best to deliver difficult news relating to diagnosis, treatment plan and prognosis. Findings suggest a direct correlation between increased communication between clinician and patient and a reduction in patient distress (Nelson et al., 2011). However, in more recent findings, it emerged only one third of cancer patients discuss the emotional impact of cancer with their healthcare professional (Bonito, Horowitz, McCorkel & Chagpar, 2013). This appears to reinforce Madden’s study which found that there still tends to be a focus on the physical aspects of the disease and the psychological aspects can still be largely ignored (Madden, 2006). In one study, medical staff expressed the tendency of psychological support to be forgotten in the midst of a busy hospital environment where the physical cure is dominant and patients can be treated as a “set of symptoms” (Towers & Diffley, 2011). To counteract this problem and with a movement towards caring for the whole person, measuring devices have been implemented across national healthcare systems to screen for distress in cancer. This creates a more standardised framework to recognise distress, normalise it and if/when required attend to it.

2.3 Screening for Distress in Cancer

A variety of instruments are used to measure patients' psychological distress as they journey through the cancer trajectory. Some of the most popular include, the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Smith, 1983), the Beck Depression Inventory (BDI) (Beck, Steer & Brown, 1996), the European Organisation for Research and Treatment of Cancer, Quality of Life Questionnaire (EORTC) (QLQ-C30, The European Group, 1990), and the Distress Thermometer (DT) and Problem Checklist (PL) (Roth et al., 1998). Some of these measures are used together to capture as much information as possible relating to the patients' psychological welfare. However, all instruments are criticised for not being sufficiently capacious with the result that a patient's life circumstances and needs are not being adequately identified. In order to address this limitation, the DT and PL was created, implemented and is now the most commonly used screening device to assess and monitor distress amongst those suffering from cancer and availing of oncology care services. The DT and PL were designed and implemented by the National Comprehensive Cancer Network (NCCN) in conjunction with the American Cancer Society (ACS) to monitor distress among cancer patients, offer and provide intervention when necessary, thus improving patient care.

The DT is a self-rating scale measuring distress levels from 0 – 10 with 0 being no distress and 10 being severe distress. Generally, a score > 4 requires referral onto psycho-oncology services whereby further assessment is conducted and suitable interventions are pursued. Alongside the DT, is the PL which includes 35 problems of which patients answer yes/no. Problems relate to physical, emotional, spiritual, familial and practical factors which may contribute to an individual’s self-reported distress. The DT and PL is an efficient questionnaire that can be filled out in the hospital waiting room, can be posted out or sent home for patients to complete and bring back in at their next appointment. It is a screening device that enables healthcare professionals to assess and monitor patients’ psychological welfare from diagnosis right through to end of treatment. It provides a platform for patients themselves to express issues relating to above named factors that they may be experiencing throughout the cancer trajectory, can share with oncology staff and avail of professional psychological support if/when required. For the NCCN, the main objective of the DT and PL is “to ensure that no patient with distress goes unrecognised and untreated. Therefore, the first principle is that distress, like pain, should be recognised, monitored, documented, and promptly treated at all stages” (NCCN, 2007b, p. MIS-3).

It is essential to be able to differentiate between those who are more susceptible to psycho-social difficulties and those who are experiencing normal reactive psychological distress which can occur in times of crisis. Studies that have investigated the prevalence of distress in cancer patients have all identified the contribution and importance of factors that can increase distress and therefore significantly affect capacity to effectively cope with the disease and quality of life. It has been found that as distress levels rise, quality of life can reduce, thus impacting patients’ response to treatment, ability to cope and adjust to changes that occur in daily life (Zabora et al., 2001). Studies tend to use similar self-rating measurement tools to capture levels of distress which can prove to be misleading. They are quick and efficient to fill out, but whether they sufficiently capture the nature of distress experienced by every individual remains questionable. However, identifying and being aware of contributory factors that can increase distress is essential to address those needs and provide psychological support to care for them.

2.4 Moving Towards "Caring for the Whole Patient" in Cancer Care

The publication in 2002 of "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs" by the Institute of Medicine (IOM) has emphasised the need to provide care for all aspects of cancer along the disease trajectory, including emotional distress. Ensuring effective care-based communication throughout the disease trajectory can help provide patients with the accessibility and availability of psychological support as part of their cancer care. It is widely accepted that good and effective communication is key to good cancer care (Epstein & Street, 2007). It is essential to provide effective communication skills that cater for the individual needs and deliver an effective and tailored approach to address such needs, thereby improving a whole person approach to cancer care (Badger et al., 2013). To adequately meet the psychological needs of cancer patients, it is essential to firstly have effective measures in place to screen for distress and then the available and accessible support structures in place to care for this distress. This increased awareness has stimulated positive change to occur. This includes the provision of psychological care to patients, results of which include the reduction of emotional distress, better management and adherence to adverse effects of treatments in addition to an increase in QoL (Jacobsen, Holland & Steensma, 2012). Psychotherapy in cancer is now commonly known as psycho-social oncology or psycho-oncology. A main aspect of this specialist care is individual psychotherapy. Much research has been conducted in this specific area which has informed practice and thus provided evidence to base recommended guidelines in this clinical context.

2.5 Psycho-oncology - Psychotherapy in Cancer Care

Many healthcare systems worldwide have developed and implemented psycho-oncology services to provide care for the distress in cancer and meet patient needs (Bultz & Carlson, 2006). A myriad of evidence based psychotherapeutic approaches are applied and deemed effective in cancer care. Psycho-oncologists come from a variety of different backgrounds and theoretical orientations including psychodynamic, humanistic, existential, second and third wave CBT (Cognitive Behavioural Therapy) all of which vary in theory and practice.

It is widely accepted within the field of psycho-oncology that supportive psychotherapy is the essential ingredient in all therapeutic interventions when working with cancer patients and their families. Supportive psychotherapy is highly skilled and emotionally challenging with a level of care and personal involvement that requires constant monitoring (Lederberg & Holland, 2011). The key parameters of practice that are necessary in effective supportive psychotherapy demonstrate an integration of several therapeutic models, drawing on different interventions that best meet the often-changing needs of the patient. These include:

- Capacity to discuss highly charged information which can arouse strong emotions
- Familiarity with cognitive and behavioural techniques to help with coping and problem solving
- Flexibility with location, timing and therapeutic approach to adapt to the often changing physical and emotional needs of the patient
- Therapist understanding and knowledge of the disease is required to provide adequate psychological support

- Capacity to draw on multiple therapeutic interventions including crisis intervention, systemic issues, and subjective and intersubjective dynamic processes to address the issues that emerge within the cancer world
- Ready to guide patient and family to available resources
- Ability to work within a multidisciplinary team and communicate with medical teams about relevant patient information in a compassionate manner and without breaking patient confidentiality
- Regular therapist self-care

Supportive psychotherapy has been difficult to formally study due to its flexible, integrative and rather elusive nature. When considering its aforementioned parameters of practice, it is evident that several theoretical approaches are included, thus emphasising the often challenging and complex nature of cancer and of psychotherapeutic practice in this context. Most of the existing research focuses on specific, time-limited and manualised models of therapy via Randomised Control Trials (RCTs) which adhere to strict guidelines and results of which can be quantitatively measured via pre and post therapy outcome measures (Lederberg & Holland, 2011). Qualitative research studies, of which there are few, have produced complimenting data on such studies, eliciting knowledge on aspects of therapy that cancer patients find most helpful. However, qualitative studies have also adhered to strict guidelines and parameters of practice which have included specific, time-limited and often manualised therapeutic models being explored. While such studies provide knowledge and inform practice, they lack insight into the real-life practice of psycho-oncology as outlined and recommended in supportive psychotherapy guidelines. Models of therapy such as existential and psychodynamic approaches prove more difficult to formally study. As such, they are less evidence-based and therefore tend not feature as prominently in the current medical model as the manualised therapies such as CBT (Cognitive Behavioural Therapy). They nonetheless provide sophisticated and highly appropriate therapeutic interventions in cancer and as such, are embedded as key ingredients in supportive psychotherapy's best practice guidelines. The practice of psychotherapy in cancer care is often more complex and nuanced than is presented in research studies, especially RCTs. So, while knowledge in the field has expanded exponentially over the years, there still exists gaps in research that require further exploration of psycho-therapeutic practice in cancer. A review of several current studies exploring psychotherapy in cancer follows.

CBT has shown to be an effective model of therapy in dealing with the psychological impact of cancer (Moorey, Greer & Greer, 2002). It is valued as a favourable, appropriate and effective therapeutic intervention for cancer patients within the current medical model and for right or for wrong is often advocated as *the* chosen model of therapy within many leading healthcare systems. The collaborative and directive nature of CBT frames the therapeutic experience as one that includes cognitive and behavioural change to occur both in-session and throughout the patient's week via homework tasks. In this way, the patient has formed a therapy blueprint to become their own therapist in maintaining change and overcoming potential future difficulties (Westbrook, Kennerley & Kirk, 2011). Compliance therefore is considered an essential ingredient in the successful outcome of CBT in treating psychological distress.

CBT can produce positive outcomes over a relatively brief timeframe by helping patients with problem solving skills and practical coping strategies in addition to modifying unhelpful thinking styles and behaviours. It has shown to significantly reduce anxiety and helplessness among cancer patients when compared with no treatment control group, thereby demonstrating its efficacy in this specific clinical context (Moorey et al., 2002). Adopting a fighting spirit and coping strategies that are associated with such have shown to reduce distress, improve quality of life (Classen, Koopman, Angell & Spiegel, 1996; Nordin & Gilmelius, 1998) and indeed support adherence to cancer treatments which can ultimately increase survivorship (Aapro & Cull, 1999). However, variables can affect the treatment outcome of CBT with some studies demonstrating its unsuitability to personal situations.

In a study that examined the predictive variables of treatment outcome in breast cancer patients availing of CBT (Hopko et al., 2015), it emerged that the therapeutic intervention was most successful with those who were married, had previously attended psychotherapy and were not actively engaged in cancer treatment. The latter variable (cancer treatment) appears to point towards the distress associated with the side effects of cancer treatment itself. Common physical side effects such as hair loss, fatigue, nausea, pain, decreased sexuality and psychological symptoms such as hopelessness, rumination, fear and worry can all contribute to problems engaging with psychotherapy, especially one such as CBT which requires in between session homework and arguably lacks flexibility. Those who had previous experience of psychotherapy expressed an increased openness and willingness to avail of the therapy, thus showing stronger commitment and motivation. Such a study echoes much of what has emerged before. So many variables play a role in the successful outcome of psychotherapy among cancer patients. In fact, it could be argued, based on the above study, those who are in most need of psychological support (unmarried, never having access to psychotherapy before and are actively engaged in cancer treatment) are those who are not receiving it.

With many cancer patients not responding to CBT, it is essential to offer other therapeutic models that meet the different and diverse needs of this clinical population. Research has found that for patients who are continuing to fight hard and yet the cancer continues to spread and their health gradually deteriorates, their sense of personal failure can be magnified (Sontag, 1978) thus potentially leading to strong feelings of guilt and shame (Taylor, 1983). With these psychological processes present, psychotherapeutic interventions in cancer have moved away from the idea that it can help improve survival (Walker, Heys & Eremin, 1999) towards the goal of managing treatment side-effects, reducing distress and improving quality of life (Hulbert-Williams, Storey & Wilson, 2015).

Unlike protocol lead CBT, third wave CBT models such as Acceptance and Commitment Therapy (ACT) and Mindfulness-Based Cognitive Therapy (MBCT) are considered appropriate and effective interventions for cancer patients. They do not rely on challenging cognitive distortions, but rather gently nudge patients towards curiously exploring their psychological experience (positive and negative) in an accepting and compassionate way, thereby reducing its behavioural impact (Hubert-Williams, et al., 2015). They acknowledge the normality and variance of psychological distress as part of cancer and emphasise self-regulation and acceptance of positive and negative experiences. Instead of focussing on cognitive change, third wave models support patients to face suffering in an accepting and compassionate way (Bishop et al., 2004). ACT focuses on causing a shift from “psychological rigidity” (avoidance) to “psychological flexibility” (acceptance) (Hayes et al., 2006) to enhance the capacity to accept and cope with the illness, live with uncertainty and improve quality of life (QoL) (Hulbert-Williams et al., 2015).

This shift from psychological rigidity to flexibility can often entail an experience of profound personal growth whereby individuals learn to accept all experiences (positive and negative), respond to them compassionately and choose directions in life based on personal values. One breast cancer patient expressed feeling more like her ‘old self’ and experiencing more life enjoyment after ACT (Karekle & Constantinou, 2010). Cancer patients availing of Mindfulness-Based Stress Reduction (MBSR) therapy recorded improved sleep, mood and quality of life, reduced fatigue and better psychological wellbeing (Smith, Richard, Hoffman & Pilkington, 2004; MacKenzie, Carlson & Speca, 2005; Ott, Norris & Bauer-Wu, 2006; Schroerers & Brandsma 2010). A meta-analysis of the impact of MSBR within this context indicated efficacy in improving psychological wellbeing among cancer patients, more so than the physical symptoms associated with the disease (Ledesma and Kumano, 2009).

Humanistic therapy or counselling, which unlike CBT, is non-directive and has been found to be beneficial to patients undergoing cancer treatment (Boulton et al., 2001). Benefits include helping them come to terms with and accept their situation, regain control of their lives and assist them with their thoughts and feelings during this challenging time. After regularly attending a humanistic counsellor, patients believed their emotional state was much stronger. In fact, 95% of patients indicated that they would continue with counselling if available (Boulton et al., 2001). While these findings illustrate a strong desire and need for psychological support among a certain sample population, the results of this study were based on those who responded to the feedback questionnaires (50% of sample population) and who regularly attended their counselling sessions. Some who were disappointed and frustrated with the humanistic approach expressed a need for more directive therapy. An increased focus on coping with the nature of the disease itself and adopting strategies to alleviate the distress associated with it were expressed. Important information elicited from such a study highlights that one specific therapeutic approach will not meet all cancer patient needs. Those frustrated and disappointed with the humanistic approach may have benefitted from a more directive therapy such as CBT. Such different needs mirror the wide ranging differences that are part of the cancer experience such as diagnosis, prognosis, stage along the disease trajectory and personal circumstances. Boulton's study (2001) veered away from the usual RCTs that are more commonly used in research to ascertain efficacy and effectiveness of therapeutic interventions in cancer. This study provided more detailed data on the benefits derived from a cancer counselling service and the aspect of therapy which the cancer patients valued. As part a larger study, the parameters remained tight. It was based on a set number of counselling sessions, all within a humanistic approach and feedback questionnaires were designed by the researchers (Boulton et al., 2001).

Another study looked at the importance of the provision of nurse-led cancer counselling services within oncology units. In one example highlighted by a nurse counsellor, a man who was struggling to come to terms with the disease and its terminal nature began to gain perspective and identify relationships in his life from which he could seek comfort and support. Counselling provided the space for him to reflect and share his fears and help him overcome anxieties that were directly associated with his cancer (Towers & Diffley, 2011). This highlights again the context specific nature of each patient, where they are along the cancer trajectory and how 'a one cap fits all' approach does not adequately meet the needs of all patients.

Around the same time as Boulton's study, MacCormack and colleagues (2001) conducted a qualitative study investigating the processes involved in two psychotherapeutic modalities, namely CBT and Relaxation Therapy. Motivated for similar reasons, this study wanted to transcend current knowledge and find out what aspects of the therapy were deemed most helpful to cancer patients. Again, being part of a larger study, its sample population included metastatic cancer patients, half of whom availed of CBT and half of Relaxation Therapy. Results found that there was no difference between outcome measures pertaining to the models of therapy with participants hardly making any reference to the therapeutic models. The most helpful aspects of therapy across both sample populations included being part of a positive relationship where they could share their thoughts and feelings with someone who “truly cared”.

A more recent qualitative study exploring primary cancer patients’ experiences of cancer psychological therapy via an NHS psycho-oncology service found similar value in forming a therapeutic relationship and being able to talk to someone who understood cancer. Other helpful processes included problem solving and CBT (Omylinska-Thurston, & Cooper, 2014). Therapy was delivered by a team of clinical and counselling qualified and trainee psychologists who provided a pluralistic approach to care thereby supporting previous studies claiming multiple therapeutic approaches are deemed effective in cancer care.

While both studies captured aspects of the participants’ experiences and in so doing provided rich and detailed knowledge on such, they were limited in their findings and therefore certain aspects of therapy remain unexplored. In MacCormack’s study, interviews were conducted via the telephone and therefore other important mediums of communication as evident in face to face may have been missed. In both studies, participants attended a set number of therapy sessions and again were receiving specific models of therapy and/or accessing cancer psychological therapy via the same service. Such strict guidelines limit the results within a narrow framework and therefore fail to capture a more real-life setting whereby patients experience the flexibility of care that is encouraged and deemed necessary in psycho-oncology.

Psychodynamic and existential therapy are more difficult to formerly study. Such theoretical orientations often require more long-term work and do not adhere to manualised treatments or strict guidelines which most RCTs require. Therefore, there exists a deficit of research on these models within the cancer context, a deficit which does not necessarily reflect the frequency and effectiveness of their practice. However, clinical practice guidelines have tended to move away from these less manualised models of therapy towards those which can be more easily monitored and measured via self-report assessment scales as discussed in the above studies (Anderson, DeRubeis & Berman, 2014).

Most of the studies exploring psychodynamic therapy in cancer have drawn on clinical case studies to more accurately capture the nature of therapeutic work conducted in this field. Such research lacks evidence-based knowledge from the patient perspective which is now considered an important method to measure therapeutic outcome and therefore carries significant weight to base best practice guidelines. In Straker's article, he describes how psychodynamic therapy formulates distress in cancer and the effective ways this therapeutic approach has helped patients cope more effectively with the cancer experience (Straker, 1997). His various clinical case examples demonstrate the unconscious processes that emerge for patients at various stages of the disease trajectory and how core conflicts and defences are presented in the present situation, in their past and in the transference. From a psycho-dynamic perspective, lifelong defences can often no longer be effective, underlying vulnerabilities are exposed, the integrity to the self is threatened and being mortal becomes very real in cancer (Straker, 1998). The experience can trigger unconscious fears of death and dying, abandonment, physical incapacity and dependency. Such unconscious fears can impact how an individual relates to the disease, treatments, caregivers and unfamiliar hospital settings.

Patients' unconscious meanings attributed to the entire cancer experience impacts the way they relate to the disease and can intensify levels of distress (Postone, 1998). The capacity to depend on others and seek comfort in social support is essential to cope in times of crisis. However, such capacity is often borne out of having a secure base (an emotionally responsive and available primary caregiver) in childhood, where trust in the external world is nurtured, and relational tendencies are formed (Bowlby, 2012). For example, unconscious emotions can be reactivated amongst survivors of childhood abuse as soon as they are exposed to new caregivers in the hospital setting, as often the perpetrators of childhood abuse are early caregivers (Yuppa & Meyer, 2017). This insight-oriented perspective provides a valid and sophisticated understanding of the patient-caregiver relationship, the patient's compliance or non-compliance to treatments and the use of defences to protect against internal psychic pain. Psycho-dynamic psychotherapy in cancer encourages a common-sense approach to defences in addition to a flexibility of care that may not be seen in other psychodynamic contexts. This is due to the changing and often unpredictable landscape of the disease and each patient's medical condition. According to Straker (1998), the main objective of this therapy in the context of cancer is to reduce the emotional symptoms of distress and nurture a positive transference which are exemplified in his clinical case studies.

From an existential perspective, psychic distress is an expression of internal pain, a sign that something is threatening our vital being (May, 2015). The existential psychotherapist, Irvin Yalom, uses the analogy of "staring at the sun" to capture the experience of being confronted with death. According to Yalom, it is an experience that we instinctively turn away from to protect us from the painful reality of our mortality. Cancer can represent an internal threat for patients, one that arises within their own being and thus patients are forced to engage with it, albeit they might deny. Deemed an existential crisis – cancer can be a time of danger and distress yet at the same time it can be a time of opportunity and personal growth (Yalom, 1980). Cancer confronts an individual with life's ultimate limitation, the state of being to non-being (May, 2015). It confronts an individual with the finality of what they have made of their life and what they are going to make of it now and going forward (Frankl, 2004). In Frankl's words, "everything can be taken from a man but one thing: the last of human freedoms – to choose one's attitude in any given set of circumstances, to choose one's own way" (Frankl, 2004). Such a profound encounter with oneself can present a profoundly distressing and at the same time life-changing transition. The distress in cancer can therefore manifest in being faced with the personal freedom and responsibility to make choices about our way of being in the world.

Like psycho-dynamic therapy, existential therapy tends to be presented from the therapist perspective via the illustration of clinical examples. However, a manualised and time limited meaning centred psychotherapy based on Frankl's existential theory was devised by Brietbart and colleagues and has been shown to be particularly helpful and effective for terminal cancer patients (Brietbart et al., 2010). Embracing the existential framework, it includes themes of personal legacy across the lifespan and having meaning and purpose in life even in the midst of human pain and suffering. Brietbart and colleagues (2010) focussed on spiritual wellbeing, meaning and purpose in life, quality of life and distress as the key factors to measure before and after the seven-session manualised therapy programme. Results showed that patients benefited considerably from this course of therapy with an increase in QoL and spiritual wellbeing. However, the distress, as measured via depression and anxiety measures remained the same, thereby indicating the prevalence and normality of such symptoms as part of the cancer experience. Due to its manualised intervention (seven sessions) it is well monitored, adheres to strict guidelines of practice and thus supports a pre and post therapy outcome measure as stipulated by a RCT. As such, it has been promoted as an effective and increasingly used therapeutic intervention to use in the oncology setting.

A rich tapestry of therapeutic approaches has been reviewed with efficacy and benefit derived from them all, thus indicating that no one model of therapy is deemed more superior than another. Both quantitative and qualitative research have elicited important and valuable information with the former producing objective outcome measures and the latter producing more subjective data, both of which inform further research and practice in psycho-oncology. Evidence based guidelines tend to be based on a set number of sessions of a specific model of therapy and the aspects of the specific model which are most effective and beneficial to cancer patients. However, the studies which adopt a qualitative approach suggest that positive therapeutic outcome or change is not necessarily related to the specific model of therapy but due to the relational dynamics, therapist values and the capacity to practice pluralistically. These latter mentioned insights are due to a platform for cancer patients to provide their own perspectives rather than outcome measures designed by the researchers themselves. Such results seem to elicit strong evidence for a pluralistic approach to therapeutic practice in cancer care, thereby suggesting a one cap does not fit all in this specific context (Cooper & McLeod, 2012). Perhaps supportive psychotherapy is another way of framing pluralistic psychotherapy in cancer and indeed why psycho-oncologists require these key therapeutic ingredients to most effectively deliver this aspect of cancer care and meet patient needs.

2.6 Psycho-Oncology in The Republic of Ireland

An average of 20,000 new cases of cancer are diagnosed in Ireland every year with an expectation of one in two people developing the disease by 2020 (National Cancer Registry Ireland (NCRI), 2018). Accounting for circa 30% of deaths annually, cancer is the second leading cause of death after heart disease (which accounts for 31%). The most common cancers in Ireland include skin, prostate, breast, bowel and lung with the latter having the highest mortality rate and it ranked as the most common form of cancer death (NCRI, 2018). Historically, Ireland’s oncology care focussed mainly on curing, treating and managing the physical symptoms of the disease. However, in recent years, the psychological impact of cancer and patient QoL are both considered important factors in dealing with the cancer coping process. Drawing on best practice guidelines from leading nations such as the U.K., Australia, Canada and the U.S.A., Ireland has continued to implement psycho-oncology services nationwide with the objective of improving and providing quality, holistic and patient-centred cancer care (Coleman, Hession & Connolly, 2011).

At present, cancer patients can access psychological support via in-house psycho-oncology departments and/or via community-based settings. It is early days for Ireland in its development of psycho-social oncology care and the provision of such is still under-resourced and quite ad hoc. However, the commitment to integrate a psycho-social domain to cancer care remains strong and 2016 saw the launch of the Irish Psycho-Social Oncology Network (IPSON)¸ thus demonstrating a pivotal time in Irish cancer care.

The IPSON is a representative network of professionals including doctors, nurses, psychologists, psychotherapists, academics and researchers, social workers and other therapists all actively involved in cancer care in Ireland. IPSON is a leading advocate for the improvement of cancer services in Ireland and liaises with professional bodies across several settings to ensure psycho-social oncology is gradually becoming an integral part of cancer care. IPSON also works closely with the Irish Cancer Society (ICS) to advance services, including individual cancer psychological therapies for cancer patients in Ireland. Their vision for 2020 is:

- The development of first-class psycho-oncology services in both Ireland’s hospitals and community settings
- Ensuring these services are equitable and inclusive
- Developing a strong psycho-social research focus with international links

Psycho-oncology in Ireland is evidently on the agenda to further develop and integrate into nationwide cancer care settings. Research in Ireland indicates that cancer patients require psychological support with one hospital experiencing a 30% increase (10-40%) of referrals to psycho-oncology services over a two-year period (Coleman et al., 2001). Such an increase, albeit from a low base, indicates that psychological issues in cancer patients are being recognised with an increased need for psycho-social care amongst this population. Other studies have reinforced and further added to this finding, showing a similar percentage of distress in Irish cancer patients as other international studies, thus highlighting the need for increased psychological support. A pilot study to roll out the Distress Thermometer (DT) was conducted in a large Irish oncology hospital and 38% of cancer patients had heightened levels of distress and thus required psychological intervention. Some went on to avail of psycho-social support via social workers and counsellors and others required professional psychological intervention by clinical/counselling psychologists or psychiatrists (O’Donnell, D'Alton, O’Malley, Gill & Canny, 2013).

Analysis of the DT elicited rich data. Younger patients rated their distress higher than older patients with fear, worry and sadness being the most common problems, more so than physical, family or financial problems. This study has proven to be unique in Ireland and has acted as a catalyst to implement the DT into all oncology hospital settings, therefore alerting and educating staff to the role of psychological intervention as a key part of quality oncology care. O’Donnell’s study (2013) also provided feedback from patients via interviews on their perception and understanding of psycho-social services. Some patients expressed concerns about psycho-social intervention being linked to child protection services and/or the social welfare department which may cause added problems for them and their families. Others expressed a reluctance to express a need for psychological intervention as it may be perceived as lacking mental strength. Such findings reinforce the existing stigma and reluctance of individuals to access psychological support. Considering these perceptions and beliefs of psycho-social services, it also raises the question of whether patients are truthfully answering the self-rated questionnaires.

Ireland appears to have improved psycho-oncology services within the national healthcare system via the gradual implementation of the DT and the increase of psycho-social services accessible to cancer patients and their families. With the IPSON's vision for 2020, it seems developments are in place to improve and provide quality whole person cancer care. With access to psycho-social oncology via the hospitals and community settings and edging ever closer to 2020, detailed feedback from cancer patients who have accessed and availed of psychological care may yield important and highly relevant results both for practitioners and patients alike. Studies tend to focus on healthcare practitioners' perspectives and the benefits they receive from measures implemented to identify and treat this distress (O'Donnell et al., 2013). The information drawn from cancer patients via the study above elicited important data on the obstacles that seem to prevent access to support. Perhaps it's time to find out what the service user who has accessed and availed of psychotherapy in cancer care has to say!

2.7 Rationale and Aims of Study

As a growing field, psycho-oncology is fast becoming an integral component of oncology care. The shift in cancer care has relied heavily on active research which deepens knowledge and informs practice within the field. Much of the research has provided rich and informative data that has further supported the growth of psycho-oncology as a sub-specialist field. The leading healthcare systems worldwide – the USA, Australia, Canada and UK in particular have established and adopted best practice guidelines that many other nations continue to adopt with the objective of improving and delivering a whole person approach to care. Research in psycho-oncology has been predominantly focussed on the psychological distress in cancer and effective therapeutic interventions to help cope with the disease and its aftermath. It appears that many therapeutic approaches are deemed effective in addressing the psychological impact of cancer with no one therapeutic model deemed more effective than another. In fact, it is suggested that supportive psychotherapy is the key ingredient in cancer care and therefore must underpin all theoretical practice in this context.

Oncology units have implemented measures via screening tools such as the Distress Thermometer to assess patients' distress levels (O'Donnell et al., 2013) and if required are then referred onto psycho-oncology care. Several studies mainly using quantitative analyses and/or randomised control trials have explored patients' responses to ascertain which intervention alleviates the distress most effectively. The difference and diversity within this clinical population has elicited varying responses (negative and positive) to a range of psycho-therapeutic interventions (CBT, humanistic, existential or third wave therapies such as mindfulness, MBSR and ACT). Underpinned by the need to feel unique and humanised and a strong and trusting therapeutic relationship, a more tailored and client-centred psychotherapeutic intervention is deemed most effective (MacCormack et al., 2001). Qualitative studies investigating cancer patients' experience of psychological support appear to be mainly retrospective, conducted in the same psycho-oncology setting, based on specific models of therapy and/or set number of sessions. These have often served to highlight cancer patient needs and to inform practitioners on the psychotherapeutic interventions which are deemed most effective. However, research thus far has yet to explore the subjective experiences of psycho-oncology via cancer patient perspectives who avail of this care in a real life setting and not part of a RCT with strict guidelines and parameters of practice.

The Republic of Ireland has adopted guidelines for best (psycho) oncology practice with the objective of improving and providing a quality and patient centred healthcare system (Coleman et al., 2011). While research has shown that an increase in psycho-social oncology has reflected the demand of its cancer patient needs, it is still an aspect of oncology care that appears peripheral and under-resourced. However, it does exist, and its presence seems to be increasingly valued by healthcare staff and patients alike. Studies tend to focus on healthcare practitioners' perspectives and the value they receive from measures implemented to address this distress (O'Donnell et al., 2013). Quantitative research has also shown a significant increase in the number of cancer patients accessing psycho-oncology care, thus reflecting the increased need and desire for its service. Building on this knowledge and current trend, it would be a valuable and relevant research study to explore cancer patients' subjective experiences of their psycho-oncological care as it currently exists within the Republic of Ireland.

By giving voice to a small sample population, this study aims to elicit detailed and rich information on cancer patients' subjective lived experience of psycho-oncology. It hopes to understand what it means to them, how it impacts each individual, their relationship with the disease and their day to day lives. Using a specific methodology to explore this topic, it aims to investigate this aspect of oncology care within a real-life setting, thus potentially adding more ecological validity and rigour than research previously conducted. Based on existing theory, research, practice and policy, CoP appears to sit comfortably within the field of psycho-oncology, arguably providing research and practice that can meet individual cancer patient needs. A qualitative study from a CoP perspective study hopes to transcend current research and furthermore make a unique contribution to knowledge and practice for patients and practitioners alike within psycho-oncology, CoP and indeed all related fields.

"We know not through our intellect but through our experience"
- Merleau-Ponty

CHAPTER 3: METHODOLOGY

3.1 Research Design

The qualitative methodology, Interpretative Phenomenological Analysis (IPA), was employed for the analysis of this doctoral research study. Semi-structured interviews were used to collect data which was then analysed following IPA's methodological techniques.

3.1.1 Rationale to Adopt a Qualitative Approach

Qualitative research seeks to explore complex processes - subjective meanings, values, perceptions, beliefs and contexts - that exist in all human experience, but that are often not observable and governed by natural predetermined laws (Willig, 2013). Unlike quantitative research, qualitative research does not make assumptions or hypotheses prior to conducting research, but rather aims to elicit rich and detailed data from experiential viewpoints and make sense of what new and informative findings emerge from such personal experience (Bazeley, 2013). By doing such, it aims to produce knowledge that further informs, transcends and deepens understanding of specific areas of psychological interest and concern. In accordance with the philosophy of Counselling Psychology (CoP), qualitative research embraces a phenomenological approach to deepen understanding of human experience (BPS, 2005). As a Trainee Counselling Psychologist (TCP), it felt congruent to engage in a process of enquiry that seeks to explore subjectivity and inter-subjectivity when experiencing life events. Current research within the field of psycho-oncology lacks a phenomenological focus and it was quickly evident that IPA, the chosen qualitative approach, was the preferred and most suitable option to pursue. Hence, the rationale for adopting a qualitative methodology was based on a combination of three salient factors – firstly, its suitability with the research question itself, secondly, its capacity to produce new knowledge on the chosen topic of concern and thirdly, its compatibility with the philosophical ethos of Counselling Psychology and indeed my own. These three overriding factors supported me to maintain transparency and congruence throughout a complex and challenging process of discovery. This process always endeavoured to deepen understanding of human experience, its complexity and the nature of things.

3.1.2 Ontology and Epistemology

Ontology and epistemology relate to assumptions about the nature of the world. In other words, what do I, as the researcher, believe reality to be and how do I seek to know that reality. These underlying beliefs about the nature of the world are fundamental to the quest of understanding the phenomenon in question.

This research is concerned with individual subjective experiences of the world and how they are grounded in social interactions with the external world. Hence, it adopts a critical realist position with an emphasis on symbolic interactionism. With this philosophical viewpoint, it refutes the positivist stance and assumes that there is no one observable reality that can be measured by cause and effect. In fact, there is potentially as many interpretations of reality as there are people in this world. Each human being has a complex and unique experience of past and present phenomena and it is each individual's subjective sense-making of these experiences that determines each unique version of reality. Critical realism does not accept the idea of an existence of multiple realities, but rather the existence of different and valid perspectives of reality (Willig, 2013). This research does not make any claims about the external world, but rather is interested in exploring each person's perception, interpretation and sense making of it. It is this exploratory process that produces knowledge and insight into the nature of reality.

Considering the complex nature of cancer, the ontological position of this research claims that gaining insight into psycho-social care from the perspective of those that it serves may shed valuable and informative light on an active and increasingly valued aspect of healthcare. Being guided by this critical realist stance, it assumes that the phenomenon, psycho-oncology, exists, but that each cancer patient will have a unique and subjective experience of it. Therefore, to best answer the research question “how do cancer patients experience their psycho-oncology care?” I believe, the most suitable method to explore this phenomenon, is to elicit subjective data from a sample population who have direct experience of the phenomenon itself. Such a phenomenological epistemology acknowledges that each experience of reality (both internal and external processes) is unique, valid and relative to each person. By valuing and emphasizing subjectivity, I must assume that each participant will have a subjective experience of individual psycho-oncology and therefore will potentially diverge and converge in that phenomenological experience. Therefore, in exploring this topic via a small and specific sample population, we may discover as many different and valid perspectives of it as those that experience it. This, in of itself, is fascinating and will provide informative and valuable knowledge to build upon and use in further research and practice within the field of psycho-oncology and indeed all related fields.

3.1.3 Rationale for Choosing IPA

IPA first became established in the field of health psychology as a valuable inquiry into individual experiences of specific health conditions, treatments and decision making (Smith, Flowers & Larkin, 2009). Since then, it has gradually grown and is now common research practice in counselling and clinical psychology within a health psychology context. IPA is the chosen methodology to conduct this doctoral research study due to its goodness of fit with the research question itself. Its philosophical and methodological basis emphasises the detailed and subjective exploration of a specific aspect of human experience from an "insider's perspective" (Conrad, 1987) which is exactly that my research study aims to achieve. Other qualitative methodologies were also considered when researching my topic to ensure that my rationale to adopt IPA was based on a serious and thorough decision-making process. These included Grounded Theory (GT), Discourse Analysis (DA), Foucauldian Discourse Analysis (FDA) and Thematic Analysis (TA), all of which are deeply illuminating processes of enquiry, but have different foci of attention and therefore elicit different knowledge. During this critical decision-making process, it was essential that I fully understood these alternative approaches so that I could form a solid rationale to employ IPA as the most suitable methodology.

GT's main focus is on the recognition and identification of social processes, how people manage and negotiate social situations and how these dynamics elicit underlying social processes (Willig, 2013). Like IPA, it adopts a bottom up approach to analysing data and it is via this analytic process that new theory or theories emerge. It is therefore not particularly interested in subjectivity and the meanings individuals give to their personal experience. DA is focussed on discourse and how people construct their meanings through language and conversation. In this way, DA is interested in observable behaviour and not in the more internal, unobservable processes occurring in human beings (Willig, 2013). FDA is interested in subjectivity as well as discourse in that it is concerned with people's thoughts, feelings and behaviours and the relationship between subjectivity and language. Therefore, each reality is constructed and understood through language and its use. While IPA acknowledges the importance of language, it does not view it as the sole medium of understanding reality. Unlike the aforementioned methodologies, TA provides a flexible methodological approach that can be underpinned by phenomenology and indeed a range of other theoretical orientations. As such, it can, via this flexibility, adopt a strong phenomenological lens. However, its flexible nature means that it lacks a pre-existing theoretical framework and therefore its approach fails to explore the underlying depth and meaning embedded in the research questions itself. Unlike IPA, TA lacks an idiographic focus. It identifies and develops patterns that exist across small or large data sets (Braun & Clarke, 2006) and fails to explore in detail the specificity of each subjective experience as emphasised in IPA (Smith, Flowers & Larkin, 2009). A key objective of this study is to capture first person accounts of personal and subjective lived experiences. It therefore seeks to emphasise a strong idiographic focus with a small and specific sample population. As such, TA was discarded as it lacks this level of specificity and pre-existing philosophical framework, which is one of the core components of this research study.

IPA's focus is on the subjective lived experience of a specific phenomenon and all that this experience entails. My research is concerned with subjectivity and individual experience - the external and internal processes at play as cancer patients reflect on and express their experience of psychotherapy in cancer care. I am approaching my research from a phenomenological and idiographic standpoint and thus not focussed on identifying social processes, creating theory or analysing discourse when talking about psycho-oncology. Therefore GT's, DA's, FDA's and TA's foci of inquiry is not in line with what my research question asks and thus seeks to answer. IPA is a highly regarded, rigorous and accessible research methodology and surprisingly has not yet been used to explore my chosen research topic. It echoes my epistemological and ontological standpoint as a TCP which has helped to maintain personal and professional congruence throughout this exploratory process.

3.1.4 What is IPA?

IPA is a relatively recent yet rapidly growing qualitative research methodology. It emerged during the 1990s to explore human behaviour from a more phenomenological and experiential dimension. Its arrival served to revive a more pluralistic approach to inquiry, thereby emphasising the need for both experimental (quantitative) and experiential (qualitative) research in psychology (Smith et al., 2009). In contrast to positivism, IPA assumes no objective nature of the world. It values **subjectivity** and explores individual accounts to gain insight into the psychological factors at play during specific life transitions. In this way, IPA considers the possibility of as many realities as individuals in the world (Willig, 2013). It focusses on exploring **specific human experiences** and/or predicaments that occur across the lifespan and how people make sense of them. Its exploratory process provides the space for people to engage with a significant experience in their life and reflect on it in a rich and meaningful way. IPA's role is to actively engage with these reflections in a hermeneutic or **interpretative process** whereby the researcher is trying to make sense of the participant trying to make sense of their experience. To remain as close to the data as possible, it is essential that the researcher maintains transparency and reflexivity throughout the research process via the medium of bracketing or epoche. This reflexive component is central to IPA and is key to its ecological validity and rigor as a highly regarded research methodology.

IPA is embedded in three main philosophical concepts – phenomenology (subjectivity), hermeneutics (interpretation) and idiography (specificity) (Smith et al., 2009).

Phenomenology, first construed by the philosopher, Edmund Husserl (1869-1938) and later developed by Heidegger (1889-1976), Merleau-Ponty (1908-1961) and Sartre (1905-1980) to mention a few, is concerned with the structure of human consciousness and existence, what experience is like, how we make sense of it and what it means to us.

In this way, phenomenology carefully explores consciously aware human experience – our thoughts, feelings and perceptions of self and the world around us - our lifeworld. To understand human experience, Husserl argued that we need “to go back to the things themselves”, i.e. the content and nature of experience requires a level of consciousness that pays attention to that experience in an embodied and deeply reflective way (Giorgi & Giorgi, 2008). Therefore, human experience or consciousness is always in relation to a particular phenomenon (event, process, relationship), and it is the experience or consciousness of this phenomenon that is the focus of phenomenological inquiry. To achieve this level of reflection and consciousness, phenomenology seeks to bracket aspects of the lifeworld that can interrupt or interfere with actual experience. By doing such, Husserl claims that a more concentrated and detailed experience of a specific phenomenon occurs. It is the process of engaging with phenomena in an embodied and deeply reflective way that a greater understanding of it can be achieved. This phenomenological approach seeks to explore and understand the essence of human experience.

Idiography is concerned with the singular or the specific (Smith et al., 2009). It focuses on this specificity by its attention and commitment to detail via an in-depth analytic process. This idiographic underpinning manifests via its focus on exploring a specific sample population’s experience of a specific phenomenon within a specific context. Idiography also acknowledges and emphasises the relational nature of human beings. While it focuses on the specific, it is always in relation to something or someone. It is this subjective insight that sheds light on important phenomena and therefore can often challenge and/or support current assumptions and expectations. Goethe (1749 - 1832) claims that underneath and within every general, lies the particular and by delving into the particular or “diving for pearls” (Smith, 2011), we draw closer to the general and consequently can deepen our understanding of human experience and complexity (Hermans, 1988).

Hermeneutics is the theory of interpretation. It is concerned with the relation between experience itself and how experience is interpreted by self and others (Giorgi & Giorgi, 2008). IPA's hermeneutic component therefore rests on the premise that access to experience is based on the researcher making sense of the participant making sense of their experience. It is for this reason, that IPA is a double hermeneutic process. Embedded in hermeneutics is an iterative process too. It requires going over and over the data and its associated interpretations so that both manifest (conscious) and latent (unconscious) meanings of the phenomenological experience is thoroughly explored. This double hermeneutic and iterative process relies heavily on the role of bracketing. This is realised via its reflexive component which aims to retain a level of transparency, validity and rigour to the entire research process.

The above components are the basis of IPA's epistemological orientation. Considering the researcher's influence on and interpretation of the phenomenon under investigation, IPA seeks to produce knowledge (its epistemology) that adopts a phenomenological approach with a reflexive component. IPA's process of stepping into the shoes of each participant and bracketing as much as possible of one's own biases and presuppositions, it aims to capture the unique lifeworld of each participant (Willig, 2013).

3.2 Sample Population

One of the main theoretical foundations of IPA is its idiographic focus (Smith et al., 2009). It tends to involve small homogenous sample sizes and an intensive data analysis to elicit rich and detailed information from each participant (Willig, 2013). According to Smith and colleagues (2009) and the development of IPA, sample sizes have tended to decrease over time. Hence, IPA is all about quality not quantity. A sample size of between 4-10 participants is advised for professional doctorate students (Smith et al., 2009). This sample size caters for logistical constraints while meeting IPA's methodological commitments. It enables sufficient data to be collected with meaningful similarities and differences drawn between participants.

The sample size of this study is six participants (five women and one man). All participants are adults (age ranges between early 40s to early 60s), five of whom have been diagnosed with breast cancer and one with lung cancer (primary and secondary/metastatic). Participants have experienced individual cancer psychological therapy within Ireland at different stages of the disease trajectory (see Table 1). All participants have had a subjective lived experience of this phenomenon and were given the space and opportunity to voice their thoughts, feelings and perceptions of it. The sample size of this study also took into consideration the actual phenomenon being explored. To gain as deep an insight as possible into the experience of cancer psycho-social care, it was essential that the sample population did not experience this aspect of their cancer care via the same service or same psycho-oncologist/psychotherapist. While making the recruitment process more challenging, it provided a wider and more balanced reflection of the phenomenon itself as experienced in a real-life setting. Therefore, the sample population accessed individual psycho-oncological care via different pathways and services available within Ireland.

Table 1. Summary of participants' characteristics

Name	**Age range**	**Cancer (current stage)**	**Time of Psycho-oncology**
David	50s	Metastatic Lung (in remission)	Ongoing
Amanda	50s	Metastatic Breast (in treatment)	Ongoing
Gloria	50s	Breast (survivorship)	During treatment and in remission
Susan	60s	Breast (survivorship)	After Treatment
Clare	40s	Breast (in remission)	After initial diagnosis and during treatment
Valerie	60s	Breast (in remission)	After treatment and in remission

3.3 Recruitment

The participants were recruited via three main pathways - cancer charitable organisations, word of mouth and psycho-oncologists. The recruitment process started by liaising with individuals actively involved in general healthcare and more specifically cancer care settings (GPs, organisation directors, administrative staff, oncologists, psycho-oncologists). Several email correspondences and meetings took place with oncologists, psycho-oncologists, heads of services and GPs regarding my research. Details of the study were forwarded on to relevant committees to discuss recruitment via their service. Several organisations declined, but those who expressed a willingness and capacity to support my research then distributed my information leaflet/poster to potential participants attached to their organisation. Potential participants who freely and in their own time expressed interest in taking part in the study either contacted me directly or I contacted them as per the form of interest. Once contact (via email or phone) was made we discussed the nature of the research and any outstanding queries or concerns. If participants were still willing and able to take part in the study, we arranged a suitable date, time and location for the interview to take place.

It proved to be a challenging recruitment process lasting almost 18 months. It required several changes to the sample population and subsequent applications to and approvals from the research ethics board at London Metropolitan University (LMU). Explaining this process serves to demonstrate the initial efforts to recruit a highly homogenous sample population and the recruitment challenges I faced along the way. Having to expand the inclusion criteria twice, thereby applying for ethical approval three times in total, demonstrates the efforts made to successfully conduct this research within the bounds of IPA's methodological constraints.

The original sample population of this study had a high level of homogeneity - lung cancer patients at the palliative stage of the disease. This was based on the heightened levels of distress experienced with this specific type of cancer (lung) and stage of the disease (palliative). However, over a period of 5-6 months, no successful recruitment occurred. In order to recruit participants from public hospitals in Ireland, ethical clearance has to be conducted via each hospital which is a lengthy process and one I was advised against. Professionals working in the field expressed ethical concerns around conducting qualitative research with palliative stage cancer patients such as length of interviews, fragility of patient health and responsibility of follow up participant/patient care. Due to these legitimate concerns and ongoing difficulty to recruit participants, I decided to expand the inclusion criteria to lung cancer patients at any stage of the disease trajectory.

I applied and received ethical approval from LMU on such (see Appendix M). This caused advancement in the recruitment process with two participants being successfully recruited (via the same source) over a 7-month period. As the main objective of this research was to recruit participants from several settings (unlike other research studies), it was essential that I approached other relevant pathways that were accessible, efficient and supported my research. Many hospitals and charitable organisations said they were unable to support the study due to issues with time, other commitments and organisational procedures/issues. However, a small number of oncology clinicians, healthcare practices and charitable organisations agreed to support my study and flyers/posters were distributed accordingly. A period of unsuccessful recruitment occurred and it transpired that the lung cancer diagnosis was stalling the process significantly. In agreement with my supervisor, I decided to change the inclusion criteria once again to include the current sample population – adult cancer patients who have experienced psycho-oncology within the specific healthcare setting, the Republic of Ireland (RoI). This reduced the level of homogeneity, but it still adhered to a level of homogeneity in line with IPA guidelines. With IPA, the homogeneity of a participant group involves two factors. Firstly, interpretative concerns – the degree of similarity or variation that can be contained in the analysis of the phenomenon and secondly, pragmatic considerations – ease or difficulty of contacting potential participants and relative rarity of the phenomenon itself (Pietkiewicz & Smith, 2014). Considering these two factors, the third and final participant group was deemed suitable and in accordance with IPA guidelines. The final change to the participant group was conducted and ethically approved by LMU. The recruitment process advanced accordingly and over a period of 8 months, the remaining four participants were successfully recruited.

3.4 Materials

An introductory letter/email (Appendix A) was used as a preliminary introduction to relevant points of contact (healthcare and administrative staff) in Ireland's healthcare and cancer care services. An information leaflet (Appendix B) and poster/flyer (Appendix C) were used to advertise and outline the research in relevant locations such as healthcare centres and cancer related care services in Ireland. A form of interest (Appendix D) was used between potential participants and points of contact in the relevant organisation to provide consent for me to contact participants. A consent form (Appendix E) was used to gain official consent from participants that they were freely agreeing to take part in the research interview. An audio recorder was used to record the interview and an encrypted usb was used to securely store all data. An interview schedule (Appendix F) was compiled and referred to if/when required the interviews. A debrief sheet (Appendix G) was discussed and given to each participant following the interviews to provide support and appropriate contact details should any emotional difficulties arise. A distress protocol (Appendix H) outlining procedures taken to deal with participant distress was also available if/when required.

3.5 Ethical Considerations

Ethical considerations as per the British Psychological Society's (BPS) (2018) and Health and Care Profession (HCPC) (2016) code of conduct were adhered to during all aspects of the study. Ethical approval was granted by London Metropolitan University (Appendix M) prior to all data collection. Interviewing a clinical population, it was essential that as a Trainee Counselling Psychologist (TCP), I had psychological knowledge in the theoretical and practical sense in addition to ongoing professional supervision and personal therapy to draw upon to manage and contain any potential participant distress.

A distress protocol (Appendix H) was devised to manage and safeguard any possible distress exhibited by participants during the research process. Following the BPS ethical code (2018), the key values and principles (respect, competence, responsibility and integrity) were adhered to at all times. In addition, the following ethical procedures were taken.

3.5.1 Informed Consent: it was imperative that all participants were well informed and freely taking part in the research. Keeping in mind the emotive nature of the research study itself, it was essential, pre-interview, to discuss with each participant that the interview may elicit strong emotions, both positive and negative. They were informed that they could stop and/or pause the interview at any time and then could proceed if/when they were willing and able. I also informed each participant that a debrief would be conducted after the interview. When participants were happy to proceed, consent forms, outlining the nature of the study and its ethical guidelines, were signed prior to data collection.

3.5.2 Anonymity and Confidentiality: all information obtained throughout the data collection process remained strictly secure and confidential. Interviews were audio recorded and transcribed. Transcripts were made anonymous. Participant and any other identifiable names used in the data collection have been changed to pseudonyms to retain full anonymity. It was explained to all participants that the data collection process was a necessary component of the research process and that academic staff involved in reviewing the study would have access to the data. Again, it was emphasised to each participant that academic staff who had access to the data will always adhere to BPS (2018) and HCPC (2016) ethical guidelines pertaining to research conducted on human participants. Participants were informed that all collected data would be destroyed after successful completion of the doctoral research study.

3.5.3 Right to Withdraw: participants were informed that they could withdraw from the research study up to 4 weeks after the audio recorded interviews. If this occurred, all data belonging to the relevant participant would be destroyed immediately. Participants were reassured that their participation in or decision to withdraw from this research would in no way affect their cancer care and should they wish to withdraw they could contact me directly or communicate their decision via their healthcare provider.

3.5.4 Debriefing: all participants were fully debriefed after the interview. It was necessary to discuss with each participant their experience of the interviewing process to monitor any possible negative effects. A debrief sheet was provided to each participant with my contact details and relevant organisations involved in cancer care. If required, a distress protocol form was followed to safeguard participant wellbeing and ensure follow-up support was in place.

3.6 Data Collection

Interviews took place in participants' homes or a quiet, safe and convenient location close by, as agreed between myself and each participant. To ensure personal safety, I had agreed with a member of my own family that if I had not telephoned within a certain time frame, they were to call me. Should I not answer the call, and concerns of my safety were being raised, I had left the address of the interview location in a secure place that they could access in case of an emergency.

Before the interview commenced, all ethical considerations were discussed and reviewed and a Consent Form was read and signed by both participant and I. Due to the nature of the sample population, it was made clear that they could pause at any time during the interview and resume if/when they felt ready and willing to proceed. No risk or cause for concern was raised during the entire data collection process.

Adopting IPA's methodology, semi-structured interviews lasting between 50 and 90 minutes were conducted to collect data. Such an interviewing style aimed to elicit rich and detailed information, gaining insight into the subjective lived experience of each participant's lifeworld, thus supporting IPA's and indeed my preferred phenomenological epistemology. Each interview aimed to provide a platform for each participant to talk freely and openly, thereby providing personalised and informative data on their experience of individual psycho-oncology. Interviews were recorded via an audio recorder and immediately transferred onto an encrypted USB file which was securely stored until successful completion of the thesis. Once all interviews were conducted and all data was collected, each interview was then transcribed. All participant names and identifiable names have been changed to pseudonyms throughout this study to retain full anonymity. All data has been securely and confidentially stored throughout the research study.

3.7 Stages of Analysis

While IPA allows for some flexibility in its analytic approach, the objective was to remain close to the data to gain a deep understanding of the participant's experience of the topic (Smith, Jarman & Osborn, 1999). Based on IPA guidelines, the data analysis was conducted over five stages (Smith et al., 2009).

The first stage involved familiarizing myself with the data. This entailed reading and re-reading the transcript, making notes, initial observations and bracketing any personal biases or presuppositions that were deemed necessary. These preliminary notes were accessible to me later in the process. It was important at this initial stage to feel like I had begun to enter the participant's lifeworld, to have consistently remained close to the participant's description and meaning making of how they experience the phenomenon being explored.

The second stage involved initial coding. Exploratory comments were noted in the right-hand margin. The main objective here was to actively engage with the data, while always maintaining a phenomenological focus. This ensured exploring the subjective world of each participant and remaining close to their interpretation of it. The exploratory comments included linguistic, descriptive and conceptual notes which provided a method of becoming closer to the data and consequently, closer to participants lifeworld (see Appendix I).

Thirdly, examination of each line of the transcript in conjunction with reading and interpreting the exploratory comments in the right-hand margin was conducted. I started to capture the data and exploratory comments as thematic labels, writing them down in the left-hand margin. The identification of themes was to assign psychological meaning to specific parts of the data and indeed those that weaved themselves throughout the transcript. This stage of analysis focussed more on interpretation whereby I linked meaning and understanding to the data and exploratory comments from the initial stages. Emergent themes were noted in the left-hand margin of the transcript (see Appendix I).

The fourth stage involved a clustering of themes. I wrote down all the themes identified in the text in the order of emergence (see Appendix J). I clustered themes that appeared to hang together. Some were discarded due to their irrelevance to the actual research question(s). A master theme table was composed for each participant, displaying the relevant themes (with quotes) and their overarching theme titles (see Appendix K).

The final stage of analysis involved the distillation process of themes across all six participants culminating in the production of the Master Theme Table (see Appendix L). The production of the Master Theme Table is to provide clarity and a systematic overview of the data analysis. It is the culmination of distilling all relevant themes from across the six participants down to those that captured the sample population's experience of the phenomenon under investigation. The table displays the three master themes, corresponding sub-themes and quotes pertaining to all six participants' experiences. Each master theme and its corresponding sub-themes were analysed via the use of verbatim quotes taken from all six transcripts and interpreted using IPA's methodological techniques. This interpretative phenomenological analysis is demonstrated in Chapter 4.

3.8 Reflexivity

The role of reflexivity is an essential component of IPA. It adds rigor, validity, and transparency to the research findings by always reflecting on the impact and role of the researcher on the topic under exploration. The three main philosophical underpinnings of IPA - idiography, hermeneutics and phenomenology – are central to its epistemological and ontological basis. Therefore, it is imperative that the specific, interpretative and subjective nature of the chosen phenomenon is safeguarded and attended to throughout the research process. This means staying as close as possible to each participant's subjective experience in addition to identifying emerging themes derived from the idiographic accounts. By always adopting a reflexive stance, I continually acknowledged and reflected upon my own personal involvement in the study and how this interacts with the data provided. It is this emphasis on reflexivity which serves to maintain a level of objectivity (via epoche or bracketing), thus giving IPA its ability to produce rich and detailed knowledge.

As the researcher, it is crucial to remain as transparent as possible. This requires reflecting on aspects of my personal and professional identity as a TCP which may have influenced stages of the research process. My evolving personal and professional experience proved beneficial and at times problematic, particularly during the data collection and analysis stages. However, what remained essential was to retain a strong reflexive component throughout the process. Being one half of a double hermeneutic process, (i.e. I am making sense of the participants making sense of their own experience), there may have been times when my interpretations presented an interference between my role as practitioner and my role as researcher. This was a dynamic during data collection and analysis that I became acutely aware of. It highlighted the nature of subjectivity in human experience and the necessity to recognise and monitor differences between the participants and the researcher. The following reflections intend to capture relevant factors that I felt may have influenced this intersubjective process and more importantly how I responded to them.

I had accrued experience of working therapeutically with clients and within multi-disciplinary teams in both general and specialist healthcare settings across my doctoral training. These two factors contributed to my ever-increasing phenomenological lens as a way to obtain meaningful data and understand human experience. My clinical experience helped me feel comfortable relating to the participants in a professional yet human way, setting out the parameters of the study, just like boundaries in therapy, and hence demonstrating a capacity to create a safe and confidential space where they seemed to feel at ease to openly discuss personal experiences.

The personal and professional knowledge of cancer and psycho-oncology (I conducted a twelve-month clinical placement as part of my doctoral training in a psycho-oncology service of a large UK hospital) provided me with a type of “insider” knowledge. As the researcher, it was important to be aware that I was someone who was personally invested in and practicing in the field. It was crucial to reflect on these factors and consider how they may have influenced the research. It proved helpful to share a common language in building confidence and rapport in each researcher/participant relationship. Understanding cancer related issues and terms which emerged during the interviews helped to maintain a smooth interview flow and demonstrate the capacity to delve more deeply into each participant's lifeworld. However, I also wondered if this intimacy with the subject matter at times prevented me from retaining a more objective stance. This merging of both disciplines tended to show its face when I became too focused on an aspect of a participant's experience which perhaps was informing me as a therapist rather than as a researcher. This reflexivity caused me to bracket my own agenda and ensure that the direction of each interview was driven by the experience as communicated by the participant and not my own. This was further supported by a decision to transcribe all six interviews only after full completion of all data collection.

During the data analysis. I tended to be primed towards themes which recurred across participants and which tended to catch my therapist rather than my researcher attention. This attentional tendency could have dominated if I had failed to adopt a reflexive stance. It may have resulted in neglecting to pay close attention to the differences rather than the similarities which existed across data. It was crucial therefore to notice, step back from, reflect on and bracket these personal and professional assumptions, agendas and tendencies and ensure as little researcher and more importantly therapist interference occurred during this in-depth process of enquiry. Such reflexivity served to retain a strong level of self-awareness and enable me to ground myself in the data and obtain a deeper insight into the subjectivity of each participant's experience.

"What is taken away is greater than the sum of what was there. This may not be mathematically possible; but it is emotionally possible"

- Julian Barnes, Levels of Life

CHAPTER 4: ANALYSIS

The following Interpretative Phenomenological Analysis presents the findings of six Irish cancer patients' experiences of their psychotherapy in cancer care. The analytic process distilled the data down to three master themes and nine corresponding sub-themes as presented in Table 2 below and an expanded version (with quotes) in Appendix L (pp. 150).

Table 2. Summary of Master Themes and Sub-Themes

MASTER THEMES	SUB-THEMES
CANCER PATIENT NEEDS	• **The Competent Therapist – Someone who understands cancer** • **A Secure Base** • **Knowing "how to access support – the accessibility and availability"**
THE POWER OF TALKING	• **"A Different Conversation"** • **Eases the Psychological Pain** • **Acceptance**
THE THERAPEUTIC RELATIONSHIP	• **A Goodness of Fit** • **"A Safe Space"** • **"The help that helps you help yourself"**

The findings aim to capture, under relevant headings, the subjective and idiographic experiences of this specific sample population. This chapter demonstrates the analysis of each master theme and its corresponding sub-themes. The six participants featured across all themes, sharing experiential commonalities and differences of their individual psycho-oncological care. Such divergence and convergence will be explored below, thereby highlighting the subjective nature of human experience and how “going back to the things themselves” can deepen knowledge and understanding of events and processes across the lifespan.

The stages of analysis proved to be a deeply iterative, immersive and challenging process. It wasn’t until I found myself experiencing the actual process that I started to fully grasp the true nature of it. This personal realisation reinforced the power of experience as a unique and illuminating way to understand phenomena. Holding this in mind supported me in trying to remain as close as possible to each individual participant’s experience. It was a challenging yet rewarding thematic distillation process, with many sub-themes merging into one another and arguably being able to feature under more than one master theme. While they warranted their own separate themes, the therapeutic relationship proved to be an overarching theme which threads through all data. Arguably, the strength of the therapeutic relationship tended to hinge on therapist knowledge and experience of cancer and from which many other themes emerged. In-depth discussions with my supervisor and an ongoing process of zooming in and zooming out of the data was essential to successfully achieve this analytic process and arrive at a point where themes were distilled down to those presented in Table 2.

It must also be acknowledged that my interpretations may not mirror the interpretations of other researchers. The following findings are based on addressing the research question itself. Therefore, the analysis does not include every aspect of the participants’ experiences or indeed what other researchers may derive from the same data. All interpretations are grounded in the participants' data via verbatim quotes drawn directly from the interview transcripts. I endeavoured to remain data driven throughout this entire process and as close as possible to the phenomenological experiences of each participant. Let us dive straight in and start with the first master theme, Cancer Patient Needs.

4.1 Cancer Patient Needs

All participants expressed the importance and value of having psychological support at different stages along the disease trajectory. As a disease which has a psychological impact, each participant acknowledged the difficulty of adjusting to life since initial diagnosis, struggling at various points of the disease trajectory and the personal challenges they each faced along the way. They all emphasised needs that their psycho-oncological care met or at times failed to meet and what this experience meant to them. Such detailed experiences indicate the importance of both knowing cancer patient needs and the aspects of psychological care that can most effectively attend to them, thus providing helpful therapeutic interventions. These are discussed below under the following three sub-themes, *The Competent Therapist – Someone who understands cancer, A Secure Base and Knowing "how to access support – the accessibility and availability".*

4.1.1 The Competent Therapist – Someone Who Understands Cancer

It is evident from each participant's experience that a therapist with knowledge and experience of cancer is deemed particularly helpful. Each person spoke about having someone who understands as an important part of their cancer care to help them cope with having the disease and associated emotional distress, thereby pointing towards the value and efficacy they derived from it. This seems to imply that cancer patients accessing psycho-oncology require a therapist who is not only professionally qualified, but who has an understanding and experience of cancer itself. The combination of therapeutic professionalism and expertise appears to provide the participants with a sense of being "in good hands", "understood" and who implicitly "gets it". The following extracts capture what this experience means, thus highlighting the role of psycho-oncology as a highly specialist field designed to cater to the specific population it serves. In this first extract, David talks about feeling understood.

"I was on chemotherapy and it's very tough, it's very tough physically and psychologically, it just it gets you down, so you really need somebody to talk to and you can't just talk to anybody…somebody who specialises…..she calls it psycho-oncology….I certainly had the feeling that I was being understood" (David, 17-30)

David acknowledges psycho-oncology as a specialist field and one which contributed to him feeling heard and understood during his cancer treatment. David expresses the fact that chemotherapy had a difficult physical and psychological impact on him, causing him to feel down and in need of someone to talk to. He seems to want to make the point that it is not anyone he needs or wants to talk to, but "somebody who specialises". It appears he wants and needs a specialist, a therapist who knows and understands cancer and who he can feel a level of safety discussing his issues with. This is further reinforced when he describes the experience of "being understood". David seems to feel confident and safe with his therapist, states of being that appear to help him during a time of emotional and physical distress.

For Amanda, part of feeling understood is due to her therapist knowing the difference between primary and secondary cancer.

“the distinction between primary and secondary and having someone who knows that distinction and acknowledges it is important…It’s great to have someone who is helping who gets it and at the same time doesn’t treat you like something they’re looking at under a microscope” (Amanda, 141-163)

Similar to David, Amanda expresses the value she gains from seeing a therapist who also demonstrates professional competency and knowledge of cancer. Earlier in the interview, Amanda had spoken about her frustration with the disease being misunderstood. She had struggled to tolerate the misconceptions that exist in society and which she perceives as negatively affecting how cancer patients can be treated. It seems important for Amanda that her psycho-oncologist knows the difference between primary and secondary cancer and therefore understands what she personally contends with as a secondary cancer patient. Knowing and understanding this distinction appears to be very important to Amanda in feeling understood. Her *“microscope”* reference suggests her appreciation of having someone who “gets it”, who does not need to ask questions and scrutinise her to gain more clarity, but rather has an implicit understanding of what she experiences. This implicit understanding appears to provide Amanda with the comfort and support that she has a professional in her life who fully understands cancer and therefore has a deeper understanding of her and what she is going through.

Clare also talks about how her therapist’s knowledge of cancer helps her to understand her own experience.

“presumably he’s never had cancer himself but he’s studied it and been around so many people who have that he knows how to…like he has a knowledge about the whole thing and it’s important because you’re hyper sensitive to the things people say and the amount of people who want to tell you that people died (laughs) like it’s kind of it’s a bit of a joke

like but yeah, people are quite awkward around cancer. You don't know what to say and mmm I think if somebody is going to be working with people with cancer, it's important to find out what to say and what not to say" (Clare, 514-520)

Clare seems to tap into the same experience that Amanda shares - the importance of having psychological support from someone who has knowledge and understanding of cancer. Here, Clare acknowledges how sensitive she is with regards to what people say about cancer, hinting that people can be awkward around the topic and can say things that heighten the reality of being confronted with a life-threatening disease. Clare seems to value the fact that her psycho-oncologist does not approach the topic with such insensitivity, but via his knowledge and experience, he demonstrates skill, competency and sensitivity when discussing such subject matter. This therapeutic sensitivity and knowledge seems to make Clare feel understood and attuned to, perhaps states of being that help ease her emotional distress. This differs from an experience she had with another therapist working in psycho-oncology.

"Yeah and even if even if it was my imagination it's still real for me and you kind of have to understand the seriousness of what I thought I was dealing with rather than just a vague idea of breast cancer" (Clare, 387–389)

This experience upset Clare, invalidating her worries and fears and failing to take them, and consequently her, seriously. Clare insinuates here that the therapist's lack of knowledge of breast cancer results in a lack of empathy for her personal situation and as a result she feels invalidated and psychologically unmet.

Susan also expresses the impact of a therapist who understands cancer.

"that to me was the release of talking about things that really no one would understand unless it was through somebody who knew about cancer or who dealt with people who had cancer" (Susan, 476-478)

Susan emphasises the positive therapeutic effect of being able to talk to someone who understood cancer and who had experience of dealing with other cancer patients. These characteristics were essential to Susan feeling understood during a time where she did not seem to feel understood by others. This "release" conveys Susan's sense of relief to be able to talk to someone who she felt understood her situation, thus making her feel less stranded and alone with her cancer.

Gloria captures the therapeutic effect of having a "fellow survivor" as her therapist.

"well I mean you know you're with somebody who has, let's face it, it's like you show me and I'll show you. It's that kind of giving and it's very powerful when you have that with somebody who is professionally able to help you as well eh because you really then can absolutely go to the darkest recesses of your fear, your vulnerability, your terror and you can really put it out there now. I think because the person opposite you has been there and understands it and more importantly knows how to help you which is a bonus. Like this isn't just somebody you meet who is a fellow survivor or whatever, this is somebody who is professionally capable and I believe that it brings it to another level" (Gloria, 163-170)

Gloria expresses her experience of therapy as a process that was able to be with her fear, terror and vulnerability. Having a therapist who also had cancer seems to nurture an even deeper level of professional therapeutic care and provide a space that Gloria feels safe and brave enough to go to the "darkest recesses" of her emotional distress. Gloria emphasises the importance of cancer psychological care embodied in someone who is professionally qualified and who also has a lived experience of having cancer. This, she later describes, is the "*magic combo*". She makes the comparison that confiding in her therapist is different from confiding in a "*fellow survivor*". For Gloria, the knowledge and experience of cancer as well as being a professional can bring the therapy to "another level" of feeling understood. This other level seems to provide Gloria with a strong and "powerful" sense of being understood and therapeutically held, one which helped her to feel safe to express her distress and as a result, psychologically met.

4.1.2 A Secure Base

Deemed an appropriate theme title, *A Secure Base* captures the participants' experience of psycho-oncology as an available and responsive source of support in times of need. A secure base is a term used by the attachment theorist, John Bowlby, to explain the presence of a responsive and available primary caregiver in childhood to meet developmental needs and affects our capacity to explore the external world, form attachments with others, develop relationships and navigate events across the lifespan (Bowlby, 2012). This relational dynamic seems to emerge via the therapeutic relationship and the comfort it provided the participants throughout their cancer experience. All participants spoke about periods of time since initial diagnosis of feeling emotionally distressed and these personal portrayals elicit the human need and desire for a secure base across the lifespan. While the participants spoke of their therapy and what it meant to them, they also spoke of times when they felt its absence. In the following extract Susan draws on a poignant analogy of her own experience as she finishes her treatment.

"*it's funny when you finish your treatment, no one is there to help you or to pick up the pieces afterwards and it is that terrible feeling of being adrift with no oars. You're just in a boat and off you go"* (Susan, 90-92)

Susan captures the sense that she is abandoned at sea with nothing or no one to help her navigate onwards. This image evokes feelings of fear, uncertainty and aloneness. She pinpoints the exact timing of this situation of ending treatment, which implies that she felt supported beforehand. Perhaps during treatment she had her "oars" and therefore was able to draw on objects to help her navigate that part of her cancer journey. However, this excerpt beautifully captures the lost feeling within her as she appears to grapple with a sense of abandonment after her cancer treatment ended and she was no longer attending regular hospital appointments. After a period of feeling "adrift", Susan accesses psycho-oncology and describes her experience as,

"I wasn't cast adrift anymore. I was regaining, I got the oars and I could start going down my way again" (Susan, 542-543)

This vivid image of Susan being at sea again, but unlike the time before, she no longer feels abandoned, alone, uncertain or scared. Having accessed psycho-oncology, she seems to have regained her confidence and feels the support necessary to help navigate her journey ahead. Susan goes on to describe the comfort she feels in knowing she can access therapy if/when needed.

"I know I can go into XXXX at any time if I want to or if I can't deal with how I'm feeling. But I do feel good so hopefully, but it's nice to know that they're there" (Susan, 544-546)

This quote also highlights the ongoing journey and uncertainty that can prevail for Susan even in survivorship.

In her own survivorship stage, Gloria describes how life events continue to trigger cancer related fears.

"I was grieving my father and then also my father had died of cancer so it had really just brought up so much more stuff and I found that it had actually reactivated a lot of the

terror that I had experienced when I had had the diagnosis…I lost the handle of things a little bit at that point and that's why I needed support" (Gloria, 22-28)

Gloria acknowledges the death of her father from cancer as reactivating her underlying fear of death. Her use of the word "*terror*" vividly captures her intense fear of being diagnosed with a life-threatening disease, which at a later stage took the life of her own father. This reality has caused her to feel vulnerable again and lose "*the handle of things*". Perhaps she started to feel out of control, a common feeling amongst cancer patients. The capacity to access and avail of cancer psychological support seemed a valuable source of comfort to Gloria at a time of emotional need, the sense that knowing a responsive support base exists and can be accessed seems to be, itself, enough provide a form of solace and comfort.

David has been attending the same psycho-oncologist since he started treatment and in the following excerpt he talks about his experience of having ongoing psychological support as integral to his cancer care.

"It is very important that I know she is there…as long as I know there is an appointment it's fine even if it's six months or a year away, that's ok….because cancer messed with my mind. It really did and I would be afraid that it would do it again and I should be better equipped the next time but you never know, you never know. All I can say is that it is important that it's there" (David, 295-307)

David clearly expresses the psychological impact cancer has had on him. His honest admittance of being scared of how it could mess with his mind again implies that cancer is a disease that he cannot trust and therefore can feel vulnerable to its unpredictability. Knowing this, David seems to seek comfort and security by the fact that he knows his therapist is available to him, acting as his secure base, someone he can trust to be there and to respond to his emotional needs. This implicit sense of security within David seems to point towards the strong attachment he has formed with his therapist, a relationship that he feels secure in and knows he has close proximity to, which combined, seem to have helped him face difficult personal experiences as a cancer patient.

Amanda echoes much of what David talks about.

"there may be periods when it wouldn't be for a few months and then like it's not every week or every month or anything like that. It doesn't need to be" (Amanda, 445-446)

Amanda describes not needing to see her therapist all the time, but that a flexible availability is both a valued and necessary part of her cancer care. This therapeutic flexibility seems to make Amanda feel implicitly understood and secure in the knowledge that her emotional needs are attended to at different junctures across her disease trajectory. In this way, it appears that the disease can affect her psychologically at different points and knowing that she has an available, flexible and responsive therapist as a part of her cancer care has helped her navigate difficult times and provided her with a continuity of care and source of support.

Valerie also expresses the security and comfort she appears to feel simply knowing that psychological support is available if/when required.

"if I wasn't feeling great that I had somewhere to go eh that I could go to somebody you know what if all else fails as I say going down the swanny that you have support to go to somebody" (Valerie, 209-210)

Here, Valerie acknowledges that she could go "down the swanny", a sense within her that cancer can make her feel very distressed. This analogy echoes Susan's analogy of being adrift with no oars and the prospect of having no support and things going badly wrong. Having "*somewhere to go*" appears to ease this distress and give Valerie a source of comfort and support during a time of deep fear and uncertainty. Cancer seems to trigger a sense of vulnerability within Valerie and brought to her conscious awareness that it could recur. However, the attachment formed between Valerie and her therapist provides her with a strong sense of comfort that has a secure base to return to if/when she experiences such psychic pain again.

4.1.3 Knowing "how to access support – the accessibility and availability"

This sub-theme brings to attention the need for psycho-oncology at different stages along the disease trajectory. Knowing how to access it proved more straightforward for some than for others. The extracts below demonstrate that psycho-social care in cancer lacks a visible presence in many settings and therefore, for this specific sample population, knowing "*how to access support*" was or would have been helpful. Similar to having a Secure Base, it highlights the importance of relevant information and increased awareness of psychological support as part of patient care and how the provision of such can normalise and validate the emotional distress associated with the disease.

In the following extract, Valerie explains the need for psychological support after her surgery.

"I think like that time when I came out of hospital I think they should have had somebody in place that you go to. I think that was horrendous when people are going through so much and they don't know what to do or who to turn to….It's how to access support really - the accessibility and availability" (Valerie, 628-634)

Valerie expresses the need for support after leaving hospital, a resource which appears to have been absent and one which could have helped her make sense of and cope with such a "horrendous" experience. Valerie implies that the presence of someone attached to the hospital or knowing how to contact someone professional could have provided reassurance and support during what seems to have been a very frightening time. The absence of such support appears to have exacerbated an emotionally distressing time for Valerie, one which she suggests could have been avoided if she had someone "*to turn to*".

Susan describes how she felt when she was discharged from hospital and ended treatment.

"You've had your treatment and now you go, fine. And I don't think they realise, you know, what this time is like for people. They never discuss it, mmmm, you're just, right NEXT!" (Susan, 92-94)

There's a sense here that Susan felt abandoned and pushed aside once her treatment had ended. She insinuates that there was a lack of concern or awareness of how she felt at this time, manifesting in no acknowledgement nor discussion of the potential difficulties that can exist for patients after treatment ends. Susan's perception implies that once the physical treatment had ended, the oncology team were finished with her and ready to turn their attention to the next patient in line. Her use of language and tone of voice to mimic her experience at this time suggests a lack of acknowledgement by the medical staff of her feelings post treatment. It seems Susan may have appreciated being asked how she was doing on a more holistic level and perhaps to have a conversation about the impact of ending treatment and what that entails. This extract demonstrates the importance of feeling humanised to Susan, for the oncology team to include *all* of her being and not solely focussed on the physical aspect of the disease and its treatment.

Valerie talks about the distress in cancer and the need for available support to help cope.

"Yeah it's being frightened. You need somebody to see the state that you are in and to come along and say look maybe we can do this or maybe we can do that or it's ok to be like this it will pass or it's just eh it's just I suppose it's like if somebody is really really

ill and you don't know what to do or where to go or you just don't know what to do with it, it's scary stuff" (Valerie, 649-652)

Valerie feels very scared with how cancer affected her both physically and psychologically. As she transitioned from being an in-patient to an out-patient, it appears she felt very alone with no one from her cancer team seeing her this way and therefore left stranded not knowing what was normal or not normal. This quote emphasises the intense vulnerability Valerie felt during this "*scary*" time and the need for someone who was attached to her oncology team to provide emotional support, reassurance and guidance to help her cope with the symptoms she was experiencing. However, it was the not knowing what to do, who to talk to or how to access professional support that seemed to further exacerbate her distress.

Amanda expresses her recent awareness of a psycho-oncology department in the hospital she attends.

"I think in the hospital I go to, I think in the last few months, got a psycho-oncologist. Yeah a psycho-oncologist but only in the last few months and it was mentioned but up until then and I'm going for eight years there was no mention of any of that kind of support. In fact, there was no mention, there wasn't any mention of any kind of support actually" (Amanda, 273-277)

Amanda self-referred to a psycho-oncologist soon after her diagnosis. According to Amanda, psychological support was not an aspect of her cancer care that she was ever made aware of in the hospital she attends up until the last few months. This is not something that seemed to particularly bother Amanda as she had sought support independently. However, from her comment above and the tone she used, it seemed she never expected the provision of such care. Ironically, this experience runs alongside the fact that Amanda, as expressed earlier in the interview, has valued the relationship with her psycho-oncologist as integral to helping her cope with her cancer experience and the only professional cancer related relationship that has remained constant since initial diagnosis.

Clare had a different experience and talks about being referred to the in-house psycho-oncologist.

"it was my surgeon that….she's the one who gave me the diagnosis and mmm and mmm yeah she said that it's usually people who are a bit younger at the time of diagnosis have a harder time coping than an older person and I mean I didn't plan on having cancer at any point but yeah I felt I could do with talking to somebody. I always thought that. I've never had counselling or seen a psychologist but I always thought if something happened, I would do that. I was always yeah, I was open to the idea, but, so yeah it felt like ok this is this is the biggest thing that has ever happened to me and yeah and I was so scared that it was good to have someone to talk to about it" (Clare, 53-60)

Clare seems to have appreciated the referral from her surgeon to the psycho-oncologist. She alludes to the shock she felt at diagnosis which seemed to be compounded by her being diagnosed at a young age. The acknowledgement of the surgeon to communicate this to Clare seemed to help her recognise the emotional impact of her diagnosis and the role of psychological support as part of the available care to help her deal with this difficult time. What seemed like a seamless referral process, Clare was evidently able to avail of psychotherapy as part of her cancer care, thereby providing her with helpful professional support during a time of need.

Like Clare, David also talked about his referral to cancer psychological support.

"It was my oncologist who actually sent me or suggested I see this particular woman so there must have been some kind of knowledge there that she knew this was the right kind of person to go to.....I was specifically referred to this one" (David, 66-70)

It is clear from David's conversation with his oncologist that he was referred onto a therapist with specialist knowledge and experience of cancer and who practised in a specialist service for cancer patients outside of the hospital. David went on to explain further;

"I didn't know such a service existed and I don't think it does. I think you have to be really lucky with what oncologist you're with who would point you in the right direction because there are no psycho-oncology departments in the hospitals, certainly not in the hospital I go to....It meant I could start dealing with some of the things that were bothering me" (David, 214-221)

David acknowledged being unaware of psycho-oncology as a sub-specialism of oncology and therefore had no knowledge of being able to access or avail of such support as part of his ongoing cancer care. David expresses gratitude towards his oncologist who he said earlier in the interview tended to focus on the physical aspect of cancer but during one consultation had asked him about his psychological wellbeing and mood. This resulted in providing David with appropriate information to access specialist support and help him cope with this aspect of the disease. From David's experience, it was an aspect of cancer care that he did not know existed and as soon as he had the opportunity to express his needs, he valued knowing how to access and avail of such support.

4.2 The Power of Talking

The second master theme, The Power of Talking, aims to capture the impact of having someone to talk to about personal experiences of cancer. Each participant's experience is unique and can change over time, but talking with a therapist appears to have a strong impact on navigating the cancer process. Some participants spoke about two different worlds, the idea that once diagnosed with cancer, they entered another world and henceforth, everything changed. Talking about cancer and its emotional impact appears to be a difficult conversation for the participants to have with others. Therefore, having someone to talk to who is not emotionally involved seems to be a meaningful part of coping with cancer and its aftermath. David talks about the difficulty in discussing cancer with friends and family.

"most people don't want to know about cancer whether its family members or friends, I'm not saying that nobody cares but they don't really. Maybe if they did want to talk about it, they don't understand what it's like" (David, 20-22)

It seems David feels that Cancer is taboo, an unspoken topic that people avoid. As a result, this experience can make him feel isolated and assume that friends and family don't care. In this master theme, the participants' experiences emphasise the emotional and relational impact of having cancer and the value derived from talking to an empathic and caring therapist. These subjective experiences are further explored in the following sub-themes A Different Conversation, Eases the Psychological Pain and Acceptance.

4.2.1 A Different Conversation

This sub-theme emerged from Amanda's candid description of the differences between conversations she has with her therapist versus those she has with others. Chosen as an appropriate theme, Amanda's words represent elements of all participant's experience. Similar to entering a different world, she seemed determined to emphasise the isolating nature of having cancer, unable to have open conversations with friends and family about the illness and its impact on her life.

"everybody is afraid of cancer. I mean, some people still lower their voice when they say the word or call it the Big C" (Amanda, 165-166)

Amanda expresses an acute awareness of cancer as a taboo topic, a word she feels people avoid or instead, opt for an alternative phrase. This experience is further echoed by the other participants. Susan goes further to say;

"people will cross the road so that they won't have to talk to you because they can't face speaking about it or can't acknowledge or they want you to look well or they don't want anything to happen so then they'll try and avoid you altogether" (Susan, 165-168)

Susan suggests that as a result of cancer being a topic to avoid, people with cancer can be avoided too. Susan's experience of this implies that people are afraid of cancer, perhaps unconsciously afraid of what it can lead to – death - and therefore afraid of what she triggers within them. The consequence of this human behaviour potentially is that Amanda and Susan feel isolated and pushed away from society.

David demonstrates his own difficulty with talking about death until cancer confronted him with it and he could no longer push it away.

"I did always communicate, I was always articulate, but some subjects I would never face and just getting encouragement to face them whether it's death it's eh, you know the really heavy stuff that you normally wouldn't be bothered with and when you're faced with them, yeah you really have to learn to handle them. So, she certainly helped me with that" (David, 120-124)

David acknowledges his reluctance to talk about "*the really heavy stuff*" until he was faced with it, which is perhaps what happens in situations articulated by Amanda and Susan above. However, with David, he emphasises the fact that he never struggled with articulating himself, but cancer placed him in unsettling territory whereby cancer forced him to confront his mortality. It seems that David was scared and understandably avoided talking about the reality of his situation. As David credits his therapist for helping him to face such difficult topics and in so doing, he felt less scared and therefore more able to deal with them.

Susan's account evokes a similar yet different sense of relief as she talks about her fear of dying with her therapist.

"I just broke down and I just talked it through and it, I suppose your, you just want somebody to listen because you can't really tell your family the way you're really really feeling because you don't want them to feel, you know maybe this business of what if, what if, what if I die, what if it doesn't work so mmm that's why I think the counselling was brilliant" (Susan, 56-60)

Susan raises the difficulty she has with talking about her fear of death with loved ones. It seems she wants to protect them from further pain and yet at the same time yearns for someone to hear and understand her own emotional pain. The moment she could talk about those fears with someone, she "broke down", almost seeming like she was openly acknowledging her emotional pain and via that process, she could let it all out and in a meaningful sense start to process it. Her description of her counselling as "*brilliant*" gives a sense of a brightness during a dark time, providing her with a safe outlet that she could confide in someone about her deepest fears.

Similar to Susan, Clare also talks about the ability to share difficult thoughts and emotions with her therapist.

"when you have all these fears and you can't tell the people closest to you because….well they're going through terrible time themselves because as in mmmm well cancer affects everybody around you, not just the patient so you want to protect them so you hold back

on the stuff you're thinking to a certain degree and mmmm when when you talk to a psychologist you can just let it all out….it's liberating" (Clare, 281-289)

Clare also brings up the need to protect significant others from the pain that cancer can also inflict on them. This protective nature appears to cause Clare to keep her own fears to herself. The *"liberating*" experience of being able to talk openly to her therapist enables Clare to feel less burdened with the difficult thoughts and emotions she carries within. Her sense of freedom seems to help ease her emotional distress and reassure her that she now has someone to talk to, making her feel less alone and thus supported to cope with her experience of cancer.

Valerie talks about the difference between talking with her therapist and talking with others.

"I wasn't afraid to say anything to her no matter what it was you know. Sometimes I suppose you're kind of saying well you don't say stuff because people may judge you if you're telling them stuff but I didn't feel like that with her, I just felt I could say whatever" (Valerie, 358-361)

Valerie acknowledges the difficulty with talking about cancer which results in her being unable to express her true thoughts and feelings. It appears that Valerie is able to have a *different conversation* with her therapist, a conversation that no topic is taboo and she could "say whatever" without feeling ill-judged. This seems to provide Valerie with a strong sense of comfort and validation, a place where she can perhaps feel her true authentic self.

4.2.2 Eases the Psychological Pain

Eases the Psychological Pain captures how psychotherapy in cancer care helps deal with the emotional distress associated with the disease. Each participant spoke openly about the distress endured at different stages of their cancer journey and the need for emotional support to help them cope with it. The power of talking to someone who understood, who cared and who was not "*emotionally involved*" appears to provide a sense of comfort to the participants and relief that specialist care is present to help process the emotional impact of cancer.

Clare succinctly expresses what it meant to her.

"I was so scared that it was good to have someone to talk to about it" (Clare, 59-60)

This captures the terrible fear Clare felt after being diagnosed. Having someone to confide in proved to be beneficial for Clare at this time.

As Amanda describes the discomfort people have around cancer and how isolating the experience can be, she experiences her therapy as something which *"normalises it, it gets rid of the sense of isolation"* (Amanda, 161). Psycho-oncology seems to create an environment where Amanda does not feel different or isolated, implying that, as someone with cancer, she can feel this way in other environments. Her therapist's acceptance and normalisation of her emotional response to cancer helps rid Amanda of feeling isolated and therefore provides her with a sense of being understood, accepted and less alone.

This is further reinforced by Valerie's experience.

"if I'm feeling low or anything like that I don't say it to anyone, but I'll say it there, I'll say, I'll do it there but I won't do it anywhere else" (Valerie, 455-456)

Valerie seems to derive value and comfort from having someone to talk to about the psychological impact cancer has had on her. It appears that therapy is the only place where Valerie is willing and able to share her distress.

David describes how talking to his therapist helped him regain his confidence.

"I lost my confidence…. It's a consequence of the treatment and just what it does to you. You really need to, you really need to talk to somebody to get it back" (David, 357-359)

David struggled with a loss of confidence when undergoing his cancer treatment, unable to conduct activities such as driving and travelling abroad which, pre-cancer, had been routine. Here, he describes his own need to talk to somebody during this emotionally vulnerable time. David clearly identifies the need for someone to help him re-build his confidence. This is in the context of him finding it difficult to talk to others as expressed above. As David repeats the *"really need to talk to someone to get it back*", he seems to want to emphasise the meaning he derived from his therapy. According to this quote, David's regained confidence to resume important activities and support his adjustment to life after treatment was the due to having his therapist to talk to. David seems to feel very certain that the need to talk to someone and that need being met via his psycho-oncology played a significant role in rebuilding his confidence and helping him to "get it back".

Susan also describes needing someone to talk to.

"as strong as you are, you need someone to help, just to be there and help you along" (Susan, 302-303)

Her preface of *"as strong as you* are" implies the powerful nature of cancer. No matter how strong she thought she was, she acknowledges her need for psychological support to help her *"heal"*. This is further reinforced with another quote from Susan.

"*you may as well try to climb you know a fifty-foot high wall and not getting anywhere. So I think until you've found your mmm I think until you speak out how you really feel, you can't have the peace"* (Susan, 458-460)

There is a sense that she was struggling to overcome a challenge too great to conquer alone. When Susan accessed professional help and could start talking about her difficulties, it appears she could only then find the strength to start dealing with them. For Susan, this quote describes her therapy as a source of strength to help her navigate a difficult time and without which she would have continued to struggle on her own.

Clare speaks about her therapist knowing how to deal with the trauma of cancer.

"I think if the person has empathy and they kind of know how to handle how to say things in a gentle way… I think it shows that they realise how traumatic this whole journey is for people mmm yeah it's devastating" (Clare, 212-216)

Clare reinforces her message of having someone who understands cancer and who is sensitive in their interaction with her. Her acknowledgment of the devastating impact cancer can have, implies the devastation it has caused her. With devastation comes much emotional pain and Clare seems to experience her therapist as someone who helps alleviate this pain via a deep understanding of the disease and its effect on her.

Gloria talks about what her therapist meant to her.

"she was able to help me gain so much from what's happened to me. I didn't think I could gain anything except terror and sadness. I didn't think there was anything more to be gained from a cancer diagnosis except be so sad and so worried and yet it gave me so many other things" (Gloria, 452-455)

Gloria vividly describes the terror, sadness and worry she felt with cancer and the initial belief that it could involve no other emotional states, least of all, anything positive. It appears from her experience of therapy that she unexpectedly learned to view cancer differently and consequently, feel less distressed. Therapy seemed to have helped Gloria experience her emotional distress evolve into a process of discovery and personal growth, an unexpected yet welcomed outcome of what she had only anticipated as a frightening and sad transition.

4.2.3 Acceptance

Acceptance leads on from the above two sub-themes in what feels like a natural progression. The participants all describe their experience of therapy as a helpful and valued part of their cancer care. Having someone professional to talk to and help ease their emotional distress, the participants appear to have arrived at a place of acceptance, in particular, an acceptance of cancer, loss of control and uncertainty. Amanda's analogy of cancer being *"a houseguest that you're not that fond of, but you just get along with"* (Amanda, 729-730) exquisitely captures her own experience of living with cancer. In the following excerpt she describes a sense of personal self-acceptance.

"I needed to accept that I couldn't do anything about it, that this was something I was going to have to have to hand over and she helped me to learn about myself, that that's the way I am and she helped me learn it's not going to work here. That was very helpful…I am able to let things go, it's very difficult for me to let anything go but I've learned to let some things go" (Amanda, 589-610)

Amanda explains the difficulty she has in relinquishing control and how her therapist helped her not only understand this part of her personality, but to accept it and know when it proves helpful and unhelpful when dealing with her cancer and all cancer related issues. There appears to be a strong trust between Amanda and her therapist, a trust that Amanda believes her therapist has her best interest at heart. This is exemplified when Amanda describes the rich self-learning she has experienced via therapy and how it has served her well in different contexts. Her newfound ability "*to let things go*" appears to relieve her of unwanted struggles and bring her to a place where she can accept aspects of life and of cancer that she has little or no control over.

Clare also describes her sense of relief in accepting a lack of control in relation to cancer.

"Yeah and once you kind of accept that, it's really hard to accept that you have no control over an illness and mmm and whether the treatment works, it's hard, it's hard to accept that but it also gives you then a certain mmmm relief from the pressure to control it" (Clare, 115-117)

Susan talks about the help therapy gave her in moving forwards.

"I mean the counselling helped you just to live really, it helps you put one foot in front of the other and it's ok to be feeling the way you are 'cause then you can go onto the next step and the next step" (Susan, 539-541)

Susan's therapy appears to have normalised and validated her emotional responses which in return seemed to have helped Susan accept those same emotions too. These combined experiences have given Susan the ability to become unstuck and be able to move forward.

Valerie alludes to a similar experience of reaching a place of acceptance.

"I think it helped me to maybe heal with it, you know because I suppose I feel I'll probably always have something slight, something I dunno, a slight fearing….but that's ok once I can get on with my life because I think you, for me I really appreciate anything I can do you know" (Valerie, 378-382)

Valerie acknowledges the fear and uncertainty that she will always have, but it appears therapy has helped her to accept it and therefore live more at ease with it. This acceptance seems to have given Valerie an appreciation of all that she can do in her life in the midst of an ever-present underlying anxiety associated with her cancer experience. This acceptance suggests that Valerie no longer feels the intensity of the emotional distress she had described feeling earlier on, but has learned to live with uncertainty and as a result has learned to live her life with a sense of fulfilment and gratitude.

Gloria describes her therapy as a time when she found the ability to accept and live with cancer.

"I slowly emerged, we *emerged, we started to re-emerge with the ability and the strength to start to accept actually. That was it when you start to accept and in that acceptance, hugely powerful you know it's like yeah you just accept it, you I can't even talk about it now without getting emotional because eh you have to accept it and the acceptance is the beginning of making sense of everything for you. You know and then once you start to make sense, then you start to be at peace and then that's really powerful. You know that's how you move on, you learn to live with it"* (Gloria, 379-385)

Gloria's language here moving from *I* to *we* seems to express the sense that her experience is one where she feels her therapist has travelled with her on this journey and one in which they emerged together. Via this intimate process, Gloria has "slowly emerged" stronger and with a deeper sense of self-awareness. Her repetition of the word *accept* or *acceptance* emphasises this profoundly moving and powerful therapeutic experience, one which seems to have enabled Gloria to accept her cancer diagnosis, to make sense of it, learn to live with it and therefore empowered her to be able to "move on".

4.3 The Therapeutic Relationship

The therapeutic relationship is deemed the most influential factor in contributing towards positive psychological change. The participants frequently talked about aspects of the therapeutic relationship which they valued and which played a significant role in therapeutic outcome. In fact, the other two master themes and corresponding sub-themes, are arguably based on the strength of the therapeutic relationship. While it is not addressed explicitly, it underlies every aspect of the therapy. Capturing what makes their individual therapeutic experiences so meaningful, or not in some cases, appears difficult for the participants to articulate at times. It is almost as if the therapeutic relationship is something intangible or elusive. However, it is this intangibility or elusiveness that appears to lie at the heart of the experience and from which all other therapeutic interventions seem to stem. The therapeutic relationship is present throughout all data and so, it warrants its own master theme. Its three corresponding sub-themes, The Goodness of Fit, "A Safe Space" and "The Help That Helps You Help Yourself" aim to capture the essence of these experiences.

4.3.1 A Goodness of Fit

Goodness of Fit is a developmental psychological term that describes the compatibility of an individual's temperament with the features of their specific environment, including significant others. For individuals with emotional challenges, goodness of fit is an important factor in the adjustment process to life transitions. As the therapeutic relationship is part of each client's environment, it is the goodness of fit between client and therapist which seems to help each participant cope with having cancer and navigate this emotionally difficult transition. This compatibility or goodness of fit appears to be a key ingredient in forging a strong therapeutic alliance. It seems to be the bedrock to cope with emotionally distressing transitions and upon which rich and supportive therapy can occur.

Amanda captures this goodness of fit in her own words, acknowledging that it is not a guarantee.

"I found it helpful and I would imagine not every therapist and every patient match or get on well together or they suit each other. I'm sure there's strokes for blokes, but she certainly suits me" (Amanda, 269-271)

In the following extract, Gloria tries to articulate her sense of what good therapy means for her.

"they have to connect with me but not to the point that they're angry with me and sad with me to the point that they can't help me. But of course they're not going to be as angry or as sad. In fact, it's hard to explain. They have got to feel my anger and my sadness but it doesn't make them angry and sad 'cause they've got their job to do. They can recognise it and help me do something with it so yeah that's key. They have to come with you. They have to jump down in there and get their hands dirty and be willing to do that because they care, you know? To me it is about care, you know. It's almost like, I'd almost say it comes down to, that's too extreme a word, but it almost comes down to a love, d'you understand but it's just…love that word wouldn't be appropriate, but I think care is really where you're trying to say. I think that's really what what...I think that's the big thing for a counsellor or a psychologist or someone who is trying to help, they really have to care. They have to be able to care, care enough but be able to remain professional" (Gloria, 487-497)

Gloria gives an in-depth account of what she wants and hopes for in her therapeutic experience. This is based on her own experiences and therefore she tries to articulate the essence of what a "powerful" therapeutic experience entails. Her first need is to feel connected with. Gloria experiences the connection as a strong willingness within and from her therapist to emotionally connect with her. Gloria's reference to "jump down in there" seems to be linked to her earlier reference of *"that pit"*, a place of unknown territory, a *"fearful"* or *"sad"* place which she is unable to charter alone, but with her therapist, she can. As cancer has confronted Gloria with her mortality, it appears that the *"pit"* refers to her fear and terror of death. For Gloria, having someone professional and who "really cares" seems to help her navigate this emotionally difficult time. Gloria struggled to articulate how she felt with her therapist, suggesting love as “inappropriate” and yet it seemed to evoke a feeling of love within. This struggle was also evident in her body language as she held her hands in a way that was trying to grasp something. She seemed to want to be able to describe exactly what this experience involved and what it meant to her and yet gave the impression that she could not quite capture the experience in words. Gloria appears to experience her therapy as one of containment, demonstrating a capacity and a willingness to fully connect with Gloria’s experience and at the same time be able to tolerate it and help Gloria tolerate it too. Gloria’s unique experience is captured in her own words at the end of this extract – *“someone who is trying to help”, “they really have to care*” *“but be able to remain professional”* – three key characteristics that help her feel safe, deeply connected with and yet have a level of expertise and emotional composure to help the experience feel contained, thereby helping her to make sense of, process and deal with this life changing transition.

The above therapeutic relationship differs from another one she experienced after her father died.

“*She did help, but I didn’t find her warm and I like warm. I found her to be honest eh I found her too clinical and for me clinical doesn’t work, I’m sorry maybe for somebody they want that clinical approach but I think it’s the wrong way to go”* (Gloria, 322-324)

Here, Gloria states that what she felt as a clinical approach lacked warmth, did not meet her emotional needs and therefore seemed to lack a goodness of fit. Her use of the word clinical suggests that Gloria knew she was in the company of a professional, but the perceived lack of warmth that she so craved was missing. Gloria’s use of language here suggests that she may have felt somewhat uncared for and/or not therapeutically met. This therapeutic relationship ended after a few sessions which implies that without a willingness or capacity to emotionally connect with Gloria, the therapeutic relationship did not have the necessary rapport to continue.

Valerie describes the comfort and compatibility she felt with her therapist.

"it was feeling comfortable with somebody that mmm you'd nearly feel like, I nearly felt like if it was in another, if it was another time she'd be a nice friend" (Valerie, 349-350)

Here, Valerie describes the comfort she feels with her therapist by comparing it to a close friendship. Her phantasy of having a friendship with her therapist beyond the therapeutic relationship suggests a strong attachment she feels with her therapist, someone who understands her and is responsive to her needs. The therapeutic relationship appears to help Valerie feel at ease with her true self, reinforced later in the interview when she describes it as *"a place to be myself"*.

In contrast to Valerie, Clare talks about a lack of connection in her therapeutic relationship.

"it was a complete low for me and I arranged to meet the counsellor here I kind of, I got it all off my chest how I was feeling and what had happened and she was visibly upset by it…. Yeah and yeah and I realised that this is not actually going to help me and it's because she is a nice sensitive person but she wasn't mmmm it wasn't going to, I kind of said all the things that I was thinking that I couldn't say at home (Clare, 313-319)….Then suddenly I had to measure what I'm saying and then there was no point in seeing her again because well I could talk to somebody on the bus" (Clare, 576-577)

Clare described the time around her cancer diagnosis as "a complete low", a time when she experienced a sense of desperation and was "grasping at straws". Unable to turn to family and friends without feeling she was causing them more pain, she appeared to recognise her psychological struggle and needed someone to talk to. As Clare evidently shared her own concerns, it appears the therapist's incapacity to contain her own emotions caused Clare to feel she had to refrain from expressing her own distress. Again, Clare had previously spoken about cancer as a confrontation with death and the ability to talk about this in therapy rather than at home was important for her. It seems that Clare expected that therapy would be a safe space to talk about such personal matters. Clare's words in the extract above demonstrates her inability to explore certain subject matter without feeling like her therapist was able to deal with it herself. This therapeutic dynamic upset Clare, comparing it with being on the bus. Such an analogy suggests being in an open and public place where she could talk to anybody. Clare's need to talk to someone professional in a private and confidential setting and who could withstand her emotional distress was not met and therefore the relationship lacked a goodness of fit and ended soon after.

Similar to Clare, Amanda also describes a similar therapeutic experience.

"I wouldn't say anything against her except she started crying. She was out of her depth. *I can't remember anything else about her. She should have been counselling* in a different *area or something, but I felt she was in the wrong field so there wasn't any point in continuing"* (Amanda, 381-426)

Here, Amanda expresses her expectation of therapists working with cancer patients being able to tolerate and contain the emotional processes that can emerge with this population. Her perception of her therapist being "*out of her depth*" appears to echo Clare's experience. It seems Amanda thinks that she was exposing the therapist to subject matter beyond their therapeutic capacity and as a result there was no point in continuing therapy. There's a strong sense here that Amanda expects therapists working in cancer to have the experience and be able to deal with cancer-related processes. Amanda seems to quickly decide that this lack of experience is not going to work for her and the fit between Amanda and therapist transpires as not good enough.

Here, Susan expresses her need for empathy within the therapeutic relationship.

"I think that if they understand or you think that they are understanding you even if they're not, that doesn't matter, as long as you feel it mmm that made me feel better" (Susan, 281-282)

Echoing Gloria, Susan not only values the therapist understanding her, but also values the therapist's willingness and curiosity to try to understand her as equally therapeutic and thus helps Susan "feel better".

Amanda also describes the deep empathy she feels from her therapist.

"I am really grateful to have met Elaine who has an understanding, who has a complete understanding so you feel, I just feel very comfortable with her" (Amanda, 157-159)

The connection that Amanda captures in this therapeutic relationship seems to be the sense of feeling truly understood. In this experience, she feels at ease to be herself with someone who understands her and what she is going through. This deep sense of feeling understood and safe appears to sustain the relationship and provide Amanda with gratitude.

4.3.2 "A Safe Space"

"A Safe Space" and Goodness of Fit overlap on so many levels. Without one, the other cannot exist and without either, the therapeutic relationship is fragile and can end quickly. Much of what is experienced via the quotes above is reinforced in the quotes below.

David talks about what having "a safe space" means to him.

"it's just to have that safe place…it took a while to feel safe, but once it's safe, it's safe and you can let things out…it's a space, it's a trust, it's permission…to talk" (David, 199-207)

David expresses the gradual process of feeling safe in the therapeutic relationship. It appeared to develop over time, where trust had to be earned and was necessary for him to "let things out". David had earlier described his first impressions of his therapist as liking "*her from the first time I met her, but just 'cause you like someone does not mean that you'll trust them"* (David, 89-90).

This distinction between liking and trusting emphasises the vital distinction between feeling safe and unsafe *"to let things out*". His use of language and his tone of voice both suggest an assertiveness and certainty about transitioning into a safe place and one which would never not feel safe again. *"Permission to talk*" alludes to a trust between David and his therapist, a trust that he feels safe to disclose his inner thoughts and feelings, thereby letting his therapist into his inner world. This safe space seems to give David the capacity to open up and help him deal with issues he was struggling to face which consequently helped him regain his confidence and sense of hope.

Clare describes a similar therapeutic experience.

"it was just the word is behaviour but it's not behaviour as that sounds like he was doing something, it wasn't like that no no it was….nothing was going to faze him, he was kind of mmm…. controlled…. well I felt like it was a safe space" (Clare, 543-556)

Clare struggles to articulate exactly what it was about her therapist that seemed to create a place where she felt safe. This is evident when she searches for a word that is like behaviour but not behaviour. It seems she is trying to describe a way of being. A therapist who is not fazed seems to be one who embodies composure, containment and experience.

This way of being appears to create a safe space for Clare where she can engage with her emotional distress and feel confident that her therapist will remain "controlled" and not fall apart.

In the following extract, Amanda talks about her freedom to express in therapy.

"I can have whatever attitude to cancer or to my own cancer that I want in that room and nobody's going to be offended, hurt, threatened, scared, angry, disappointed, any of those things. It's a professional relationship….I can say anything…it's like throwing off your shoes and sitting back and going wait til I tell you. I don't have to structure it, typex bits out or mould it" (Amanda, 485-508)

Amanda feels free to say and feel anything in therapy in the knowledge and safety that her therapist will not judge her nor be emotionally affected like perhaps she experiences with others in her life. This accepting, non-judgemental responsiveness by her therapist provides Amanda with a safe space to feel at ease and refreshingly candid about her cancer and related issues. A "professional relationship" seems to be the only place she can feel truly relaxed being this way. This ability to express herself without having to edit her words or emotions seems to provide Amanda with a sense of relief and freedom, knowing that she can be herself in the presence of someone who remains reliably safe and accepting to be so.

Gloria draws on her analogy of "the pit" again to describe her experience of feeling safe.

"they've got to pull their sleeves up and get in the pit, get into that pit, digging with you and dig with you and see what you are finding and help you to understand what you are finding, what YOU are finding because everyone is different. They can really help you, you know what you uncover and if it scares you or it doesn't make sense to you, that's what their job is, in that pit with you and help you make sense of it as you dig away and

you dig that and you uncover that and it's fearful or it makes you sad and then you've got somebody there to help you with that sadness" (Gloria, 468-477)

Gloria's vivid description of the therapeutic relationship provides her with a safe space to be able to dig deep within so that she can start to understand and make sense of her cancer experience. Gloria's image of the therapist rolling up their sleeves implies a willingness to embark on a process of excavation with her. As her therapist "*digs"* with her, she starts to feel in safe hands and as a result no longer feels so alone to confront what scares and saddens her the most about having cancer. For Gloria, it seems that this willingness and capacity to "dig" with her and to be with her throughout this sense making process, is the most powerful therapeutic intervention in helping her to cope and come to terms with this difficult life transition.

4.3.3 "The Help That Helps You Help Yourself"

The above sub-theme is a quote from Amanda (Amanda, 38) who used it to describe what her therapy meant to her. It embraces the overall message that each participant expressed as a meaningful and helpful part of their cancer care at various stages of the disease trajectory. No participant spoke about a model of therapy practiced or any knowledge of such, but Amanda's words and indeed those that follow suggest that their therapy was at times directive, providing helpful strategies while adjusting to life with cancer. The effectiveness and indeed acceptance of these interventions seemed to be contingent on a strong and trusting therapeutic relationship and the ongoing relational processes that existed within each relationship.

Gloria describes the permission to demonstrate therapist theory and knowledge only after demonstrating a capacity to connect with her as a human being.

"I'm going to give you your licence if you connect with me as a human being….now you can go into your bag and get your tricks out. Because you want them, to have some tricks. That's what you're there for. I feel they have the right then…..but that initial thing is so important and it has to happen early because if you don't, you can lose the person and you lose them terribly" (Gloria, 517-527)

Here Susan describes how certain therapeutic interventions helped her cope with returning to work.

"I went back to work….and I was starting to find that anxiety levels were starting to increase….I did go to a counsellor….I found that very helpful in just getting to my place of mindfulness, that stillness, that piece of blue sky that I can look out on and for just a couple of seconds just think of nothing" (Susan, 253-263)

Susan seemed to be lacking confidence as she returned to work, worried about her ability to perform tasks. This transitional period caused her to start feeling anxious again after a time of feeling stronger within herself. Susan's description demonstrates the difficulty she had in adjusting to life after treatment and the anxiety she felt as she returned to work, thus acting as a catalyst to seek professional help. Without explicitly knowing or stating any specific therapeutic model, it appears Susan learned a mindfulness practice which served to alleviate her anxiety and helped her to "think of nothing" only an appreciation of the present moment. Knowing she can draw on this technique appears to give Susan a sense of control at a time of uncertainty and when she seemed to feel particularly unsure of herself.

Valerie describes a similar outcome of therapy.

"I had stopped travelling, I had panic attacks but anyway so I wasn't kind of going anywhere and then and while I was going to her eh I started travelling again and going

places. It was all through actually going to her, I kind of I suppose built up my confidence again and I started doing things….she was really excellent" (Valerie, 273-277)

Valerie expresses her loss of confidence and intense fear after her personal experience with cancer. Without going into explicit detail of what she learned in therapy, Valerie identifies therapy as a medium of change. The therapeutic relationship helped her to re-build her confidence and resume activities that she had been fearful to do on her own. It seems Valerie learned to overcome these fears, regain her sense of independence and adjust to life while she was attending therapy.

David talks about how therapy helped him through his cancer treatment.

"when I was on treatment, to say that it got me through, it certainly got me in the right frame of mind to actually tackle these kind of things" (David, 11-12)

During the interview, it seemed David wanted to articulate the seriousness of his state of mind when undergoing chemotherapy and the value he derived from having psycho-oncology to help him cope with it. In this excerpt, David credits his therapy with helping him to mentally deal with the physical and psychological pain he endured at this time. David alludes to the fact that his psycho-oncologist helped him approach his treatment with a more helpful perspective. This therapeutic experience seems to have given David the mental strength to better deal with cancer and its treatments, thus potentially making him feel less vulnerable.

Clare articulates how a therapeutic intervention immediately helped her feel better.

"it kind of gave me the permission to have all my emotions and not feel bad about feeling bad or negative and instantly I started to feel more positive so from that perspective it was just really helpful" (Clare, 16-18)

Clare seems to feel huge relief in being given permission to feel all the emotions she was feeling. Clare had shared earlier in the interview that her therapist had informed her that her emotional state would not affect the treatment. This key piece of information "backed by science" (Clare, 92) provided Clare with a huge sense of relief and rid her of the guilt of not always feeling positive. This therapeutic intervention appeared to help Clare feel more relaxed and less burdened with a responsibility to try to control her emotions and via this, control the outcome of treatment. Clare goes on to say.

"If I hadn't had this the counselling at time of treatment well I'd have gone through it all without those key things that helped so it was good to hear those things up front" (Clare, 505-507)

These helpful therapeutic interventions seemed to serve Clare well to better deal with her own cancer experience.

“Out of the crooked timber of humanity, no straight line was ever made”
- Immanuel Kant, Idea for a Universal History with a Cosmopolitan Purpose

CHAPTER 5: DISCUSSION

Conducting this study elicited important knowledge and understanding on the lived experience of psychotherapy in cancer care. Unlike previous studies, it did not focus on a time-limited or specific model of therapy and as such, the findings presented a deep exploration into what aspects of the phenomenon was most meaningful and therapeutic to each participant. This study set out to explore cancer patients’ experience of individual psycho-oncology in a specific healthcare setting, the Republic of Ireland. Based on the qualitative methodology employed, namely IPA, the study hoped to discern from these subjective lived experiences, cancer patients’ feelings, thoughts, perceptions and sense making of psycho-oncology and to understand what it means to them during the cancer coping process. Another aim of the study was to give voice to cancer patients so that the experience of psychotherapy in cancer care is expressed and understood from the service user perspective. The results elicited rich and detailed data and have provided valuable knowledge to further inform and develop practice in the specialist field of psycho-oncology. The main themes that emerged included *Cancer Patient Needs, The Power of Talking* and *The Therapeutic Relationship,* all of which seemed to capture the essence of this sample population’s lived experience of individual psychotherapy in cancer care. This final chapter will review the outcomes of the study, identify its limitations, suggest potential areas for further research and discuss implications for clinical practice and training in psycho-oncology, counselling psychology and indeed all related fields.

5.1 Review of the Current Findings

The six cancer patients' accounts capture both positive and negative experiences of therapy with no mention of specific theoretical orientations employed. This suggests that patient focus is not necessarily on specific models of therapy, but rather on therapist values and relational capacities and processes within this specific context. Future research should arguably therefore shift focus from investigating and comparing specific theoretical models towards other aspects of psychotherapy in cancer care. It is evident across all themes that the most useful therapeutic help and support were based on a strong and trusting therapeutic relationship. The Therapeutic Relationship underpinned all relevant data, hence supporting the claim "it is in the therapeutic relationship that therapists either make or break therapy" (Blow, Sprenkle & Davis, 2007). It lies at the heart of this phenomenon, upon which positive and negative experiences occurred, thus reinforcing the words of existential psychotherapist, Yalom (1989, pp 91) "it's the relationship that heals, the relationship that heals, the relationship that heals". Each participant spoke openly about feeling safe and understood in therapy, thus nurturing a comfortable and supportive space for them to freely express their thoughts and feelings across different stages of the cancer trajectory. A knowledge of cancer and its processes, a capacity to engage in emotionally charged conversations, 'being with' rather than 'doing to' and a flexible approach to care seem to be crucial factors in creating a safe space for patients to process their emotional distress. The three master themes encompass these phenomenological experiences, thereby supporting and further adding to existing knowledge in this specialist field.

The first master theme *Cancer Patient Needs* and its three corresponding subthemes all relate to specific aspects of the sample population's experience which carried substantial value and meaning for each person, especially in meeting individual needs. *The*

Competent Therapist – Someone Who Understands Cancer was an essential ingredient for patients feeling understood. Knowledge and experience of cancer gave the patients a sense of confidence, safety and relief. Such knowledge normalised and validated worries and fears associated with the disease and its treatments, thus supporting existing theory and practice in the field (Schmale, 1976; Omylinska-Thurston & Cooper, 2014). Therapist competency seemed to nurture a trusting space for patients to discuss subject matter that was difficult to talk about with others. It provided reassurance during a time of fear and uncertainty. Patients expected therapists working in psycho-oncology to have a knowledge of cancer so that they could more easily bring up topics directly related to the disease. This medical expertise served to help patients in the adjustment process via explicit and implicit knowledge of cancer and its impact. This capacity supported patients in feeling understood and safe to explore strong emotional experiences associated with the disease, thus reinforcing the key ingredients of supportive psychotherapy in cancer care (Lederberg & Holland, 2011). Such an experience meant therapy could inform patients which helped ease their distress and as a result reclaim a sense of agency back into their life.

Due to the real-life setting of this study, patients were also able to report on experiences whereby they perceived a lack of therapist knowledge and experience of cancer. Such an experience resulted in patients feeling upset, invalidated and misunderstood. Patients valued therapist capacity to delve deep into what the cancer meant to them. This involved processing a poor prognosis and the reality of being faced with one's mortality, thus demonstrating the relevance and appropriateness of existential and psychodynamic interventions in the cancer setting. For some, death anxiety presented itself overtly or consciously and for others it was unconscious, concealed behind other symptoms which were brought to the surface via a deep exploratory and dynamic process. The experience of being able to charter such topics with someone who understood but who was not emotionally involved helped patients to process this difficult transition via normalisation validation and containment. Again, when patients perceived a lack of therapist capacity to explore, tolerate and contain such emotionally charged material, patients stopped sharing such internal processes and ended therapy. Containment, a psycho-dynamic term (Bion, 1962) is crucial to allow patients to explore feelings that are experienced as overwhelming or frightening. Containment in therapy demonstrates to the patient that such feelings are manageable, can be tolerated and explored, thereby reducing their distressing impact. This capacity in psycho-oncology is essential to help and guide the patient through the cancer experience, especially when facing fears of death and dying (Lederberg & Holland, 2011).

This study also found that feeling understood was further reinforced by the therapist being a "*fellow survivor*" and sharing such information. Therapist disclosure is a debatable topic in psychotherapy, but this study supports evidence that disclosure can be meaningful and of value when it is of benefit to the client/patient (Spinelli, 2002) and can further strengthen the therapeutic relationship (Henretty & Levitt, 2010). Therapist disclosure in this context strengthened the therapeutic relationship, made the cancer patient feel deeply understood and cared for, thus providing help and support to navigate a "*terrifying*" process.

Other meaningful experiences associated with psycho-oncology included accessibility and availability of psychological support for patients and a flexible approach to care, including timing and frequency of therapy. Unlike other studies whereby participants had a set number of sessions within a limited timeframe, this study found that patients accessed psycho-oncology sporadically. Timing of therapy depended on individual needs and therefore it varied from one individual to another depending on stage of the disease and personal circumstances. Knowing that psycho-oncology is available if/when required provides the patients with a secure base – a sense of security and comfort, perhaps providing them with a sense of certainty during uncertain times (Nelson, 1996) or towards what Mason (2015) describes as a position of "safe uncertainty". It demonstrates the value and role of having a strong and trusting therapeutic relationship to provide patients with consistency, comfort and security throughout the cancer experience and not one that they need to access regularly, but more that they hold it in mind. This attachment to a secure base appears to provide positive therapeutic outcome, mirroring our need for it across the lifespan.

Patient knowledge of psycho-oncology seemed to be lacking prior to the referral process and eventually accessing appropriate services. Cancer patient unawareness of psycho-oncology as a specialism within cancer care highlights the lack of psycho-oncology prominence in this specific healthcare setting. It also raises the possibility that hospital appointments/consultations tend to focus on the physical aspects of the disease with the psychological impact of cancer still not receiving much attention and therefore not yet integrated into overall oncology care (Madden, 2006; Towers & Diffley, 2011). Patients all experienced comfort and support in being informed of and recommended appropriate psychological support and thus availed of it when required. This supportive and flexible base seemed to give them a type of safety blanket which they knew they could avail of if/when required. Knowing they could draw on it at specific times proved to be an important aspect of their overall experience. Improved communication and increased awareness of psycho-oncology in hospital settings could educate and prepare patients for the psychological aspect of the disease and then provide them with optional access to psychological support at times of need during the cancer journey.

Themes relating to *The Power of Talking* all captured the impact and meaning derived from the experience of psycho-oncology as a place to talk about cancer and related issues with someone who understood the disease. For patients, cancer can still be perceived as a taboo topic, one that others do not want to discuss and therefore patients can refrain from talking to others about. According to patients, it can also be difficult to talk to family about cancer. They want to protect loved ones from more suffering and therefore do not want to burden them with their own distress. This can make living with cancer an isolating and lonely experience for cancer patients. Having someone to talk to who is not emotionally involved and who listens in a non-judgemental, empathic and caring way provides much relief for patients. Therapy eases the isolation and stigma that exists with cancer and therefore can help patients feel less alone and more related to as a human being. These findings echo other qualitative studies exploring psychotherapy in cancer care (MacCormack at al., 2001; Boulton et al, 2001; Omylinska-Thurston & Cooper, 2014) and thus reinforce Carl Roger's (1961) emphasis on humanistic core values as central components of positive therapeutic outcome.

These relational qualities are emphasised by cancer patients as the most meaningful moments in their therapeutic experience, when they feel understood, deeply connected with and therapeutically met. In fact, it seems from the subjective experiences reflected in this study, the "licence" to "do to" in therapy will only be accepted if the capacity to "be with" is explicitly and implicitly demonstrated. Therefore, more directive therapeutic interventions associated with "doing to" therapy were more openly received after trust and rapport had been firmly forged in the therapeutic relationship. This "doing to" versus "being with" in therapy supports MacCormack's (2001) study which elicited similar findings from cancer patients' experiences of psycho-oncology. These findings challenge studies exploring psychotherapy from therapists' perceptions which tend to point towards the “doing to” approach (Timms & Blampied, 1985). This study brings to light the relevance and value of obtaining client/patient experience to understand from their perspective what really helps in therapy. The key ingredients of supportive psychotherapy in cancer care stretch back to the early 20th Century when “caring for the patient is CARING for the patient” (Peabody, 2015) which emphasises a truly human interaction and connection with the patient. In light of this study’s findings, the relational processes and the emphasis on “connectedness above all else” (Yalom, pp 206, 2008) must be closely attended to in this context. Research to date has focussed more on the delivery of manualised therapies which can more easily be monitored and measured via pre and post outcome measures. However, this study’s exploration into the lived experience of psychotherapy in cancer indicates aspects of psychotherapeutic interventions which are not manualised and time-limited, but attend closely to the relational processes that exist within the therapeutic relationship and over time.

As a confrontation with death, cancer is deemed an existential crisis. Yalom’s analogy of engaging with death as “staring at the sun” aptly captures this encounter as one that we instinctively turn away from to protect us from the painful reality of being mortal (Yalom, 2008). It can be difficult to express fears and thoughts relating to death and dying. This study showed how having the opportunity to talk to someone about these anxiety provoking processes provided cancer patients with a sense of relief or letting go. In being able to freely express themselves in therapy, confront and discuss such difficult topics as death and dying, the patients became less scared and less burdened. Having the space to confidentially talk to someone who understood and cared helped the patients come to terms with their diagnosis, regain a sense of self-confidence and adjust to life post diagnosis. The process of talking to a therapist in cancer care about deeply personal concerns emphasised the strength and value of genuine human connection as “the antidote to much anguish” (Yalom, pp. 205, 2008; Yalom, 2010)

The relationships in this study between therapist and patient had a considerable impact on patient experience, thus corroborating the key role of the therapeutic relationship in therapeutic process and outcome (Safran, 1993; Yalom, 1980, 2010; Orlinsky & Howard, 1986). The patients experienced warmth, non-judgement, professionalism and care as important therapist values. The capacity of the therapist to demonstrate a willingness and curiosity to understand the patient in addition to having the capacity to understand cancer and its processes were crucial to patients reflecting on meaningful and positive experiences of therapy. Some patients reluctantly criticised occasions when the therapist became emotional and therefore negatively affected the therapeutic process. Such experiences made patients feel like they were with someone who was “*out of their depth”* and therefore unable to help them. Cancer patients need to be able to talk about their disease and what it means to them with a therapist and therefore it is important that the therapeutic space is containing and safe to do so. Feeling safe in therapy was vital to the patients’ candid expression of difficult psychological processes.

Patients spoke about the meaning derived from having someone who really cared and who connected with them as a human being. It was this trust and care that evolved in therapy that helped patients start to re-gain self-confidence, learn to cope and adjust to life with cancer. This relational bond was forged and strengthened by feeling safe in the company of an empathic, non-judgemental and genuine therapist. This was further reinforced by therapist capacity to demonstrate professionalism and competency in psycho-oncology, thus providing appropriate and well-timed therapeutic interventions to meet individual needs. These combined therapeutic skills seemed to help patients feel more deeply supported, understood and cared for along the disease trajectory. This study emphasises the need for psycho-oncologists to be able to draw on several therapeutic interventions. Such findings support a pluralistic approach to therapy in this context (Cooper & McLeod, 2012), thereby conducting meaningful and individualised therapy that remains, at its core, patient or client-centred.

5.2 Evaluation and Limitations of Study

This qualitative study, as with all research studies, has its strengths and limitations. As the sample population included four cancer patients who had accessed therapy in the past and two who were currently accessing therapy as part of their ongoing care, there were different time frames from which patients were recalling their experiences. This was due to the stage of cancer each participant was at and when psycho-oncology was availed of. Therefore, the experience of psycho-oncology was based on both retrospective and current experiences. Retrospective experiences via personal recall may not have captured all aspects of the experience as they lived through it, but instead were articulated thoughts, emotions and perceptions which remained in their memory as meaningful at the time of interviewing. However, due to factors pertaining to time lapse, some valuable subjective data may have been missed in their recall of events. Therefore, as much as rich and meaningful data was elicited via this exploratory process, some experiences that were also important but were potentially less remembered may have been overlooked. Perhaps an area for future research would be to only include a sample population of cancer patients who are all currently attending psychotherapy in cancer care. This would counteract any interference that time may have played in experiential recall.

Also relating to the sample population, therapy was accessed via different clinical pathways and therefore experiences varied from one participant to another such as number of sessions, stages of disease trajectory, number of therapists seen and capacity to avail of ongoing psycho-oncology. While this provided insight into the experience of the phenomenon itself, it did provide a variety of data which again may have interfered with recall, thereby overlooking certain important experiential information. However, these variations reflected the real-life experiences of these six cancer patients as experienced in a real-life setting and therefore were integrated into the overall outcome of the study as deemed relevant and appropriate to the research question.

Due to the nature of this qualitative research, little is known on the specific details of therapist or service that each cancer patient accessed and/or availed of. While this served to capture a real-life experience whereby patients were not involved in an RCT, knowingly receiving a specific model of therapy nor accessing one psycho-oncology service, it did mean that details of psychotherapists were unknown such as theoretical orientation, training, qualification, years of experience etc. While this may have helped to identify some important data on the phenomenon, the absence of such information contributed to a very organic bottom-up exploration of psychotherapy in cancer care. Such a process supported the investigation to focus on the very essence of what the lived experience entailed for each participant without any preconceived ideas or biases about therapeutic model or concrete therapist values.

5.3 Future Research Directions

Due to informative qualitative studies pertaining to psychotherapy in cancer care, a deeper understanding of psycho-oncology from the patient perspective has been gradually accrued. Such research has provided rich data on therapeutic processes in psycho-oncological care. A qualitative study exploring this same phenomenon from the therapist perspective would provide insight from the practitioner side that could have valuable implications for training and practice in this specialist field. Little is known about therapist experiences of working in the cancer context and exploring such would therefore give another “insider perspective” to further inform practice and training in this field.

Based on this study and existing research in the field, it seems a pluralistic approach is deemed most effective for cancer patients. Several theoretical models have been of value to cancer patients with no one therapeutic orientation deemed more superior than another. The capacity to draw on several therapeutic interventions with supportive psychotherapy acting as the key ingredient is in fact favoured in psycho-oncology (Lederberg & Holland, 2011). Therefore, a qualitative study investigating cancer patient experiences of psycho-oncology at specific stages of the cancer trajectory could potentially inform psycho-oncologists on the most appropriate interventions to use at specific time points. This could elicit important information in terms of the best use of resources and at the same time endeavouring to best meet cancer patient needs.

Results of this study suggest that accessibility and availability of psycho-oncology is not yet straightforward with many of the participants being unaware of specialist psychotherapeutic resources in cancer care. A useful study would be to explore oncology practitioner perspectives on integrating psycho-oncology into the cancer care plan and ways in which they think this could be more easily communicated and implemented in the cancer setting. This could provide ways to improve referral pathways and to ensure that patients are informed of psycho-oncology as an integral part of cancer care.

Future research directions are endless as methodologies to investigate areas are many and all elicit different yet valuable data. It is about how methodological approaches can compliment each other to further deepen understanding and knowledge on important aspects of cancer care. Many healthcare systems, including RoI, are working towards fully integrating psycho-oncology into cancer care. It seems appropriate and of immense value to understand from both patient and practitioner perspective how this can most easily be achieved so that the transition to a whole person approach to care is as seamless as possible, and most importantly, patient needs are met in a realistic and timely manner.

5.4 Implications for Clinical Practice and Training

The implications from this study for clinical practice and training include emphases on relational aspects of therapy, attending to dynamic processes, embodying humanistic or Rogerian core values, therapist knowledge and understanding of cancer, capacity to explore existential concerns and flexibility of care. Patients did not reflect on a specific model of therapy, but instead valued having a safe space to openly and freely express themselves, to process the impact of cancer and its treatment, charter fears around death and to help cope with it going forward. This safety emerged from having a therapist who was empathic and caring, who demonstrated knowledge and competence in cancer-related issues and was willing and able to explore and contain emotionally charged material. Having the capacity to access and avail of psychological support at different stages along the trajectory was also a valuable part of psycho-oncology. These key findings suggest that clinical practice and training in psycho-oncology and indeed other relevant psychotherapeutic fields need to emphasise the importance of relational values in therapy, competency in the specific topic(s) addressed, flexibility of care and therapist self-care to manage intersubjective processes in the therapeutic relationship.

Core Humanistic Values and Relational Capacities in psycho-oncology: The core humanistic values including empathy, authenticity, positive regard and non-judgement are therapist qualities that seem to be of utmost importance for cancer patients and arguably other clinical populations. The findings of this study imply that training and practice needs to dedicate significant time and space for these core values and skills and to emphasise the importance of embodying them as a way of being so that their manifestation is authentic and real. Psychotherapy training and practice can sometimes spend much time on theory and applying that to practice, but it seems that core humanistic values require considerable attention and upon which all other therapeutic interventions can be most effectively applied. All models of therapy emphasise the therapeutic relationship as the key medium for change. This study reinforces the relational capacity of the therapist to attune to and connect with the patient as powerful therapeutic interventions, thus highlighting the relational processes as key to meaningful therapy.

Flexibility of care: psycho-oncology is not necessarily required by patients at one stage of the cancer trajectory, constantly throughout the cancer experience or for a set number of sessions. Therefore, therapeutic boundaries need to be somewhat flexible in cancer care. This includes being more available at specific times along the disease trajectory, knowing and understanding when the patient requires psychological support and therefore having a flexible approach to care. Therapist boundaries in psycho-oncology therefore need to be more flexible than perhaps in other psycho-therapeutic settings. This needs to be outlined to psycho-oncologists (especially those starting off) working in this field so that they can adequately adapt their practice to the cancer context and meet cancer patient needs.

Knowledge and competency of cancer and related processes: This is essential when working therapeutically with cancer patients. This study implied that without pre-existing knowledge and/or experience of the disease, patients can feel invalidated and misunderstood. Conversely, therapist knowledge and experience of the disease contributed to patients feeling safe and understood and their thoughts and emotions normalised and validated. Therapists need to ensure sufficient background knowledge of the disease is accrued, an aspect of psycho-oncological practice that needs to be emphasised to trainees and qualified practitioners. Patients who have been referred on for psycho-oncology understandably expect a level of expertise in cancer care which is meaningful and helpful for them in dealing with this challenging life experience.

Therapist Self Care: Cancer brings up challenging and highly charged emotional processes. A disease that confronts patients with their mortality, cancer also confronts the therapist with his/her own mortality as conversations around illness, death and dying occur. The implications of this study suggest that therapist capacity to engage in such conversations has a strong effect on patient experience of psycho-oncology. Those therapists who could engage with and contain these emotionally charged conversations were considered profoundly helpful and meaningful. Conversely, therapists who struggled to engage with and contain such emotionally charged processes were considered unhelpful and out of their depth, thus resulting in patients deciding to end therapy. Therapists working with cancer patients therefore need to be able to engage in a meaningful sense with death and other existential related issues. To best meet cancer patient psychological needs, a strong level of therapist self-care and reflexivity is required to be able to deal with the challenging processes that emerge within the therapeutic relationship.

Psycho-oncology requires a flexibility that is unlike other psychotherapeutic settings. Location, timing and therapeutic approach needs to adapt to the often changing physical and emotional needs of the patient. Evidence based research has shown that cognitive behavioural interventions can often prove effective with patients, when for instance a more structured and solution focused approach can reclaim a sense of control that can at first be perceived as lost. A psycho-dynamic approach allows psycho-oncologists to interpret the lifelong narratives of the patients that can contribute to their entire relational experience with cancer (Nash, Kent & Muskin, 2009). Current research in this field focusses more on RCTs and manualized therapies which can therefore result in a prominence of these approaches in the current medical model. Therapies such as existential and psychodynamic, which do not conform to this form of manualized and time-limited practice, have shown to be highly appropriate to use in the cancer context and this study demonstrates such. While the theoretical interventions are not necessarily obvious in terms of participant language, their experiences allude to central dynamics of these relationally focused models such as containment (Bion, 1962) and a strong holding environment (Winnicott, 1953) to explore difficult emotional experiences.

The participants did not mention any specific model of therapy. However, their subjective experiences expressed a need for and value in aspects of several therapeutic interventions. These include a capacity to gain new and more helpful perspectives, draw on strategies that helped gain sense of control and calm, move towards acceptance, feel deeply connected with and understood, capacity to explore and process (conscious and unconscious) fears triggered by the cancer experience and feel contained and therapeutically held to experience such exploration. Such findings demonstrate value and meaning from a range of therapeutic interventions, all of which are based on several theoretical approaches, including CBT (2nd and 3rd wave), existential, humanistic and psychodynamic. The complexity of the disease and each individual case therefore seems to require a more flexible and holistic approach whereby therapeutic interventions are grounded rather than driven by theory and the client rather than the model maintains centrality Being able to integrate appropriate therapeutic models provides deeper insight into an individual's internal and external world, thus enabling the experience to provide space for further therapeutic exploration and support. Adopting an integrative or pluralistic approach within the therapeutic relationship arguably provides greater opportunity to connect more deeply with patients and attune to their lifeworld. Restricting practice to a one model approach in my opinion, would therefore hinder this rich process and diminish the opportunity to conduct meaningful therapy that remains, at its core, client-centred.

5.5 Reflexive Conclusion

Conducting this research has been one of the most profound experiences across my doctoral training. An immersive experience, digging deep within each participant's lifeworld, it has emphasized to me the complexity and richness of research and its role in informing practice. Pausing to reflect on this experience, I will attempt to articulate these reflections as transparently as possible in this final reflexive conclusion. These include my impact on the study, the study's impact on me and with the gift of hindsight, would I make any changes if given the same opportunity again. All of the aforementioned are inextricably linked, with a constant ebb and flow occurring between my impact on the study and the study's impact on me.

I was working therapeutically with cancer patients for a substantial part of the data collection. During this time, I had an insatiable appetite to accrue knowledge and further develop my practice in this specific context. This project sporadically served to satisfy that hunger by enabling me to gather rich and detailed experiential knowledge on a phenomenon that I was actively involved in as a researcher and as a trainee practitioner. It was crucial to be aware of this ongoing process of osmosis between research and practice and respond to it accordingly.

My insatiable curiosity manifested during data collection and analysis whereby my impact on the study was most evident. It is an aspect of myself that I always need to remain aware of and recognize its strengths and limitations. During the data collection, this natural predisposition to want to obtain as much information as possible alongside a strong motivation to meet patient needs, positively affected my capacity to conduct interviews which elicited rich and detailed data on the phenomenon in question. However, I was also aware that sometimes my probing was more practitioner led than researcher led. This same tendency recurred during analysis whereby I recognised the lines between researcher and practitioner being somewhat blurred, resulting on occasions with my own personal agenda taking precedence. Retaining a strong level of objectivity is crucial in research and therefore, it was necessary to be acutely aware of my own biases and motivations, ensure appropriate response to them and minimize as much as possible any personal interference. This was made manifest via a reflective journal and use of supervision which supported me in bracketing such potential interferences and staying rooted in the data itself.

Echoing my opening reflexive statement, nothing quite matches real life experience to deepen human understanding. The actual experience of conducting this study connected me more deeply as a human being with the phenomenon of research itself and indeed the phenomenon under exploration, psycho-oncology. It emphasized the important role research plays in informing practice and at the same deepened my own understanding and knowledge of how cancer patients experience therapy. It has provided me with a fertile foundation on which to continue my personal and professional development in Counselling Psychology. As part of my identity as a Trainee Counselling Psychologist (TCP), I value subjectivity and individual needs and this study enriched my experiential understanding of these two concepts. Interviewing a small sample population, gathering rich and subjective data and analyzing it with a phenomenological lens contributed hugely to my growth as a TCP. It reinforced the value and role of this lens to deepen knowledge and inform practice.

The intersubjective nature of IPA appeared to support the participants' willingness and ability to discuss such personal stories and delve deep into the essence of their human experience, thus ensuring each voice was heard. Their honest expression of how cancer confronted them in a very meaningful sense with death demonstrates how cancer can penetrate the ultimate limitation of human existence, being mortal. Therapist capacity and willingness to discuss emotionally charged material and navigate difficult existential concerns highlighted to me the immense value and importance of such therapeutic interventions when working with this clinical population. I carried these experiences with me during clinical placement and I believe it helped me to engage and connect more deeply with my client's fear of death and indeed my own, a dynamic I have discovered as integral to working within this specific context, but on further reflection, is integral to all psycho-therapy.

This study is what it is because of the experience it has been, and I wouldn't change that experience for anything. However, I must recognize that hindsight can be a wonderful thing and it offers an opportunity to reflect on the past and learn from experience. The difficulty in shifting between researcher and practitioner proved challenging at times. Perhaps I would conduct the study while not simultaneously working therapeutically with cancer patients. This may have enabled me to more fully embody the researcher stance and arguably at times retain a stronger level of objectivity. That said, my emotional involvement, curiosity and passion for pursuing this specialist field have all been key factors in conducting this study and creating an exploratory process where *diving for pearls* (Smith, 2011) became a reality.

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APPENDICES

APPENDIX A: Introductory Letter

LONDON
METROPOLITAN
UNIVERSITY

Dear

Re: Research exploring *cancer patients' experience of their psycho-oncology/psychotherapy in cancer care*

I am currently attending London Metropolitan University on the Professional Doctorate in Counselling Psychology. My chosen area of doctoral research is in the area of psycho-oncology. As an Irish citizen, currently living and studying in London, I have both personal and professional interest in pursuing this area of research. Having read much research already conducted within this field, I have decided to pursue a particular aspect of psycho-oncological care that is under researched with the hope of producing valuable knowledge for patients and practitioners alike. The topic is to investigate, via qualitative analysis, cancer patients' experiences of their psycho-oncology within the Republic of Ireland.

My aim is to learn from the experiences of cancer patients currently accessing and availing of psycho-oncology, with a view to enhancing our understanding of the experience and informing future care for patients. Please find an information sheet and form of interest attached herewith for you to give potential participants.

Should you have any queries, please do not hesitate to contact me via email or telephone as listed below.

Tel: [redacted]

Email: [redacted]

Yours sincerely,

Libby Lyons.

Doctoral Researcher, London Metropolitan University

APPENDIX B: Research Information Leaflet

Cancer patients' experience of their psycho-oncology/psychotherapy in cancer care

Hello,

My name is Libby Lyons and this research study forms part of my Professional Doctorate in Counselling Psychology. As an increasingly important aspect of cancer care, psycho-oncology seeks to help cancer patients understand and manage the psychological impact of the illness. My research seeks to explore **cancer patients' experiences of their professional psychological support within Ireland.** Such insight hopes to deepen understanding and further inform and improve practice in this field.

Participants for this research need to be:

- Adults of 18+ years
- Diagnosed with cancer
- Experience of individual psycho-oncology (psychotherapy in cancer care)

Taking part in this research involves having an informal interview for approximately one hour and sharing your personal experience of your psycho-oncological care. All information will be anonymised and securely and confidentially stored until successful completion of the doctoral study. Participation is voluntary and will not affect any aspect of your healthcare. Should you wish to participate, you are free to withdraw up until 4 weeks after the interview whereby all data will be destroyed.

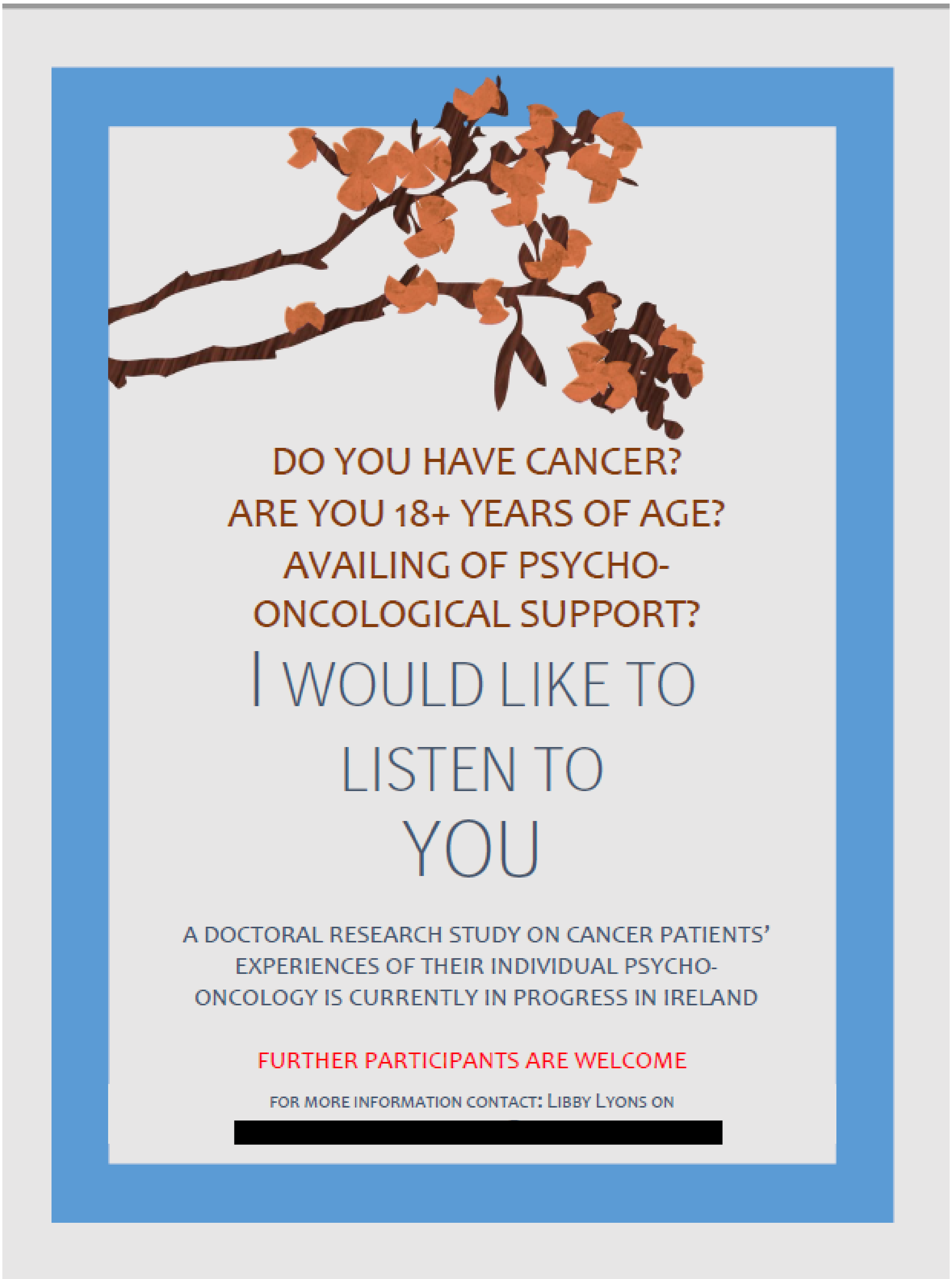
Many thanks for your interest and time. Should you have any queries relating to the above, please do not hesitate to contact me via email ([redacted]) or telephone ([redacted]).

Kind regards,

Libby Lyons

Doctoral Researcher, London Metropolitan University.

APPENDIX C: Research Poster/Flyer



DO YOU HAVE CANCER?
ARE YOU 18+ YEARS OF AGE?
AVAILING OF PSYCHO-ONCOLOGICAL SUPPORT?

I WOULD LIKE TO LISTEN TO YOU

A DOCTORAL RESEARCH STUDY ON CANCER PATIENTS' EXPERIENCES OF THEIR INDIVIDUAL PSYCHO-ONCOLOGY IS CURRENTLY IN PROGRESS IN IRELAND

FURTHER PARTICIPANTS ARE WELCOME

FOR MORE INFORMATION CONTACT: LIBBY LYONS ON

[redacted]

APPENDIX D: Form of Interest

Research: ***Cancer patients' experience of their psycho-oncology/psychotherapy in cancer care***

Please read the included information leaflet before completing this form of interest

I am interested in participating in Libby Lyons' research study about my personal experience of psycho-oncological care.

I give permission for Libby Lyons to contact me by telephone/email to provide me with further information regarding participation in this research study.

Name: ....

Contact Number:..

Email:...

Thank you for your interest

Libby Lyons

Doctoral Researcher, London Metropolitan University

APPENDIX E: Consent Form

LONDON
METROPOLITAN
UNIVERSITY

Research: ***Cancer patients' experience of their psycho-oncology/psychotherapy in cancer care***

Please read carefully before completing this consent form

1. I confirm that I have read and understood the information sheet detailing this research. I have had the opportunity to consider the information and been given the opportunity to ask questions. I am aware that I may contact the researcher for any further information.
2. I am fully aware that my participation is voluntary and that I am free to withdraw within 4 weeks of the audio recorded interview, without giving any reason, without my health care or legal rights being affected.
3. I understand that this interview will be audio-recorded and following the interview, it will be transcribed.
4. I understand that this interview is part of a doctorate research project and that anonymous quotes from my interview may be published in a thesis or article.
5. I understand that any information I provide will be confidential and that all material relating to the research will be anonymised, stored securely on a computer and will be destroyed after full completion of the study.
6. I agree to participate in this research.

______________________	______________________	______________________
Name of Participant	**Date**	**Signature**

______________________	______________________	______________________
Name of Researcher	**Date**	**Signature**

APPENDIX F: Interview Schedule

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- What were your perceptions of psycho-oncological care?
    - What led you to accessing psycho-oncological care?
    - What were you hoping it would provide you with?
    - Were those hopes realized? If so, how? If not, in what way?
- How have you been finding your psycho-oncological care?
    - How has it impacted you?
    - What have been the most important aspects of it for you?
    - Have there been aspects of it that have proved challenging?
    - What does your psycho-oncological care mean to you?
- How has your psycho-oncological care helped/not helped you?
    - Emotionally
    - Behaviourally
    - Relationally
    - Physically
    - Spiritually
- Looking back, how has the experience of psycho-oncological impacted your life?
- Is there anything else you feel you would like to share?

APPENDIX G: Debrief Sheet

Sometimes, after talking about our experiences with somebody, we can find ourselves being more upset than usual and thinking more about the concerns we talked about. Should this happen, please do not hesitate to contact someone for some support.

You can contact your GP and/or cancer support services. It is best to discuss your concerns with your healthcare provider who will be able to take further action.

You can contact the researcher (Libby Lyons) who will think, together with you and her supervisor, of the most appropriate local services available to you. If you leave a message on this number, the researcher will call you back: [redacted].

Other helplines include:

Irish Cancer Support: [redacted]

If you ever feel so distressed that you consider causing harm to yourself or to others, go immediately to your GP practice and request an emergency appointment. If you feel this way when the GP practice is not open, go to A&E or your nearest hospital and they will arrange for you to meet with someone.

If you have any further queries please do not hesitate to contact the researcher on the above number.

Yours Sincerely,

Libby Lyons

Doctoral Researcher, London Metropolitan University

APPENDIX H: Distress Protocol

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UNIVERSITY

This protocol has been devised to deal with the possibility that some participants may become distressed and/or agitated during their involvement in our research into their experience of psycho-oncology care, as some by definition will already be suffering from psychological distress as a result of their cancer or other underlying psychological issues. There follows below a three step protocol detailing signs of distress that the researchers will look out for, as well as action to take at each stage. The researcher (Libby Lyons) is a trainee counselling psychologist, and so has experience in monitoring and managing situations where distress occurs. It is not expected that extreme distress will occur, nor that the relevant action will become necessary. This is because most of the participants will be approached through contacts in professional services and so there will usually be an existing structure set up to deal with extreme distress which professionals can implement. However, it is included in the protocol, in case of emergencies where such professionals cannot be reached in time.

Mild distress:

Signs to look out for:

1) Tearfulness
2) Voice becomes choked with emotion/ difficulty speaking
3) Participant becomes distracted/ restless

Action to take:

1) Ask participant if they are happy to continue
2) Offer them time to pause and compose themselves
3) Remind them they can stop at any time they wish if they become too distressed

Severe distress:

Signs to look out for:

1) Uncontrolled crying/ wailing, inability to talk coherently
2) Panic attack- e.g. hyperventilation, shaking, fear of impending heart attack
3) Intrusive thoughts of the traumatic event- e.g. flashbacks

Action to take:

1) The researcher will intervene to terminate the interview/experiment.
2) The debrief will begin immediately
3) Relaxation techniques will be suggested to regulate breathing/ reduce agitation
4) If any unresolved issues arise during the interview, accept and validate their distress, but suggest that they discuss with mental health professionals and remind participants that this is not designed as a therapeutic interaction
5) Details of counselling/therapeutic services available will be offered to participants

Cocking, C. (2008) *Protocol to follow if participants become distressed during participation.*

London Metropolitan University

APPENDIX I: Sample of Coded Transcript for Clare

EMERGENT THEMES	TRANSCRIPT	INITIAL COMMENTS
PO as directive therapy – helpful Talking to others about cancer Patient Needs Fears in cancer Difficulty to express them to others Protecting family and friends A place to let it all out Talking therapy - a different type of conversation PO as liberating experience Fear of death Confrontation with mortality Therapy as emotional connection and separation Therapeutic relationship	stick your head into the book and yeah don't talk to anybody that's what she said and mmmm yeah it was the psychologist who, I can't quite remember but I know he suggested the headphones and I did that yeah… L: So doing something…. C: Yeah I think for some people talking to other people helps and for me no it didn't…. L: So I know it's very different talking with others like the lady in the waiting room and hearing stories that you don't want to listen to right now C: Yeah, it's not going to help me L: Yeah, exactly…..so how was it when you were in your psychology consultations or meetings….I know you're not sharing stories or listening to stories, but how was it talking about what you were going through? C: Yeah, it's it's …..when you have all these fears and you can't tell the people closest to you because….well they're going through terrible time themselves because as in mmmm well cancer affects everybody around you, not just the patient so you want to protect them so you hold back on the stuff you're thinking to a certain degree and mmmm when when you talk to a psychologist you can just let it all out….. L: And was that one of your expectations or hopes before going or was that just the way it was? C: Mmm It kind of felt a bit strange because I'm not used to opening up to a complete stranger (chuckles) mmmm which I'm doing it again today (both laugh) so yeah I guess I'm getting used to it now so yeah it was kind of strange from that perspective but mmm it's liberating yeah L: OK so in the strangeness it felt liberating? C: Yeah, to be able to kind of vocalise your fears and well a lot of what you deal with is the fear of the unknown and thinking the worst is going to happen so yeah	Taking helpful advice from Psycho-oncologist (PO) during treatment Not wanting to talk to others during treatment - knowing what helps her and seeking /taking advice Struggling/contending with fears and unable to share them with loved ones Impact of cancer on family and friends and C's awareness of this Desire to protect others and hide her own internal processes from them Opportunity to let everything out with PO – not having to protect Initial discomfort with opening up to a stranger Compares with similar situation today – acknowledges the irony of current experience (body relaxes as we both laugh) Acknowledges how it feels liberating; frees her of; ability to hear herself speak and articulate her fears – of uncertainty and the worst – death? PO (referring to PO in the plural (they) – part of

Accessing PO Therapeutic attunement Emotional impact of cancer Desperation and Fear Uncertainty Therapeutic relationship Attunement Panic Loss of Control Fighting to survive Confronting mortality Emotional impact of cancer Cancer Patient Needs Containment	L: So being able to air that with someone who you feel you don't have to protect…. C: Yeah, they're not emotionally involved so yeah mmmm and actually the the counsellor that I saw here she was a very nice woman and I saw her a few times and mmmm L: At what stage…. C: At the same time because I remember well she was a nice lady but I didn't feel it was helping me…. L: OK can you say a bit more? C: Mmm well she would kind ask me questions that were (pause)….like I remember I was doing lots of research online to try and find the cure for myself because I felt that with the first treatment I didn't know at this point but I felt like it wasn't working and I thought ok the treatment is not working I have to find another, an alternative and eh I was telling her about this and mm and It said it feels like I'm clutching at straws to save my life and she said and how does it feel to be clutching at straws and just like I didn't want to talk about how that made me feel and eh she was kind of pressing the wrong buttons for me and eh and then eventually when I'd gone in this day I thought I was having treatment and that's the day I was told oh no we're stopping this treatment and mmm the, my oncologist said that we're going to start the other treatment and if that doesn't work we'll go straight to surgery and I said how many of the next treatments would you try and she said oh just one so I started googling as you do when you go home and when the first treatment doesn't work it's unlikely that the second one will work so at that point I was thinking ok so it's unlikely that this other one is going to work so it'll be going to surgery and I knew if the chemos don't work then I guess it would be months that we'd be talking about not years you know so I….it was a complete low for me and I I arranged to meet the counsellor here I kind of, I got it all off my chest how I was feeling and what had happened and she was visibly upset by it. L: So she was showing emotion? C: Yeah and yeah and I realised that this is not actually going to help me	oncology team?) - as different from others – expressing her fears with someone who is not emotionally involved – a sense that she feels safe that she is not emotionally affecting PO Cancer therapist from other avenue as nice but an unhelpful experience Reluctant to expand…eyes lower and she stops talking…I probe… Asking questions that perhaps irritated her?? – voice changed to one that expressed a sense of irk Explains what she was going through and her sense of desperation – clutching at straws as powerful metaphor to describe emotions Therapist question annoys her – pressed the wrong button – lack of connection Feeling of panic as treatment options are reducing Desperate to know outcome of treatment – chances of it working Taking things into her own hands – grasping at some level of control when things are spiraling out of control – time is running out Need to seek help as never felt so down Let everything out – need to release everything to someone who was not emotionally involved or who she did not need to protect – seeing therapist get upset as unhelpful

APPENDIX J: Initial List of Emergent Themes for Clare

Accessing PO

Initial Impressions of PO

PO as helpful experience

Information and Knowledge

Freedom to express all emotions

Understanding and Knowledge of cancer

PO as Specialist Field

Psychological/Emotional Impact of Cancer

Excessive Worry

Cancer Patient Needs

Age and cancer diagnosis

Cancer patient needs - Somebody to talk to

Timing of PO

Loss of Control – “like trying to hold back a river”

Impact of Cancer on Family

Expertise

Normalising

Confronting Mortality

Cancer as a “rollercoaster”

Acceptance

Fighting to survive

Communication Styles in Oncology Care

Death anxiety

Responsiveness

Hope

Empathy

Cancer as a trauma

Cancer as a death

Life changing experience “old life is gone”

Connecting with peers

PO as directive experience

Learning to Self Care

Talking to Others

A place to let it all out

A liberating experience

Someone who is not emotionally involved – a “stranger” who understands

Therapeutic Relationship

Attunement

Containment

Letting go

Goodness of Fit

Professionalism

Connection

Curiosity and Willingness

Being taken seriously

Validation

Building Strength

Sharing Dilemmas

Being understood

Fear of recurrence

Stages along the cancer trajectory

Cancer as Taboo

A place to talk about cancer

Helps to cope with treatment

PO as a safe place

A different conversation

Confidentiality

APPENDIX K: Sample of Theme Table for Clare

TABLE OF MASTER THEMES AND SUB-THEMES FOR CLARE

PO as specialism – the specialist therapist

- **Expertise** “he said was your frame of mind is not actually going to influence how the treatment works…..it kind of gave me the permission to have all my emotions and not feel bad about feeling bad or negative and instantly I started to feel more positive so from that perspective, it was just really helpful”
  “he said that evidence shows that the mind doesn’t impact on if the treatment works or not…he said that I was having a very normal reaction to being in the situation I was in which is suddenly you’re in a life threatening situation and yeah of course you’re going to have a whole range of emotions and yeah it’s it’s nobody can sail through it and say ah this is grand like it’s going to impact on every part of your life so yeah anything that impacts on your life is going to yeah you’re going to have, it’s going to be a rollercoaster”
  “Yeah I think I guess it probably comes down to he’s been dealing like he’s onco psychology so he’s been dealing with this for I don’t know how many years and I think I may have been her first cancer patient”
  “Yeah and even if even if it was my imagination it’s still real for me and you kind of have to understand the the seriousness of what I thought I was dealing with rather than just a vague idea of breast cancer”
  “presumably he’s never had cancer himself but he’s studied it and been around so many people who have that he he knows how to…like he he he he he has a knowledge about the whole thing and it’s important because you’re hyper sensitive to the things people say and the amount of people who want to tell you that people died (laughs) like it’s kind of it’s a bit of a joke like but yeah people are quite awkward around cancer you don’t know what to say and mmm I think if somebody is going to be working with people with cancer, it’s important to find out what to say and what not to say”
- **Limited Resources** “I didn’t make to my last session. I had been in hospital and had just got out and I just didn’t want to go in the next day so yeah I postponed it and then I just never got an appointment. They’re quite, they’re very busy, they don’t have a lot of resources”
  “I haven’t seen the psychologist since when I was in treatment…it was about every once a month….I think I probably would have preferred it more frequently but mmm yeah I think it was resources”
- **Meeting patient needs** “I was so scared that it was good to have someone to talk to about it”
  “so it helped me to just decide to block everything else out and well to not worry about anything else. Well if I was gone I wouldn’t have to worry about the other stuff in the family so yeah yeah so yeah I was able to block it out”
  “If I hadn’t had this the counselling at time of treatment well I’d have gone through it all without those key things that helped so it was good to hear those things up front”

- **Acceptance “**Yeah and once you kind of accept that, it’s really hard to accept that you have no control over an illness and mmm and whether the treatment works, it’s hard, it’s hard to accept that but it also gives you then a certain rrr mmmm relief from the pressure to control it”

The Therapeutic Relationship

- **Empathy** “I think if the person has empathy and they they kind of know how to handle how to say things in a gentle way… I think it shows that they realise how traumatic this whole journey is for people mmm yeah it’s devastating”
- **Goodness of Fit** “I was telling her about this and mm and It said it feels like I’m clutching at straws to save my life and she said and how does it feel to be clutching at straws and just like I didn’t want to talk about how that made me feel and eh she was kind of pressing the wrong buttons for me”
- **Containment “**it was a complete low for me and I I arranged to meet the counsellor here I kind of, I got it all off my chest how I was feeling and what had happened and she was visibly upset by it... Yeah and yeah and I realised that this is not actually going to help me (sighs with a light chuckle) and it’s because she is a nice sensitive person but she wasn’t mmmm it wasn’t going to…..I kind of said all the things that I was thinking that I couldn’t say at home…. then suddenly I had to measure what I’m saying and then there was no point in seeing her again because well I could talk to somebody on the bus (laughs)”
  “it was just the word is behaviour but it’s not behaviour as that sounds like he was doing something it wasn’t like that no no it was…..(struggling to find words)…. nothing was going to phase him, he was kind of mmm…. controlled…. well I felt like it was a safe space”

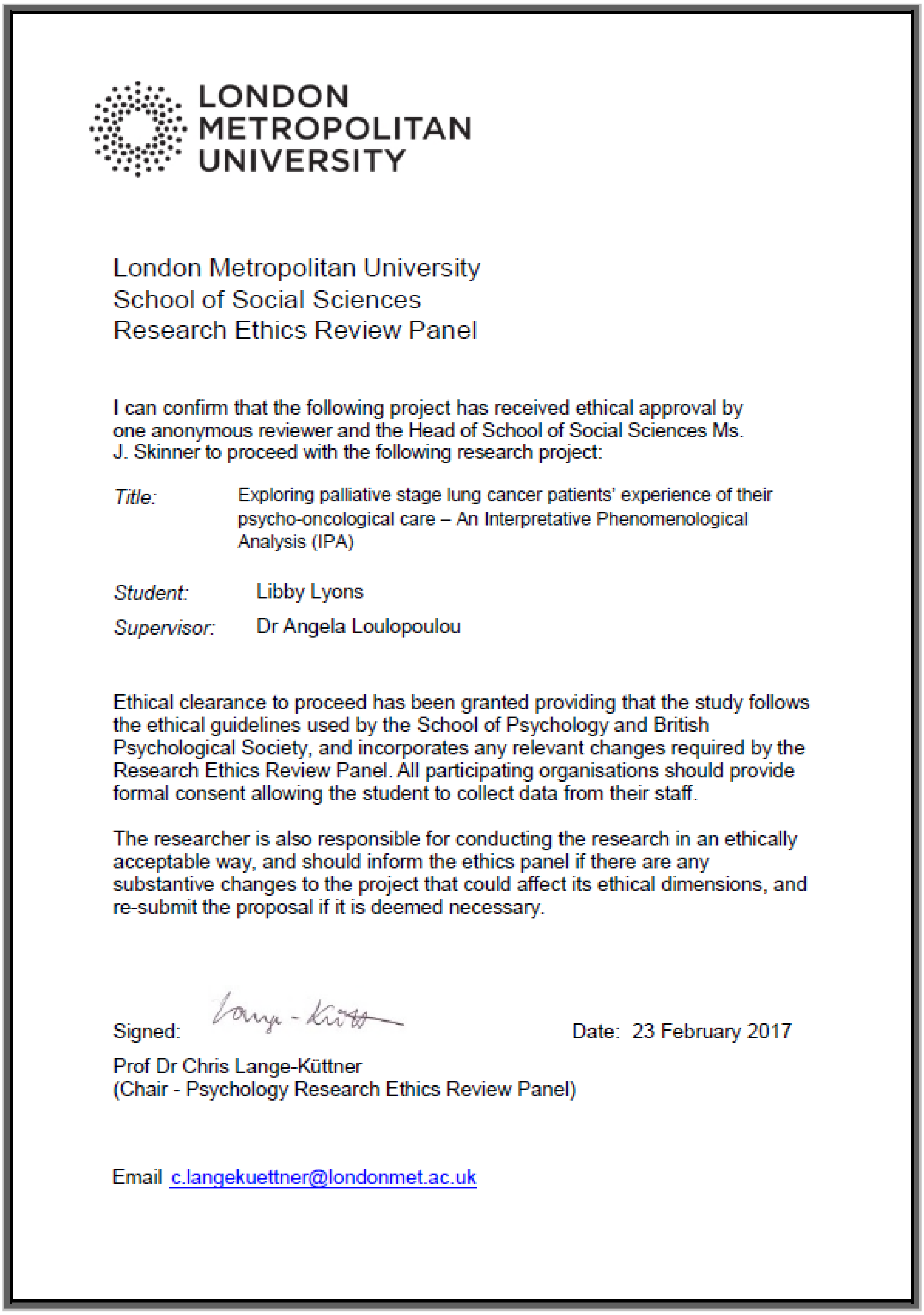
The Power of Talk

- **A place to let it all out “**when you have all these fears and you can’t tell the people closest to you because….well they’re going through terrible time themselves because as in mmmm well cancer affects everybody around you, not just the patient so you want to protect them so you hold back on the stuff you’re thinking to a certain degree and mmmm when when you talk to a psychologist you can just let it all out...it’s liberating”
  “I I knew that yeah I have somewhere where I can say it all and be open so well I feel like it helped me”
- **Permission to express and feel emotions** “before I had cancer I wasn’t positive all the time so it’s impossible to be positive but you feel this pressure that you have to be positive or you’ll die…..it kind of gave me the permission to have all my emotions and not feel bad about feeling bad or negative and instantly I started to feel more positive so from that perspective it was just really helpful”

APPENDIX L: Master Theme Table (including quotes)

MASTER THEMES	SUB-THEMES	QUOTES
CANCER PATIENT NEEDS	**THE COMPETENT THERAPIST – SOMEONE WHO UNDERSTANDS CANCER** **A SECURE BASE** **KNOWING "HOW TO ACCESS SUPPORT – THE ACCESSIBILITY AND AVAILABILITY"**	***"somebody who specialises…..she calls it psycho-oncology….I certainly had the feeling that I was being understood"*** ***"I know I can go into XXXX at any time if I want to or if I can't deal with how I'm feeling. But I do feel good so hopefully, but it's nice to know that they're there"*** ***"I think that was horrendous when people are going through so much and they don't know what to do or who to turn to….It's how to access support really - the accessibility and availability***
THE POWER OF TALKING	**A DIFFERENT CONVERSATION** **EASES THE PSYCHOLOGICAL PAIN** **ACCEPTANCE**	***"when you have all these fears and you can't tell the people closest to you… when you talk to a psychologist you can just let it all out"*** ***"I was so scared that it was good to have someone to talk to about it"*** ***"I slowly emerged, we emerged, we started to re-emerge with the ability and the strength to start to accept actually"***
THE THERAPEUTIC RELATIONSHIP	**A GOODNESS OF FIT** **"A SAFE SPACE"** **"THE HELP THAT HELPS YOU HELP YOURSELF"**	***"I would imagine not every therapist and every patient match or get on well together or they suit each other. I'm sure there's strokes for blokes, but she certainly suits me"*** ***"it took a while to feel safe, but once it's safe, it's safe and you can let things out"*** ***"If I hadn't had this the counselling at time of treatment well I'd have gone through it all without those key things that helped so it was good to hear those things up front"***

APPENDIX M: London Metropolitan University Ethics Approval Certificates



LONDON
METROPOLITAN
UNIVERSITY

London Metropolitan University
School of Social Sciences
Research Ethics Review Panel

I can confirm that the following project has received ethical approval by one anonymous reviewer and the Head of School of Social Sciences Ms. J. Skinner to proceed with the following research project:

Title:	Exploring palliative stage lung cancer patients' experience of their psycho-oncological care – An Interpretative Phenomenological Analysis (IPA)
Student:	Libby Lyons
Supervisor:	Dr Angela Loulopoulou

Ethical clearance to proceed has been granted providing that the study follows the ethical guidelines used by the School of Psychology and British Psychological Society, and incorporates any relevant changes required by the Research Ethics Review Panel. All participating organisations should provide formal consent allowing the student to collect data from their staff.

The researcher is also responsible for conducting the research in an ethically acceptable way, and should inform the ethics panel if there are any substantive changes to the project that could affect its ethical dimensions, and re-submit the proposal if it is deemed necessary.

Signed: Date: 23 February 2017

Prof Dr Chris Lange-Küttner
(Chair - Psychology Research Ethics Review Panel)

Email c.langekuettner@londonmet.ac.uk

LONDON
METROPOLITAN
UNIVERSITY

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I can confirm that the following project has received ethical approval by one anonymous reviewer and the Head of School of Social Sciences Ms. J. Skinner to proceed with the following research project:

Title:	Exploring lung cancer patients' experience of their psycho-oncological care – An Interpretative Phenomenological Analysis (IPA)
Student:	Libby Lyons
Supervisor:	Dr Angela Ioanna Loulopoulou

Ethical clearance to proceed has been granted providing that the study follows the ethical guidelines used by the School of Psychology and British Psychological Society, and incorporates any relevant changes required by the Research Ethics Review Panel. All participating organisations should provide formal consent allowing the student to collect data from their staff.

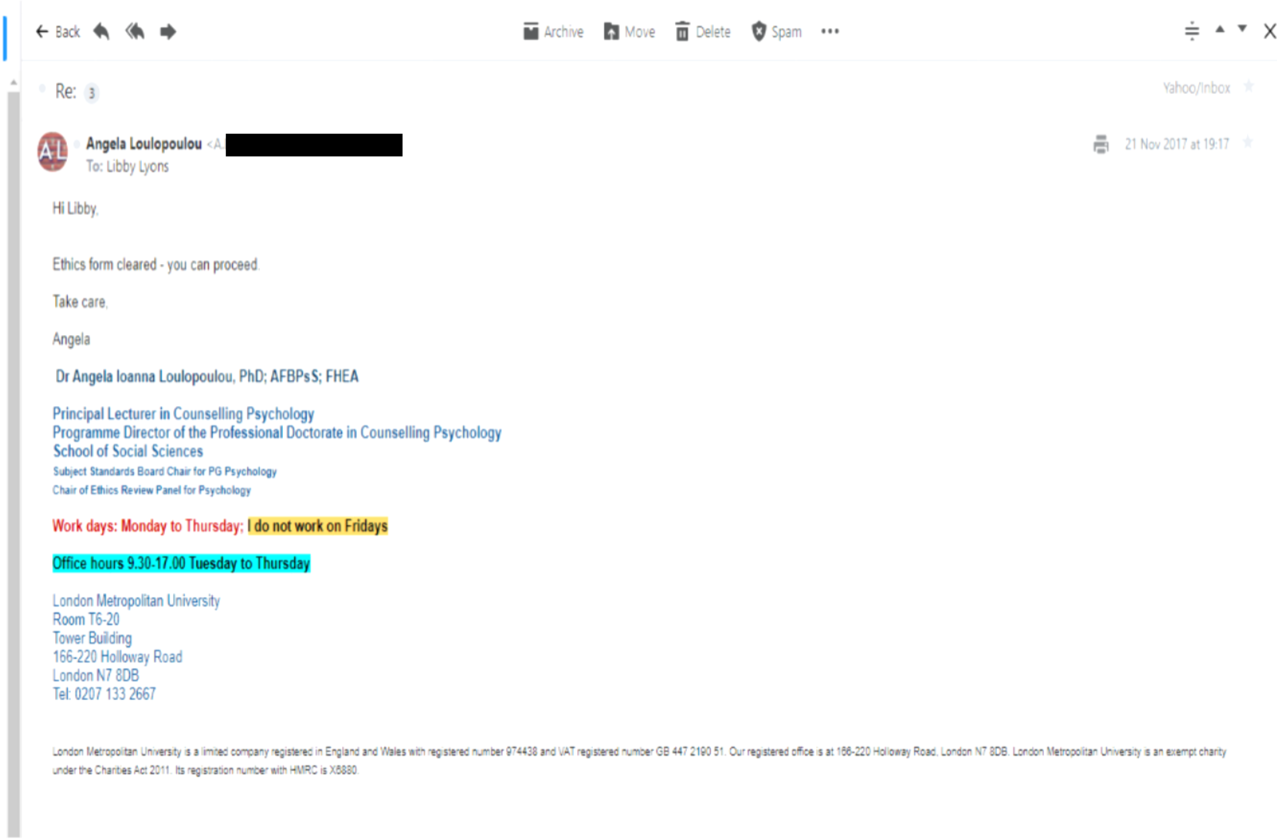
The researcher is also responsible for conducting the research in an ethically acceptable way, and should inform the ethics panel if there are any substantive changes to the project that could affect its ethical dimensions, and re-submit the proposal if it is deemed necessary.

Signed: Date: 11 June 2017

Dr Angela Ioanna Loulopoulou
(Chair - Psychology Research Ethics Review Panel)

Email a.loulopoulou@londonmet.ac.uk

Final LMU Ethics Certificate (amending sample population to include all cancer patients) approved via email



Re:

Angela Loulopoulou <A [redacted]
To: Libby Lyons

21 Nov 2017 at 19:17

Hi Libby,

Ethics form cleared - you can proceed.

Take care,

Angela

Dr Angela Ioanna Loulopoulou, PhD; AFBPsS; FHEA

Principal Lecturer in Counselling Psychology
Programme Director of the Professional Doctorate in Counselling Psychology
School of Social Sciences
Subject Standards Board Chair for PG Psychology
Chair of Ethics Review Panel for Psychology

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