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Cancer diagnosis, treatment and engagement with Psycho-oncology services- the patients' perspective.

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Doctor in Medicine

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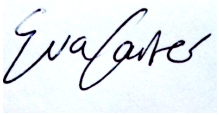
Signed: 

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Abstract

The burden of cancer worldwide is rising, with 20 million new diagnoses annually and 9.7 million deaths. The psychological needs of cancer patients are increasingly recognised, and specialist psycho-oncology teams are developing. Despite this, various barriers diminish access to psycho-oncology services. This work aimed to better understand the experience of cancer patients and their families, and to assess their attitudes towards different aspects of the psycho-oncology service. This was a cross-sectional survey completed on the oncology day-ward of a large urban hospital in Ireland, using an established survey tool. Patient-rated distress at cancer diagnosis, treatment and attitudes towards psycho-oncology services were assessed in 142 cancer patients. This study found that women reported more extreme distress than men during cancer diagnosis and treatment. Patients were likely to perceive their families as more distressed than themselves, and report more extreme distress at diagnosis than treatment. Patients reported work, fatigue, and fear for the future as areas of life most extremely affected by cancer. Under one third of cancer patients (30.3%) knew the meaning of 'psycho-oncology', and two thirds (67.2%) were ambivalent about a referral. One fifth (21.0%) would be somewhat/extremely uncomfortable disclosing attending palliative care, compared to 17.9% for psychiatry, 14.4% for psychology, and 5.8% for cardiology. More patients were happy to disclose taking medication for physical over psychological symptoms. On multi-variable testing, female gender was independently associated with higher patient distress at diagnosis and treatment and pre-existing psychiatric/psychological difficulty was independently associated with belief that a psycho-oncology referral would be beneficial. This study highlights high rates of extreme distress for cancer patients, particularly women, and their families and limited awareness of psycho-oncology services. This emphasises the need for enhanced, targeted, gender-aware, family-oriented psychological supports during cancer diagnosis and treatment.

Lay Abstract

Background: The rates of cancer around the world are rising, with an estimated 20 million new cancer cases diagnosed in 2022. Cancer causes significant levels of emotional distress for patients and their carers. Psychological supports have been shown to reduce distress experienced by cancer patients and their families and there are 'psycho-oncology' specialist teams developing in recent years to address these needs. Lack of awareness of supports available and stigma around accessing psychological help have reduced the use of these services. Patients attending for cancer treatment in a large hospital in Dublin were asked to complete a survey to further understand their emotional experience during diagnosis and treatment and their views on psycho-oncology as a specialty.

Findings: Women experience more extreme levels of distress than men during cancer diagnosis and treatment. Patients felt that their families distress levels were higher than their own. Patients experience higher levels of distress at cancer diagnosis than treatment. They felt that work, fatigue and fear for the future were the areas of their lives most affected by cancer. There are ongoing barriers which exist in relation to psychiatric and psychological care with less people likely to disclose attending these services than a medical specialist. Patients were more comfortable disclosing attendance at a specialist nurse than a psychiatrist or psychologist and taking medications for physical rather than psychological symptoms.

What this means: This study found that women experience more extreme levels of distress than men during cancer diagnosis and treatment. Patients reported that their families experience more extreme distress than themselves. Cancer patients with a history of psychiatric or psychological difficulties are more likely to believe that they would benefit from engaging with psycho-oncology teams. Services should be developed in line with this need and future research could include family members to explore their experience further.

Aims and Hypothesis of this Project

This study aimed to examine cancer patients experience of cancer diagnosis and treatment as well as their attitudes towards engaging with various members of medical and allied health professionals, including that of the multidisciplinary psycho-oncology team. It also aimed to evaluate patients attitudes towards taking medications for physical and psychological symptoms, willingness to engage with various medical health professionals including psychiatry and psychology, and to explore any stigma associated with disclosing seeking help for mental versus physical health to others.

We chose to explore differences in gender and those with a previous history of psychiatric or psychological difficulty in detail. We hypothesised that there may be gender-based differences in experiences of cancer diagnosis and treatment and reduced willingness to engage with psychiatric or psychological care compared to other medical and allied health professionals. We also hypothesised that those with a pre-existing psychiatric or psychological difficulty may be more vulnerable to experiencing extreme distress during cancer diagnosis and treatment and therefore more likely to require support from the psycho-oncology team.

Given that psycho-oncology is a relatively new branch of subspecialist psychiatry, there is limited knowledge as to how these factors interact within the Irish context. We hoped that results of this study may help shape psycho-oncology services in line with patient need as they continue to develop nationally under the Health Service Executive and National Cancer Programme ‘Hospital and Community-based Psychosocial Care for Patients with Cancer and their Families: A Model of Care for Psycho-Oncology’(Greally, 2020).

Value of this Research

To our knowledge, this research is the first of its kind in Ireland in almost a decade, during which time psycho-oncology services have been developing nationally. Service development should be aligned with patient experience and need and this body of work should help shape psycho-oncology services within the Irish context.

This research will help to communicate the patient experience of cancer diagnosis and treatment and allow clinicians to identify those who are most likely to require targeted psycho-oncological care and supports. There has been a 50% increase in those living with cancer in the last decade, with 1 in 24 people living with an invasive cancer in Ireland (National Cancer Registry, 2022). Cancer survivorship is on the rise due to advances in oncological treatments and so the need for psycho-oncological supports will also rise in line with this. Given finite resources, this research will inform service delivery and ensure policymakers can provide targeted and efficient psycho-oncological care to those who are most in need and therefore most likely to benefit.

The results of this research add to the already existing literature on the psychological needs of cancer patients. This research sheds light on the experience of Irish cancer patients and highlights, in particular the psychological needs of female cancer patients, with high levels of extreme distress reported in our study. Given the ongoing development of psycho-oncology teams both nationally and internationally, consideration should be given to how best to engage this vulnerable and distressed group to provide effective multidisciplinary care.

Outputs

As this thesis progressed, the following relating to this work were accepted for publication in peer reviewed journals

Carter, E., Collier, S., Plunkett, R. *et al.* Gender disparities in extreme psychological distress at cancer diagnosis and patients access to psycho-oncological care. ***Irish Journal of Medical Science*** (2025). https://doi.org/10.1007/s11845-024-03852-w

Appendix D

Carter, E., Collier, S., Plunkett, R. *et al.* Cancer patient distress- roles of gender, family and psychological care. ***Irish Medical Journal*** (2025). https://imj.ie/wp-content/uploads/2025/08/Cancer-patient-distress-%E2%80%93-roles-of-gender-family-and-psychological-care.pdf

Appendix E

Carter, E., Plunkett, R., Collier, S., Kelly, BD. Psycho-Oncology Care for Women with Cancer in Ireland: Overview, Evidence, and Future Directions. **Advanced online publication** in the Irish Journal of Psychological Medicine (2025) 1-4. https://doi.org/10.1017/ipm.2025.10144

Appendix F

Chapter 1: Introduction

In this introduction chapter, I will begin by discussing the global impact of cancer as a disease (section 1.1). I will then discuss the psychological impact of cancer for patients (section 1.2) and the impact of psychological difficulties on cancer outcomes (section 1.3). This will be followed by section 1.4, 'potentially vulnerable subgroups' and section 1.5 'survivorship beyond cancer'. In section 1.6, I will discuss the development of Psycho-Oncology services internationally and section 1.7 will highlight the development of Psycho-Oncology services in Ireland. Section 1.8 will outline the aims and objectives of this study and finally, section 1.9 will highlight my contribution to this research study. I will now open the chapter with section 1.1, 'the global impact of cancer as a disease'.

1.1 The global impact of cancer as a disease

The burden of cancer worldwide is rising, with 20 million new cancer cases diagnosed in 2022 and 9.7 million cancer related deaths (World Health Organisation, 2024). One fifth of the global population will develop cancer over the course of their lifetime. The most common type of cancers are female breast, lung, bowel and prostate cancers, which account for forty percent of cancers diagnosed worldwide (Cancer Research Cancer Research UK, 2024). It is estimated that there will be over 35 million cancer diagnoses in 2050, representing a significant increase in the number of people who will experience a cancer diagnosis and undergo cancer treatment during their lifetime.

In Ireland, there are over 41,000 new cancer diagnoses annually, and 1 in 3 people will receive a cancer diagnosis over the course of their lifetime (National Cancer Registry, 2022). Cancer is a growing issue, affecting a majority of the Irish population either directly or indirectly through family members or loved ones. The most commonly

diagnosed cancers in Ireland, for both men and women, are prostate, breast, lung, colorectal and melanoma skin cancer. This is in line with global figures, as mentioned previously. Cancer is responsible for approximately thirty percent of deaths annually in Ireland. The number of the Irish population living with a cancer diagnosis is anticipated to increase exponentially in coming years. Those not directly affected by a cancer diagnosis are likely to be indirectly affected through a diagnosis in a loved one due to these increasing rates. This, therefore, represents a significant problem facing Irish society in the coming years and one which will need to be addressed at a national level in order to ensure high level quality care for cancer patients and their families.

There have been several advances in relation to cancer diagnosis and treatment over the last number of decades. Public health initiatives have led to improved recognition and early detection through development of public awareness campaigns and national screening programmes. Breakthroughs in clinical medicine have led to improved medical and surgical treatments. These innovations have led to timely diagnosis and improved physical treatment for cancer patients and this has resulted in increased survival rates and life expectancies for these patients who previously experienced a poor prognosis.

As a result of improved screening practices and advances in cancer treatment, there has been a fifty percent increase in people living with cancer in Ireland in the last decade. It is estimated that there are close to 215,000 people in Ireland currently living with cancer; representing almost five percent of the population (National Cancer Registry, 2022). Despite these improvements in cancer diagnosis and treatment, the psychological needs of cancer patients and their families have been neglected historically, with the primary focus on medically treating cancer patients in order to improve survival rates and life expectancy. While this is a medical success story in terms of cancer treatment, it is

important to acknowledge, recognise and address the psychological needs of cancer patients and their families in order to ensure that we are providing high quality, holistic, patient-centred care.

1.2 The psychological impact of cancer for patients

The National Cancer Institute in the United States defines distress as the

> 'Emotional, social, spiritual, or physical pain or suffering that may cause a person to feel sad, afraid, depressed, anxious, or lonely. People in distress may also feel that they are not able to manage or cope with changes caused by normal life activities or by having a disease, such as cancer. Cancer patients may have trouble coping with their diagnosis, physical symptoms, or treatment.'
>
> *(National Cancer Institute)*

The distress related to cancer is often considered along a spectrum called the 'distress continuum'. This ranges from normal adjustment and coping with an understandably difficult situation and diagnosis; through to more significant adjustment disorders, subclinical mental health diagnoses and clinical psychiatric disorders such as major depressive disorder, anxiety disorders and psychotic disorders for which patients require treatment (National Cancer National Cancer Institute, 2023)

A study conducted by a research group in Cork University Hospital, Ireland in 2015 looked at correlates of distress among cancer patients referred to the local psycho-oncology team. They found that gender and age were associated with subjective levels of distress. They reported that females were more likely than men to report high levels of distress and advancing age was associated with reduced levels of distress (Lavelle et al.,

2017). Against this background, we sought to further explore this aspect of cancer care among Irish patients and further investigate other aspects of the psychological impact of cancer by exploring distress in a sample of patients attending for cancer treatment, not necessarily referred to the psycho-oncology team and therefore perhaps a more representative sample of the general population of cancer patients in Ireland.

Another Irish study which reviewed a year of referrals to a newly established psycho-oncology service in a large Dublin hospital, over twenty years ago, reported affective spectrum disorders in over half of cancer patients referred to the service and a past psychiatric history in one fifth of referred patients (Hallahan et al., 2004). A high proportion of patients in this sample (82.5%) required a form of clinical intervention from the psycho-oncology service, indicating a high need among this patient population.

In line with the increasing recognition of the psychological needs of cancer patients, the International Psycho-Oncology Society recommends that 'psychosocial cancer care should be recognised as a universal human right' and incorporated into routine cancer care (International Psycho-Oncology Society, 2014). In addition, 'distress should be measured as the 6th Vital Sign after temperature, blood pressure, pulse, respiratory rate and pain'.

There are many aspects associated with a cancer diagnosis and treatment which can provoke significant emotional and psychological distress for patients. The source of this distress is often multifaceted, complex and individual to the circumstances of the patient. There are several distinct timepoints during a patients cancer journey which can cause an increase in psychological and emotional distress for patients. These timepoints can vary among individuals but will often include the time of diagnosis, prior to commencing cancer treatment, while waiting for interval scans or other investigations to

assess response to treatment, approaching the end of a cycle of treatment, when patients experience a recurrence of cancer and if patients progress towards end of life or palliative care. The uncertainty around prognosis, treatment and survival can be significantly anxiety provoking for cancer patients and their loved ones.

To quote an Irish cancer survivor of Hodgkin's Lymphoma, Peter Corcoran, '*I found myself very anxious and highly strung. I did a lot of irrational worrying around control, fear, guilt - all of that. I was thinking 'I must have done something myself here', questioning various different things: karma, religion, anything that could be questioned just to find a reason'* (Irish Cancer Society, 2021). This description of the psychological impact of a cancer diagnosis from the patient's perspective highlights the wide range of emotions that can be experienced by a patient along their cancer journey a well as individual factors such as religion, cultural beliefs and self-blame which can modify this emotional and psychological experience for patients. Patients are all individuals with different early life experiences, personality types, internalised coping styles and support structures which they will utilise to cope at different timepoints along their cancer journey. Recognition of these differences is crucial in providing high quality, individualised psychosocial care which is tailored to the needs of these patients.

The source of distress for cancer patients is often multifactorial in nature, ranging from the worry associated with uncertainty around the future, ability to cope with living with cancer and physical symptoms as well as undergoing oncological, surgical or radiotherapy treatment

Practical aspects associated with a cancer diagnosis include the financial impact of being unable to work either due to associated physical symptoms or attendance at medical appointments for medical investigations or treatment. This can result in loss of income

and employment and cause a significant level of worry and emotional distress for cancer patients and their families. There are also geographical aspects to the navigation of a cancer journey for some patients, which can affect their ease of access to care for cancer treatment and medical appointments. This can add another layer of complexity for some patients in relation to cancer diagnosis and treatment. Things which appear simple for one patient such as the ability to drive to appointments, being in possession of a driving licence or having access to a car or public transport can prove enormously challenging for other patients who are unable to drive or access public transport and may be reliant on goodwill from others or self-fund private transport to make long journeys to frequent hospital appointments. This can lead to significant levels of stress and worry and increase the financial and emotional burden associated with a cancer diagnosis for some patients.

Physical symptoms such as pain, loss of appetite, poor energy and sleep disturbance can have an impact on the emotional wellbeing of cancer patients. These can all have direct effects on the patients ability to function in their daily life and have remarkable impact on their quality of life.

When someone receives a cancer diagnosis, there is an immediate shift of identity from a ‘healthy person’ to a ‘cancer patient’. This can prove incredibly difficult for some patients who were previously healthy and can have negative impacts on self-esteem and self-confidence. Patients can have diverse preconceptions and lived experiences pertaining to what a cancer diagnosis might mean for them, which can lead to varying emotional responses and meaning attributed to a diagnosis. Given the indiscriminate nature of cancer, affecting a wide spectrum of ages, there can be significant pressures placed on families when a working parent or a child is diagnosed with cancer, leading to changes within the family dynamic. There can be a role transition within the household

for people once they are diagnosed with cancer and this change can be a major source of psychological distress for some people affected by cancer and their families.

Patients come from a variety of different socioeconomic backgrounds and will have differing psychosocial supports available to them to utilise during this time, as well as varied underlying personality structures, internalised coping mechanisms and ways to manage and cope with psychological distress as and when it arises during the cancer journey. It is important to recognise these individual differences among cancer patients in order to be able to provide patient centred, appropriate and targeted psychosocial support to those in need.

There are various levels of clinically significant psychological distress among cancer patients reported in the literature, ranging from one quarter to half of cancer patients. (Mehnert et al., 2018, Strong et al., 2007). The study published by Menhert et al, describes distress among German adult cancer patients and reported 52% of their patients (n=3724) experienced clinically significant levels of distress. They reported that the most prevalent issues facing cancer patients included fatigue, sleep and logistical issues relating to transport. They found that patients who experienced an increasing number of problems were found to have higher distress levels, indicating that there may be a cumulative relationship between particular stressors and psychological distress for cancer patients.

A large published meta-analysis found high rates of psychiatric disorder among cancer patients in oncological and haematological settings across 14 countries (Mitchell et al., 2011). Results of this meta-analysis reported rates of depression as 18.5%, anxiety disorders as 10.3% and adjustment disorder as 9.4% in studies of oncological and haematological patients across a variety of hospital and community based settings. The

authors did not report a significant association between gender and diagnosis of mental disorder.

There are hypotheses that cancer tumours may directly be involved in the development of depression via proinflammatory cytokines and inflammation released by the tumour. These cytokines including IL-6, and TNF-α lead to dysregulation of the hypothalamic-pituitary-adrenal axis which leads to symptoms of depression including impaired sleep, energy and appetite (Aldea et al., 2014). Depression itself also results in further dysregulation of the hypothalamic-pituitary-adrenal axis, thus further potentiating the inflammatory effect via cytokines which could, in theory, lead to cancer progression, however more research is needed to investigate this theory.

Of interest, there have been particularly strong links noted in the literature between pancreatic cancer and depression (Kenner, 2018). It is well described that early detection of pancreatic cancer is difficult due to lack of clinical symptoms, leading to a poor prognosis for patients. There is significant overlap between symptoms of both pancreatic cancer and depression including loss of appetite and energy. A systematic review conducted to investigate mood disturbances as early signs of the development of medical illness, found that depression was consistently reported prior to the development of pancreatic cancer (Cosci et al., 2015). A study based in the United States, which explored the relationship between depression prior to a diagnosis of pancreatic cancer, via a health claims database, found that men who had a claim for mental health disorders were more likely to develop pancreatic cancer than their counterparts without a claim relating to mental health (Carney et al., 2003). This may indicate that depression and other mental disorders may act as an early indicator of the development of pancreatic cancer, however, further research is needed to clarify this association. There have been

several proposed theories which may account for this relationship including the involvement of cytokines, hormones and immunological responses (Kenner, 2018).

A Swedish cohort study which included over 300,000 cancer patients and over 3 million cancer-free individuals, reported that the relative rate for mental disorders is increased among cancer patients from ten months prior to a cancer diagnosis and remained elevated for a decade after diagnosis (Lu et al., 2016). This interesting finding from a large scale study also supports the theory that cancer itself may have a role in the development of mental disorders.

Cancer treatments, including the use of steroids can have well recognised psychological side effects including insomnia, emotional lability, increased anxiety and occasionally manic or psychotic symptoms. Side effects of chemotherapy include hair loss and fluctuations in weight. These changes in physical appearance can have an impact on cancer patients' emotional wellbeing.

Cancer patients have a significantly increased risk of suicide compared to the general population (Heinrich et al., 2022). Suicide risk has found to be increased in cancer patients who are male, over 65 years of age and in the first year following diagnosis. (Anguiano et al., 2012). Specific cancers including prostate, lung, pancreatic and head and neck cancers have been found to carry an increased risk of suicide.

1.3 Impact of psychological difficulties on cancer outcomes

It has been shown that cancer patients who experience clinically significant levels of anxiety and depression have poorer cancer survival and increased cancer incidence (Wang et al., 2020). A meta-analysis of over two-thousand cancer patients has shown

that mortality rates from cancer are 25% higher in cancer patients with depressive symptoms and increased by 39% in cancer patients with a clinically diagnosed depressive episode (Satin et al., 2009). There is evidence that patients with solid tumours, who experience high levels of psychological distress may have reduced survival rates (Roche et al., 2023).

A study comparing results of distress thermometer screening in lung cancer patients found significant correlation between a high distress score and one year survival as well as a lower quality of life and increased scores for depression and anxiety on the Hospital Anxiety and Depression Scale (Geerse et al., 2019). The results of these studies demonstrate that emotional distress experienced by patients during the cancer journey can have a significant impact on cancer outcomes and are therefore worthwhile recognising and addressing in order to further improve cancer outcomes. A study of patients admitted to hospital for stem cell transplant treatment of haematological malignancy, found that psychiatric comorbidity was associated with a longer hospital stay. (Prieto et al., 2002)

The relationship between psychological distress and poor cancer outcomes has been well described in the literature (Chida et al., 2008). There have been various theories proposed which may mediate this relationship. Proinflammatory cytokines released by cancer cells, dysregulation of the hypothalamic-pituitary-axis, immune activation and neuroinflammation have all been implicated as potential mediators of this association (Bortolato et al., 2017). These emerging pathways may act as targets for future treatments in order to reduce the increased mortality observed in depressed cancer patients compared to non-depressed cancer patients, however, more research into the area is needed (Aldea, 2014).

Cancer itself is also associated with adverse consequences for mental health, with increased rates of psychological distress, anxiety, depression, and post-traumatic stress disorder noted in cancer patients (Fortin et al., 2021, McFarland et al., 2019). Cancer patients have an increased risk of mortality from suicide compared to the general population (Heinrich et al., 2022).

Given the recognition and development of psycho-oncology as a subspecialty of psychiatry in recent years, there is a growing body of evidence published in the literature on the links between cancer related distress, mental disorders and cancer outcomes. There is some encouraging evidence that there has been a decrease in suicide rates among cancer patients from 2013- 2017, potentially in line with an increased recognition and implementation of psycho-social care programmes for cancer patients (Liu et al., 2024).

Some studies have shown that patients with higher levels of distress and psychiatric symptomatology demonstrate poorer treatment adherence and lower satisfaction with their oncological care providers (Arrieta et al., 2013, Meggiolaro et al., 2016). This finding may go some way towards explaining the somewhat controversial conclusion that lower levels of psychological distress and fatigue were associated with longer disease-free and overall survival in a study of primary breast cancer patients, after controlling for multiple biological variables, not including treatment adherence (Groenvold et al., 2007). A recently published systematic review of the link between psychological distress and survival in solid tumour patients suggested that there may indeed be a correlation between psychological distress, survival and other disease related outcomes, however, the authors identify that more research is needed to confirm if such a relationship exists (Roche et al., 2023).

1.4 Potentially vulnerable subgroups

A recent policy paper from the European Cancer Organisation titled 'Women & Cancer: More Than 12 Million Reasons for Actions' highlights the specific set of challenges faced by women in the context of cancer diagnosis and treatment (L'Hôte M et al., 2024). That paper highlights significant cancer burden among women in Europe, as well as the disparities in care and difficulties they face. The authors write that 'above all, the psychological impact of a cancer diagnosis and treatment is significant, as women may face additional stress related to family care responsibilities, societal expectations and stigmatisation' (p. 6).

The authors make clear recommendations for psycho-oncology services and survivorship programmes to address the unmet needs of female cancer patients so as to 'properly address the psychological needs of women affected by cancer, tailoring them to their needs' (p. 28). This call for action highlights women as a potentially vulnerable subgroup and highlights the importance of specifically recognising and addressing the psychological distress of women diagnosed with cancer.

People with mental illness experience multiple forms of healthcare disadvantage and have poorer physical health outcomes compared to the general population (Lawrence et al., 2010). These disadvantages also translate to cancer care, with people who suffer from mental disorders at risk of increased mortality from cancer compared to those without mental illness (D'Alton et al., 2021). A study of mortality in breast cancer patients has shown that those with a pre-existing diagnosis of severe mental illness have a two-fold increase in all-cause mortality compared to those without a pre-existing diagnosis of severe mental illness (Iglay et al., 2017). They are also less likely to engage with various

elements of cancer care such as screening, diagnosis, treatment, and palliative care compared to those without a history of psychiatric difficulty (Grassi et al., 2020, O'Dwyer, 2023).

Patients suffering with mental disorders such as depression and anxiety, generate increased healthcare costs compared to people without these mental disorders, through frequent hospital presentations (Lamoureux-Lamarche et al., 2022)

A scoping review of the literature, aiming to identify the impact of severe mental illness on cancer outcomes confirmed increased cancer related mortality among people with pre-existing severe mental illness along with an increased likelihood of late diagnosis of metastatic disease at time of diagnosis. Interestingly, this scoping review did not identify any studies which focused on impact of cancer on quality of life from the perspective of the service user with severe mental illness, highlighting a significant gap in evidence with a lack of the patients' voice within the published literature (Charlesworth et al., 2023).

While it has been hypothesised that those with pre-existing mental illness may experience poorer cancer outcomes due to a lack of engagement with healthcare, reduced access to screening and early treatment, a study of military patients in the United States, with equal access to healthcare and treatment, showed that pre-existing mental illness remained an independent risk factor for increased cancer mortality from non-small cell lung cancer (Lin et al., 2016). This raises the question that the link between increased cancer mortality for vulnerable patients with pre-existing mental illness may be much more complex than simply due to reduced engagement with services and late diagnosis.

Certain types of cancer can carry inherent mental health risks, as mentioned previously for example, there is a high incidence of depression reported among pancreatic

cancer patients (Green et al., 1993). It has been hypothesised that this relationship may be biological in nature, with a study in the last decade identifying the kynurenine pathway and subsequent redirection of tryptophan, an essential precursor of serotonin as a potential biological basis for this relationship (Botwinick et al., 2014)

In relation to suicide risk, particular cancer diagnoses have been found to carry an increased risk of completed suicide. The literature has shown that head and neck cancer patients are twice as likely to die from suicide compared to those with other forms of cancer (Osazuwa-Peters et al., 2018). This may be attributed to the profound physical impact of many head and neck cancers and their treatments which lead to significant challenges for affected individuals in communication, physical appearance and nutritional intake (Nelson et al., 2023).

A study looking at the engagement of those with severe mental illness, a well-recognised vulnerable cohort, in psycho-oncological services found significant disparities in the type of care offered. The study conducted in Switzerland, found that those with severe mental illness were less likely to be screened both for cancer at an early stage and for psychological distress during the course of their cancer treatment, indicating discrepancies in the psychological care of those suffering with severe mental illness and those without a history of mental illness (Günther et al., 2022). A systematic review of barriers in engagement with cancer care experienced by patients with severe mental illness found several factors which may contribute to the poor cancer outcomes experienced by those with severe mental illness, including patient related factors relating to recognition of symptoms, healthcare provider related factors, including preconceptions towards those with severe mental illness and also system related factors including geographical distance between psychiatric and oncology facilities (Bentson et al., 2023).

1.5 Survivorship beyond cancer

Cancer survivorship, defined in the literature as living beyond cancer is increasing due to the implementation of national screening programmes, early detection and advances in the medical and surgical care of cancer patients. In the United States, there are 18.1 million cancer survivors, representing 5% of the population (Tonorezos et al., 2024). In the United Kingdom, survival from cancer in England and Wales has been shown to have dramatically increased in the last forty years, with half of all cancer patients surviving the first year of diagnosis in 1971 increasing to half of all cancer patients surviving at ten years in 2011(Quaresma et al., 2015). In Australia, the five year survival rate for all cancers is around 70%, with over 1.1 million people or approximately 5% of the population currently living in Australia with a history of a cancer diagnosis (Australian Institute of Health and Welfare, 2021).

In the Irish context, the number of the population surviving beyond a cancer diagnosis is also increasing. In 2020 there were approximately 207,000 cancer patients or former cancer patients alive in Ireland, representing roughly 4.2% of the population. Five year survival rates in Ireland have improved significantly and were on average 65% for patients diagnosed between 2014 and 2018, compared with under half of patients (48%) for those patients diagnosed twenty years previously, between 1994 and 1998 (National Cancer Registry, 2022).

Cancer survivors have been reported to show increasing rates of mental and physical health diagnoses compared to the general population (Ng et al., 2018). In relation to mental health diagnoses, cancer survivors show increased rates of emotional distress, anxiety, depression and post-traumatic stress disorder compared to the general population

(Yi et al., 2017). A population based study of female survivors of childhood cancers showed that young adult female survivors of cancer displayed more depressive symptoms than matched cohorts without a history of cancer (Cantrell et al., 2014).

A systematic review of breast cancer survivors showed increased rates of anxiety, depression, suicide and neurocognitive dysfunctions compared to females with no history of a cancer diagnosis (Carreira et al., 2018). A review of survivors of colorectal cancer also reported increased incidence of clinically significant levels of anxiety and depression among patients (Mosher et al., 2016). These findings indicate that the psychological needs for cancer patients extend beyond the diagnosis and treatment of cancer itself and indicate that psychosocial care for cancer patients should continue to be provided after active treatment of cancer ends.

There are several specific fears and psychological difficulties identified among cancer survivors in the literature. A cross-sectional survey of breast cancer survivors identified fear of recurrence, long-term effects of treatment, osteoporosis and cancer treatment as the key fears identified among cancer survivors (Chua et al., 2020).

In Ireland, the National Cancer Control Programme has established a Survivorship Programme in order to recognise and address the ongoing physical and psychological needs of cancer survivors. Recommendation 43 of the Irish National Cancer Strategy 2017 – 2026 highlights the need for development and implementation of survivorship programmes:

> ‘Designated cancer centres working with the NCCP, the ICGP, primary care services, patients and voluntary organisations will develop and implement survivorship programmes. These programmes will emphasise physical,

> psychological, and social factors that affect health and well-being, while being adaptable to patients with specific survivorship needs following their treatment'.
>
> (Department of Health, 2017) (p. 114)

In response to this specific recommendation in the National Cancer Strategy, the Health Service Executive have established the first cancer survivorship programme in Ireland 'The Cancer Surviving and Thriving Programme' which is based on a rehabilitation practice model and uses a structured programme to provide self-management support to survivors of cancer. (Gibbons et al., 2020)

In section 13.5 of the National Cancer Strategy 2016 – 2027, 'Late and chronic effects of cancer treatment' a respondent to the public consultation describes the wide range of persistent needs of cancer survivors.

> 'Coming through a cancer diagnosis brings many new physical, mental and emotional challenges. We need to concentrate on creating strong supports for these areas so as to allow people to integrate back into family and society so that they can contribute competently and rebuild themselves strongly.'
>
> (Department of Health, 2017)

A qualitative study of Irish cancer survivors identified several barriers to engagement with self-management support for cancer survival, described as the delivery of programmes aimed at improving individuals' ability to self-manage a chronic disease. Barriers identified to accessing care in this study included a lack of knowledge of supports available, the emotional impact of a cancer diagnosis leading to fear of engagement and practical aspects such as the convenience of the location where support was provided and accessibility and advertising of the services. Significantly, this study suggests that emotional and psychosocial factors may play a role in preventing cancer

survivors from accessing self-management supports, potentially highlighting a role for psycho-oncology services in improving the ability of these vulnerable individuals to access supports offered. (Pallin et al., 2024)

1.6 The development of Psycho-oncology services internationally

Given the improved recognition of psychological distress among cancer patients, and the negative impact that psychological distress can have on cancer-related outcomes, specialist psycho-oncology teams are developing around the world since the 1980s as a sub-specialty of liaison psychiatry. This relatively new branch of psychiatry, aims to reduce the levels of emotional distress experienced by cancer patients and their families, and also to address the biopsychosocial factors which may mediate cancer morbidity and mortality.

The development of Psycho-oncology services around the world has grown, however, there are varying levels of services available to cancer patients depending on the country in which they live and receive cancer treatment. In particular, it has been noted that in developing countries, where basic cancer care is behind that of developed countries, there is a lack of psycho-oncology services available (Grassi et al., 2012).

In Australia, the New South Wales Cancer Plan 2022- 2027, sets out a clear priority to provide cancer patients with optimal support, care and treatment. They define a clear action under this priority to:

> ‘Ensure people who experience cancer, their families and carers are actively linked with supportive care and services such as psychosocial care, allied health care and financial counselling.’
>
> (Cancer Institute NSW, 2022) (p.9).

In the United Kingdom, the National Health Service Long Term Plan sets out clear goals in its plan for cancer. In Chapter 3.64, they set out these goals:

> ‘By 2021, where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. […] This will empower people to manage their care and the impact of their cancer, and maximise the potential of digital and community-based support. Over the next three years every patient with cancer will get a full assessment of their needs, an individual care plan and information and support for their wider health and wellbeing. All patients, including those with secondary cancers, will have access to the right expertise and support, including a Clinical Nurse Specialist or other support worker.’
>
> (National Health Service UK, 2019)

The Canadian Strategy for Cancer Control, identifies psychosocial needs of cancer patients as one of its eight priorities to be addressed by 2029.

> ‘The burden on people living with cancer and their families is not limited to the direct physical effects of the disease. People often have to deal with a wide range of emotional, psychological, social and practical challenges throughout their

journeys. The Strategy calls for a system where people living with cancer have seamless and integrated access to primary care, specialty care, community care, information and psycho-social support across their cancer journey. […] This requires a wide range of supports, including rehabilitation therapy, specialized mental health care, peer support, appropriate educational and employment services.'

(Canadian Partnership Against Cancer 2019) (p.30).

The recognition by these international government bodies of the psychosocial care needs of cancer patients, demonstrates the increasing awareness of the psychological needs of these patients and the need to provide enhanced support to manage these needs. There is evidently a drive around the world to provide these supports at a population level and have equitable access to these services for all patients who experience a diagnosis of cancer and are undergoing treatment.

There is evidence that psychosocial interventions can help reduce emotional distress and improve quality of life and physical symptoms for cancer patients (Benedict et al., 2022). A lack of awareness of psycho-oncology services and stigma have been identified as barriers to accessing psycho-oncology services (Schuit et al., 2021).

1.7 The development of Psycho-oncology services in Ireland

In Ireland, the National Cancer Strategy, aims to develop services nationally for cancer patients and their families. This strategy specifically aims to develop psycho-oncology services nationally by 2026 (Greally, 2020) to address:

> ‘The psychological responses of patients to cancer at all stages of the disease (and that of their families and carer); and the psychological, behavioural and social factors that may influence the disease process.’
>
> (Department of Health, 2017) (p.93).

The National Cancer Control Programme Psycho-Oncology Model of Care was launched in 2020 (Greally, 2020) and aims:

> ‘To provide a framework to support the way psychosocial care is delivered to patients with cancer and their families. The document aims to promote psychological wellbeing and improve access to psychological services at both acute hospital and community level’
>
> (Greally, 2020) (p.8).

The current model of care for psycho-oncology in Ireland operates via a hub and spoke model, aiming to provide psychosocial care for cancer patients and their families. This model of care is an example of integration of physical and mental health care for patients. It aims to provide multidisciplinary care to cancer patients on a stepped approach based on the level of clinical distress experienced by each individual.

Under the proposed model of care, the intervention required for patients is a five tiered approach based on their level of distress. It is suggested that those in the first tier, with transient distress can be signposted to psychoeducational resources. Cancer patients who experience persistent mild distress should be supported by their cancer teams and local community cancer support centres. Patients who are in the third tier and experiencing a moderate level of distress should be referred to medical social work, a mental health clinical nurse specialist and group psychological interventions and therapy for psychosocial support. Those experiencing what is classified as severe distress and

meet the diagnostic criteria for clinical disorders such as depression and anxiety should receive individual interventions and support from Psychology and Psychiatry. Cancer patients in the fifth tier, experiencing organic states including psychosis and suicidality should be referred to a psycho-oncology psychiatrist for ongoing support and management. This stepped wise approach aims to ensure the finite resources are used appropriately, and that the majority of patients experiencing transient or mild distress can be managed early with community based interventions.

The Irish National Cancer Strategy 2017-2026 defines the multidimensional aspects of psycho-oncology and also barriers to its implementation to date in the Irish health system. Section 10.9 of the policy document outlines the following:

> 'Psycho-oncology is concerned with the psychological, social, behavioural and ethical aspects of cancer. It addresses the two major psychological dimensions of cancer: the psychological responses of patients to cancer at all stages of the disease (and that of their families and carer); and the psychological, behavioural and social factors that may influence the disease process. Access to appropriate psycho-oncology services within cancer centres has not developed as envisaged in A Strategy for Cancer Control in Ireland (2006), an issue highlighted in the report of the Evaluation Group. Only two of the eight designated cancer centres have a dedicated psycho-oncology service, and one of these is part-time. This needs to be addressed, particularly given the predicted growth in incidence of cancer and demand for cancer services'.
>
> (Department of Health, 2017)

It is important that the implementation of this strategy is informed by evidence. Evidence to date indicates a clear need for psycho-oncology services, (O'Sullivan et al.,

2011, Hallahan et al., 2004) but further and ongoing evidence is required to shape services and ensure maximal patient benefit. It is crucial that services are developed in line with patient experience and need within the Irish context. Despite a wealth of literature detailing the experience of cancer patients globally, the experience of cancer patients in Ireland and their attitudes towards psycho-oncology services have yet to be formally evaluated.

1.8 Aims and objectives of this study

As described in the National Cancer Control Programme, 'A Model of Care for Psycho-Oncology':

> 'It is critical to promote an understanding of the speciality of Psycho-Oncology and recognition that these services are a vital part of the cancer treatment by all medical professionals. To that end the visibility and promotion of the service, which has an impact on referrals, will also be important. The educational and information needs of both cancer patients, their families and carer, and healthcare professionals will need to be developed'
>
> (Greally, 2020) (p.20).

As discussed previously, the model of care in Ireland aims to provide psychosocial care to cancer patients on a stepped approach based on the level of clinical distress experienced by patients. It is therefore important to have an understanding of the level of distress experienced by Irish cancer patients in order to help shape service delivery and have an understanding of the level of needs Psycho-oncology service users. Against this background, we aimed to assess distress among cancer patients in the

haematology oncology day-ward of a large urban hospital in Dublin, Ireland. We assessed patient rated distress at a single timepoint, with patients reporting their distress at time of initial cancer diagnosis and current distress level during treatment and examined its relationship with other variables, in order to inform psycho-oncology service delivery.

We sought to identify awareness of and factors associated with willingness to engage with psycho-oncology services among cancer patients, including those with a history of psychiatric and psychological problems and those without such a history. We aimed to identify different symptoms associated with cancer which patients were struggling to deal with, as well as highlight which areas of their lives they feel is most greatly affected by cancer and its treatment. We aimed to ascertain the emotional experience of the cancer journey for the families and carers of cancer patients by asking participants about their perceived level of distress experienced by their loved ones. We also endeavoured to identify if there were any differences in patients attitudes towards engaging with both professional support and pharmacological treatments for a variety of physical and psychological symptoms to ascertain any potential underlying stigma or bias experienced by patients which may act as a barrier towards accessing these services for patients.

An important aspect of this study is that it provided a platform for the cancer patients' perspective to be conveyed in terms of their experience of their cancer journey and attitudes towards engagement with various treatments which may be recommended as part of their individualised care plan.

1.9 My contribution to this research study

My role in undertaking this research study included the following:

- I wrote the study protocol under supervision from a Consultant Psychiatrist with an interest in the sub-specialty of Psycho-oncology.
- I prepared the study protocol with supervision for ethical approval and submitted to the Joint Research Ethics Committee for St James's and Tallaght University Hospitals.
- I prepared a Data Protection Impact Statement as part of the ethical approval process to identify and mitigate any data protection related risks arising from the project.
- I revised and finalised the study tool for use in this study.
- I prepared a patient information leaflet for participants of the study, which is included in the appendix of this thesis.
- I identified patients for inclusion in the study.
- I distributed and collected the survey instrument from patients (assisted by a clinical nurse specialist in psycho-oncology).
- I entered and collated the data from the participant surveys into SPSS for statistical analysis.
- I completed statistical analysis of the data under supervision.
- I wrote, submitted and revised papers for submission to peer reviewed journals.
- I wrote this thesis.

Chapter 2: Methods

This methods chapter will outline an overview of the methods implemented in this study (section 2.1), inclusion criteria for participants in this study (section 2.2), exclusion criteria for participants of this study (section 2.3), data collection (section 2.4), ethical approval (section 2.5), data protection (section 2.6) and statistical analysis (section 2.7). Therefore, this chapter now starts with an overview of the methods implemented in this study (section 2.1).

2.1 Overview of the methods implemented in this study

This was a cross-sectional, observational study. The study was based in St James's Hospital in Dublin, Ireland's largest acute academic teaching hospital. This is the largest designated national cancer centre in the country, with 17,243 outpatient cancer treatments provided annually (Trinity St James's Cancer Institute, 2023).

Patients were recruited from the Haematology Oncology Day Ward where they received outpatient cancer treatment over an eight week period April to May 2023. This site was chosen given its convenient location, as patients were able to partake in the study while they were receiving treatment for several hours, without impacting their time in hospital. Patients were invited to participate in the study through a participation information leaflet provided to them by the clinical nurse specialists on the day ward or by me when I was available. A convenience sampling method was used and all patients on the day ward were invited to take part in the study. An established survey tool (Appendix B) was used to obtain data from patients (O'Sullivan et al., 2011),

As outlined in the Irish National Cancer Strategy, section 10.9.2,

> ‘the term ‘distress’ is the preferred term to describe the psychological challenges that patients with cancer experience. Cancer related distress is best conceptualised as existing on a continuum of severity ranging from mild (adaptive, ‘normal’ levels of sadness and fear) to severe (disabling symptoms such as clinical depression, anxiety, panic disorder, body image problems or relationship and family breakdown). The degree of severity experienced by the cancer patient will dictate the level of intervention and expertise required.’
>
> (Department of Health, 2017).

We therefore aimed to assess the level of distress experienced by patients undergoing cancer treatment in our study, in order to define their subjective experience and utilise this experience to inform any recommendations from the study.

2.2 Inclusion Criteria

To be included in the study, patients were required to be aged 18 years or over. They required a cancer diagnosis. Patients had to be proficient in the English language, given that the participant information leaflet and study tool were in English. They also had to provide consent to participate in the study, this was implied consent by virtue of completing and returning the study tool. Patients were provided with a Patient Information Leaflet at the time of recruitment (Appendix A). All patients meeting the inclusion criteria were invited to participate.

2.3 Exclusion Criteria

Patients were excluded from the study if:

- they did not provide consent.
- they declined to participate or were not proficient in the English language
- they lacked capacity to consent (e.g. due to dementia or intellectual disability or another reason)
- they were too acutely medically unwell

2.4 Data collection

We assessed patients' attitudes towards services a pre-designed participant survey tool (Appendix B) (O'Sullivan et all, 2011). Patients were invited to complete the survey while undergoing cancer treatment on the haematology oncology day ward and asked to return their survey prior to their departure from the ward. The surveys were collected at the end of each day and stored in a locked office on the hospital campus.

Patients were asked for their age, which was broken down into categorical variables for the purpose of the survey. The age categorical variables were:

- 18-21 years
- 22-25 years
- 26-30 years
- 31-35 years
- 36-40 years

- 41-50 years
- 51-60 years
- Over 61 years.

Gender was defined as male, female or other to allow inclusion of all gender identities. Marital status was recorded as ‘single’, ‘long-term partner’, ‘married’, ‘divorced’ and ‘widowed’.

Type of cancer was defined as:

- ‘Lung’
- ‘Breast’
- ‘Prostate/ renal/ bladder’
- ‘Lymphoma/ leukaemia’
- ‘Colon/ rectal’
- ‘Gastric/ oesophageal’
- ‘Melanoma’
- ‘Head/ neck’
- ‘Gynaecological’
- ‘Other’. If patients selected other, they were asked to describe their cancer using free text.

Time since initial cancer diagnosis was recorded as follows;

- ‘Under one month’
- ‘One to three months’
- ‘Four to six months’

- ‘Seven to twelve months’
- ‘Over one year’.

Patients were asked if they had experienced a recurrence of their cancer with a ‘yes’ or ‘no’ response. If patients indicated that they had experienced a recurrence, they were asked how many recurrences and provided with a free text box to indicate the number.

Patients were asked about the cancer treatment that they had received to date. This was categorised as:

- ‘Surgery’
- ‘Chemotherapy’
- ‘Radiotherapy’
- ‘Hormonal treatment’
- ‘Bone marrow transplant’
- ‘Steroids’
- ‘Other’

Patients were provided with a free text option after ‘other’ to allow them to elaborate on any other types of cancer treatment that they had received. There was no limitation on how may treatments patients could select in this section.

In relation to distress of cancer diagnosis and treatment, this was categorised as:

- ‘Extremely’
- ‘Very’
- ‘Moderately’

- ‘A little’
- ‘Not at all’

Patients were asked to rate the level of distress that they experienced during cancer diagnosis and treatment. They were also asked to rate their families’ level of distress during cancer diagnosis and treatment using these categories.

We asked patients about the negative impact of cancer and its treatment on aspects of daily life. Responses were categorised as:

- ‘Not at all’
- ‘Not very much’
- ‘Moderately’
- ‘A great deal’

Patients were asked about the degree to which cancer and its treatment had affected their quality of life. As previously, responses were categorised as ‘not at all’, ‘not very much, ‘moderately’ and ‘a great deal’.

Patients were asked to disclose a history of psychological or psychiatric difficulty prior to cancer diagnosis or treatment; this was categorised as ‘yes’ or ‘no’ and patients were invited to elaborate with free text if they indicated that they had such a history. We asked about patients opinion on their coping with cancer, cancer treatment and associated side effects. Coping was categorised as:

- ‘Poorly’
- ‘Less well than I would like’
- ‘Very well’

- ‘Reasonably well’
- ‘Varies’

To explore aspects of cancer that patients were experiencing problems with, we listed symptoms of:

- Pain
- Fatigue/ energy
- Sleep
- Physical appearance
- Anxiety or worry
- Sadness/ low mood
- Fear of recurrence
- Fear for the future
- Sexual intimacy
- Work
- Parenting
- Fertility
- Finances
- Relationships
- Other.

If patients selected ‘other’, they were encouraged to elaborate with free text.

Patients were asked to indicate the level of difficulty that they experienced in relation to each symptom, on a spectrum from:

- ‘Not at all’
- ‘A little bit’
- ‘Moderately’
- ‘Quite a bit’
- ‘Extremely’.

Patients were then asked to list the three areas in their life that cancer and its treatment had the most negative or serious impact.

Patients were asked if they knew the meaning of ‘psycho-oncology’ and if they knew of its existence in St James’s Hospital, where they were attending for cancer care. We asked patients if they felt they would benefit from attending the psycho-oncology service. Patients were asked about their willingness, if referred, to attend both the psycho-oncology Psychiatrist and Psychologist. Responses to these questions were ‘refuse’, ‘reluctantly attend’ and ‘attend with no difficulty’.

Patients were asked for their level of comfort with referral to various specialties within the hospital including:

- Cardiology
- Dermatology
- Physiotherapy
- Occupational therapy
- Dietetics
- Psychiatry

- Psychology
- Social work
- Palliative care.

Level of comfort ranged from:

- ‘Extremely uncomfortable/ embarrassed’
- ‘Somewhat uncomfortable/ embarrassed’
- ‘Neutral’
- ‘Happy’
- ‘Very happy’

With the same list of specialities and categories of level of comfort, patients were asked about their satisfaction with disclosing attendance at specialists to others. Finally, patients were asked about their level of comfort taking medications for physical and psychological symptoms including:

- ‘Heart problems’
- ‘Stomach problems’
- ‘Nausea’
- ‘Fatigue’
- ‘Mood’
- ‘Anxiety’
- ‘Pain’
- ‘Hot flushes’

2.5 Ethical approval

This study received ethical approval from the St James's Hospital/ Tallaght University Hospital Joint Research and Ethics Committee in November 2022. The Project ID number is 2178. The review reference for the ethical approval is 2022-Nov -23552355. The ethical approval is included in the Appendix of this thesis document (Appendix C). It was performed in accordance with the Declaration of Helsinki (World Medical Association, 2008).

2.6 Data protection

Patient surveys were securely stored in a locked office and contained no identifying details. Data was stored on a password protected computer in a locked office in the hospital. Data was anonymised and stored in line with General Data Protection Regulation guidelines. A Research Data Protection Impact Statement was prepared as part of the ethical approval process for the study.

2.7 Statistical analysis

For statistical analysis, we used SPSS (Version 26) (IBM Corp, 2019). Bivariable analysis was complete using the Pearson Chi-square test ($\chi 2$). We looked for differences in cancer type across gender. We also assessed for difference in distress experienced by cancer patients at time of diagnosis by cancer type, age, gender and for those with and

without a pre-existing psychiatric or psychological history. We compared change in distress levels from time of diagnosis to treatment by assigning distress scores to patient responses, with 0 indicating that they responded 'not at all distressed' to 4 indicating 'extremely distressed'. We explored differences in patients' belief that they would benefit from referral to psycho-oncology services from perspectives of both gender and age. Analysis was performed for gender differences in level of comfort with disclosing to others that they were attending a psychiatrist or psychologist (Pearson- Chi Square test). Bonferroni corrections were applied to statistical analyses comparing more than 20 variables, including small numbers.

We performed three multi-variable regression analyses. We included level of distress at diagnosis and treatment and whether patients felt they would benefit from a referral to psycho-oncology as the dependent variables. We coded the patient responses about perceived benefit from referral to psycho-oncology service as follows for the purpose of the analysis;

0: patient felt that they would benefit

1: patient was unsure

2: patient did not feel they would benefit.

Independent variables were age, gender, single or not single, type of cancer and history of psychiatric or psychological difficulties pre-cancer diagnosis.

To test for multicollinearity, whereby two or more independent variables are so similar that the model cannot differentiate them, a "tolerance value" was calculated for each independent variable; tolerance values below 0.25 indicate possible multicollinearity, and tolerance values below 0.10 indicate significant problems with

multicollinearity (Katz, 1999). There was no evidence of multicollinearity in either model.

Chapter 3: Results

This results chapter will present the demographic and clinical characteristics of the study sample (section 3.1), cancer diagnosis reported in the study sample (section 3.2), level of patient distress and subjective coping with cancer (section 3.3), patients' level of distress associated with cancer diagnosis by gender (section 3.4), patients' level of distress by cancer type, age and past psychiatric history (section 3.5), level of distress at cancer diagnosis for patients and their families (section 3.6), level of distress at cancer treatment (section 3.7), level of distress at cancer diagnosis compared to cancer treatment (section 3.8), impact of cancer diagnosis and treatment on patients' lives (section 3.9), patient knowledge of the psycho-oncology service (section 3.10), patient views on benefits of referral to psycho-oncology team (section 3.11), patient attitudes on referral to various specialities (section 3.12), patient attitudes towards disclosing attendance at various specialties (section 3.13), patient attitudes towards taking medications for a variety of symptoms (section 3.14) and multivariable analyses (Section 3.15).

I will begin by discussing demographic and clinical characteristics of the study sample (section 3.1).

3.1 Demographics and clinical characteristics of the study sample

One hundred and forty-two patients participated in the study. Owing to General Data Protection Regulations (GDPR), it was not possible to collect any data about patients who declined to participate in the study. Almost two thirds (64.1%) were female; 46.5% were aged 61 years or over; and 64% were married (Table 1). The majority of patients reported no known history of psychiatric or psychological difficulties (90.9%).

Table 1: Demographic and clinical characteristics of the study sample

Variable		*n*	*%*
Gender * *(n=142)*	Female	91	64.1
	Male	51	35.9
Age (years) *(n=142)*	22 – 25	1	0.7
	26 – 30	2	1.4
	31 – 35	3	2.1
	36 – 40	9	6.3
	41 – 50	27	19.0
	51 – 60	34	23.9
	61 +	66	46.5
Marital status *(n=139)*	Single	21	15.1
	Long-term partner	9	6.5
	Married	89	64.0
	Divorced	6	4.3
	Widowed	14	10.3
Past psychiatric history *(n=132)*	Yes	12	9.1
	No	120	90.9
Type of cancer *(n=142)*	Breast	48	33.8
	Colorectal	16	11.3
	Lymphoma/leukaemia	16	11.3
	Gastric/oesophageal	12	8.5
	Gynaecological	12	8.5
	Prostate/renal/bladder	10	7.0
	Lung	9	6.3
	Multiple myeloma	6	4.2
	Melanoma	3	2.1
	Head/neck	2	1.4
	Other **	8	5.6
Time since diagnosis	<1 month	4	2.8

(n=141)	1-3 months	23	16.3
	4-6 months	19	13.5
	7-12 months	30	21.3
	>1 year	65	46.1
Recurrence of cancer *(n=133)*	Yes	41	30.8
	No	92	69.2
Surgical treatment *(n=142)*	Yes	57	40.1
	No	85	59.9
Chemotherapy *(n=142)*	Yes	121	85.2
	No	21	14.8
Radiotherapy *(n=142)*	Yes	39	27.5
	No	103	72.5
Hormonal therapy *(n=142)*	Yes	13	9.2
	No	129	90.8
Bone marrow transplant *(n=142)*	Yes	8	5.6
	No	134	94.4
Steroids *(n=142)*	Yes	51	35.9
	No	91	64.1
Immunotherapy *(n=142)*	Yes	2	1.4
	No	140	98.6

Table 1 Notes:

* No participant reported non-binary gender identity.

** 'Other' diagnoses not provided as potentially identifying.

3.2 Cancer diagnosis reported in the study sample

Breast cancer was the most commonly diagnosed cancer (33.8%) followed by colorectal cancer (11.3%), lymphoma/leukaemia (11.3%), gastric/oesophageal cancer (8.5%), gynaecological cancer (8.5%) and prostate/renal/bladder cancer (7.0%). Type of cancer differed significantly between genders (Pearson Chi-Square= 64.621, $p<0.01$) (Table 2). Among women, the most common cancers were breast (51.6%), gynaecological (13.2%) and colorectal (7.7%). Among men, the most common cancers were lymphoma/leukaemia (21.6% of men), colorectal (17.6%) and prostate/ renal/ bladder (17.6%).

Approximately half of patients (53.9%) had received their cancer diagnosis within the previous year and almost one third (30.8%) were experiencing a recurrence of a primary cancer. Of those who specified the number of recurrences experienced (n=31), 58.1% (n=18) reported one recurrence; 16.1% (n=5) two recurrences; and 25.8% (n=8) three recurrences or more. Chemotherapy was the most common treatment that patients reported receiving (85.2%), followed by surgery (40.1%), steroids (35.9%), radiotherapy (27.5%), hormonal therapy (9.2%), bone marrow transplant (5.6%), and immunotherapy (1.4%).

Table 2 Cancer type by gender

Variable	Overall (Female and male)	Female *n (%)*	Male *n (%)*
Breast	48 (33.8%)	47 (51.6%)	1 (2.0%)
Colon/ rectal	16 (11.3%)	7 (7.7%)	9 (17.6%)
Lymphoma/ leukaemia	16 (11.3%)	5 (5.5%)	11 (21.6%)
Gastric/ oesophageal	12 (8.5%)	6 (6.6%)	6 (11.8%)
Gynaecological	12 (8.5%)	12 (13.2%)	0 (0%)
Prostate/ renal/ bladder	10 (7.0%)	1 (1.1%)	9 (17.6%)
Lung	9 (6.3%)	2 (2.2%)	7 (13.7 %)
Other *	8 (5.6%)	6 (6.6%)	2 (3.9%)
Multiple myeloma	6 (4.2%)	2 (2.2%)	4 (7.8%)
Melanoma	3 (2.1%)	2 (2.2%)	1 (2.0%)
Head/neck	2 (1.4%)	1 (1.1%)	1 (2.0%)

Table 2 Notes:

* 'Other' diagnoses not provided as potentially identifying.

3.3 Level of patient distress and subjective coping with cancer

Table 3 outlines levels of distress associated with cancer diagnosis for patients and cancer treatment for patients and their families. Over two thirds of patients rated their cancer diagnosis as very distressing (33.3%) or extremely distressing (36.4%).

Table 3 Distress of cancer diagnosis for patient and treatment for patient and family

Variable	Extremely *n (%)*	Very *n (%)*	Moderately *n (%)*	A little *n (%)*	Not at all *n (%)*
Distress of diagnosis for patient *(n=129)*	47 (36.4%)	43 (33.3%)	32 (24.8%)	6 (4.7%)	1 (0.8%)
Distress of treatment for patient *(n=124)*	20 (16.1%)	38 (30.6%)	47 (37.9%)	16 (12.9%)	3 (2.4%)
Distress of treatment for family *(n=123)*	22 (17.9%)	48 (39.0%)	43 (35.0%)	5 (4.1%)	5 (4.1%)

3.4 Patients' level of distress associated with cancer diagnosis by gender

Table 4 outlines patients' levels of distress of their cancer diagnosis by gender. There were statistically significant differences across genders (Pearson Chi-Square = 13.166, p=0.01) with females experiencing more extreme levels of distress (46.4%) than males. Over three quarters of females (76.2%) rated their distress levels as 'extremely' or 'very' high in relation to their cancer diagnosis. Approximately one third of males (31.1%) rated their cancer diagnosis as moderately distressing compared to approximately one fifth of females (21.4%)

Table 4 Level of distress of cancer diagnosis by gender

Variable	Overall n (%)	Female *n (%)*	Male *n (%)*
Extremely	47 (36.4%)	39 (46.4%)	8 (17.8%)
Very	43 (33.3%)	25 (29.8%)	18 (40.0%)
Moderately	32 (24.8%)	18 (21.4%)	14 (31.1%)
A little	6 (4.7%)	2 (2.4%)	4 (8.9%)
Not at all	1 (0.8%)	0 (0.0%)	1 (2.2%)

3.5 Patients' level of distress by cancer type, age and past psychiatric history

Distress of diagnosis for patient did not differ across cancer types (Pearson Chi-Square= 50.422, p=0.125; Table 5) or age (Pearson Chi-Square= 17.233, p=0.839; Table 6). There was no difference in distress of diagnosis for patients with a history of psychiatric or psychological difficulties and those without a psychiatric history (Pearson Chi-Square 0.818, p=0.936; Table 7).

Table 5: Level of distress of diagnosis by cancer type

Variable	Extremely *n (%)*	Quite a bit *n (%)*	Moderately *n (%)*	A little bit *n (%)*	Not at all *n (%)*
Breast (n=46)	24 (51.1%)	8 (18.6%)	13 (40.6%)	1 (16.7%)	0 (0.0%)
Colon/ rectal (n=15)	7 (14.9%)	5 (11.6%)	2 (6.3%)	1 (16.7%)	0 (0.0%)
Gynaecological (n=10)	4 (8.5%)	6 (14.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Gastric/ oesophageal (n=10)	3 (6.4%)	2 (4.7%)	4 (12.5%)	1 (16.7%)	0 (0.0%)
Multiple myeloma (n=6)	3 (6.4%)	0 (0.0%)	3 (9.4%)	0 (0.0%)	0 (0.0%)
Lymphoma/ leukaemia (n=15)	2 (4.3%)	6 (14.0%)	4 (12.5%)	2 (33.3%)	1 (100.0%)
Lung (n=8)	1 (2.1%)	5 (11.6%)	1 (3.1%)	1 (16.7%)	0 (0.0%)
Melanoma (n=3)	1 (2.1%)	1 (2.3%)	1 (3.1%)	0 (0.0%)	0 (0.0%)
Other (n=7)	1 (2.1%)	6 (14.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Prostate/ renal/ bladder (n=7)	1 (2.1%)	3 (7.0%)	3 (9.4%)	0 (0.0%)	0 (0.0%)
Head/ neck (n=2)	0 (0.0%)	1 (2.3%)	1 (3.1%)	0 (0.0%)	0 (0.0%)

Table 5 Notes: Numbers for different cancers differ from other tables owing to non-response to specific questions.

Table 6: Level of distress of diagnosis by age

Variable	Extremely *n (%)*	Quite a bit *n (%)*	Moderately *n (%)*	A little bit *n (%)*	Not at all *n (%)*
26-30 years (n=2)	2 (4.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
31-35 years (n=3)	2 (4.3%)	0 (0.0%)	1 (3.1%)	0 (0.0%)	0 (0.0%)
36-40 years (n=9)	4 (8.7%)	2 (4.7%)	3 (9.4%)	0 (0.0%)	0 (0.0%)
41-50 years (n=26)	6 (13.0%)	11 (25.6%)	9 (28.1%)	0 (0.0%)	0 (0.0%)
51-60 years (n=32)	11 (23.9%)	13 (30.2%)	7 (21.9%)	1(16.7%)	0 (0.0%)
Over 61 years (n=56)	21 (45.7%)	17 (39.5%)	12 (37.5%)	5 (83.3%)	1 (100.0%)

Table 7: Level of distress of diagnosis for patients with a history of psychiatric or psychological difficulties

Variable	Overall *n (%)*	History of psychiatric or psychological difficulties *n (%)*	No history of psychiatric or psychological difficulties *n (%)*
Extremely	47 (36.4%)	5 (41.7%)	42 (35.9%)
Very	43 (33.3%)	4 (33.3%)	39 (33.3%)
Moderately	32 (24.8%)	3 (25.0%)	29 (24.8%)
A little	6 (4.7%)	0 (0.0%)	6 (5.1%)
Not at all	1 (0.8%)	0 (0.0%)	1 (0.9%)

3.6 Level of distress at cancer diagnosis for patients and their families

Almost half of patients (49.6%) rated their cancer diagnosis as extremely distressing for their family. Table 8 outlines patients level of distress at diagnosis compared to their perception of their families' level of distress at diagnosis. Patients were more likely to perceive their families as extremely distressed compared to themselves (Pearson Chi-Square 70.016, $p<0.01$).

Table 8: Level of distress of diagnosis of patients and their family

Variable	Distress of diagnosis for patient *n (%)*	Distress of diagnosis for family *n (%)*
Extremely	47 (36.4%)	64 (49.6%)
Very	43 (33.3%)	44 (34.1%)
Moderately	32 (24.8%)	16 (12.4%)
A little	6 (4.7%)	4 (3.1%)
Not at all	1 (0.8%)	1 (0.8%)

3.7 Level of distress at cancer treatment.

Almost half of patients rated their treatment as very distressing (30.6%) or extremely distressing (16.1%). Females experienced more distress than males during cancer treatment, with 21.2% (n=82) of females reporting cancer treatment as "extremely" distressing compared to 4.7% (n=43) of males (Pearson Chi-Square= 11.526, p=0.042). Over half of patients rated their cancer treatment as very distressing (39.0%) or extremely distressing for their family (17.9%).

3.8 Level of distress at cancer diagnosis compared to cancer treatment

Table 9 outlines patient distress at diagnosis compared to patient distress at treatment. Patients were more likely to experience extreme distress at diagnosis than treatment (Pearson Chi-Square 49.455, $p<0.01$). Table 10 outlines change in distress levels from diagnosis to treatment (n=125). Sixteen people experienced more distress at treatment than diagnosis. While almost half of patients (47.2%; n=59) reported increased distress at treatment compared to diagnosis, 40.0% (n=50) reported no change in distress and 12.8% (n=16) described decreased distress at treatment. The majority of patients experienced equal or reduced levels of distress at treatment than at diagnosis.

Table 9: Level of distress for patient at diagnosis and treatment

Variable	Distress of diagnosis for patient *n (%)*	Distress of treatment for patient *n (%)*
Extremely	47 (36.4%)	20 (16.1%)
Very	43 (33.3%)	38 (30.6%)
Moderately	32 (24.8%)	47 (37.9%)
A little	6 (4.7%)	16 (12.9%)
Not at all	1 (0.8%)	3 (2.4%)

Table 10: Change in distress from diagnosis to treatment

Change in distress score from diagnosis to treatment *	*n (%)*
Increase of 4 points	2 (1.6%)
Increase of 3 points	2 (1.6%)
Increase of 2 points	15 (12.0%)
Increase of 1 point	40 (32.0%)
No change	50 (40.0%)
Decrease of 1 point	14 (11.2%)
Decrease of 2 points	2 (1.6%)

Table 10 Note:

*Distress score ranges from 0 (not at all distressed) to 4 (extremely distressed).

3.9 Impact of cancer diagnosis and treatment on patients' lives

Almost half of patients (48.9%, n=64) reported that cancer diagnosis and treatment impacted a great deal on daily life. A majority (84.8%, n=111) reported that cancer diagnosis and treatment had a moderate or great deal of impact on their quality of life. Less than a quarter of patients (22.7%, n=30) felt that they were coping very well with cancer treatment and associated side effects. Approximately half of patients (47.7%, n=63) felt that they were coping reasonably well with cancer treatment and its side effects.

Table 11 outlines the impact of cancer and its treatment on patients' lives as reported by patients. The areas in life that were most extremely affected by cancer and its treatment were work (27.9%) followed by fatigue (19.0%) and fear for the future (17.3%). The areas least extremely affected by cancer and its treatment were relationships (2.6%), parenting (4.8%) and fertility (6.7%).

Table 11: Areas patients had difficulties with due to cancer and its treatment

Variable	Extremely *n (%)*	Quite a bit *n (%)*	Moderately *n (%)*	A little bit *n (%)*	Not at all *n (%)*
Work *(n=111)*	31 (27.9%)	29 (26.1%)	11 (9.9%)	8 (7.2%)	32 (28.8%)
Fatigue *(n=126)*	24 (19.0%)	47 (37.3%)	33 (26.2%)	20 (15.9%)	2 (1.6%)
Fear for the future *(n=127)*	22 (17.3%)	33 (26.0%)	30 (23.6%)	27 (21.3%)	15 (11.8%)
Sexual intimacy *(n=113)*	20 (17.7%)	28 (24.8%)	17 (15.0%)	15 (13.3%)	33 (29.2%)
Fear of recurrence *(n=122)*	19 (15.6%)	32 (26.2%)	26 (21.3%)	31 (25.4%)	14 (11.5%)
Finances *(n=119)*	15 (12.6%)	21 (17.6%)	25 (21%)	27 (22.7%)	31 (26%)
Physical appearance *(n=122)*	14 (11.5%)	34 (27.9%)	20 (16.4%)	32 (26.2%)	22 (18.0%)
Anxiety or worry *(n=123)*	14 (11.4%)	34 (27.6%)	34 (27.6%)	30 (24.4%)	11 (8.9%)
Pain *(n=115)*	10 (8.7%)	21 (18.3%)	26 (22.6%)	31 (27.0%)	27 (23.5%)
Sleep *(n=125)*	7 (5.6%)	37 (29.6%)	28 (22.4%)	29 (23.2%)	24 (19.2%)
Low mood or sadness *(n=126)*	6 (4.8%)	20 (15.9%)	41 (32.5%)	41 (32.5%)	18 (14.3%)
Fertility *(n=90)*	6 (6.7%)	4 (4.4%)	4 (4.4%)	8 (8.9%)	68 (75.6%)
Parenting *(n=105)*	5 (4.8%)	14 (13.3%)	19 (18.1%)	27 (25.7%)	40 (38.1%)
Relationships *(n=115)*	3 (2.6%)	15 (13.0%)	23 (20%)	24 (20.9%)	50 (43.5%)

Over a quarter of patients (27.9%) experienced extreme difficulties relating to work. Over half of patients (56.3%) reported 'quite a bit' or 'extreme' difficulties with fatigue. Over two thirds (66.9%) reported at least moderate difficulties of fear for the future. Less than one third of patients (29.2%) reported no difficulties with sexual intimacy. Overall, 63.1% of patients experienced at least moderate difficulties relating to fear of recurrence. Almost one third of patients (30.2%) experienced 'extreme' or 'quite a bit' of difficulties with their finances due to cancer and its treatment. Over a quarter of patients (27.9%) experienced 'quite a bit' of difficulty with their physical appearance due to cancer and its treatment.

Two thirds of patients (66.6%) experienced at least a moderate level of anxiety and worry relating to cancer and its treatment. Almost half (49.6%) of patients reported that cancer and its treatment caused them to experience at least a moderate level of pain. Over one third of patients (35.2%) rated that their sleep was impacted 'quite a bit' or 'extremely' by cancer and its treatment. Over half of patients (53.2%) experienced at least moderate levels of low mood or sadness due to cancer and its treatment. Over one third of patients (38.1%) experienced no difficulties with parenting due to cancer and its treatment. Over three quarters (75.6%) reported that cancer and its treatment had no impact on their fertility. Less than half of patients (43.5%) experienced no difficulties in their relationships due to cancer and its treatment.

In terms of other areas affected by cancer and its treatment, one patient identified planning for the future (0.7%), one identified social restrictions (0.7%) and one identified social life (0.7%) as areas that they had difficulty with due to cancer and its treatment.

The areas of life affected by cancer and its treatment did not differ significantly across genders, apart from levels of anxiety and worry, with females experiencing higher

levels of anxiety and worry (Table 12; Pearson Chi-Square 10.792, p=0.029). However, when adjusting for multiple testing, this relationship did not retain statistical significance.

Table 12: Level of anxiety/ worry due to cancer and its treatment by gender

Variable	Extremely worried *n (%)*	Quite a bit *n (%)*	Moderately *n (%)*	A little bit *n (%)*	Not at all *n (%)*
Female *(n=81)*	12 (14.8%)	28 (34.6%)	19 (23.5%)	16 (19.8%)	6 (7.4%)
Male *(n=42)*	2 (4.8%)	6 (14.3%)	15 (35.7%)	14 (33.3%)	5 (11.9%)

3.10 Patient knowledge of the psycho-oncology service

Less than a third of patients (30.3%, n=40) knew the meaning of psycho-oncology. One quarter of patients (25.6%, n=34) were aware that there was a psycho-oncology service operating in St James's Hospital where they were receiving cancer treatment. Two thirds of patients (67.2%, n=84) were unsure if they would benefit from a referral to the psycho-oncology service. Majorities of patients reported that they would attend the psycho-oncology psychiatrist (71.9%, n=87) and psycho-oncology psychologist (73.5%, n=86) without any difficulty.

3.11 Patient views on benefits of referral to psycho-oncology team

Patient views as to whether they would benefit or not from a referral to the psycho-oncology service were not related to gender (Table 13; Pearson Chi-Square 0.192, p=0.908) or age category (Table 14; Pearson Chi-Square 9.808, p=0.633).

Table 13: Benefit from referral to psycho-oncology service by gender

Variable	Yes *n (%)*	No *n (%)*	Don't know *n (%)*
Female *(n=80)*	14 (17.5%)	13 (16.3%)	53 (66.3%)
Male *(n=45)*	8 (17.8%)	6 (13.3%)	31 (68.9%)

Table 14: Benefit from referral to psycho-oncology service by age

Variable	Yes *n (%)*	No *n (%)*	Don't know *n (%)*
26-30 years (n=2)	0 (0%)	0 (0%)	2 (1.6%)
31-35 years (n=3)	1 (0.8%)	0 (0%)	2 (1.6%)
36-40 years (n=8)	1 (0.8%)	0 (0%)	7 (5.6%)
41-50 years (n=26)	6 (4.8%)	5 (4.0%)	15 (12.1%)
51-60 years (n=30)	8 (6.5%)	6 (4.8%)	16 (12.9%)
Over 61 years (n=55)	6 (4.8%)	8 (6.5%)	41 (33.0%)

3.12 Patient attitudes on referral to various specialities

Table 15 outlines patients' level of comfort with referral to various medical specialties and allied health disciplines. Over two-thirds of patients would be happy or very happy with a referral to cardiology (70.2%). Just over half of patients (54.7%) would be happy or very happy with a referral to psychiatry and 62% would be happy or very happy with a referral to psychology.

Table 15: Level of comfort with referral to various disciplines

Variable	Extremely uncomfortable/ embarrassed *n (%)*	Somewhat uncomfortable/ embarrassed *n (%)*	Neutral *n (%)*	Happy *n (%)*	Very happy *n (%)*
Social Work *(n=118)*	7 (5.9%)	6 (5.1%)	38 (32.2%)	33 (28.0%)	34 (28.8%)
Palliative Care *(n=117)*	5 (4.3%)	3 (2.6%)	30 (25.6%)	36 (30.8%)	43 (36.8%)
Specialist Nurse *(n=117)*	5 (4.3%)	3 (2.6%)	30 (25.6%)	36 (30.8%)	43 (36.8%)
Psychiatrist *(n=117)*	4 (3.4%)	8 (6.8%)	41 (35.0%)	33 (28.2%)	31 (26.5%)
Psychologist *(n=116)*	4 (3.4%)	6 (5.2%)	34 (29.3%)	39 (33.6%)	33 (28.4%)
Dietician *(n=118)*	3 (2.5%)	2 (1.7%)	24 (20.3%)	41 (34.7%)	48 (40.7%)
Occupational Therapy *(n=119)*	3 (2.5%)	2 (1.7%)	33 (27.7%)	40 (33.6%)	41 (34.5%)
Cardiology *(n=121)*	2 (1.7%)	0 (0%)	34 (28.1%)	43 (35.5%)	42 (34.7%)
Dermatology *(n=121)*	2 (1.7%)	2 (1.7%)	34 (28.1%)	42 (34.7%)	41 (33.9%)
Physiotherapy *(n=119)*	2 (1.7%)	1 (0.8%)	32 (26.9%)	44 (37.0%)	40 (33.6%)

3.13 Patient attitudes towards disclosing attendance at various specialties

Table 16 outlines patient's level of comfort with disclosing to others that they are attending various disciplines. Almost all patients (94.2%) would be neutral or comfortable with telling others that they were attending cardiology. Over one fifth (21.0%) of patients would be somewhat or extremely uncomfortable disclosing that they were attending palliative care. Just under one fifth of patients (17.9%) would be somewhat or extremely uncomfortable disclosing attendance at a psychiatrist and 14.4% of patients at disclosing attendance at a psychologist.

These proportions did not differ across genders for attending a psychiatrist (Table 17; Pearson Chi-square 4.775, p=0.311, *n=117*) or attending a psychologist (Table 18; Pearson Chi-Square 3.616, p=0.606, *n=118*).

Table 16: Level of comfort telling others about attending various disciplines

Variable	Extremely uncomfortable/ embarrassed *n (%)*	Somewhat uncomfortable/ embarrassed *n (%)*	Neutral *n (%)*	Happy *n (%)*	Very happy *n (%)*
Palliative Care *(n=114)*	17 (14.9%)	7 (6.1%)	36 (31.6%)	36 (31.6%)	18 (15.8%)
Psychiatrist *(n=117)*	10 (8.5%)	11 (9.4%)	33 (28.2%)	44 (37.6%)	19 (16.2%)
Psychologist *(n=117)*	9 (7.6%)	8 (6.8%)	34 (29.1%)	44 (37.6%)	22 (18.8%)
Social Work *(n=117)*	9 (7.7%)	10 (8.5%)	33 (28.2%)	43 (36.8%)	22 (18.8%)
Specialist Nurse *(n=118)*	7 (5.9%)	4 (3.4%)	31 (26.3%)	47 (39.8%)	29 (24.6%)
Cardiology *(n=121)*	5 (4.1%)	2 (1.7%)	34 (28.1%)	54 (44.6%)	26 (21.5%)
Occupational Therapy *(n=120)*	5 (4.2%)	1 (0.8%)	33 (27.5%)	53 (44.2%)	28 (23.3%)
Dermatology *(n=119)*	4 (3.4%)	2 (1.7%)	35 (29.4%)	53 (44.5%)	25 (21.0%)
Dietician *(n=120)*	4 (3.3%)	2 (1.7%)	33 (27.5%)	53 (44.2%)	28 (23.3%)
Physiotherapy *(n=119)*	4 (3.4%)	3 (2.5%)	34 (28.6%)	52 (43.7%)	26 (21.8%)

Table 17: Level of comfort telling others attending a Psychiatrist by gender

Gender	Extremely uncomfortable/ embarrassed *n (%)*	Somewhat uncomfortable/ embarrassed *n (%)*	Neutral *n (%)*	Happy *n (%)*	Very happy *n (%)*
Female *(n=77)*	8 (10.4%)	5 (6.5%)	22 (28.6%)	27 (35.1%)	15 (19.5%)
Male *(n=40)*	2 (5.0%)	6 (15.0%)	11 (27.5%)	17 (42.5%)	4 (10.0%)

Table 18: Level of comfort telling others attending a Psychologist by gender

Gender	Extremely uncomfortable/ embarrassed *n (%)*	Somewhat uncomfortable/ embarrassed *n (%)*	Neutral *n (%)*	Happy *n (%)*	Very happy *n (%)*
Female *(n=77)*	7 (9.1%)	4 (5.2%)	21 (27.3%)	28 (36.4%)	17 (22.1%)
Male *(n=40)*	2 (5.0%)	4 (10.0%)	13 (32.5%)	16 (40.0%)	5 (12.5%)

3.14 Patient attitudes towards taking medications for a variety of symptoms

Table 19 outlines patients' level of comfort taking medications for various symptoms. The majority of patients would be happy or very happy to disclose that they were taking medications for their heart (65.9%), stomach (68.8%), nausea (72.4%), fatigue (73.2%), hot flushes (56.6%) or pain (73.8%). Less than half of patients would be happy or very happy disclosing that they were taking medication for mood (45.4%) or anxiety (41.6%).

Table 19: Level of comfort taking medication for various conditions

Variable	Very unhappy *n (%)*	Somewhat unhappy *n (%)*	Neutral *n (%)*	Somewhat happy *n (%)*	Very happy *n (%)*
Mood *(n=122)*	17 (13.9%)	24 (19.7%)	27 (22.1%)	19 (16.7%)	35 (28.7%)
Heart *(n=123)*	11 (8.9%)	9 (7.3%)	22 (17.9%)	30 (24.4%)	51 (41.5%)
Anxiety *(n=65)*	10 (15.4%)	14 (21.5%)	14 (21.5%)	9 (13.9%)	18 (27.7%)
Hot flushes *(n=113)*	8 (7.1%)	8 (7.1%)	33 (29.2%)	19 (16.8%)	45 (39.8%)
Fatigue *(n=123)*	7 (5.7%)	4 (3.3%)	22 (17.9%)	29 (23.6%)	61 (49.6%)
Nausea *(n=123)*	6 (4.9%)	6 (4.9%)	22 (17.9%)	29 (23.6%)	60 (48.8%)
Stomach *(n=125)*	6 (4.8%)	7 (5.6%)	26 (20.8%)	30 (24.0%)	56 (44.8%)
Pain *(n=61)*	5 (8.2%)	5 (8.2%)	6 (9.8%)	12 (19.7%)	33 (54.1%)

3.15 Multivariable analyses

We performed regression analysis with level of distress at diagnosis as the dependent variable. The independent variables were age, gender, single or not single, type of cancer and history of psychiatric or psychological difficulties pre-cancer diagnosis. Table 20 outlines the results of this multivariable analysis. Level of distress at cancer diagnosis was rated from 0, indicating no distress and 4, indicating extreme distress. Of the variables included in the model, female gender was the only one associated with higher levels of patient distress at cancer diagnosis. The R^2 value was 12.0%, indicating that variables in the model explained 12.0% of the variance in level of distress at cancer diagnosis.

Table 20: Predictors of level of patient distress [a] of cancer diagnosis: multi-variable linear regression model

Independent variables	β	Standard error	p value	Tolerance value [b]
Age	-0.033	0.069	0.637	0.942
Gender	0.624	0.176	0.001	0.916
Single or not single	0.226	0.156	0.151	0.971
Type of cancer	0.022	0.027	0.401	0.962
History of psychiatric or psychological difficulties pre-cancer	0.115	0.276	0.679	0.975
Constant	2.441	0.480	<0.001	-

Notes

This multi-variable linear regression model includes all patients who responded to the survey on the Oncology Day ward during the recruitment period for the study.

R square value was 12.0% indicating variables in the model explained 12% of the variance in level of distress.

[a] The dependent variable was level of distress at cancer diagnosis, where 0 indicates no distress and 4 indicates extreme distress.

[b] To test for multicollinearity, a "tolerance value" was calculated for each independent variable; tolerance values below 0.25 indicate possible multicollinearity, and tolerance values below 0.10 indicate significant problems with multicollinearity (Katz, 1999).

We also preformed regression analysis with level of patient distress at treatment as the dependent variable, with 0 indicating no distress and 4 indicating extreme distress. The independent variables were age, gender, single or not single, type of cancer and history of psychiatric or psychological difficulties pre-cancer diagnosis. Table 21 outlines the results of this multivariable analysis. Of the variables included in the model, female gender was the only one associated with increased distress at time of cancer treatment. The R^2 value was 8.2%, indicating that variables in the model explained 8.2% of the variance in the level of distress.

Table 21: Predictors of level of patient distress [a] of cancer treatment: multi-variable linear regression model

Independent variables	β	Standard error	p value	Tolerance value [b]
Age	-0.038	0.077	0.626	0.936
Gender	0.425	0.196	0.032	0.925
Single or not single	0.279	0.176	0.115	0.967
Type of cancer	0.017	0.030	0.564	0.973
History of psychiatric or psychological difficulties pre-cancer	0.468	0.306	0.128	0.974
Constant	2.009	0.532	<0.001	-

Notes

This multi-variable linear regression model includes all patients who responded to the survey on the Oncology Day ward during the recruitment period for the study.

R square value was 8.2% indicating variables in the model explained 8.2% of the variance in level of distress at treatment.

[a] The dependent variable was level of distress at cancer treatment, where 0 indicates no distress and 4 indicates extreme distress.

[b] To test for multicollinearity, a "tolerance value" was calculated for each independent variable; tolerance values below 0.25 indicate possible multicollinearity, and tolerance values below 0.10 indicate significant problems with multicollinearity (Katz, 1999).

A linear regression analysis was performed with whether patients felt they would benefit from a referral to psycho-oncology as the dependent variable. 0 indicated that they would benefit, 1 indicated that they were unsure if they would benefit and 2 indicated that they did not feel they would benefit from a referral to the psycho-oncology service. The independent variables were age, gender, single or not single, type of cancer and history of psychiatric or psychological difficulties pre-cancer diagnosis. Table 22 outlines the results of this multivariable analysis. Of the variables included in this model, having a history of psychiatric of psychological difficulties pre-cancer diagnosis was associated with a higher likelihood of believing that a psycho-oncology referral would be beneficial. The R^2 value was 7.7%, indicating that variables in the model explained 7.7% of the variance in patients' belief of benefit of referral to psycho-oncology.

Table 22: Predictors of patients' belief of benefit from referral to psycho-oncology service [a]: multi-variable linear regression model

Independent variables	β	Standard error	p value	Tolerance value [b]
Age	0.051	0.044	0.257	0.938
Gender	0.093	0.114	0.418	0.898
Single or not single	0.002	0.101	0.986	0.978
Type of cancer	0.005	0.017	0.788	0.955
History of psychiatric or psychological difficulties pre-cancer	-0.537	0.190	0.005	0.971
Constant	0.644	0.312	0.041	-

Notes

This multi-variable linear regression model includes all patients who responded to the survey on the Oncology Day ward during the recruitment period for the study.

R square value was 7.7% indicating variables in the model explained 7.7% of the variance in level of distress at treatment.

[a] The dependent variable was patients' belief of benefit from referral to psycho-oncology service, where 0 indicates a 'yes' response, 1 a 'don't know' response and 2 a 'no' response.

[b] To test for multicollinearity, a "tolerance value" was calculated for each independent variable; tolerance values below 0.25 indicate possible multicollinearity, and tolerance values below 0.10 indicate significant problems with multicollinearity (Katz, 1999).

Chapter 4: Discussion

This discussion chapter will present a summary of discussion (section 4.1), summary of the results of this study (section 4.2), comparison of the results of this study to the national literature (section 4.3), comparison of the results of this study on distress levels in cancer patients to the international literature (section 4.4), comparison of the results of this study on areas of life affected by cancer to the international literature (section 4.5), comparison of the results of this study on engagement with psycho-oncology services to the international literature (section 4.6), implications of this study for clinical practice (section 4.7), how this study fits into Irelands National Cancer Strategy 2017 – 2026 (section 4.8), strengths of the study (section 4.9), limitations of this study (section 4.10) and finally discuss directions for future research in this field (section 4.11). Therefore, this chapter now starts with section 4.1, summary of discussion.

4.1 Summary of discussion

In this discussion chapter, I will summarise the results of this study. I will compare the results found in this Irish study to what is published in both the national and international literature. I will highlight the implications of this study for future clinical practice in the area of psycho-oncology. I will discuss the strengths and limitations of this study. Finally, I will highlight the directions for future research in the field of psycho-oncology.

4.2 Summary of the results of this study

In summary, this study found that cancer patients experience high levels of distress. A majority of patients rated their cancer diagnosis as 'very' or 'extremely' distressing. Almost half of patients in this study found their cancer treatment 'very' or 'extremely' distressing. We found that females experienced more extreme levels of distress than males during both cancer diagnosis and treatment, with almost half of females reporting 'extreme' distress at diagnosis and over one-fifth during treatment. This compares to less than one-fifth of males at diagnosis and under five percent during treatment.

Patients were likely to perceive their families as more distressed than themselves and almost half of patients reported that their families experienced their cancer diagnosis as 'extremely' distressing. Patients were less likely to report extreme distress at treatment than cancer diagnosis. Gender based differences were also observed in relation to distress during cancer treatment, with over one fifth of females experiencing 'extreme' distress at cancer treatment, compared to under five percent of males. Most patients experienced equal or less extreme levels of distress during cancer treatment than diagnosis.

Almost half of patients in the study reported that cancer diagnosis and treatment impacted 'a great deal' on daily life. Most patients reported that their cancer diagnosis had at least a moderate impact on their quality of life. Patients reported work, fatigue and fear for the future as the areas of life most extremely affected by cancer and treatment. Only 2.6% of patients reported extreme difficulties with relationships due to their cancer diagnosis and treatment. Of note, almost two thirds of patients reported at least moderate difficulties with fear of recurrence. Similar levels reported moderate levels of anxiety due

to cancer and its treatment. Approximately half of patients reported at least moderate levels of low mood or sadness related to their cancer diagnosis and treatment.

Despite high levels of extreme distress during both cancer diagnosis and treatment in our study population, under one third of patients knew the meaning of 'psycho-oncology' and most were unaware that this service was available in the hospital where they were receiving cancer treatment at the time of the study. Most patients, regardless of age or gender, were ambivalent about the benefits of psycho-oncology referral. Despite this, most patients reported they would attend both the psycho-oncology psychiatrist and psychologist without any difficulty.

Although most patients would be happy or very happy to attend psychology or psychiatry, there was a higher level of discomfort reported with disclosing to others that they were attending a psychiatrist, compared to other medical specialties such as a cardiologist or a dermatologist, irrespective of gender. In terms of allied health professionals, patients reported a higher level of 'extreme' discomfort or embarrassment with referral to social work compared to dietician or physiotherapy. Our study highlights that patients are more open to engaging with a specialist nurse than a psychiatrist or psychologist. Specialist psycho-oncology nurses embedded within the psycho-oncology multidisciplinary team may play a vital role in engaging and treating these highly distressed patients to improve outcomes.

Patients were more happy to be prescribed and disclose the use of medications for physical symptoms such as hot flushes, fatigue, nausea and pain over psychological symptoms of mood and anxiety.

On multi-variable testing, female gender was the only variable independently associated with higher levels of patient distress during both cancer diagnosis and cancer

treatment. We also found that having a history of psychiatric or psychological difficulty was the only variable independently associated with perceived benefit from a referral to psycho-oncology.

4.3 Comparison of the results of this study to the national literature

A previous Irish study highlighted significant levels of distress in psycho-oncology patients with 57.9% of patients reporting 'very' high or 'extreme' levels of distress in relation to their cancer diagnosis, but that study did not report differences in gender (O'Sullivan et al., 2011). This study, published over a decade ago, also reported similar reluctance to disclose attendance at a psychiatrist (19.3%) or psychologist (18.7%), compared to a dietician (3.7%), for example.

A qualitative study of Irish cancer survivors also identified lack of knowledge and the emotional impact of cancer as potential barriers to engagement with a self-management supports programme established to improve quality of life for cancer survivors (Pallin et al., 2024). Our study adds to this finding, with high rates of our study population unaware of the existence of or benefits of being referred to the psycho-oncology service.

An audit of psycho-oncology referrals received over a one year period in 2003 to the psycho-oncology service from medical oncology teams in Beaumont Hospital, another tertiary cancer centre in Dublin reported that over half of patients referred to their service (54%, n=63) were diagnosed with an affective illness. This finding shows high rates of mood disorders among those diagnosed with cancer, treated in the inpatient hospital setting and referred to the psycho-oncology service. (Hallahan et al., 2004).

Another Irish study, which conducted a review of referrals to the psycho-oncology service in separate tertiary cancer centre (Cork University Hospital) ten years ago also found that females experienced significantly increased levels of psychological distress compared to males, regardless of cancer type (Lavelle et al., 2017). Our study looks at a different patient population to these two studies, including all patients receiving cancer treatment in a tertiary cancer centre, rather than those already referred to psycho-oncology.

Despite these differences in study population, our study replicates the findings of the Cork research group, linking female gender with increased distress levels due to cancer in Ireland. In addition, we report that over two thirds of patients rate their cancer diagnosis as very or extremely distressing and have aimed to expand on the patient experience and areas of life which they feel is most impacted by cancer and it's treatment, in order to streamline services and ensure that the needs of cancer patients are reflected in service provision.

A recently published evaluation of paediatric psycho-oncology services in Children's Health Ireland found that the Cancer Support Specialist Service had a positive impact when they looked at qualitative data from both MDT members working within the service and from interview with families engaged with the service (Murphy et al., 2026). This study shows the positive impact of psychosocial supports for cancer patients' families in the paediatric setting in Ireland.

A qualitative exploration of the lived experience of partners of Irish women diagnosed with cervical cancer, published by a research group in 2021, highlighted a need and deficits in terms of psychological support for partners and families of those diagnosed with cancer (D'Alton et al., 2021). A participant in this study described the need for

improved psychosocial services in Ireland to support the loved ones of those diagnosed with cancer.

> ‘Something should be in place for the partners…they're trying to put on a strong face and be in a supportive role, but they can't actually say anything because they're not the one with the cancer, so you can't even grieve, or you can't show that you're feeling anything at all’ (Participant 5)
>
> (D’Alton et al., 2021)

The findings from this study are replicated in our results with patients reporting high rates of psychological distress experienced by their families during both cancer diagnosis and treatment – these results reflect the ongoing significant need for Psycho-Oncology services and supports to be extended to not only those directly impacted by cancer but also their loved ones in order to provide them with the appropriate psychosocial supports during a challenging time.

4.4 Comparison of the results of this study on distress levels in cancer patients to the international literature

International studies report varying levels of distress among cancer patients. In Canada, a large-scale study estimated that 37% of patients experienced significant distress levels (Carlson et al., 2004). An international study of female breast cancer patients has also shown a decrease in distress over time from diagnosis to treatment (Hinnen et al., 2008).

A large multicentre study in Canada reported 19% of cancer patients had clinical levels of anxiety with 22.6% experiencing subclinical symptoms (Linden et al., 2012).

That research found that women under the age of fifty had subclinical or clinical levels of anxiety in 50% of cases.

As mentioned in the introduction of this thesis, a study published by Mehnert et al, which explored distress among German cancer patients, found that patients who experienced an increasing number of problems had increased distress levels (Mehnert et al., 2018). These findings may indicate a need to explore the breadth of issues faced by Irish cancer patients in order quantify and address them in an attempt to alleviate levels of psychological distress.

Gender based differences have been found during cancer diagnosis and treatment in other international studies, with females diagnosed with non-metastatic renal cell carcinoma experiencing higher levels of anxiety and distress (Ajaj et al., 2020). A Chinese study of patients with gastro-entero-pancreatic neuroendocrine tumour estimated the prevalence of psychological distress as 31.5%, with females experiencing more distress (Song et al., 2022). Another Chinese study of gastrointestinal cancer patients found that a greater proportion of females (52.8%) had clinically significant psychological distress compared to males (35.9%) (Cheng et al., 2024).

A study of over 21,000 patients in Germany classified patients with all cancer types into five distress cluster groups: : ‘minimally distressed’, ‘highly distressed’, ‘mainly physically distressed’, ‘mainly psychologically distressed’, and ‘mainly socially distressed’. Men were over-represented in the ‘minimally distressed’ cluster, and women were over-represented in the ‘highly distressed’ and ‘mainly psychologically distressed’ clusters. (Herschbach et al., 2020). These findings from a large multi-centre European study including all cancer types, are consistent with the findings in our study which found

gender based differences in cancer related distress, with females reporting more significant levels of distress relating to their cancer diagnosis and treatment than men.

A prospective cohort study evaluating cancer survivor distress over time reported that while females did experience higher levels of distress than their male counterparts initially, during follow-up females tended to show a stable or decrease in distress levels while the distress levels of males increased over time (Rondanina et al., 2024). This interesting finding may demonstrate that men have increasing psychological needs over time but more longitudinal research is needed to support this finding.

Upon consideration of the underlying reasons why these gender based differences may exist among cancer patients and their experience of distress, there are many dimensions worth exploring. The increased levels of psychological distress experienced by female cancer patients are likely multifaceted and complex, incorporating biological, emotional, psychological, societal, and economical dimensions. Women appear to express distress differently to men, as reflected by differing rates of mental disorders among men and women: women display increased rates of depression, anxiety, and eating disorders compared to men, while men have increased likelihoods of substance use (European Institute for Gender Equality, 2021, Boyd et al., 2015).

In addition, background risk factors for mental distress differ significantly between women and men. For example, findings from one European survey of violence against women, show that over one-quarter (26%) of women surveyed in Ireland experience physical and/or sexual violence by a partner or non-partner since the age of 15 years (European Union Agency for Fundamental Rights, 2015). This indicates a high level of pre-existing adverse life experiences among women which might predispose

them to increased rates of psychological distress following the additional challenge of a cancer diagnosis.

There are also socioeconomic factors which might play a role in the relationship between cancer and psychological distress, especially among women. There are particular norms and gender roles assigned to women in society which might be relevant. For example, as is the case elsewhere, women in Ireland are more likely than men to assume informal care roles, with 61% of informal carers identified as females (Central Statistics Office, 2025). A gender-pay gap also persists in Ireland and is widening, with 2024 figures estimating that men are paid 1.78% more than females for the same role, an increase of 0.2% from 2023 (National Shared Services Office, 2024).

Taken together, the impact of previous adverse life experiences, carer roles, financial inequity, and a range of other factors might increase the likelihood of psychological distress among women who are diagnosed with cancer. More specifically, the increased caring responsibility placed on women and their financial challenges might become more prominent when a woman is diagnosed with cancer and she finds herself unable to fulfil her usual caring roles and other responsibilities and leading to an increase in subjective levels of psychological distress.

Studies published in the literature corroborate the findings in our study relating to the extreme distress experienced by family members of cancer patients. It has been reported that the relatives living with cancer patients are themselves at an increased risk of developing a clinically diagnosed depression than those not living with cancer patients (Cho et al., 2018).

4.5 Comparison of the results of this study on areas of life affected by cancer to the international literature

We also report that work is the area of life most commonly impacted by cancer diagnosis and treatment. Relationships were reported as the least affected area of life, suggesting that the impact of cancer on relationships is more nuanced rather than solely negative.

A cross-sectional study of partners of cancer patients conducted by a research group in Germany, aimed to explore the impact of cancer on relationships and found that the separation rate was marginally lower for cancer patients than the general population (Nalbant et al., 2021). However, among those who did separate, over half reported that cancer had contributed to the separation. Of those who remained in a relationship, 83.7% reported that cancer had an impact on the relationship, and of these over half (55.9%) reported a negative impact. This study looks at relationships from a different perspective than our study, from that of the cancer patients' partner and shows increased impact of cancer on relationships than was found in our study.

Most of the research literature exploring the impact of cancer on work looks at the return to work in cancer survivors. A registry based cohort study conducted in Taiwan looked at 23,220 patients diagnosed with breast cancer and the correlation of cancer diagnosis and stage with return to work two years post breast cancer diagnosis. They reported that cancer stage was inversely associated with likelihood with return to work and that patients who received chemotherapy were also less likely to return to work (Yang et al., 2022). A systematic review exploring factors associated with return to work of breast cancer survivors identified several factors including chemotherapy, fatigue and psychological factors including depression and emotional distress as barriers to return to

work (Islam et al., 2014). A study based in the United States, which explored factors associated with a return to work for breast cancer survivors, reported that employer factors including workplace accommodations played a positive role and perceived employer discrimination because of cancer was negatively associated with a return to work (Bouknight et al., 2006).

These findings again emphasise a potential link between cancer treatment with chemotherapy and emotional distress and patients ability to resume occupational functioning post cancer treatment. The study from the US also highlights a potential need to engage employers in cancer patients return to work.

While these studies are exploring a different patient population; survivors of breast cancer, their findings that chemotherapy treatment can adversely impact on patients return to work is interesting and potentially shows the long term effects that our study population will experience in relation to return to work.

A systematic review which explored the prevalence of financial hardship among cancer patients found that the prevalence rates range from 14.8 to 78.8%, indicating a significant financial burden experienced by some cancer patients and their families (Azzani et al., 2015).

These findings combined with the findings of our study highlight the potential for a role within the psycho-oncology services in supporting cancer patients earlier in their cancer journey in order to maintain occupational and financial functioning, if that is what the patient wishes. A high proportion of our study participants were uncomfortable with referral to social work and this may present as a barrier to supporting these patients. However, more exploratory research is needed in this area in the first instance to define the problem and issues at hand in order to plan service delivery.

4.6 Comparison of the results of this study on engagement with psycho-oncology services to the international literature

Research has shown that approximately 20% of cancer patients will warrant referral to a psychiatrist for management of mental illness during their cancer journey and a further 15% will warrant referral to a psychologist for management of emotional distress (Carlson et al., 2003). This correlates with the findings of our study, with approximately one-third of patients reporting that they felt they would benefit from referral to psycho-oncology.

It was notable in our study that there was a large proportion of patients who were unsure or ambivalent about a referral to psycho-oncology. International studies have identified lack of knowledge and negative attitudes towards mental health supports as significant barriers to accessing psycho-oncology services (Normen et al., 2021, Vu et al., 2023). A study in the United States, reported that most cancer survivors (55.1%) reported that they had not had discussions about counselling and support groups with their clinician or utilised these services (Forsythe et al., 2013). This study highlighted that those who engaged with psychosocial care were more likely to be 'very satisfied' that their emotional and social care needs were met, again highlighting a lack of knowledge of psycho-oncology services and significant benefits for cancer patients when they do engage with these services. This study highlighted that the primary barrier for poor engagement with psychosocial oncology services was lack of knowledge or unavailability (92.9%).

Our study reinforces some of these findings and confirms that, despite increased awareness of the benefits of psychological supports for cancer patients, and despite the

benefits of high levels of trust in services for patients (Thomas et al., 2021), that significant barriers and stigma towards psycho-oncology services still persist among Irish cancer patients.

4.7 Implications of this study for clinical practice

Our study highlights high levels of psychological distress experienced by cancer patients during both diagnosis and treatment. We also highlight increased levels of distress among family members of cancer patients. Despite this highly distressed cohort of individuals, limited awareness exists among cancer patients of psycho-oncology services in Ireland. This is in spite of the fact that there was a fully operational psycho-oncology multidisciplinary team accessible in the hospital where the cancer patients in our study were receiving treatment and this may highlight the need for improved psychoeducation for cancer patients on the role and availability of psycho-oncology teams and other psychosocial supports which are accessible to them during their cancer journey. Patients report increased levels of distress at cancer diagnosis compared to treatment. This may signify the importance of providing adequate psychosocial support for patients at the time of receiving a diagnosis.

The results of this study show that there appears to be ongoing reluctance to engage with psychiatry and psychology compared to other medical specialties among our study population, which may highlight potential barriers experienced by cancer patients in terms of accessing these services and the supports required to help them to deal with their psychological distress. This information is highly relevant to the clinical practice of psycho-oncology in Ireland and highlights a potential unmet psychological need for

cancer patients who are experiencing significant distress but may be unaware of, or struggle to access services for support due to underlying stigma in relation to seeking support for psychological needs over physical needs.

The patients in our study reported work, fatigue and fear for the future as the areas of life most significantly affected by cancer diagnosis and treatment. This highlights the important role of the multidisciplinary team in the psycho-oncological care of these patients, with a need for social work input, potentially increased social supports around sick leave to access treatment, ongoing medical input from oncology around physical symptoms of fatigue as well as psychological input around survivorship and fear of recurrence.

We also report reluctance of cancer patients to tell others about the use of psychotropic medications compared to medications for physical symptoms. This may reflect some preconceived stigma associated with psychological and psychiatric treatment. It is important for clinicians to be aware that these attitudes continue to exist among cancer patients as it is vital that they are acknowledged and addressed in order to openly discuss options and potential treatment options with patients with significant psychological difficulties who may benefit from pharmacological treatment in order to ameliorate their symptoms .

Given that cancer patients with a pre-existing psychiatric or psychological difficulty felt that they would benefit most from psycho-oncology referral, and it is widely recognised that those with mental illness suffer poorer outcomes from cancer, active engagement of this particular group in psycho-oncological care is likely to both improve outcomes and prove an especially efficient use of limited psycho-oncological resources. It is well recognised that those with severe mental illness can have poor engagement with

health services in general, and the evidence from this study may help direct psycho-oncological care towards these patients when they are undergoing cancer treatment given that they perceive that they would likely benefit. Psychoeducation about psychosocial support services for cancer patients might also help to improve engagement in services, given that patients with a previous history of service contact had greater confidence that they would benefit from engaging. This is a positive finding from this study and suggests that previous experience with a mental health service may foster confidence in further engagement and the benefits of psychological support for distress. As services develop nationally, there may be a role for patient educators in order to improve awareness of the supports available and increase awareness of services through lived experience. This may also help to address any barriers to engagement such as stigma.

Finally, we found that pre-existing psychiatric/psychological difficulty was the only variable independently associated with a belief that a psycho-oncology referral would be beneficial. This means that this group of cancer patients who are at increased risk of poorer outcomes from cancer are especially open to psycho-oncological intervention. This novel finding suggests that targeted psycho-oncological interventions for this group are likely to prove especially acceptable to these patients and, therefore, an optimal use of limited resources in this area for a vulnerable subgroup who are especially in need.

4.8 How this study fits into Irelands National Cancer Strategy 2017 – 2026

This study is more recent than that of Lavelle and colleagues in Co. Cork and confirms their findings that female cancer patients in Ireland experience increased levels of psychological distress than their male counterparts. Our study strengthens this finding and

also makes it more generalisable to all cancer patients undergoing cancer treatment rather than those already referred to the psycho-oncology service, potentially highlighting an unmet need for all cancer patients who may not be referred for multidisciplinary input with the psycho-oncology service. Our study also adds some new findings with cancer patients reporting their families to be more distressed than themselves during both cancer diagnosis and treatment, highlighting the need for provision of psychosocial services to loved ones of those affected by cancer.

Our study has also highlighted that cancer patients experience a significant impact on their quality of life as a result of cancer diagnosis and treatment. We have explored the specific areas of life that are affected and highlighted that work, fatigue and fear for the future we most commonly reported as severely impacted by cancer diagnosis and treatment. This information can be used to direct provision of psycho-oncological care for patients and shows the ongoing need for social work input and survivorship programmes as outlined in the National Cancer Strategy.

The Irish National Cancer Strategy clearly highlights:

> ‘Two essential issues need to be considered when planning psycho-oncology and psycho-social support services. The appropriate level of expertise and intervention required relative to patients’ needs; and the development of a model for psycho-oncology that has the capacity to cross the voluntary, primary and acute services’.
>
> (Department of Health, 2017) (p.96).

As outlined, the delivery of psycho-oncology services nationally needs to be appropriately matched to the patients' level of psychosocial needs in order to maximise the use of both voluntary community and more specialised psycho-oncology services to meet the complex psychosocial needs of cancer patients in Ireland. Therefore, it is a crucial component of psycho-oncology service delivery in Ireland, that there is an accurate representation of the distress and psychosocial needs of cancer patients, from the patients' perspective. This study constitutes an important part of this and will hopefully help shape psycho-oncology service delivery in Ireland, ensuring maximal use of finite resources in the sector.

The National Cancer Strategy 2017 – 2016 Implementation report 2023, reports several key recommendations relating to psycho-oncology services (Department of Health, 2023). Recommendations 29 – 31 in this report relate to the provision of psycho-oncology services in Ireland. As reported in this document, a national clinical lead has been appointed for Psycho-oncology in order to manage the delivery of psycho-oncology services. It aims to establish a dedicated service in each cancer centre in Ireland in order to help support the psychosocial needs of cancer patients and their families, utilising a multidisciplinary team approach.

This study is well positioned in line with these national recommendations as it not only highlights the level of distress among cancer patients in Ireland during their cancer journey, but it also assessed cancer patients attitudes towards engaging with various members of the multidisciplinary team. Patients experience on the areas of life most affected by cancer and it's treatment may also help to guide service delivery nationally. For example, cancer patients in our study reported that that work, fatigue and fear for the future were the areas of life most impacted by cancer and its treatment. This may highlight the need for increased social work input on psycho-oncology teams and

potential increased financial supports for cancer patients due to loss of earnings through non-attendance at work and poor energy due to cancer and treatment.

Fear for the future, a significant issue for cancer patients in our study, can be addressed through survivorship programmes, for which the model of care for psycho-oncology has already made provisions. As highlighted in the Psycho-Oncology Model of Care:

'Survivorship services for patients with cancer are one of the key drivers in terms of psychological well-being for cancer patients and their families. Having access to Psych Oncology services in hospitals and/or in the community is key to best practice survivorship care. The National Cancer Survivorship Needs Assessment identified the need to build expertise to meet the needs for symptom burden in the physical and psychological domains as one of the priority actions.'

(Greally, 2020) (p.24) (Mullen et al., 2019).

Our study found that less than a third of patients in our sample knew the meaning of psycho-oncology despite the fact that there was a multidisciplinary psycho-oncology team available to them in the hospital where they were receiving cancer treatment. Encouragingly, most patients reported that they would attend both the psycho-oncology psychologist and psychiatrist without difficulty. This may highlight lack of knowledge as a potential barrier to engaging these highly distressed individuals in appropriate psycho-social care and shows that psycho-education may form a vital role in enabling these patients to access the psycho-oncology care required for their significant levels of distress.

In relation to the gender based differences in distress levels in our study, there is increasing awareness within Ireland's mental health policies about the need to provide gender informed mental health services. In *Sharing the Vision: A Mental Health Policy for Everyone*, the Department of Health set clear goals to 'ensure that mental health priorities and services are gender-sensitive and that women's mental health is specifically and sufficiently addressed in the implementation of policy' (Department of Health, 2020). As part of this initiative, a Women's Health Taskforce was established and, as a result of the findings of this taskforce, the *Women's Health Action Plan 2024-2025: Phase 2: An Evolution in Women's Health* was published in 2024 (Department of Health, 2024). Ireland thus became one of the first countries worldwide to develop a specific women's health action plan, which has been informed by women for women. This aims to revolutionise the management of women's health in Ireland, incorporating both mental health and physical health including cancer care.

In terms of mental health in particular, a 2022 report on *Embedding Women's Mental Health in Sharing the Vision* emphasises the need for gender awareness so 'that women experience an inclusive, supportive and effective mental health service that meets their needs' (Department of Health, 2022) This policy commits to providing 'a gender-aware approach to the delivery and accessibility of all care'; 'a trauma-aware approach by all staff who contribute to the service'; and 'the systematic collection and analysis of data on gender, ethnicity, disability and other risk factors for marginalisation of women' (p. 6). The policy makes specific recommendations for 'integrated models of care for women', combining physical and mental health (p. 16). In addition, the recently published *Sharing the Vision: Implementation Plan 2025-2027* sets out specific recommendations for implementation, including development and rollout of 'a toolkit for embedding women's mental health in policy implementation' (Health Service Executive et al., 2025).

The findings of this study may help provide useful information to policy makers and those developing services nationally in Ireland by representing the opinions and experiences of cancer patients who will be the users of these services and strengthens the basis for gender informed mental health services.

4.9 Strengths of this study

This study addresses an important topic of cancer. As we know the burden of cancer worldwide is rising with twenty million new diagnoses and over nine million cancer related deaths in 2022 (World Health Organisation, 2024). One in five people will develop cancer in their lifetime. In Ireland, this increases to a third of the population expected to receive a cancer diagnosis in their lifetime and one third of deaths nationally reported as cancer related (National Cancer Registry, 2022). There is a growing number of the Irish population currently living with cancer, increased by fifty percent in the last decade alone, and this number is expected to rise exponentially in coming years. This study is an important representation of the psychological impact of cancer in an Irish patient population.

Strengths of this paper include that this is the first significant report of patient attitudes towards psycho-oncology services in Ireland in approximately the last decade, since the work of Lavelle and colleagues (Lavelle et al., 2017). During this interval, specialist services have been developing nationally under the Health Service Executive 'A Model of Care for Psycho-oncology'(Greally, 2020). The study also includes all cancer types and, for the first time, identifies a subgroup of cancer patients with a history of psychological or psychiatric difficulties who are more likely to benefit from early

engagement with psycho-oncology services. Given that this subgroup of patients likely had previous engagement with psychological or psychiatric services, it suggests that a history of engagement with such services might help to reduce stigma and build trust.

This is the first significant study of gender based distress amongst all cancer patients in Ireland in the last decade. A previous study has reported significant gender based distress among patients referred to the psycho-oncology service of a tertiary cancer centre, however, this study expands on this finding and explores gender based distress in Irish cancer patients in general. In addition, this study identifies a potentially vulnerable patient cohort who may benefit from increased psychological support during cancer diagnosis and treatment, allowing streamlining of psycho-oncology services nationally.

This study uses bivariable and multivariable analyses allowing analysis of the complex relationships of variables in the study data. This study also investigated the possibility of collinearity. There was no evidence of collinearity. To test for multicollinearity, a "tolerance value" was calculated for each independent variable; tolerance values below 0.25 indicate possible multicollinearity, and tolerance values below 0.10 would indicate significant problems with multicollinearity (Katz, 1999). All tolerance values in all models were greater than 0.10, therefore there was no evidence of multicollinearity in any of the models in this study .

4.10 Limitations of this study

Limitations of this study include possible selection bias owing to the fact that patients were recruited from a single haematology oncology day-ward where they were undergoing outpatient cancer treatment. This would exclude patients receiving solely

radiation or surgical treatment for cancer, those not currently on active treatment and those in end-of life care or on surveillance treatment. Due to the fact that these patients were undergoing cancer treatment on the haematology oncology day ward at the time of recruitment to the study, there may have been a bias introduced around their reported experiences of cancer treatment and side effects.

In relation to type of cancer within our study sample, most patients were diagnosed with breast cancer, followed by colorectal and haematological malignancy. The most common type of cancers in the general Irish population are prostate, breast and lung. The under representation of prostate and lung cancer in our sample may have been due to the recruitment site on the haematology oncology day ward, where people were receiving day treatment (most often chemotherapy, immunotherapy or hormonal therapy). The mainstay of prostate cancer treatment is often with surgical intervention or radiotherapy and so this cancer type may have been under-represented in our sample compared to the general Irish population. By increasing the number of prostate cancer patients in future studies, there may be a greater representation of male participants which could have strengthened any findings relating to gender based differences in our sample. As mentioned previously, future research could recruit from alternative locations in order to increase the representation of cancers not treated on the haematology oncology day ward and ascertain any differences of patient experiences who are undergoing alternative forms of cancer treatment.

Owing to General Data Protection Regulations (GDPR), it was not possible to collect any data about patients who declined to participate in the study. This information could have proven useful in order to ascertain differences between participants and non-participants but was not possible in the Irish context. In future studies it would be useful to obtain ethical approval to collect data for all patients who are approached to participate

in the study, even if they decline to participate. We would seek ethical permission to record basic demographic data to help ascertain the representatives of the participants and highlight any basic demographical differences between participants and non-participants in the study.

This study relied on patients own subjective assessments of their distress. This has the merit of focussing on the patients' own assessment of their distress as suggested by the National Cancer Strategy 2017 - 2026:

> 'The term 'distress' is the preferred term to describe the psychological challenges that patients with cancer experience. Cancer related distress is best conceptualised as existing on a continuum of severity ranging from mild (adaptive, 'normal' levels of sadness and fear) to severe (disabling symptoms such as clinical depression, anxiety, panic disorder, body image problems or relationship and family breakdown). The degree of severity experienced by the cancer patient will dictate the level of intervention and expertise required.'
>
> (National Cancer Strategy, Department of Health, 2017) (p. 96)

However, such ratings are likely inconsistent across participants owing to differing levels of distress tolerance due to individual differences.

Patients in this study reported their distress at cancer diagnosis retrospectively, due to the cross-sectional nature of the study and therefore, this may have been subject to recall bias. It is difficult to speculate on the likely direction of such bias, it is possible that some people would rate their psychological distress as higher in retrospect and it is possible that some people would rate their psychological distress as lower in retrospect. There is a need for more studies on the nature of recall bias, but in the context of psycho-

oncology we address this further in the next section 4.8, directions for future research in this field.

While this study was focussed on patients subjective experience of distress, it would nonetheless have been helpful to have patient involvement at the time of study design. We did not however have research ethics approval for this but future research could usefully involve patients, families and carers at the stage of research design to ensure that their attitudes and opinions are accurately represented.

Age categories were used in this study, future studies could usefully ask patients for their mean age. This study was cross-sectional in design, with patients reporting their attitude toward psycho-oncology services at a single time-point. We will address this issue in more detail in the next section (section 4.8), which is entitled 'Directions for future research in this field'

In global terms, this study was conducted in a high income country and therefore may have limited generalisability to middle or low income countries. In addition, we did not have research ethical approval to collect research data about ethnicity, nor did we have financial supports for translators, therefore this study was restricted to English language speaking individuals. Given that participation required completion of a written survey, only those who could read and write could participate. Unfortunately we did not have the resources for literacy assistance in this study. The written survey tool would also have excluded those with visual impairments for similar reasons. Future research could address these limitations through resource allocation for translators and literacy aids to allow inclusion of the valuable opinions of these participants.

We did not have research ethics approval to include children in this research project and the clinical site chosen did not treat patients under the age of 18 years. Future

research could usefully include children in research to assess their experiences and understand any differences in the experiences of children and adults undergoing cancer treatment.

It is likely that the cognitive requirements of participating in the study meant that people with intellectual disabilities were less able to participate in the study. We did not have the financial resources to actively include these individuals in the study but hopefully future studies could include funding to help assist with the inclusion of these participants.

The tool we used to assess distress had face validity and was previously used to assess distress of patients in the context of psycho- oncology (O'Sullivan et al., 2011). However in the absence of another gold standard tool to assess for distress in psycho oncology patients, it was not possible for us to compare our tool with a gold standard in this field. A standardised measurement of functioning such as the Global Assessment of Functioning (GAF) Scale or Social and Occupational Functioning Assessment Scale (SOFAS) and quality of life data could have proven useful to quantify the impact of cancer and cancer treatment on participants functioning and would assist in demonstrating this impact in future research studies. This study focused on quantitative data but qualitative data on the experience of cancer patients and their families would enrich our understanding on this topic and would be useful to expand on the knowledge from this study in the future.

4.11 Directions for future research in this field

The area of psycho-oncology is one which is developing rapidly both nationally and internationally. This study has highlighted some valuable insights into the experience of cancer patients and their families of cancer, diagnosis and treatment and their attitudes towards engaging with health professionals and pharmacological treatment for psychological distress.

Due to the method of recruitment for participants in this study, from the Haematology-Oncology Day ward in St James's Hospital, by nature of their presence in this ward, all participants were currently undergoing cancer treatment. This study did therefore not include cancer patients who were undergoing only surgical or radiotherapy for their cancer, those on active surveillance and those referred to palliative care. In order to gain representation of these patients, future studies could usefully assess the attitudes of these patients by recruiting through oncology, palliative care, and cancer surgery teams. A multi-site national study could also help to ensure a broad demographic of patients are represented in the study findings. This could be rolled out through all of the national cancer centres in Ireland.

Given the selected study site, where there was a psycho-oncology multidisciplinary team available to patients, there may have been increased knowledge of psycho-oncology services in our study sample. As discussed in section 4.3, 'Comparison of the results of this study to the international literature', previous research has highlighted lack of accessibility and knowledge as potential barriers to engagement (Pallin et al., 2024, Normen et al., 2021, Vu et al., 2023). Future work could look to include other hospitals where cancer patients are treated for cancer but perhaps do not

have such readily available access to psycho-oncology teams to identify if there may be differences between the groups depending on geographical location and accessibility to a service.

Our study has shown that patients also perceive their families as highly distressed, future research to expand on this could usefully include family members to highlight supports which may be of benefit to them. This research could also be qualitative in nature in order to identify any prevailing themes or areas which may help focus psychosocial supports for family member of cancer patients.

Given that this research was cross-sectional in nature, with cancer patients reporting their distress and recall of distress at a single timepoint, future research could aim to assess distress levels among cancer patients longitudinally in order to clearly establish any trends in distress from the time of diagnosis and over the course of cancer treatment. However, this may prove ethically challenging owing to the sensitive nature of the subject, and in particular, assessing distress at time of cancer diagnosis could prove quite difficult. This research could also usefully help to evaluate the impact of psychological supports and work by psycho-oncology teams on distress.

Future work may look to assess attitudes towards services longitudinally from both cancer patients and their families. This work could include qualitative data to elaborate on patient views, barriers to engagement and any potential underlying stigma which may still be present among cancer patients in terms of accessing supports for mental health rather than physical health. Qualitative data may highlight specific themes which could prove useful when planning service delivery in order to ensure that the patient experience is directing the type of care provided nationally.

It would be beneficial if there were more cross national studies comparing the extent and nature of distress in psycho-oncology patients in different cultural settings around the world. This would add to our knowledge about distress experienced by cancer patients, as it is possible that ways of expressing distress are culturally mediated. It would also be useful to explore distress experienced by cancer patients and their families during diagnosis and treatment in quantitative, qualitative, sociological, anthropological and psychospiritual domains.

Psycho-oncology is a relatively new subspecialty of psychiatry and has developed as a result of improved cancer outcomes, improved survivorship and the fact that there is an exponentially increasing number of people living with cancer. This has allowed the focus to shift from lifesaving treatment to more holistic life enhancing treatments for cancer patients. Future work looking at cancer related distress in countries with poorer cancer outcomes may prove a useful comparison to the results of our study in order to see if distress experienced by cancer patients is mediated by their prognosis. Inclusion of cancer patients in the palliative setting, who are not undergoing active cancer treatment may provide valuable insights into any similarities or differences experienced by these patients in terms of psychosocial needs.

Future research could also link these psychological and emotional parameters like distress with cancer disease pathogenesis using biological indicators. There has been early work in this area as mentioned in section 1.2, ‘the psychological impact of cancer’ but more work is needed in this area in order to expand our understanding on the subject and any pathophysiological links between cancer and distress which could act as potential future targets for specific treatments for patients.

As discussed in section 1.2, ‘the psychological impact of cancer’ cancer treatments can have direct effects on emotional well-being, distress and mental health of cancer patients. The use of steroids and other chemotherapeutic agents have well recognised psychological impacts. Future research could usefully links psychological and emotional parameters like distress with the physical effects of treatment.

As discussed in section 1.5, ‘Survivorship beyond cancer’, there are increasing numbers of those living beyond a cancer diagnosis globally. Our study reports that at least two-thirds of participants reported that they experience at least moderate difficulties associated with fear of recurrence. Notably, these participants are currently undergoing active treatment for their cancer but despite this are already experiencing fear and anxiety about the future and recurrences. This highlights a particular psychological need among cancer patients which could be usefully explored and expanded on through both quantitative and qualitative research with cancer survivors. This work would be useful in informing the delivery of cancer survivorship programmes internationally, including the ‘Cancer Thriving and Surviving’ programme currently running in Ireland (Gibbons et al., 2020).

Chapter 5: Conclusions

This conclusions chapter will address conclusions from this study (section 5.1) and recommendations for Irish health service reform (section 5.2). I will begin by summarising the conclusions from this study (section 5.1).

Section 5.1 Conclusions from this study

This study set out to identify the experience of Irish cancer patients during cancer diagnosis and treatment. We aimed to identify any particular areas of cancer patients lives which were particularly affected by cancer. We sought to identify any potential barriers to engaging with psycho-oncology services compared to other medical and allied health professionals as well as any difficulty with being prescribed and disclosing prescription of medications for physical versus psychological symptoms. This study is timely given the rapidly growing burden of cancer affecting Irish society and the ongoing development of psycho-oncology services nationally.

Our cross-sectional study of 142 Irish cancer patients highlights significant rates of extreme distress for cancer patients and their families during both diagnosis and treatment. There were particularly high levels of extreme distress experienced by women in our study population. The findings in our study highlight the need for enhanced provision of psychological support for patients during both cancer diagnosis and treatment. The results of this study will help to inform the delivery of psycho-oncology services in Ireland to both cancer patients and their families. As I have discussed, psycho-oncology services in Ireland have been developing nationally under the National Cancer Strategy 2017-2026 and this research emphasises the ongoing need for this service for the

Irish population and will hopefully help direct the provision of these services, making use of finite resources which are in increasing demand.

Ongoing barriers exist for cancer patients in relation to accessing psycho-oncology services, with a lack of awareness of the existence of such services and the benefits of engagement. Our study highlights a subgroup of patients with pre-existing psychiatric or psychological comorbidity who are more likely to feel that they would benefit from psycho-oncology referral and are therefore more likely to be open to engagement. Given that this sub-group have poorer cancer outcomes (Iglay et al., 2017) , it would be prudent to offer them enhanced psycho-oncological care from an early stage.

Our study is in line with international reporting on high rates of psychological and emotional distress experienced by cancer patients in relation to both diagnosis and treatment. It is also notable that the level of participants in our study in the Irish population is also in keeping with international findings that approximately one third of patients would warrant referral to psycho-oncology (Carlson et al., 2003). Although it is worth noting that due to a high proportion of patients in our study who had no knowledge of the specialty of psycho-oncology, the number of people who, if they were informed of the availability and benefits of such a service, may actually be higher than international reports. In line with this assumption, there may be a role for increased psychoeducation of cancer patients and their families on emotional, psychological and social supports available to them along their cancer journey in the Irish context to ensure adequate uptake and utilisation of the services for maximal benefit for patients and their families. As recommended by the psycho-oncology model of care, cancer patients should regularly be screened for distress during their cancer journey, these screening timepoints could act as crucial opportunities to acknowledge, recognise and engage those experiencing

psychological distress with appropriate psycho-social interventions using the stepped approach as outlined in the model of care (Greally, 2020).

This study found that patients were more open to being prescribed medications for physical rather than psychological symptoms. They were also more comfortable disclosing to others that they were taking medications for physical over mental health needs. These findings warrant further exploration but may indicate an underlying cultural stigma attached with accessing treatments for emotional and psychological needs and may present as a barrier in engaging these highly distressed individuals in appropriate care.

While this study highlights that Irish patients with cancer and their families experience high levels of distress during both cancer diagnosis and treatment, there is future work which could be done to increase awareness of the psycho-oncology services available nationally in order to improve engagement with psychosocial interventions to help manage this distress and ultimately improve the emotional, psychological, social and physical experience of cancer patients and their families.

Section 5.2 Recommendations for Reforms of the Irish Health Service

This study fits into Ireland's National Cancer Strategy (Department of Health, 2017) as the first Irish study in the last decade detailing the psychological experience of cancer patients during their cancer journey. As outlined in the National Cancer Strategy (section 4.4, p. 40),

> 'this strategy will aim to create an environment that empowers patients to become active participants in their own healthcare and supports them in making decisions

about their treatment. Programmes will be put in place to ensure that patients are supported to return to their normal life as much as is possible following treatment. Individual patients will have different requirements for survivorship care and this will be taken into consideration in the development of survivorship programmes. Structures will be put in place to facilitate patient involvement in policy development and planning of cancer services. This will ensure that the patient voice is represented at all stages of the cancer continuum, during and after their treatment as well as in service planning'.

(Department of Health, 2017)

The work in this study embodies this goal of the National Cancer Strategy, by providing an opportunity for cancer patients to detail their experience and cancer diagnosis and treatment as well as any barriers which they experience in accessing psychosocial supports to address difficulties relating to their cancer. This research should be helpful in maximising the informed delivery of psycho-oncology services in Ireland to cancer patients.

In more specific terms we recommend that:

- We reiterate the importance of distress screening among cancer patients as outlined in the second recommendation in the Psycho-Oncology Model of Care, '*screen for distress for all patients with cancer, as per Appendix 5, followed by a comprehensive evaluation of individual patients needs and referral to the appropriate type, setting, and level of service*.' (Greally, 2020).

- The current *Model of Care for Psycho-Oncology* could usefully place greater emphasis on gender-specific care provisions which recognise the increased psychological needs of women with cancer. This recommendation is in line with findings from our study, which showed notable levels of extreme distress among women. This recommendation aligns with the 2022 report on *Embedding Women's Mental Health in Sharing the Vision*, which emphasises the need for gender awareness so 'that women experience an inclusive, supportive and effective mental health service that meets their needs.' (Department of Health, 2022)
- There is enhanced provision of psycho-oncology care to cancer patients with a previous history of psychiatric difficulty. As discussed in this thesis, there is well recognised evidence that those with a history of mental illness experience poorer cancer outcomes compared to the general population. Findings in our study indicate that these patients are most likely to feel that a referral to the psycho-oncology team would be beneficial. This vulnerable cohort of patients appear to feel that they would benefit from engagement with psycho-oncology teams. We recommend that this subgroup of patients, with a history of mental illness receive a separate action point in the next Implementation Report for the National Cancer Strategy.
- There are improved supports for family members of cancer patients. The results of this study show that patients perceive their families to be more distressed than themselves throughout their cancer journey, with over half of patients reporting their families experienced 'extreme' distress at the time of their cancer diagnosis. This strongly reinforces the fourth key recommendation in the Psycho-oncology Model of Care, '*recognise the*

psychological and social impact of a cancer diagnosis on family members and carers'.

Cancer can be a devastating illness with significant physical and psychological sequelae for patients and their families. Cancer is an exponentially growing problem affecting a huge proportion of the Irish population either directly through a diagnosis or indirectly through the diagnosis of a family member or loved one. Cancer is the leading cause of death in Ireland.

In recent decades, there have been significant advances made in screening programmes and the medical and surgical treatment options available for cancer patients. This has resulted in improved survival rates and increased numbers of those living with cancer. In light of these medical advances, there are more people living with direct and indirect effects of cancer than ever before. These patients and their families cancer deserve an efficient, optimally functioning and appropriate level of psychosocial support in order to address the often unseen and unmet psychological needs of cancer patients and those of their families.

Given that Ireland's National Cancer Strategy will be reviewed and revised as it comes to its end in 2026, there is a timely opportunity to address the particular set of challenges faced by cancer patients and their families which have been highlighted by this thesis. Hopefully, this will provide policymakers in Ireland with a roadmap of how these needs might be addressed, so that the lives of those living with cancer and their families can be more fulfilled through a holistic approach encompassing their physical and psychosocial health needs relating to cancer diagnosis and treatment.

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Appendix A: Participant Information Leaflet

ADULT PARTICIPANT INFORMATION LEAFLET

To explore patient's beliefs and attitudes towards the Psycho-Oncology service, a 12 year follow-up study.

Principal investigator's name: **Dr Roisin Plunkett**

Principal investigator's title: **Consultant Psychiatrist,**

Psych-Oncology Service

Telephone number of principal investigator: **01 410 3457**

Data Controller's/joint Controller's Identity: **St James's Hospital**

Data Controller's/joint Controller's Contact Details: **01 410 3021**

Date Processors Identity: **N/A**

Data Processors Contact Details	**N/A**
Data Handler's Identity:	**Dr Roisin Plunkett, Dr Eva Carter, Dr Hailey Carroll, Dr Sonya Collier**
Data Handlers Contact Details:	**roplunkett@stjames.ie** **ecarter@stjames.ie** **hcarroll@stjames.ie** **scollier@stjames.ie**
Data Protection Officer's Identity:	dataprotection@stjames.ie
Data Protection Officer's Contact Details:	dataprotection@stjames.ie

Patient Information Leaflet:

‘To explore patient’s beliefs and attitudes towards the Psycho-Oncology service, a 12 year follow-up study’.

You are being invited to take part in a research study to be carried out at St James’s Hospital by the Psych-Oncology Team.

Before you decide whether or not you wish to take part, you should read the information provided below carefully and, if you wish, discuss it with your family, friends or GP (doctor). Take time to ask questions – don’t feel rushed and don’t feel under pressure to make a quick decision.

You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as ‘Informed Consent’. You don't have to take part in this study. If you decide not to take part it won’t affect your future medical care.

You can change your mind about taking part in the study any time you like.

PART 1 – THE STUDY

Why is this study being done?

This research study is being carried out to assess the attitudes of oncology patients towards accessing care for emotional and mental health needs which may arise during their treatment. The results from this study will allow us to better understand attitudes towards services and treatments reduce any barriers to accessing care.

Why am I being asked to take part?

You are being asked to take part in this study because you are currently under the care of the Oncology Team in St James's Hospital.

Do I have to take part? What happens if I say no? Can I withdraw?

Participation is **voluntary**. A decision not to consent will have **no adverse consequences or affect future medical treatment**. You can withdraw your consent to participate at any time. You don't have to give us a reason. If you do opt out, rest assured it won't affect the quality of treatment you get in the future. *If you wish to opt out, please contact Dr Eva Carter, Registrar in Psych-Oncology via (01) 4103457 who will be able to organise this for you.*

How will the study be carried out?

Patients attending Oncology Day ward and the Psych-Oncology service will be asked to participate in the study. Participation involves completion of a questionnaire which should take about ten minutes. The questionnaire will include questions on cancer, mood and attitudes towards services and treatments. You will also be asked general questions about your life (e.g. employment, living situation, social supports, relationships) and your attitudes towards or experience of attending Psycho-Oncology.

Should you chose to participate in this study and fill out the associated questionnaire, all data will be anonymised and the information will not be traceable to you. We are aiming for approximately 300 participants in the study.

What will happen to me if I agree to take part?

If you agree to take part, you will be asked to complete the questionnaire provided and this will take about ten minutes. You will then return the questionnaire to the researcher in the envelope provided. Participation in this study will not change your routine care received.

Your medical record will not be accessed as part of the study.

Are there any benefits to me or others if I take part in the study?

Taking part in this study may not directly benefit you. However, the findings from this study will allow us to better understand attitudes towards services and treatments and to reduce possible barriers to accessing care

Are there any risks to me or others if I take part in the study?

It is not expected that participation in this study will pose a risk to you. In the unlikely event that you become distressed as a result in participating in the study, you will be given the opportunity to discuss this with a member of the Oncology team or the Psychological Medicine service.

All data in the questionnaire will be anonymised and is not traceable to you.

What will happen if something goes wrong when I'm taking part in the study?

In the unlikely event that you become distressed as a result in participating in the study, you will be given the opportunity to discuss this with a member of the Oncology team or the Psychological Medicine service.

Will I be told the outcome of the study? Will I be told the results of any tests or investigations performed as part of this study that relate to me?

The results of the study will be reported in medical/scientific journals and disclosed at medical/scientific conference. The results will also be disseminated through various forums in the hospital. No information which reveals your identify will be disclosed.

PART 2 – DATA PROTECTION

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

There will be no identifiable information collected as part of this study. All information collected in the questionnaire will be anonymised; this means that it will no longer be traceable to you. Your medical records will not be accessed as part of the study.

What will happen my personal data?

Completed questionnaires will be taken by researchers in a sealed envelope and kept in a secure office on site in St James's Hospital. Anonymous results will be uploaded to a

data processing software and the hard copies of the questionnaires will be destroyed. The spreadsheet will be encrypted and will be deleted once the study is complete. Only researchers on the study will have access to the data.

Who will access and use my personal data as part of this study?

All data will be anonymised and will not be traceable to you. The data will be accessed by researchers involved in the study (Dr Roisin Plunkett, Dr Eva Carter, Dr Hailey Carroll and Dr Sonya Collier). Your medical records will not be accessed.

Surveys which have been completed will be reviewed by the researchers and put into Data Processing Software.

Results of this study will no longer be traceable to you and may be presented at medical conferences and in medical journals.

Will my personal data be kept confidential? How will my data be kept safe?

Questionnaires will contain no identifiable information which can be traced to you. They will be returned to the researcher in a sealed envelope and brought to a secure, locked office. The results will be input into Dara Processing Software and the paper copies of the questionnaires will be destroyed as per hospital policy. Copies within the Data Processing Software will be encrypted and will be kept for future potential research by the Psych-Oncology Department but again will not be traceable to you.

The results of the research may be presented within the hospital, at medical conferences and published in medical journals but will not be traceable to you in any way.

Personal information about you, including the transfer of this personal information about you outside of the EU, will be protected in accordance with the General Data Protection Regulation

What is the lawful basis to use my personal data?

Under GDPR law, we can use your personal information for scientific research (in the public interest). We will also ask for your explicit consent to use your data as a requirement of the Irish Health Research Regulations.

What are my rights?

By law you can exercise the following rights in relation to your personal data, unless the request would make it impossible or very difficult to conduct the research:

- The right to access to your data held and receive a copy of the data
- The right to restrict or object to processing of your data
- The right to have any inaccurate information about you corrected or deleted
- The right to have your personal data deleted.
- The right to data portability, meaning you have a right to move your data from one controller to another in a readable format.
- The right to withdraw consent
- The right to lodge a complaint with the Data Protection Commissioner via dataprotection@stjames.ie

PART 3 – COSTS, FUNDING & APPROVAL

Will it cost me anything if I agree to take part?

There will be no costs incurred by you and no compensation provided for participation in this research study. All investigators are employees of St James's Hospital and as such are covered by Indemnity Scheme.

Who is funding this study? Will the results study be used for commercial purposes?

Researchers are not being paid to recruit patients to this study and there is no funding or sponsorship received to carry out this study. Results of this study will not be used for commercial purposes.

Has this study been approved by a research ethics committee?

This research study has been approved by the Joint Research and Ethics Committee, St James's Hospital and Tallaght University Hospital.
Approval date tbc (application pending).

PART 4 – FUTURE RESEARCH

Will my personal data be used in future studies?

This study is a repeat of a study completed 12 years ago, in the future we may use your anonymised personal data again to compare to future populations by the Psych-Oncology Department – this data will be in no way traceable to you. You will not be contacted in the future if this data is to be used again.

PART 5 – FURTHER INFORMATION

Where can I get further information?

If you have any further questions about the study or if you want to opt out of the study, you can rest assured it won't affect the quality of treatment you get in the future.
If you need any further information now or at any time in the future, please contact:

Name : Dr Eva Carter

Address:
Department of Psychological Medicine, St James's Hospital, James's Street, Dublin 8
Phone number: 01 410 3457

What happens if I wish to make a complaint?

Should you wish to make a complaint, you can contact one of the researchers directly of

contact the complaints Officer in St James's Hospital

Will I be contacted again?

You will not be contacted again in relation to this research study.

Appendix B : Participant Survey

1. Age (please tick the appropriate box):

18 – 21years □ 22 - 25years □ 26 – 30 years □ 31 – 35 years □

36 – 40 years □ 41 – 50 years □ 51 – 60 years □ 61 years + □

2. Gender

Male □ **Female** □ **Other (please describe)**_____

3. Marital Status:

Single □ Long term partner □ Married □ Divorced □ Widowed □

4. Type of cancer:

Lung □ Gastric/Oesophageal □

Breast □ Melanoma □

Prostate/Renal/Bladder □ Head/Neck □

Lymphoma/Leukaemia □ Gynaecological □

Colon/Rectal □

Other (Please state) _____

5. How long has it been since your initial cancer diagnosis:

< 1 month □ 1 – 3 months □ 4-6 months □ 7 – 12 months □ >1 year □

6. Have you had a recurrence of your cancer?

Yes □ No □

If Yes, how many _____

7. What treatment have you received for your cancer to date?

Surgery □ **Bone marrow transplant** □

Chemotherapy □ **Steroids** □

Radiotherapy □ **Other (Please describe below)**

Hormonal treatments □

8. How distressing or stressful were the following aspects for you, and for your family:

	Extremely	Very	Moderately	A little	Not at all
How distressing or stressful was your cancer **diagnosis** for **you?**					
How distressing or stressful was your					

cancer **diagnosis** for **your family?**					
How distressing or stressful was your cancer **treatmen**t for **you?**					
How distressing or stressful was your cancer **treatment** for **your family?**					

9. To what degree do you find that your diagnosis of cancer and its treatment has negatively affected aspects of your daily life?

☐ Not at all ☐ Not very much ☐ Moderately ☐ A great deal

10. To what degree do you find that your diagnosis of cancer and its treatment has negatively affected your quality of life?

☐ Not at all ☐ Not very much ☐ Moderately ☐ A great deal

11. Do you have a history of psychological or psychiatric difficulties prior to your cancer diagnosis and treatment?

☐ No ☐ Yes (please describe) _____

12. How well do you think you are coping with cancer, treatment and side-effects?

Poorly □

Less well than I'd like □

Reasonably well □

It varies □

Very well □

13. Has cancer and its treatment caused you to experience problems with? (please tick)

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Pain					
Fatigue / energy					
Sleep					
Physical Appearance					
Anxiety or worry					
Sadness / Low mood					
Fear of recurrence					
Fear for the future					
Sexual intimacy					
Work					
Parenting					
Fertility					

Finances					
Relationships					
Other (please state)					

14. Please list the three areas in your life that cancer and its treatments has had the most negative or serious impact.

A)_____

B)_____

C)_____

15. Do you know what Psycho-Oncology means?

Yes □ No □

If *Yes* please describe: _____

16. Did you know that St James's Hospital has a Psycho-Oncology Service?

Yes □ No □

17. If your doctor referred you to the Psycho-Oncology Service *Psychiatrist* would you:

Refuse □ Reluctantly attend □ Attend with no difficulty □

18. If your doctor referred you to the Psycho-Oncology Service *Psychologist* would you:

Refuse □ Reluctantly attend □ Attend with no difficulty □

19. Do you think you would benefit from attending the psycho-oncology service?

□ Yes □ No □ Don't Know

20. If your doctor thought it would be helpful, how happy or comfortable would you be attending the following specialties (please tick)?

	Extremely uncomfortable / embarrassed	Somewhat uncomfortable/ embarrassed	Neutral	Happy	Very happy
Cardiology (Heart Specialist)					
Dermatology (Skin Specialist)					
Physiotherapist					
Occupational therapist					
Dietician					
Psychiatrist					
Psychologist					
Social Worker					
Palliative care					

Specialist nurse					

21. How happy or comfortable would you be telling your close friends or family that you were attending the following specialties (please tick)?

	Extremely uncomfortable / embarrassed	Somewhat uncomfortable/ embarrassed	Neutral	Happy	Very Happy
Cardiology (Heart Specialist)					
Dermatology (Skin Specialist)					
Physiotherapist					
Occupational therapist					
Dietician					
Psychiatrist					
Psychologist					
Social Worker					

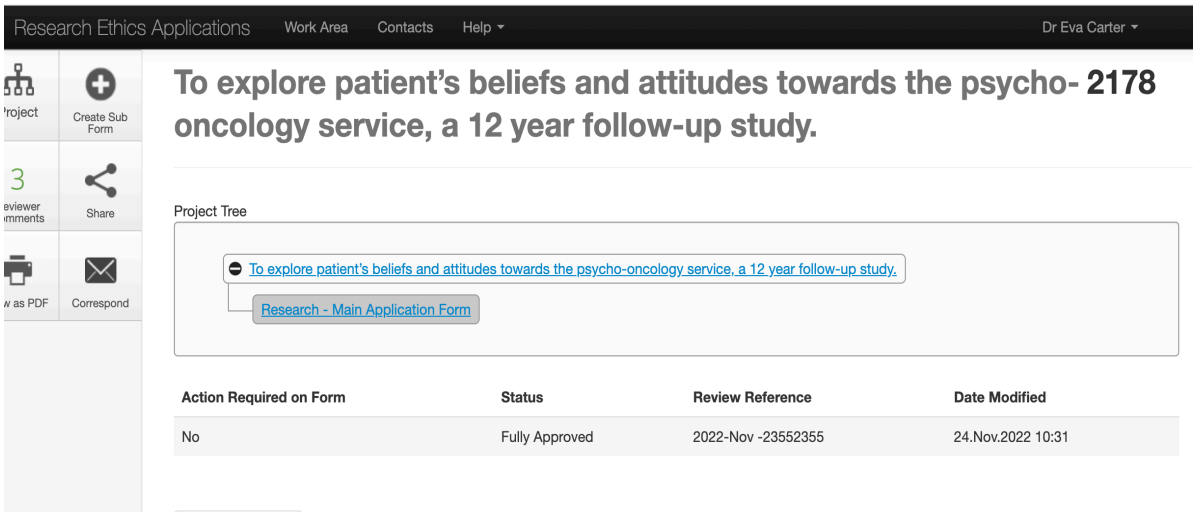
Palliative care					
Specialist nurse					

22. If your doctor thought that it would be helpful to you, how happy or comfortable would you be taking medication for the following problems (please tick)?

	Very unhappy	Somewhat unhappy	Neutral	Somewhat happy	Very happy
Heart problems					
Stomach (e.g. anti-acid)					
Nausea					
Fatigue					
Mood (anti-					

depressants)					
Anxiety (e.g. Valium)					
Pain					
Hot flushes					

<u>Appendix C: Ethical Approval</u> (St James's Hospital/ Tallaght University Hospital Joint Research Committee)



Appendix D: Gender disparities in extreme psychological distress at cancer diagnosis and patients access to psycho-oncological care. Published in Irish Journal of Medical Science

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ORIGINAL ARTICLE

Gender disparities in extreme psychological distress at cancer diagnosis and patients access to psycho-oncological care

Eva Carter[1,2] · Sonya Collier[1] · Roisin Plunkett[1] · Eugene Beirne[1] · Brendan D. Kelly[2]

Received: 21 October 2024 / Accepted: 1 December 2024

Abstract

Background Cancer has adverse consequences for mental health, especially in women. Lack of awareness of services and stigma diminish access to psycho-oncology services.

Aims To assess psychological distress and willingness to engage in multidisciplinary psycho-oncological services among cancer patients.

Methods Cross-sectional survey of attitudes towards psycho-oncology services in 142 cancer patients.

Results Women experienced more extreme distress than men, with 46.4% of females and 17.8% of males reporting "extreme" distress. Under one third of cancer patients (30.3%) knew the meaning of 'psycho-oncology'; one quarter (25.6%) knew of the psycho-oncology service, and two thirds (67.2%) were unsure if referral would be beneficial. One fifth (21.0%) would be somewhat/extremely uncomfortable disclosing attending palliative care, compared to 17.9% for psychiatry, 14.4% for psychology, and 5.8% for cardiology. On multivariable analysis, pre-existing psychiatric/psychological difficulty was the only variable independently associated with belief that a psycho-oncology referral would be beneficial.

Conclusions Limited awareness of psycho-oncology services exist despite high rates of extreme distress among women with cancer.. Given that women have higher levels of extreme distress, it would be prudent to offer them enhanced psycho-oncological care.

Keywords Mental health · Mental illness · Oncology · Psychological distress · Psycho-oncology

Background

Psychological distress is high among cancer patients, with 45–65% of cancer patients reporting extreme distress according to the literature [1, 2]. It is suggested that women with cancer experience higher levels of distress than men [1]. People with mental illness experience multiple forms of healthcare disadvantage and have poorer physical health outcomes compared to the general population, [3] including increased mortality from cancer compared to people without mental illness [4]. They are also less likely to engage with various elements of cancer care such as screening, diagnosis, treatment, and palliative care compared to those without a history of psychiatric difficulty [5, 6].

Cancer itself is also associated with adverse consequences for mental health, with increased rates of psychological distress, anxiety, depression, and post-traumatic stress disorder [7, 8]. Cancer patients have an increased risk of mortality from suicide compared to the general population [9].

There is evidence that psychosocial interventions can help reduce emotional distress and improve quality of life and physical symptoms for cancer patients [10]. Psycho-oncology services have been developing internationally and aim to provide multidisciplinary care to cancer patients and their families who experience psychological difficulties and mental illness during the course of cancer diagnosis and treatment. A lack of awareness of psycho-oncology services and stigma have been identified as barriers to accessing psycho-oncology services [11].

Against this background, we sought to identify level of distress among cancer patients and identify factors associated with willingness to engage with psycho-oncology

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services among cancer patients, including those with a history of psychiatric and psychological problems and those without such a history.

Methods

This cross-sectional, observational study was based in St James's Hospital in Dublin, Ireland's largest acute academic teaching hospital. This is the largest designated national cancer centre in the country, with 17,243 outpatient cancer treatments provided annually [12].

Patients were recruited from the Haematology Oncology Day Ward where they received outpatient cancer treatment from April to May 2023. Inclusion criteria were that the patient was aged 18 years or over; had a cancer diagnosis, was proficient in the English language, and provided consent. All patients meeting these criteria were invited to participate. We assessed patients' attitudes towards services using an established survey tool (Appendix 1) [13]. Patients were asked if they knew the meaning of 'psycho-oncology', if they knew of its existence where they were attending for cancer care, and if they felt they would benefit from attending the psycho-oncology service. Patients were asked for their level of comfort with referral to various specialties within the hospital, disclosing attendance at specialists to others, and taking medications for physical and psychological symptoms.

For statistical analysis, we used SPSS (Version 26). Multiple regression analysis was performed with whether patients felt they would benefit from a referral to psycho-oncology as the dependent variable (0: patient felt that they would benefit; 1: patient was unsure; 2: patient did not feel they would benefit). Independent variables were: age, gender, marital status, type of cancer, and pre-existing psychiatric or psychological difficulty. To test for multicollinearity, a 'tolerance value' was calculated for each independent variable; tolerance values below 0.25 indicate possible multicollinearity, and tolerance values below 0.10 indicate significant problems with multicollinearity [14]. There was no evidence of multicollinearity in the model. Ethical approval granted in November 2022.

Results

One hundred and forty-two patients participated in the study. A majority were female (64.1%; $n=91$); 70.5% ($n=98$) were married or had a long-term partner; 53.4% ($n=76$) were under 60 years, and 46.5% ($n=66$) were over 60. Almost 1 in 10 patients had a history of psychiatric or psychological difficulties pre cancer diagnosis (9.1%; $n=12$).

The most commonly diagnosed cancer overall was breast cancer (33.8%; $n=48$), followed by colorectal (11.3%; $n=16$), lymphoma/ leukaemia (11.3%; $n=16$), gastric/ oesophageal (8.5%; $n=12$), gynaecological (8.5%; $n=12$), prostate/ renal/ bladder (7.0%; $n=10$), lung (6.3%; $n=9$), multiple myeloma (4.2%; $n=6$), melanoma (2.1%; $n=3$), head/ neck (1.4%; $n=2$) and other cancers (5.6%; $n=8$). Among women, the most common cancer was breast cancer (51.6%; $n=47$), while lymphoma/leukaemia was the most common among men (21.6%; $n=11$; Pearson Chi-Square = 64.621, $p<0.01$).

At the time of the study, almost half of patients (46.1%; $n=65$) had received their cancer diagnosis more than a year previously and a majority (69.2%; $n=92$) had never experienced a recurrence. Chemotherapy was the most common treatment (85.2%; $n=121$), with surgery the next most common (40.1%; $n=57$), followed by steroids (35.9%; $n=51$), radiotherapy (27.5%; $n=39$), hormonal therapy (9.2%; $n=13$), bone marrow transplant (5.6%; $n=8$), and immunotherapy (1.4%; $n=2$).

One third of patients rated their cancer diagnosis as 'very' distressing (33.3%; $n=43$) and one third as 'extremely' distressing (36.4%; $n=47$). Women experienced more distress than men, with 46.4% ($n=39$) of females reporting "extreme" distress at their cancer diagnosis, compared to 17.8% ($n=8$) of males (Pearson Chi-Square = 13.166, $p=0.10$). Patients were more likely to perceive their families as extremely distressed rather than themselves (Pearson Chi-Square 70.016, $p<0.01$).

Less than a third of patients (30.3%, $n=40$) knew the meaning of psycho-oncology. One quarter of patients (25.6%, $n=34$) were aware that there was a psycho-oncology service operating in the hospital where they were receiving cancer treatment. Two thirds of patients (67.2%, $n=84$) were unsure if they would benefit from a referral to the psycho-oncology service. Majorities of patients reported that they would attend the psycho-oncology psychiatrist (71.9%, $n=87$) and psycho-oncology psychologist (73.5%, $n=86$) without any difficulty. Patient views as to whether they would benefit or not from a referral to the psycho-oncology service were not related to gender (Pearson Chi-Square 0.192, $p=0.908$) or age (Pearson Chi-Square 9.808, $p=0.633$).

Table 1 outlines cancer patients' level of comfort with referral to and disclosing attendance at various disciplines. Over two-thirds of cancer patients would be happy or very happy with referral to cardiology (70.2%); over half (54.7%)

Table 1 Cancer Patient Attitudes Towards Multi-Disciplinary Oncology Services

Variable		Extremely uncomfortable/ embarrassed *n (%)*	Somewhat uncomfortable/ embarrassed *n (%)*	Neutral *n (%)*	Happy *n (%)*	Very happy *n (%)*
Level of comfort with referral to various disciplines	Social Work *(n = 118)*	7 (5.9%)	6 (5.1%)	38 (32.2%)	33 (28.0%)	34 (28.8%)
	Palliative Care *(n = 117)*	5 (4.3%)	3 (2.6%)	30 (25.6%)	36 (30.8%)	43 (36.8%)
	Specialist Nurse *(n = 117)*	5 (4.3%)	3 (2.6%)	30 (25.6%)	36 (30.8%)	43 (36.8%)
	Psychiatrist *(n = 117)*	4 (3.4%)	8 (6.8%)	41 (35.0%)	33 (28.2%)	31 (26.5%)
	Psychologist *(n = 116)*	4 (3.4%)	6 (5.2%)	34 (29.3%)	39 (33.6%)	33 (28.4%)
	Dietician *(n = 118)*	3 (2.5%)	2 (1.7%)	24 (20.3%)	41 (34.7%)	48 (40.7%)
	Occupational Therapy *(n = 119)*	3 (2.5%)	2 (1.7%)	33 (27.7%)	40 (33.6%)	41 (34.5%)
	Cardiology *(n = 121)*	2 (1.7%)	0 (0.0%)	34 (28.1%)	43 (35.5%)	42 (34.7%)
	Dermatology *(n = 121)*	2 (1.7%)	2 (1.7%)	34 (28.1%)	42 (34.7%)	41 (33.9%)
	Physiotherapy *(n = 119)*	2 (1.7%)	1 (0.8%)	32 (26.9%)	44 (37.0%)	40 (33.6%)
Level of comfort telling others about attending various disciplines	Palliative Care *(n = 114)*	17 (14.9%)	7 (6.1%)	36 (31.6%)	36 (31.6%)	18 (15.8%)
	Psychiatrist *(n = 117)*	10 (8.5%)	11 (9.4%)	33 (28.2%)	44 (37.6%)	19 (16.2%)
	Psychologist *(n = 117)*	9 (7.6%)	8 (6.8%)	34 (29.1%)	44 (37.6%)	22 (18.8%)
	Social Work *(n = 117)*	9 (7.7%)	10 (8.5%)	33 (28.2%)	43 (36.8%)	22 (18.8%)
	Specialist Nurse *(n = 118)*	7 (5.9%)	4 (3.4%)	31 (26.3%)	47 (39.8%)	29 (24.6%)
	Cardiology *(n = 121)*	5 (4.1%)	2 (1.7%)	34 (28.1%)	54 (44.6%)	26 (21.5%)
	Occupational Therapy *(n = 120)*	5 (4.2%)	1 (0.8%)	33 (27.5%)	53 (44.2%)	28 (23.3%)
	Dermatology *(n = 119)*	4 (3.4%)	2 (1.7%)	35 (29.4%)	53 (44.5%)	25 (21.0%)
	Dietician *(n = 120)*	4 (3.3%)	2 (1.7%)	33 (27.5%)	53 (44.2%)	28 (23.3%)
	Physiotherapy *(n = 119)*	4 (3.4%)	3 (2.5%)	34 (28.6%)	52 (43.7%)	26 (21.8%)

would be happy or very happy with referral to psychiatry, and 62.0% would be happy or very happy with referral to psychology. One fifth of patients (21.0%) would be somewhat or extremely uncomfortable disclosing that they were attending palliative care, compared to 9.3% for a specialist nurse and 5.8% for cardiology. Just under one fifth of patients (17.9%) would be somewhat or extremely uncomfortable disclosing attendance at a psychiatrist and 14.4% of patients would be somewhat or extremely uncomfortable disclosing attendance at a psychologist; these proportions did not differ across genders (psychiatry: Pearson Chi-square

4.775, $p=0.311$, $n=117$; psychology: Pearson Chi-Square 3.616, $p=0.606$, $n=118$).

Majorities of cancer patients would be happy or very happy to disclose that they were taking medications for their heart (65.9%, $n=81$), stomach (68.8%, $n=86$), nausea (72.4%, $n=89$), fatigue (73.2%, $n=90$), hot flushes (56.6%, $n=64$) or pain (73.8%, $n=45$). Fewer than half of patients would be happy or very happy disclosing that they were taking medication for mood (45.4%, $n=54$) or anxiety (41.6%, $n=27$).

On multivariable analysis, a higher likelihood of believing that a psycho-oncology referral would be beneficial was independently associated with only one of the independent variables included in the model: having a history of psychiatric of psychological difficulties pre-cancer diagnosis (Table 2). The R^2 value was 7.7%, indicating that the model explained 7.7% of the variance in patients' belief in the benefit of referral to psycho-oncology.

Discussion

We found that cancer patients experience high levels of distress relating to their diagnosis and treatment. We report gender differences in cancer patient's experience of distress, with almost half of women reporting 'extreme' levels of distress, compared to under one-fifth of men. Despite high levels of distress, under one third of patients knew the meaning of 'psycho-oncology' and most were unaware that this service was available in the hospital where they were receiving cancer treatment. Most patients, regardless of age or gender, were ambivalent about the benefits of psycho-oncology referral. Despite this, most patients would attend both the psycho-oncology psychiatrist and psychologist without difficulty.

Although most patients would be happy or very happy to attend psychology or psychology, there was a higher level of discomfort reported with disclosing to others that they were attending a psychiatrist, compared to a cardiologist or dermatologist, irrespective of gender. Patients were also more comfortable disclosing use of medications for physical than psychological symptoms. On multi-variable testing, a history of psychiatric of psychiatric difficulty was the only variable independently associated with perceived benefit from a referral to psycho-oncology.

The findings in our study are consistent with figures already published in the literature and show that women continue to experience more extreme psychological distress than men at cancer diagnosis, with almost half of female respondents reporting 'extreme' levels of distress [1, 2]. International studies have identified lack of knowledge and negative attitudes towards mental health supports as significant barriers to accessing psycho-oncology services [15, 16]. Another Irish study, published over a decade ago, reported similar reluctance to disclose attendance at a psychiatrist (19.3%) or psychologist (18.7%), compared to a dietician (3.7%), for example [13]. Our study reinforces some of these findings and confirms that, despite increased awareness of the benefits of psychological supports for cancer patients [17], significant barriers and stigma towards psycho-oncology services persist. Patients were more comfortable

Table 2 Predictors of patients' belief of benefit from referral to psycho-oncology service [a]: multi-variable linear regression model

Independent variables	β	Standard error	p value	Tolerance value [b]
Age	0.051	0.044	0.257	0.938
Gender	0.093	0.114	0.418	0.898
Single or not single	0.002	0.101	0.986	0.978
Type of cancer	0.005	0.017	0.788	0.955
History of psychiatric or psychological difficulties pre-cancer	−0.537	0.190	0.005	0.971
Constant	0.644	0.312	0.041	-

This multi-variable linear regression model includes all patients who responded to the survey on the Oncology Day ward during the recruitment period for the study.

R square value was 7.7% indicating variables in the model explained 7.7% of the variance in level of distress at treatment.

[a] The dependent variable was patients' belief of benefit from referral to psycho-oncology service, where 0 indicates a 'yes' response, 1 a 'don't know' response and 2 a 'no' response.

[b] To test for multicollinearity, a "tolerance value" was calculated for each independent variable; tolerance values below 0.25 indicate possible multicollinearity, and tolerance values below 0.10 indicate significant problems with multicollinearity [14].

disclosing attendance at a specialist nurse than a psychiatrist or psychologist.

In addition, we found that pre-existing psychiatric/psychological difficulty was the only variable independently associated with a belief that a psycho-oncology referral would be beneficial. This means that this group of cancer patients who are at increased risk of poorer outcomes from cancer are especially open to psycho-oncological intervention. This novel finding suggests that targeted psycho-oncological interventions for this group are likely to prove especially acceptable to these patients and, therefore, an optimal use of limited resources in this area.

Strengths of this paper include that this is the first significant report of patient attitudes towards psycho-oncology services in Ireland in the last decade, a time during which specialist services have been developing nationally. The study also includes all cancer types and, for the first time, identifies a subgroup of cancer patients with a history of psychological or psychiatric difficulties who are more likely to benefit from early engagement with psycho-oncology services. Given that this subgroup of patients likely had previous engagement with psychological or psychiatric services, it suggests that a history of engagement with such services might help to reduce stigma and improve access to services.

Study limitations

This paper was based on a convenience sample, relied on self-report for past mental health problems, and did not examine potentially relevant variables such as ethnicity, level of education, and current engagement with other mental health services. These variables merit exploration in future studies on this topic. Given that patients were recruited from a single day-ward where they were undergoing outpatient cancer treatment, there may have been an element of selection bias as this would exclude patients receiving solely radiation or surgical treatment for cancer and those in end-of life care or on surveillance treatment.

Future studies could usefully assess the attitudes of these patients by recruiting through oncology, palliative care, and cancer surgery teams. In addition, owing to data protection regulations, it was not possible to collect any data about patients who declined to participate in the study. The study was cross-sectional in design, with patients reporting their attitude toward psycho-oncology services at a single time-point. Future research could address attitudes towards services longitudinally and include qualitative data to elaborate on patient views and barriers to engagement.

Clinical implications

Our study highlights gender differences in distress experienced by cancer patients and highlights a female subgroup of patients who experience high levels of 'extreme' distress. Despite high levels of distress, there was limited awareness among cancer patients of psycho-oncology teams and ongoing reluctance to engage with psychiatry and psychology compared to other medical specialties. Given that patients were more comfortable disclosing attendance at a specialist nurse compared to a psychiatrist or psychologist, specialist nurses working within psycho-oncology multidisciplinary teams may be best placed to engage this vulnerable subgroup of extremely distressed patients.

We also report reluctance of cancer patients to disclose use of psychotropic medications which may reflect stigma associated with psychological and psychiatric treatment. Given that cancer patients with a pre-existing psychiatric or psychological difficulty felt that they would benefit most from psycho-oncology referral, and it is widely recognised that those with mental illness suffer poorer outcomes from cancer, active engagement of this particular group in psycho-oncological care is likely to both improve outcomes and prove an especially efficient use of limited psycho-oncological resources. Psychoeducation about psychosocial support services for cancer patients might also help to improve engagement with services, given that patients with a previous history of service contact had greater confidence that they would benefit from engaging.

Conclusion

Ongoing barriers exist for cancer patients to access psycho-oncology services, with a lack of awareness of the existence of such services and their benefits. Our study highlights a subgroup of female patients who experience high levels of distress during cancer diagnosis and treatment and those with pre-existing psychiatric comorbidity who are more likely to feel that they would benefit from psycho-oncology referral and are therefore more likely to be open to engagement. Given that women are more likely to experience extreme distress, renewed efforts should be made to address gender equality in services with an emphasis on the role of the specialist nurse within the team.

Appendix 1: Participant survey

1. Age (please tick the appropriate box):

18 – 21years ☐ 22 - 25years ☐ 26 – 30 years ☐ 31 – 35 years ☐

36 – 40 years ☐ 41 – 50 years ☐ 51 – 60 years ☐ 61 years + ☐

2. Gender

Male ☐ **Female** ☐ **Other (please describe)**_____

3. Marital Status:

Single ☐ Long term partner ☐ Married ☐ Divorced ☐ Widowed ☐

4. Type of cancer:

Lung	☐	Gastric/Oesophageal	☐
Breast	☐	Melanoma	☐
Prostate/Renal/Bladder	☐	Head/Neck	☐
Lymphoma/Leukaemia	☐	Gynaecological	☐
Colon/Rectal	☐		
Other (Please state)	_____		

5. How long has it been since your initial cancer diagnosis:

< 1 month ☐ 1 – 3 months ☐ 4-6 months ☐ 7 – 12 months ☐ >1 year ☐

6. Have you had a recurrence of your cancer?

Yes ☐ No ☐

If Yes, how many _____

7. What treatment have you received for your cancer to date?

Surgery	☐	**Bone marrow transplant**	☐
Chemotherapy	☐	**Steroids**	☐
Radiotherapy	☐	**Other (Please describe below)**	
Hormonal treatments	☐		

8. **How distressing or stressful were the following aspects for you, and for your family:**

	Extremely	Very	Moderately	A little	Not at all
How distressing or stressful was your cancer **diagnosis** for **you?**					
How distressing or stressful was your cancer **diagnosis** for **your family?**					
How distressing or stressful was your cancer **treatmen**t for **you?**					
How distressing or stressful was your cancer **treatment** for **your family?**					

9. **Do you know what Psycho-Oncology means?**

Yes ☐ No ☐

If *Yes* please describe: _____

10. **Did you know that St James's Hospital has a Psycho-Oncology Service?**

Yes ☐ No ☐

11. **If your doctor referred you to the Psycho-Oncology Service *Psychiatrist* would you:**

Refuse ☐ Reluctantly attend ☐ Attend with no difficulty ☐

12. **If your doctor referred you to the Psycho-Oncology Service *Psychologist* would you:**

Refuse ☐ Reluctantly attend ☐ Attend with no difficulty ☐

13. **Do you think you would benefit from attending the psycho-oncology service?**

☐ Yes ☐ No ☐ Don't Know

14. **If your doctor thought it would be helpful, how happy or comfortable would you be attending the following specialties (please tick)?**

	Extremely uncomfortable / embarrassed	Somewhat uncomfortable/ embarrassed	Neutral	Happy	Very happy
Cardiology (Heart Specialist)					
Dermatology (Skin Specialist)					
Physiotherapist					
Occupational therapist					
Dietician					
Psychiatrist					
Psychologist					
Social Worker					
Palliative care					
Specialist nurse					

15. **How happy or comfortable would you be telling your close friends or family that you were attending the following specialties (please tick)?**

	Extremely uncomfortable / embarrassed	Somewhat uncomfortable/ embarrassed	Neutral	Happy	Very Happy
Cardiology (Heart Specialist)					
Dermatology (Skin Specialist)					
Physiotherapist					
Occupational therapist					
Dietician					
Psychiatrist					
Psychologist					
Social Worker					
Palliative care					
Specialist nurse					

16. **If your doctor thought that it would be helpful to you, how happy or comfortable would you be taking medication for the following problems (please tick)?**

	Very unhappy	Somewhat unhappy	Neutral	Somewhat happy	Very happy
Heart problems					
Stomach (eg. anti-acid)					
Nausea					
Fatigue					
Mood (anti-depressants)					
Anxiety (eg. Valium)					
Pain					
Hot flushes					

Data availability Data to support the findings of this study is not publicly available to preserve individuals' privacy under the European General Data Protection Regulations.

Declarations

Conflict of interest None declared.

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Appendix E: Cancer patient distress – roles of gender, family and psychological care. Published in Irish Medical Journal

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Cancer patient distress – roles of gender, family and psychological care

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Abstract

Introduction

Cancer burden is rising worldwide, with 20 million new diagnoses annually. Psychological needs of cancer patients are increasingly recognised, and psycho-oncology teams are developing. We aimed to assess distress among cancer patients in the oncology day-ward of a large urban hospital in Ireland.

Methods

Cross-sectional observational study of patient-rated distress at cancer diagnosis and treatment. We assessed distress among 142 patients using an existing survey tool.

Results

Women reported more extreme distress during cancer diagnosis and treatment, with 39 (46.4%) reporting 'extreme' distress at diagnosis and 82 (21.2%) during treatment, compared to 8 (17.8%) men at diagnosis and 43 (4.7%) men during treatment. Patients were likely to perceive their families as more distressed than themselves. On multi-variable testing, female gender was independently associated with higher patient distress at diagnosis and treatment. Patients reported work, fatigue, and fear for the future as areas of life most extremely affected by cancer. Only 3 (2.6%) patients reported extreme difficulties with relationships.

Discussion

High rates of extreme distress for cancer patients, particularly women, and their families highlights the need for enhanced, gender-aware, family-oriented psychological supports during cancer diagnosis and treatment. Future research could usefully include family members, assess distress longitudinally, and evaluate the impact of psychological supports.

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Introduction

The burden of cancer worldwide is rising, with 20 million new cancer cases diagnosed in 2022 and 9.7 million cancer related deaths.[1] One fifth of the population will develop cancer in their lifetime. It is estimated that there will be over 35 million cancer diagnoses in 2050. Advances in medicine have led to timely diagnosis and improved cancer treatment, resulting in increased survival rates. Despite these advances, the psychological needs of cancer patients and their families have been neglected historically with the primary focus on medical treatment. While this is a medical success story, it is important to acknowledge, recognise and address the psychological needs of cancer patients and their families.

These needs are increasingly recognised in recent years and specialist psycho-oncology teams are developing worldwide. In Ireland, the National Cancer Strategy, aims to develop psycho-oncology services nationally by 2026 to address "the psychological responses of patients to cancer at all stages of the disease".[2] As defined in this strategy, 'the term 'distress' is the preferred term to describe the psychological challenges that patients with cancer experience'[3].

The distress related to cancer is often considered along a spectrum called the 'distress continuum'. This ranges from normal adjustment and coping, through to adjustment disorders, subclinical mental health diagnoses and clinical psychiatric disorders[4]. There are many aspects associated with a cancer diagnosis and treatment which can cause significant emotional and psychological distress for patients. The uncertainty around prognosis, treatment and survival can be significantly anxiety provoking for patients. Practical aspects associated with a cancer diagnosis include sick leave due to physical symptoms or attendance at medical appointments, resulting in loss of income and employment and a significant level of emotional distress for cancer patients. Physical symptoms such as pain, loss of appetite, poor energy and sleep disturbance can have an impact on cancer patients' emotional wellbeing. The identity shift from a 'healthy person' to a 'cancer patient' can affect self-esteem and self-confidence.

There are various levels of clinically significant psychological distress among cancer patients reported in the literature, ranging from one quarter to half of cancer patients [5,6]. A large published meta-analysis found high rates of psychiatric disorders among cancer patients, including depression (20.7%), anxiety (10.3%) and adjustment disorder (19.4%)[7].

The literature reports that cancer patients who experience clinically significant levels of anxiety and depression have poorer cancer survival and increased cancer incidence[8]. A meta-analysis has shown that mortality rates from cancer are 25% higher in cancer patients with depressive symptoms and increased by 39% in cancer patients with a clinically diagnosed

depressive episode [9]. There is some evidence that a reduction in distress levels can lead to improved cancer outcomes for breast cancer patients[10].

It is important that the implementation of the National Cancer Strategy is informed by evidence. Evidence to date indicates a clear need for psycho-oncology services[11], but further and ongoing evidence is required to shape services and ensure maximal patient benefit.

Against this background, we aimed to assess distress among cancer patients in the oncology day-ward of a large urban hospital in Ireland. We assessed patient rated distress and examined its relationship with other variables. We also sought to identify the areas of patients' lives most affected by cancer and cancer treatment in order to inform psycho-oncology service delivery. Results of this study may help shape psycho-oncology services in line with patient need as they continue to develop nationally.

Methods

This cross-sectional, observational study was based in St James's Hospital in Dublin, Ireland's largest acute academic teaching hospital. It is the largest designated national cancer centre in the country.

Patients were recruited from the Haematology Oncology Day Ward where they received outpatient cancer treatment, from April to May 2023. Inclusion criteria were that the patient was aged 18 years or over; had a cancer diagnosis, was proficient in the English language and provided consent. All patients meeting these criteria were invited to participate.

We assessed distress among patients using an existing survey tool (Appendix 1).[11] The self-report tool asked patients about their type of cancer, time since diagnosis, if they had experienced a recurrence, areas of life affected by cancer and their self-perceived coping with cancer and cancer treatment. Patients were asked to recall the level of distress they and their family experienced at time of diagnosis and about their current level of distress during cancer treatment.

For statistical analysis we used SPSS (version 26). We performed two multi-variable regression analyses with level of distress at diagnosis and treatment as the dependent variables; independent variables were age, gender, single or not single, type of cancer and history of psychiatric or psychological difficulties pre-cancer diagnosis. To test for multicollinearity, a "tolerance value" was calculated for each independent variable[12], with no evidence of multicollinearity in either model.

Results

One hundred and forty-two patients participated in the study. Almost two thirds (64.1%; n=91) were female; 64% (n=89) were married; 10.5% (n=15) were aged under 40 years, 42.9% (n=61) were between 40 and 60, and 46.5% (n=66) were over 60. A majority had no history of psychiatric or psychological difficulties (90.9%; n=120).

Breast cancer was the most common cancer (33.8%) (Table 1). Among women, the most common cancers were breast (51.6%), gynaecological (13.2%) and colorectal (7.7%), while lymphoma/leukaemia (21.6%), colorectal (17.6%) and prostate/renal/bladder cancers (17.6%) were most common among men (x^2= 64.621, p<0.01). At the time of the study, approximately half of patients (53.9%; n=76) had received their cancer diagnosis within the previous year; almost one third (30.8%; n=41) were experiencing a recurrence; and chemotherapy was the most common treatment (85.2%; n=121), followed by surgery (40.1%; n=57), steroids (35.9%; n=51), radiotherapy (27.5%; n=39), hormonal therapy (9.2%; n=13), bone marrow transplant (5.6%; n=8), and immunotherapy (1.4%; n=2).

Over two thirds of patients rated their cancer diagnosis as very distressing (33.3%) or extremely distressing (36.4%) (Table 2). Females experienced more distress than males, with 46.4% of women reporting "extreme" distress at their cancer diagnosis, compared to 17.8% of men (x^2 = 13.166, p=0.10). Distress at diagnosis for patient was not related to cancer type (x^2 = 50.422, p=0.125), age (x^2= 17.233, p=0.839), or history of psychiatric or psychological difficulty (x^2= 0.818, p=0.936). Patients were more likely to perceive their families as extremely distressed compared to themselves (x^2= 70.016, p<0.01).

Almost half of patients rated treatment as very (30.6%) or extremely distressing (16.1%), but patients were, overall, less likely to report extreme distress at time of treatment compared to time of diagnosis (x^2 = 49.455, p<0.01). Females experienced more distress than males during cancer treatment, with 21.2% (n=82) of females reporting cancer treatment as "extremely" distressing compared to 4.7% (n=43) of males (x^2 = 11.526, p=0.042).

Almost half of patients (48.9%; n=64) reported that cancer diagnosis and treatment impacted a great deal on daily life. A majority (84.8%; n=111) reported that cancer diagnosis and treatment had a moderate or great deal of impact on their quality of life. Less than a quarter of patients (22.7%; n=30) felt that they were coping very well with cancer treatment and associated side effects. The areas in life that were most extremely affected by cancer and its treatment were work (27.9%), fatigue (19.0%) and fear for the future (17.3%); the areas least extremely affected were relationships (2.6%), parenting (4.8%) and fertility (6.7%) (Table 3). Other areas affected by cancer and its treatment, included planning for the future (0.7%; n=1), social restrictions (0.7%; n=1) and social life (0.7%; n=1).

Areas of life affected by cancer and its treatment did not differ significantly across genders, apart from levels of anxiety and worry, with more females reporting 'extreme' or 'quite a bit' of worry (49.4%; n=40), than men (19.1%; n=8; x^2=10.792; p=0.029).

On multi-variable testing, female gender was the only variable associated with higher levels of patient distress at cancer diagnosis and treatment (Table 4).

Discussion

In summary, this study found that females experienced more extreme levels of distress than males during both cancer diagnosis and treatment, with almost half of females reporting 'extreme' distress at diagnosis and over one-fifth during treatment. This compares to less than one-fifth of males at diagnosis and under five percent during treatment. Patients were likely to perceive their families as more distressed than themselves. Patients were less likely to report extreme distress at treatment than cancer diagnosis.

On multi-variable testing, female gender was the only variable independently associated with higher levels of patient distress at cancer diagnosis and treatment.

Patients reported work, fatigue and fear for the future as the areas of life most extremely affected by cancer and treatment. Only 2.6% of patients reported extreme difficulties with relationships due to their cancer diagnosis and treatment.

A previous Irish study highlighted significant levels of distress in psycho-oncology patients with 57.9% of patients reporting 'very' high or 'extreme' levels of distress in relation to their cancer diagnosis, but that study did not report differences in gender.[11] Another Irish study of patients already referred to the psycho-oncology service reported that females experienced increased levels of distress[13]. An international study of female breast cancer patients has also shown a decrease in distress over time from diagnosis to treatment.[14] International studies report varying levels of distress among cancer patients. In Canada, a large-scale study estimated that 37% of patients experienced significant distress levels.[15]

A large multicentre study in Canada reported 19% of cancer patients had clinical levels of anxiety with 22.6% experiencing subclinical symptoms.[16] Other international studies report gender based differences in distress among cancer patients, with females diagnosed with non-metastatic renal cell carcinoma experiencing higher levels of anxiety and distress.[17] A Chinese study of patients with gastroenteropancreatic neuroendocrine tumour estimated the prevalence of psychological distress as 31.5%, with females experiencing more distress.[18] Another Chinese study of gastrointestinal cancer patients found that a greater proportion of females (52.8%) had clinically significant psychological distress compared to males (35.9%).[19]

Our study replicates these findings, linking female gender with distress in cancer in Ireland. In addition, we report that over two thirds of patients rate their cancer diagnosis as very or extremely distressing. We also report that work is the area of life most commonly impacted by cancer diagnosis and treatment. Relationships were reported as the least affected area of life, suggesting that the impact of cancer on relationships is more nuanced rather than solely negative.

Strengths of this paper include that to our knowledge, this is the first significant study of gender based distress among Irish cancer patients in the last decade and includes all cancer types. In addition, we identified a potentially vulnerable patient cohort who may benefit from increased psychological support during cancer diagnosis and treatment, allowing streamlining of psycho-oncology services nationally.

Limitations of this paper include possible selection bias given that patients were recruited from the haematology oncology day ward where they were undergoing cancer treatment. This would not include cancer patients undergoing surgical or radiation therapy only, those not on active treatment, and those in palliative care. Future studies could look to include these patients by recruiting via palliative care, radiotherapy centres, oncology and surgical teams. In addition, it was not possible to collect any data about patients who declined to participate owing to data protection regulations.

Our study was cross-sectional in nature, with participants reporting distress at diagnosis retrospectively, which may have been subject to recall bias. Future work may look to follow up distress longitudinally, although assessing distress at time of diagnosis for patients would be difficult owing to the sensitive nature of the subject and would be ethically challenging.

In conclusion, the high rates of extreme distress for cancer patients and their families in our study, particularly among women, highlights the need for enhanced provision of psychological support for patients during both cancer diagnosis and treatment, informed by patterns identified in evidence such as this study. In Ireland, services have been developing nationally under the National Cancer Strategy 2017-2026 and this research emphasises the ongoing need for this service for the Irish population. Future research could usefully include family members, aim to assess distress amongst cancer patients longitudinally and evaluate the impact of psychological supports on distress.

Declarations of Conflicts of Interest:

None declared.

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Table 1 Cancer type:

Variable	Overall (Female and male)	Female *n (%)*	Male *n (%)*
Breast	48 (33.8%)	47 (51.6%)	1 (2.0%)
Colon/ rectal	16 (11.3%)	7 (7.7%)	9 (17.6%)
Lymphoma/ leukaemia	16 (11.3%)	5 (5.5%)	11 (21.6%)
Gastric/ oesophageal	12 (8.5%)	6 (6.6%)	6 (11.8%)
Gynaecological	12 (8.5%)	12 (13.2%)	0 (0%)
Prostate/ renal/ bladder	10 (7.0%)	1 (1.1%)	9 (17.6%)
Lung	9 (6.3%)	2 (2.2%)	7 (13.7 %)
Other	8 (5.6%)	6 (6.6%)	2 (3.9%)
Multiple myeloma	6 (4.2%)	2 (2.2%)	4 (7.8%)
Melanoma	3 (2.1%)	2 (2.2%)	1 (2.0%)
Head/neck	2 (1.4%)	1 (1.1%)	1 (2.0%)

Table 2: Distress of cancer diagnosis and treatment for patient and family

Variable	Extremely *n (%)*	Very *n (%)*	Moderately *n (%)*	A little *n (%)*	Not at all *n (%)*
Distress of diagnosis for patient *(n=129)*	47 (36.4%)	43 (33.3%)	32 (24.8%)	6 (4.7%)	1 (0.8%)
Distress of diagnosis for family *(n=129)*	64 (49.6%)	44 (34.1%)	16 (12.4%)	4 (3.1%)	1 (0.8%)
Distress of treatment for patient *(n=124)*	20 (16.1%)	38 (30.6%)	47 (37.9%)	16 (12.9%)	3 (2.4%)
Distress of treatment for family *(n=123)*	22 (17.9%)	48 (39.0%)	43 (35.0%)	5 (4.1%)	5 (4.1%)

Table 3: Areas patients had difficulties with due to cancer and its treatment

Variable	Extremely *n (%)*	Quite a bit *n (%)*	Moderately *n (%)*	A little bit *n (%)*	Not at all *n (%)*
Work *(n=111)*	31 (27.9%)	29 (26.1%)	11 (9.9%)	8 (7.2%)	32 (28.8%)
Fatigue *(n=126)*	24 (19.0%)	47 (37.3%)	33 (26.2%)	20 (15.9%)	2 (1.6%)
Fear for the future *(n=127)*	22 (17.3%)	33 (26.0%)	30 (23.6%)	27 (21.3%)	15 (11.8%)
Sexual intimacy *(n=113)*	20 (17.7%)	28 (24.8%)	17 (15.0%)	15 (13.3%)	33 (29.2%)
Fear of recurrence *(n=122)*	19 (15.6%)	32 (26.2%)	26 (21.3%)	31 (25.4%)	14 (11.5%)
Finances *(n=119)*	15 (12.6%)	21 (17.6%)	25 (21%)	27 (22.7%)	31 (26%)
Physical appearance *(n=122)*	14 (11.5%)	34 (27.9%)	20 (16.4%)	32 (26.2%)	22 (18.0%)
Anxiety or worry *(n=123)*	14 (11.4%)	34 (27.6%)	34 (27.6%)	30 (24.4%)	11 (8.9%)
Pain *(n=115)*	10 (8.7%)	21 (18.3%)	26 (22.6%)	31 (27.0%)	27 (23.5%)
Sleep	7 (5.6%)	37 (29.6%)	28 (22.4%)	29 (23.2%)	24 (19.2%)

(n=125)					
Low mood or sadness *(n=126)*	6 (4.8%)	20 (15.9%)	41 (32.5%)	41 (32.5%)	18 (14.3%)
Fertility *(n=90)*	6 (6.7%)	4 (4.4%)	4 (4.4%)	8 (8.9%)	68 (75.6%)
Parenting *(n=105)*	5 (4.8%)	14 (13.3%)	19 (18.1%)	27 (25.7%)	40 (38.1%)
Relationships *(n=115)*	3 (2.6%)	15 (13.0%)	23 (20%)	24 (20.9%)	50 (43.5%)

Table 4: Predictors of level of patient distress at cancer diagnosis and treatment: multi-variable linear regression models

Independent variables	Level of patient distress at cancer diagnosis [a]				Level of patient distress at cancer treatment [b]			
	β	Standard error	p value	Tolerance value [c]	β	Standard error	p value	Tolerance value [c]
Age	-0.033	0.069	0.637	0.942	-0.038	0.077	0.626	0.936
Gender	0.624	0.176	0.001	0.916	0.425	0.196	0.032	0.925
Single or not single	0.226	0.156	0.151	0.971	0.279	0.176	0.115	0.967
Type of cancer	0.022	0.027	0.401	0.962	0.017	0.030	0.564	0.973
History of psychiatric or psychological difficulties pre-cancer	0.115	0.276	0.679	0.975	0.468	0.306	0.128	0.974
Constant	2.441	0.480	0.000	-	2.009	0.532	0.000	-

Notes

This multi-variable linear regression model includes all patients who responded to the survey on the Oncology Day ward during the recruitment period for the study.

[a] The dependent variable was level of distress at cancer diagnosis, where 0 indicates no distress and 4 indicates extreme distress. R square value for this model was 12.0%, indicating that variables in the model explained 12% of the variance in level of distress.

[b] The dependent variable was level of distress at cancer treatment, where 0 indicates no distress and 4 indicates extreme distress. R square value for this model was 8.2%, indicating that variables in the model explained 8.2% of the variance in level of distress at treatment.

[c] To test for multicollinearity, a "tolerance value" was calculated for each independent variable; tolerance values below 0.25 indicate possible multicollinearity, and tolerance values below 0.10 indicate significant problems with multicollinearity [12].

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Appendix 1: Participant survey

1. **Age (please tick the appropriate box):**

   18 – 21years □ 22 - 25years □ 26 – 30 years □ 31 – 35 years □

   36 – 40 years □ 41 – 50 years □ 51 – 60 years □ 61 years + □

2. **Gender**

   Male □ **Female** □ **Other (please describe)**_____

3. **Marital Status:**

   Single □ Long term partner □ Married □ Divorced □ Widowed □

4. **Type of cancer:**

   Lung □ Gastric/Oesophageal □

   Breast □ Melanoma □

   Prostate/Renal/Bladder □ Head/Neck □

   Lymphoma/Leukaemia □ Gynaecological □

   Colon/Rectal □

   Other (Please state) _____

5. **How long has it been since your initial cancer diagnosis:**

   < 1 month □ 1 – 3 months □ 4-6 months □ 7 – 12 months □ >1 year □

6. **Have you had a recurrence of your cancer?**

   Yes □ No □

   If Yes, how many _____

7. **What treatment have you received for your cancer to date?**

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Surgery	□	**Bone marrow transplant**	□
Chemotherapy	□	**Steroids**	□
Radiotherapy	□	**Other (Please describe below)**	
Hormonal treatments	□		

8. How distressing or stressful were the following aspects for you, and for your family:

	Extremely	Very	Moderately	A little	Not at all
How distressing or stressful was your cancer **diagnosis** for **you?**					
How distressing or stressful was your cancer **diagnosis** for **your family?**					
How distressing or stressful was your cancer **treatment** for **you?**					
How distressing or stressful was your cancer **treatment** for **your family?**					

9. To what degree do you find that your diagnosis of cancer and its treatment has negatively affected aspects of your daily life?

☐ Not at all ☐ Not very much ☐ Moderately ☐ A great deal

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10. To what degree do you find that your diagnosis of cancer and its treatment has negatively affected your quality of life?

☐ Not at all ☐ Not very much ☐ Moderately ☐ A great deal

11. Do you have a history of psychological or psychiatric difficulties prior to your cancer diagnosis and treatment?

☐ No ☐ Yes (please describe) _____

12. How well do you think you are coping with cancer, treatment and side-effects?

Poorly □

Less well than I'd like □

Reasonably well □

It varies □

Very well □

13. Has cancer and its treatment caused you to experience problems with? (please tick)

	Not at all	A little bit	Moderately	Quite a bit	Extremely
Pain					
Fatigue / energy					
Sleep					
Physical Appearance					
Anxiety or worry					
Sadness / Low mood					
Fear of recurrence					
Fear for the future					
Sexual intimacy					
Work					

Parenting					
Fertility					
Finances					
Relationships					
Other (please state)					

14. Please list the three areas in your life that cancer and its treatments has had the most negative or serious impact.

A)_____

B)_____

C)_____

Appendix F: Psycho-oncology care for women with cancer in Ireland: overview, evidence, and future directions. Published in Irish Journal of Psychological Medicine

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Perspective Piece

Psycho-oncology care for women with cancer in Ireland: overview, evidence, and future directions

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Abstract

The burden of cancer worldwide is rising, with 20 million new cases diagnosed in 2022. In Europe, 1.2 million women are diagnosed with cancer annually and an estimated 600,000 women die from cancer each year. International research and data from Ireland demonstrate that women with cancer face a particular set of challenges, including increased psychological distress compared to men. As a result, Ireland's *Model of Care for Psycho-Oncology* could usefully place greater emphasis on gender-specific provisions which address the increased psychological needs of women. To date, Ireland has made some progress in recognising the physical and mental healthcare needs of women and developing gender-informed policies. It is essential that such policies are implemented fully so as to reduce and eliminate disparities in care. A more tailored, gender-informed approach would also help ensure the provision of gender-aware psycho-oncological care for all women and men as they navigate their cancer journeys.

Keywords: Cancer; distress; Ireland; liaison psychiatry; men; mental health; mental health services; psycho-oncology; women

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Introduction

The burden of cancer is rising worldwide, with 20 million new cases diagnosed in 2022 and 9.7 million cancer-related deaths (World Health Organisation 2024). In Europe, 12 million women are living with cancer, 1.2 million women are diagnosed with cancer annually, and an estimated 600,000 women die from cancer each year (L'Hôte et al., 2024).

At the outset of this article, we note that sex is a biological variable and gender is a complex sociocultural construct. We use the gender binary of women and men throughout this article because that is how the majority of research literature is framed. We acknowledge that this is a limiting binary framework. Hopefully, future research will better reflect evolving understandings of gender.

Recent decades have seen improved recognition of psychological distress among cancer patients. Specialist psycho-oncology teams have been developing around the world since the 1980s, usually as a sub-specialty of liaison psychiatry. This relatively new branch of practice aims to reduce the levels of emotional distress experienced by cancer patients and their families, and address the biopsychosocial factors that mediate cancer morbidity and mortality.

In line with the increasing recognition of the psychological needs of cancer patients, the International Psycho-Oncology Society recommends that 'psychosocial cancer care should be recognised as a universal human right' and incorporated into routine cancer care (International Psycho-Oncology Society 2014). In addition, 'distress should be measured as the 6th Vital Sign after temperature, blood pressure, pulse, respiratory rate and pain'.

A recent policy paper from the European Cancer Organisation titled *Women & Cancer: More Than 12 Million Reasons for Actions* highlights the specific set of challenges faced by women in the context of cancer diagnosis and treatment (L'Hôte et al., 2024). That paper highlights significant cancer burden among women in Europe, as well as the disparities in care and difficulties they face. The authors write that 'above all, the psychological impact of a cancer diagnosis and treatment is significant, as women may face additional stress related to family care responsibilities, societal expectations and stigmatisation' (p. 6). The authors make clear recommendations for psycho-oncology services and survivorship programmes to address the unmet needs of female cancer patients so as to 'properly address the psychological needs of women affected by cancer, tailoring them to their needs' (p. 28). This call for action highlights the importance of specifically recognising and addressing the psychological distress of women diagnosed with cancer.

Specific challenges faced by women when diagnosed with cancer

Gender-based differences in psychological distress following cancer diagnosis and treatment are widely reported in the international literature. A Canadian study of patients diagnosed

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with non-metastatic renal cell carcinoma found that women experience higher levels of anxiety and distress than men at several timepoints in their cancer journey, including at diagnosis, biopsy, and surgical treatment (Ajaj et al., 2020). A study of gastrointestinal cancer patients in China found that a greater proportion of females (52.8%) than males (35.9%) had clinically significant psychological distress (Cheng et al., 2024).

A German study of over 21,000 patients with all cancer types classified patients into five distress cluster groups: 'minimally distressed', 'highly distressed', 'mainly physically distressed', 'mainly psychologically distressed', and 'mainly socially distressed' (Herschbach et al., 2020). Men were over-represented in the 'minimally distressed' cluster, and women were over-represented in the 'highly distressed' and 'mainly psychologically distressed' clusters. These findings confirm that females experience higher levels of distress relating to cancer diagnosis and treatment than men.

In the Irish context, we recently published a study which explored the experience of cancer patients attending for oncological treatment in the largest national cancer centre in the country (Carter et al., 2025). We confirmed gender disparities in the psychological experience of Irish cancer patients during diagnosis and treatment, with women reporting more extreme distress than males. In our study, almost half of females who participated (46.4%) reported 'extreme' distress at cancer diagnosis compared to 17.8% of males. Consistent with the international literature, our results confirm that gender differences exist among Irish cancer patients, with women experiencing increased levels of 'extreme' distress compared to men.

These findings have both therapeutic and – possibly – prognostic significance. Some studies have shown that patients with higher levels of distress and psychiatric symptomatology demostrate poorer treatment adherence and lower satisfaction with their oncological care providers (Arrieta et al., 2013, Meggiolaro et al., 2016). This finding may go some way towards explaining the somewhat controversial conclusion that lower levels of psychological distress and fatigue were associated with longer disease-free and overall survival in a study of primary breast cancer patients, after controlling for multiple biological variables, not including treatment adherence (Groenvold et al., 2007). While a recently published systematic review of the link between psychological distress and survival in solid tumour patients suggested that there may indeed be a correlation between psychological distress, survival, and other disease related outcomes, the authors identify that the studies reviewed had a moderate to high level of bias and that more research was needed to confirm if such a relationship exists (Roche et al., 2023). More robust studies clarifying this issue would be welcome.

The increased levels of psychological distress experienced by female cancer patients are likely multifaceted and complex, incorporating biological, emotional, psychological, societal, and economical dimensions. Women appear to express distress differently to men, as reflected by differing rates of mental disorders among men and women: women display increased rates of depression, anxiety, and eating disorders compared to men, while men have increased likelihoods of substance use and conduct disorders (Boyd et al., 2015; European Institute for Gender Equality 2021). Overall, the *Adult Psychiatric Morbidity Survey: Survey of Mental Health and Wellbeing, England, 2023/4* showed that one in five (20.2%) adults in England has a common mental health condition, with the overall prevalence higher in women (24.2%) than men (15.4%) (Liubertiene et al., 2025).

In addition, background risk factors for mental distress differ significantly between women and men. For example, findings from one European survey of violence against women, show that over one-quarter (26%) of women surveyed in Ireland experience physical and/or sexual violence by a partner or non-partner since the age of 15 years (European Union Agency for Fundamental Rights, 2015). This indicates a high level of pre-existing adverse life experiences among women which might predispose them to increased rates of psychological distress following the additional challenge of a cancer diagnosis.

There are also socioeconomic factors which might play a role in the relationship between cancer and psychological distress, especially among women. There are particular norms and gender roles assigned to women in society which might be relevant. For example, as is the case elsewhere, women in Ireland are more likely than men to assume informal care roles, with 61% of informal carers identified as females (Central Statistics Office, 2025). A gender-pay gap also persists in Ireland and is widening, with 2024 figures estimating that men are paid 1.78% more than females for the same role, an increase of 0.2% from 2023 (National Shared Services Office, 2024).

Taken together, the impact of previous adverse life experiences, carer roles, financial inequity, and a range of other factors might increase the likelihood of psychological distress among women who are diagnosed with cancer. More specifically, the increased caring responsibility placed on women and their financial challenges might become more prominent when a woman is diagnosed with cancer and she finds herself unable to fulfil her usual caring roles and other responsibilities. It is also relevant that some of those carer roles can involve caring for, and supporting, other family members with cancer.

Gender based differences exist in terms of preference for therapeutic intervention. There is evidence that accommodating patient treatment preferences is associated with fewer treatment dropouts and improved treatment outcomes, thereby indicating that a gender-specific approach to psychological treatment may result in enhanced patient outcomes (Swift et al., 2018). The literature has shown that women are more likely than men to prefer psychological over pharmacological treatment (McHugh et al., 2013), a female therapist (Liddon et al., 2018), and three times more likely to use an information-based helpline (Manning and Quigley 2002).

Ireland's current provisions for mental health and psycho-oncological care for women with cancer

In *Sharing the Vision: A Mental Health Policy for Everyone*, the Department of Health set clear goals to 'ensure that mental health priorities and services are gender-sensitive and that women's mental health is specifically and sufficiently addressed in the implementation of policy' (Department of Health, 2020). As part of this initiative, a Women's Health Taskforce was established and, as a result of the findings of this taskforce, the *Women's Health Action Plan 2024–2025: Phase 2: An Evolution in Women's Health* was published in 2024 (Department of Health, 2024). Ireland thus became one of the first countries worldwide to develop a specific women's health action plan, which has been informed by women for women. This aims to revolutionise the management of women's health in Ireland, incorporating both mental health and physical health, including cancer care.

In terms of mental health, a 2022 report on *Embedding Women's Mental Health in Sharing the Vision* emphasises the need for gender awareness so 'that women experience an inclusive, supportive and effective mental health service that meets their needs' (Department of

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Health, 2022) This policy commits to providing 'a gender-aware approach to the delivery and accessibility of all care'; 'a trauma-aware approach by all staff who contribute to the service'; and 'the systematic collection and analysis of data on gender, ethnicity, disability and other risk factors for marginalisation of women' (p. 6). The policy makes specific recommendations for 'integrated models of care for women', combining physical and mental health (p. 16). In addition, the recently published *Sharing the Vision: Implementation Plan 2025–2027* sets out specific recommendations for implementation, including development and rollout of 'a toolkit for embedding women's mental health in policy implementation' (Health Service Executive, 2025).

In relation to cancer, the *National Cancer Strategy* aims to develop services nationally for cancer patients and their families. This strategy seeks to develop psycho-oncology services nationally to address 'the psychological responses of patients to cancer at all stages of the disease (and that of their families and carer); and the psychological, behavioural, and social factors that may influence the disease process' (Department of Health, 2017) (p. 93). The National Cancer Control Programme *Model of Care for Psycho-Oncology*, which was launched in 2020, also aims 'to provide a framework to support the way psychosocial care is delivered to patients with cancer and their families [and] promote psychological wellbeing and improve access to psychological services at both acute hospital and community level' (Greally et al., 2020, p. 6).

The current model of care for psycho-oncology in Ireland operates via a hub and spoke model, aiming to provide psychosocial care for cancer patients and their families. This model of care is an example of integration of physical and mental health care for patients. It aims to provide multidisciplinary care to cancer patients on a stepped approach based on the level of clinical distress experienced by each individual.

Other countries have addressed this issue in different ways, but definitive evidence about the benefits of any given approach is not yet available. In Germany, for example, a new form of care called *nFC-isPO* (integrated, cross-sectoral psycho-oncology/integrierte, sektorenübergreifende Psycho-Onkologie) is currently being developed, implemented, and studied (Kusch et al., 2022). This approach seeks to advance the goals of Germany's *National Cancer Plan* by making psycho-oncological care available to all cancer patients according to their individual needs. The German programme involves structured, legally binding cooperation between different professional groupings and/or institutions in both medical and non-medical care. This approach bears certain similarities to Ireland's model of care, but it is too early in Germany's initiative to be certain about medium-term and long-term outcomes.

Conclusions: bridging the gap between need and care provision

The number of women who will be directly or indirectly affected by cancer is increasing, with an estimated 11,282 women diagnosed with invasive cancer each year in Ireland (National Cancer Registry, 2024). There is a large body of international evidence that women affected by cancer experience greater psychological distress than men, and this has been replicated in the Irish context (Carter et al., 2025). It is essential that relevant services are developed in line with patient experience and evidence-based need. In Ireland, the current *Model of Care for Psycho-Oncology* could usefully place greater emphasis on gender-specific care provisions which recognise the increased psychological needs of women with cancer.

In recent decades, Ireland has made significant, albeit limited, progress in recognising the physical and mental healthcare needs of women and developing gender-informed policies in certain areas. In the area of perinatal mental health, there are now integrated mental health teams within physical healthcare settings. While there is further progress to be made in this area, the number of full-time staff working in perinatal mental health increased from five in 2017 to close to 100 in 2023 (Duffy et al., 2023). Positive change is therefore possible, even if it is sometimes challenging to achieve.

To make this happen more broadly, it is essential that relevant policies are implemented fully so as to reduce and eliminate disparities in access to care. As identified in *Embedding Women's Mental Health in Sharing the Vision*, there is a particular need for improved understanding of women's experiences of mental healthcare (Department of Health, 2022). Hopefully, this will be addressed through the policy's aim of collecting and analysing data on gender and other risk factors for marginalisation of women. Improved understanding of gender-based treatment choices within the Irish context is needed in order to shape services in line with patient preference and acceptibility.

Further work is needed to enhance our knowledge of gender-specific cancer experiences in both national and international contexts, especially in relation to psychological distress and mental health. Future research could usefully incorporate evolving understandings of gender, given that most existing literature uses a somewhat limited binary framework for gender.

The next iteration of Ireland's *Model of Care for Psycho-Oncology* could also place greater emphasis on the physical health of people with major mental illness who develop cancer in the context of higher than usual risk factors (e.g., smoking), poor pre-existing physical health, issues with accessing screening, therapeutic complexities (owing to treatment combinations and psychiatry medications), and possible worse prognosis (owing to later diagnosis, among other potential disadvantages). Shared management with primary care would likely optimise screening practices, facilitate earlier intervention, and improve cancer outcomes in this population.

This paper focused on psychological and social factors in psycho-oncology care. Other factors are also relevant and merit further attention, including biological factors that are specific to females such as the impact of cancer treatment on female reproductive hormones (e.g., surgical menopause, complexities with use of hormone replacement therapy) and implications for fertility. Further work could also look in greater depth at the possible impact of cancer treatment on female identity, particularly where mastectomy or hysterectomy/oophorectomy are required.

Given that Ireland's *National Cancer Strategy* will be reviewed and revised as it comes to its end in 2026, there is an opportunity to address the particular challenges faced by women with cancer, including their increased levels of psychological distress. A more tailored, gender-informed approach could be taken when reviewing the strategy to ensure the provision of gender-aware psycho-oncological care for all women and men as they navigate their cancer journeys.

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