





# Development, Implementation and Evaluation of a Multidisciplinary Cancer Rehabilitation Programme

# The CANSURVIVOR Project: meeting post-treatment cancer survivors' needs

Cancer Care Services HSE Dublin Mid-Leinster 2009

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The Cancer Rehabilitation Programme (CanSurvivor) clearly demonstrates that many cancer survivors have a range of needs which require a multidisciplinary approach to improving their quality of life and their ability to cope with life after cancer. We welcome this innovative project, which makes key recommendations for the follow-up care of the many patients who successfully complete their treatment for cancer.

Cancer remains a major cause of morbidity and mortality in Ireland, with nearly every family throughout the country touched at some point by this disease. One of the most important advances that has taken place in the management of cancer patients is the focus on their post-treatment needs. Recognizing the profound effect of a cancer diagnosis on a family, its implications and its appropriate management, has made a major contribution to the quality of life of cancer patients as they go through treatment and indeed as they live long and happy lives following successful treatment of their cancer.

The National Cancer Strategy (2006) recommends access to multidisciplinary psycho-oncology services for cancer patients and their families, providing an integrated service for cancer patients across all stages of the care journey.

Cardiac rehabilitation units with multidisciplinary teams have become established in this country as a routine evidence-based service following acute cardiac events. Significant advances have been made in assisting the cardiac patient's recovery, secondary prevention and return to former roles at home and in the workplace. No such comprehensive rehabilitation programme is routinely available for cancer patients.

The current establishment of centres of excellence for cancer care in Ireland through the implementation of the HSE Cancer Control Programme provides a unique opportunity to provide an integrated service for cancer patients. The establishment of Primary Care Teams will also facilitate primary and secondary prevention of cancer (e.g. smoking cessation support) and follow-up care of cancer patients in the community setting.

This study was completed thanks to the hard work of Dr Mary Ivers (School of Psychology, UCD) and the direction and innovation of the project steering group, in particular Ms Ursula Bates (Psycho-oncology Unit, SVUH), Ms Mary O'Connell (Assistant National Director, HSE), who conceived the programme and Ms Niamh O'Rourke (National Planning Specialist, HSE), whose hard work, skill and dedication brought this project from concept to fruition so successfully.

We have no doubt that this rehabilitation initiative is only the beginning of what will prove to be a fundamental component of integrated multidisciplinary patient care for cancer survivors in the future.

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# **Executive Summary**

# Background

The population of cancer survivors in Ireland is increasing due to earlier detection of the disease and the success of modern cancer treatments. However, while length of life may be extended, the literature clearly shows that many cancer survivors experience late emerging and long-term effects of the disease and its treatment long after medical treatment has ended. These effects impact on quality of life at a physical, psychological, social and vocational level. The new and growing area of cancer 'Survivorship' has highlighted the need for health service providers to focus on the quality of life of cancer survivors and the need for aftercare services.

In Ireland, the increasing numbers of cancer survivors, coupled with an escalating older population, are clear indicators of the need to develop survivorship services to minimise the impact of cancer and its treatment and to reduce the future burden on the survivor and on health services. Specific support for the cancer survivor who has completed their medical treatment is not formalised and service development has been hindered by a lack of information about post-treatment survivors' needs. The current research brief arose from this lack of evidence and is the first step in the development of an appropriate post-treatment rehabilitation service for cancer survivors in Ireland.

#### **Research Aims**

The major aims of this research project were:

- To develop a profile of post-treatment survivors in the former ECAHB<sup>1</sup> area,
- To assess their quality of life and health service needs and
- To develop and evaluate a pilot rehabilitation programme to address those needs.

# Methodology

To develop such a programme it was necessary to conduct three studies. The first two studies were exploratory and conducted to gather information about the experience of post-treatment survivors and the factors impacting on their quality of life. This information provided an evidence base upon which to build the rehabilitation programme, which was the focus of the final study.

Study 1. A preliminary exploration of 'Survivorship' from multiple perspectives.

Study 2. A comprehensive assessment of survivors' quality of life and service needs.

Study 3. A pilot rehabilitation programme aimed at maximising survivors' quality of life.

# Study 1.

Since there was a lack of information in the published literature about the factors impacting on the quality of life of cancer survivors in Ireland, it was considered appropriate to examine the experience of being a cancer survivor from a number of perspectives. A qualitative study was conducted with 56 participants to form a comprehensive picture of survivorship in an

<sup>1</sup>East Coast Area Health Board

Irish context. This study explored the experiences of those who had completed their medical treatment (surgery, chemotherapy, radiotherapy). Survivors, carers and health professionals were all asked to speak about the physical, psychological, social and socio-economic impact of cancer and its treatment on the survivors' quality of life after medical treatment was completed.

Using interviews, focus groups and a workshop setting, this study found that cancer and its treatment impacts on quality of life in many ways. There are long-term physical effects such as fatigue and insomnia, psychological effects such as fears and anxieties about a cancer recurrence and social effects such as changes in family roles and social isolation. This exploration also found that lower socio-economic status places a financial burden on the survivor in terms of their recovery.

The study found a clear need for post-treatment services. Survivors expressed a wish to be advised about what they **can do** to maximize the quality of their lives after cancer, not only what they should avoid doing. The study also found that health professionals need education regarding a range of survivorship issues. Furthermore, a specific need was identified for good quality written information about 'after cancer' to be provided to survivors as they complete medical treatment.

# Study 2.

Study 2 was a large comprehensive survey and needs analysis of 262 post-treatment breast, prostate, colorectal and lung cancer survivors living in the former ECAHB area. These survivors had completed their medical treatment by a minimum of 12 months (surgery, chemotherapy, radiotherapy). Their quality of life, current physical and mental health and current lifestyle practices were assessed. In addition, dispositional characteristics that can affect the way the individual copes with adjustment after cancer, such as hope and optimism, coping strategies and efficacy beliefs were also measured.

The average age of participants was 62 years and the average time since they completed their treatment was just over four years. Although most survivors recovered very well from their cancer and its treatment, over 25% had considerable difficulties with quality of life functioning and symptoms. In particular, there were difficulties with physical, emotional andsocial functioning and with the symptoms of insomnia, constipation and diarrhoea. Furthermore, 33% had anxiety levels above the normal range and indicative of possible clinical disorder. In terms of lifestyle behaviours, over 51% were overweight and a sizeable proportion of these were obese. Over 35% had reduced their physical activity levels when compared to levels before their cancer diagnosis, 13% continued to smoke post-treatment and the majority of survivors had a poor diet. Furthermore, higher levels of anxiety were associated with poorer quality of life while, in contrast, higher hope and optimism were associated with better quality of life. Those who were younger had greater difficulties than older survivors in terms of emotional functioning and also had higher anxiety levels. Moreover, those in the lowest socio-economic group had greater difficulty with physical functioning, more problems with symptoms and lower levels of hope and optimism than those who were financially better off.

While cancer survivors gave high praise to health professionals regarding the quality of their medical treatment, they felt that there was a real need for a specific post-treatment service. A particular deficit in terms of the provision of information about 'after cancer' was highlighted. Survivors pointed to the need for information on post-treatment effects as well as the need for advice and direction with regard to diet and physical activity after cancer. The deficit in the provision of information was viewed as a consequence of the lack of knowledge on the part of health professionals about survivorship.

These findings have implications for the type of services that need to be developed. It is clear that survivors need information but they also need help with anxiety reduction and lifestyle behaviour change, in order to maximise their quality of life and reduce the impact of late and long-term effects. The findings from this study informed the development of a pilot intervention programme and aided the identification of those who were at risk for poor quality of life. These individuals were targeted for inclusion in the pilot programme to follow.

# Study 3.

This study focused on the development and implementation of a comprehensive, multi-disciplinary pilot rehabilitation programme, based on the findings of the earlier studies. The overall aim of this initiative was to improve the quality of life of post-treatment cancer survivors. An eight-week programme was developed and delivered by a team of psychologists, a dietitian and physiotherapists.

The programme incorporated three modules: A Psychosocial Module, a Physical Activity Module and a Nutrition Module. The programme took a positive approach using hope therapy as a scaffold to facilitate anxiety reduction and lifestyle behaviour changes. It concentrated on providing the survivor with skills to achieve physical and mental health-related goals such as improving activity levels, fitness, strength and diet. Twentytwo survivors took part in the programme and sixteen others formed a comparison group. All but one of the participants completed the programme and the attendance rate was high.

An analysis of the main outcome measures before and after the pilot programme found that the intervention resulted in significant increases in the quality of life of programme participants in terms of physical and emotional functioning and in terms of a reduction in symptom difficulties. Furthermore, there was a significant increase in hopeful thinking and a significant reduction in anxiety levels. There were also significant increases in physical activity levels, fitness and strength as well as in fruit & vegetable and fibre intake. In addition, there were significant reductions in weight, saturated fat consumption and the number of overall calories consumed at programme end. Unfortunately, a limited similarity between the intervention group and the comparison group undermined the study's ability to draw firm conclusions.

# **Evaluation**

The programme was evaluated by the programme participants and by the programme delivery team. Feedback was very positive both in terms of the content of the programme and its delivery. The participants and the delivery team endorsed the efficacy of the programme to enhance the survivor's quality of life and they recommended that a programme such as this should be mainstreamed as part of an ongoing cancer care plan for survivors.

# **Conclusion and Recommendations**

This project represents the first step in the development of a post-treatment service for cancer survivors in Ireland. The data will provide an evidence base for future research and for further service development. In addition, the development of an evidence-based pilot multi-disciplinary rehabilitation programme that took a positive and comprehensive approach to enhancing quality of life after cancer was successful in meeting its aims. Based on this research, several recommendations for the future development of rehabilitation services and future research in Ireland are made. These include the development of good quality written information about post-treatment survivorship, the development of a formal post-treatment information and support service and further refinement of the rehabilitation programme.



# Acknowledgements

The researchers would like to acknowledge the contribution of numerous individuals to this project. The research would not have been possible without the commitment of the many cancer survivors who took part in the three studies. In particular, we would like to extend a very big thank you to the pilot programme participants and their families, who committed wholeheartedly to the 8-week programme.

This project was conceived by Ms Mary O'Connell (Assistant National Director, HSE), and was ably supported by HSE personnel: Ms Niamh O' Rourke (National Planning Specialist), Ms Yvonne Durac and Ms Patricia O'Callaghan (Senior Project Officers - Cancer & Palliative Care Services).

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The pilot programme was developed and delivered with the co-operation of Ms Elizabeth Barnes of the Department of Dietetics and Ms Pauline Leahy, Ms Catherine Toole, and Ms Karen Craddock at the Department of Physiotherapy in SVUH. They made a major contribution to the design and the logistical arrangements for delivering the programme. Special thanks go to Ms Ursula Bates, Ms Elizabeth Barnes, Ms Claire O'Reilly and Ms Michelle Slevin who delivered the psychology, nutrition and physical activity modules with much enthusiasm and dedication.

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# Chapter 1. Cancer Survivorship: An Overview

#### **1.1 Introduction**

This research was commissioned by the Health Service Executive - Dublin Mid-Leinster and funded by their Department of Cancer and Palliative Care. The research project was carried out by the UCD School of Psychology with the collaboration of the Psycho-Oncology service, the Department of Physiotherapy, and the Department of Dietetics at St. Vincent's University Hospital, Dublin. The geographical catchment area for the project was the former East Coast Area Health Board (ECAHB), which mainly encompasses South Dublin and Wicklow.

#### The Research Commission

The main research commission was:

- To investigate the bio-psycho-social factors impacting on the quality of life of post-treatment cancer survivors in the catchment area and to identify their service needs.
- To develop, implement and evaluate an appropriate evidence-based, multidisciplinary, pilot rehabilitation programme for post-treatment cancer survivors.

#### **1.2 Cancer Survivorship**

Cancer survivorship is a new and growing area and survivorship research is expected to explode in the next ten years (Holland, 2007). The recent Institute of Medicine (IOM) report *From cancer patient to cancer survivor: Lost in transition* (2005) has recommended that cancer survivorship be established as *a distinct phase of cancer care* (p.3) and that health providers work to deliver appropriate care to survivors.

Such an approach involves identifying and examining disease and treatment related outcomes and developing a knowledge base for optimising follow-up care and health after cancer treatment (Aziz, 2002). While post-treatment survivors may be disease free, there is evidence that up to 20% experience negative late or long-term disease or treatment-related physical and psychological side effects (Ganz, 2003; Wenzel et al., 2002). As a result, the survivor's quality of life may be compromised (IOM, 2005).

#### **1.3 Cancer Incidence**

According to the National Cancer Registry of Ireland (NCRI) there were 26,776 cases of cancer diagnosed in Ireland in 2005 (NCRI, 2007) and in the Dublin Mid-Leinster region, there were 60,348 cases in the period from 1994 to 2003 (NCRI, 2006). Of more relevance to the current project, the estimate is that within the specific geographic catchment area that this research is concerned with, there were 18,809 cancer cases registered between 1996 and 2003.<sup>2</sup>

<sup>2</sup> Data supplied by Regional Database Manager, St. Vincent's University Hospital in 2006.

In addition to the above figures, NCRI have predicted a 90% increase in cancer incidence rates between 1998 and 2020 due largely to an increasing elderly population (NCRI, 2006). This growth will impact significantly on the former ECAHB area, as population growth in the over 65s was projected to increase by 40% and in the over 80 year olds by 60% up to 2011 (Hayes, 2002). This information has major implications for cancer services.

## 1.4 Cancer Survival in Ireland

Advances in the diagnosis and treatment of cancer over the last two decades have led to greater expectations regarding survivability, with cancer being increasingly regarded as a chronic illness rather than a fatal one (Gerber, 2001; Ganz, 2003; Brennan, 2004). It is difficult to compare cancer survival rates between countries, but across Europe, cancer survival rates are increasing and range from less than 20% to over 80%, depending on the type of cancer (Berrino et al., EUROCARE-4, 2007). For cancer patients diagnosed between 1995 and 1999, the overall relative five-year survival rate was 52% (Coleman et al., 2008). In Ireland, the five-year relative survival rates for those diagnosed between 1994 and 2001 were 75.4% for breast cancer, 69.5% for prostate cancer, 49.2% for colorectal cancer and 8.6% for lung cancer.

The National Cancer Forum report *A Strategy for Cancer Control in Ireland* (DoHC, 2006) reports that, in 2002, there were approximately 120,000 cancer survivors in Ireland due to better treatments and earlier detection. Increasing survival rates and an escalating older population are clear indicators of a rising need for health service providers to focus on understanding the impact of cancer on the quality of life of cancer survivors and the ever-increasing need for cancer aftercare services.

# **1.5 Cancer Rehabilitation and Survivorship Programmes**

Cancer rehabilitation is recognised as an important means of assisting survivors to improve physical and psychological functioning and improve their quality of life (Ganz, 1990; Brennan, 2004). There are several types of rehabilitation but most focus on physical rehabilitation (Brennan, 2004). The development of rehabilitation programmes for cancer survivors has lagged behind similar developments for other chronic diseases (Brennan, 2004; IOM, 2006). Despite early efforts to establish such programmes, there are relatively few organised health service led programmes worldwide. Most survivorship efforts are led by voluntary or charitable organizations providing information services and peer support (DeLisa, 2001; Brennan, 2004; IOM, 2006).

A number of survivorship programmes have emerged in the US and Canada in recent years, with the Memorial Sloan Kettering Cancer Centre, the Dana Farber Cancer Institute, the Lance Armstrong Foundation and The Wellness Community leading the way in developing their services. In the UK, Europe and Australia, the Expert Patient Programme is a programme that trains survivors to self-advocate and self-manage their care and in the UK there is a move to improve the limited provision of exercise rehabilitation to those just out of treatment (Stevinson & Fox, 2006). However, there are few health service led programmes that take a bio-psychosocial approach incorporating psychological support with efforts to improve physical functioning, symptom reduction and lifestyle change to improve overall quality of life for post-treatment cancer survivors.

In Ireland, the treatment, recovery and rehabilitation of the cancer patient has focused, almost exclusively, on medical treatment (surgery, chemotherapy, radiotherapy) followed by regular post-treatment check-ups. In 2000, Laffoy and Scallan expressed concerns about the distress evident in many cancer patients, commenting that anxiety and depression and a decline in quality of life are common. They called for the development of a multidisciplinary service with a particular need for the provision of psychosocial cancer support services. This, along with the recommendations of the *National Review of Support Services for Patients with Cancer* (Laffoy, 1999) provided the context in which psycho-oncology services in Ireland began in earnest. However, a 2004 survey of part of cancer care services (Steggles, Gauthier-Frohlick & Carr, 2004).

In addition to the psychological impact of cancer and its treatment, cancer survivors may experience a range of long-term or late emerging physical symptoms that impinge on their daily functioning. Furthermore, their lifestyle behaviours may exacerbate the overall impact of cancer and its treatment on their quality of life and future health (IOM, 2006). A variety of behavioural interventions to assist with lifestyle change such as increasing physical activity levels and improving nutritional intake are the subject of a number of current research studies in the US, Canada and Europe but such interventions are few (Bloom, Peterson, et al., 2007).

In Ireland, specific support for the cancer survivor who is post medical-treatment is not formalised but left for the most part to the individual, their family and volunteer organisations, some of which receive a little formal funding. There are no standardised national services with the specific remit of helping survivors adjust and cope with any long-term physical or mental sequelae of the disease or its treatment. Neither is there support to help maximise their quality of life and reduce their future health risks and potential burden on acute health services.

In 2003, the Department of Health and Children commissioned an *Evaluation of Cancer Services in Ireland: A National Strategy* (1996). This report identified a number of cancer service gaps and made some key recommendations, three of which have provided the impetus for the current research.

These include:

- The great need for patient support following discharge from the acute service.
- The need to increase emotional and psychosocial support services to cancer patients.
- The need for patients to be managed via an integrated multidisciplinary approach.

#### 1.6 The Research Rationale

Service development for post-treatment cancer survivors in Ireland has been hindered by the dearth of information regarding their needs. To be effective long-term, any service development must be evidence-based. The current research brief, to carry out the first comprehensive study of cancer survivors service needs and to develop and pilot a bio-psychosocial programme, arose from a lack of such evidence. The research aims to provide a base from which to build a quality post-treatment service for cancer survivors. The following chapters present a concise summary of the research literature on the issues impacting on the quality of life of post-treatment survivors along with a brief review of interventions aimed at enhancing their physical and mental health. Subsequent chapters present the research design of the project followed by details of each study in turn. Finally, the report draws together conclusions based on the findings of these studies and presents recommendations for the future development of services for post-treatment survivors.



# Chapter 2. The Survivorship Literature

## 2.1 Defining 'Survivors'

It is important to point out at the outset that definitions of the term "cancer survivor" vary in the literature. The US National Coalition for Cancer Survivorship uses the following definition "from the time of its discovery and for the balance of life, an individual diagnosed with cancer is a survivor" (NCCS Charter, 1986, p.2). The US National Action Plan for Cancer Survivorship (CDC & LAF, 2004) extended the definition to include "...people who have been diagnosed with cancer and the people in their lives who are affected by their diagnosis, including family members, friends and caregivers". In contrast, the American Cancer Society uses a narrower definition referring to those who are disease free for five years (ACS, 2002).

Such variation is a stumbling block when examining the literature, as authors often do not clarify their use of the term, nor do they specify the status of their study population. This is especially relevant to the current project as the current research remit was to investigate post-treatment survivors only but not necessarily long-term survivors exclusively. A more appropriate definition for the current research comes from The Centre for Values, Ethics, and the Law in Medicine in Australia who define survivors as those who are "*living apparently free of cancer at any time after treatment*" (Centre for Values, Ethics, & the Law in Medicine, 2001).

In examining the literature below, the reader is asked to keep in mind the variety of definitions used and the lack of clarification provided by authors in their use of the term. For clarity in the reading of the later study chapters of this report, the term "cancer survivor" is used to refer to the individual cancer patient who is at least six months post-medical treatment<sup>3</sup> (surgery, chemotherapy, radiotherapy).

#### 2.2 The Importance of Survivorship Research

Most non-medical cancer research effort has concentrated on the initial phases of the disease, with a considerable spotlight on the impact of a cancer diagnosis on the individual and their family and on the management of symptoms, coping with treatment and coping with a terminal prognosis (Tomich & Helgeson, 2002; Helgeson, Snyder & Seltman, 2004). There is a scarcity of research on post-treatment survival issues, although *survivorship* is a growing area of interest (Holland, 2007). Ganz (2003) sets out a number of reasons why the study of survivorship is important:

The information gained from such research helps to refine treatments to minimize late effects, as there is little information of the late effects of cancer treatment in adults. Much of the existing survivorship literature focuses on long-term survivors of childhood cancers. Findings from that research have informed refinements in treatments for children suffering from cancer today, thus reducing for them some of the long-term effects of treatments offered in the past.

<sup>3</sup> In practice, the survivors in this research were at least twelve months post-treatment due to the time lag between identifying individuals on the hospital databases and bringing them to the data collection stage.

- The number of cancer survivors is growing and attention needs to turn to their future needs; preventive interventions for late effects; surveillance for second malignancies; and high-risk survivor groups. This information is needed so that survivors and those who will be looking after their health needs can be prepared.
- It is necessary to be knowledgeable about the long-term impact of cancer at a physical and psychosocial level so that health services can help survivors maximise quality of life and health services are utilised most effectively and efficiently.
- An ageing population means an increase in the numbers of cancer cases in the future, with a resulting increase in the numbers of cancer survivors.

#### 2.3 Quality of Life

The concept of quality of life has become a core concern for many healthcare professionals (Brennan, 2004). Surviving cancer does not necessarily mean a return to 'normal' life, as cancer and its treatment impact on the overall quality of life of the survivor with physical, psychological and social effects taking their toll. The majority of cancer survivors fare well after treatment. However, as mentioned in the previous chapter, although survivors may be disease free, up to 20% of them may experience negative long-term or late-emerging effects, either from the cancer itself or as a result of the type of treatment received (Ganz & Coscarelli, 2000; Aziz, 2002). Van Harten et al (1998) reported that 26% of cancer patients articulated a need for rehabilitation services up to four years after treatment. More recently, Aziz and Rowland (2003) suggest that up to 75% of survivors will experience some health-related consequence of their treatment. Such effects may impact on the survivor's functioning in many domains of life including physical, psychological, social and vocational areas.

#### 2.4 The impact of Cancer and its Treatment

Most survivorship research in the past has tended to focus on breast cancer survivors, who are the single largest grouping of long-term survivors (Cimprich, Ronis & Martinez-Ramos, 2002; Stanton et al., 2002). That research includes a number of studies on quality of life, social networks, fatigue, anxiety and depression (Ganz et al., 1996; Meyerowitz, Desmond et al., 1999; Cimprich, Ronis & Martinez-Ramos, 2002; Montazeri, Jarvandi et al., 2001; Servaes, Prins, Verhagen & Bleijenberg, 2002). There is a growing body of survivorship literature now focusing on other cancer types. Below is a brief summary of the findings from research examining the physical, psychological and social impact of cancer and its treatment on quality of life.

#### 2.4.1 The Physical Impact

At a purely physical level, recovery from cancer and its treatment may take some time once treatment is over. Physical sequelae directly impact on the patient level of function and interfere with activities of daily living (ADLs) (Ganz, 2001; Aziz, 2007). These sequelae may include fatigue and pain, scars and disfigurement, weight gain or loss, lymphoedema and nausea (Loescher, Welch-McCaffrey & Leigh, 1989; Sklar, 1999; Andrykowski, Curran and Lightner, 1998). Dimeo (1998) reports that up to 30% of survivors are not able to carry out their usual ADLs due to post-treatment fatigue, resulting in reduced activity to conserve energy and leading to loss of muscle mass and a reduction in cardio-respiratory fitness.

Fatigue also prevents survivors from returning to work and results in reduced levels of activity, loss of a sense of control, loneliness and isolation (Servaes, Van der Werf et al., 2001). Furthermore, pain is a significant predictor of difficulty with physical, sexual and psychological functioning (Tunkel & Passik, 1989). Physical symptoms may also have a very powerful impact on psychological, social and emotional adjustment, affecting body image, role functions and a return to 'normality' (Brennan, 2004).

#### 2.4.2 The Psychological Impact

There are a number of negative psychological and emotional consequences of cancer and its treatment including psychological distress, anxiety and depression, alterations in body image, fears about recurrence, stress, grief, lack of control and anger (Ferrell, Grant, Funk et al., 1998; Gotay & Muraoka, 1998; Kornblith, 1998; Ogden, 2004; Molassiotis, Chan, Yam, Chan & Lam, 2002; Ganz, 2003; Grassi & Travado, 2008). Insomnia. poor concentration and altered cognitive function are also outcomes for some survivors (Manne, 2002). Grassi and Travado (2008) cite reduced self-esteem, a dependency on others, changes in future perspective, marginalisation and stigmatisation as other possible impacts of cancer and its treatment. Furthermore, the use of avoidant coping strategies and low levels of social support are significant predictors of difficulty with physical, sexual and psychological functioning, all of which are detrimental to guality of life (Tunkel & Passik, 1989).

#### 2.4.3 The Social Impact

The social impact of cancer and its treatment may include social isolation, disruption to work and family life, changes to social and personal relationships and financial difficulties (Manne, 1999). Physical and psychological effects may be at the root of such changes. In breast cancer survivors, sexual difficulties may result from the early onset of menopausal symptoms or changes in body image. Sexual relationships and quality of life are also affected in those with prostate and colorectal cancers, with sexual dysfunction becoming a major stressor (Molassiotis et al., 2002). In addition, survivors often experience unsupportive behaviours towards them that are risk factors for distress (Thornton & Perez, 2006). Furthermore, many cancer survivors experience employment problems due to their cancer and the resultant strain and additional financial burden increases their psychological burden (Spelton, Sprangers & Verbeek, 2002). As can be seen from the above, physical, psychological and social effects interact with each other.

#### 2.5 Socio-economic Disadvantage and Quality of Life

Socioeconomic factors are key determinants of general health status, with evidence that poor people get sick more often and have shorter life expectancy than the better off (Fahy, 1997; DoHC, National Health Promotion Strategy, 2000). Furthermore, poverty can lead to difficulties in accessing health care and a reduction in the opportunity to adopt healthy lifestyles (Combat Poverty Agency, 2004).

Few studies have focused on cancer survivors in the lower socio-economic groupings but there is some evidence that they have worse outcomes for pain, ambulation and social and emotional well-being (Ramsey, Anderson, Etzioni, et al., 2000). The pursuit of good health for the post-treatment cancer survivor in the lower socio-economic grouping may be limited in such circumstances.

The reasons for this are many and varied and include access to and availability of health services, lifestyle behaviours, health beliefs, language barriers, ethnicity and of course, financial constraints (Brennan, 2004).

#### 2.6 Cancer Rehabilitation

The US National Action Plan for Cancer Survivorship: Advancing Public Health Strategies (CDC & LAF, 2004) highlights some myths about cancer survivorship. One of these is that "the need for care of survivors ends once treatment is complete "(p. 7). The quality of follow-up care for cancer survivors can have implications for future physical and mental health and for the overall quality of life of the cancer survivor. Not only are there long-term and late-emerging effects of cancer and its treatment but cancer survivors are at increased risk of developing a range of health difficulties including second cancers, cardiovascular disease, osteoporosis and other chronic illnesses (IOM Report, 2006). Tesauro, Rowland and Lustig (2002) point to the limited services for cancer survivors even though health services are beginning to recognise the distinct service needs of survivors.

As a concept, cancer rehabilitation developed in the US and Canada and stemmed from early concerns about the traumatic impact of cancer on the patient and about the physical impact on activities of daily living (Mullan, 1985). According to Kaplan (2004) cancer rehabilitation is

"a process that assists the cancer patient to obtain maximum physical, social, psychological, and vocational functioning within the limits created by the disease and resulting treatment" (p.1).

However, in practice, the main focus of rehabilitation of cancer patients has tended to be on maximising neuro-musculoskeletal function (Tunkel & Passik, 1989; Kuhn et al., 2005) and cancer rehabilitation specialists tend to be physiatrists, who specialise in physical medicine and rehabilitation. The psychosocial care of cancer patients via support groups, symptom control and palliative care has developed separately. There are very few post-treatment programmes worldwide.

There are some comprehensive integrated services for survivors who are either in treatment or very early post-treatment in the US, for example, Memorial Sloan-Kettering Comprehensive Cancer Centre offers survivorship information and support services to those who have just completed treatment. These services include counselling, smoking cessation and physical rehabilitation, and they also provide an informational website for Living Beyond Cancer<sup>4</sup>. However, integrated bio-psychosocial programmes are not the norm.

Although research on survivorship and rehabilitation in the UK is being conducted (Stevinson et al., 2006; Daley et al., 2007), Doyle and Kelly (2005) have pointed out that cancer rehabilitation is relatively unknown with the exception of a service developed at the Royal Marsden Hospital in London, which is primarily an in-patient service. Stevinson et al. (2007) point out that less than 9% of NHS hospitals in the UK include exercise as part of their rehabilitation services for cancer patients and these are primarily for those in treatment or very early post-treatment.

<sup>4</sup> www.mskcc.org/livingbeyondcancer

Cancer rehabilitation is more widely known in Europe, particularly in Germany, Denmark and Sweden. However, the main focus there is on physical rehabilitation, usually in an in-patient context (Spruit et al., 2006). An example is the 12-week fitness programme offered by the Swedish Cancer Institute to those living with cancer.

In Ireland, cancer rehabilitation is almost unknown but there are some research efforts to understand post-treatment issues such as fatigue (Dillon & Kelly, 2003). As yet there are no formalised programmes specifically for post-treatment survivors.

## 2.7 A Bio-psychosocial Approach

According to McQuellon and Danhauer (2007), the bio-psychosocial model is the most useful approach to rehabilitating the cancer patient as it views health outcomes as a consequence of the relationship between biological, psychological and social factors. A number of successful psychosocial interventions have been developed and implemented with cancer patients to reduce depression and anxiety but Ronson and Body (2002) point out that such efforts cannot be completely effective without "simultaneous efforts to promote improvement of the physical condition" (p. 282). According to Ogden (2004) up to eighty-five percent of cancers are potentially avoidable, and individual beliefs, attitudes and health behaviours are implicated in its initiation. Given the previously mentioned risks to future health, the post-treatment cancer survivor may need to make lifestyle changes (exercise, diet, smoking) in order to maximize survival and quality of life. However, little is known about the health-related behaviours of long-term survivors and their association with quality of life outcomes.

There is a growing body of literature examining the importance of exercise and dietary interventions. The American Cancer Society convened an expert group to develop guidelines for nutrition and physical activity after cancer treatment. They stressed the importance of "setting and achieving life-long goals" (Brown et al., 2003, p. 271) such as appropriate weight, a healthful diet, and a physically active lifestyle to promote quality of life and longevity (Brown, Byers, Doyle, Courneya, Demark-Wahnefried et al., 2003). The next section summarises the literature on psychosocial, exercise and dietary interventions for cancer survivors and where available, expert recommendations are presented to aid the development of a comprehensive bio-psychosocial rehabilitation programme.

#### 2.7.1 Psychosocial Interventions

The goal of psycho-oncology is to provide optimal psychosocial care to all cancer patients and their families at all stages of the cancer journey including survivorship (Holland, 2003). In general, psychosocial interventions in cancer care are aimed at influencing adaptation and adjustment to the diagnosis and treatment of cancer. They focus on quality of life and aim to reduce anxiety, depression, distress and some physical symptoms. They further help the patient to engage in behaviours more conducive to better health (Spiegal & Bloom, 1983; Fawzy & Fawzy, 1998; IOM, 2006; Nezu & Nezu, 2007). However, psychosocial problems that might affect the cancer patient at diagnosis or during treatment do not vanish when treatment is over and for some may not emerge until treatment is complete (Brennan, 2004).

This transition may be a time when the survivor is particularly vulnerable to depression and anxiety and support may be needed to adjust to physical changes, changes in relationships, return to work and anxieties about the future (IOM, 2006).

McQuellon and Danhauer (2007) point out that between 30% and 50% of cancer patients may need professional intervention during survivorship. However, routine referral to psychosocial care is not widely available in Europe (Rueben, 2004).

Most of the literature on psychosocial interventions in cancer refers to breast cancer patients either in active treatment or in palliative care (Helgeson et al., 1999; Ronson & Body, 2002; McQuellon & Danhauer, 2007). A series of reviews have produced mixed findings as to the efficacy of these interventions. This is partly due to the very large range of intervention types and also the wide variety of outcome measures. However, cognitive behaviour therapy (CBT) interventions were considered to be effective in reducing distress and reducing symptoms (Meyer & Mark, 1995; Newell, Sanson-Fisher & Savolainen, 2002; Rehse & Pukrop, 2003). The recent IOM report (2004) concluded that psychosocial intervention should be included in routine clinical care and noted that psychosocial factors not only impact on emotional wellbeing but also impact on physical side effects of cancer and its treatment.

Stanton, Danoff-Burg & Huggins (2002), referring to specific factors relating to adaptive survivorship, found that avoidance coping was associated with greater fear of recurrence and suggested that dispositional characteristics such as hope, optimism and situation-specific coping strategies are protective factors for adaptation to cancer. Cancer and its treatment can severely disrupt normal motivations, leading to a failure in formulating goals for the future but a positive approach facilitates engagement in healthy behaviours and with planning for the future (Frijda, 1986; Brennan, 2004). Tomich & Helgeson (2002) found a strong relationship between beliefs about personal control and quality of life in cancer survivors. In addition, efficacy enhancement is an important component of behaviour change strategies and measurable improvements in self-efficacy during a treatment programme are associated with long-term behaviour change (Walker, 2001). Rehse and Pukrop (2003) and Grassi and Travado (2008) conclude that psychosocial interventions have a positive effect on quality of life in cancer survivors.

#### 2.7.1.1 The structure of Psychosocial Interventions

There are different types of psychosocial interventions including supportive, educational, cognitive and behavioural therapies (Ronson & Body, 2002; Nezu & Nezu, 2007). Structured group programmes have been shown to be effective in the management of post-treatment effects such as depression and anxiety and in the provision of peer support and social contact (Brennan, 2004). Basic interventions involve information giving and the provision of a safe environment for asking questions to those with low levels of anxiety and distress but such interventions have little effect on symptoms or quality of life (IOM, 2006; Lent, 2007). Cognitive behaviour techniques (CBT) have been shown to have positive effects on levels of depression, anxiety and quality of life (Osborn, Demoncada & Feuerstein, 2006). In addition, a problem solving and emotion focused approach to strengthen coping efficacy and goal pursuit ultimately results in empowering people to exert more control over their wellbeing (Lent, 2007).

There is huge variation in the duration of psychosocial interventions ranging from the one-off 20-minute encounter to years of psychotherapy for those with severe depression or adjustment difficulties. Heinrich and Schag (1985) conducted a successful six-week programme involving information about cancer and coping with it, relaxation and exercise, and group sessions to problem-solve any cancer related concerns, while Rehse and

Pukrop (2003) suggest that interventions should be at least 12 weeks in duration. More recently, McQuellon and Danhauer (2007) conducted a review of randomized controlled psychosocial interventions and concluded that the growing body of literature supports the effectiveness of psychosocial interventions to rehabilitate cancer patients. They found that most interventions were conducted within the first year post-treatment, there was wide variation in the duration of these interventions and the majority included the use of relaxation training and cognitive behavioural techniques.

#### 2.7.1.2 Expert Recommendations

Effective interventions include cognitive behaviour therapies, progressive muscular psycho-educational programmes relaxation. and structured that include problem-solving and/or supportive expressive therapy (McQuellon & Danhauer, 2007). The majority of interventions have been run with breast cancer patients and as yet, there is no consensus on the optimum duration or therapeutic approach for successful intervention.However, Sheard and Maguire (1999) conducted two meta-analyses of psychosocial interventions to examine their impact on anxiety and depression and concluded that targeted interventions are the most effective (ie. targeted at a specific outcome measure, such as anxiety or depression), group based interventions are equally effective as individual interventions and relatively short interventions delivered by experienced professionals are most effective.

#### **2.7.2 Exercise Interventions**

Cancer survivors are at an increased risk of becoming too sedentary due to reduced levels of fitness, stamina and strength and they seldom return to pre-diagnosis activity levels (Brown et al, 2003). Watson and Mock (2003) comment that exercise, as an intervention, is *"remarkably underutilized"* and should be the treatment of choice for cancer related fatigue. It is most commonly used to help strengthen weakened muscles and aerobic exercises are necessary to increase endurance (Tunkel & Passik, 1989). The American Cancer Society (ACS) recommend regular physical activity with the goal of maintaining a healthy body weight, reducing the risk of recurrence and reducing the risk of other chronic diseases (Brown et al., 2003).

A series of recent reviews has concluded that exercise has consistent positive effects on physical, psychological and emotional wellbeing, positively influencing fatigue, nausea, cardio-respiratory fitness, body composition and functional capacity. It improves quality of life, vigour and vitality, increases immune function and reduces depression and anxiety (Courneya & Friedenreich, 1999; Pinto & Maruyama 1999; Courneya et al., 2000; Thune & Smeland, 2000; Courneya et al., 2003; Holtzman, Schmitz, Babes, Kane, Duval, Wilt, MacDonald and Rutks, 2004). In the short term, exercise helps to preserve physical function, manage treatment-related symptoms and enhance psychological wellbeing. In the long term, adopting a physically active lifestyle helps to maximise health related quality of life and prevent chronic diseases like obesity and osteoporosis (Stevinson & Fox, 2005).

Unfortunately, physical activity is not normally part of the cancer rehabilitation programme, although exercise-based cancer rehabilitation programmes are growing in the US & Canada (Thune & Smeland, 2000). In the UK, while there are reports of the benefits of exercise on physical and psychological recovery, the use of exercise in cancer care is rare (Stevinson, Lawler & Fox, 2004; Stevinson & Fox, 2005).

Holtzman, Schmitz, Babes, Kane, Duval, Wilt, MacDonald and Rutks (2004) prepared an evidence-based report on the effectiveness of interventions to modify physical activity in both the general population and in cancer survivors. They concluded that the evidence is mounting that exercise is an effective therapy in these populations and that it reduces fatigue, depression and anxiety, improves cardio-respiratory fitness, vigour and vitality, functional capacity, immune function and quality of life.

#### 2.7.2.1 The Structure of Exercise Programmes

Courneya, Karvinen and Vallance (2007) highlight the fact that, as yet, there are few studies examining the effects of exercise interventions. The literature on exercise programmes for cancer survivors coming from the US and Canada reveals that the typical programme is a planned, supervised group programme in an exercise facility at no cost to participants (Pinto et al., 1999; Holtzman, et al., 2004). There is huge variation in the duration of programmes ranging from 6 – 12 weeks (Mock et al., 1997; Dimeo et al., 1997, 1998; Schwartz et al. 2001; Courneya et al. 2001; Peterson, 2003). Most programmes focus on aerobic activity at moderate intensity for 20-30 minutes, two or more times a week with a short follow-up (Courneya & Friedenreich, 1999; Holtzman, et al., 2004). However, low to moderate intensity exercise for a healthy person may be high intensity for some survivors (Brown et al., 2003) so programmes need to be individualised.

#### 2.7.2.2 Expert Recommendations

Individualised prescriptions are the ideal, with programmes to suit age, fitness, cancer type, treatment type, stage of treatment, and co-morbid conditions (Brown et al., 2003). The recommendation from the ACS is that those who were active pre-diagnosis should aim to maintain activity; those who were sedentary should adopt low-intensity activities and be slowly advanced, while older people and those with significant impairments like arthritis need to be monitored to assess balance and avoid falls and other injuries (Brown et al., 2003). Courneya et al. (2000) recommend that exercise programmes should be "*enjoyable, build confidence, develop new skills, incorporate social interaction and take place in an environment that engages the mind and spirit*" (p. 56).

The conclusion is that it is safe for most cancer survivors to engage in predominantly aerobic physical activity, to recommend low to moderate intensity as the most appropriate level, 3 to 5 days per week and to suggest caution for those with certain types of health problems (Pinto & Maruyama, 1999; Watson & Mock, 2003; Holtzman et al., 2004, IOM, 2006). As yet, there are no recommendations to help distinguish between those that could safely exercise on their own and those who need supervision.

#### **2.7.3 Nutrition Interventions**

Small, Carrara, Danford, Logemann & Sella (2002) highlight the critical role of nutritional status in maintaining a positive quality of life during and after treatment. Physically, poor nutrition affects immune system functioning, wound healing, response to chemotherapy, morbidity and mortality. Emotionally, nutrient intake is affected by fear, anxiety, grief and depression and socially, low levels of enjoyment of food can affect social interactions with family and friends. Increased body mass index or body weight has been found to be a significant risk factor for breast cancer and colorectal cancer recurrence (Tartter et al., 1984; Rock et al., 2002). Furthermore, results from the Nurses Health Study (2005) showed that

large weight gains after breast cancer diagnosis are associated with a 64% higher risk of recurrence, compared with those women who maintained their weight.

Demark-Wahnefried, Peterson et al. (2000) also found a distinct need for interventions that target increased fruit and vegetable consumption. They found a strong relationship between diet and exercise behaviours and noted the possible benefits of multiple risk factor interventions. However, such interventions for post-treatment survivors are still rare.

#### 2.7.3.1 The Structure of Nutritional interventions

for Services that address dietary concerns those in include treatment weight-reduction, low-fat diets, healthy cooking and dietary restrictions related to treatment. Nutritional information is usually communicated by face-to-face counselling (Tesauro et al., 2002). Rock and Demark-Wahnefried (2002) reviewed a number of studies including the Women's Intervention Study (WINS) which aimed to reduce dietary fat intake to less than or equal to 15% of energy. They found that increased BMI was a significant risk factor for cancer recurrence in 17 out of 26 studies. They point to the two main issues of concern in nutrition intervention for breast cancer survivors. The first is the prevention of weight gain after diagnosis in those at risk of weight gain and the second is the achievement of weight loss in those who are overweight or obese at diagnosis and after. They also point to the strong evidence for the link between increasing physical activity (including strength training) and weight loss for obese women.

A CBT approach may be one solution in terms of bringing eating patterns to a healthy level, particularly if combined with an exercise programme and can result in significant weight loss (Pendleton et al., 2001). The Healthy Weight Management for Breast Cancer Survivors Study (Rock & Demark-Wahnefried, 2002) used a group based programme to promote physical activity and healthy eating attitudes and behaviours over a 16-week intensive treatment period. They set their intervention in a structured CBT curriculum. Dietary guidance was individualised, with a focus on choosing low-energy density foods and excessive dieting was not encouraged. The intervention was successful in reducing weight and cholesterol levels in the intervention group.

There is a growing body of evidence that dietary interventions may reduce cancer recurrence (Chlebowski & Anderson, 2005) and the evidence is accumulating that intervention can help maintain body weight, reduce fatigue, minimise complications and enhance well-being (Pakiz et al., 2005). Nutritional plans as well as other lifestyle changes are now being considered part of preventative care strategies for recovered patients. However, an important point to take cognisance of is that dietary intervention programmes can place a burden on the individual in that a lot of time needs to go into food selection and preparation in addition to possible increases in the cost of healthier foods and the need to develop a taste for new foods and flavours (Pakiz et al., 2005).

#### 2.7.3.2 Expert Recommendations

The American Cancer Society expert group (Brown et al., 2003) evaluated the scientific evidence and clinical practice for nutrition after the diagnosis of cancer. This is viewed as the best information for making informed choices, even where no nutrition problems are obvious. The ACS guidelines should be regarded as "*the basis for a healthful diet*". As yet, there is no clear link between appropriate weight, healthful diet, physically active lifestyles and cancer recurrence or survival rates, with the exception of obesity and breast cancer recurrence.

Brown et al. (2003) point out that those who have been diagnosed with cancer may be at increased risk of a second cancer or cancer recurrence, heart disease, diabetes and/or osteoporosis. Therefore, guidelines for preventing these diseases are very important for cancer survivors. Giving information about the type of fat, protein or carbohydrate, as well as information on the food source is essential, as all fats, proteins and carbohydrates are not similar in their health effects.

The American Cancer Society (2001) make a number of suggestions for cancer survivors (including those in treatment). These, along with further suggestions from the Healthy Eating After Cancer document are included in Table 1 (ACS, 2005).

 TABLE 1. ACS (2005) Recommendations for Healthy Eating After Cancer

- 1. Check with your doctor for any food or diet restrictions and before starting any exercise programme.
- 2. Ask your dietitian to help you create a nutritious, balanced eating plan.
- 3. Choose a variety of foods from all the food groups.
- 4. Try to eat at least 5-7 servings a day of fruits and vegetables, including citrus fruits and dark green and deep yellow vegetables.
- 5. Eat plenty of high-fiber foods, such as whole grain breads and cereals.
- 6. Buy a new fruit, vegetable, low-fat food, or wholegrain product each time you shop for groceries.
- 7. Decrease the amount of fat in your meals by baking or broiling foods.
- 8. Choose low-fat milk and dairy products.
- 9. Some treatments can result in anaemia, however, iron supplements should be taken only after consulting a clinician.
- 10. Early menopause after treatment for breast cancer can increase the risk of osteoporosis. As some hormonal treatments increase risk of breast cancer recurrence, other ways of increasing bone strength include exercise, calcium and vitamin D supplements.
- 11. Avoiding caffeine and reducing alcohol can help reduce other menopausal symptoms.
- 12. Although some recommend low salt for preventing lymphoedema, there is little scientific evidence to support this.
- 13. Avoid salt-cured, smoked, and pickled foods.

14. Drink alcohol only occasionally.

15. For loss of appetite and nausea eat small frequent meals and snacks.

16. If you are overweight, consider losing weight by reducing the amount of fat in your diet and increasing your activity (choose activities that you enjoy).

## 2.8 Summary

The literature clearly shows that cancer has a physical, psychological and social impact and that psychosocial interventions have a positive effect on quality of life in cancer survivors (Rehse & Pukrop, 2003; Grassi & Travado, 2008). Given the growing number of cancer survivors in Ireland, health services need to be concerned with physical, social, emotional and psychological functioning after cancer.

A number of initiatives are required to maximise quality of life post-treatment including addressing physical and psychological disease and treatment sequelae, changing risky health behaviours, and increasing positive health-enhancing beliefs, behaviours and coping resources. Unfortunately, there is very little research upon which to base the development of such services in Ireland.

Tunkel and Passik (1989) believe that behavioural interventions aimed at increasing motivation are very useful in maximising compliance with the rehabilitation process and the American Cancer Society (ACS) guidelines for post-treatment survivors stress the importance of "*setting and achieving life-long goals*" such as appropriate weight, healthful diet, and physically active lifestyle to promote quality of life and longevity (Brown et al., 2003).

Ideally, there should be specialised programmes at cancer centres to monitor and care for survivors and to research cancer survivorship (Ganz, 2003). Grassi and Travado (2008) refer to the European recommendations for best practice and the need for a multidisciplinary team approach and note that the quality of cancer care is becoming a priority for many countries across Europe. The development of the Cancer Control Strategy in Ireland and the current research brief are evidence that Ireland is joining these countries.

The current research is the first step in the development of an appropriate service for post-treatment survivors in Ireland and the next chapter details the research design and methodology of this research.

# Chapter 3. Research Design and Methodology

#### 3.1 Project Development

The CANSURVIVOR Project encompassed a number of studies culminating in the piloting and evaluation of a multidisciplinary rehabilitation programme for post-treatment cancer survivors. After an initial review of the literature an exploratory study was conducted. This was followed by a profiling and needs assessment study and a multidisciplinary pilot intervention was then implemented and evaluated.

The project focused on the four main life-threatening cancers in Ireland, namely, breast, prostate, colorectal and lung cancers (NCRI, 2005). Those who had a Stage I or II diagnosis were the main focus of attention, as those with early stage disease have a more favourable prospect of long-term survival (Friedlander, 1998). Due to the lack of specificity in current definitions of the term 'survivor' it was decided to use an operational definition, which, for the purposes of this project refers to those who are minimum six months<sup>3</sup> (see page 5) post-medical treatment (surgery, chemotherapy, radiotherapy).

## 3.2 Research Design Overview

The project used a mixed methods design across three studies using both quantitative and qualitative methods. Given the dearth of bio-psychosocial data on post-treatment survivors in Ireland, it was considered appropriate to begin by using a qualitative approach to explore the issues impacting on the quality of life of post-treatment survivors from multiple perspectives (Study 1: n = 56). This study enabled the identification of issues salient to the post-treatment experience as well as giving an insight into differences in perspective about this phase of the cancer journey.

Next, was the profiling and needs assessment, using both quantitative and qualitative methods (Study 2: n = 262). This study involved a comprehensive survey of post-treatment cancer survivors examining demographic, medical, psychological, social, and behavioural variables, as well as variables relevant to health-behaviour change. Data from this study then facilitated the identification of the participants to be included in the intervention phase of the research by using the variables that were identified as risk factors for poor quality of life as selection criteria.

The final study involved the development, piloting and evaluation of a multidisciplinary rehabilitation programme for post-treatment cancer survivors (Study 3: n = 38). The programme was developed based on the findings from the literature review, the factors highlighted in Study 1, and the salient risk factors and needs identified in Study 2. Using a repeated measures design this programme was run over eight weeks and consisted of three modules (Physical activity, Dietary education and Hope Therapy for Cancer Survivors). On completion, both participants and the multidisciplinary programme delivery team evaluated the programme's effectiveness.

## 3.3 Research Aims

To fulfil the main research brief it was necessary to develop a number of overarching research aims and then further refine these for each specific study.

The overall research aims were to:

- Explore the bio-psycho-social issues impacting on the post-treatment experience of cancer survivors in the former ECAHB Area.
- Develop a profile of these survivors and assess their quality of life on a number of bio-psychosocial variables.
- Explore and evaluate post-treatment needs to allow identification of areas of care requiring intervention.
- Identify the variables considered to be risk factors for poor quality of life post-treatment and use these to identify participants for inclusion in the pilot rehabilitation programme.
- To develop, pilot and evaluate an appropriate, evidence-based, multidisciplinary, cancer rehabilitation programme with the ultimate aim of enhancing and maximising the survivor's quality of life.

The specific research aims of each study are presented in the following chapters.

## 3.4 Study 1: A Qualitative Study of Perspectives on Survivorship

This brief exploratory study used interviews and focus groups to elicit views on post-treatment outcomes and to identify the service needs of cancer survivors from multiple perspectives in order to gain a comprehensive representation of the Irish cancer survivor's experience. Interviews were conducted with Cancer Nurse Specialists (CNSs) and focus groups were conducted with cancer survivors and separately with carers of cancer survivors. The Irish Cancer Society also facilitated the running of a survivorship workshop with cancer support group representatives from around the island of Ireland consisting of survivors, health professionals, carers and volunteers.

All participants were asked to discuss the bio-psycho-social issues impacting on the life of post-treatment cancer survivors in light of their own experiences. They were also asked to discuss their perceptions of the effects of socio-economic disadvantage on cancer survivorship and to highlight any service needs that they felt were relevant. The data gathered supplemented the findings highlighted in the survivorship literature to give insight into the design of the survey in Study 2 and the development of the intervention to follow.

#### 3.5 Study 2: Profiling and Needs Assessment Survey

Using the information gathered in Study 1, along with the findings highlighted in the literature, this study used a survey design to further explore the bio-psycho-social factors identified as having an impact on recovery and quality of life and to ascertain patient outcomes and service needs in the post-medical treatment population of ECAHB.

The survey instruments reflected a focus on three main areas, namely:

- Demographic, medical and socio-economic information,
- Quality of life, current physical and mental health and health behaviours,
- Psychological variables related to adjustment to cancer and behaviour change.

Eligible participants were identified after a lengthy process involving accessing numerous databases in St. Vincent's University Hospital (SVUH), examining paper-based patient records and checking each individual with the General Registrar's Office. A number of standardised screening instruments and open questions were then used to profile the sample and assess their health service needs.

Participation was voluntary with the requirement to give informed consent. During the survey process the support of the clinical psycho-oncologist was available to participants who may have felt vulnerable during and after survey administration. The results of the survey then aided in identifying the target participants for the intervention and facilitated the tailoring of the pilot programme to meet their needs.

## 3.6 Study 3: The Pilot Rehabilitation Programme

Using a mixed model complex repeated measures design, this study sought to fulfil the core remit of the commissioned research: to develop and pilot a post-cancer-treatment rehabilitation programme. The main aim was to optimise physical and mental health by reducing health risks and enhancing quality of life via lifestyle behaviour and belief change and anxiety reduction.

All programme participants were identified from the Study 2 data and invited to participate based on the variables identified as risk factors for poor quality of life. Participants were included in either an intervention group or a comparison group and were assessed before and after the programme. The development of the eight-week multi-disciplinary curriculum was based on theory and clinical practice guidelines to meet the needs highlighted by the literature, the interviews, the focus groups, and the survey data.

The programme was multidisciplinary in nature and consisted of a physical activity module delivered by the physiotherapy team, a nutrition module delivered by the dietitian and a psychosocial intervention in the form of Hope Therapy for Cancer Survivors delivered by the psycho-oncologist. This combined approach aimed to increase effective coping skills and build up resources and strengths within the participants to maintain the goals for lifestyle change brought about by the physical activity and dietary components.

The effectiveness of the intervention programme was evaluated in terms of its efficacy to enhance positive health outcomes and quality of life in contrast to the comparison group.

The main programme goals were:

- Increased quality of life in terms of functioning and symptom reduction,
- Increased fitness and strength,
- Improved diet,
- Reduced weight,
- Reduced anxiety levels and
- Increased positive beliefs in the ability to maintain lifestyle change goals.

Participants completed a programme satisfaction questionnaire after the intervention and made suggestions for future development, while the intervention delivery team participated in a focus group to discuss the efficacy of the programme and generate suggestions for a future service.

# 3.7 Ethical Issues

Ethical issues are very important when carrying out research with groups who are vulnerable (Beaver, 1999) and due to the sensitive nature of the research and the focus on working with a patient population it was necessary to seek approval from the Medical and Ethical Research committee at St. Vincent's University Hospital (SVUH) before conducting this research. The main ethical concerns were the physical and mental wellbeing of the survivor during each of the studies and the issues of consent, confidentiality and anonymity.

Approval was initially sought and granted for Studies 1 and 2, as the details of the intervention phase could not be finalised until the results of these studies were analysed. Detailed research protocols with copies of the survey instruments, invitation letters, information leaflets, focus group and interview protocols and consent forms were submitted for the first two studies. Subsequently, approval was sought and obtained for the intervention study and this involved submission of the intervention protocol and programme content documents along with copies of the pre and post assessment instruments and the protocol for the evaluation of the programme.

All eligible participants were assigned an ID code, which was used on all correspondence and in data collection and data entry, analysis and storage. Reporting of results refers to group means rather than to individual data profiles. In addition, the support of the researcher and the clinical psycho-oncologist were made available to participants who may have felt vulnerable during and after survey administration and at any time during the intervention.

# Chapter 4. Study 1: A Qualitative Study of Perspectives on Survivorship

# 4.1 Research Design

This study used a qualitative approach to better understand the quality of life of post-treatment survivors in terms of their treatment outcomes and service needs. It also set out to gain an insight into the different perspectives on the survivors' experience and service needs and to augment the existing survivorship literature with any relevant additional issues that might surface in an Irish context. A qualitative approach was appropriate at this phase of the research as the purpose of qualitative research is "to understand and represent the experiences and actions of people as they encounter, engage, and live through situations" (Elliott, Fischer & Rennie, 1999, p. 216).

The methodology involved semi-structured interviews with health care professionals and a series of focus group interviews with separate groups of female and male cancer survivors and with carers of survivors. Finally, a workshop was also conducted with representatives from cancer support groups across the island of Ireland. All participants were asked to discuss the survivors' experience from their own viewpoint and all data were examined using Thematic Content Analysis.

# 4.2 Study Aims:

The aims of this study were:

- To identify the outcomes and service needs of post-treatment cancer survivors using a bio-psychosocial approach to better understand their quality of life.
- To gain an insight into the Irish post-treatment survivorship experience from a number of different perspectives.
- To identify whether socio-economic disadvantage impacts on the survivor's post-treatment experience.
- To discover whether there were issues, additional to the literature, that were of relevance in the Irish context that would contribute to the design of the profiling survey and the development of the pilot intervention programme in the following studies.

# 4.3 Method

#### 4.3.1 Participants:

Fifty-six individuals (n = 56) took part in the study, including two health professionals; eighteen cancer survivors (8 male, 10 female), four carers of survivors (2 female, 2 male) and 32 support group representatives. Participants were recruited via the clinical psycho-oncology service in SVUH, the Irish Cancer Society and the Lios Áoibhean and Bray Cancer Support Centres.

Each of the health professionals had experience of the post-medical care of cancer survivors in both an inpatient and outpatient context. The survivor groups ranged from eighteen months to twenty-nine years post-treatment. The support group representatives included male and female cancer survivors, relatives of cancer survivors, volunteers working in cancer support centres and a number of health professionals involved in running cancer support groups around the country.

#### 4.3.2 Procedure:

Firstly, having received ethical clearance and obtained informed consent, the researcher conducted two separate one-hour, semi-structured, face-to-face interviews with each health professional. The aim was to explore their perspective on salient post-treatment issues. The interview schedule was purposely developed to allow participants bring any issue they felt was relevant to the fore under the broad headings of: (1) Physical, (2) Psychological, (3) Social, (4) Vocational, (5) Socio-economic, (6) Service issues and (7) Other issues. Participants were asked to speak about these issues in light of their own professional experiences.

Next, the researcher conducted five separate one-hour focus group interviews with female only (2 groups) and male only (2 groups) survivors and with a mixed gender group of carers (1 group) to elicit their views on the issues that were most pertinent to their post-treatment experience. The focus group schedule was identical to that used for the earlier interviews. The interviews and focus groups were recorded on audiotape and later transcribed for analysis.

Finally, a survivorship workshop with support group representatives was conducted. All participants were also asked to speak about the bio-psychosocial issues impacting on the survivorship experience and to highlight their service needs as per the interview and focus group schedule used earlier.

#### 4.3.3 Analysis

Thematic content analysis was used to develop a coding-frame, which was applied to the entire data set<sup>5</sup> (interview, focus group and workshop transcripts). Inter-rater agreement was used as an analytic check and the average agreement level for this study was 83.70%. A "Thematic Map" was generated with all identified themes represented under the section headings of (1) Physical, (2) Psychological/ emotional, (3) Social (4) Vocational, (5) Socio-economic, (6) Service issues and (7) Other issues (see Figure 1).

<sup>5</sup> A large amount of material in the transcripts digressed from the research questions or was not of direct relevance and this material was not coded. The researcher believes that many participants found it difficult to speak only of the post-treatment experience without referring to issues occurring during treatment. While codes were devised to be as mutually exclusive as possible, there are many cases where one piece of data could have been represented by various combinations of codes.

## 4.4 Results

The main post-treatment issues that emerged from each of the differing perspectives are presented below.

#### 4.4.1 Physical Issues

All participants were asked to discuss the physical issues impacting on the post-treatment experience. The main themes that were identified related to treatment effects, physical adaptation to life post-treatment and changes to lifestyle.

#### 4.4.1.1 Treatment Effects

There were differences in perspectives regarding the physical issues that impacted on the survivors' post-treatment experience. The health professional focus was medical in nature and related to the type of cancer and the type of treatment the survivor had received. In their view, late treatment effects were uncommon, although the presence of occasional lingering effects particularly in the early post-treatment phase, such as fatigue, were identified.

As might be expected, the survivors and their carers and support groups had a different view, listing several lingering and long-term physical effects. These included pins and needles, scarring, damage to lungs from radiotherapy, impact of treatment on fertility, discomfort in the arm, insomnia, migraine, tiredness, deterioration in eyesight, reduced bone density and problems with the lining of the stomach.

#### 4.4.1.2 Physical Adaptation

In relation to physical adaptation, the health professionals spoke only of the implications for colorectal cancer survivors, who had difficulty adapting to life with a stoma. However, many survivors spoke of fatigue and the need to take regular "*cat-naps*". Colorectal cancer survivors spoke about the changes they were forced to make due to the presence of a colostomy bag, including changes to the type of clothing worn and the requirement to interrupt sleep to go to the bathroom. An example of the impact of this on daily living is illustrated by the following comment from an eight years post-treatment male,

"Well I have it eight years, ... you get used to it. But it's totally physical, you've got to worry about clothes, that you wear loose clothing and if you're going anywhere you've got to say 'well I'd want to be careful about this because I've got to go to the bathroom'. The first thing you do when you go to a place is you find out where the bathroom is, that's the very first thing, in a restaurant or anything".

Neither the carers nor the support group representatives spoke about physical adaptation specifically.

#### 4.4.1.3 Lifestyle Change

In terms of changes to lifestyle, the health professionals did not mention either positive or negative changes in the survivors' lifestyle. However, for survivors there were both. Some survivors spoke about their diets and activity levels changing in a general way, but there were some specific mentions of changes such as being too tired to swim or to engage in a game of football, or, with regard to dietary changes, being told to cut out eating red meat. One male colorectal cancer survivor spoke of not being able to participate in sports anymore, not being able to lift anything heavy and having to be careful out and about to avoid bumping into things for fear of damaging his stoma.

On a positive note, a number of male survivors spoke of changing their diet and activity levels in a positive way. The carers or supporters agreed that there were lifestyle changes but were not specific about these.

#### 4.4.2 Psychological Issues

The main psychological themes that were identified referred to expectations about 'normality', fear and anxiety around cancer recurrence, other cognitive and emotional sequelae, and psychological resources to cope with survivorship (internal and/or external).

#### 4.4.2.1 Expectations of Normality

The health professionals felt that survivors would be able to move on with life without too much difficulty and get back to 'normal' once treatment was over. A comment illustrates the point in reference to returning to work post-treatment,

"There's probably no reason why they can't and people usually are anxious to go back to work either during treatment or after treatment just to get back to the normality of life and they feel well you know - I'm back in my routine and that's what I want - and just to get over and I guess in some way forget about what's happened just you know not to have the cancer as the big focus of their life anymore that it used to be when they were on treatment and stuff".

As for survivors, they had mixed feelings about this, there was delight to have survived mixed with an apparent inability to look too far into the future. One female survivor spoke of being unable to move on as she felt somewhat disregarded and bewildered by the trauma she had just come through.

Survivors felt somewhat let down by the health service's expectation that they could get back to normal without much assistance and also by their own families' expectations of 'normality' once treatment was over. One female survivor who suffered from depression said,

"Once you've finished your treatment... end of story, 'go home, you're better' and that I believe is when the troubles really start."

Another female felt that as soon as she finished her treatment her family had the attitude of

"Ok now you're better and that's it you know, let's get back to normal".

Male survivors spoke of returning to 'normality' in a different way, with personal expectations of getting back to daily living and doing the "ordinary things". The carers were more negative in their outlook with one female carer saying

"Sure nothing's ever normal again, it'll never be".


## 4.4.2.2 Fears and Anxieties about Cancer Recurrence

One of the weightiest themes in the study as a whole was in relation to fears and anxieties about cancer recurrence. This persistent theme manifested in a constant vigilance of bodily sensations and was one of the few themes where all study participants agreed on the huge impact on the survivors' post-treatment life and that of their families. The health service effort to ensure early detection of a recurrence appeared to inadvertently contribute to the survivors' fear, as survivors felt they were never completely discharged from the health services. One health professional noted that patients engaged in misinterpreting every pain as a "cancer pain" and survivors admitted to the tendency to view "everything is cancer". As one male survivor said,

"Every morning you get up and you're feeling for lumps".

A comment by a female survivor sums up the feeling for all that

"There's never an 'over'... with cancer".

The carers spoke about a shared "*whole family fear*" and the support group representatives about the concept of "*anxiety pain*" in terms of this fear of recurrence being almost physically painful.

## 4.4.2.3 Other Emotional and Cognitive Effects

A range of other positive and negative emotional and cognitive factors impacting on the survivors experience, distinct from the above theme, were acknowledged by all participants. Health professionals spoke little of other psychological sequelae of cancer and its treatment, mostly mentioning body image issues, although one was aware that some survivors had memory problems. Even survivors themselves differed somewhat as females in particular, and their carers, were more vocal on the negative psychological effects while males' focus was more on the importance of having hope and a positive attitude and dispelling the idea that "once you have cancer that's the end".

Female survivors were most vocal on emotional and cognitive effects and spoke about body image, low self-esteem, depression, loss of control and forgetfulness due to "*chemo-brain*". They specifically spoke about depression and about concerns about relationships and the impact of mastectomies. Carers spoke simultaneously about the emotional effects on themselves and the survivor they cared for, as one carer spoke of how the whole family were struggling emotionally.

## 4.4.2.4 Resources to Cope with Survivorship

Views on the resources needed to cope with survivorship were quite different from the various perspectives. The health professionals spoke of age being a major factor in coping ability with a suggestion of acceptance and an implied need for less support in older survivors. They spoke of the need for emotional support post-treatment and recognised the importance of support from other survivors.

This was in complete agreement with survivors' views on both the need for support and the importance of cancer support groups. Survivors agreed that sometimes a psychological service was required and felt that other survivors were a great resource for emotional support.

With regard to personal resources to help them cope, survivors spoke of using many differing strategies ranging from gaining a sense of comfort from their spiritual life to using humour to deal with the various post-treatment issues that arose. Many female survivors spoke of keeping busy and distracting themselves to avoid the fear arising from various bodily sensations and symptoms but a number of survivors noted the need for help at a professional level.

## 4.4.3 Social Issues

The findings with regard to the social issues considered important in the survivors' posttreatment experience focused on two main themes namely, changes in social relationships and changing roles within the family. Perhaps the most striking finding is that the health professionals had nothing to say on either theme.

## 4.4.3.1 Changes in Social Relationships

In terms of changes to social relationships, survivors had very varied experiences, with some experiencing great kindnesses and others experiencing extreme rudeness and social isolation. A number of female survivors spoke of people treating them differently once they found out they had had cancer. One spoke of neighbours crossing to the other side of the road while in contrast another spoke of a stranger giving her a big hug in the street. Another had the experience of getting used to

"... people holding a conversation with [her] bust line".

## 4.4.3.2 Changes in Family Roles

Survivors, carers and the support group representatives spoke of changes in home life. This was in reference to changing roles within the family, with male spouses in particular taking on traditionally female roles within the home. All of these participants also endorsed the need for social support in general.

#### 4.4.4 Vocational Issues

The main theme within this section concentrated on current employment, with mixed views on the issue.

#### 4.4.4.1 Current Employment

The health professionals felt that most employers were supportive and that survivors usually had the resources or potential resources to see them through until they were either ready to return to work or they retired.

Male survivors seemed to endorse this view somewhat, while in contrast, females spoke of changing their work to suit their changed life and spoke with concern about those women who had to return to work, perhaps earlier than they should, for financial reasons. The issue of the carer having to find ways of maintaining an income was also raised, as carers often had to take a break from employment to care for the early post-treatment survivor. The support group representatives spoke of expectations being too high with regard to returning to work. Female survivors and support groups representatives both endorsed the view that having cancer had a damaging impact on one's future career.

One female survivor spoke of the impact of cancer on young people in particular and referred to the fact that their careers were put at risk as

"once they put cancer down on their forms well, you know you don't get your job promotion".

The support group representatives also spoke about cancer having a detrimental effect on the survivors' career prospects.

#### 4.4.5 Socio-economic Issues

All participants were asked to speak about any socio-economic issues that they felt impacted on the survivors' post-treatment experience. This included the ability to avail of a variety of therapeutic services such as counselling and the ability to access aids purported to improve physical and mental wellbeing such as complementary therapies. Three major themes emerged in this section relating to differences in access to services, financial burden on recovery and practical hardship.

#### 4.4.5.1 Differences in Access to Services

The health professionals appeared to have a good understanding of the implications for survivors of being socio-economically disadvantaged in terms of accessing post-treatment counselling and using complementary therapies, although they said it was not an issue raised much in their contact with survivors. They spoke of the free services offered by the cancer support centre and felt that once health professionals passed on the information about that service there was nothing further they could do.

Male survivors were quite vocal about differences in access to services, focusing on two main issues. The first of these was the dependency of those in the lower socio-economic groupings on the existing public services and the accompanying lack of choice regarding their healthcare. The second was the issue of waiting times for check-ups, which was considered to be alarming when faced with symptoms that could possibly indicate a potentially fatal disease recurrence. Private patients were considered at an advantage in this regard, with the perception of an almost immediate service available to them. Female survivors spoke particularly about the difficulty of accessing psychological help if on a low income, and of the cost of travelling to cancer support centres to avail of services.

A surprising issue that arose was the potential impact on the survivor's access to post-treatment services that arose from differences between the public and private health care experienced as an in-patient. Although medical health care was considered identical, both health professionals and survivors agreed that **public patients fared better than private patients in terms of having access to a range of services as an in-patient**, for instance links to social workers. One health professional explained that there are more nurse specialists in the public hospital and there are more supports available on a public ward (beyond the doctor and nurse). Consequently, it is easier to get access to services outside the hospital if the links are made as an in-patient in a public ward. This is in marked contrast to the general public's view of the differences between public and private healthcare in Ireland.

## 4.4.5.2 The Financial burden of Recovery

Quite apart from accessing post-treatment services, another theme was the financial burden of recovery experienced by those who were financially disadvantaged. Health professionals did not speak of this, while both survivors and their carers spoke of financial hardship, particularly in the first year post-treatment. The general feeling was that **those who were not entitled to medical card services were worse off, as the illness and recovery from it, drained their finances.** Female survivors spoke particularly about the huge financial strain in the early post-treatment phase, as partners used up all their sick leave and holiday entitlements to care for them and they would recommend that social welfare services be extended to people who are seriously ill. Others, speaking in the context of the survivor needing enough time to recover, spoke of the financial burden as some survivors did not have the resources to take a year out to recover and returned to work before they were ready, particularly those who did not have a partner to help with the financial burden.

Carers also spoke about the financial burden on the family as a whole during the recovery process. This was in the context of loss of earnings due to taking time off work to care for the survivor and also in reference to the cost of medication<sup>6</sup>. They spoke of the anomaly of those who were entitled to a medical card being better off while if you were

"a person with money it's going to drain you very quickly".

They also spoke of "*surviving*" without much money and of learning to ask for help from various welfare services, which they seemed to equate with begging, referring to it as going "*cap in hand*".

## 4.4.5.3 Practical Hardship

The final theme in this section related to practical hardships in terms of travelling to and from hospital and other health services for check ups, as well as home help for those who were less well off, with both health professionals and survivors in agreement on this.

## 4.4.6 Service Issues

When asked to speak about the service issues that impacted on the survivor's quality of life post-treatment, a number of gaps were identified and suggestions were made to improve existing services and develop new ones. Three major themes were identified and these relate to the inadequacy of existing post-treatment services, knowledge and information deficits, and meeting service needs in the future.

#### 4.4.6.1 Inadequate Post-treatment Services

From the health professionals' point of view the most salient factor contributing to the inadequacy of existing post-treatment services was the low level of contact with post-treatment survivors, which was limited to a few minutes at the three, six or twelve month check-up. At these there was limited scope to "*probe*" for "*other issues*" as the focus of their attention was on the clinical examination.

<sup>6</sup> It is not clear from the data whether the participants were aware of the Drugs Payment Scheme. This scheme allows individuals and families who do not hold medical cards to limit the amount they have to spend on prescribed drugs. Specific mention was not made to the costs associated with breast prostheses or to the costs of hormone treatment.



Both male and female survivors spoke of the time gap between ending treatment and the first check-up, which was usually a three-month gap. Moving from a very intense regime to "*nothing*" created a void that was emphasised by several survivors who felt cut off from medical and emotional support, feeling they were now "*out of the net*". One survivor commented that the service approach was

"get you in, get you fixed, get you out".

A female survivor spoke of the particular gap in services for emotional needs and that hospitals were not providing survivors with the opportunity to avail of a service even when it did exist. One survivor spoke of not being given any information about the help available via the Irish Cancer Society or Reach to Recovery. Another spoke of finding out by accident that there was a stoma-care clinic attached to a community health service but had not been informed of this by the health professionals in the hospital.

Carers spoke of a "*support gap*" in terms of health and welfare services and also about the survivor being set adrift and "*in no-man's land*" after treatment ended. One carer, speaking about the gap in psychological services felt that the family was left to provide psychological and emotional support. The following comment illustrates the point,

"The doctors kind of feel, I think, emotionally, well you know it's up to you, physically we can sort her [daughter] out, emotionally we can't, and that's where the gap is unfortunately".

The support group representatives spoke of little or no long-term follow-up services for survivors. There was agreement that the post-treatment survivor's needs were not served in any substantial way by existing services apart from the purely medical.

Carers also spoke of the **lack of co-ordination** in health care, even within the hospital, as far as they were aware, case reviews did not include the presence of social workers and only recently had begun to include psychologists. This meant that certain welfare and psychological support needs were not catered for. One carer's comment illustrates the point when speaking of seeking help,

"It'd nearly make you sick having to go around all these places".

There was a sense that carers were weary of having to fight to get a service (information, welfare entitlements, emotional support). The support group representatives also spoke of service difficulties due to the geographic location of existing services.

## 4.4.6.2 Knowledge and Information Deficit

Even where some post-treatment services existed there was a sense that the survivor was very dependent on the knowledge and willingness of the health professional in terms of referral to such services and it was apparent that such knowledge was limited. This deficit of knowledge was freely admitted by the health professionals and was a source of amazement to the survivors. Linked to health professional's knowledge about post-treatment issues is the knock on effect on the information provided to survivors post-treatment, particularly written information which, if available, was felt to be provided in an ad hoc manner and was generally of poor quality.

A number of male and female survivors and carers spoke about the poor provision of information about post-treatment effects by their consultants. They had to rely on getting information from various other sources over a period of time if they were fortunate enough. One male carer told how his General Practitioner admitted to not knowing any more about cancer than he did but he referred him to the local cancer support centre where he got the information required. The support group representatives spoke of little or no information being provided at discharge and a huge gap in the availability of written information on every level (physical, psychological, social, vocational and services).

## 4.4.6.3 Service Needs

A number of service needs were suggested including the need for a structured, co-ordinated approach, with links to the General Practitioner and volunteer services. Within the theme of service needs, three sub-themes were identified. These relate to suggestions regarding the type of service needed, dissemination of information and practical help.

The differences in perspective emerged here, with health professionals commenting that the gap in post-treatment services would be resolved by better management of the existing service while survivors and their carers saw the need for a more focused service. Health professionals felt that nurse-led follow-up clinics might be one answer to the post-treatment service gap but felt there were a lot of "*pros and cons*" and that it was preferable to see the current system with the doctor and nurse available for a chat.

Survivors spoke more about specific post-treatment help. A male survivor felt that, at the very least, survivors should be told about diet, exercise and alcohol intake. A female survivor felt that the General Practitioner should also be more involved in the patient's care during and post-treatment while yet another suggested that there should be a structured approach to the post-treatment phase, with a co-ordinator and a resource centre that had better communication with support groups.

Carers spoke in terms of the need for better welfare services and wished for a single walk-in service that would give information about all the **entitlements** and the range of services available. Carers also spoke about the need for cancer support in "*every town in this country*".

There was a huge emphasis on the need to distribute **information about post-treatment** issues as well as health and welfare services and entitlements. The preference appears to be for the provision of written, verbal and visual information about post-treatment issues and about the availability of support groups and other services. A male survivor spoke of the need for more information to be provided to those coming off treatment about the cancer support centre and its services. There was the suggestion from both male and female survivors that the consultants and General Practitioners should have literature in their offices and should speak to survivors about accessing services that would enhance their post-treatment experience.

The loud and clear message about needing information is best conveyed by one female survivor who felt that all the resources in the world were useless if

"you're not told about it...the hospital doesn't pass the patient through to some form of support 'after-care', let's put it that way, and rehabilitation after-care, then there is no point in having all these centres. It starts with the medical team."

The support group representatives suggested that an information pack about post-treatment services and information about possible post-treatment effects should be made available at discharge.

Finally, the need for specific help regarding the practicalities of living post-treatment for some were brought to light by some female survivors, particularly the need for swift practical assistance like transport or home help for those living alone or with young children.

#### 4.4.7 Other Issues

All participants were asked to speak about any other issues that impacted on the survivors' post-treatment experience. The only theme that emerged was in regard to feelings of being victimised and discriminated against.

#### 4.4.7.1 Victimisation and Discrimination

This issue was one that only survivors spoke of. It relates to feeling victimised and discriminated against for the rest of one's life by various decision makers who placed financial constraints on future security.

The factors that contribute to this theme included issues such as increases in the cost of life insurance and the availability of mortgages, pensions and mortgage protection, post-treatment. As one female survivor put it

"The overall message is that survivors are victimised rather than being sort of congratulated for having survived a fatal illness as such".

Some male survivors felt that such effects were a form of discrimination and spoke of them being a constant reminder of being different. They viewed it as a stumbling block for the rest of life as the illness never leaves them. This victimisation, as survivors saw it, also contributed to a reminder about the uncertainty of the future and fear of recurrence, as financial companies appeared to not trust that they would live long and expected that they would be a financial burden. They made comparisons with getting points on one's driving licence or crashing the car and losing the no claims bonus and spoke of such things being time-limited but that the financial consequences of having survived a serious illness remain forever. The health professionals, carers or support group representatives did not speak in any way on this issue.

## 4.5 Summary of Findings

This study set out to explore the outcomes and service needs of post-treatment survivors using a bio-psychosocial approach to better understand their quality of life post-treatment. A number of themes were identified. Psychological effects and service issues produced the largest number of distinct themes regarding outcomes, with fear of recurrence being a significant theme. A number of significant service needs were also identified, including the need for a structured and co-ordinated post-treatment service, the education of health care staff regarding post-treatment issues and the structured provision of good quality written information to post-treatment survivors.

This study also aimed to gain an insight into the survivors' post-treatment experience from a number of perspectives to develop a complete picture of that experience. An analysis of the themes that emerged revealed that there were differing views on the factors important to the post-treatment experience. A summary of the differing perspectives is provided in Figures 2, 3 and 4.

The major themes that were acknowledged as significant by **all participants** were fear and anxiety of cancer recurrence, emotional and cognitive factors, employment issues and all of the service related themes.

**Only Survivors** identified a number of themes. These relate to changes to social relationships and feelings of being penalised by various financial institutions for surviving. The overwhelming finding emerging was the sense that the survivor rarely felt able to live a life free of cancer, even when quite well.



FIGURE 2. Health professionals' perceptions of post-treatment survivorship

A number of themes were **not mentioned by health professionals** including lifestyle changes imposed on the survivor by the disease or its treatment, changes to social relationships, changed family roles, the financial burden on recovery (as distinct from difficulties accessing services) and the victimisation and discrimination felt by survivors.





# FIGURE 3. Carers' and support group representatives' perceptions of post-treatment survivorship

The study also aimed to identify whether socio-economic status impacted on the post-treatment experience. It is evident that it does have has a detrimental impact, both in terms of accessing services and lifestyle enhancements (e.g. using a gym or complementary therapies), as well as in terms of the financial burden on recovery.

The final aim of this study was to discover whether there were any other issues relevant to the survivor's experience not already explored and whether there were any issues that would be specific to the Irish context that were not highlighted in the existing survivorship literature. The only additional issue that was identified was in relation to the feeling of victimisation and discrimination. There was no significant theme that was new in terms of the existing literature or specific to the Irish context.

# 4.6 Conclusion

Study 1 was an exploratory study conducted for the purpose of identifying variables of significance that would contribute to the comprehensive profiling survey to be conducted in Study 2. It also served to identify service gaps that would facilitate the development of the intervention in Study 3. In addition, service needs were identified and form part of a set of recommendations for a future service for post-treatment survivors presented in the final chapter of this report.

The above findings have facilitated the choice of variables appropriate for inclusion in the survey, including anxiety, coping, social support, and psychological variables that facilitate behaviour change and assist with moving forward positively after cancer. These, along with quality of life measures and health behaviour measures will form the basis of profile development and needs assessment. Box 1 provides a summary of the study conclusions.



FIGURE 4. Cancer survivors' perceptions of post-treatment survivorship





# Chapter 5. Study 2: Profile and Service Needs of Post-treatment Cancer Survivors

# 5.1 Introduction

This study was the profiling and needs assessment phase of the research. A questionnaire was developed using the information gleaned from the literature and reinforced by the themes that were identified as noteworthy in the Study 1 investigation.

# **5.2 Aims**

The aims of this study were as follows:

- To profile a sample of Irish cancer survivors in the former ECAHB, by assessing their quality of life and service needs on the following physical, psychological and social variables
  - Current health and lifestyle, return to work, contact with rehabilitation-related services.
  - Levels of functioning and symptomology, using the EORTC QLQ-C30.
  - Levels of anxiety, depression, hope, optimism, health-related control beliefs, coping and social support.
- To examine the relationship between quality of life, anxiety, depression, hope and optimism.
- To identify the risk factors that are most significant in terms of identifying participants that would benefit from the Study 3 pilot rehabilitation programme. To this end, it was intended to investigate gender differences<sup>7</sup>, cancer-specific differences, treatment type differences, age group differences and differences between socio-economically diverse groups in terms of quality of life, anxiety, depression, hope and optimism.

# 5.3 Research Design

This study used a cross-sectional survey design including a number of standardised screening instruments along with measures developed specifically for the study. A full enumeration of the eligible population of post-treatment survivors on the databases held in St. Vincent's University Hospital (SVUH) was conducted. This led to the development of cancer-specific lists that were used to invite all eligible participants to contribute to the research.

The main variables of interest were the survivor's quality of life in terms of levels of functioning and symptomology, along with levels of anxiety, hope and optimism and current health behaviours. In addition, social and economic factors were assessed. The survey data were subsequently used to construct a profile of post-treatment survivors, to assess their needs on physical, psychological, social and behavioural factors and to identify the participants for inclusion in the intervention in Study 3.

<sup>7</sup> As gender co-varied with cancer type (breast, prostate and lung cancer), gender analyses were conducted on the colorectal cancer group only as the group size for lung cancer was too small (n=7). If no significant gender differences arose, then gender would not be considered an important factor in the reporting of quality of life, anxiety, depression and hope and optimism for the sample as a whole and any differences observed between groups would most likely be due to cancer type than due to gender.

# 5.4 Method

## 5.4.1 Participants

Two hundred and sixty two post-treatment cancer survivors took part in this study (n = 262). A breakdown by cancer type is given in Table 2. The process of accessing eligible participants is detailed below, followed by a section on the response rate and participant characteristics.

TABLE 2. Breakdown of survey participants by cancer type

Cancer Type	No. of Participants
Breast	169
Prostate	37
Colorectal	49
Lung	7
Total	262

## 5.4.2 Sample Selection

Previous research has focused on either breast cancer survivors only, or, where a mix of cancer types was included in a study, there was a failure to differentiate sufficiently between cancer types and treatment types to enable cancer or treatment type effects to be teased out. In an effort to address this failing, a decision was made to focus in this study on breast, prostate, colorectal and lung cancer survivors as these are the four main causes of cancer death in Ireland (NCRI 2005). The aim was to invite as many early-stage, post-treatment survivors to participate in the survey as possible. It was decided to initially access records from 2003 back to 1996 and to extend beyond those years if the data were available and time permitted. The study inclusion and exclusion criteria were as follows:

#### Inclusion criteria:

- Breast, Prostate, Colorectal or Lung cancer
- 1st diagnosis (no recurrence)
- Early stage cancer with no metastases (1, 2, 3, M=0),
- Cancer is 'primary diagnosis'
- Post-medical treatment by at least 6 months
- Age 18 yrs 75 yrs
- Living within the former ECAHB area.

#### **Exclusion criteria**

- Impaired cognitive function
- Evidence of psychosis, drug or alcohol dependency.

## 5.4.3 Data Access

A number of avenues were considered to enable access to the potential sample, with the aim of constructing four cancer-specific project databases from which to invite participants to take part in the survey. Having considered the hospital-based HIPE database (Hospital In-Patient Enquiry) and the National Cancer Registry of Ireland (NCRI), it was decided that these routes were not suitable for the present research<sup>8</sup> and the Regional Cancer Database located in SVUH was used instead.

This relatively new system amalgamates information from many smaller databases within the hospital. The Regional Database manager advised that, as the system was new, the most reliable route to identifying a sample was to access the data at source (via the various medial oncology teams who held cancer specific databases). This involved obtaining permission from the relevant medical and surgical oncology consultants and the chair of the Cancer Co-ordinating Committee in SVUH, then liaising with the appropriate cancer nurse co-ordinators to identify those fitting the eligibility criteria.

Data sources varied in complexity and level of information and most were maintained and updated by the relevant cancer nurse co-ordinators (CNCs). Potential colorectal and lung cancer participants were identified from the electronic databases with the assistance of these nurses and potential breast cancer participants were identified with the aid of the BreastCheck data manager using the eligibility criteria above.

As there were no substantial electronic records of prostate cancer patients pre 2004, potential prostate cancer participants were identified, with the assistance of the relevant CNCs, from hospital charts and pathology reports beginning in 2003 and working backwards to 2000. The prostate cancer survivors were selected based on staging information using a low to intermediate Gleason score<sup>9</sup> and whether or not they had radical curative treatment (e.g. surgery or radiotherapy). Regardless of the system used for each specific cancer type, the overriding criterion was that the participants were considered eligible if they were deemed 'early stage'. <sup>10</sup>

Ultimately, four project databases were constructed and colour coded and all potentially eligible participants assigned an ID code, which was used throughout the project in all correspondence and statistical packages.

Before invitations to survey could go ahead, two further issues required attending to. These were:

- 1) Geographically coding the data and
- 2) Death record updates.

Since SVUH serves patients from all parts of Dublin City and County, as well as patients from around the island of Ireland, it was necessary to exclude those living outside the boundaries of the former ECAHB area on the basis of address. This was accomplished using postal codes and community care area identifiers, as defined by the HSE.

<sup>8</sup>Patient addresses were not part of the HIPE database at the time and although NCRI were very willing to send invitations to eligible participants, those individuals would be anonymous to the researcher thus posing problems with conducting the survey in a group setting and in identifying the target participants for inclusion in the intervention. In addition, death record time lags existed on the registry at that time.

<sup>9</sup>The staging information used to construct the project's prostate cancer database was based on Gleason scores. This system assigns a grade to the two largest areas of cancer in the biopsy sample. Grades range from 1-5 with 5 being the most aggressive. The two grades are then added to produce a Gleason score. The combined scores are indicative of a low (2-4), intermediate (5-7), or high grade tumour (8-10). Low grade tumours typically do not pose a threat to life during the patients lifetime.

<sup>10</sup>A number of differences were observed in the way cancer staging information was classified across different cancers. The breast cancer database used the stage I, II, III system as did lung cancer, while the colorectal database used an A, B, C staging system as well as Dukes scores and the prostate patients charts focused on using Gleason scoring.

To overcome the issue of incomplete death records and to ensure that no contact would be made with families of deceased individuals, all records were checked against the electronic death records in the General Registrar's Office (GRO). Those who were identified as deceased were excluded from the project databases.

## 5.4.4 Response Rate

A total of eight hundred and fifty six (856) cancer survivors were identified as being eligible for initial invitation to the survey, including 529 breast cancer survivors, 130 prostate cancer survivors, 165 colorectal cancer survivors, and 32 lung cancer survivors.

These were initially invited to participate in the survey on foot of having had a serious illness<sup>11</sup> rather than on the basis of cancer. Eighty-two (82) of these were later found to be unavailable for survey for a number of reasons including being deceased, being ill, not being aware of their diagnosis of cancer or having moved house, leaving 774 available for the study (See Table 3 for breakdown by cancer type).

Of these, 328 consented to take part in the survey and were invited to a survey session. Sixty-six of these were not surveyed for a number of reasons:

a) They did not respond to this invitation,

b) They were unable to make themselves available for any survey session despite being offered a number of dates and times,

c) They did not show up for an agreed survey session.

	Breast	Prostate	Colorectal	Lung	Total
Identified Pool	529	130	165	32	856
Not available*	53	8	10	11	82
Total available	476	122	155	21	774
Surveyed = n % Response	169 (35.5%)	37 (30.3%)	49 (31.6%)	7 (33.3%)	262 (33.85%)

#### TABLE 3. Response rate to survey invitation by cancer type

\*Not available due to death, moved home, not aware of cancer or ill at present time.

Ultimately, 262 individuals completed the survey, giving an overall response rate of 33.85%. There were 169 breast cancer survivors (35.50% response rate), 37 prostate cancer survivors (30.33% response rate), 49 colorectal cancer survivors (31.61% response rate), and seven (7) lung cancer survivors (33.33% response rate), who completed surveys.

## **5.5 Survey Instruments**

The survey consisted of a number of demographic and medical information questions, as well as questions about current health behaviours and several standardized measures of quality of life and psychological wellbeing. All measures were self-report.

<sup>11</sup>NCRI had earlier alerted the researcher that a number of cancer patients are not aware of their diagnosis of cancer, particularly the elderly. Thus the decision to initially invite based on serious illness to avoid upset. Further details are provided in the procedure section to follow.

*Demographic and Medical Information Questionnaire*: This measure was designed to collect demographic and medical information on the survey participants (see Appendix A).

The EORTC Quality of Life Questionnaire (version 3.0) (Aaronson, NK. et al 1993): This measure assessed quality of life on five functional scales: physical functioning, role functioning (spouse, provider, parent), emotional functioning, cognitive functioning and social functioning, three symptom scales, fatigue, nausea and vomiting and pain and a global health status scale. Six single-item questions assess dyspnoea, insomnia, appetite loss, constipation, diarrhoea and financial difficulties. Scores range from 0 to 100 with a high functioning scale score representing higher quality of life and a higher symptom score indicative of problematic symptom levels.

*The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983)*: This is a widely used screening instrument for identification of clinical anxiety and depression.

The *Life Orientation Test – Revised (LOT-R) (Scheier, Carver & Bridges, 1994)*: This measure assesses generalized optimism versus pessimism. An optimistic disposition predicts coping after a cancer diagnosis and pessimism is a risk factor for poor adjustment (Carver et al., 1993).

*The Hope Scale (HS) (Snyder et al., 1991a)*: Hope is conceptualized as a cognitive approach focusing on goal directed determination and an ability to generate plans to achieve goals. Hope is a significant predictor of problem-focused coping and facilitates positive appraisals of adverse situations such as chronic illness (Snyder, 1999).

#### Health Behaviour Questionnaire:

This was developed to gather data on current health related behaviours including physical activity and dietary information (see Appendix B).

Additional standardised measures of locus of control, self-efficacy, coping strategies and social support were also used.

#### **Open-ended Questions:**

A number of open ended questions concluded the survey, giving the survivor the opportunity to comment on challenges post-treatment, suggestions for improving post-treatment health services and identification of the factors that health professionals should be more aware of with regard to life after cancer.

#### 5.6 Procedure

Having received ethical clearance and compiled the databases, the initial invitation to take part in the research was framed as an invitation to post-treatment survivors of a serious illness rather than survivors of cancer specifically. Preliminary letters were sent to all 856 potential participants with a reply card to be returned indicating consent to take part and an option to choose cancer (among other illnesses) as the relevant serious illness experienced.

Only those who replied indicating awareness of their cancer diagnosis were considered eligible for the study. In all, 82 individuals were excluded from the study for a variety of reasons (see previous section) including six individuals who replied with an apparent lack of awareness of their cancer diagnosis. The total number of cancer survivors considered available for survey was 774.

Of these, 328 individuals returned consents and were then sent an information leaflet giving further details of the project, its purpose and aims, the survey procedure and assurances of confidentiality (see Appendix C). As the questionnaire was long and the research team wanted to maximise response rates, a decision was made to administer the questionnaire to groups of survivors rather than using a postal questionnaire approach.

Participants were invited to complete the survey in the Lios Áoibhean Cancer Support Centre in SVUH, or in the Cancer Support Centre, Bray, with the kind permission of the directors of these centres. Potential participants choose from a selection of survey dates and times.<sup>12</sup> These sessions took, on average, one hour and were run over four sessions a week from March to the end of June 2006. On average, 12 people attended each session and the research team were available at all times to deal with any queries that participants may have had.

In all, two-hundred and sixty-two individuals completed the survey, giving an overall response rate of 33.85% (see Table 3).<sup>13</sup> Finally, all participants were informed that the research team might contact them (with their permission) at a later stage, as a pilot rehabilitation programme would be the next phase of the project.

# 5.7 Data Management and Analysis

Data were entered into the SPSS (Statistical Package for the Social Sciences) for Mac Version 11.0.4 (Norusius, 2004) and analysed using both parametric and non-parametric procedures.

<sup>12</sup> Survey sessions were conducted over four sittings per week for sixteen weeks with a choice of either a late afternoon or an evening on one of two weekday offerings.

<sup>13</sup>Where potential participants had indicated consent to partake in the research and had made an appointment for a survey session but did not show up, a follow-up telephone call was made to reschedule.

# 5.8 Profile of Cancer Survivors

The first aim of the current study was to profile a sample of Irish cancer survivors in the former ECAHB area by assessing their quality of life on a number of demographic, physical, psychological and social variables. Below, a frequency analysis of responses provides the basic profiling information. Included are responses to a number of key demographic questions presented as participant characteristics and treatment characteristics.

This is followed by summary data on current physical and mental health, current lifestyle, returning to work after treatment, and contact with supports that might facilitate rehabilitation. Then, descriptive statistics are presented based on responses to the EORTC quality of life measures, along with measures of anxiety and depression, hope, optimism, control beliefs, coping and social support. Where possible, these data are compared with international reference data. Mean scores and standard deviations for each of the standardised measures are presented in Appendix D.

#### 5.8.1 Participant characteristics

Basic demographics for survey participants are presented below (see Table 4).

#### Age

The overall mean age of participants was 61.96 years (SD 8.21) with an age range of 34-75 years. The mean age for each cancer type was: breast cancer 59.69 years (SD 7.82), prostate cancer 66.54 years (SD 5.50), colorectal cancer 65.57 years (SD 8.45), and lung cancer 67.29 years (SD 6.94) (see Figure 5). Statistical analysis revealed that the breast cancer survivors were significantly younger than prostate and colorectal survivors<sup>14</sup>.



FIGURE 5. Mean age in years by cancer type.

#### Gender

Seventy males (26.7%) and one hundred and ninety two females (73.3%) participated in the study. The gender breakdown by cancer type is presented in Table 5.

 $^{14}$  A one-way ANOVA revealed a significant age difference between cancer types F(3, 261) = 14.14; p < .05.

Characteristic			
Age (yrs)		Mean	SD
	Total sample	61.90	8.21
	Males	66.30	6.03
	Females	60.15	8.15
		n	%
Gender	Male	70	26.7
	Female	192	73.3
Marital Status	Married/living with partner	182	69.7
	Single/widowed/separated/ divorced	79	30.3
Education (highest completed)	Primary	30	11.5
	Secondary	138	53.1
	Third level	92	35.4
Occupational status	Retired	100	38.8
	Employed	93	36.0
	Homemakers	55	21.3
	Unemployed	10	3.9
Income			
Low <€30,000	Self	137	60.9
	Spouse	74	46.8
Middle €30,000 - €59,999	Self	61	27.0
	Spouse	46	29.4
High €60,000+	Self	27	12.0
	Spouse	38	24.0
Private health insurance		193	75.1
Medical Card <sup>a</sup>		100	38.8
Type of treatment	Combination	170	65.6
	S+C+R*	81	31.2
	S+C	42	16.2
	S+R	39	15.0
	Surgery only	65	25.0
	Chemotherapy only	1	0.4
	Radiotherapy only	23	8.8
		Mean	SD
Time since treatment (yrs)	Overall	4.44	2.72
	Breast	4.95	2.83
	Prostate	3.12	0.94
	Colorectal	3.50	2.65
	Lung	4.16	2.20

TABLE 4. Socio-demographic and treatment characteristics of participants (n=262)

\*Note: S=surgery, C=chemotherapy, R=radiotherapy

<sup>a</sup>A number of those with private health insurance are also eligible for a medical card.

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## TABLE 5. Gender breakdown by cancer type

	Males	Females
Breast	0	169
Prostate	37	0
Colorectal	29	20
Lung	4	3
Total	70	192

## Martial Status

In terms of marital status, 38 were single (14.6%), 182 were married or living with a partner (69.7%), eight were separated (3.1%), six divorced (2.3%), twenty six widows or widowers (10%), one 'other' (0.4%) and one declined to specify (0.4%).

## Education level

With regard to education level, 11.5% (n = 30) of the sample completed primary level education but not second level, 53.1% had completed second level (n=138), and 35.4% had a third level education (n = 92) (see Figure 6).





# 5.8.2 Socio-economic status

## Employment

With respect to employment, 36% (n = 93) were in employment and the remainder either retired 38.8% (n = 100), homemakers 21.3% (n = 55) or unemployed 3.9% (n = 10).

## Accommodation

In relation to home ownership, 87.8% (n = 224) of the sample were home owners, with the remainder living in either rented accommodation (7.8%, n = 20), a family member's home (2.4%, n = 6) or as part of a religious community (1.6%, n = 4). As well as this, 18.8% (n = 49) of participants lived alone.



#### Income

In terms of income, 60.9% (n = 137) of the sample had a personal income of less than  $\in$  30,000 per year, 27% (n = 61) had an income between  $\in$  30,000 and  $\in$  59,000 and 12% (n = 27) had a personal income of  $\in$  60,000 or more. Spousal income was also measured and 46.8% of participants (n = 74) had a spousal income of less than  $\in$  30,000 per year, 29.1% (n = 46) had a spousal income between  $\in$  30,000 and  $\in$  59,000 and 24% (n = 38) had a spousal income of  $\in$  60,000 or more.

When incomes within the household were combined, just over half the sample were found to be living with a household income of less than  $\in$ 35,000 (51.4%, n = 131), 18.4% (n = 47) with incomes between  $\in$ 35,000 and  $\in$ 54,999, 12.9% (n = 33) with incomes between  $\in$ 55,000 and  $\in$ 74,999 and 16.8% (n = 44) with combined incomes of  $\in$ 75,000 or more (see Figure 7).



FIGURE 7. Combined household income levels of survey sample.

#### Health Insurance

Just over seventy five percent of the sample had private health insurance (75.1% (n = 193). Thirty-eight percent (38.8%, n = 100) were entitled to a medical card (51 of these were aged 70 or older<sup>15</sup>).

## **5.8.3 Treatment Characteristics**

#### Type of Treatment

In terms of treatment-related information, the majority of these participants had received a combination of medical treatments for their cancer (65.6%, n = 170) (see Figure 8). Most had received surgery plus chemotherapy plus radiotherapy (31.2%) while the next most frequent treatment combination was surgery plus chemotherapy (16.2%) followed by surgery plus radiotherapy (15%). In the case of a single treatment type, 25% of the overall sample received surgery only, 0.4% received chemotherapy only and 8.8% received radiotherapy only.

<sup>15</sup>In Ireland, those aged seventy and over are entitled to a medical card regardless of means thus a number of participants may have both which may explain the apparent anomaly with private health insurance and medical card numbers.



FIGURE 8. Percent of survey sample receiving each treatment type.

#### Time since Treatment Ended

Table 4 shows the average time since treatment ended by cancer type. The overall mean number of months since medical treatment ended was 53.29 (SD 32.7) months (4.44 years) ranging from 1 year to 14 years.<sup>16</sup> Just over twenty percent (20.5%, n = 48) were 1-2 years post treatment, 48.3% (n = 113) were between 2 and 5 years and 31.2% (n = 73) were more than 5 years post treatment. Figure 9 illustrates this breakdown by cancer type for time since treatment ended. Statistical analysis revealed that breast cancer survivors were significantly longer out of medical treatment than the prostate group with no prostate cancer survivors in this study who were more than 5 years post-treatment.<sup>17</sup>

#### Post-treatment Medication

When asked about current medication 35.4% (n = 91) indicated that they were on medication, whilst the remainder were not (64.6%, n = 166). The most frequent medications were those related to the treatment of breast cancer and included Arimidex (10%; n = 26) followed by Tamoxifen (8.9%; n = 23) and Femara (3.1%; n = 8). The remainder were on various medications for high blood pressure, high cholesterol, heart medicine and unspecified hormone medication.

#### 5.8.4 Current Self-Reported Health

#### Co-morbidities

As an indicator of current physical health, co-morbid health conditions were assessed. Of those who responded, 18.7% (n = 49) indicated no other health problems and of the remainder, the most frequently mentioned condition was arthritis/osteoarthritis (20.22%; n = 53) followed by hypertension (17.6%, n = 44), osteoporosis (6%, n = 15) and diabetes (3.2%, n = 8).

<sup>16</sup> Some participants from the BreastCheck database were diagnosed in 1988.

<sup>17</sup>A one-way ANOVA revealed a significant difference between cancer types in terms of time since medical treatment ended F(3,233)=5.75, p < .05.



FIGURE 9. Time since medical treatment ended by cancer type for survey sample.

#### Anxiety about Recurrence

As a brief indicator of mental health, participants were asked to indicate on a scale from 0-6 the extent to which they were worried about a recurrence of their cancer. Just over forty percent were a little worried (40.6%, n = 106), while 38.7% (n = 101) were moderately worried and 20.7% (n = 54) were very or extremely worried.

## 5.8.5 Current Lifestyle

With regard to current lifestyle, participants were asked a number of health-related behaviour questions and about changes to their behaviour, reasons for any change and barriers to changing behaviours (see Figure 10 for a summary of risky health behaviours).

#### Weight

Since diagnosis, almost 21% of participants had lost weight (n = 53), however, over twice that number had put on weight (48.2%, n = 118). The mean BMI<sup>18</sup> score for the sample was 25.80 (SD 4.51). Two percent of the sample had a BMI score less than 18.50 (n = 5) and were considered underweight, over forty six percent (46.6%, n = 116) had scores within the normal range (18.5-24.99), 35.7% (n = 89) were in the overweight range (25-30) and 15.7% (39) were classified as obese with scores of 30 or more.

#### Smoking

With regard to smoking, 43.8% of the sample had never smoked (n = 114), 43.1% used to smoke (n = 112) and 13.1% were still smoking (n = 34). All lung cancer survivors used to smoke. Those currently smoking were mostly female 70.5% (n = 24), of these, twenty-one were breast cancer survivors and three were colorectal cancer survivors.

<sup>18</sup>The BMI scores for all participants were calculated using the Quatelet formula BMI = Weight in Kg / Height in Meters <sup>2</sup>.

#### Physical Exercise

Participants were asked to indicate whether or not they engaged in any regular physical exercise.<sup>19</sup> Over seventy four percent (74.2%, n = 184) indicated that they exercised on a regular basis while 25.8% (n = 64) did not. Walking was the most frequent form of exercise (85.5%, n = 223) followed by swimming (14.2%, n = 37), going to the gym (7.3%, n = 19) and golf (6.5%, n = 17).



FIGURE 10. Percent of survey sample with risky health behaviours.

## Activity Change

When asked if their activity levels had changed since before their cancer diagnosis, almost half the sample indicated that their activity levels were the same as before (46.9%, n = 120) while 35.2% (n = 90) had decreased activity levels and 18% (n = 46) had increased theirs. For those who reduced their activity levels, the main reasons were 'lack of energy' (also referred to as 'fatigue' or 'tiredness') (12%) and age (5.2%), while those who increased their activity levels, said they did so because they realised that exercise was good for them and they wanted to maintain their health post treatment (12.4%).

## Alcohol

Regarding alcohol consumption, 38% (n = 98) rarely or never drank alcohol, 27.1% (n = 70) drank alcohol once or twice a week and 34.9% (n = 90) drank three or more times a week.

#### Diet

In relation to diet, participants were asked to report how many of each of the major food groupings they consumed on a typical day. There was an almost universal inability on the part of participants to conceive of food portion sizes, so all participants were assisted with the aid of a food pyramid chart.

"Regular physical exercise is defined as any activity performed on a repeated basis over an extended period of time, with the intention of improving physical fitness and health at least 3 times a week for at least 20-30 minutes."

<sup>&</sup>lt;sup>19</sup> Participants were then given the following definition of regular physical exercise,

Table 6 presents the percent of participants consuming below and above the recommended daily amount (RDA) from each food group, as advocated by the Irish Nutrition and Dietetic Institute (INDI), the Health Promotion Unit (HPU) of the Irish Department of Health and Children (DoHC) and the National Nutrition Surveillance Centre (NNSC) at UCD. As can be seen from this table, the majority of the study participants consumed less than the recommended amount for each of the food groups with the exception of the high sugar/high fat group where too much of this food group was consumed.

Food Group	% Below RDA	HPU RDA	% Above RDA
Bread, cereal, potatoes	73.4%	6+	14.5%
Fruit and vegetables	56.1%	5+	19.7%
Dairy produce	62.6%	3	12.3%
Meat, poultry and fish	53.3%	2	18.5%
High sugar/high fat foods	21.7% <sup>20</sup>	Use Sparingly	45% <sup>21</sup>

TABLE 6. Percent of survey participants above and below RDA food groups

## 5.8.6 Returning to Work

Participants were asked a number of questions about returning to work since completing treatment. Just over half returned to work once their treatment was over (50.2%, n = 128) while 24.7% (n = 63) did not. Just over a quarter of the sample (25.1% (n = 64) replied that this question did not apply to them.<sup>22</sup> Of those who returned to work, 15.6% (n = 20) found it 'quite' or 'very' difficult to do so. Of those who did not, 36.1% (n = 30) said that their changed occupational status was due to their cancer.

#### 5.8.7 Links to Support for Rehabilitation

In an effort to determine the levels of recovery and rehabilitation related services and aids used by this sample, participants were asked about their contact with allied health professionals during their treatment, and also about their use of complementary and alternative therapies and their awareness of cancer support centres locally.

First, they were asked to recall whether any cancer nurse specialist, physiotherapist, chaplain, dietitian, social worker, occupational therapist or psychologist had attended them during the course of their illness and their treatment. Table 7 presents the percent of participants who reported contact with each specific health professional during that time.

The most striking finding is the number who did not see these professionals during their illness or treatment, as 36.4% (n = 95) did not see a cancer nurse specialist, 62.1% (n = 162) did not see a physiotherapist and over 85% did not see a dietitian, a social worker, an occupational therapist or a psychologist during their illness or treatment.

<sup>20</sup>This number reported that they consumed no high sugar or high fat foods.

<sup>21</sup>This number consumed more than one portion of this food group per day (1 teaspoonful).

<sup>22</sup>This may be a reflection of the number of retirees in the sample and the number of homemakers who may not consider their contribution in the home as 'work'.

In fact, 30 colorectal cancer patients (61%) reported that they never saw a dietitian during their illness or treatment. The consultant generally makes these referrals.

Health/Allied Professional	%	n
Cancer nurse specialist	63.6	166
Physiotherapist	37.9	99
Chaplain	22.3	58
Dietitian	14.6	38
Social worker	10.0	26
Occupational therapist	2.7	7
Psychologist	2.3	6

TABLE 7. Percent of survey participants who reported contact with health/allied professionals

## Use of Complementary and Alternative Medicine

Next, survivors were asked if they had used any of a number of complementary care services to help them deal with the after effects of their cancer and its treatment. An examination of Table 8 shows the most frequently used complementary therapies.

Complementary Therapy	%	n
Massage	16.9	44
Yoga	13.8	36
Reiki/ Reflexology	11.2	29
Counselling	10.8	28
Meditation	9.6	25
Aromatherapy	6.2	16
Acupuncture	4.6	12
Art Therapy	3.5	9
Other	7.3	19

 TABLE 8. Percent of survey participants who used complementary care therapies

## Awareness of Local Cancer Support

Participants awareness of local area cancer support services was very low, with most unaware of any local cancer support service (62.2%, n = 163). Of those who were aware of local support, only 19.3% (n=37) had availed of that support.

# 5.8.8 Current Health and Lifestyle Profile Summary

In summary, the majority of the current study participants reported co-morbid health problems in addition to cancer. The most frequently reported being arthritis/osteoarthritis. In terms of mental health, well over half the sample reported moderate to extreme anxiety about a recurrence of their cancer.

In terms of lifestyle, just over half the sample were overweight, including a significant number in the obese category and almost half the participants had put on weight since diagnosis. Furthermore, a worrying number of breast cancer survivors were still smoking.



With regard to physical activity, a quarter of the sample reported that they did not engage in any regular physical activity and for those who did, the most frequent form of exercise was walking. In addition, over a third had reduced their physical activity levels since their diagnosis, with the main reason for this being fatigue. Over a third of the sample drank alcohol three or more times a week and the average daily diet does not compare favourably with recommended levels, with participants consuming too much high sugar and high fat foods and not enough of the other food groups.

During their treatment there was a striking lack of contact with health professionals that might be influential in facilitating their recovery and rehabilitation. The most frequently seen professional in the hospital setting was the cancer nurse specialist, yet over a quarter of participants did not have that contact and most had no contact with a physiotherapist, dietitian or psychologist during their treatment. Furthermore, most participants did not use complementary therapies and were not aware of any cancer support centre local to them and of those that did, most did not avail of the services offered.

# 5.9 Quality of Life

An examination of Figures 11 and 12 reveal that the current sample exhibit quite high quality of life levels in each functional domain (maximum level = 100) and moderately low symptom levels. Figure 11 shows that overall, this sample are doing particularly well in terms of physical, role and social functioning and less well on cognitive and emotional functioning and overall Global Quality of Life (albeit all still at a relatively high level).



FIGURE 11. Survey participants mean quality of life functional scores (0-100 scale) (Higher scores = higher quality of life)

The current sample also exhibit quite high quality of life levels in terms of cancer-related symptoms, with the most problematic symptoms being insomnia and fatigue and, to a lesser extent, pain and dyspnoea<sup>23</sup> (Figure 12). Financial impact, constipation and diarrhoea were even less of a problem and the least bothersome symptoms were nausea,

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<sup>23</sup> Shortness of breath derived from a medical condition and not due to physical exertion.



FIGURE 12. Survey participants mean quality of life symptom scores (0-100 scale) (Higher scores = lower quality of life)

A more detailed analysis was conducted to ascertain the percentage of participants who were experiencing quality of life function and symptom difficulties. The percentage of participants scoring below one standard deviation from the mean on quality of life functions and above one standard deviation from the mean for the symptom scales were examined.<sup>24</sup> This analysis reveals that up to 20% of the sample had levels of poor function that are a cause for concern and up to 26.5% had symptom levels that cause concern (see Table 9).

TABLE 9. Percent of participants scoring	< 1 SD below mean on functions and > 1 SD
above the mean on symptoms	

Functioning	% (n)	Symptoms	% (n)
Physical functioning	19.8% (52)	Insomnia	26.5% (69)
Emotional functioning	15.4% (40)	Constipation	24.7% (64)
Social functioning	11.9% (31)	Diarrhoea	16.9% (44)
Role Functioning	11.1% (29)	Low appetite	13.0% (34)
Cognitive functioning	5.8% (15)	Pain	12.6% (33)
		Fatigue	11.6% (30)
Global Quality of Life	15.4% (40)	Dyspnoea	9.3% (24)
		Financial impact	8.5% (22)
		Nausea and vomiting	6.9% (18)

<sup>24</sup>This method is conservative in terms of identifying the percent of participants with difficulties, as the method used by Michelson et al., (2000) and by Osaba et al., (1998) uses the degree of 10 on the 0-100 scale to be indicative of an important difference in health related quality of life. Since the standard deviations from the current sample subscale means are all in excess of 10 the above methodology is considered to be more appropriate.

TABLE 10 Descriptive statistics for sample on EORTC-QLQ-C30 with one-sample t-test comparisons to Michelson el al. (2000).

Scale	Subscale	Current Study Mean (SD)	۲ ۲	Cancer Sample Mean <sup>25</sup>	Healthy Sample Mean	Comparison cancer sample One sample t-test <sup>26</sup>	Comparison healthy sample One sample t-test
0C-30							
Functioning	Physical functioning	83.25 (16.12)	262	81.5	97.0	t(261) = 1.75, p >.05	t(261) = -13.75, p < .05**
	Role functioning	87.02 (20.71)	262	81.6	94.0	$t(261) = 4.24$ , $p < .05^{**}$	$t(261) = -5.45$ , $p < .05^{**}$
	Emotional functioning	75.78 (23.27)	260	81.5	85.6	t(259) = -3.96, p < .05**	t(259) = -6.80, p < .05**
	Cognitive functioning	79.81 (21.41)	260	86.6	93.1	t(259) = -5.11, p < .05**	t(259) = -10.01, p < .05**
	Social functioning	83.91 (24.39)	260	87.5	96.6	t(259) = -2.37, p < .05*	t(259) = -8.38, p < .05**
	Global QoL	77.53 (19.71)	260	73.2	85.2	$t(259) = 3.54, p < .05^{**}$	$t(259) = -6.27$ , $p < .05^{**}$
Symptoms	Fatigue	23.02 (21.78)	262	27.0	13.4	t(261) = -2.95, p < .05**	$t(261) = 7.15, p < .05^{**}$
	Nausea and Vomiting	4.13 (13.32)	262	Not re	ported	•	
	Pain	15.90 (25.17)	261	25.7	9.0	t(260) = -6.28, p < .05**	$t(260) = 4.42, p < .05^{**}$
	Dyspnoea	14.16 (25.17)	259	25.4	12.8	t(259) = -7.18, p < .05**	t(259) = 0.86, p > .05
	Insomnia	30.78 (34.62)	261	Not re	ported	-	I
	Low appetite	6.02	261	24.9	10.9	t(260) = -17.10, p < .05**	$t(260) = -4.43, p < .05^{**}$
	Diarrhoea	6.79	260	Not re	ported	I	I
	Constipation	10.55	259	Not re	ported	I	I
	Financial impact	11.62 (25.85)	258	7.6	1.2	t(257) = 2.50, p < .05*	$t(257) = 6.48, p < .05^{**}$
	.+	- <del>-</del>					

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\$SD not reported; \* p<.05; \*\* p<.01</pre>

<sup>25</sup>The first mean is for the subset of the Michelson et al (2000) sample who reported cancer as a health problem (n=134) and the second mean is for the subset of the sample that reported having no health problems (n = 721). <sup>26</sup>The first t-test statistics refers to a comparison between the current study mean score and the reported mean score for those who reported cancer and the second refers to the comparison with those who reported no health problems in that study.

## Comparison to Reference Data

The current sample were compared as a whole with two subsets of a large scale study of the Swedish population to obtain quality of life reference data on a number of health conditions (n = 3,069) (Michelson, Bolund, Nilsson and Brandberg, 2000) (see Table 10). One subset of that sample reported cancer as a chronic health problem (n = 134) and another subset reported no health problems (n = 721). The quality of life scores for the current (Irish) sample were compared to both of these sub-sets (referred to as the Swedish cancer sample and the Swedish healthy sample for the purpose of clarity).

The rationale for this approach is the argument made by Michelson et al (2000) that there is a need to examine whether or not the health related quality of life of long-term cancer survivors returns to general population levels after treatment. However, some caution should be exercised in interpreting any differences found between the current sample and these reference values, as details of time since treatment were not available for these reference data and thus they may not be entirely comparable.

As can be seen in Table 10, when compared to the Swedish cancer sample, the Irish sample do not differ in terms of physical function, they have significantly higher levels of role function and overall Global Quality of Life but significantly lower emotional, cognitive and social function scores than that sample. In addition, the Irish sample exhibited significantly lower levels of physical, role, emotional, cognitive, social functioning and overall Global Quality of Life when compared to the Swedish healthy sample.

In terms of the symptoms, the Irish sample exhibit significantly higher levels of fatigue and pain than the Swedish healthy sample but significantly lower levels of those symptoms than the Swedish cancer sample. With regard to dyspnoea, the Irish sample was not observed to differ from the Swedish healthy sample and the mean score was significantly lower than the Swedish cancer sample indicating a return to a healthy population level of dyspnoea. In addition, the Irish sample exhibited significantly less problems with low appetite but a significantly greater level of financial impact than either Swedish samples (albeit still at a low level).

# 5.9.1 Cancer Specific Quality of Life

#### Quality of Life in the Breast Cancer Group

The quality of life of breast cancer survivors in the current sample was next examined. They had quite high functioning scores, the lowest being emotional functioning and with regard to symptoms, insomnia and fatigue were most problematic, followed by pain. All mean scores had high standard deviations indicative of a wide variation in symptom experience.

When compared to a sample of 77 French breast cancer survivors who were, on average, 9.1 years post treatment and had received chemotherapy (Joly, Espié, Marty, Héron and Henry-Amar, 2000), this Irish sample of breast cancer survivors had significantly higher levels of role and cognitive function but lower social function. In all other functions, they were similar to that group. With regard to symptoms, they had significantly higher levels of fatigue, insomnia and financial impact, and significantly lower levels of constipation.

Concerning the breast cancer-specific functions and symptoms, when compared to the Joly et al. (2000) sample, the Irish breast cancer survivors compared favourably in terms

of body image and sexual enjoyment but had significantly lower levels of sexual functioning and breast symptoms and significantly higher future perspective scores<sup>27</sup> and arm symptom scores.

#### Quality of Life in the Colorectal Cancer Group

On average, the colorectal cancer survivors in the present study exhibited very high function levels in all domains and their most problematic symptoms were insomnia and fatigue. However, there was a wide variation in symptom experience.

When compared to a sample of 222 German colorectal cancer survivors who were 3 years post diagnosis (Arndt, Merx, Stegmaier, Zeigler, & Brenner, 2006), the current (Irish) sample had significantly higher functioning scores on all functions. In terms of symptoms, they had better quality of life, with the exception of nausea and vomiting, low appetite and diarrhoea where they did not differ from the German sample.

Concerning colorectal specific functions and symptoms, the Irish sample exhibited quite varied scores. Their body image was quite high but sexual functioning quite low. With regard to symptoms, male and female sexual problems, along with stoma-related problems were the most troublesome but there was wide variation in symptom levels. When compared to the German survivors (Arndt et al., 2006) a significant difference was not observed with the exception of significantly lower scores for sexual functioning and sexual enjoyment. However, the Irish sample had significantly lower levels of stoma-related problems than the German sample.

#### Quality of Life in the Prostate Cancer Group

Quality of life function scores were high for all domains, with overall global quality of life being the lowest. In relation to symptoms, the most problematic were insomnia and fatigue but with a wide variation in response. When compared to a group of 42 Swedish prostate cancer survivors who were at least 3 years post treatment (Wahlgren, Brandberg, Häggarth, Hellström & Nilsson, 2004), the Irish sample exhibited no significant differences apart from having a significantly lower score for diarrhoea.

With reference to the prostate cancer-specific functions and symptoms, the symptom scores were quite low and the sexual functioning score was in the moderate range. No comparative data using these subscales were available.

Although the data was available, the lung cancer group (n=7) was considered too small to conduct cancer specific analysis.

#### 5.9.2 Quality of Life Summary

In summary, although the majority of the sample have quite high quality of life, a substantial percentage (up to 26%) have difficulty in terms of overall global quality of life, specifically with physical, emotional, social, and role function and with insomnia, constipation, diarrhoea, low appetite, pain and fatigue.

When compared with similar European groups, the Irish sample have poorer emotional, cognitive and social functioning than either a Swedish cancer sample or healthy sample and they fall in between the cancer sample and the healthy sample in terms of all

<sup>27</sup> One of the subscales on the cancer-specific EORTC measures is called Future Perspective.



symptoms, with the exception of financial impact which is greater in the Irish sample than in either of the Swedish groups.

The breast cancer sample in the current study have high functional quality of life overall with the only cause for concern being in the emotional functioning domain. In terms of symptoms, insomnia, fatigue and pain are the most problematic. When compared to the French post-treatment survivors, they are quite similar but have better role and cognitive function and greater difficulty with fatigue, insomnia, and financial impact. In relation to specific breast cancer function and symptoms, the Irish sample compare favourably in most functional domains, with the exception of poorer sexual functioning and better future perspective. They also have significantly less difficulty with breast symptoms but greater difficulty with arm symptoms than the French sample.

The colorectal group have high quality of life in terms of function and symptom levels. They compare favourably with the comparison group and in fact have higher levels of function in many domains and less difficulty with symptoms. The only exceptions to this are in the sexual functioning and sexual enjoyment domains where their quality of life is poorer than a German sample but they have significantly less difficulty than that sample with regard to stoma-related problems.

Finally, the prostate cancer group report high quality of life in all domains and symptoms. They compare favourably with the reference group and the Swedish comparison group and even have significantly higher quality of life in a number of domains than the reference group.

# 5.10 Psychological Wellbeing

Psychological wellbeing was assessed via a number of measures including measures of anxiety and depression, hope, optimism, control beliefs, coping and social support (see Appendix D for summary data).

#### Anxiety and Depression

An examination of the distribution of anxiety scores reveals that 67% (n = 173) of participants were within the normal range for anxiety levels, 18.2% (n = 47) were mildly anxious, 10.9% (n = 28) were moderately anxious and 3.9% (n = 10) severely anxious (see Figure 13). In all 33% of the sample had above normal levels of anxiety with a possible need for clinical intervention.

With regard to depression, most participants were within the normal range (90.7%, n=234), 6.9% (n=18) were mildly depressed, 2% (n=5) were moderately depressed and one participant was severely depressed (0.4%).

When compared to a study of 154 Australian breast, prostate and colorectal cancer survivors who were, on average, four years post-treatment (Hodgkinson, Butow, Hunt, Wyse, Hobbs, & Wain, 2007), the present study participants exhibited significantly higher levels of anxiety and depression.



FIGURE 13. Distribution of mean anxiety levels in survey sample.

#### Hope and Optimism

Just over 60% of the sample had high levels of hope<sup>28</sup> (60.4%; n = 142) and 39.6% (n = 93) had low hope levels (see Appendix D for summary data). The mean hope score compared favourably with a sample of 91 American breast cancer survivors who were, on average, seven months post-treatment (Stanton, Danoff-Burg, Cameron, Bishop, Collins, Kirk & Sworowski, 2000). However, optimism levels were significantly lower than a sample of 165 Norwegian breast cancer patients at the time of their diagnosis (Schou, Ekeberg, Ruland, Sandvik & Karesen, 2004), indicating that the Irish sample was more pessimistic. Further analysis using a median split revealed that 56.8% (n = 129) were pessimists while 43.2% (n = 98) were optimists.<sup>29</sup>

## Control and Efficacy Beliefs

Control beliefs impact on the survivor's ability to take on board lifestyle change as well as effecting their cognitive expectations. Average health-related locus of control was significantly higher in the current sample than in a sample of 109 American breast cancer survivors who were on average 4.3 years post-treatment (Naus, Price & Peter, 2005). However, they exhibited significantly lower levels of self-efficacy when compared to a sample of 97 German patients with a variety of cancers who were one month post-surgery (Luszczynska, Mohamed & Schwarzer, 2005).

#### Coping and Social Support

The coping strategies of taking positive action and using positive reframing were emphatically endorsed by most of this sample (see Appendix D). The use of emotional support, humour and religion were normally distributed across the sample, while the negative strategies of denial, negative action and self-blame were not widely used. No comparative data were available.

Finally, with regard to social support, the current sample exhibit significantly lower overall social support than a mixed gender sample of Canadian head and neck cancer survivors who were 2.4 years, on average, post-treatment (Katz, Irish, Devins, Rodin & Gullane, 2003).

<sup>28</sup> As defined by the authors' cut-off scores for high and low hope.

<sup>29</sup> This is a conservative figure using the median score for the current sample of 16 compared to Schou et al., (2004) who used a median score of 18 as a cut-off to categorise pessimists and optimists.

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# 5.11 Overall Profile Summary

The largest group of survivors in the current study were breast cancer survivors, and the smallest group were lung cancer survivors. This is representative of the survival rates for these cancer types. The average age was 62 years and the majority were married, had a second level education, owned their own homes, had household incomes of less than 35,000 euro per year and had private health insurance.

Most participants received a combination of medical treatments and the average time since treatment ended was just over four years. The majority of participants had co-morbid health problems and in terms of mental health, 33% of the sample had anxiety scores in the clinical range for possible disorder but very few suffered from depression. On balance, the sample was split evenly in terms of negative and positive mental approach and used positive coping strategies. However, their social support was quite low, as were their selfefficacy beliefs.

With regard to lifestyle, over half of the sample were overweight and of these a significant number were in the obese category. Almost half the participants had put on weight since diagnosis. Some participants were still smoking after cancer and a third drank alcohol three or more times a week. Concerning physical activity, a quarter of the sample did not engage in any regular physical activity and over a third had reduced their physical activity levels due to fatigue. The average diet was poor in comparison to recommended levels.

This sample had little contact with any resources that would aid their recovery and rehabilitation, both during their time in the hospital setting and post-treatment. There was a striking lack of contact with a dietitian, physiotherapist or a psychologist during their treatment. What is more, most participants did not avail of cancer support centres or use complementary therapies largely due to a lack of information about such resources.

# 5.12 The Relationship between Quality of Life and Mental Wellbeing

The second aim of the current study was to examine the relationship between quality of life, anxiety, depression, hope and optimism.

The data revealed that there was a positive relationship between quality of life, hope, optimism and self-efficacy in every functional domain. Furthermore, there was a negative relationship between quality of life and anxiety, depression and negative coping strategies such as denial and substance use.

In addition, difficulty with almost all of the quality of life symptoms was associated with higher levels of anxiety, depression and negative coping strategies. Conversely, lower symptom levels were associated with higher levels of hope and optimism.

In summary, better functional quality of life in all domains was related to higher levels of hope and optimism and lower levels of anxiety, depression and negative coping strategies. The strongest relationship overall was that high anxiety was associated with poorer emotional functioning. Vis-à-vis symptoms, higher levels of anxiety, depression and maladaptive coping strategies were associated with more problematic symptoms, whilst higher levels of hope and optimism were related to reduced symptom difficulties.

# **5.13 Group Differences**

The third aim of the current study was to identify the risk factors that are most significant in terms of identifying participants that would benefit from the pilot intervention programme in the next study. To fulfil this aim, a number of group differences were investigated using parametric analyses.

The variables of interest were age, gender<sup>30</sup>, cancer type, treatment type, time since treatment and socio-economic status. Furthermore, hope, optimism and anxiety were significant correlates of quality of life and were negatively related to each other. Given that the proposed intervention in Study 3 involved a positive approach to rehabilitation, comparisons were made between high and low hope and optimism and between high and low anxiety groups with respect to quality of life<sup>31</sup> to facilitate identification of intervention selection criteria. Since there were only seven lung cancer participants, a decision was made to exclude this group from further analysis.

## 5.13.1 Comparisons between Age Groups

Participants were separated into three age groups to examine possible age differences in quality of life, anxiety, depression, hope and optimism.

The groups were as follows:

Group 1	=	Up to and including 55 years of age
Group 2	=	Over 55 years and up to and including 65 years
Group 3	=	Over 65 years of age

Significant age group differences were found in terms of emotional, cognitive and social functioning, and further analysis revealed that the younger age group had significantly lower levels of emotional functioning than the oldest group but the age-related source of difference for cognitive or social functioning was not determined.

In relation to symptoms, the 55 - 65 years group had significantly higher levels of nausea and vomiting than the older age group and the two older age groups had significantly higher levels of dyspnoea than the younger group. In terms of financial impact, the youngest group had significantly greater difficulties than the oldest group and moreover, the youngest age group had significantly higher levels of anxiety than the oldest group.

## 5.13.2 Comparisons between Cancer Types

Possible cancer type differences in quality of life, anxiety, depression and hope and optimism were examined next. Analyses revealed that the breast cancer participants had significantly lower levels of emotional and cognitive functioning and had significantly higher levels of anxiety and depression than the colorectal cancer participants. No other cancer type differences were found.

<sup>30</sup> Gender co-varies with cancer type in this study and the only groups with both genders were the colorectal cancer group (males = 29; females = 20) and the lung cancer group (n=7). The lung cancer group were excluded based on group size. Independent t-test analyses revealed a single gender difference, that is, females have significantly higher levels of anxiety than males t (28.11) = -3.01, p < .01. Further analysis with gender is not carried out as cancer type is considered the more salient variable and gender cannot be separated from this.

<sup>31</sup> Differences between high and low levels of depression were not examined since the majority of the sample (over 90%) were within the normal range for depression (see previous chapter section 9.9.2.3).

## 5.13.3 Comparison Between Treatment Types and Time Since Treatment

The next analyses examined possible treatment type differences in quality of life, anxiety, depression, hope and optimism. Given the large variety of treatment combinations, groups were categorised as follows:

Group 1	=	Surgery only
Group 2	=	Combination of surgery plus chemotherapy and/or radiotherapy
Group 3	=	No surgery

No significant differences were observed on any of the study variables.

Analyses were also conducted to examine possible differences in terms of the length of time since treatment ended. Groups were categorised as follows:

Group 1	=	Up to two years since treatment ended
Group 2	=	More than two and up to five years since treatment ended
Group 3	=	Five or more years since treatment ended

No significant group differences were found for any of the dependent variables.

## 5.13.4 Impact of Socio-Economic Status

To investigate whether socio-economic status impacted on quality of life, anxiety, depression, hope and optimism, the participants combined household income was calculated and categorised into four groups as follows:

Group 1	=	Less than €35,000
Group 2	=	€35,000 to €54,999
Group 3	=	€55,000 to €74,999
Group 4	=	€75,000 or more

Significant group differences were observed and further analysis revealed that the lowest income group had significantly lower levels of physical function, hope and optimism than the highest income group.

They also had significantly greater difficulty with the symptoms of nausea and vomiting and dyspnoea than the highest income group. Group differences were also observed for diarrhoea, however, the source of this difference was not identified by post hoc analysis.

## 5.13.5 Comparisons on the basis of Hope and Anxiety levels

The final series of analyses were conducted to further aid identification of selection criteria for the pilot intervention to follow in Study 3. Participants were grouped according to the cut-off scores recommended by the scale authors into high and low hope groups and into high and low anxiety levels.

Analyses revealed that the high hope group had significantly better physical, emotional, cognitive, and social functioning and better overall global quality of life than the low hope group. Furthermore, they fared better in terms of symptoms, as the low hope group had
significantly higher levels of dyspnoea, insomnia, constipation and financial impact. Furthermore, the high hope group had lower levels of anxiety and depression.

Possible differences between the high and low anxiety groups were also examined and revealed that the high anxiety group had significantly poorer quality of life in terms of physical, role, emotional, cognitive and social functioning and overall global quality of life. Additionally, the high anxiety group had significantly greater difficulty with the symptoms of fatigue and pain, insomnia, low appetite, constipation and financial impact. As might be expected, the high anxiety group also had significantly lower levels of hope and optimism than the low anxiety group.

### 5.13.6 Summary of Group differences

In examining group differences, the analyses found that younger survivors had lower quality of life in terms of emotional function. They also experienced greater financial impact and had higher anxiety levels than the older groups. No age group differences in hope and optimism were observed.

In terms of cancer type, breast cancer patients had lower functional quality of life in the emotional and cognitive domains and significantly higher levels of anxiety than the colorectal cancer group who had the highest quality of life function scores. It appears that the type of treatment received by this sample did not make a difference in terms of quality of life and the length of time since treatment only impacted on social functioning, which improved over time.

With regard to socio-economic status, the lowest income group fared less well than the highest income group in terms of physical function and lower levels of hope and optimism. They were worse off in terms of symptoms, as they experienced more problems than the highest income group.

Finally, participants with higher levels of hope and low anxiety had better overall quality of life in all functional domains with the exception of social functioning. They also fared better in terms of symptoms, particularly with regard to fatigue, pain and insomnia.

# 5.14 Findings from open-ended questions

Participants were asked a number of open-ended questions at the end of the survey. There is a wealth of data in the responses to these questions but an analysis of all these responses is beyond the scope of the present report. However, given the ultimate aim of the project, which was to develop and evaluate a pilot rehabilitation programme, it is considered appropriate to present summary findings from a brief analysis of the two most salient questions to that aim.

The first question asked participants to suggest ways in which the health services could have been more helpful to them and the second asked for views on the factors health professionals should be more aware of about living after cancer.

# 5.14.1 How Health Services Could have been More Helpful

Participants were asked the following question:

Now that you have finished your medical treatment, do you feel the health services could have been more helpful to you in any particular way?

Over eighty three percent of the sample responded to this question (83.6%, n = 209). Responses were very varied and the majority of participants referred to the excellent treatment they had received. However, there were a number of specific themes identified in relation to how health services could have been more helpful in the context of recovery and rehabilitation after cancer. Participants felt that health services could be more helpful in terms of

- a) Follow-up Post-treatment,
- b) Better Information about Emotional and Psychological Support,
- c) Advice on Diet and Exercise,

A brief summary of these themes is presented below, with the number of participants raising particular issues presented in brackets (n).

# a) Follow-up Post-treatment

The most frequently raised issue was in relation to the lack of health service involvement once medical treatment was complete (26). Participants told of feeling like they had been "*set adrift*" with no back up. One participant said that

"The lack of after-care made me feel like I was dealing with things on my own. Once I had left the hospital there was no back-up and it was only through my own endeavours that I finally got my life back on track".

A number of participants (14) spoke about the poor quality of information given about the post-treatment phase, including what to expect in terms of after-effects, as evidenced by the following comment,

"During my treatment and about 2 years after I was ok. Then it seemed to hit me, what happened to me, and I fell apart. I would like to have known this might happen".

Participants wanted better information about positive action they could take after treatment rather than

"Being constantly told there are things you can't do e.g. gardening. This side of things should be more positive".

# b) Better Information about Emotional and Psychological Support

Participants referred not only to the lack of psychological support (7) but also the lack of any information about counselling and support groups (6). A number stated that they would have liked counselling or some form of emotional support or connection to a support group and to 'survivors' so that it would foster a positive approach during and after treatment (9).

### c) Advice on Diet and Exercise

A number of participants spoke specifically of the need for help with diet and nutrition post treatment (9), and also about physiotherapy and exercise (3).

### 5.14.2 Health Professionals' Awareness of Life After Cancer

Participants were asked the following question:

Are there any factors that you feel health professionals should be more aware of about living after cancer?

Sixty three percent of the sample gave responses to this question (n = 168). The responses were also varied but again a number of common themes were identified. Participants felt that health professionals should be more aware of

- a) Practical Post-treatment Issues,
- b) The Need to Communicate and Support, and
- c) The Significance of Fears and Anxieties about Recurrence.

These themes are presented below with the number of participants raising particular issues presented in brackets.

### a) Practical post-treatment issues

The most frequently raised issue here was the need for health professionals to become aware of the post-treatment effects of cancer (33). A very specific need was for professionals to be aware that survivors need advice about nutrition and diet post treatment (12) and to be aware of the practical, as opposed to surgical issues, of living with a breast-prosthesis (6).

### b) The Need to Communicate and Support

While many participants pointed out that their experience with health professionals was positive in regard to communication and support (24), a number felt that health professionals need to listen to and talk to survivors, to reassure them, and give them advice (33). In addition, participants felt that health providers should give cancer survivors more information about getting counselling and making contact with support groups (23).

### c) The Significance of Fears and Anxieties about Recurrence

Participants spoke of their ongoing anxieties, fears and worries about recurrence and that the health professionals need to be aware of this (21).

### 5.14.3 Summary of Reponses to Open Questions

Briefly, the responses to the open questions overwhelmingly praised the health professionals in terms of the quality of their medical treatment. However, there was a strong feeling that a follow-up service was necessary. Participants felt that health professionals were not concerned with the emotional impact of cancer, and there was little or no helpful advice on what to expect in terms of after-effects, diet or exercise or information on support services.

# 5.15 Study 2. Conclusion

The findings from the present study indicate that the majority of participants are doing very well in terms of quality of life post-treatment. However, up to a quarter of the sample need assistance to enhance their functioning or reduce symptoms.

The results show a clear need for intervention in terms of anxiety reduction, weight management, diet, and physical activity levels. In addition, there are clear relationships between hope and optimism and better quality of life and between higher anxiety levels and poorer quality of life.

The project set out to take a positive approach to survivorship and the findings from the literature and from the current study emphasise the importance of hope and optimism in terms of successful survivorship. It is patently clear that participants who have low quality of life levels, high anxiety, low levels of hope and optimism, as well as being overweight, having low physical activity levels and poor diet are in need of intervention to improve their quality of life after treatment.

Finally, when participants were given the opportunity to identify ways in which the health services could better meet their needs, there was a strong feeling that cancer health professionals need to be more aware of post-treatment issues to prepare their patients for 'after cancer'. A clear need for a post-treatment service was also identified, with a specific need for psychological support and understanding of anxiety and specific help with diet and physical exercise.

# 5.16 Selection Criteria for Intervention

Given the findings of Study 2, a number of key risk factors for poor quality of life were identified. These formed a set of selection criteria for participant inclusion in the pilot intervention programme to follow in Study 3. These risk factors were:

- 1. Low quality of life
- 2. High anxiety levels
- 3. Low levels of hope and optimism
- 4. BMI greater than  $25^{32}$
- 5. No physical activity or decreased physical activity levels since diagnosis

There is no evidence from the findings that a particular cancer type should be targeted, apart from higher levels of anxiety in breast cancer survivors than in others. Neither is there evidence that the type of treatment received resulted in differences in quality of life or that the amount of time since treatment impacted on quality of life, apart from social functioning, which improves over time. Therefore, time since treatment, cancer type and treatment type were not used as eligibility criteria.

With regard to socio-economic status, those in the lowest grouping had lower levels of physical function and greater difficulty with symptoms than the highest grouping and they had significantly lower levels of hope and optimism. However, socio-economic status was not considered a major criterion for eligibility for inclusion or exclusion from the pilot study.

The pilot programme participant selection process is described in the next chapter followed by a description of the intervention, its outcomes and evaluation.

<sup>32</sup>Since the majority of the sample appeared to have a poor diet, diet was not considered a useful variable for selection purposes.



# Box 2. Study 2. Summary of Conclusions

- Cancer survivors need a structured, co-ordinated approach to the post-treatment phase.
- They need a service that will enhance their quality of life in terms of functioning and symptom management.
- They need health professionals to be knowledgable about post-treatment issues and to pass that knowledge on to their patients.
- They need specific help with dietary change, weight and anxiety reduction and increasing physical activity levels.



# Chapter 6. Study 3: The Pilot Rehabilitation

# Programme

# 6.1 Introduction

This chapter outlines the development and implementation of a multidisciplinary, bio-psychosocial cancer rehabilitation programme for post-treatment survivors in the former ECAHB area. The major objective of the programme was to meet their bio-psychosocial needs and enhance their quality of life by supporting health-enhancing behaviour change.

The findings from Studies 1 and 2 revealed that the post-treatment survivor's needs are not adequately met and that there is a need for a structured and co-ordinated post-treatment service. Study 2 also showed that although the majority of survivors are doing very well in terms of quality of life post-treatment, up to one quarter need assistance to enhance their functioning and reduce symptoms. A clear need emerged for specific assistance in the areas of anxiety reduction, weight management, dietary advice and physical activity levels.

These findings map very nicely onto the American Cancer Society (Brown et al., 2003) recommendations for appropriate post-treatment goals for cancer survivors. These state that cancer survivors should aim for:

- An appropriate weight,
- A healthful diet and a
- Physically active lifestyle.

However, from a bio-psychosocial viewpoint there remains a gap in these recommendations, with no explicit mention of psychological or emotional goals for the survivor. Psychological factors are well documented as influences on health behaviour and health behaviour change (Ogden et al., 2007).

With regard to cancer survivors, Tunkel and Passik (1989) believe that behavioural interventions aimed at increasing motivation are very useful in maximising compliance with the rehabilitation process. Moreover, Andrykowski, Schmidt, Beacham, Salsman, Averill, Graves, and Harper, (2004) have highlighted the lack of investigation into the relationship between physical and psychosocial variables in cancer survivors.

Given the positive relationship between hopeful thinking and quality of life that emerged from Study 2 and the high anxiety levels evident in survivors, it was considered appropriate to add a psychological goal to the above ACS recommendations.

Therefore, a more complete recommendation for appropriate post-treatment goals would include the objective of:

Hopeful thinking as an aid to anxiety reduction and support for the positive behaviour changes advocated in the other goals.

# 6.2 Study Aims

This study aimed to develop a multidisciplinary pilot programme that would improve functional status, reduce symptoms and improve the health-related behaviours of the participants. The specific programme objectives were to:

- Increase quality of life by means of
  - Improving levels of function and
  - Reducing symptoms
- Reduce anxiety levels
- Increase levels of hopeful thinking
- Effect lifestyle changes in the form of
  - Increased levels of physical activity, fitness and strength

Effect lifestyle changes in the form of

- Increased fruit and vegetable intake (as measured by vitamin C intake), reduced intake of saturated fat and overall calories and
- Achieving weight, BMI reduction and a reduction in waist measurement.

# 6.3 Research Design

A mixed model, complex, repeated-measures design (Time 1, Time 2) was used to ascertain the impact of a purposely designed rehabilitation programme on the quality of life and health behaviours of programme participants (see Table 11). The independent variables were group (treatment, comparison) and time (pre and post intervention). Programme design and delivery involved the collaboration of the UCD School of Psychology along with the Psycho-oncology Unit and the Physiotherapy and Dietetics departments in St. Vincent's University Hospital.

 TABLE 11. Intervention research design

en ect	Time 1	Time 2
twe bje acto	Treatment Group	Treatment Group
su fa	Comparison Group	Comparison Group

# Within Subject factor

Thirty-eight breast, prostate and colorectal cancer survivors selected from the Study 2 sample were allocated to either an intervention or comparison group.<sup>33</sup> All eligible participants retained the ID code assigned for the Study 2 survey. To facilitate selection of participants for the intervention, a number of key Study 2 variables informed the selection criteria. These included address<sup>34</sup>, overall quality of life, physical activity variables and nutrition variables, as well as levels of anxiety, hope and optimism (see next page for details of selection process).

The programme consisted of three modules, a physical activity module, a dietary training module and a psycho-educational (Hope Therapy) module. It was run over 8 weeks with participants attending two hospital-based sessions per week and engaging in a

<sup>34</sup> Due to the heavy time commitment for the programme and the timing of evening sessions, a decision was made to exclude those who lived beyond Bray, Co. Wicklow and those living on the south-west boundaries of the former ECAHB area.

<sup>&</sup>lt;sup>33</sup> The lung cancer survivors that took part in Study 2 were excluded from the selection process for Study 3 due to concerns about their lung capacity and the inclusion of a physical activity component in the proposed programme.

personalised exercise prescription at the weekends. Hospital based sessions were outside of normal working hours. Each hospital-based session was run back to back over a 2.5 to 3-hour session. Those in the comparison group were offered a place on a Mindfulness course after the programme was completed.

All participants were pre-screened by senior clinicians from each of the relevant disciplines before the programme to ascertain whether there were any physical or psychological co-morbidities that would impinge on their successful participation in the programme.<sup>35</sup>

Participants completed a battery of pre and post assessment measures. The major independent variables were group assignment (treatment or comparison) and time of testing (pre, post intervention). The major dependent variables reflected the three intervention components as well as overall quality of life, including anxiety, hope, optimism, fitness, strength, weight, waist circumference and nutritional intake.

The efficacy of the programme was evaluated in terms of:

- a) Changes in outcome measures,
- b) Participant satisfaction, and
- c) Programme delivery team satisfaction.

The evaluation is presented in the next chapter.

# 6.4 Participant Selection

Participation in this study was dependent on previous participation in the Study 2 survey. Selection for invitation to take part in the intervention was then based on a points system that was developed for selection purposes. A decision was made to exclude those over 65 years of age from this pilot study based on evidence that 80% of those who are over 65 years have at least one co-morbidity and may have difficulty in adhering to a supervised exercise regime and require a modified programme compared to younger or middle-aged survivors (Malek and Silliman, 2007; Courneya, Karvinen & Vallance, 2007).

After excluding those over 65 years, only three lung cancer survivors remained. These were excluded along with the individuals who were current smokers, as there were concerns about their lung capacity in relation to the physical activity component of the intervention. Finally, those living outside a practical distance boundary were excluded from participation in this study due to concerns about attendance and adherence.

Points were allocated for both physical and psychological variables that were identified as key factors in Study 2.

The inclusion and exclusion criteria for selection are outlined below:

### Inclusion criteria:

- Breast, prostate and colorectal cancer survivors who met the original inclusion criteria for Study 2.
- Study 2 participants who rated a minimum of 2 points on a selection scale where at least 1 point related to physical function and 1 point related to psychological function.

<sup>35</sup> This involved the use of the Structured Clinical Interview for DSM-IV (SCID 1) and a musculoskeletal assessment.

Points were allocated for each of the following key variables

- Low or decreased levels of physical activity,
- High BMI,
- High levels of anxiety,
- Low hope and/ or high pessimism,
- Low Global quality of life,
- Low physical or emotional function

### Exclusion criteria

- Age over 65 yrs
- Lung cancer survivors
- Current smokers
- Living in Co. Wicklow (excluding Bray town) (attendance too onerous)

Sixty-five survey participants (n = 65) met the inclusion criteria, from the original pool of 262, and were invited to take part in the programme. All participation was voluntary and informed consent to participate was required. Eligible participants received a letter inviting them to take part in the pilot programme along with an information leaflet, consent form and a stamped addressed envelope. They were asked to read the information leaflet and if they were willing to take part in the study to show the information leaflet to their General Practitioner to verify their suitability for the programme screening. Thirty-nine participants agreed to take part in the study, however, one of these withdrew at pre-programme screening. In all, thirty-eight participants took part in the study, giving a response rate of 58.5%.

# **6.5 Development Process**

Given the findings of studies 1 and 2 and the clear need for intervention on physical and psychological levels, a programme was developed consisting of three modules based on expert recommendations and intervention best practice with the needs of survivors to the fore. This is in accord with Nigg and colleagues' (1997) recommendation that interventions should address multiple behaviours. The intervention was developed with co-operation from the physiotherapy and dietetics managers in St. Vincent's University Hospital (SVUH), and after discussions with a member of the cardiac rehabilitation programme team at SVUH and an exercise physiologist. Over a number of months the programme was refined to identify module content, identify and procure assessment materials, develop pre-intervention screening criteria, formulate the optimum schedule for delivery and put in place the necessary supports and personnel to deliver the programme.

Once approval was obtained from the Medical Ethics Committee in SVUH, the process of recruitment of the delivery team and participant selection began. Two physiotherapists were recruited to deliver the physical activity module under the direction of the deputy manager of the physiotherapy department.<sup>36</sup> The dietetics manager delivered the nutrition module and the researcher assisted the senior clinical psychologist who delivered the hope therapy module. All of the programme delivery team had experience of working with cancer patients in the past. Additional physiotherapists and nutritionists were recruited to assist with pre and post assessments, which took place at weekends.

<sup>36</sup> Best practice guidelines in group exercise programmes in physiotherapy recommend that two fully qualified staff are on duty simultaneously.

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# 6.5.1 Location

The physiotherapy department facilitated the project team with the use of the gym facilities and organised the cleaning of the gym after the business of the day and before the programme sessions began. There were significant difficulties getting a suitable classroom in the hospital for the nutrition and psycho-educational sessions. Again, the Physiotherapy department facilitated the programme with the use of a second gym room for a number of weeks and then the programme transferred to one of the hospital boardrooms.

# 6.5.2 Safety

The intervention was under the supervision of fully qualified hospital personnel and took place in SVUH. Indicators of exercise stress e.g., blood pressure, heart rate, perceived exertion and shortness of breath were monitored for each participant pre and post each physical activity session. In addition, participants were educated in self-monitoring for exercise safety.

Both of the physiotherapy instructors were trained in basic life support and aware of how to react in case of an adverse event. An advanced life support team was in place in the hospital but physiotherapists are experienced in leading exercise classes in ill populations and adverse events are extremely rare. If a participant's condition deteriorated, there was direct access to the A&E service, which had been alerted about the timing and content of the programme. A senior clinical psychologist was also available to participants throughout the programme should the need arise. Fortunately, no incidents arose during the programme that required such services.

# 6.6 Pre-programme Screening and Assessment

# 6.6.1 Screening

Participants who agreed to take part in the study (n = 38) were given an appointment to attend the Physiotherapy gym for pre-programme screening. At this appointment they were pre-screened for suitability to take part in the programme using the Structured Clinical Interview for DSM-IV Axis 1 Disorders (SCID -1/NP (Non-Patient Edition), First et al., 1997) administered by the senior clinical psychologist. Participants also underwent a musculoskeletal assessment carried out by the physiotherapists in the hospital gym. This evaluation enabled the identification of any conditions that might affect participation in class and facilitated the tailoring of individualised exercise prescription.

# 6.6.2 Pre and Post Programme Assessment

All participants in the study completed a battery of pre and post-treatment measures to examine overall programme and specific module-related effects. Quality of life, health-related behaviours (physical activity and diet) and behaviour change variables were the main variables of interest.

The primary outcome measures were:

The EORTC Quality of Life Questionnaire QLQ-C30 (version 3.0) (Aaronson, NK., et al

1993) as used in the earlier survey to assess functional status in a number of domains (higher scores = higher quality of life) and to assess the level of symptom difficulty impacting on quality of life (higher scores = poorer quality of life).

- The 1xRepetition Maximal Strength Test. This measure of muscle strength involves the participant using quadriceps to lift weights of 5lb intervals (Abernethy, 1996).
- The Modified Shuttle Walk Test (Singh, 1996; Win et al., 2006). This progressive walk test was used as an objective measure of fitness and functional capacity.
- Anthropometric measurements including weight, Body Mass Index, waist circumference (cm), triceps skin-fold thickness and mid-arm muscle circumference to determine change in fat and muscle mass were used.
- The Three Day Food Diary to document all food and drink consumed over the course of two days of the week and one weekend day. This self-report measure is considered a reliable indicator of nutritional intake (Day et al., 2001).
- The State Hope Scale (HS) (Snyder et al., 1996) was used to measure increases in hopeful thinking.
- The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) measured anxiety and depression levels.
- The Godin Leisure-Time Exercise Questionnaire (Godin & Shepard, 1985; Godin et al., 1986).

# **6.7 Intervention Timeline**

The programme was run over 8 weeks, however, additional time was built in for pre-programme screening and completion of assessment instruments pre and post intervention.

Week 1	Introduction and completion of pre-intervention assessment
Weeks 2 to 9	Intervention (twice-weekly sessions plus home-based activity prescription)
Week 10	Completion of post-intervention assessment measures and graduation

### 6.7.1 Programme Timetable

One of the primary concerns of the research team was to balance good research design with the burden of participation on the survivor in order to maximize adherence and benefit for the participants. To reduce the level of burden on the participants, while at the same time trying to implement best-practice recommendations was particularly important for the physical activity component of the programme where the recommendation is to engage in physical activity at least 3 times per week. To this end, a schedule was worked out that involved attendance at SVUH twice a week, on two weekday evenings, and participants were asked to engage in a home-based activity at the weekends.

The programme ran in the evenings for a number of reasons:

- To facilitate participants in employment
- To facilitate staffing (as most of the delivery team worked fulltime in SVUH)
- To allow for use of the physiotherapy department gym facility after hours

The intervention was designed to run over eight weeks with three physical activity sessions scheduled each week (two hospital-based and one home-based), as well as one hope therapy session and one nutrition session per week. A copy of the programme schedule is presented in Table 12.

### TABLE 12. Pilot rehabilitation programme weekly schedule

Day 1		Day 2		Weekend
6pm - 7 pm	7pm - 8pm	6 pm - 7.30pm	7.30pm - 9pm	Home
Physical activity	Physical activity	Hope Therapy	Hope Therapy	Physical activity
Nutrition	Nutrition	Physical activity	Physical activity	Physical activity

Pink=Breast cancer group; Blue=mixed cancers group

Twenty two participants formed the intervention group. This group was divided into two smaller groups (11 in each), as there was a maximum group size that could be accommodated in the physiotherapy gym due to space and staffing restrictions. These two smaller groups consisted of a breast cancer only group and a mixed cancers/gender group.

These two groups ran back to back over a 3-hour session (participants attended an exercise session and then moved on to either a dietary training session or a hope therapy session and vice-versa e.g. while the breast cancer group attended the physical activity session the other group took nutrition class, then the groups changed over and attended their other class). This schedule was in place for the entire programme.

# 6.8 Programme Content

The programme focused specifically on the highlighted needs to:

- o Increase physical activity levels,
- o Get assistance with dietary change and weight reduction, and
- o Reduce anxiety and increase hopeful thinking.

The programme combined three modules:

Hope Therapy for Cancer Survivors. This module was designed to educate participants regarding survivorship issues and to facilitate the enhancement of hopeful thinking around behaviour change. It combined the principles of Hope Theory with a cognitive behaviour therapy approach (McDermott & Snyder, 1999; Snyder, 2000) and was based on previous work by Cheavens, Feldman, Gum, Michael and Snyder (2006) and adapted for the current study. Participants attended class on one evening per week for one and a half hours.

Hope theory frames goals as positive outcomes to be actively pursued rather than focusing on ways to avoid problems or remove symptoms. This module may be viewed as a scaffold supporting the other two modules. Specifically, it aimed to help participants to formulate appropriate physical activity and dietary goals and build motivation to achieve and sustain those goals as well as encouraging the individual to formulate goals in all domains of their lives. The main outcome measures of interest were, quality of life, levels of hope and optimism and anxiety levels.

- The Physical Activity Module This module involved the development of a personalised physical activity prescription for each participant and was designed to be enjoyable, build confidence and include a social element as per Courneya et al.'s (2000) recommendations. Participants engaged in a circuit of aerobic and weight training exercises twice a week under the supervision of the physiotherapy team (40-50 minutes per session including a 10 minute warm-up/cool-down). They also engaged in an unsupervised but personalised weekend walking programme. The participants were monitored throughout and provided with healthy refreshments after their session. The prescription was supported by the Hope Therapy module via the use of strategies to facilitate physical activity goal setting and attainment, and motivation for adherence to the programme. The main outcome measures for this module were increased aerobic fitness, strength and activity levels.
- The Dietary Training Module This module involved educating participants to engage in healthful eating to bring their nutritional intake in line with expert recommendations. Personalised advice was given where necessary. Demark-Wahnefried, Peterson et al. (2000) pointed to the need for interventions targeting increased fruit and vegetable consumption and further noted the strong relationship between diet and exercise behaviours and the possible benefits of multiple risk factor interventions.

Participants attended class on one evening per week for one hour. They were presented with information on a balanced diet, nutritional counselling, how to aim for a healthy weight, limit fat intake and increase fruit and vegetable intake. Information was also provided on reading food labels, food portion sizes, cooking methods, and the adaptation of recipes for those with specific dietary needs. Again this module was supported by the Hope Therapy module via the use of strategies to facilitate dietary goal setting and attainment, as well as motivation for adherence to the programme. The major outcome measures of interest were weight change, BMI and waist circumference, overall daily calories consumed, daily saturated fat intake and fruit & vegetable intake as measured by vitamin C levels.

# 6.9 Method

# 6.9.1 Random Assignment

The ideal method of group assignment of participants in intervention studies is randomisation. However, the practicalities of this were not feasible for the present pilot study due in part to the low number of participants involved and also to the time commitment required. The difficulty arose after pre-assessment and screening, when a number of study participants revealed that either they were not available to attend on the scheduled evenings or that they would miss more than 2 sessions over the course of the 8 weeks, for a variety of reasons. These participants were then asked to be part of the comparison group and were offered a place on a Mindfulness course run in the cancer support centre at programme end.

### 6.9.2 Participants

38 post-treatment cancer survivors took part in this study, 22 in the treatment group and 16 in the comparison group. These consisted of 26 breast cancer survivors (68.4%), 5 prostate cancer survivors (13.2%) and 7 colorectal cancer survivors (18.4%). Six males (15.8%) and 32 females (84.2%) participated in the study and the gender breakdown by cancer type and group assignment is presented in Table 13. All participants were 2-10 years post-treatment.

	Intervention G (n = 22)	iroup	Comparison G (n = 16)	roup	
Cancer Type	Males	Females	Males	Females	Total
Breast	0	16	0	10	26
Prostate	3	0	1	0	4
Colorectal	0	3	2	3	8
Total	3	19	3	13	38

TABLE 13. Gender breakdown by	cancer type in intervention
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The treatment group (n = 22) (age range 48-65 yrs; Mean age = 59.27; SD = 6.11)<sup>37</sup> consisted of one subgroup of breast cancer survivors and a mixed gender subgroup of breast, prostate and colorectal survivors. The comparison group (n=16) (age range 47-66 yrs; Mean age = 58.69; SD = 6.26) consisted of breast, prostate and colorectal cancer survivors. Table 14 presents the characteristics of study participants in the intervention and comparison groups at pre-assessment.

# 6.9.3 Programme Delivery

The treatment group were presented with an individualised exercise prescription after initial assessment and the programme began. It ran smoothly given the constraints of accommodation and the increased workload of staff.<sup>38</sup> The researcher and a research assistant were in attendance for every programme session and maintained attendance records, dealt with any difficulties that arose and reimbursed participants' parking costs. In addition, all participants were provided with healthy refreshments (fruit, cereal bars and water) at each programme session to ensure adequate energy levels since many participants came straight from their place of work.

During the early weeks of the programme there were concerns about the blood pressure of two participants and upon consultation with all concerned, including the relevant General Practitioners, these individuals did not continue with the exercise module but did continue with the other components of the programme. Both were advised to attend their General Practitioners.

<sup>&</sup>lt;sup>37</sup> Participants were selected on the basis of age at the time of the Study 2 survey. However, some participants had a birthday since the survey.

<sup>&</sup>lt;sup>38</sup> Staff in SVUH finished work @ 4.30pm and were ready to run the programme from 6pm-9pm twice a week

TABLE	14. Study	' 3	participant	charac	teristics	by	group	at pre	-assessm	ent
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Characteristic		Intervention (n=22)	Comparison (n=16)
Age (yrs)		Mean (SD)	Mean (SD)
		59.27 (6.11)	58.69 (6.26)
Time since treatment		4.18 (2.40)	3.21 (1.38)
(yrs)			
Marital Status		n (%)	n (%)
	Married/living with partner	18 (81.8)	12 (75)
	Single/widowed/ separated/divorced	4 (18.1)	4 (25)
Highest			
Level	Primary	4 (18.2)	2 (12.5)
20101	Secondary	10 (45.4)	3 (18.6)
	Third level	8 (36.3)	11 (68.8)
Occupational			
Status	Retired	3 (14.3)	4 (25)
	Employed	11 (52.4)	7 (43.8)
	Homemakers	6 (28.6)	4 (25)
	Unemployed	1 (4.8)	1 (6.2)
Household			
Income	Low <€35,000	10 (45.5)	7 (43.8)
	Middle €35,000- <€75,000	8 (36.4)	5 (31.3)
	High €75,000+	4 (18.1)	4 (25)
Private health insurance		15(68.2)	14 (87.5)
Medical Card <sup>a</sup>		2 (9.5)	4 (25)
Treatment type <sup>b</sup>			
	S+C+R	10 (45.5)	6 (37.5)
	S+C	1 (4.5)	3 (18.8)
	S+R	3 (13.6)	1 (6.2)
	S+C+R+Other	1 (4.5)	1 (6.2)
	Surgery only	6 (27.3)	5 (31.2)
	Radiotherapy only	1 (4.5)	0 (0)

<sup>a</sup> A number of participants appeared to have a medical card and private health insurance.

<sup>b</sup> S = Surgery; C = chemotherapy; R = Radiotherapy.

# 6.9.4 Attendance and Attrition

The attendance rate was very high at 76.5% and **21 of the original 22 participants completed the programme.** This was considered an exceptional result given the high level of time and work commitment involved in the programme.

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# 6.9.5 Post-Programme Take-home Literature

At programme end participants were given handouts with information about each aspect of the programme to facilitate continued adherence to each of the various elements of the programme.

This literature included advice on:

- Setting and maintaining hope goals
- Maintaining physical activity goals and
- Maintaining dietary change.

### 6.9.6 Post-programme Assessment

the treatment Once the programme was completed, group was given appointments to attend for post-intervention assessment and completed the post-assessment measures. This was later followed by the post-assessment of the comparison group which continued for a number of weeks with the aim of getting as many pre-assessed individuals as possible to complete as many of the post-assessment measures as possible (all 16 in the comparison group completed some measures). The comparison group were then invited to begin a Mindfulness course in the Lios Áoibhean Cancer Support Centre, attached to SVUH.

### 6.9.7 Graduation

Finally, a graduation ceremony was held in SVUH to present the treatment group participants with their certificates of completion and to acknowledge their contribution to the research. Family members were invited to attend along with all those who assisted in bringing the project to completion. All participants and the delivery team were thanked for their commitment to the research.

# 6.10 Data Management and Analysis

Data were entered into the SPSS statistical package and analysed. A preliminary analysis was conducted to examine whether there were group differences on the major pre-assessment study variables to ascertain the true level of comparability between the groups given that random assignment was not attainable in this study.

These analyses were followed by two-way repeated measures analyses of variance (ANOVA) to identify significant interactions between group (treatment x comparison) and time of assessment (time 1 x time 2). Where a significant interaction occurred, tests of simple effects were conducted to locate the source of the difference.

Finally, having excluded the comparison group from the analyses, a series of dependent t-test analyses were conducted to identify pre and post differences within the treatment group alone given that random assignment was not attained and in an effort to further determine the ability of the programme to bring about changes in the outcome variables.

# 6.11 Results

The findings of the present study are presented in the following sections. These are presented in order, according to the aims of the study. To begin with, independent groups analyses were conducted to examine whether there were any pre-programme differences between the intervention and comparison groups given that random group assignment was not achieved.

# 6.11.1 Pre-assessment Group Comparisons

Independent groups analyses revealed that the groups did not differ on any of the demographic or treatment variables (gender, age, level of education, marital or occupational status, household income, time since treatment ended or type of treatment received).<sup>39</sup> However, although the groups were selected from the same original dataset, significant differences were found on a number of the major pre-assessment study variables. Table 15 below presents the variables where significant pre-programme differences were found between the treatment and comparison groups.

These findings reveal that the treatment group had poorer quality of life in terms of functioning and symptoms on three of the EORTC subscales, with significantly lower evels of physical functioning and significantly higher levels of insomnia and pain than the comparison group before the programme began. However, in terms of physical functioning, it should be noted that the groups did not differ on the physical functioning scale of the MOS SF-36 measure suggesting that the measure used can influence the findings.

Variable	Treatment Mean (SD)	Comparison Mean (SD)	<i>t</i> -value
QoL Function <sup>a</sup>			
Physical	76.06 (16.67)	87.59 (10.29)	t(36) = -2.42, p < .05*
QoL symptom <sup>a</sup>			
Insomnia	46.96 (39.38)	22.91 (26.44)	<i>t</i> (36) = 2.25, <i>p</i> < .05*
Pain	28.03 (29.27)	9.37 (16.06)	<i>t</i> (36) = 2.30, <i>p</i> < .05*
Fitness	436.72 (59.18)	505.12 (74.77)	<i>t</i> (36) = -3.15, <i>p</i> < .05**
BMI	30.38 (5.26)	26.07 (4.13)	<i>t</i> (36) = 2.71, <i>p</i> < .05**
Weight (Kg)	81.23 (12.22)	71.15 (13.34)	<i>t</i> (36) = 2.41, <i>p</i> < .05*
Daily saturated fat (g)	36.16 (13.15)	25.68 (7.14)	t(33) = 2.64, p < .05*
Daily vitamin C (mg)	79.36 (41.92)	162.10 (96.34)	<i>t</i> (33) = -3.52, <i>p</i> < .05**

### TABLE 15. Pre-programme differences between treatment and comparison groups

<sup>a</sup> QoL = Quality of Life as measured by the EORTC QLQ-C30. \* p < .05; \*\*p < .01.

<sup>39</sup> Chi square analyses and independent t-test analyses were conducted where appropriate.

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The treatment group was also significantly less fit in terms of their scores on the shuttle walk test and they had significantly higher BMI and weight levels<sup>40</sup> than the comparison group. In addition, the treatment group had a significantly higher daily saturated fat intake and significantly lower vitamin C intake than the comparison group.

These findings have implications for the power of this study to detect interactions between group type and pre and post differences at programme end. As a result of the above findings caution must be observed when interpreting any pre and post intervention group differences found in the following sections.

### 6.11.2 The Impact of the Programme

The following sections present the findings from a series of two-way repeated measures analyses of variance (ANOVA). In this study, the major finding of interest is whether there is an interaction between group (treatment x comparison) and time of assessment (time 1 x time 2). Where a significant interaction occurred, tests of simple effects are conducted to locate the source of the interaction. In a 2 x 2 research design there are four simple effects tests carried out. The following sections present the findings from these analyses for each of the major variable categories in the study.

# 6.11.2.1 The Impact of the Programme on Quality of Life

The first aim of the study was to improve overall global quality of life, increase functioning and reduce symptoms. A graphic representation of changes over time for scores in each functional domain can be observed in Figure 14 and for each of the symptoms in Figure 15. Repeated measures ANOVA were conducted for each functional domain and each symptom subscale of the EORTC measure.

It emerged that no significant interaction was observed in terms of overall global quality of life or any of the functional domains. However, significant interactions were observed for the symptoms of pain and insomnia (see Table 16). To locate the source of the interaction, tests of simple effects were conducted. It emerged that the intervention and comparison groups differed at pre-assessment on both variables. This is in line with tests of equivalence previously reported. However, at post-assessment, this difference was not observed.

Looking at the effect of time, the intervention group improved significantly from pre to post assessment in terms of a reduction in pain and insomnia levels, however, this effect was not observed for the comparison group. This demonstrates the positive impact of the programme, however, one should be cautious, as the groups were not equivalent pre-programme on either variable.

Analyses were also conducted on the SF36 subscales to gain further insight into the impact of the programme. A significant interaction was observed for the 'role physical'<sup>41</sup> and the 'vitality' subscales. Again, to locate the source of the interaction, tests of simple effects were conducted. It emerged that the intervention and comparison groups differed at pre-assessment on both variables. However, at post-assessment, this difference was not observed for 'role physical', but remained for 'vitality'.

<sup>&</sup>lt;sup>40</sup> The use of self-report in the study 2 survey has implications here as participants may have overestimated their weight.

<sup>&</sup>lt;sup>41</sup>This subscale assesses the individual's role limitations due to physical health.





TABLE 16. Comparisons between intervention and comparison groups on major variables using repeated measures ANOVA.

Scale Variable	Intervention Group (T1) Mean (SD)	Intervention Group (T2) Mean (SD)	Comparison Group (T1) Mean (SD)	Comparison Group (T2) Mean (SD)	F value (Interaction analyses)	Direction of change
EORTC						
Physical function	75.87 (17.05)	83.80 (14.23)	86.11 (11.17)	88.33 (9.89)	F (1, 31) = 1.67; p > .05	NS
Role function	81.74 (27.33)	87.30 (14.81)	83.33 (30.15)	83.33 (17.40)	F (1, 31) = 0.42; p > .05	NS
Emotional function	65.21 (20.02)	79.36 (16.47)	68.05 (25.33)	75.69 (19.61)	F (1, 31) = 0.52; p > .05	NS
Cognitive function	73.80 (27.16)	75.39 (23.93)	73.61 (21.85)	81.94 (15.00)	F (1, 31) = 1.44; p > .05	NS
Social function	76.98 (30.94)	86.50 (14.54)	86.11 (19.89)	88.88 (20.51)	F (1, 31) = 0.56; p > .05	NS
Global QoL	59.92 (23.21)	73.80 (18.87)	66.66 (24.36)	72.22 (16.02)	F (1, 31) = 1.25; p > .05	NS
Fatigue	28.57 (23.19)	21.16 (11.60)	32.40 (18.01)	27.77 (18.65)	F (1, 31) = 0.14; p > .05	NS
Nausea & Vomiting	05.55 (21.94)	01.58 (7.27)	05.55 (10.85)	04.16 (7.53)	F (1, 31) = 0.13; p > .05	NS
Pain	28.57 (29.88)	12.69 (14.81)	11.11 (17.88)	13.88 (15.62)	F (1, 31) = 4.58; p < .05*	→
Dyspnoea	28.57 (30.34)	14.28 (19.92)	13.88 (22.28)	16.66 (22.47)	F (1, 31) = 2.38; p > .05	NS
Insomnia	47.61 (40.23)	22.22 (19.24)	22.22 (25.94)	27.77 (31.24)	F (1, 31) = 6.09; p < .05*	<b>→</b>
Low appetite	12.69 (30.68)	03.17 (10.02)	05.55 (19.24)	02.77 (9.62)	F (1, 31) = 0.73; p > .05	NS
Diarrhoea	04.76 (11.95)	04.76 (11.95)	00.00 (0.00)	05.55 (12.97)	F (1, 31) = 1.16; p > .05	NS
Constipation	12.69 (19.65)	09.52 (18.68)	13.88 (22.28)	11.11 (16.41)	F (1, 31) = 0.07; p > .05	NS
Financial impact	15.87 (30.94)	04.76 (11.95)	19.44 (30.01)	05.55 (12.97)	F (1, 31) = 0.06; p > .05	NS
Physical Activity Level	10.47 (13.27)	27.70 (13.28)	16.85 (16.08)	23.42 (15.99)	F (1, 22) = 02.72; p > .05	NS
Fitness (mtrs) <sup>a</sup>	436.95 (60.62)	516.42 (70.39)	521.58 (75.61)	534.08 (72.96)	F (1, 31) = 17.66; p < .05**	¢
Strength (1 RM <sup>)b</sup>	25.71 (18.39)	55.38 (18.0)	32.50 (22.20)	36.66 (20.37)	F (1, 31) = 27.94; p < .05**	÷
BMI	30.38 (5.39)	30.05 (5.13)	26.18 (4.24)	26.02 (4.12)	F (1, 31) = 1.09; p > .05	NS
Weight	80.99 (12.46)	80.12 (12.20)	70.32 (14.34)	69.98 (14.27)	F (1, 31) = 1.56; p > .05	NS
Waist circumference	99.20 (15.08)	97.44 (11.68)	92.08 (14.85)	90.96 (13.39)	F (1, 31) = 0.11; p > .05	NS
Daily saturated fat	36.67 (13.69)	19.04 (9.84)	25.16 (8.12)	32.83 (15.08)	F (1, 28) = 17.52; p < .05**	<b>→</b>
Calorie intake	2192.48 (681.81)	1538.28 (328.17)	2032.76 (542.73)	1948.20 (498.40)	F (1, 28) = 4.89; p < .05*	<b>→</b>
Vitamin C intake mg	79.91 (38.32)	176.93 (104.93)	142.61 (90.65)	104.56 (57.28)	F (1, 28) = 10.85; p <.05**	←
HADS-Anxiety	7.66 (4.22)	5.61 (3.20)	8.08 (5.35)	6.33 (3.93)	F (1, 31) = 0.06; p > .05	NS
Total Hope	30.00 (8.17)	41.14 (5.56)	35.53 (7.58)	37.92 (5.29)	F (1, 32) = 14.89; p < .05**	÷
* n/ 05: ** n/ 01: NS-no	tianificant interact	ion between time	Me out allow page	dified Shuttle walk	tast. b1 repetition maximal	

, p<.U1; NS=no significant interaction between time and group type. "Modified Shuttle walk test; "I repetition maximal strength test. . :cn∙>d

Looking at the effect of time, the intervention group improved significantly from pre to post assessment on both variables. This effect was not observed for the comparison group. Again, this finding demonstrates the positive impact of the programme but caution needs to be maintained, as the groups were not equivalent pre-programme.

# 6.11.2.2 Impact of Programme on Anxiety and Hopeful Thinking

The second and third aims of this study were to reduce levels of anxiety and increase levels of hopeful thinking. The changes over time in anxiety and hope levels can be observed by examining Figure 16. Repeated measures ANOVA were conducted for each of these variables.

It emerged that no significant interaction was observed for anxiety. However, a significant interaction was observed for total hope (see Table 16). To locate the source of the interaction, tests of simple effects were conducted. It emerged that the intervention and comparison groups differed at pre-assessment on hope levels. However, at post-assessment, this difference was not observed.



FIGURE 16. Group comparisons of mean scores over time on Hope and Anxiety levels

Looking at the effect of time, the intervention group improved significantly from pre to post assessment in terms of increased hope levels, and this effect was not observed for the comparison group thus demonstrating the positive impact of the programme. However, again one should be cautious in interpreting this, as the groups were not equivalent pre-programme.

# 6.11.2.3 Impact of Programme on Physical Activity Variables

The next aim of the study was to effect lifestyle changes in the form of increased levels of physical activity, fitness and strength. The changes over time for these variables are illustrated in Figure 17. Repeated measures ANOVA were conducted for each of these variables and an examination of Table 16 revealed that no significant interaction was observed for physical activity levels, however, significant interactions were observed for both fitness and strength.

To locate the source of the interaction, tests of simple effects were conducted. It emerged that the intervention and comparison groups differed at pre-assessment on fitness levels.

This is in line with the tests of equivalence that were previously reported. However, at post-assessment, this difference between the groups was not observed.

Looking at the effect of time, the intervention group improved significantly from pre to post assessment in terms of increased fitness levels and this effect was not observed for the comparison group, again demonstrating the positive impact of the programme. However, once more, one should be cautious in interpreting this, as the groups were not equivalent pre-programme.

In terms of strength, it emerged that the intervention and comparison groups did not differ at pre-assessment. However, they did differ significantly at post assessment. Furthermore, with regard to the effect of time, the intervention group significantly increased in strength from pre to post assessment, but this effect was not observed for the comparison group. This is evidence that the programme had a positive impact on the intervention group in terms of increasing strength.



FIGURE 17. Group comparisons of mean scores over time on Physical Activity variables

# 6.11.2.4 Impact of Programme on Nutrition Variables

The final aim of this study was to effect lifestyle changes in the form of increased fruit and vegetable intake (as measured by vitamin C intake), reduced daily saturated fat intake and overall calories consumed on a daily basis. In addition, the study set out to achieve weight reduction and reduce BMI levels and waist measurement.

An examination of Table 16 shows that no significant interactions were observed for weight, BMI levels or waist circumference. However, a significant interaction was observed for levels of daily saturated fat, the daily amount of calories and daily vitamin C intake. Figure 18 illustrates the changes in dietary variable levels pre and post programme.



To locate the source of the interactions, tests of simple effects were conducted. It emerged that the intervention and comparison groups differed at pre-assessment on daily saturated fat intake and vitamin C intake levels but did not differ in overall daily calories consumed. In addition, the intervention group and comparison group differed in daily saturated fat intake at post-assessment.

Looking at the effect of time, the intervention group improved significantly from pre to post assessment in terms of reduced intake of saturated fat, increased levels of vitamin C, and in a reduction in the amount of overall calories consumed on a daily basis. This effect was not observed for the comparison group on these variables. Again, this finding demonstrates the positive impact of the programme in terms of nutrition variables. However, again one should be cautious in interpreting this, as the groups were not equivalent pre-programme on saturated fat and vitamin C intake.



FIGURE 18. Group comparisons of mean scores over time on Dietary variables.

# 6.11.3 Analyses of intervention group only

Given the lack of equivalence between the intervention group and the comparison group at pre-assessment, a final set of analyses was carried out omitting the comparison group. This was to assess the impact of the pilot programme on variables under study. The analyses carried out were dependent t-tests (summary data and test statistics are presented in Appendix E).

These analyses revealed that the **quality of life of the intervention group improved significantly over time** in terms of increased scores on physical and emotional function as well as overall global quality of life. Their quality of life also improved via a reduction in pain, dyspnoea and insomnia symptom levels.

Furthermore, levels of hope increased significantly and anxiety levels were significantly reduced. In addition, physical activity, fitness and strength all improved significantly from pre to post intervention. Moreover, levels of fruit and vegetables consumed were significantly increased while saturated fat intake and overall calories consumed were significantly reduced at programme end. There were also significant reductions in weight and in BMI levels (see Appendix E for details).

# 6. 12 Summary of Study 3 Findings

This study involved designing, piloting and evaluating an intervention programme to reduce health risks and maximise quality of life. The intervention was multidisciplinary in nature with input from relevant health professionals including a dietitian to provide dietary counselling, a physiotherapy team to deliver an exercise programme and a psychologist to implement a psycho-educational intervention designed to enhance belief and behaviour change and increase quality of life.

The use of a control group was built into the research design but it was not possible to randomly assign participants to intervention or control groups. Therefore, those who did not form part of the intervention group became a comparison group. Unfortunately, a limited similarity between the intervention group and the comparison group undermined the study's ability to draw firm conclusions. Using a rigorous analytic approach, pre-programme differences were revealed between groups on several outcome variables, thereby reducing the likelihood of detecting changes in the intervention group pre and post programme. Nevertheless, the pilot programme did have a positive impact as a number of significant pre/post differences were observed. The intervention group significantly improved in terms of their quality of life, their mental health, their physical fitness and diet.

### Box 3. Study 3. Summary of Conclusions

- The pilot multidisciplinary bio-psychosocial rehabilitation programme positively impacted on the quality of life of post-treatment cancer survivors with regard to improving functioning and reducing symptoms.
- The programme positively impacted on the mental attitude of the participants by increasing levels of hopeful thinking thereby increasing motivation and problem solving for goal attainment.
- The programme positively impacted on the fitness and strength of the participants.
- The programme positively impacted on the diet of the participants by reducing saturated fat and increasing the consumption of fruit and vegetables.
- The lack of equivalency between the intervention and comparison groups the interpretability of the study findings.

# Chapter 7. Programme Evaluation

# 7.1 Introduction

The efficacy of the programme was measured in three ways:

- The success of the programme in effecting changes in outcome measures (see previous chapter).
- The participant's satisfaction with the programme.
- The programme delivery team evaluation of programme success.

The effectiveness of the intervention programme was evaluated in terms of its efficacy to enhance positive health outcomes and increase quality of life. Both service providers and programme participants were asked to rate their level of satisfaction with the intervention and to speak about positive and negative aspects of the programme. They were further asked to make some recommendations for a future service. These data in conjunction with the outcome analyses provide a comprehensive assessment of the intervention.

# 7.2 Participant Evaluation

# 7.2.1 Method

When the programme drew to a close the participants were asked to complete a programme satisfaction questionnaire that was designed to assess satisfaction with the overall programme and each of the modules. They were also given the opportunity to write comments about positive and negative aspects of the programme and make suggestions for a future service.

# 7.2.2 Results

Twenty participants completed this questionnaire and the overall feedback was extremely positive. Table 17 shows that the participants were very satisfied with the various aspects of the programme and would do it again if offered a place. Furthermore, they would recommend the programme to a friend.

Item	Rating	% Response
Quality of the programme	Excellent	85%
Would you recommend to a friend	Yes	95%
Satisfaction with Dietary Module	Very satisfied	60%
Satisfaction with Physical Activity Module	Very satisfied	84%
Satisfaction re: Hopeful thinking and goal setting	Very satisfied	85%
Overall satisfaction with the service	Very satisfied	85%
Would you do the programme again	Yes definitely	90%

TABLE 17. Participants	' Evaluation of the	pilot programme	(n = 20)
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Participants also commented on both positive and negative aspects of the programme and made suggestions for future programmes. The overall feedback was positive with many participants suggesting that the programme was very balanced and should be mainstreamed. A detailed content analysis revealed a number of common themes, which are outlined below. These themes refer to positive and negative aspects of the programme and recommendations for future services. Five main themes were identified that relate to positive aspects of the programme. These relate to the benefits of supervised exercise, being with other cancer survivors, weight loss and a new awareness of diet, the benefits of goal setting and an increased positive outlook and hope for the future. These points are presented below with comments to illustrate.

### The benefits of supervised exercise

"The supervised regime helped me to understand how to exercise successfully and to know my limits in a very enjoyable manner".

"This was different to a normal gym as you felt in a medical setting it was more controlled".

### Being with others who were also cancer survivors. One participant said

"[being] in the gym working out with others that understood as most were in the same position".

### Weight loss and increased awareness of diet. A sample comment is

" I have lost weight and am very pleased with that".

### The benefits of goal setting. Two comments illustrate this point:

"The psychology (Hope) sessions were very interesting and helped me put a perspective on goals such as losing weight bit by bit and focusing on achieving small goals over a longer period of time rather than a crash diet response".

### Increased positive outlook and hope for the future.

Some of the comments that illustrate this point were:

"The programme made me realise how I had let things go because I was tired all the time. Now I feel I can do almost anything I turn my mind to. I feel more positive about everything and I would like everyone with cancer to get the same thing we got".

"The programme has changed my way of thinking to a definitely more positive way. I feel better in myself and have a general sense of wellbeing".

#### Negative aspects of the programme

Two main themes were identified that related to negative aspects of the programme and these referred to the length of time since treatment before this programme was made available to them and also to the heavy time commitment involved in taking part in the programme. These points are presented below with comments to illustrate.

**The length of time since treatment** – (this refers to the length of time between treatment end and the programme)

"The fact that I did this [only] 5 years after my illness did not allow me to reap the full benefits as I have had a lot of time where I had to deal with all the issues myself".

### The heavy time commitment

"The time commitment of two evenings per week at times was a lot but worth it".

### Participant Recommendations

With regard to recommendations for future development of a service, the participants of this pilot programme made two points based on their experience of the programme. These referred to the timing of the intervention and the need for follow-up or refresher sessions. These points are presented below with comments to illustrate.

### The timing of the intervention

*"I feel this programme is excellent but it is vital that it should be offered very early in the recovery process".* 

### The need for follow-up sessions

"I think it would be a good idea if there was a follow-up session in about 6 months' time. Then we would be motivated to keep our goals in sight".

# 7.3 Programme Delivery Team Evaluation

# 7.3.1 Method

The psychology, physiotherapy and nutrition teams participated in a focus group (n = 8) to discuss their experience of the programme and give their views on how effective it was in carrying out its goals. They were further asked to speak on the programme as a whole as well as on the specific modules with regard to content, delivery and results. Participants were also asked to make recommendations for a future service based on this experience.

The focus group was audio-taped with the teams' consent and transcribed. A detailed content analysis of the transcript revealed a number of common themes outlined below with examples of comments provided to illustrate the points made. The findings are presented under the headings of programme content, aspects of the programme to cause concern and recommendations from the programme delivery team for a future service.

# 7.3.2 Results

### Programme Content

Three main themes were identified in terms of programme content. These referred to the positive approach taken in the intervention design, the impact of physical activity, the impact of the Hope Therapy module on the other modules and the efficacy of the programme as a unit. These points are made below with sample comments to illustrate the points made.

The positive approach moved participants from an illness perspective to a 'taking control' perspective.

### A sample response illustrates the feeling,

"I think it was an interesting sort of a change from an illness-related behaviour for them to a very much 'I'm taking control of this you know'. By the end of the programme that was the perception ... and I think that was very much achieved over that short period of time, that very short intervention of 8 weeks."

### The impact of physical activity on confidence to 'do',

"I would say just some feedback from the people. Exercise I thought was the biggest thing they got from it, you know that confidence to do exercise, whereas before they were perhaps protecting themselves or were unsure as to what they should do."

# The positive and practical impact of the Hope Therapy module on the other 2 modules.

"I was delighted you know when you said you were doing the focused goal-setting for people because certainly from a nutrition point of view while you know you can give people the advice and this is what you have to do, actually implementing and changing dietary habits is the biggest hurdle that people have to overcome and I really think things like the psychology element of that really help people to try and look at how they can change their diets."

# The efficacy of the programme as a unit - with Hope Therapy underpinning the exercise and dietary goals and exercise impacting on the dietary elements and vice versa.

"I thought they were engaging and making themselves better, which was what we had hoped to achieve as well, so that was very positive and I think from the point of view of exercise it is good they get a confidence boost and things like that but it's the other changes as well that they need to make that will probably make an impact as well, so exercise I suppose has a dual action that it will improve their fitness level but it also will sort of give them the confidence to pursue goals with their food diaries and things like that, so I think the programme, how it was delivered and everything was very precise in achieving that and the psychological component then coming in to give them skills was exceptional."

### Aspects of the programme to cause concern to the delivery team

Two main issues were a cause for concern to the delivery team. These related to the late timing of the programme in terms of the time since treatment and to structural aspects of programme delivery including the lack of suitability of the accommodation arrangements and the lack of changing facilities. These points are presented below along with comments that illustrate them.

### The timing of the programme should be earlier to minimize de-conditioning.

Two comments illustrate these concerns:

"Some of these patients, it's quite a while after their diagnosis so time had been quite an element in their de-conditioning" "I think they're frustrated because some of them have gone five or six years post-treatment and wished they'd you know they've been not eating well for those five years and they've had their cancer and would somebody in the medical world not have told them when they finished their treatment that this is what they should be doing now".

### The structural aspects of programme delivery.

This theme included comments on accommodation, equipment, parking costs etc. which were not ideal.

### Delivery Team Recommendations

The team made two main recommendations based on their experience of the programme. These recommendations were

### Programme deliverers need to have knowledge of cancer survivorship issues.

A sample comment illustrates:

"Whoever is delivering it either needs to bring in someone with a knowledge of cancer or else have some basic knowledge of the cancer journey in particular the difference between the stages they're at."

### Planning time is needed before service is mainstreamed.

*"*[Make] a recommendation that there is quite an amount of time given over to planning pre-programme start."

# 7.4 Summary of Evaluation

The evaluation feedback from the participants and the programme delivery team was very positive both in terms of programme content and delivery. The feedback provides further evidence to support the efficacy of the programme to impact on the quality of life and the physical and mental wellbeing of post-treatment cancer survivors. It also provides support with regard to the need for a comprehensive, multidisciplinary cancer rehabilitation programme for cancer survivors after cancer treatment, preferably in the early post-treatment stage. Both participants and providers expressed support for such a programme to be mainstreamed as part of an ongoing cancer care plan for survivors.

# **Chapter 8. Conclusions and Recommendations**

# 8.1 Project Conclusions

The CANSURVIVOR Project set out to explore the quality of life and service needs of post-treatment cancer survivors in the former ECAHB area. The research findings show that the majority of post-treatment cancer survivors have a high quality of life in terms of functioning and symptom burden. However, there was a variety of long term and late-emerging post-treatment effects that impacted on the quality of life of this sample of cancer survivors long after medical treatment had ended. These were physical, psychological, social and vocational in nature and require a bio-psychosocial intervention approach to ameliorate their effects.

Survivors and health professionals both agreed that existing follow-up services are inadequate, inconsistent, lacking in co-ordination and a poor experience for survivors. They endorsed the need for a multidisciplinary, structured and co-ordinated approach to the post-treatment phase of the cancer trajectory.

The research also showed that there is a need to educate health professionals on post-treatment issues that can impact on quality of life post cancer and its treatment and that there is a need for good quality written information about 'after cancer' to be provided to survivors as they finish treatment.

Up to one quarter of survivors had significant levels of difficulty with quality of life functioning and symptoms. Furthermore, in terms of mental health, anxiety and fear of recurrence were particular difficulties with 33% of the survey sample reporting anxiety levels above the normal range. With regard to current health and lifestyle, the research findings show that the majority of the survey sample reported co-morbid health conditions in addition to their cancer. A quarter of the sample were not physically active and over 35% had reduced their activity levels since before their diagnosis. Moreover, of particular concern was the finding that over half of the sample was overweight, including 15% who were obese. Furthermore, 13% continued to smoke after cancer treatment.

With regard to diet, survivors had difficulty with portion sizes and the majority fell below recommendations in terms of the quantities consumed from all food groups including fruit and vegetables, with the exception of high sugar/high fat foods where 45% consumed above the recommended daily amounts. Recently, the World Cancer Research Fund (2007) (WCRF) made specific recommendations for cancer survivors to follow the recommendations for cancer prevention.

The multidisciplinary bio-psychosocial pilot rehabilitation programme that was developed based on the evidence from the earlier studies was successful in bringing about changes in physical and mental wellbeing in the programme participants, thus enhancing their quality of life. The integrated programme design was effective in that it took a positive approach to survivorship and the psychological component acted as a scaffold for the physical activity and dietary components by supporting motivation for goal attainment in those areas. Unfortunately, the lack of an equivalent control group limited the ability to draw firm conclusions. Nevertheless, the intervention group improved significantly on key variables including quality of life, anxiety levels, physical fitness, strength, BMI levels, weight and diet. Both survivors and service providers endorsed the efficacy of the programme in terms of its content and its delivery and made recommendations for the development of a future service.

# 8.2 Research Limitations

Research is not complete without due consideration of its limitations. A number of limitations of this research are recognised. One of the limitations of the survey in Study 2 was its cross-sectional nature. Ideally, participants should be followed in a longitudinal study over a period of time to ascertain the level of change in the relevant variables from pre to post cancer. Furthermore, the use of objective measures would go some way towards avoiding the biases inherent in self-report. Moreover, the lack of comparability between the comparison and treatment groups in Study 3 severely limited the detection of interactions. A larger sample size would allow for random assignment to treatment and control groups thus ensuring group equivalence before the intervention commences. Finally, time did not permit a follow up of the treatment group to ascertain the longer-term impact of the programme.

# 8.3 Recommendations

A number of recommendations are made below with regard to meeting the needs of post-treatment survivors, service development and future research.

The current research project highlighted the need for a post-treatment information and support service with both participants and providers endorsement. Findings also suggest a clear need for an early post-treatment rehabilitation programme for those at particular risk for poor quality of life. To fulfil these needs two recommendations are made. The first refers to the development of a post-treatment information and support service and the second to a more focused intervention programme to positively enhance quality of life in terms of physical and psychological functioning and health behaviour change:

### Recommendation 1:

There is a need to develop a comprehensive, multidisciplinary, post-treatment service that connects with patients at time of diagnosis and outlines an after-care plan to prepare them for the post-treatment phase of their cancer journey. This service should integrate with all multidisciplinary professionals involved in the patient's treatment and after-care and link with primary care teams/networks and hospitals, to provide a co-ordinated and structured service.

### **Recommendation 2:**

The post-treatment service should include a rehabilitation/survivorship programme that focuses on reducing the potential need for acute care in the post-treatment phase and the resultant potential burden on the survivor and the health service. This can be achieved by focusing on enhancing quality of life in terms of functioning and symptom management and effecting lifestyle changes that are conducive to good physical and mental health. It is suggested that a rehabilitation/survivorship programme includes physical activity, dietary and psychological support as the major components, as used in the pilot study, as they have been shown to work well together in producing an integrated and effective programme. The programme should also include the opportunity for the survivor to avail of refresher sessions from time to time.

Based on the research findings, it is suggested that all cancer survivors coming off treatment be referred immediately to the post-treatment service in the first instance. This will ensure that all cancer survivors receive information on survivorship issues and have a connection to a service should they require it in the future. The following recommendation is made regarding referral to the post-treatment service.

### **Recommendation 3:**

Participants should be informed of the post-treatment service at diagnosis, or at the very least, during treatment. It is recommended that health professionals (oncologists) refer the cancer patient to the post-treatment service, as their referral appears to endorse the benefits of such a service. Both public and private cancer patients should be informed of and referred to post-treatment services.

Regarding the above recommendation, there is no evidence to suggest that males and females have differing needs in terms of the type of service developed, or that a specific service be developed for those who are socio-economically disadvantaged. Neither is there evidence that specific services should be developed for each cancer type providing that the health professionals involved in service delivery are knowledgeable of cancer specific post-treatment effects.

Two recommendations with regard to who should be referred to take part in a specific rehabilitation/survivorship programme are made, based on the evidence from the pilot study.



In addition to the above, a number of key risk factors for poor quality of life were identified in this research. These formed a set of selection criteria for inclusion in the pilot programme.

These risk factors are:

- BMI greater than 25
- Self-report of no physical activity or decreased activity levels since diagnosis,
- High anxiety levels,
- Low quality of life and
- Low hopeful thinking.

Based on the criteria, the following recommendation is made:

### Recommendation 5:

Post-treatment cancer survivors who are at risk with regard to poor quality of life in terms of functioning and symptom levels due to their cancer or its treatment, as well as those with elevated anxiety levels and those who are at risk for poor quality of life due to poor diet, being overweight and having low physical activity levels post cancer treatment, will most likely benefit from the programme.

With regard to the delivery of a post-treatment intervention programme the following recommendation is made:

### Recommendation 6:

Senior clinicians, who are knowledgeable of the impact of cancer and its treatment, should deliver any proposed programme. Therefore, it is recommended that professionally qualified physiotherapists, a dietitian and a psychologist deliver the programme. The post-treatment programme should be well planned and should be co-ordinated by an expert in post-treatment survivorship.

Based on the pilot programme findings it is not possible to make definitive recommendations on the duration of any proposed programme. However, the 8 weeks of the pilot programme appeared to maximize the effect and avoid attrition.

The pilot study was carried out after hours. This was purely for practical reasons and there is no reason why a formal service should not operate during normal hours, however, it is suggested that cancer survivors who have returned to work be facilitated with evening sessions.

There should be a follow-up assessment of all programme participants to investigate the longer-term effects of the programme. No specific recommendation can be made with regard to the follow-up period but 6 - 12 months is suggested at a minimum.

The survivors who took part in this pilot programme felt that the location of the programme along with the involvement of health professionals provided a sense of security, safety and confidence to engage in the programme. The following recommendation is made:

### **Recommendation 7:**

A post-treatment service should be initially based within the health services rather than volunteer-led services, as the link between the survivor and the health service already exists and many survivors do not avail of voluntary services. It is believed that the expertise of various health professionals available through a health service-led initiative would be more conducive to meeting the ultimate aim of the service which is to maximise physical and psychological wellbeing of post-treatment survivors.

With regard to programme outcomes and their measurement, it is difficult to be definitive given the plethora of measures available. The following recommendation is made:

### **Recommendation 8:**

It is recommended that the cancer patient's mental health be assessed at the time of diagnosis to identify the need for psychological help and to provide a baseline for assessing the future impact of any intervention. In addition, quality of life, exercise history, strength, fitness and diet should all be assessed to facilitate the identification of the impact of cancer and its treatment on the physical and mental health of the patient and to aid in targeting those who need post-treatment rehabilitation.

The specific findings that cancer survivors need good quality written information 'after cancer' and that health professionals need to be educated on post-treatment effects shaped the next two recommendations.

### Recommendation 9:

It is recommended that cancer-specific information packs providing information about 'after cancer' should be produced and provided to cancer survivors. These should include information about late emerging and long-term effects of cancer and its treatment and direct the survivor to possible actions they can take to minimize such effects, including information about lifestyle changes to enhance physical and mental health.

#### Recommendation 10:

It is strongly recommended that education on 'Cancer Survivorship' be included in the training curricula for relevant health professionals and that this education takes a bio-psychosocial approach to expand the professional's knowledge to include post-treatment issues and the availability of services that ameliorate their effects.

To further ensure that post-treatment survivors needs are met, the following recommendation is made:

### Recommendation 11:

Despite the recommendation for a health service led post-treatment service, it is important to liaise with existing voluntary cancer support structures to promote a more integrated system of care and

a) to maximise the dissemination of information on the post-treatment phase of the cancer trajectory, as well as

b) avail of the many benefits of voluntary cancer services.

A number of recommendations for future research are made to further aid the development of services to post-treatment survivors given the growing population of survivors. Developing an efficacious rehabilitation/survivorship programme that is evidence-based necessitates long-term follow-up and further research for programme refinement.

### Recommendation 12:

It is recommended that a post-treatment needs analyses survey be extended to the wider Irish cancer survivor population to assess their service needs and build a profile to assist future service development nationwide.

### Recommendation 13:

It is recommended that a multi-site randomised controlled trial of the piloted rehabilitation programme be conducted to give sufficient power to the research design to examine the impact of the programme and to further aid programme refinement. This trial should include pre, post and follow-up testing.

### Recommendation 14:

It is recommended that the programme be manualised to facilitate consistency in programme implementation and treatment fidelity across multiple service sites.

Finally, in line with best practice, a recommendation is made with regard to ongoing monitoring and evaluation.

### Recommendation 15:

It is recommended that the proposed post-treatment service and rehabilitation/ survivorship programme be monitored on an ongoing basis. An evaluation framework should be developed to:

(a) review service/ programme implementation,

(b) assess the continued efficacy of the service/ programme,

(c) make recommendations for change, so that the service is dynamic and consistent with the needs of post-treatment survivors and,

(d) assess the long-term impact of the service and rehabilitation programme.
## 8.4: Conclusion

To date most cancer-related research has focused on the diagnosis and treatment related phases of the cancer journey. However, post-treatment survivorship is increasingly a concern for health service providers worldwide. Unfortunately, the post-treatment period is "*uncharted territory in terms of evidence-based guidance for providers of survivorship care*" (IOM, 2006, p. 60).

The CANSURVIVOR Project was the first necessary step in charting the service needs of post-treatment cancer survivors in Ireland and the pilot study was the first stage in developing a service to meet those needs. A larger nationwide survey of the population of Irish cancer survivors and further refinement of the pilot rehabilitation programme are the next major steps forward in the effort to maximize the quality of life of those who survive cancer.



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