

**WE ARE
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CANCER SUPPORT**

**RESEARCH FIT FOR THE
FUTURE**

PREFACE

Research fit for the future is a selection of research funded by Macmillan Cancer Support. Macmillan funds focussed research to understand and improve the quality of life for people affected by cancer, and turn the results of this research into practical, cost-effective solutions and better quality services.

The project briefs presented in this document provide an overview of some of the research Macmillan Cancer Support has commissioned or funded over the last five years. Our research portfolio demonstrates that Macmillan has been a leading funder of research into the issues of particular importance to people affected by cancer, their needs and concerns and how these might be addressed.

Macmillan's vision is to reach and improve the lives of everyone living with cancer and to inspire millions of others to do the same. We will need a broad range of evidence to support this work, so we will draw on existing evidence and commission new research, analysis and evaluation to get the new evidence we need and help the organisation achieve this outcome.

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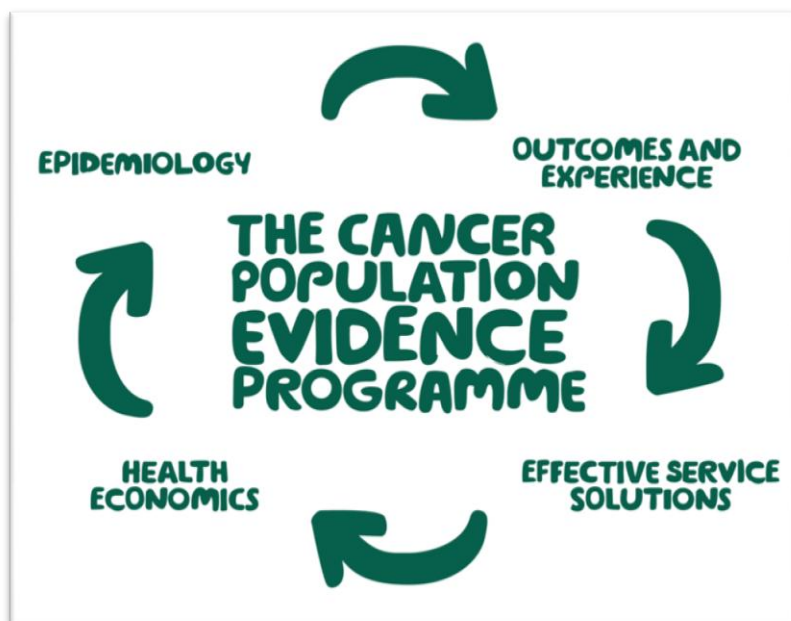
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THE CANCER POPULATION EVIDENCE PROGRAMME

Macmillan's flagship Cancer Population Evidence Programme (CPEP), will bring together the best evidence across epidemiology, health economics, patient experiences and outcomes, and effective service solutions. Together, these tools will help paint the fullest picture possible of the changes the NHS needs to make to meet the needs of the two million people currently living with cancer, and for the projected four million people who will be living with a cancer diagnosis in 2030.

Purpose of the Cancer Population Evidence Programme



The purpose of CPEP is not only to drive the generation of new evidence in each of the four domains, but also to provide an overarching framework that brings together and synthesises evidence.

There is a clear need to develop this approach. Health and social care provision is changing in the UK. There is a working assumption that the NHS will have to make efficiency savings for the foreseeable future. This coupled with increased service usage from the rising numbers of cancer survivors will place pressure on the NHS. Improved survival is a good news story but also has major implications for the planning and provision of health, social care and other services. In light of these challenges, there is a heightened emphasis on demonstrating value, that is, the ability to demonstrate that service solutions are both cost effective and maximise outcomes for people affected by cancer.

Outcomes and experience

Outcomes can refer to clinical outcomes of health care interventions such as survival and consequences of treatment, patient reported outcomes, and a range of quality of life and well being measures. CPEP is demonstrating outcomes and experience at individual, population and service levels.

Research to date includes our Routes from Diagnosis programme, which uncovers long-term survivorship outcome pathways, and our analysis and mapping of Cancer Patient Experience Survey data.

Health economics

It is becoming increasingly important to demonstrate that we understand the costs of cancer and that the resources available for cancer services are used effectively. Additional services or funding will be based on evidence and a robust understanding of the costs and benefits associated with them.

There is a pressing need for more economic evidence about the costs and effectiveness of cancer care across the whole pathway, and major new work by Macmillan and our research partners will make significant contributions to the evidence base over the next three years.

Epidemiology

We are further developing our understanding of people affected by cancer by sizing and segmenting the whole cancer population, cutting the data across cancer types, demographics and across the cancer care pathway at local and national levels.

To help achieve this, Macmillan and the National Cancer Intelligence Network are working in partnership and have developed a Macmillan-NCIN work plan, which aims to perform 'cutting edge' new analysis and use of new datasets. As these datasets become available, we will understand more about the different treatment pathways and seek to link these to patient outcomes and experience.

Effective service solutions

Macmillan is committed to providing effective service solutions to improve the lives of people affected by cancer, working with the NHS to improve existing services and test new service models. We are building understanding of the effectiveness and efficiency of our service solutions and demonstrating how our services impact on experience, costs, outcomes and quality.

Recent work includes our ongoing partnership with University College London Hospitals to build the UK's most advanced cancer facility.

Bringing it all together and making it happen

The power of the Cancer Population Evidence Programme lies not just in developing the evidence in each of the domains but in bringing this together to provide a synthesised analysis at local and national level, which will ensure we can work with planners, commissioners and decision makers to use the best evidence to meet the needs of people affected by cancer now and in the future.

We will need a broad range of evidence to support this work, so we will draw on existing evidence and commission new research, analysis and evaluation to get the new evidence we need and help the organisation achieve these aims.

OUTCOMES AND EXPERIENCES

The Macmillan Survivorship Research Group (MSRG)

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Summary: What is the MSRG?

The MSRG is a group of researchers located at Southampton University who are funded as part of a Macmillan five-year Programme Grant. The primary aim of the MSRG is to get to the heart of cancer survivors' experiences following primary treatment and identify, develop and test solutions to support self management of cancer related problems.

Background

The broad aims of the research programme are to:

- Deliver a research programme to understand restoration of health and well-being following primary treatment.
- Identify who is most at risk of problems and what helps/hinders restoration of health and well-being.
- Explore who is most likely to need support with self-management and what helps/hinders self-management.
- Develop and test ways to support self-management of cancer related problems to enhance the lives of survivors.
- Find ways to include people typically under-represented in research.
- Identify where to target interventions and services to better support survivors.

Three workstreams will be established to achieve these aims. Each stream of work is summarised below and each project explained in more detail in its own project brief.

Stream 1: Understanding recovery and self management following primary treatment

MSRG will conduct the following studies to further understand the problems experienced following primary treatment.

- a cohort study of 1,000 colorectal cancer patients to explore the recovery of health and well-being following primary treatment (the CREW study)
- an online survey of patients who have completed primary radiotherapy/chemotherapy treatment to identify self-management of treatment related problems and barriers/supports to self-management

Stream 2: Co-creating and testing interventions to support self-management

In partnership with cancer survivors, Macmillan partners, clinical teams and academic experts, MSRG will develop and test an online resource to manage cancer related fatigue, bringing together clinical knowledge and lay expertise for people who have completed treatment.

User involvement and including those typically under-represented

MSRG will continue to develop effective ways to involve people typically under-represented in research.

Why is this work important?

By focusing on the experiences of recovery following primary treatment the programme will generate new knowledge about who is at risk of problems following cancer treatment, inform the provision of more efficient and effective services and identify self-management support interventions which could enhance people's return to productive lives following cancer.

Cohort Study Explore the Recovery of Health and Well-being Following Primary Treatment (the CREW study)

MSRG Stream 1 Project 1

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Summary

A cohort of 1,000 colorectal cancer patients will be established and followed over time to map their recovery following primary surgery. The study will provide information on a range of variables associated with health. This project is funded as part of the Macmillan Survivorship Research Group (MSRG) Programme Grant.

Background

Survivors of colorectal cancer form the largest group of cancer survivors affecting men and women. Incidence is high and survival rates have doubled in recent years with around 250,000 UK survivors. Poor quality of life has been identified in the three years following diagnosis with the greatest impact on pain, functional and social well being. Self care capacity, mental health and activity level deteriorate following colorectal surgery. Low socio-economic status is associated with poorer quality of life in this group of survivors. Furthermore, worry about recurrence can impair health and well being and social support can have a positive role. However, how health and well being change over time is not clear.

MSRG will follow 1, 000 colorectal cancer patients over 24 months to

- identify who is most at risk of problems
- explore factors which aid/hinder resolution of health and well-being
- identify areas that could be improved through appropriate follow-up or self management support
- make recommendation for where interventions/services should be targeted to support survivors in an effort to prevent problems occurring or reduce their impact

1,000 colorectal patients have been recruited from 30 cancer centres. Patients will receive a number of validated questionnaires at five time points. The primary outcome of the study will be 'health and well-being' as measured by the Quality of Life in Adult Cancer Survivors (QLACS) which measures seven generic domains (e.g. pain and fatigue) and five cancer specific problems (e.g. recurrence distress, appearance concerns).

Key Findings

This study is ongoing and findings will be in March 2015.

Why is this work important?

This project will directly contribute to the wider understanding of those living after a cancer diagnosis, particularly in understanding the issues influencing the restoration of health and well-being, and areas for potential supported self-management by colorectal patients. As well as improving our understanding of recovery after cancer, this study will add the patient voice and perspective to complement and inform the Natural History Risk Stratification Project funded by the Macmillan through the National Cancer Survivorship Initiative (NCSI) and projects arising from the Supported Self Management Work stream of the NCSI.

An online survey to assess self management strategies used following primary treatment and barriers and supports to self management.

MSRG Stream 1 Project 2

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Summary

An online survey was conducted with patients from all diagnostic groups following chemotherapy and radiotherapy to explore how people self-manage problems experienced following primary treatment and barriers and supports to the self management of these.

Background

Patients often experience debilitating side effects during and after chemotherapy and radiotherapy which may continue for a number of years. Often both physical and emotional stresses are considerable and it can take a long time to recover. Self management can empower patients to act for themselves, increase their confidence in their ability to manage the problems associated with the treatment and enhance quality of life.

Specifically the survey will:

- describe cancer survivors' levels of self-efficacy to self-manage cancer and its treatment related problems in the year following primary cancer treatment
- examine relationships between self-efficacy and coping, self-management strategies used, perceptions of problems, health and well-being as well as pre-existing (age, gender, cancer type etc), personal and environmental variables
- identify who is most likely to need support to self-manage cancer/treatment related problems following primary treatment

Key Findings

182 respondents were recruited. Respondents represented a range of ages, cancer and treatment types. Respondents reported a range of self-efficacy (confidence) scores to manage problems related to their illness, reporting lower self-efficacy to manage problems such as fatigue, emotional distress and health problems.

Self-efficacy scores were associated with several variables including gender, caring responsibilities, whether or not cancer affected work, health and well-being, self-management activity, personal and environmental resources.

Factors contributing the most to a low self-efficacy were having a more threatening perception of cancer, having a low subjective sense of well-being, experiencing a high level of fatigue/low amount of energy, having limited social support.

Other significant factors that contributed to low self-efficacy were more difficulties with sexual function, reporting fewer benefits from having had cancer and being female.

Why is this work important?

With a rising emphasis on supported self-management this study provides important information for clinical practice with regards identifying people more likely to have lower levels of confidence to manage cancer and treatment related problems. Further research is needed in this area to develop interventions to support self-efficacy in specific situations such as helping people feel more confident to manage fatigue in their everyday life.

Access the survey at www.soton.ac.uk/msrg/onlinesurvey

The Relationship between the NHS Staff Survey and the Cancer Patient Experience Survey (CPES)

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Summary

This study demonstrates a number of relationships between CPES and staff survey results at a trust level. The underlying reasons for these relationships were not necessarily clear and likely to be complex and affected by unmeasured variables.

Background

Studies have shown examples of positive links between employee engagement and patient experience. The precise nature of the relationship between staff and patients' experience is only beginning to be understood by researchers. This study sought to understand at an organisation level what, if any areas of staff experience are associated with good or poor cancer patient experience.

Data from the 2011 CPES and 2011 NHS Staff survey were analysed in two stages. First a correlation analysis was conducted on trust-level results for both surveys. Then promising results were followed up using a two-level regression model allowing adjustment of patient results for demographic variables and trust level factors, to identify the strongest links between the two surveys. Regression models were constructed using composite scores representing CPES items of similar thematic content.

Key findings

At a trust level, there were a number of moderate to large relationships found between some aspects of staff experience and cancer patient experience. This means, where a trust had a high/low score on the staff experience in question, they also tend to have a high/low score on patient experience.

However, by looking at the correlations at a trust level, it is not possible to take into account other factors about a trust that might impact on patient experience (e.g. patient population characteristics and type of trust). At an individual patient level (modelled using an approach which took into account factors such as patient demographics and some trust characteristics) the strength of the links between patient and staff experience appear much weaker.

Key considerations for interpretation

Whilst this analysis does suggest that relationships exist between patient and staff experience, the complexity of the relationships involved means that the exact findings may be sensitive to the particular samples involved and assumptions underlying the analysis. In addition to the effects on patient experience associated with staff survey indicators, there were effects (sometimes substantial) associated with background variables such as age, gender, and cancer type. No causal relations can be concluded from this analysis. There are likely to be complex determinants that impact on the results of both cancer patient and staff experience that are beyond the scope of this piece and available data, including other contextual factors of trusts and individuals.

Why is this work important?

This study supports emerging evidence of the link between patient and staff experience. It is beyond the scope of this study to determine the nature of these links or how any initiatives to improve staff experience might impact on cancer patient experience, or vice versa. However there does appear to be value in a more in-depth exploration of this.

Independent Associations between Socio-demographic Characteristics or Tumour Types and Aspects of Experience of Care: Evidence from the 2011/12 Cancer Patient Experience Survey

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Summary

This summarises work undertaken by Cambridge Centre for Health Services Research (CCHSR), University of Cambridge, on behalf of Macmillan Cancer Support relating to the results of the Cancer Patient Experience Survey (CPES).

Background

Compared to the measurement of clinical processes and outcome, measuring patient experience is a relatively new field. Understanding variation in the experience of patients with different characteristics or cancers is vital to inform health care initiatives. The objective of the research was therefore to identify patient groups that are more likely to report a negative experience of care, in order to help guide improvement efforts and further research.

For the socio-demographic characteristics, variation was explored in respect of age group, gender and ethnicity. Variation by cancer type was analysed by classifying all neoplasms into 36 different cancer types, 31 of which fall within 10 broader cancer MDT/specialty groups (neuro-oncology; head & neck; lung; breast; upper GI; lower GI; urology; gynaecological oncology, and haemo-oncology).

For each CPES question, binary definitions of more / less positive experience categories were used, following the Department of Health's definitions for purposes of public reporting of hospital patient experience performance. Consideration of all socio-demographic characteristics and cancers at the same time enabled the independent associations of each of those variables with cancer patient experience to be identified.

Findings

The key findings included:

- confirmation that there are some independent associations between more/less positive patient experience and certain socio-demographic characteristics and types of cancer
- the widest variation was found across cancer diagnoses – less so by socio-demographic variables
- generally, younger patients and those from an ethnic minority group tended to report more negative experience of cancer care - in contrast, variation by socioeconomic status was limited and inconsistent
- women tended to report slightly worse experience than men
- findings on differences by speciality / MDT groups will be published later in 2013

Why this work is important?

Specialty / MDT groups can use the research results to focus improvement initiatives on the patients of their specialty with types of cancer that are associated with more negative reported experience. For example, consideration can be given to providing additional consultation time with a doctor or a specialist nurse, or enabling better access to peer support groups and provision of more information.

Is Case-mix Adjustment Important for the National Cancer Patient Experience Survey in England (CPES)?

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Summary

Some patient groups, such as ethnic minorities, younger people and some rarer cancers, typically report poorer patient experience. Hospitals trusts tend vary in terms of the types of patients they treat and may specialise in certain cancer types. However analysis shows that case mix does not explain differences in hospital rankings.

Background

The Cancer Patient Experience Survey (CPES) is a survey of cancer patients' experiences of care and treatment that allows hospitals in England to benchmark their performance on patient experience. Understanding the reasons for a hospital's performance on patient experience is key to developing successful improvement initiatives. However, uncertainty about the influence of the socio-demographic makeup or clinical case-mix of the patients served by different hospitals on hospital performance can lead to reluctance to use the survey results.

Frontline clinicians and managers working in poorly performing hospitals may attribute bad performance to (a perceived) 'more difficult case-mix of patients'. Such a perception leads to staff disengagement and de-motivation in the hospitals where staff need to be most engaged and motivated in improvement work. Case-mix adjustment can be used to create a 'level playing field' when comparing performance between hospitals that serve very different patient populations, thus allowing fairer comparisons between hospitals.

This study uses evidence from 2011/12 CPES to provide empirical evidence about whether poor performance can be explained by case-mix.

The methodology uses case-mix adjustment, a statistical technique that can be used to predict hospital scores should their case-mix be the same as the national profile.

Key findings

Overall, case-mix does not matter greatly for hospital performance on the CPES, with the rankings of hospitals broadly similar with and without case-adjustment. In other words, relatively few hospitals become big "winners" or "losers" following case-adjustment.

Questions relating to pre-hospital diagnosis are a notable exception; these were very sensitive to case-mix adjustment. Up to half of the hospitals in the top or bottom fifth would become big winners or big losers as a consequence of case-mix adjustment. This is likely to be because these questions do not directly measure hospital performance – variation in time to diagnosis, for example, depends on GP and patient factors (particularly cancer diagnosis) far more than hospital factors.

Why was this work important?

Current hospital scores do in fact reflect the actual reported experience of the patients that attend each hospital. Using case-mix adjustment might be seen as a fairer way to compare hospitals but no degree of adjustment can 'correct' for the poorer experience of certain groups of cancer patients. Efforts should always be made to address systematic differences in experience between patient groups.

The Late Effects of Pelvic Radiotherapy in Long Term Cancer Survivors: a Feasibility Study

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Summary

The aims of this study were to estimate the prevalence of bladder, bowel and sexual dysfunction late effects in a sample of cancer survivors; assess the impact of time since treatment on symptom prevalence; and explore the relationship between symptoms, psychological morbidity and quality of life.

Background

As cancer survival rates continue to increase, it is important to maximise the quality of life of cancer survivors. Pelvic radiotherapy is a common cancer treatment. Bladder, bowel and sexual dysfunction are recognised side-effects of treatment, and yet relatively little is known of the extent to which they remain problems in the longer term when patients are often managed by primary care, nor of the psychological impact of symptoms and effects on quality of life.

Findings

In total, 418 (55.9%) completed questionnaires were received. Moderate/severe problems with bowel, urinary and sexual functioning were relatively common: bowel urgency (59% women, 45% men); urine urgency (49% women, 46% men); ability to have a sexual relationship affected (24% women, 53% men). Symptoms were just as frequent in those 6 - 11 years after treatment as in those 1 - 5 years after treatment. Symptom severity was significantly associated with poorer overall quality of life and higher levels of depression.

Why is this work important?

Late effects are common among long-term cancer survivors who have had pelvic radiotherapy, and are associated with reduced quality of life and psychological morbidity. It is imperative due attention is paid to this issue during the follow-up phase - both in secondary and primary care. Health care professionals providing follow-up care need to be aware of the importance of assessing and monitoring symptoms, and need to be adequately informed on the most appropriate management strategies.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

The Long-term Consequences, Quality of Life, and Unmet Needs of Head and Neck Cancer Survivors

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Summary

This study aimed to identify the psychological distress, symptom concerns and quality of life issues experienced by survivors of head and neck cancer. The results provide detailed insights into the most prominent concerns and consequences of treatment affecting this group, as well as evidence of the factors influencing poor quality of life. This information could be used to inform targeted service provision and increase awareness of the consequences of head and neck cancer treatment.

Background

Over 9000 people are diagnosed with head and neck cancer in the UK each year, and five year survival across all sites exceeds 50%. The psychological impact of head and neck cancer is significant, and patients can experience high levels of depression and anxiety. The location and visibility of the disease often lead to major changes in body image and sexuality, as well as impairment to social functions. The physical consequences of surgery, radiotherapy, and chemotherapy frequently last well beyond the treatment period itself, and include difficulties with fundamental activities of daily living such as eating, drinking and speech.

A postal survey was distributed to 488 head and neck cancer survivors in Central and East Scotland to investigate demographic and clinical characteristics, levels of distress, quality of life, patient concerns, and unmet needs. Data from the survey were linked to socio-economic and diagnostic data from the cancer registry.

Key findings

319 patients responded to the survey. One third of participants had cancers of the larynx, one third had cancers of the oral cavity and the remainder had oro-pharyngeal cancers (20%) or other head and neck cancers (13%). Survey responses show that around a third of survivors were distressed and had poor quality of life, and more than half had some level of unmet need. The most prominent concerns included oral and eating problems, fatigue and fears of recurrence. Regression analysis revealed particular characteristics that were independently predictive of poor quality of life. The detailed results of the study will be published in peer-reviewed journals within the next 12 months.

Why is this work important?

This is one of the few studies to investigate the unmet needs of head and neck cancer survivors and to use a quality of life questionnaire focussed on abilities and perceptions of survivors towards everyday activities in the first five years after treatment. Although some head and neck cancer survivors fare reasonably well after treatment, a significant proportion experience a complex range of symptoms, both physical and psychological, that may interfere with quality of life. Identifying those in greatest need of support is important to the provision of individualised and holistic survivorship care to this under-recognised group.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Living Beyond Cancer and Long-term Bone Health in Cancer Survivors

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Summary

The purpose of this work is twofold. The first aim is to consolidate previous research in the area of risk of fracture and osteoporosis amongst cancer survivors receiving hormonal therapy, and to develop a testable risk stratification algorithm to predict risk of bone related morbidity in cancer survivors. Secondly, this project aims to conduct a systematic review in the use of bisphosphonates for prevention of fracture and osteoporosis amongst long-term cancer survivors.

Background

Bone is a dynamic tissue that undergoes a lifetime cycle of remodelling, loss and growth. Changes in bone physiology and increases in osteoporosis are increasingly found in cancer patients treated with hormone deprivation and chemotherapy. Additional patient characteristics pre-cancer and post-cancer diagnosis, such as gender, BMI, smoking, degree of ovarian failure and menopausal status pre-cancer diagnosis (amongst women), history of orchiectomy (amongst men), diet and exercise habits can also cause bone loss.

Prostate and breast cancer survivors account for 31% and 46% of male and female cancer prevalence respectively, and constitute the largest group at risk of developing treatment related osteoporosis. The population of cancer survivors is increasing at a rate of 3.2% annually, and the long-term bone health of this group of patients is an increasingly important issue.

Treatment of osteoporosis with bisphosphonates is well established. Bisphosphonates decrease bone resorption (loss) and are standard treatments for osteoporosis. Bisphosphonates have been shown to protect against bone loss, and are currently used as primary treatment for osteoporosis. A comprehensive systematic review and meta-analysis is needed to combine previous research and summarize the benefits and risks associated with prophylactic bisphosphonate therapy amongst different patient groups.

This study will take a phased approach

- Phase 1: development and validation of a bone health risk stratification tool based on an individual patient meta-analysis of prostate cancer and risk of fracture following androgen deprivation therapy (ADT)
- Phase 2: systematic review of preventative therapies for breast and prostate cancer survivors at risk of fracture or osteoporosis

Findings

This study is ongoing and findings will be available in December 2014

Why is this work important?

There remains a paucity of data to guide the management of treatment effects amongst long-term survivors of cancer. This project fits in with the UK National Cancer Survivorship Initiative to understand secondary effects of treatment amongst cancer survivors and to develop risk stratification tools, and will provide background data to enable further work in the field of managing and preventing bone loss amongst this population.

A comparison of Patient-Reported Late Effects and Consequences among Patients Treated for Hodgkin Lymphoma as Adults and Children

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Summary

This study funded by Macmillan Cancer Support and Queen Mary, University of London, began in September 2011 and recruitment ended in May 2012. The overall aim of the study was to investigate the impact of Hodgkin Lymphoma and its treatment on the physical and psychological health of patients alive at least five years post diagnosis.

Background

Hodgkin lymphoma accounts for 0.6% of cancer in the UK, affecting children, young adults and older adults. Survival for both children and adults has improved dramatically over the last 40 years due to increasingly effective chemotherapy and radiotherapy. While there is a clear need for survivorship care in this group, the ideal frequency, duration, components and provision of follow-up remain unclear.

Three sets of follow-up guidelines exist for childhood Hodgkin lymphoma; however, there are no agreed guidelines for managing late effects in those treated as adults. It can be argued that to date adults treated for childhood cancer have been followed-up in an unsystematic manner. New patient pathways are being developed including possible coordinating care with the adult patient pathways. However, further evidence is needed to identify the similarities and differences between the needs of patients diagnosed in different stages of their lives.

The aims of the study were to

- Investigate the impact of Hodgkin Lymphoma and its treatment on the physical and psychological health of patients alive at least five years post diagnosis.
- Compare the needs of adults treated for Hodgkin Lymphoma with those in patients treated in childhood.
- Provide a rationale for systematic, late effects-oriented, long-term management of survivors in an appropriate care setting.

Key findings

Levels of depression and anxiety symptoms are higher in long-term cancer survivors than in the general population, and strongly correlated with the impact of cancer in all types of haematological malignancy, regardless of prognosis. Other factors, such as age, years since diagnosis and degree of social support, are also contributory. A greater understanding of how these interact is needed to improve quality of life and other healthcare needs of long-term survivors.

Why is this work important?

With increasing numbers of patients living beyond cancer, it is imperative to address the issue of long-term follow-up (beyond five years) from the point of view of the cancer survivor.

Social Difficulty and Appearance Concerns in Lymphoedema Secondary to Cancer

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Summary

This study examined the social consequences of Secondary Lymphoedema (SL) among people who develop the condition as a result of cancer and its treatments.

Background

Information for this study was gathered through interviews, focus groups and a postal questionnaire. A total of 120 participants were included. Interviews were conducted with 20 people with lymphoedema (in the upper and lower limb) who identified themselves as experiencing difficulties with social interaction. Focus groups were held with 20 people with lymphoedema who are not experiencing social anxiety – their views were sought on what the general relevance of these concerns might be among people with SL. Postal questionnaires were sent to 80 people with SL to get a clearer indication of the extent and nature of social difficulties within this group.

Some of the specific aims of the study were to

- identify the nature of social difficulty, avoidance and reaction to visible difference in people with SL as a result of cancer and its treatment
- explore the extent to which questionnaires validated in other contexts capture social anxiety, avoidance and isolation and reaction to visible difference in people with SL
- identify measures to capture this information that would be most appropriate to people with SL

Findings

People feel self-conscious about the change in the appearance of their bodies, and lymphoedema can affect patients' families and friends, creating difficulties for intimate and social relationships, through loss of independence and reliance on others, resulting in feelings of burdening family and friends. Information about lymphoedema is often not available and people are frequently unaware of the risk of developing it. Furthermore, health care professionals are insufficiently knowledgeable about the condition.

People experienced difficulties getting treatment, particularly to help them deal with the psychological impact of the condition. There is a lack of funding for treatment such as manual lymphatic drainage (participants often paid for this themselves). There is unmet need for interventions to address social interaction and body image concerns in lymphoedema.

Why is this work important?

Therapies are available for treatment of the physical effects of lymphoedema there is little information about the social and emotional impact of SL on cancer survivors and further information is needed on the type of social difficulties experienced by cancer patients with SL.

The overall purpose of this study was to gather more information about the nature and extent of social difficulties experienced by people with SL in order to establish what the most appropriate types of interventions might be and how these interventions might be made available.

Survivors of Adult Cancer – Their Use of Primary Services and Unmet Needs

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Summary

The main aim of the research was to examine the use of primary care services by cancer survivors and to identify their unmet needs for health care.

Background

The research focused on the survivors of breast, colorectal and prostate cancer. The specific aims of the study were to:

- compare the use and quality of primary care services in a group of long-term survivors of breast, colorectal and prostate cancer
- compare the risks associated with being a cancer survivor in a group of long-term survivors of breast, colorectal and prostate cancer
- investigate the views of long-term cancer survivors on their unmet needs and how these needs might be addressed

Data was analysed for a group of 145,662 patients – comprising 29,244 cancer survivors and 116,418 controls. In addition the study had a qualitative component, comprising qualitative interviews with 40 survivors of breast, colorectal and prostate cancer.

Findings

The study found differences between cancer survivors and the control group in terms of their use of primary care services. For example, cancer survivors were found to have a higher rate of primary care consultations compared to controls up to 10 years post-diagnosis and accessed more anti-depressants and anxiolytics compared to controls. In addition differences were found in relation to morbidity and mortality. Breast cancer survivors were found to be at increased risk of developing heart failure, coronary artery disease, hypothyroidism and lymphoedema. There was evidence for increased risk of dementia and diabetes amongst colorectal cancer survivors and all three groups of cancer survivors were at significantly higher risk of developing osteoporosis more than 5 years post-diagnosis. The qualitative interviews found that some long-term cancer survivors had on-going needs such as needs for psychological services, access to complementary therapies and information. The qualitative interview project is available for use on the Health Talk Online website (www.healthtalkonline.org).

Why is this work important?

Five- and ten-year survival rates have been improving steadily for the last 30 years. As more people diagnosed with cancer survive for longer, it is increasingly important to consider the long-term needs of this group. In the UK, most patients are followed up in secondary care for three to five years and then discharged back to primary care. Primary care may be well placed to cater for the needs of these patients. However, patients are currently discharged back to primary care without any special follow-up arrangements.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

A National Survey of the Impact of Cancer on Employment

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Summary

The overall purpose of this study is to examine the impact of cancer diagnosis and treatment on people's working lives.

Background

Work and employment in cancer survivor studies indicate there are areas of uncertainty and lack of information. It is not known whether unemployment is due to the consequences of cancer and its treatment alone or whether a diagnosis of cancer prompts individuals to refocus their life work balance. Age and type of work are also key factors leading to a review of lifestyle and work choices.

This study aimed to identify and describe the impact of cancer diagnosis on people surviving treatment, in relation to impact on work activities; available sources of advice and support for return to work decisions, and the role of employers in supporting employees with cancer.

A quantitative cross-sectional survey was used. A structured questionnaire identified and described the impact of a cancer diagnosis on the employment activities and decision to return to work of people surviving treatment. Participants completed the survey online or by telephone interview. An initial sample of cancer survivors was randomly selected from the databases of two Cancer Registries in England. Eligible individuals were invited to participate via their GPs (April and October 2011). Survey weights were applied before descriptively and statistically analysing the data, to ensure responses were representative of cancer survivors in the initial sample, making the findings more generalisable.

Findings

382 people completed the survey, 27% of those invited to participate.

- Fulltime employment fell from 53% to 33% and working hours reduced from 38 hours prior to diagnosis to 32.
- Support services for advice on work were not widely used.
- Three quarters of employers were perceived to have been very supportive during the respondent's illness and just over half were receptive to a phased return to work or a reduction in working hours.

Why is this study important?

Studies undertaken in other countries have found an increase in unemployment among people who have had a cancer diagnosis although this has been found to vary with cancer site and length from diagnosis. However, it is not always clear whether unemployment following cancer is due to the consequences of cancer and its treatment alone or whether a diagnosis of cancer prompts individuals to refocus their work life balance. This study begins to answer those questions.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

The Experience of Long Term Cancer Survivorship: a Multiple Case Study

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Summary

This study is jointly funded by Macmillan and the Economic and Social Research Council (ESRC) through a CASE studentship, in collaboration with the School of Health Sciences at the University of Nottingham. The overall purpose of the study is to explore the experience of long-term cancer survivorship (5 years or more post-treatment).

Background

This exploratory study aimed to describe, and further understanding of, the cancer experience during the long-term survivorship phase. The specific aims of the study were to:

1. Describe the experience of long-term cancer survivorship
 - Explore how the concept of 'survivorship' has been constructed in relation to cancer, and what 'survivorship' means to those who are living five years or more post-treatment
 - Explore the impact of cancer on daily living, self, outlook on life and relationships (the illness experience)
2. Explore the utility of liminality as a framework for understanding the experience of long-term cancer survivorship.

A multiple-case study design was adopted, with narrative interviews and semi-structured follow-up interview held with thirteen long-term survivors.

Findings

Long-term survivors diagnosed with breast, gynaecological, prostate, testicular and colorectal cancer, five to sixteen years post-treatment, took part in the study. Cancer has left a legacy of benefits and losses. In particular, a legacy of lingering uncertainty, which manifests itself in different ways, and to different extents, is evident across cases. The most common manifestation is fear of recurrence. A typology of the place of cancer was developed: cancer is in the past, past-present or present-future for the participants in this study. However, the place of cancer is not static. It can oscillate between the past, present and future, and foreground and background of survivors' lives as a result of the lingering uncertainty and various 'reality checks' experienced.

Most, but not all, long-term survivors live in a state of 'sustained' liminality. Perceiving the five-year survival marker as a 'milestone' is key to transitioning out of the liminal state. Some survivors have put cancer in the past, but consequences of treatment that affect physical functioning result in them living a liminal life, on the threshold between 'sickness' and 'wellness'. Others perceive they are living with cancer within them, and experience liminality existentially.

Why is this work important?

This study makes several contributions to new knowledge. It presents a narrative understanding of the long-term survivorship experience. With little UK-based research on the experience of long-term survivorship, the study lays the foundations for further exploration of the illness experience in this population.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Living with and Beyond Cancer in Northern Ireland

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Summary

This study was commissioned in 2010. The main aim of the research was to improve our understanding about the health and wellbeing of adult cancer survivors and their adult caregivers in Northern Ireland. It is intended that the study will inform the work of service planners and providers in terms of improving the match between the support needs of people affected by cancer and services.

Background

Little is known about the profile of the two million people living with cancer in the UK including approximately 51,000 survivors who live in Northern Ireland. As the prevalence of cancer rises and models of care change, there is an increasing emphasis on the role of informal caregivers after active treatment has been completed.

Only a few studies have systematically assessed the needs of cancer survivors and empirical evidence regarding the health and wellbeing of their primary caregivers is sparse. It is important that the needs of this population are identified to enable the care and support systems currently in place to be adapted to improve the quality of life of cancer survivors and their primary caregivers.

Key questions include:

- What is the health and wellbeing of adult cancer survivors and their adult caregivers?
- What is the nature and extent of health service use by adult cancer survivors and their adult's carers?
- How does the health and wellbeing of cancer survivors compare to a General Practice population?
- What is the prevalence of 'late effects' among cancer survivors?

Findings

Key cancer survivors and their caregivers reported poorer health and wellbeing and health service utilisation than the general population. Despite this poorer health the majority of cancer survivors and their caregivers reported satisfaction with services and the majority of survivors did not report any needs. There is, however, a subgroup of survivors and caregivers who warrant specialist support, particularly survivors who experience late effects and who have co-morbid conditions. Future research and practice should focus on developing methods that could be used in routine clinical care to identify 'at risk' or vulnerable patients and to provide tailored, appropriate and timely support.

Why is this work important?

This work addresses a knowledge gap by providing information about the health and wellbeing of cancer survivors and their primary caregivers. The results will be used to devise tailored, personal care and support services with the aim of improving the quality of life for people affected by cancer.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

International Benchmarking Project (ICBP)

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Summary

Macmillan Cancer Support is funding module four of the International Cancer Benchmarking Project in Northern Ireland. The study will examine where delays occur in the patient pathway from first awareness of symptoms to treatment.

Background

The International Cancer Benchmarking Partnership (ICBP) was established in December 2009 to gather evidence of reasons for variations in cancer outcomes across OECD countries. The partnership comprises 12 jurisdictions: New South Wales (Australia), Victoria (Australia), Sweden, Denmark, Norway, England, Northern Ireland, Wales, Alberta (Canada), British Columbia (Canada), Manitoba (Canada), and Ontario (Canada). All of these jurisdictions have high quality cancer registries, covering comprehensive populations and can therefore contribute to the in-depth analysis of causes of survival differences.

Module four explores differences in delay in the pathway to treatment for four cancer types (breast, lung, colorectal and ovarian). Standardised questionnaires will be used to survey 800 recently diagnosed cancer patients and their GPs.

The specific aims of the study are to:

- identify and describe factors affecting diagnostic delays at patient, primary care and hospital level in Northern Ireland for cancers of the breast, colon, rectum, lung and ovary
- quantify the patient and organisation contribution to delays in cancer diagnosis
- provide data for the ICBP in order to benchmark the performance of cancer services in NI against cancer services in other countries

Findings

The Northern Ireland study will be completed in December 2014.

Why is this work important?

There is an unexplained variation of outcomes in cancer survival across countries with similar levels of spend and resources. Further, there is a wide range of views but a lack of clear evidence as to why cancer outcomes vary and therefore about how resources can be used most effectively. The findings from this study will contribute to that evidence gap.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Older Women's Experience of Breast Cancer alongside Other Health Conditions: The EPAN Study of Women Aged 70 Years and Over

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Summary

The purpose of the study was to examine the experiences of breast cancer among women over 70. Particular emphasis is placed on older women's experiences of living with breast cancer alongside other health conditions.

Background

A User Reference Group was established to inform conduct of the research and methodology. The research was conducted through in-depth one to one interviews and two focus groups. Interviews were conducted with 32 women over 70 who had been diagnosed with breast cancer between 1977 and 2008. During interviews women were asked about their experiences of living with breast cancer alongside other illnesses and about the difficulties associated with this.

Findings

Some of the key findings of the study were:

- Some women were surprised to be diagnosed with breast cancer as they had assumed, from the way it is portrayed in the media, that it is a young person's disease.
- Women felt that pre-existing conditions were not taken into account when planning treatment or rehabilitation.
- Women reported enduring physical problems from surgery, such as lymphoedema, reduced functional ability of their arms and scarring.
- Women may have difficulty interpreting symptoms between cancer, ongoing effects of cancer treatment and co morbidities, such as arthritis, which may delay diagnosis of metastatic disease.
- Body image is a concern, especially around mastectomy scars. Participants were keen to stress that they wanted to look good despite their age. One concern was a lack of prostheses and bras designed to meet their particular needs.
- They stressed that they were not a homogenous group and that assessment of their needs should be holistic and personalized, with recognition of the possible complexity of needs because of the physical and social effects of ageing.

Why is this work important?

Over 40,000 women are diagnosed with breast cancer in the UK each year and more than one third of these are women aged over 70. There is a growing body of research about women's experience of living with breast cancer but the experiences of women over 70 have largely been neglected. This study begins to fill this evidence gap.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

PACE Study: Plans and Care Expectations

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Summary

This study seeks raise the standards of care for all people at the end of life through investigating the existence and nature of the transition to palliative and end of life care in two contrasting illnesses; incurable lung cancer and advanced chronic obstructive pulmonary disease (COPD).

Background

Research over the last 30 years has shown that whilst many people received excellent care in the last year of life from GPs and District Nurses, many do not due to late identification of nearing life's end, inadequate communication about the illness and its future implications, inadequate symptom control, insufficient nursing support and uncoordinated care out-of-hours.

Over two-thirds of lung cancer patients are incurable at presentation, some with a rapid trajectory to death that is potentially well served by current palliative care models. Death from COPD often occurs after a long period of functional decline, uncontrolled symptoms, emotional distress and social isolation. Current services frequently do not meet these patients' needs.

Using interview methodology this study seeks the views of patients with progressive cancer and COPD, their lay carers and health professionals on the appropriateness of a palliative care approach and conversations concerning the end of life. Interviews will explore their views on:

- The existence and nature of their transition from chronic illness to palliative and end of life care
- Their care, support and information needs at this stage of illness
- The aspects of care they regard as key markers of high quality care at this stage of illness

Findings

This study is ongoing and findings will be available March 2015

Why is this work important?

This project will help identify best practice in service delivery, end of life care and support, and will involve people affected by cancer in research. The project also reflects the top priority research theme of the Macmillan Listening Study: the impact cancer has on life, how to live with cancer and related support issues.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

The Use of Herbal Medicines by People with Cancer

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Summary

The purpose of this study was to examine use of herbal medicines by people affected by cancer and to identify information needs in relation to this.

Background

The first stage of the study comprised a review of UK literature and the second stage of questionnaires and focus groups with people affected by cancer. The study included up to 60 cancer patients six months after diagnosis and within a five-year follow-up period. The specific aims of the study were to:

- understand better how and why people with cancer use herbal remedies to support their cancer treatment
- explore patients' knowledge, beliefs and attitudes in relation to herbal medicines and how far they are aware of the potential for harm in herbal self-medication
- investigate when, why, how or if people living with cancer currently obtain information on herbal remedies they use to support their cancer treatment
- establish what kinds of information people with cancer want or need in relation to herbal medicines and, how and from what sources they would like to be able to obtain it

Findings

The systematic review of literature found that most studies did not report information specifically on herbal medicines as distinct from complementary and alternative therapies in general. No studies examined participants' information sources for herbal medicines and the socio-demographic characteristics of herbal medicine users. It is likely that herbal medicines are used by about 20% of cancer patients. Women, those in younger age groups and the more affluent are most likely to use them.

People use herbal medicines to address the long-term consequences of cancer and its treatment. Using herbal medicines gives people a sense of control over their cancer diagnosis and a feeling that they are assisting their survival. There is limited awareness amongst those wishing to use herbal medicines of the potential risks of their use whilst taking other medications.

Why is this work important?

Self-medication with natural remedies is becoming increasingly popular but little information is available on the types of herbal remedies cancer patients use. Some herbal remedies can interfere with conventional treatments and cancer patients are generally advised to inform the professionals treating them if they are taking any form of herbal medicines and supplements.

Studies suggest, however, that only about half of cancer patients do so and that professionals have very limited knowledge in this area and feel unable to give informed advice. Therefore recommendations about the provision of information for herbal remedies for people living with cancer are important in improving and meeting the needs of people affected by cancer.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Exploring the Key Concerns and Support Needs of Older Carers of People with Advanced Cancer

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Summary

This study explored the experiences and support needs of older carers of people affected by advanced cancer.

Background

With developments in cancer treatments and care an increasing number of people are surviving cancer and reaching old age before facing the end of life. Also in the UK there are increasing numbers of people diagnosed with cancer in older age, often in conjunction with other illnesses. The number of older carers is increasing, often with their own health problems. The 2001 UK National Census reported the number of older carers as 1.5 million, with one in eight people over 60 being a carer.

34 carers participated in one of a series of workshops (and an addition 5 were interviewed) where they described and discussed their personal experiences of care-giving and support, identified key challenges and concerns and, as a group, prioritised older carers' needs for support.

Some of the specific aims of the study were to

- examine the impact of caring for someone with cancer towards the end of their life on older carers' everyday lives
- better understand the key challenges, concerns and support needs of older carers of people with advanced cancer approaching the end of their life
- work with older carers to identify key research questions to reflect their needs and priorities

Findings

The findings indicate that for a minority of the participants, their caring experience was a positive experience in which they were able to give tangible expression to their love for someone with whom they had shared much of their life and for whom they cared deeply. Whilst their loss and grief in bereavement was intense and sustained it appeared to be tempered by a sense of satisfaction that they had been able to provide love and care to the person they had cared for which facilitated them having a 'good' death. However, these individuals did report distressful emotional experiences and physical consequences of caring.

Sadly in contrast to this, the majority of participants had a predominately difficult caring experience. The findings are suffused with examples of miscommunication, disorganisation, lack of services, lack of information and an overreliance on informal carers. This related to or resulted in, amongst other things: poor pain control for the dying person, crisis admissions to hospital, carers feeling overwhelmed, exhausted and frustrated, and residual feelings of anxiety, anger and guilt in bereavement.

Why is this work important?

Little information is available on the particular impact of caring for people with cancer towards the end of their life on the growing population of older carers; this study begins to fill this evidence gap.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

I'm Just in the Shadow to Keep an Eye: an Investigation to Understand the Need for Support in Family Members of People Having Chemotherapy

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Summary

This study examined the support needs of family members of people having chemotherapy.

Background

Most of the information for the study was gathered through interviews. Interviews were conducted with 25 family members/care-givers. During interviews participants were asked about their experiences at three stages of chemotherapy (commencement of chemotherapy, mid-course and at the end of treatment). In addition, four focus groups were conducted. Two of the focus groups were attended by family care-givers and two by healthcare professionals.

The specific aims of the research were to:

- describe the experiences of family members supporting relatives through chemotherapy
- conceptualise their evolving need for information and support
- examine factors that impact their confidence in supporting a patient
- identify feasible and acceptable interventions to be tested in the future

Findings

Carers of patients having curative treatment experienced considerable distress throughout treatment. At the root of this anxiety was fear of recurrence. Carers of those having palliative treatment typically saw chemotherapy in a positive light. Their anxiety was focused on how they would manage the patient's decline.

Carers felt the personal impact of treatment most keenly when it impacted on daily life, (e.g. limiting social arrangements or needing to take on chores or activities usually carried out by the patient). Relationships were impacted by cancer and chemotherapy and the end of treatment brought new concerns.

There was clear consensus on the following areas

- carers should be given practical advice about how the side effects of chemotherapy can be managed
- carers should be given details of sources of information for financial, emotional and practical support
- carers should be clearly informed about how to access out of hours chemotherapy services and what to expect from them

Why is this work important?

There is growing recognition that carers have unmet needs that impact on their ability to support a family member through chemotherapy. But there has been little information available to health professionals to enable them to develop chemotherapy services to respond to the needs of carers. As more treatment is delivered within day care it is becoming increasingly important to identify and address the support needs of carers in this context.

Support for People with Learning Disabilities Affected by a Person with Cancer

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Summary

This study examined the experiences of adults with learning disabilities (LD) who have a relative or friend with cancer.

Background

Three focus groups were convened, with a total of 17 participants, and each group met four times. Semi-structured interviews were held with four participants. The participants were adults with mild to moderate learning disabilities who had a close relative/friend with cancer, now or in the past.

Specific aims of the research were:

- To explore the experiences of adults with LD who have a relative or friend with cancer
- To identify the support and information needs of this group
- To identify the barriers people with LD face to receiving adequate support and information when a relative or friend has cancer
- To make recommendations for practice, the development of resources and future research, to ensure that people with LD are adequately supported when a relative or friend has cancer

Findings

The key findings were

- Participants who had not been told about the patient's illness felt excluded and being told that someone had cancer did not necessarily mean that the participant had understood the implications.
- Participants had vivid memories of events and feelings. They worried about their families. Several had become carers themselves.
- Participants lacked knowledge about cancer and wanted to know more. Many were worried that they themselves would get cancer
- Participants would have liked to share their feelings and questions with family, friends or professionals, but most had not done so.

Recommendations

Health care professionals should offer support to families. This includes passing on factual information about the cancer; advice on including the person in what is happening; and advice on normal emotional responses. Health care professionals should also receive training on learning disability and communication with people with LD, as well as familiarise themselves with the availability of accessible cancer information materials.

Why is this work important?

There is insufficient literature to guide the development of best practice guidelines in this area and very few studies have explored the experiences of people with LD themselves around cancer, death and dying. Evidence suggests, however, that people with LD can and want to be involved in such research.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Routes from Diagnosis

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Summary

Macmillan's 'Routes from Diagnosis' is a programme of research performing retrospective analysis of almost 85,000 cancer patients' interactions with the NHS in England over seven years – the richest picture yet of cancer survivorship.

By linking and analysing routinely collected data, such as Cancer Registry data and Hospital Episode Statistics, it allows us to map the cancer journey from diagnosis to death or continued survival, describing the health outcomes that patients experience. This can include survival times as well as the rate and frequency of cancer, and non-cancer related morbidities.

The approach also lets us see how the frequency and rate of cancer diagnoses is affecting the health care system, for example the length of time patients spend in hospital, when they access a health care service, and how much this costs.

Background

The story of cancer is changing – by 2020, nearly half of us can expect to get cancer in our lifetime, but almost four in ten will not die from the disease. The number of people living with cancer in the UK will double from today's two million to four million in the next twenty years. But until recently, patients' clinical journeys after diagnosis and treatment have not been well understood.

Routes from Diagnosis shows that with the technology and data already available to the NHS it is possible to understand cancer journeys in an unprecedented level of detail. This is useful because all the clinicians who see cancer patients after their treatment need to be aware of the issues cancer survivors may face.

Side effects of cancer treatment affect quality of life; a significant proportion of patients have ongoing health and support needs. However, many do not experience any side effects and have minimal support needs. At the moment health care systems are not set up to distinguish between these two groups or to cope with the growing cancer population.

Understanding the health implications can ensure successful planning, development and implementation of cancer services. Cancer services need to be tailored to meet the different health and support needs of people living with cancer, be effective and make economic sense.

Macmillan is beginning to learn much more about the two million people currently living with cancer. Routes from Diagnosis provides an evidence-based view of the effect of disease on the people living with cancer and on the health system

Findings

The 'Routes from Diagnosis' work was carried out by Macmillan with the University of Leeds and Monitor Group and has begun to identify what happens to cancer patients from the point of diagnosis. By linking cancer registry and Hospital Episode Statistics inpatient data it has been possible to create a detailed picture of the health service utilisation for people with colorectal cancer, multiple myeloma and Hodgkin's disease. The findings of the work are currently being written up for publication.

An example of a key statistic identified amongst other key outcome data that 24% of people with colorectal cancer had intestinal problems which led to a number of inpatient episodes whereas patients with myeloma had renal problems and other co-morbidities.

Since the pilot Macmillan has built on the knowledge captured in the pilot work and developed the 'Macmillan Routes from Diagnosis' programme which will:

- Map the clinical pathway of other cancer sites incorporating more data sets e.g. from primary care, outpatient attendances, emergency admissions, treatment data as well as to triangulate the analysis with information collected through the PROMs survey and other key projects and initiatives.
- Test the applicability of these analyses to service improvement within the NHS. Macmillan is currently working with in Sheffield and Manchester to develop self management models of care for colorectal, breast and lung cancer patients with the intention of reducing emergency admissions by improving community support

Discuss the approach with new NHS structures – introducing those working in Clinical Commissioning Groups and Commissioning Support Units to this new and insightful way of understand the cancer population;

In April 2014, we published [Routes from Diagnosis: The most detailed map of cancer survivorship yet](#), which contains findings for [breast](#), [prostate](#) and [lung](#) cancers and [brain and central nervous system](#) tumours.

Some of the key findings were

- 69% of breast cancer patients experienced ongoing survival
- less than 1% of lung cancer patients survive past 7 years
- 55% of patients with prostate cancer survived for 7 years or more
- brain and CNS tumours survival varied considerably between the different tumours.

Why is this work important?

This work directly addresses a key aim of the NCSI: to improve patient outcomes by informing health services planning so that the potential course of future events can be shared with patients and information, support and services can be planned and commissioned.

This work will help in understanding which consequences are likely to happen to people based on a range of factors and will enable assessment and care planning and subsequent aftercare to be tailored according to the risk of different consequences occurring. It will help identify what type of survivor people become after cancer; whether completely cured with no further impact on cancer services, to a frequent user due to necessary follow ups, side effects, of other ill health, and a range of survivorship 'types' in between.

Ultimately the project will provide important information about the natural history of cancer that will facilitate the planning, development, location and commissioning of future cancer services.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Welsh Cancer Patient Experience Survey (CPES)

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Summary

This survey was produced through a partnership between the Welsh Government, Macmillan Cancer Support and Quality Health. The Welsh Cancer Patient Experience Survey aims to help inform cancer policy by focusing on improving the experience of patients.

Background

The Together for Health - Cancer Delivery Plan was published by the Welsh Government on 13 June 2012. The Delivery Plan provides a focus for cancer services in Wales setting out a clear set of actions and measurable outcomes to drive service improvement. There is a clear focus in the plan on meeting people's need stating the objective; *'People are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer'*.

The survey provided an opportunity to test Welsh Government policy, specifically asking questions on flagship policies such as key workers and written care plans as well as allowing a better understanding of whether certain cancer types, ethnicity, communities, age groups or genders experience poorer care. The survey therefore provides a wealth of data to evaluate the implementation of current policy and help to shape the future direction of cancer services in Wales.

A total of 10,945 patients who had received treatment for cancer from 7 NHS Health Boards/Trust were included in the sample for the Wales Cancer Patient Experience Survey. These patients fell into 13 different cancer groups. A total of 7,352 patients responded which represents a response rate of 69%.

Findings

The overall scores given by patients in Wales to the cancer patient experience survey were positive. Scores were 80% or higher on 31 of 67 scored questions in the survey; however, scores of 70% or lower were given by patients on 19 questions so there is scope for improvement in some areas of clinical practice and in support for patients.

The data from special analyses on demographic and other variables show that in many cases there are considerable differences of view between patients from different social groups, and between those with different cancers. There are also some important differences in the quality of treatment and care as seen by patients in different health boards, trusts and hospitals. Work must be undertaken to understand why this variation occurs.

Why is this work important?

The survey results therefore gives clear indications to health boards, trust boards, service planners, cancer charities and to the Welsh Government, as to the priorities for continuing quality improvement initiatives. The results also point to areas of policy which could be the subject of further intervention and monitoring, such as assessing the importance of complex pathways on patient experience, where these exist; the extent to which the findings of peer review are being used; and the extent to which existing information provision created by cancer charities and the NHS generally is helpful and is being used by staff.

HEALTH ECONOMICS

Cancer's Hidden Price Tag: the Financial Impact of Cancer for Individuals and their Households

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Summary

This study explored the additional financial costs for individuals and their households that are associated with cancer, how and when these costs arise, and how these costs impact on the financial and wider well being of adults with cancer and their households. These findings have informed the development of Macmillan's Cancer's Hidden Price Tag campaign.

Background

In a challenging economic climate, serious illness is a particular financial concern. Macmillan commissioned the University of Bristol's Personal Finance Research Centre to determine the scale of the financial burden of cancer in particular to patients. The research involved 24 in-depth interviews and a UK-wide postal survey of 1,610 adults living with cancer, which ran from 17 August to 21 October 2012. The results were weighted to be representative of age, gender, cancer type and nation.

The questionnaire captured self-reported expenditure over a six-month period, covering a wide, but not exhaustive, range of costs relating to their cancer diagnosis and treatment. Respondent's income before and after their diagnosis was captured to estimate loss of income as a result of cancer.

Findings

Four in five respondents incurred an average cost of £569 a month. The costs reported by individuals ranged widely: large numbers of respondents experienced low costs, while a significant minority incurred much higher costs. The largest components of cost were income loss and outpatient costs, specifically travel costs to and from healthcare appointments.

Key factors that influenced the likelihood and size of these costs were age, employment status, current income, cancer type, and treatment. Those on low or medium to high incomes also incurred particularly high costs.

Almost half (47%) of respondents who incurred costs as a result of their diagnosis said their general financial situation had got worse since their diagnosis. Three in 10 (30%) respondents who incurred costs found it a constant struggle to pay their bills or were falling behind with payments.

Why is this work important?

This study has implications for a range of audiences including policy makers, the NHS, employers and the financial services industry, to ensure people with cancer can access benefits, support and advice services when they most need it.

It also provides valuable information on the type of people who are worst affected. The study also points to the largest components contributing to the costs of cancer and how cost components differ for different groups. However important questions remain as to why these certain characteristics (like age, income, cancer type) result in higher costs.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Acknowledging the Importance of Economic Well-being and Returning to Work after Cancer Treatment: The Role of an Occupational Therapist

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Summary

This study was designed primarily to identify the psychosocial, physical and functional obstacles complicating the return to work process in adult cancer survivors who may be at risk of developing late effects of their treatment.

The main aims were to identify the physical, functional and psychosocial barriers adult cancer survivors face upon their return to work and to examine resource use and the health care cost in adult cancer survivors who are or should be economically active.

Background

It has been shown that return to work may be expedited with the engagement of an Occupational Therapist. In addition, studies have shown that with the assistance of an Occupational Therapist, patients suffering prolonged illnesses are able to overcome the barriers that impinge on workplace functionality. Recent studies have shown that goal-setting and graded activity can contribute to successful patient rehabilitation; however, there remains a lack of information about the most appropriate interventions to assist cancer survivors.

Barriers to successful return to work for cancer survivors will be identified using a combination of questionnaires and clinical assessments. Participants will complete clinical assessments carried out by the Occupational Therapist. The assessments may run over a 4-week period and include an initial assessment, job analysis or work site assessment and other clinical assessments deemed necessary by the Occupational Therapist.

The health economic component of the study will examine the use of health and social care resources, productivity and health status of cancer survivors who were economically active. The full consequences for the use of health and social care services and time off sick will be costed. The costing will include costs associated with implementing additional investigations/interventions as a result of identifying additional needs in enabling cancer survivors' return to work. The benefits in terms of health status will be assessed using EQ-5D.

Findings

This study is ongoing and findings will be available August 2014

Why is this work important?

Despite recent studies demonstrating the potential effectiveness of an Occupational Therapist in assisting cancer survivors return to work, current practice does not routinely offer an Occupational Therapy assessment within the return to work process. Within the rehabilitation setting, the primary goal of the Occupational Therapist is to enable participation in everyday activities, including work. However, the focus is often post discharge functional abilities in the home environment rather than the long term issue of return to work and increased occupational independence. This study begins to fill this gap.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

What Explains Cancer Costs in England?

Mauro Laudicella, City University

Summary

This study will investigate related aspects of the variation in the costs of cancer in England.

Background

Producing evidence on the main drivers of the costs of cancer is essential for securing the efficient allocation of resources in the NHS. Commissioners may use such information to incentivise more efficient pathways of care and to benchmark expenditure by health care providers against their peers.

This research will provide evidence on the magnitude and variations of cancer costs across different stages of the disease, geographical areas and pathways of care. Using data on the direct cost of cancer care at the level of patient and will examine the whole population of patients with selected cancer types in England.

This study will consist of three modules that will investigate related aspects of the variation in the costs of cancer in England, examining patients with four main cancer types: lung, breast, prostate and bowel cancer. Each module will address a number of research questions:

The economic burden of cancer

- What is the economic cost of providing care to patients with cancer across the different phases of the disease?
- What is the geographical variation in the cost of cancer?

Differences in the cancer care pathways and their effects on patient survival and costs

- What are the main factors explaining the variation in the lifetime cost of cancer?
- What is the impact of treatment intensity on patient survival and on the rate of accumulation of lifetime costs?

The cost of emergency admissions of patients with cancer

- What factors explain the variation in the risk of emergency admissions and associated costs?
- Can we reduce the cost of emergency admissions by investing in primary care services?

Findings

This study is due to start in August 2014 and will be completed in August 2017

Why is the work important?

There is a pressing need for more economic evidence about the cost and effectiveness of cancer care, and producing evidence on the main drivers of the costs of cancer is essential for securing the efficient allocation of resources in the NHS. This study will begin to fill this evidence gap

EPIDEMIOLOGY

Macmillan-NCIN Work Plan - Understanding the Cancer Population

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Background

The development of robust data analysis is a crucial component of understanding the two million people currently living with cancer in the UK and to inform our understanding of the cancer survivorship population. People surviving cancer will have very different levels of need and these needs are likely to change over time and depend on the type of cancer and treatment they have had. To make personalised care a reality, we need to understand the needs of the two million, the health, social and economic impacts of cancer and the consequences of its treatment.

Macmillan Cancer Supports' ambition is to reach and improve the lives of everyone affected by cancer and inspire millions to do the same. We do that by providing medical, practical, emotional or financial support and pushing for better cancer care. The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

With the two million people in the UK living with cancer now predicted to increase to four million by 2030, these are very challenging ambitions. The collection and analysis of high quality data is critical to informing and delivering initiatives and change which will enable people affected by cancer to achieve the best possible outcomes.

To help achieve this Macmillan and the NCIN are working in partnership and have developed a Macmillan-NCIN work plan. As part of the work plan, both parties are funding two data fellows over three years who will build a programme of work to develop and apply the analysis of large scale data sets to the survivorship intelligence agenda. The analysts are jointly badged Macmillan-NCIN Data Fellows.

The Macmillan-NCIN work plan

Vision

“Macmillan Cancer Support and the National Cancer Intelligence Network are working to:

- use data and information to push the boundaries of understanding of the whole cancer population, now and in the future, of the impact and costs of cancer and it's treatment on patients, the wider community and the NHS, and
- work to enable wider health and social care services to extend the usage of this information to improve the care, experience and outcomes for patients by designing, testing and implementing better models of delivery”

Why now?

We already know a lot about people living with cancer. In order to reach and improve the lives of everyone living with cancer now and in the future, commissioners, providers and decision makers need to fully understand in this challenging economic climate the current numbers, needs and experiences of people living with cancer. We need to increase the granularity of our understanding so that we have the best intelligence to most effectively target and ensure the best outcomes for people living with cancer.

Work streams

A number of work streams will be prioritised over the course of the partnership all underpinned by the desire to increase analysis and reporting for all four nations of the UK at a national (UK), nation and local level where possible.

- Segmenting the cancer population
- Routes from Diagnosis

- Developing routine survivorship stats
- Patient Outcomes and Experience
- Costing
- Social Care

Specific projects within the work streams will be prioritised over the course of the partnership.

Current priorities

Build a greater understanding of the cancer population across the UK

Initial analysis is using national cancer datasets to analyse the cancer population. The analysis explores the number of people 'living with cancer' and their characteristics. Where possible this includes analysis by cancer type, age, gender, locality, ethnicity, deprivation, stage, time since diagnosis, care pathways, hospital utilisation and comorbidity. The initial stage of the work plan also focuses on specific areas of analysis including NHS costings, hospital outpatient activity (follow-ups) and second cancers. The depth of our understanding, and the analysis that supports this, will be developed as knowledge expands and new datasets become available.

Current analytical projects

Segmenting the cancer population – There is little granular information on the cancer survivor population. Our work uses patient-level data to quantify a united picture of need across the cancer population for the whole of UK, which is essential to understand the full burden of disease. The first stage of this work looked at people diagnosed with cancer in England between 1991 and 2010 using the National Cancer Data Repository (NCDR). We identify people alive with cancer at the end of this period (i.e. 20-year prevalence) and then explore the characteristics of this population.

The second phase of this work collates data for the whole of the UK. We will then obtain or model data prior to 1991 to enable segmentation of the total number of people living with cancer. We will also produce analysis by new breakdowns of the data. For example by care pathways, cancer types, UK and UK nations, new NHS localities, and age at diagnosis as well as attained age.

Costing the patient pathway – Evidence on the economic burden of cancer is limited due to the lack of reliable data on cost of care. In partnership with City University and Imperial College London a new dataset for England is being developed which links patients in the National Cancer Data Repository (NCDR) with data on hospital activity (Inpatient HES) and NHS costs (National Schedule of Reference Cost). This dataset will enable us to build a better understanding of the cost of patient pathways. Next steps include adding more hospital activity data (e.g. Outpatient HES), quality assurance of the dataset and cost analysis.

Understanding progressive cancer – Historically there has been limited national information on progressive cancers (recurrence, second cancers and metastatic disease), as data on these have not been routinely collected. The study assesses the quality of routine national datasets for analysing progressive cancer, and determines how these data can be used to develop a methodology to identify cancer progression. There are a number of national datasets which, when linked, can inform our understanding of how cancers progress after the first diagnosis. Initial analysis includes second cancers, hospital activity and treatment analysis with a focus on select cancers types.

Other ongoing projects

- Analysis across the UK nations
- Routes from Diagnosis
- Linking outcomes and experience
- Follow-ups

More information about these projects and new priorities will be provided in future updates of the work plan as it develops and can be found on both the Macmillan and NCIN websites.

Cancer Survivors and Cancer Survivorship: Quantifying Cancer Prevalence and Modelling its Dynamics in England and the UK

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Summary

This study was funded by the Macmillan Research Fellowship scheme. Cancer prevalence is the number of people diagnosed with cancer who are still alive, influenced both by cancer incidence (the number of new cases of a particular form of cancer) and survival rates. Prevalence rates vary with factors like age and type of cancer. The overall purpose of the study was to quantify the number of cancer survivors in the UK population and to develop a tool for estimating current prevalence and predicting future prevalence.

Background

Cancer registry data for England from the National Cancer Data Repository were used. This dataset is an amalgamation of data from the eight regional cancer registries in England and provided details of all registered diagnoses of cancer among residents of England in the period 1971 to 2008. Historical and estimated future national population data were supplied by the Office for National Statistics (ONS) and their most likely projections of the size of the population of England and the UK, by age, sex and year were used.

Using a model of prevalence as a function of incidence, survival and population demographics, projections were made to 2040. Different scenarios of future incidence and survival, and their effects on cancer prevalence, were also considered. Colorectal, lung, prostate, female breast and all cancers combined (excluding non-melanoma skin cancer) were analysed separately.

Findings

The study found that if existing trends in incidence and survival were to continue, the number of cancer survivors in the UK will increase by approximately 1 million per decade from 2010 to 2040. Particularly large increases are anticipated in the oldest age groups, and in the number of long-term survivors. By 2040, almost a quarter of people aged at least 65 will be cancer survivors.

Why is this work important?

The number of cancer survivors in the England population has been increasing each year and is expected to continue increasing. This is due to improvements in cancer treatment and survival which are leading to increases in the number and proportion of cancer survivors in the population. However, there are significant gaps in the data available about cancer prevalence and cancer survivors. This study begins to address these gaps by producing a comprehensive and detailed account of cancer survivors and cancer prevalence in England and the UK. Further, as the population of cancer survivors is likely to grow substantially in the coming decades, so will the related demands upon the health service. Plans need to be made to ensure that the varied needs of cancer survivors can be met in the future.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Use of the National Cancer Data Repository to Assess the Processes and Outcomes of Cervical Cancer in England

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Summary

This population based study examines the treatment and longer term outcomes of cervical cancer patients who been treated for the condition. Insights from the research will identify the needs of survivors of cervical cancer patients including the late effects of radiotherapy treatment and help us look at service solutions to address these. This study is part of the Routes from Diagnosis Programme.

Background

Cervical cancer is the second most common cancer to affect females worldwide and is the most common cause of cancer death in developing countries. In the UK the incidence of the disease has fallen significantly over the last few years (due to the UK screening programme) and survival rates have significantly improved with around 64% of patients now surviving at least five-years. Chemotherapy and radiotherapy are both important treatment modalities in the management of cervical cancer but whilst they can cure the disease they can, also result in long-term treatment related morbidity. Evidence available demonstrates that between 6 and 10% of survivors experience serious late complications from their treatment.

The National Cancer Intelligence Network (NCIN) has developed a new resource called the National Cancer Data Repository (NCDR) that links numerous routine datasets together to create a dataset that enables the NHS 'careers' of all cancer patients to be followed. By tracking hospital resource use following a diagnosis and active treatment for a disease it will be possible to determine the complications and morbidities experienced by cancer patients. We will also be able to look at patterns of resource use and examine when this occurs.

This research programme aims to link these datasets and
Identify whether the NCDR could provide a robust means of auditing cervical cancer management at a population level across England
Identify whether the NCDR could provide a robust method of determining any long-term complications associated with cervical cancer treatment
Identify patterns of resource use identified with cervical cancer patients.

Findings

This study is ongoing and findings will be available in August 2014

Why is this work important?

The population of people surviving from cervical cancer is growing and it is important to quantify the morbidity associated with such treatments so that the needs of the individuals experiencing them can be addressed and treatment strategies optimised. Currently there is no population-based information detailing the long-term morbidity associated with cervical cancer treatments and limited understanding of what long term effects are and in whom they occur. The patterns in resource use are increasingly important in determining what the implications are for health services. This study will play an important role in informing Macmillan how to support cancer survivors and to help develop services for them and also inform us of the feasibility of linking large data sets and their utility in helping us develop services and work with commissioners.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

EFFECTIVE SERVICE SOLUTIONS

Evaluation of the Walking for Health Scheme

Evaluation being conducted by Ecorys
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Summary

Macmillan Cancer Support commissioned Ecorys to evaluate the Walking for Health programme in August 2013. The evaluation will help us to understand the impact of the physical activity programme on helping people affected by cancer and other long term conditions to get or stay active.

Background

The Ramblers and Macmillan Cancer Support are working in partnership to deliver Walking for Health to help more people – including those affected by cancer – discover the health and social benefits of walking. The primary aim is to ensure those who are living with cancer or have other long-term health conditions (LTHC) and those who are inactive, have access to a short, free, friendly and local Walking for Health walk which will benefit their health and well-being. The programme aims to encourage health and social-care professionals to recommend Walking for Health to their service users. The programme will also aim to inspire people to give something back to Macmillan and the Ramblers, and to raise awareness of the organisations' work.

The key objectives of the evaluations are to:

- assess the extent to which the programme has been successful in engaging key target groups, including people living with / affected by cancer, and helping them to maintain or stay active
- identify best practice for raising awareness, engagement of target groups and local delivery and share this across Walking for Health schemes
- provide ongoing formative evaluation, identifying and sharing key learning and recommendations with Macmillan and the Ramblers, and draw out the strategic lessons that can inform and help shape the development of the programme
- identify the full costs and benefits of Walking for Health to provide an understanding of the value generated by Macmillan's and the Ramblers investment in Walking for Health

The evaluation uses a mixed method approach, which includes the following:

- self-reported physical and well being measures for all new Walking for Health beneficiaries in 2014 with 3 monthly follow ups for a 9 month period with a sample of walkers to measure any changes
- ten case studies of Walking for Health schemes with qualitative research with Walking for Health coordinators and volunteers, local stakeholders and beneficiaries
- measuring up to 140 beneficiaries' physical activity using pedometers
- a value for money and cost benefit analysis of the programme

Findings

The final report will be available in March 2015.

Why is this work important?

The Walking for Health's previous evaluations have not provided a robust assessment of the impact of the programme on physical activity. This evaluation aims to provide evidence of the extent to which the programme is successful in engaging and helping people affected by cancer to increase or stay active. It will be used to draw out key lessons learned to support ongoing development and improvement in Macmillan's physical activity programmes and provide an understanding of the value generated by Macmillan's and the Ramblers investment in Walking for Health. It will also consider the effectiveness of the partnership in delivering the programme.

Evaluation of the Wales Cancer Information and Support Services

Evaluation being conducted by Arad

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Summary

Macmillan Cancer Support commissioned Arad to evaluate the Wales Cancer Information and Support Services in October 2012. The evaluation will help us to understand the impact of the services and their value. It will also share learning across the services to support ongoing improvement.

Background

The number of people living with and beyond cancer in Wales is rising. There are 120,000 people living with and beyond cancer in Wales and this number is set to double by 2030 if current trends continue. People are living longer with cancer and have to deal with the long-term consequences – cancer is increasingly being seen as a chronic condition that should be managed in the community, rather than as an acute illness. The cancer information and support services in Wales, located across various hospital and community settings, aim to support and inform people affected by cancer about how to take an active role in their recovery, rehabilitation and ongoing care. The evaluation aims to measure the extent to which they effectively meet this aim and any identify improvements that can be made.

The key questions for the evaluation are:

- What works well across a number of key audiences such as service users, why, for whom and in what circumstances?
- How effective are the various models and locations of cancer information and support services?
- What lessons can be learnt to inform planning and development for the services?
- What is the sustainability and transferability of the services and what are the strategic considerations for the direction of information and support services?

The evaluation will include research with a number of key audiences including beneficiaries of the service, service managers, volunteers, partners and strategic stakeholders.

Findings

The final evaluation report will be available in June 2015.

Why is this work important?

People affected by cancer need to be supported and information about how to take an active role in their care, recovery and rehabilitation. This evaluation will help to measure the impact of information and support services on service users. It will be used to develop the understanding of different delivery models and guide the development of the services. It can also be used to make a case for sustainability and further funding.

Evaluation of the Glasgow Life Information and Support Services

Evaluation being conducted by Social Value Lab

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Summary

Macmillan Cancer Support commissioned Social Value Lab to evaluate the Wales Cancer Information and Support Services in June 2013. The evaluation helps us to understand the impact of the library-based services and their value. It also shares learning across the services to support ongoing improvement and the possible development of similar projects across the UK.

Background

The number of people living with and beyond cancer is rising. People are living longer with cancer and have to deal with the long-term consequences – cancer is increasingly being seen as a chronic condition that should be managed in the community, rather than as an acute illness. The cancer information and support services aim to support and inform people affected by cancer about how to take an active role in their recovery, rehabilitation and ongoing care. Macmillan and Glasgow Life are working in partnership to develop a tiered model of cancer information and support service in communities through libraries and sports centres. The levels of service provision will be dependent on size, footfall and social isolation. Volunteering will also be integral to service provision across the city. The project builds on learning from a pilot cancer and support service provided at the library at The Bridge, Easterhouse. This is the largest programme of its kind being funded by Macmillan and is seen as a pilot for the UK as a whole.

Key Findings

The key findings from the baseline report include:

- Over 1,500 service users were supported from June 2012 and May 2013. Half of the service users were 'patients' (50 per cent) and just under a quarter were 'family members' (24 per cent). Three out of four service users were female (74 per cent) and the vast majority (90 per cent) were 'Scottish'.
- Almost all of the support (97 per cent) was delivered face to face. The majority of visits were for emotional support (55 per cent). Other service users' visits were for a 'service enquiry' (18 per cent), physical activity advice (13 per cent) and benefits / financial support (12 per cent).
- Stakeholders feel that the roll out of the programme is going well across the city and that joint working with Macmillan, voluntary and library staff is working well as were partnerships with other providers such as Cancer Support Scotland and the Glasgow City Council financial inclusion team.
- Stakeholders have identified the need for greater promotion of the services and more targeted marketing to increase take up of the services and increase referrals.

Why is this work important?

This evaluation will be used to capture and disseminate learning from the implementation of the programme, provide evidence of the outcomes for both volunteers and service users and consider the effectiveness of the partnership. It will assess the programme's effectiveness as an agent of change and gather evidence of the viability of sustaining the work in Glasgow libraries and replicating work elsewhere in the UK. The evaluation will also draw out strategic lessons that can inform and help shape the development of the programme, in order to maximise impact and improve prospects of success.

Evaluation of Macmillan Specialist Care at Home

Evaluation being conducted by Nottingham University

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Summary

Macmillan Cancer Support commissioned Nottingham University to evaluate the Macmillan Specialist Care at Home programme in March 2014. The evaluation helps us to understand the impact of the programme and its value. It also shares learning across the services to support ongoing improvement and the possible development of similar projects across the UK.

Background

The Midhurst Macmillan Specialist Palliative Care Service is a Consultant led service which delivers specialist clinical interventions in the home operating from 8.30 – 20.30 seven days per week. It takes referrals from people with complex care needs towards the end of their life. The service is managed by a lead nurse and delivered by a multidisciplinary team of doctors, nurses, support workers and other professionals based in the community. Team members are deployed flexibly to deliver any intervention within their capability rather than being required to refer on to another professional. The Midhurst service is well integrated with primary care and has become embedded in the community, ensuring early referral.

An independent evaluation of the Midhurst service was commissioned by Macmillan and carried out by the Universities of Sheffield and Huddersfield and Monitor in 2010/2011, and an article on the evaluation was recently published in the European Journal of Cancer Care. The evaluation showed overwhelmingly positive findings, showing: improvements to the experience of care at the end of life for patients and their families; high levels of staff satisfaction; increased numbers of people enabled to die within their own home; and a cost effective specialist palliative care service, providing support more cheaply than hospice models. A key element that contributed was ensuring earlier referral through a high level of integration with local primary care services. The majority of patients referred to the service were referred at an earlier stage compared with patients referred to a hospice.

Based on these findings we developed the Macmillan Specialist Care at Home service, a partnership approach to providing palliative care to people in the community. The Macmillan Specialist Care at Home model follows national guidelines and drivers for more people to be supported at home with less unscheduled admissions in the last year of life. This will include both cancer and other life limiting conditions that require specialist palliative care. Importantly the quality and continuity of care are valued highly by people receiving the service and their families. It is similar to other approaches (e.g. hospice at home; integrated care) and therefore not completely unique but the mix of services and way they are combined to provide a seamless, tailored service to people with advanced care needs is distinctive.

Key Findings

The interim findings will be available in August 2015 and the final report will be published in 2016.

Why is this work important?

This evaluation will be used to help assess the impact of the Macmillan Specialist Care at Home programme on the experiences of specialist palliative care services for patients.

Evaluation of Macmillan Value Based Standards®

Evaluation being conducted by Brightpurpose
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Summary

The Macmillan Value Based Standards® is a practical framework to improve patient and staff experience. The evaluation will help to gain a better understanding of how the framework is used and what impact it is having on patient and staff experience.

Background

The Macmillan Values Based Standard® is a practical approach to improving patient and staff experience. Over 300 patients, staff, carers and family members co-designed the Value Based Standards, which reflects the eight 'moments that matter' most to both patients, and staff. These range from small things that matter such as 'Naming – "I am the expert on me"' to changing the dynamic of the relationships between patients and staff through 'Clinical treatment and decision making – "I'd like to understand what will happen to me"'.

Each behaviour is representative of a wider patient experience domain, ensuring that the approach can be flexed to respond to the individual needs of patients and carers and distinguishing it from a 'tick box' approach or 'charter' which organisations can 'sign up to' because it aligns with their organisational values. It is very much a practical approach to change the dynamic between patients and staff and, ultimately, change organisational culture so that patient experience becomes a priority across the organisation.

Key Findings

The first stage of the evaluation commenced in July 2014. The final report and finding will be available in January 2016.

Why is it important?

The Macmillan Value Based Standards® aims to inform and strengthen Macmillan's offer on relational care and is one of Macmillan's most high profile solutions to improve patient and staff experience. The evaluation will be used to help better understand the programme at a national level and what impact it is having on patients and staff.

Evaluation of Phase 1 of the One-to-One Support Implementation Project

Evaluation is being conducted by Frontline Consultants, University of West of England and BresMed Health Solutions
Email: dsalisbury@macmillan.org.uk

Summary

Macmillan Cancer Support is carrying out a major project that is piloting new ways of providing one-to-one support for people with cancer across the UK. The process is split across two phases, with phase 1 piloting the new approach in 15 sites across England, Wales, Scotland and Northern Ireland. Macmillan has commissioned a consortium led by Frontline, in partnership with the University of West of England at Bristol and BresMed Health Solutions, to evaluate phase 1 of the pilot.

Background

One-to-one support for cancer patients might best be understood as a service that supports the patient across the whole cancer pathway, based on the intensity and nature of patients' needs, in order to improve quality of care and patient experience and outcomes in a more cost effective way. Phase 1 of the project involves piloting the introduction of four new roles across health and social care settings: Macmillan Cancer Support Worker; Macmillan Nurse Primary Care; Macmillan Nurse Community Care; and Macmillan Complex Case Manager.

There are two main aims for this evaluation:

- to carry out an impact and process evaluation of the four new roles that provide one-to-one support to people with cancer
- to undertake economic analysis to assess cost-effectiveness of the new roles compared with current practice

The project is being conducted following the principles of realist evaluation (Pawson and Tilley 1997). The focus is therefore on collecting data which can illuminate what works for whom, in which circumstance and why. Both quantitative and qualitative data will be collected, including interviews with internal and external stakeholders, interviews with NHS pilot/education leads and post holders, study site visits, and a patient survey. Post holder and pathway data is being collected from each site.

Findings

Findings are expected in December 2014

Why is this work important?

Currently not all people affected by cancer get access to a Clinical Nurse Specialist (CNS) or a Key Worker, which we know makes a difference to patient reported outcomes and experience. We also know that current models of follow-up care, after treatment, are unsustainable. As such, Macmillan has been working across the UK to develop solutions to these issues. Redesigning the cancer care pathway and the cancer care workforce are seen as some of the solutions, and we require thorough testing of these new roles to see if they work in practice.

Evaluation of the Macmillan Cancer Improvement Partnership in Manchester

Evaluation being conducted by ICF GHK
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Summary

Macmillan Cancer Support has invested in a large-scale, Manchester-wide programme to improve care and support for people living with and beyond cancer. The programme builds on a legacy of Macmillan investment over the last eight years in Manchester to redesign pathways of care, providing a platform for the new programme of work, which will join up these services across the City. The programme aims to deliver – across the whole system in Manchester – more patient-centred and co-ordinated support from the point of presentation and diagnosis all the way through to treatment and beyond. Phase 1 is a three-year programme that will focus on primary, community, and end of life and palliative care across all tumour groups. Phase 2 will focus on redesigning follow-up pathways for breast and lung cancer patients.

Background

Macmillan has commissioned ICF GHK to undertake an evaluation of Phase 1, to provide an independent assessment of whether and how the programme is achieving the change and results it has set out to, and to gather learning and insights to shape the ongoing development of the programme. Although there are distinct workstreams within the programme, the evaluation has been commissioned as a programme level evaluation – exploring how the workstreams together help achieve the aims of the overall programme.

The evaluation has been designed as a mixed-methods evaluation that combines strong formative and summative elements, which will gather insights from a range of sources and perspectives. The theory-led approach will deliver a robust evaluation that will:

- assess the impact of the programme at all levels: patients, professionals, organisations and wider systems of care
- define what ‘cost-effectiveness’ and ‘value-for-money’ mean in the context of the programme and examine evidence for these
- explore implementation of the programme as it progresses, examining the influence of contextual factors, and identifying enablers and barriers to change
- draw out and share learning to inform the development of the programme, Macmillan’s wider programme of system redesign, and wider debates about whole system redesign

Findings

Findings are expected in March 2016

Why is this work important?

Advances in early detection, diagnosis and treatment have led to significant improvements in cancer outcomes in recent years. While this reflects achievements of cancer services, it also represents a substantial challenge to them. Cancer care and services have historically been designed to address cancer as an acute illness, with relatively little attention paid to the broader experience of cancer or survivorship and recovery needs. Moreover, with the recognition that many people now experience cancer as a long-term condition, issues of care coordination and service integration have come to the fore. This situation calls for nothing less than a transformation of cancer care and services. Macmillan is investing in transformative programmes of work, with improving patient experiences and outcomes at the heart, and measuring the impact of and learning how to implement these complex change programmes is crucial.

Evaluation of Transforming Cancer Follow Up in Northern Ireland

Evaluation being conducted by PWC

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Summary

This project provides an evaluation of the Transforming Cancer Follow Up programme in Northern Ireland. The programme was delivered in collaboration between Macmillan, the Northern Ireland Health and Social Care Board and the Northern Ireland Cancer Network (NICaN). The programme aims to transform post-treatment follow up for breast and prostate cancer patients, specifically by improving health and wellbeing; reducing inefficiencies in hospital follow up and streamlining services; and, enhancing service coordination and integration. A key part of the programme is moving patients onto a model of Self Directed Aftercare (SDA) which should help to reduce the number of surgical and oncology review appointments over a four year follow up period.

Background

The evaluation was designed utilising a mixed-method approach and adopted a theory-led approach with both formative (especially in the earlier stages) and summative elements. The evaluation aims to:

- provide regular findings that help to test whether the new models help achieve better outcomes for people with cancer and better resource utilisation
- draw out evidence and lessons learned on what works and what does not work, for whom, why and in what circumstances in order to inform the future phases of the programme

Findings

The evaluation will be reporting in three stages with further findings expected in 2014 and 2015. The first phase of the evaluation reported in September 2013 and provided a summary of the baseline situation as well as early findings on the implementation of the programme.

Patients treated for Breast Cancer in Northern Ireland between 2008/09 and 2011/12 were surveyed to identify their experience under the traditional model of follow up. Overall the majority felt they received enough support for the clinical aspects of their cancer but experiences were less positive with regard to their wider needs. There were particularly poor levels of experience reported against lifestyle changes to maximise health and wellbeing and support for the financial impact of cancer.

The wave 1 evaluation reported that 35% of all newly diagnosed breast cancer patients have been moved onto the self directed aftercare pathway and around 235 breast cancer patients had attended Health and Wellbeing Events. The programme had also established a system of remote mammogram surveillance across all Northern Ireland trusts. Furthermore, initial reports from staff suggested that the programme has already begun to improve coordination between sectors; make a contribution to the reduction of patients who were duplicated on both surgical and oncology review waiting lists and established a criterion for patients to be moved onto the self directed aftercare pathway including the development of a Patient Administration System.

Why is this work important?

Over the coming years the number of people living with cancer is expected to increase. This requires a transformation in the way cancer care services are delivered to address the needs of survivorship and recovery. Transforming Cancer Follow Up in Northern Ireland is one of Macmillan's flagship programmes which focus on improving patient experience and outcomes. Measuring the impact of and learning from these complex change programmes is crucial.

Evaluation of Phase One of the Staffordshire Transforming Cancer and End of Life Care Programme

Evaluation being conducted by OPM
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Summary

Macmillan Cancer Support, working in collaboration with Staffordshire CCGs launched the Transforming Cancer and End of Life Care Programme in April 2013. This Programme intends to transform the way services are commissioned for people with cancer and for those at the end of life for all long term conditions across the county of Staffordshire including the unitary authority area of Stoke-on-Trent (a population of over 1.1 million people).

The programme will ensure that patient care will be commissioned and managed through a single provider (the 'Principal Provider') who will be held accountable for the entire patient experience and clinical outcomes. It will enable a transformation in service design and delivery focussed on the patient and not on individual providers.

Background

The aim of the programme is to support commissioners to shift the focus of practice from providers and individual interventions to one that encompasses the whole patient journey from prevention and promotion through early diagnosis and treatment to survivorship or End of Life Care (EoLC). To achieve this CCGs will look to tender for a Principal Provider for each pathway (relating to cancer services for three tumour sites initially – lung, breast and bladder/prostate – and EoLC) who will be held accountable for the whole patient journey and will have all the individual contracts for that journey assigned to it. In this way for the first time one organisation can be held to account for ensuring both that the entire patient experience and outcome is the best they can be and has the power through contract control to manage these outcomes

The evaluation of the Staffordshire programme will adopt phased approach. The first phase considers the development phase of the programme up to the point where a principal provider is commissioned. The second phase will consider the process and impact of a principal provider once the provider is in place.

The evaluation of this first phase is heavily formative, capturing the learning in order to inform the development of the programme. The evaluation will involve a thorough literature review, consultation with local stakeholders and national and international experts. The evaluation will also provide a robust assessment of the opportunities and risks of the programme, bringing out examples from both within and beyond the field of health and social care of how these risks have been mitigated in similar models of commissioning. This will inform the development of the programme.

Findings

This study is underway and findings will be available in November 2014.

Why is this work important?

The Staffordshire programme represents an important and innovative change in the way cancer and end of life services would be commissioned. It will ensure that principal providers will have ultimate responsibility for cancer and end of life care pathways. This will reduce the number of contracts managed by CCG commissioners, allowing them to provide a stronger focus on quality and integrated care. Understanding the impact of the programme and the learning from it, including the learning about how such models of commissioning are established is crucial.

Evaluation of the Electronic Holistic Needs Assessment

Evaluation being conducted by Ipsos MORI
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Summary

The aim of this evaluation is to help Macmillan to understand the impact and cost-effectiveness of the electronic holistic needs assessment (e-HNA) as well as inform the future development and roll out of e-HNA.

Background

Macmillan has been working with NCSI to ensure that all patients are offered the chance to complete a holistic needs assessment (HNA). HNAs assess a patient's physical, emotional, spiritual, practical and social needs and result in a care plan designed to reflect the concerns raised. HNAs have been found to have various benefits including;

- Identifying specific problems of patients that may not otherwise have been raised
- Reducing patient anxiety
- Improving relationships between patients and their clinicians
- Improved staff satisfaction.

However, HNA's are used inconsistently and paper record keeping means that it is difficult for assessments and care plans to be shared appropriately with the various staff across different disciplines that may be working with patients.

The eHNA offers patients the opportunity to complete a HNA on an electronic tablet. This enables records to be kept on an independent data platform, making it easy to share data from assessments across disciplines. It is hoped that this will allow the pooling of aggregated data which can be used to support service planning in local areas. Our previous evaluation of the eHNA in four sites, carried out by Ipsos MORI found that eHNA's helped to speed up the process of conducting HNAs in addition to increasing completion of both HNAs and care plans.

The eHNA is being rolled out further. In 2013 Macmillan expanded the coverage from 4 sites to 25 and there a plans to roll out further in 2014.

Findings

The study is ongoing and a baseline report has been completed. The baseline report of the evaluation found that the administration of paper HNAs across sites remains inconsistent and is not routine. Where patients do receive an HNA they find the process both useful and cathartic and staff feel that this contributes to patient centred care. The rationale behind assessment and care planning is well understood and by health professionals who recognise that it is important to the overall care provided to their patients. Reasons for variable implementation of HNAs are generally considered to be because of barriers such as the available time and space to complete assessments. Findings regarding the impact of the e-HNA will be reported in March 2015.

Why is this work important?

This evaluation will show the impact of the e-HNA programme and help us to learn and improve the programme as it progresses. Should the e-HNA be found to be impactful through increasing the number of patients offered a HNA, converting those HNAs into care plans and providing access to aggregated data across disciplines, then this will represent a marked step forward in the provision of holistic care and follow up from people affected by cancer.

Publications and other outputs arising from this evaluation can be found at www.macmillan.org.uk/research

Survivors of adult cancer: a feasibility cohort study/ePOCS electronic Patient-reported Outcomes from Cancer Survivors

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Summary

The study was commissioned in 2009. The study aims to test the technical and clinical feasibility of innovative, electronic Patient-reported Outcomes from Cancer Survivors (ePOCS) system by running it over two years in two UK NHS settings.

Background

There is no system in the UK for regular, systemic collection of patient reported outcomes (PROs) from adult cancer patients in aftercare and follow-up. Thus, this comprised two stages: system design and system testing. The aim of the first stage was to design the electronic PROs (ePROs) collection system achieved through the development of study design and procedures, technical build and data linkage and obtaining network research nurse funding to recruit patients to the study. The results from the first stage informed the design and running of the second stage which tested the technical and clinical feasibility of ePOCS by running with a sample of potentially curable breast, colorectal and prostate cancer patients in their first 15 months post diagnosis.

Findings

Overall the ePOCS system demonstrated proof of concept. Five key themes emerged on the feasibility outcomes:

- Informatics performance; In general, results showed the system informatics performed successfully and there was 100% linkage between PROs data with clinical Registry data.
- Recruitment and representativeness; Results showed that the system successfully demonstrated encouraging rates of recruitment with a participation rate of 55%. Patients who consented were significantly younger and those who declined to join the feasibility study.
- The completeness, quality and timeliness of the questionnaire data; the higher rate of missing data was mainly related to participants choosing not to answer questions about sexual matters.
- Participant opinion about the ePOCS system; the majority of participants reported positively and endorsed the ePOCS approach, many saying they would be very likely or definitely likely to continue using ePOCS to complete questionnaires for the next 10-15 years if asked.
- The administrative burden of running ePOCS; the ePOCS system was not administratively onerous to run.

Why is this work important?

A scalable and sustainable PRO data collection system may be an effective means of generating a dataset that is sufficiently large and longitudinal to indicate which survivors experience what problems and when. Such an in-depth understanding will allow cancer patients to receive detailed, individualised information about the symptoms and challenges they may face ahead – based on the self-reported experiences of other patients.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Development and testing of an online intervention to support self-management of fatigue-related problems following primary cancer treatment: RESTORE

MSRG Stream 2 Project 3

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Summary

This project will develop an online resource and will test whether confidence to self-manage cancer related fatigue can be improved by engaging with the online form of self-management support

Background

People are increasingly turning to the internet for health related information which can help cancer patients learn about living with cancer, tackle social isolation by facilitating connection and support from others, and can be an important resource for people with limited access to information or peer support.

The Group hypothesise that an online intervention bringing together clinical and lay expertise will enhance self management of cancer related problems, such as fatigue, following treatment. Specifically the Group will:

1. Develop an online resource for cancer related fatigue, bringing together clinical and lay expertise, offering tailored self management support following primary treatment
2. Test the value of the intervention in increasing self efficacy to self-manage cancer related problems following primary treatment

There will be four phases of work:

1. Developing the intervention: Informed by previous work; establishment of a development team including Macmillan Partners, clinical and academic expertise and users; development of prototype intervention
2. Piloting: A pilot to assess proposed study recruitment strategy, recruitment rates, acceptability of the online intervention to inform phase 3
3. Evaluation: A full trial of the effectiveness of the intervention comparing those who received the online intervention and those who received usual care
4. Implementation: If the intervention is show to be beneficial this will be adapted for a broad range of users

Key Findings

Findings will be available in January 2015

Why is this work important?

This project will directly inform and complement the development of Macmillan's Self-Management learning resource. Exploring the potential of self management support is a key part of the National Cancer Survivorship Initiative (NCSI) and this work will directly compliment the work of the NCSI self-managerial work stream.

The Allograft Information Exchange (ALLINEX)

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Summary

This research seeks to develop an intervention for follow up of survivors of allogeneic haemopoietic stem cell transplants (HSCT) using the internet, referred to as the allograft information exchange (ALLINEX).

Background

There has been a considerable increase in allogeneic HSCT for blood and bone marrow disorders over the last 20 years with improving survival rates. Survival does not come without burden, with a growing number experiencing chronic Graft versus Host Disease (GvHD) which carries increased mortality and morbidity. A quarter of allogeneic HSCT patients have registered financial problems in the first two years following transplant and return to fulltime employment is slow. Partners of HSCT patients also experience psychosocial hardship.

This study will adopt a phased approach

- Phase one: To investigate standard supportive care for adults between 100 days and 18 months post-HSCT.
- Phase two: Development of an easy to access secure website for allogeneic HSCT patients.
- Phase three: A randomised pilot study of standard care versus standard care plus access to the ALLINEX website.
- Phase four: naturalistic evaluation.

Findings

This study is currently at phase three, preliminary findings will be available in March 2013

Phase one findings: - Of the 20 patients recruited, 50% had high levels of psychological distress and 30% high levels of social distress. Examination of the clinical notes revealed poor documentation of recommended psychosocial assessments. Nine patients had seen a clinical nurse specialist during this period and five patients had contact with a psychologist. Support from Professionals Allied to Medicine (PAMS) during this period was low. Other community services were accessed rarely. A service evaluation was undertaken of psychosocial supportive care in three HSCT centres: Leeds, Newcastle and Sheffield. Findings show that in two out of the three centres patients did not have access to a psychologist. A website was built during phase two.

Why is this work important?

The research builds on the informatics project commissioned by Macmillan Cancer Support on 'Survivors of Adult Cancer'. If successfully developed, the website would be made available to the HSCT team in Leeds. It may lead to real benefits for patients and staff with potential for extension to other HSCT centres, rare diseases or treatments. It could also be used in conjunction with an expert patient programme.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Pro-active Follow-up in Primary Care from Early in the Cancer Trajectory: the Introduction of a Framework Developed by Service Users - CORD

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Summary

This study tests the feasibility of anticipatory care for people with cancer in primary care from immediately after diagnosis. The study pilots a care framework generated by people affected by cancer to help primary care clinicians provide on-going holistic care.

Background

There are currently two million people living with cancer and this number is predicted to increase to four million by 2030. There is little research available which tests a primary care model of supporting this growing population.

The aim of this research was to assess the feasibility, advantages and disadvantages and cost of active follow-up of patients in primary care from immediately (within four weeks) after initial cancer treatment in GP practices in Scotland and England.

Specifically, the study aimed to:

- implement and evaluate a pro-active approach to the co-ordination of cancer in primary care in all patients who have cancer from the completion of initial cancer treatment onwards
- assess the acceptability and evaluate the use of a cancer ongoing review document with patients, their relatives, and professionals
- incorporate, monitor and evaluate the use of the Macmillan suggested Quality and Outcomes Framework cancer care template
- establish an evidence-base to guide cancer survivor follow-up nationally and future QoF developments

Findings

GPs felt that the CORD helped to structure consultations and ensure discussion of psychosocial aspects of care. The CORD was unobtrusive, promoting continuity of care and holism, the process is also fit for purpose but needs to be integrated within GP and community nursing computing and reporting systems. However most aspects needed for holistic cancer care are already integrated in cancer templates in UK primary care systems, but are underutilised.

Why is this work important?

This gives us a better understanding of how people diagnosed with cancer wish to be supported in primary care.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Unpicking the Threads: How Generalist and Specialist Nurses Work with Patients, Carers and Each Other in the Community to Support Cancer Survivors

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Summary

Using an innovative research method, the study explored the experiences of collaborative working amongst nurses responsible for the care of cancer and long term condition (LTC) patients.

Background

This study builds on the lead researcher's previous research carried out for Macmillan which investigated the role of community nurse roles in palliative and supportive care. The findings suggest that there are aspects of the care and management of LTC patients which could be applied to cancer patients but that also the co-ordination and communication between specialist and generalist nurses could be problematic.

This study used qualitative interview techniques to explore how specialist and generalist nurses understand each other and work together in supporting cancer survivors.

The specific aims were to:

- examine in one SHA how specialist and generalist nurses interact in supporting cancer patients
- compare such working practices and relationships with those relating to services for patients with long-term conditions, in the same geographical area
- Examine collaborative working between both groups of nurses and social care providers.
- draw lessons for future good practice through the active involvement of participants in the interpretation of emerging findings

Findings

Many factors have an impact on collaborative working, including: interpersonal and inter-team relationships, role understanding, professional identities, communication issues, organisational structures and processes, political context of NHS changes, wider societal attitudes towards cancer and LTCs. There was widespread belief that cancer patients were advantaged over LTC patients in the NHS, particularly in access to benefits, continuing care and palliative care. There is no difference in what makes for good or bad collaborative working according to whether the focus is on cancer or LTC patients.

Why is this work important?

This work gives us a better understanding of how to support the lives of cancer survivors generating personnel specific practical recommendations for the support of cancer patients. It is relevant for understanding whether cancer patients could benefit from the application of joint working between multi-professional teams in a model of integrated care and how the roles and relationships of specialist and generalist nurses influence care outcomes.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Evaluating the Integration of Nutritional Support into the Surgical Management of Colorectal Cancer Patients

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Summary

The aim of this study is to undertake exploratory work to investigate why 66% of patients with colorectal cancer lose weight prior to surgery and to test if a simple intervention can help with nutritional status.

Background

Previous research found that 66% of patients with colorectal cancer lose weight prior to surgery and 28% lose more than 10% of their body weight in the 6 months preceding surgery. Loss of more than 10% of body weight is an indicator of malnutrition. Research has also found that gastrointestinal surgical patients who are losing weight and malnourished suffer more post-operative complications and the length of time needed to recover is increased.

The researcher is a dietician, and work undertaken for her PhD demonstrated clinical benefits of supportive nutritional interventions. The national guidelines for Improving Outcomes in Colorectal Cancer do not mention nutrition. However, lack of research in this area is a factor in the omission of nutrition as a supportive intervention for colorectal cancer patients from pivotal reports and guidance that influence service provision. This research aims to explore the role of supportive preoperative nutritional management in the treatment of colorectal cancer patients.

Findings

The study concludes December 2014.

Why is this work important?

Nutritional support during treatment for patients forms the mainstay of work for dieticians working on gastrointestinal wards. However, benefits of preoperative nutritional support are not formally recognised in national guidelines for the treatment of colorectal cancer. This form of support could be extremely valuable to patients.

Information for this research will be gathered through interviews and focus groups with patients with colorectal cancer and a literature review. A controlled trial of a nutritional intervention in colorectal cancer patients will also be conducted as part of the study.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

A Feasibility Study of a Holistic Needs Assessment Questionnaire in a Supportive and Palliative Care Service

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Summary

This feasibility study will determine the effects of a holistic needs assessment tool on health-related quality of life and self-identified concerns of patients referred to supportive and palliative care. The study will also determine the effect of the tool on interventions, consultations and referrals within the supportive and palliative care service.

Background

Studies suggest that cancer survivors have needs which are not being met; they may have ongoing symptoms, be experiencing late effects of the disease, or suffering the impact of living with a chronic illness. At present, there is no widely used systematic, evidence-based holistic approach to screening these patients for supportive and palliative care needs.

This randomized feasibility study will explore the recruitment, data quality and the expected effect size trial of a holistic needs assessment using the Sheffield Profile for Assessment and Referral to Care (SPARC – a multidimensional screening tool which gives a profile of needs to identify patients who may benefit from additional supportive or palliative care, regardless of diagnosis or stage of disease). SPARC is intended for use by primary care, hospital teams or other services to improve patient management, either by current professional carers, or by referral to a specialist team

The overall aims of the research are:

- to determine the effect of holistic needs assessment on health-related quality of life and self-identified concerns in patients referred for supportive and palliative care
- to measure the difference between patients identified as cancer survivors, those living with a long-term condition and those receiving end of life care, in terms of their concerns, quality of life and need for supportive or palliative care

Emerging findings

- Overall the majority of patients felt nothing had changed as a result of completing SPARC, only a tiny minority who felt something had changed initiated a follow-up call from a nurse or health professional.
- Holistic needs assessments in specialised supportive and palliative care setting could be potentially harmful if not linked to a clinical assessment that informs a care plan as it may raise expectations that are subsequently not met.

The full findings of the study will be available December 2014

Why is this work important?

This study will let us know whether SPARC makes a difference in quality of life, and in referrals for help, and whether the experience is different for different groups of patients in order to plan a definitive trial.

The timely identification of patient symptoms and concerns and prompt referral to appropriate specialist teams could potentially not only reduce the burden of individual patient suffering, but also lead to earlier discharge from expensive secondary and tertiary specialist care and thus save revenue for the NHS. Similarly, earlier detection of these problems in out-patients could prevent unnecessary admissions and their attendant costs. The potential gains to patients and the NHS are large, for a relatively small investment in screening. Such research thus has

potentially significant implications for Macmillan services as well as campaigning and media for end of life care.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

A Service Evaluation of the 'Cancer Transitions' Programme at Barts Hospital, Barts Health NHS Trust, London

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Summary

The aim of the study was to implement and evaluate the outcomes of a new survivorship service entitled 'Cancer Transitions' within East London and make recommendations on further service delivery locally and regionally.

Background

The Cancer Transition Programme is based on the importance of early intervention. Adapted from a US model, this six-week programme supports cancer survivors after their treatment is completed, and seeks to maximise their ongoing physical and psychological well-being.

This project is the first rigorous service evaluation of Cancer Transitions in the UK and has generated a significant amount of information about the quality of the programme and its acceptability and benefits to East London cancer patients. It has also highlighted where improvements need to be made to increase the capacity and the reach of the programme allowing its benefits to be enjoyed by a larger cohort of cancer survivors.

Objectives of the study were to

- deliver a high quality end of treatment rehabilitation service for patients of Barts Health NHS Trust/Tower Hamlets residents
- evaluate patient satisfaction through yearly clinical audits
- evaluate equitable access
- investigate improvements in physical activity, diet, health-related quality of life and coping through four validated questionnaires

Findings

The service evaluation of the Cancer Transitions programme reveals a wide range of benefits for cancer survivors. It has been rated highly by participants who stated they would definitely recommend the programme to others. The evaluation highlighted that the programme promotes changes in lifestyle, particularly increases in physical activity and better dietary habits but more work is needed to promote long-term behaviour change. Participants reported improvements in health related quality of life, particularly increases in vitality and improvements in function, these benefits were sustained. There is some evidence that the programme resulted in a reduction of the negative impact of cancer on participants. This study did not include a control group and therefore further research is needed to explore these findings in more detail. Further work is needed to improve the accessibility of Cancer Transitions to men, a wider range of tumour groups and non-English speaking clients.

Why is this work important?

The evaluation concluded that Cancer Transitions should be made more widely available for cancer survivors, primarily across Barts Health NHS Trust geography, but ultimately, within London Cancer and beyond. Further service development work is needed in several areas to improve access for groups currently under-served but also to streamline the service and improve efficiencies.

Pilot Study: the Use of a Virtual Multidisciplinary Team to Manage the Consequences of Cancer Treatment

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Summary

The overall aim of this study is to investigate the effectiveness of convening a multidisciplinary team (MDT) around the needs of a particular group of patients in a “virtual” working environment. By “virtual” we mean a team that operates asynchronously and is not co-located. This approach has the potential to widen the expertise that can be made available to an individual patient without placing an unsustainable burden upon busy clinicians

Background

Multidisciplinary team meetings have a firmly established role in the management of cancer in the United Kingdom and the advantages of this approach are considered to be self-evident. MDTs were introduced for a variety of reasons, but the main impetus was a desire to deal with inequalities in the standard of care. There are now over 1500 cancer MDTs in the UK, discussing a total of around 200,000 patients each year. The total cost of face-to-face MDT meetings in the UK is likely to be well over £75 million per year.

The aim of this study is to assess whether it is feasible to use a virtual approach to an MDT meeting and specifically to address the problems of patients who may be disenfranchised by the current arrangements.

Some of the specific objectives of this study are to

- develop and test a working model for a virtual MDT for consequences of treatment
- to base the development of this model upon a specific team that is already functioning conventionally
- to survey the attitudes of health professionals and patients towards the concept and practical instantiation of virtual MDTs
- understand and overcome the operational challenges of representing patients’ interests in a web-based environment whilst ensuring engagement and sustained commitment from the relevant clinicians & practitioners
- examine if trust and accountability can be developed and maintained within a virtual team responsible for making recommendations for the management of individual patients
- produce a working model that will be feasible, sustainable and affordable

Findings

This study is under way and preliminary findings will be available in December 2014

Why is this work important?

The late consequences of treatment for cancer often involve complex clinical syndromes which are poorly characterised and which require specialist evaluation. Previous Macmillan research has found that thousands of cancer patients in the UK suffer distress because of late consequences of their treatment; these consequences may not be recognised and may not be appropriately managed. It is not practicable for the necessary expertise to be available locally for each patient, particularly those with more complex diagnostic and therapeutic needs. The virtual MDT approach potentially provides a means whereby patients, wherever they live, might have prompt access to the best opinions regarding the care and treatment that they require.

Advance Care Planning for Patients with Lung Cancer

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Summary

This study explored the views and experiences of people with lung cancer and their family members about discussing preferences and wishes for care and treatment at the end of life.

Background

Some of the specific aims of the study were:

- To examine internationally published evidence on Advance Care Planning (ACP) and its applicability in the UK
- To explore the views and experiences of patients with lung cancer and their family members about discussing preferences and wishes for end of life care
- To explore the possible components of care that may form an advance care planning intervention

Qualitative interviews were conducted with 48 participants in total. The sample included 25 patients (18 men, 7 women) with lung cancer, most of whom were from lower socio-economic classes, and 19 family members.

Findings

The interviews suggest that people with lung cancer seek to balance the opposing forces of not facing death and yet planning for it; managing the dilemma of living in the present and not worrying about the future. The way people acted, talked about and attempted to make sense of their future was centred on their social functioning and relationships and the desire to keep these 'normal'. Concern for their family and the social and practical aspects of dying were important to them.

Findings from this study to-date suggest that patients with lung cancer hold little relevance to expressing individual choices and preferences for end-of-life care. Instead, people in this study sought to 'carry on as normal' often out of concern for their families, but also to maintain self-integrity. They preferred to focus on living in the present and to leave decisions about future medical treatment and care to clinicians or others.

Why is this work important?

It is widely acknowledged that there is a need to facilitate the communication of patients' preferences and choices in end-of-life care. Patients' preferences are not systematically assessed and if patients have expressed preferences these are rarely recorded in medical notes or are sought too late to be arranged. However, there is an increasing trend towards facilitating patients to die at home.

ACP is one mechanism to discuss future care and record patients' preferences and choices while the patient is still able to clearly articulate their views. ACP may also enable the delivery of preferred care, treatment and place of death beyond the point at which patients can articulate these. This study suggests that future ACP interventions need to support people to live in the present, express their wishes within their social context and recognise that some people may not wish to engage in planning for future end of life care and treatment.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Exploring, Understanding and Reducing Emergency Cancer Admissions (EURECA study)

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Summary

This study explores the experiences of lung cancer patients, and their health care professionals, who have had an unplanned admission to hospital in three hospitals within the West Midlands.

Background

Emergency admissions for cancer patients have increased by around 50% in the last eight years whilst elective admissions have only increased by 8%. Unplanned admission of cancer patients frequently lead to poor patient experience and lack of appropriate and timely care following admission. The current approach in the NHS is to address the issue of unplanned admission in a variety of ways. However in order for these NHS strategies to be effectively implemented it was important to understand the reasons for admission for these patients, from the patient's perspective and those of healthcare professionals involved in their care and ambulance crews.

Findings

The decision making process that patients engaged in leading to an emergency admission was complex. The patient goes through three distinct phases leading up to emergency admission; complex self management, negotiated decision and letting go. Each phase is initiated by physical and psychological changes, culminating in a threshold where the patient and their carer see emergency admission as the only option.

Patients and relatives experience of their emergency admission was generally positive. However, concerns were evident during the recovery phase of their hospital admission. Concerns and complaints were focused in four areas

- Lack of attention to the patient's fundamental care needs.
- Lack of recognition of the expert family; there was a strong feeling that views of informal carers were not considered despite being experts in the management of the patient condition
- Poor communication; patients felt that once the initial symptoms which led to their emergency admission had been resolved details about their treatment and care for the rest of their period in hospital were not communicated well to them.
- Lack of continuity of care; care some of the patients received following their discharge from hospital was disjointed. Many of the GPs and community nurses who were interviewed expressed concerns about the quality of liaison with the hospital and were frustrated about the lack of information they received about the patient during admission.

All the emergency admissions were justified; however data reveals that there was a mismatch in patient's expectations of care and actual care provided by professionals.

Why is this work important?

The findings of this work will contribute to the evidence base for understanding unplanned admissions from the patient's perspective and the complexity of the process involved. It will inform the development of a model which will support the objective of the End of Life Care Strategy to prevent inappropriate hospital admissions at the end of life. The insights from this research will enable community and hospital services to be planned to both reduce admission rates and improve the management of patients who have been admitted.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Development and Evaluation of a Clinical Assessment System for Female Sexual Morbidity in Women Treated by Radical Pelvic Radiotherapy for Cervical or Endometrial Cancer

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Summary

The study was funded jointly by Remedi and Macmillan through Macmillan's Research Fellowship programme. The overall purpose of the study is to facilitate improvements in support for women experiencing sexual difficulties following radiotherapy for treatment of pelvic or cervical cancer.

Background

Information for the study will be gathered from the clinical oncology outpatient clinics of three London-based cancer centres. The research will have three phases.

Phase one: a prototype clinical assessment instrument will be developed examining current medical practice and clinical enquiry. This will include recording rates of clinical assessment of female sexual concerns in routine follow-up consultations at the clinics and identifying possible/available management options and referral strategies.

Phase two: testing and refining the instrument for identifying sexual concerns in women post pelvic radiotherapy.

Phase three: training will be provided for clinicians on the interpretation and use of sexual assessment data in clinical consultations. The rates of clinical enquiry and detection of sexual concerns in women post pelvic radiotherapy will then be measured and compared with rates prior to introduction of the assessment tool.

Findings

This study is underway and findings will be available in March 2014

Why is this work important?

Improvements in cancer treatment have led to significant improvements in disease control and survival. One consequence of this is that an increasing number of people experience treatment-related side-effects months or years after their cancer treatment is completed.

Pelvic radiotherapy can impact negatively on the sexual health of women and their partners – studies suggest that between 50% and 80% of women with endometrial or cervical cancer experience sexual difficulties following pelvic radiotherapy. However, while a number of studies have explored the management of treatment-induced erectile dysfunction, research evidence for the assessment and management of female sexual difficulties as a result of cancer therapy remains inadequate.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

The Family Approach to Weight and Eating: A Mixed Methods Investigation to Develop a Complex Intervention to Support the Effective Family Management of Weight and Eating Related Problems in Advanced Cancer Patients

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Summary

The purpose of this study was to develop a psycho-educational intervention for families experiencing cachexia (wasting syndrome) related problems and to conduct a preliminary exploration of its acceptability, deliverability and harm/benefit.

Background

Wasting is common in people with cancer. Weight loss and poor appetite are experienced by more than 80% of cancer patients with advanced disease. These symptoms are distressing for both patients and their family members. When cancer is incurable, pharmacological and nutritional interventions are, at best, of limited and short term benefit. However, there remains the potential for alleviating distress by addressing the psychosocial factors that cause cancer cachexia symptoms.

A Family-focused intervention could complement the current practice of individualised patient care, contributing to the relief of suffering by improving clinical outcomes, in particular emotional health outcomes, not only for those with cancer, but also their family members. It could also limit demands on services. This study concerns the development and testing of a supportive intervention: the Family Approach to Weight and Eating (FAWE).

Findings

Dietary advice for patients living with involuntary weight loss and advanced cancer should be to take an energy and protein dense diet, eat small amounts often, and take nutritional supplements.

Involuntary weight loss and changing eating habits disrupt relationships in families causing emotional insecurity. Weight and eating related distress is experienced in families where one or more of the members are resistant to this disruption. Resistance to disruption in interactions is an indicator of threat to emotional security and is driven by security hunger. When family focused interventions include a component to support interaction between family members, then they can have an effect on the emotional health outcomes of patients and their family carers.

Why is this work important?

This is the first study to develop an understanding of how cancer cachexia syndrome affects relationships within families, and then to use this understanding to develop a supportive intervention. There is evidence that well-developed family interventions are effective in improving symptom management in other areas of healthcare, such as bulimia and heart disease. However, equivalent interventions had previously not been developed for families affected by cancer-cachexia related problems. This study contributes to filling this gap. The publication of papers arising from this study has continued to influence the development of research and practice in this area.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Mastering Breathlessness in Advanced Disease

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Summary

This programme of work seeks to develop and evaluate interventions aimed at mastering breathlessness in advanced disease, thus improving the lives of patients and their families.

Background

Breathlessness is common in advanced cancer as well as in a number of non-malignant diseases requiring palliative care. It occurs in 49% of the general population with all cancers, and in 90% of patients with lung cancer. The incidence of breathlessness in cancer patients is second only to that of pain. However, it is a poorly controlled symptom in which traditional pharmacological interventions are frequently ineffective. Further, patterns of breathlessness in cancer and non-malignant disease are different. Once patients with cancer become breathless they usually have a very short time to live and may become breathless at rest. By contrast patients with chronic obstructive pulmonary disease may live with gradually-worsening symptoms for many years. As a result, patients with different diagnoses and their carers may have different needs from services. Nonetheless, the effects on the patient and family with malignant or non-malignant disease are significant and include increased social isolation, reduced activity, chronic anxiety, loss of employment and other changes in roles and perceived status.

The programme has two main strands of work:

- A randomised controlled trial of an NHS developed intervention for breathlessness called the Breathlessness Intervention Service for patients with advanced cancer and non-cancer conditions.
- The development of an educational intervention on breathlessness for carers of patients with cancer.

Findings

- The findings of the RCT demonstrate the effectiveness of the Breathlessness Intervention Service (BIS) for patients with breathlessness in advanced cancer and non-cancer diseases such as chronic obstructive pulmonary disease (COPD).
- BIS significantly reduced distress due to breathlessness in patients with advanced cancer and showed a similar trend in patients with advanced non-cancer conditions (such as COPD).
- More than 90% of participants in the randomised controlled trial of BIS reported benefit from the intervention.
- Patients and carers consistently identified specific, identifiable & repeatable aspects of the BIS model & a range of BIS interventions they found helpful in reducing the impact of breathlessness

The second component of this programme (development of an educational intervention for carers of patients with breathlessness) will conclude in January 2013.

Why is this work important?

This research programme is highly compatible with Macmillan Cancer Support's priorities for identifying best practice in service delivery; end of life care and support; supporting self-management, and involving people affected by cancer in research.

Publications and other outputs arising from this research can be found at www.macmillan.org.uk/research

Biofeedback Therapy for Individuals Following Rectal Cancer Treatment: Assessing Feasibility, Acceptability and Potential Effectiveness

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Summary

The aim of this study is to assess if a bowel management intervention based upon the biofeedback approach is acceptable to individuals treated for rectal cancer and if it is feasible to integrate this service into follow-up care. This exploratory trial will also consider the components of this intervention and their possible effects on outcomes in order to clearly define the intervention.

Background

Advances in our understanding of how to minimise local recurrence from rectal cancer have had considerable impact on treatment scheduling and with it, treatment effects. New surgical techniques have made possible the formation of ultra-low anastomoses (the join of the two resected ends of the bowel) within the rectum.

Whilst these advances in rectal treatment have had significant impact on disease outcomes, the consequences of this treatment on individual quality of life must not be overlooked. Recent studies have found that bowel effects are generally underreported as individuals tend to underplay their bowel symptoms. This may be because they are relieved they no longer need treatment, have a stoma, or feel grateful for having survived the removal of their diseased bowel. However, troublesome bowel symptoms have been shown to negatively impair quality of life and are associated with sexual difficulties, decreased participation in leisure pastimes, delay in returning to work, as well as diet and clothing concerns. It is therefore important to consider how we can offer information and support to individuals who, for a variety of reasons, may not seek it.

The study will adopt a phased approach

- Phase 1: Intervention pilot study
- Phase 2: Collection of qualitative data from study participants.
- Phase 3: Interviews with health care professionals involved in the participants follow-up care.

Both quantitative and qualitative outcomes will be assessed. The main outcomes will be potential effectiveness and acceptability of the therapy to patients. The ICIQ-B will be the main outcome measure in the intervention pilot.

Findings

Findings will be available in December 2014

Why is this work important?

There is limited evidence on how best to manage the bowel dysfunction following rectal cancer treatment. It can be argued that some distress and life disruption from rectal cancer treatment may be avoided by an intervention based upon the biofeedback approach. However, biofeedback therapy has only been tested in a limited capacity with this patient group. This study begins to fill this gap.

Development and Evaluation of Radiographer Led Telephone Follow-Up Following Radiotherapy to the Pelvis

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Summary

Mount Vernon Hospital has successfully used a radiographer led telephone service to manage acute radiation toxicity immediately after treatment. The aim of the radiographer service was to effectively triage the majority of patients who have minimal toxicity following pelvic radiotherapy, provide appropriate reassurance and feedback of biochemical outcomes whilst avoiding of the cost and inconvenience of attending an outpatient clinic. This evaluation builds on previous audit work which showed that post radiotherapy outpatient clinic could be replaced with telephone follow up with very good patient satisfaction.

Background

Prostate radiotherapy is effective and a frequently used treatment for prostate cancer. In the majority of patients radiotherapy is well tolerated with manageable acute toxicity and with a low risk of severe late reaction. NICE guidance (CG58 2008) recommends five year follow up post radical radiotherapy to provide feedback regarding treatment effectiveness, to identify early relapsing disease and to identify and effectively manage patients who do suffer significant late radiation toxicity. In a busy NHS setting the majority of patients attend routine follow up appointments based in the outpatient clinic setting. For the majority of patients this can mean significant waiting times in clinic and potential costs from missing work and travel expenditure with little personal benefit.

Some of the specific objectives of this study were to:

- Examine if telephone follow up can improve patient experience, satisfaction and reduce patient costs.
- Examine if the use of telephone triage reduces the number of outpatient attendances.
- Release valuable Consultant time whilst expanding the role of the review radiographer.
- Examine if the use of telephone follow up standardises follow up and improves the management of post radiotherapy toxicities
- Examine the cost effectiveness of telephone follow up for the health economy
- Develop a model that can be rolled out within this organisation and shared nationally

Findings

Findings will be available December 2014

Why is this work important?

To date, the development of a radiographer led clinic has overall been beneficial. It has been demonstrated that it provides a sustainable model of follow up with high rates of patient satisfaction.

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