The Marie Curie Palliative Care Institute LIVERPOOL

Excellence in Care for the Dying

Key Areas of Research

MARIE CURIE PALLIATIVE CARE INSTITUTE LIVERPOOL

RESEARCH AND DEVELOPMENT DIVISION

The Royal Liverpool and Broadgreen University Hospitals NHS Trust

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Chemical Compatibility of Drugs at the End of Life (ChemdEL 48)

Project Lead

Dr Andrew Dickman

BACKGROUND

In 2007, the National Patient Safety Agency (NPSA) issued an alert about injectable medicines after receiving reports of medication errors. Subsequent guidance recommended the compatibility of commonly used mixtures should be readily available. In 2008, the Medicines and Healthcare products Regulatory Agency (MHRA) stated that research should be commissioned to develop authoritative national advice on the compatibility and stability of medicines delivered via continuous subcutaneous infusions (CSCIs) for pain and symptom control at the end of life palliative care. An initial study (ChemdEL) tested the compatibility of common drugs mixed in a syringe and administered to patients with challenging symptoms. The findings of the study revealed that all 30 combinations, analysed at the largest and smallest potential concentrations, were chemically compatible and stable over a 24 hour period

ABOUT THE PROJECT

Cancer patients with advanced disease may experience distressing symptoms, such as pain or sickness. When medication can no longer be swallowed, a battery operated syringe pump is used to deliver medication continuously over a 24 hour period. Often, a number of medications are mixed in the same syringe to manage several symptoms at once.

Although most patients wish to be cared for and die in their own home, the majority will die in hospital. This, combined with increasing healthcare costs and a reduction in the number of clinical staff a challenge for health care services globally. New ways of providing and structuring services are required to optimise care for patients and make best use of available resources.

Following on from the ChemdEL project, this study will be the first in the world to examine whether commonly used combinations of medications can be safely mixed together and given using a syringe pump over a 48 hour period instead of 24 hours. The study will also explore what clinicians, patients and their families/carers think of using a syringe pump for 48 hours.

If possible and acceptable to deliver medications over 48 hours, this may help to improve the care received by patients with advanced disease, and their families/carers, by causing less interruption due to changing medication. This may also enable clinical staff to spend more time focusing on the core tasks of compassionate care.

BIVA - Hydration in palliative cancer patients: the testing of a new assessment method

Project Lead

Dr Amara Nwosu

BACKGROUND

Decisions surrounding the administration of clinically assisted hydration (CAH) to patients at the end-of-life are frequently challenging. There are differences in opinion between, staff, patients and relatives regarding the appropriate use of CAH in advanced cancer. This is due to a limited understanding of physiological hydration states of patients and a lack of evidence about the benefits and burdens of CAH to guide healthcare professionals.

Improving the scientific knowledge about hydration status is essential to inform the appropriate use of clinically assisted hydration in advanced cancer patients. Current hydration assessment tools have limitations when used in this group of patients. Bioelectrical impedance vector analysis has the potential to accurately assess hydration status in these patients.

ABOUT THE PROJECT

This study aims to improve the scientific knowledge of hydration states in people with advanced cancer, by using an assessment technique called “bioelectrical impedance vector analysis (BIVA)”. This is a simple, safe, bedside test which involves measuring the water content of a person, using a small, portable, handheld machine called a “body analyser”. Assessing hydration in advanced cancer is an important area as people with advanced cancer may have less desire to drink as their condition worsens. These people may lose their ability to swallow, which may be caused by medical treatments and a general worsening of their condition. This may create anxiety with relatives and carers of the individual, who may worry that their family member may suffer discomfort through a lack of hydration. In this study, people with advanced cancer admitted to a local hospice over a 12 month period will be eligible for inclusion in this study.

Participants will have routine blood tests performed by their clinical team. They will be examined by a doctor and will be asked to complete a written questionnaire. The questionnaire will ask the person about any symptoms they may currently have, such as thirst and dry mouth. Participants will then have the bedside hydration test performed by the doctor at the bedside using the “body analyser” machine. This is a simple, safe test which involves leads from the analyser being attached by sticky pads to the hand and foot of the individual. The body analyser test usually takes less than 5 minutes to complete. During the study, the assessments will be repeated on each occasion the participant has blood tests taken as part of his/her ongoing clinical care. Outcomes will demonstrate the use of the body analyser technique in assessing hydration, and will establish whether hydration is linked to specific symptoms.

Biology of the Dying: Investigation of Biological changes in Urine at the End of Life - a Feasibility Study

Project Lead

Dr Seamus Coyle

BACKGROUND

There is no evidence based method of estimating a cancer patient's prognosis, or method of recognising when a cancer patient is dying. The current methods that do exist are not superior to the subjective opinion of a multidisciplinary team (Gwilliam et al, 2011). The uncertainty over prognosis can create enormous stress and anxiety for the patient and their families. The scale of this problem is significant: there were 159,178 deaths from cancer in the UK in 2011. Little is known about the biological processes occurring in cancer patients during the last months, weeks and days of life, or of any process of dying. Our hypothesis is that there is a biological process to the last months, weeks and days of a cancer patient's life. This process may be identifiable and amenable to assessment.

ABOUT THE PROJECT

The study aims to develop a test which can help estimate the prognosis of cancer patients (in the last months or weeks of life) or identify when they are in the last days of life (when they are dying). Developing these tests will provide greater dignity for a dying patient, for example by removing uncertainty, and potentially help the patient and their families to have the best possible quality time together in the last months, weeks or days of their lives. An accurate prognostic test would have a significant impact on clinical practice. Having this knowledge would aid in the provision of appropriate care and allocation of resources to promote a patient's comfort and support, including facilitating their preferred place of care. It will promote appropriate medical treatments and help avoid futile interventions. We think that there is a process to dying and that some of the changes during this time may be predictable.

Urine from cancer patients with locally advanced disease or cancer that has spread to other parts of the body will be collected over time and analysed for Volatile Organic Compounds - the components of smell. This project is also designed to investigate and examine genetic changes in normal tissue over time as a cancer continues to grow. Further, genetic analysis will be performed on normal tissue obtained from the urine samples to look at possible genetic changes. Results from this study will be used as the basis to investigate what happens in the body of a patient with advanced cancer in the last months, weeks and days of life. By understanding the biological changes towards the end of life we will endeavor to develop a test which predicts patient's prognosis and a test for the dying process. This has the potential to improve a patient's quality of life and enable families to plan their time with their loved ones in the last months, weeks, days or hours of their life.

Teaching learning to care for the dying: a pilot survey of provision and educational outcomes of undergraduate medical curricula

Project Lead

Dr Stephen Mason

BACKGROUND

It is estimated that Foundation Year doctors will care for approximately 40 dying patients, and 120 patients that are in their last three months of life. Learning to care for dying patients is a relatively recent addition as a mandatory subject within undergraduate medical curricula. Although there has been a steady increase in the number of hours devoted to teaching "care of the dying" there is great variation in the levels, content and format of teaching. Further, the publication of the Neuberger review and "One chance to get it right" has increased public and professional focus on this complex area of care.

ABOUT THE PROJECT

This study will seek to document the provision of, and changes within, training for undergraduate medical students in the UK in light of the Neuberger Review and One Chance to Get it Right. Further, a pilot study using an electronic tool will be conducted to assess the preparedness of FY1 doctors to practice palliative care in six purposively selected sites.

Indicative information on the strengths and weaknesses within inherent teaching provision may be useful in assisting bodies, such as the GMC, to provide guidance on the level and type of education that should be being provided to undergraduate students. Additionally, the process for conducting annual or bi-annual assessments of foundation doctors will be established. This will address the challenges in monitoring and evaluating undergraduate training, as outlined in the Neuberger Review, and will also allow evaluation of the effect of these changes within undergraduate medical curricula.

How ‘real’ is the risk of head and neck cancer patients having an acute catastrophic event?

Project Lead

Dr Catriona Mayland

BACKGROUND

Patients with advanced head and neck cancer and their families have especially complex needs. The cancer and treatment cause difficulties in speaking, breathing, eating, as well as pain, social isolation and low mood. Although the hope is to cure the cancer, with advanced disease there is a high risk this may not be possible or the disease will recur. Most patients wish to die at home but at least 4 out of 10 will die in hospital. Patients can be at risk of sudden bleeding or breathing problems. This has impact on individuals, families and where care can be provided.

ABOUT THE PROJECT

Despite head and neck cancer affecting younger people and more female patients, there remains a traditional view that it only affects older men who have made particular lifestyle choices e.g. smokers resulting in a risk of stigma and an associated feeling of culpability. The relatively younger age of head and neck cancer patients, however, as well as the symptom complexity and number of specialist interventions required for end-of-life can affect place of care, reducing the likelihood of death at home. Trying to address inequalities in care and ensuring all patients are able to receive specialist care and support is extremely important. Potential improvements in symptom control, psychological support and advance care planning could help facilitate patient choice, improve overall quality of life and support for a vulnerable and complex group of patients.

We want to understand the experience of those living with head and neck cancer. In particular, we want to know more about the challenges patients and their families face; as well as those faced by the doctors and nurses caring for them. Additionally, we want to understand how patients currently use health services; what issues and challenges arise; and whether there are ways to better meet their needs.

To do this, we will undertake interviews with patients, families, doctors and nurses. Additionally, we will ask patients and their families to complete a questionnaire about their recent use of health services e.g. hospital admissions, attendance at out-patient clinics.

Diagnosing Dying? Explaining the process by which hospice staff recognise the last days of life.

Project Lead

Dr Richard Latten

BACKGROUND

Recognising when patients are approaching the imminently dying phase (the last hours or days of life) is an important aspect of providing end of life care, for example enabling appropriate communication with family and considering patient priorities such as any specific religious or cultural needs, or preferred location for end of life care. However, this recognition can be challenging and multiple factors need to be considered. Every patient, each with their own individual characteristics, makes them, and the course of their illness, unique.

ABOUT THE PROJECT

The aim of this study is to improve understanding of how hospice staff recognise the last days of life. When developing the study, careful thought will been given to appropriate research design, aiming to balance optimal theoretical method against the reality of performing research in a clinical setting with the accompanying practical and ethical challenges. Specifically, when researching in end of life care, it is paramount that the research does not adversely affect patient or relative care. As such, direct involvement of dying patients or their relatives is not proposed in this study. Qualitative methods are most suited to meeting the research aims, allowing exploration of how hospice staff recognises the dying phase and the information used to make these decisions. An ethnographic study using a combination of documentary analysis, observation and interviewing will be developed. Based in the Marie Curie Hospice Liverpool, the study has three distinct stages: 1) Retrospective case-note analysis 2) Observation of clinical meetings 3) Interviewing of hospice staff. The study is iterative in nature, with each stage building on information gained from preceding stage(s).

The decision of whether a patient with advanced disease is entering the dying phase and in the last days of life can be challenging, but this recognition is vital in order to provide appropriate end of life care. This area has not been significantly previously researched. This study aims to gain insight into the decision making process in a hospice setting. It is anticipated that the process will be repeated in a second hospice setting, in order to verify findings from this first phase, prior to widening the research to other areas of palliative care.

Serious Illness Care Programme UK

Project Leads

Dr Stephen Mason

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BACKGROUND

The Serious Illness Care Programme (SICP) is a multi-component intervention designed to improve communication between clinicians and adult patients with a life limiting illness, and who are deemed to be in the last year of life, specifically to ensure care provided is more 'person centred'. The goals of this programme are to train and support clinicians to optimise the align medical care to patients' goals, enhancing quality of life throughout the late stages of illness. Results from a large Cluster Randomised Controlled Trial in the United States (as yet unpublished) indicated that education and training alongside implementation of the SICG leads to "better and earlier conversations" by oncologists regarding end of life care, resulting in more person centred care for the patient.

ABOUT THE PROJECT

The Serious Illness Care Programme[1] UK is a partnership led by The Clatterbridge Cancer Centre NHS Foundation Trust (Merseyside, UK), with The Marie Cure Palliative Care Institute Liverpool (University of Liverpool, UK) and Ariadne Labs (Boston, USA). NHS England has provided funding for a National Pilot to implement the programme in the UK. Ahead of this pilot, a programme of work has been undertaken to adapt the programme for use in the UK, resulting in a UK specific training programme, a process for systems change and adaptation of the clinical tool – the Serious Illness Conversation Guide. The Serious Illness Care Programme UK incorporates an active research and evaluation programme, developed with reference to the MRC guidance[2] and in collaboration with Ariadne Labs. Conducted in parallel with the pilot implementation, the research studies are developing the UK evidence base, to compliment that in existence for studies carried out in the United States.

[1] http://betterconversations.org.uk

[2] Evans CJ, Stone KA, Manthorpe J & Higginson IJ. MRC guidance on developing and evaluating complex interventions: application to research on palliative and end of life care. NIHR, London: 2013.