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DEVELOPING AND IMPLEMENTING A COMMUNITY CARE PATHWAY FOR THE MANAGEMENT OF CHRONIC OEDEMA

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Background Chronic oedema has a profound impact on quality of life. It may originate from primary anatomical reasons (primary lymphoedema), be secondary to cardio-vascular dysfunction, be related to cancer or cancer treatments and is increasingly a result of obesity. The numbers of patients with chronic oedema are increasing and both specialist lymphoedema and community nursing teams are over-stretched.

Many community nurses lack evidence-based knowledge and skills in the management of chronic oedema and specialist services therefore often provide care for both complex and straightforward management.

Aims To develop and pilot an integrated community pathway for the management of chronic oedema.

Method A Knowledge Transfer Partnership project was developed by 3M (Industry) with University of Nottingham. Clinical services in Leicester were engaged and an expert advisory group formed.

A clinical care pathway was devised through Nominal Group technique. Data from a point prevalence study, across Leicester City was used to operationally define a feasibility assessment of the pathway.

Implementation was supported by a competency framework and bespoke training programme. The pathway was piloted with 30 patients receiving care from three community nursing teams.

Data collection: Quantitative and qualitative data has been collected via one-to-one interviews with the community nurses following appointments with pathway inducted patients. Such data includes; a consideration of the symptoms of oedema, a record of resource use, and questions pertaining to levels of patient and nurse knowledge.

Results to date The pilot has been underway for three months and initial results reveal an improvement in symptoms supported by an immediate reduction in nurse visits and product use; alongside greater patient concordance.

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LYMPHOEDEMA – EXPANDED PARTNERSHIPS ACROSS CARE SETTINGS CREATING BETTER PATHWAYS OF CARE

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Background Our comprehensive lymphoedema service supports primary, secondary and palliative lymphoedema, recognising long-term management striving to deliver seamless care between the primary and secondary settings.

Treatment incorporates a combination of elements, and while we carry out these specialist forms of treatment within our service, we understand that this is not achievable or sustainable in the wider community. Need is growing but the workforce is not.

Aims Through increased and innovative work with primary care the service aims to reduce the impact of lymphoedema and support management in community settings through a variety of partnership approaches, including:

- Staff rotational opportunities
- Early detection and prophylactic treatment.

Methods Recognising the demands on teams we have developed partnerships with acute and primary care settings and lead on-going education of health care professionals to consolidate their knowledge and skill base.

Two developing elements include:

A rotational post with the community allowing a nurse to spend time within our service developing lymphoedema management skills. There is potential to expand this further. Through securing substantive rotational posts within the community setting, we can consolidate their skill base and promote partnership and ongoing support for the long term care of patients.

Research indicates that within breast related lymphoedema, early detection can minimise the risk of long term complications and in some cases can reverse the clinical signs. Through close working with the local breast team detecting the presence of oedema before clinical signs are apparent, a reduction in patients developing symptomatic lymphoedema can be achieved.

Outcomes

- Improved outcomes for patients through sharing and developing skills across services
- Positive evaluation of prophylactic monitoring has the potential to be used with other diagnosed malignancies to reduce the incidence of long-term complications
- New ways of working with greater potential to develop optimal patient care through collaboration.

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MANAGEMENT OF HOSPICE PATIENTS WHO USE PRESCRIBED INTRAVENOUS DIAMORPHINE FOR OPIOID ADDICTION

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Background Whilst methadone and buprenorphine are the mainstay treatments for opioid addiction in the UK, rarely patients are maintained on prescribed intravenous diamorphine. Misuse of Drugs (Supply to Addicts) Regulations 1997 restrict prescription of diamorphine for addiction to medical practitioners with a license issued by the Home Secretary. Managing hospice inpatients with existing diamorphine maintenance prescriptions raises important practical and legal issues.

Aims and methods We aimed to highlight key issues identified when caring for two such patients at our institution. We searched for literature concerning hospice management of cancer patients with existing prescriptions for diamorphine for opioid addiction.

Results Patient 1 was admitted with a long-term prescription for drug addiction (80 mg daily intravenous diamorphine, 300mg oral morphine) dating back 20 years. His cancer pain required additional high-dose fentanyl and oxycodone due to morphine tolerance before discharge. Diamorphine prescribed for addiction should be collected daily from a designated pharmacy under normal circumstances. The Substance Misuse Team continued to prescribe the opioids for addiction, and agreed to arrange weekly collections by a relative with the patient's written permission.

Patient 2 was admitted for terminal care, with a similarly long-standing prescription (60 mg daily intravenous diamorphine, 300 mg oral morphine). Legal and practical issues made organising

injectable medication for symptom control in the community impossible in time to allow him to die at home.

Discussion There is a striking lack of literature on managing patients prescribed diamorphine for addiction in a hospice. Our experience highlighted the need for close communication with the relevant Substance Misuse Team. Patient self-administration of intravenous diamorphine can continue, provided hospice inpatient policy criteria for self-administration of controlled drugs are satisfied. Where the indication for diamorphine use changes from addiction management to symptom control in the terminal phase, hospice doctors may take over prescribing [patient 2].

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DEPRIVATION OF LIBERTY SAFEGUARDS: DEVELOPING A LEAFLET TO HELP FAMILIES UNDERSTAND DOLS AND IMPLICATIONS AT EOL

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Most hospices have supported people needing treatment and care who do not have capacity to consent to it, who need constant care and would not be allowed to leave should they try. DoLS legislation was introduced to safeguard such people from misuse of restrictions to their freedoms. Hospices have varied in their interpretation of/application of DoLS legislation, however what is widely shared is that the use of DoLS has caused distress to families, and delays to families in making arrangements after death. Our own experience of applying for DoLS for hospice inpatients is limited (4/374 admissions from April 2015-end March 16) but an increasing number of people we support in the community have a DoLS Standard Authorisation; usually care home residents with an illness affecting cognition (e.g. dementia; cancer affecting the brain). Death demands a Coroner's investigation and inquest because death under a DoLS = death in custody. We have been concerned to better support families whose relative requires a DoLS, and to better prepare them for obligatory processes after death.

We are developing a leaflet using the experiences of a relative whose late husband had a DoLS, a carer who was distressed by post-death processes, the Local Authority, police and coroner. All have commented that an explanatory leaflet which is easy to understand would be enormously helpful. Our aim is to develop something to really support carers both when a DoLS is authorised and when their loved one dies, towards a more supported care experience and smoother bereavement. It will explain simply the reason for and value of a DoLS, help support the maximising of freedoms for someone with a DoLS and prepare families for processes after death. Evaluation will be via our service users group, service users and colleagues from several local hospices who have shared similar experiences of finding the issues complex to explain.

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IMPROVING ACCESS TO PALLIATIVE CARE SERVICES FOR DIVERSE COMMUNITIES OF CARDIFF AND THE VALE

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This presentation will describe a current development project based at the Marie Curie Hospice in Wales, which aims to build

relationships with the diverse communities of Cardiff and the Vale and in particular focusing on people with learning disabilities, people with dementia and people with a religious or no religious belief, to explore and address barriers that prevent access to palliative care services.

The project was funded in January 2016, for three years, by the Big Lottery Fund and aims to:

1. Develop links and improve communication with representative organisations in regards to dementia, learning disabilities and religion in the Cardiff and the Vale area to establish a better understanding of the end of life care needs and the gaps in service provision for these groups.
2. Identify specific barriers to service awareness and access for people with dementia, learning disabilities and of a religious background in the local community in Cardiff and the Vale.
3. Advise Marie Curie services in Cardiff and the Vale on learning.
4. Work directly with people with dementia, learning disabilities and of a religious background and their carers/families to provide support and advice on services.

This presentation will outline the project activity and outline barriers identified to date as well as discuss future project activity planned.

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THE CONCEPT OF PREDICTING FUTURE RISK IN GUIDING REFERRAL TO SPECIALIST PALLIATIVE CARE SERVICES

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Identifying and responding to patient and carer need is fundamental in providing holistic end-of-life care. Numerous assessment tools are currently in use to facilitate this and whilst the advantage of these is recognised they only offer a snapshot assessment in what is often a long disease journey. It is the role of the specialist palliative care team to anticipate future needs that may be not immediately apparent but pose a risk to patients' or their loved ones in the future.

We propose the concept of risk factors for a negative death experience. These risks may not necessarily cause difficulty in the present but should alert health professionals that the patient is at risk of a turbulent disease trajectory. This is a new concept, with little supporting evidence at present.

Our review of the current literature base and local nominal group discussions have identified the following features as risk factors for a negative outcome for patients and their loved ones:

- Poor engagement with advance care planning
- Carer strain related to palliative illness
- Self-perceived burden
- Patient-carer mismatch
- High levels of service use
- Bereavement risk factors.

It is anticipated that earlier specialist palliative input in situations where these risk factors are present offers greater opportunity to intervene in order to ameliorate risk, resulting in better care for the patient and improved outcomes for those close to them.