

quality of care and aligns to the principles of prudent healthcare.

- Recognition that dementia is a terminal illness and early engagement about ACP is fundamental to improving end of life care.
- Talking about ACP requires time, knowledge and sensitivity. Everyone who interacts with the person with dementia has a role to play in ensuring an ACP discussion takes place.
- A structured approach is required to prepare, equip and support health and social care professionals to progress the discussion and the equally important documentation and communication of wishes.

Good practice is an end-to-end process which is valued and understood by everyone who is part of it. It is reliable and robust; health and social care workers feel informed, supported, protected and empowered to meet the patient's wishes.

17 PALLIATIVE RADIOTHERAPY

^{1,2}Linda Bedford. ¹Macmillan Cancer Support, UK; ²Radiotherapy Dept., Beacon Centre, Musgrove Park Hospital, Taunton and Somerset NHS Foundation Trust, Taunton, Somerset, UK

10.1136/spcare-2019-mariecuriepalliativecare.17

Introduction Radiotherapy treatment with palliative intent accounts for 35–40% of the radiotherapy department's workload. Historically, patients had a long wait to see Consultant Clinical Oncologists and receive radiotherapy for their symptoms (the most common of which is pain) (Jones et al 2014).

Service Improvement A service has been developed for rapid access to palliative radiotherapy, to improve the patient experience and access timely symptom control. This is achieved with radiographer led service where patients are seen by a Consultant Radiographer (CR), assessed for radiotherapy, consented, referred and radiation prescriptions all completed eliminating waiting times for Oncologists clinics. Including a CR led outreach service for the trust and local Hospices ensuring all patients requiring palliative radiotherapy receive timely assessment and treatment.

Aims

- Assess patients individually in terms of suitability for palliative radiotherapy.
- Promote awareness of Palliative Radiotherapy as a treatment option in managing
- metastatic cancer as a complex long term condition
- Reduction of Pill Burden (Farrell et al 2013)
- Reducing length of stay and admissions.
- Holistic pain management – liaising with palliative care teams in the community.

Results A streamlined process has been developed demonstrating continuity of care. Specialist nurses and physios now contact the CR for advice and direct referrals. Pain is managed in a timely manner.

Conclusion This work has highlighted the complex nature of palliative radiotherapy in the management of cancer as a long term condition enabling patients to access timely symptom control. There are still many challenges to overcome and this is very much work in progress.

18 USING ROUTINE DATA TO IDENTIFY THE FACTORS THAT PLACE PATIENTS AT RISK OF NOT RECEIVING PALLIATIVE CARE

¹Peter Edmunds, ²Mirella Longo. ¹Vancouver Coastal Health, Vancouver, Canada; ²University of Cardiff, Marie Curie Palliative Care Research Centre, UK

10.1136/spcare-2019-mariecuriepalliativecare.18

Introduction Despite the benefits and growing acceptance that palliative care should be made available to seriously ill, frail and dying people (Kavalieratos et al. 2016, Singer et al. 2016), for some, this is still not the case. This study used historical routine data to determine the factors associated with not receiving palliative care.

Methods Four electronic healthcare databases (Discharge Abstract Database recording Hospital care, Emergency Department Database, PARIS community care database, Palliative Care patient registry database) were linked for all deceased patients over 2 years in a suburban population of 200,000 in Vancouver, Canada.

Results 2504 deceased individuals were identified. Of these, 2424 patients could be linked and assigned to a leading cause of death (761 cancer, 689 dementia/frailty, 974 organ failure). 67% of all patients had a record of receiving palliative care, however, almost half of these received less than 56 days of palliative care.

For people facing end of life illness, factors increasing the risk of not being offered palliative care were:

- No attachment to a general practitioner,
- Organ failure/non-malignant diagnoses,
- Males with organ failure/non-malignant diagnoses,
- Very low median household income and,
- Patients with dementia living at home.

Conclusion With the use of routine data it is possible to proactively identify and respond to patients in high-risk categories, reducing reliance on referral by clinicians. Routine data can be used to predict the palliative care needs of specific geographical areas.

19 USING PROJECT ECHO TO MEET THE DEMAND FOR PALLIATIVE CARE EDUCATION AND SUPPORT ACROSS MULTIPLE SETTINGS

¹Janet Diffin, ¹Tracey McTernaghan, ²Aine McMullan, ²Martin Hayes ¹Max Watson. ¹Hospice UK, UK; ²Health and Social Care Board UK

10.1136/spcare-2019-mariecuriepalliativecare.19

Background Despite increasing demand, limited resources are often available to deliver high quality palliative care education. Project ECHO is a tele-mentoring programme that could address this disparity by using video-conferencing to deliver (i) best practice guidance and education from specialists, and (ii) case-based learning with peer discussion¹. Five ECHO networks in Northern Ireland delivered palliative care education and support (Cardiology/Heart Failure, District nurses, Community pharmacy, Paediatrics, Marie Curie registered nurses). Participants set the curriculum and network aims and objectives, which included increasing participant's palliative care knowledge and skills, enhancing confidence, improving collaboration, and facilitating peer support. 45 ECHO sessions were delivered across five networks with 194 participants attending ≥ 2 .

Aim Identify if each ECHO network achieved its aims and objectives.

Methods Retrospective online survey designed for each network administered after final ECHO session.

Results 27% (60/224) registered participants across each network responded. Overall, each network achieved its aims and objectives with participants reporting increased palliative care knowledge and increased confidence in managing end of life care scenarios. Benefits included case-based learning, professional networking, and avoidance of travel to access education.

Participants reported improved communication with patients and families, and improved decision making in relation to patient care. Time restraints due to staffing issues or workload were identified as barriers to participation.

Conclusion Project ECHO may be an ideal solution for meeting the demand for palliative care education across multiple settings. To ensure practitioners fully benefit, protected time for participation is recommended.

Funders Health and Social Care Board/Hospice UK.

20 **IMPLEMENTING AN ADAPTATION OF THE CARER SUPPORT NEEDS ASSESSMENT TOOL (CSNAT) INTERVENTION TO PROVIDE TAILORED SUPPORT FOR FAMILY CARERS OF PEOPLE WITH MOTOR NEURONE DISEASE**

¹Gail Ewing, ²Sarah Croke, ²Christine Rowland, ²Alex Hall, ²Gunn Grande. ¹University of Cambridge, UK; ²University of Manchester, UK

10.1136/spcare-2019-mariecuriepalliativecare.20

Family carers face substantial demands when supporting people with Motor Neurone Disease (MND) (Aoun et al., 2013). Timely support from healthcare professionals is crucial to enable carers to fulfil their caregiving role and to look after their own wellbeing. The CSNAT intervention is an evidence-based approach for person-centred assessment and support. This project aimed to adapt the CSNAT intervention to the context of MND care, and test its implementation within specialist MND services.

Stage 1 involved interviews and focus groups with carers (n=33) to explore carers' support needs at key stages of the patient's illness; stage 2 involved workshops with carers (n=19) and practitioners (n=22) to adapt the content of CSNAT intervention and its delivery within MND care. Stage 3 involved implementation of the adapted CSNAT-MND in three specialist MND services, and interviews with practitioners (n=6) and carers (n=6) exploring their experiences of the intervention.

Content of CSNAT-MND included an additional domain on support with relationships. Intervention implementation adapted to (1) legitimise assessment of carer support needs as part of routine care in MND by practitioners, (2) deliver of a stand-alone introduction stage of the CSNAT-MND intervention and (3) provide a dedicated assessment and planning conversation at a subsequent contact. This basic model was then suited to fit the working practices of three different MND services. This project provides insights into how carers of people with MND want to be assessed and supported, how this process can be delivered, and the feasibility of implementing the CSNAT-MND in routine practice.

21 **THE USEFULNESS AND ACCEPTABILITY OF A PERSONAL-HEALTH RECORD TO YOUNG PEOPLE WITH A LIFE-LIMITING CONDITION: A REALIST EVALUATION**

¹Janet Diffin, ²Bronagh Byrne, ²Peter O'Halloran. ¹Hospice UK, UK; ²Queen's University Belfast, UK

10.1136/spcare-2019-mariecuriepalliativecare.21

Background Communication between young people (YP) with life-limiting conditions and healthcare professionals (HCPs) can be challenging, particularly during transition from children to adult services.¹ Personal-health records (PHRs) have the potential to increase YP's selfadvocacy² yet have not been evaluated thoroughly with this population.

Aim Use realist evaluation to test and refine a programme theory on how PHRs are thought to work with YP with a life-limiting condition.

Methods Qualitative study informed by realist evaluation. YP aged 16–24 years old living in Northern Ireland with a life-limiting condition were invited to use a PHR; semi-structured interviews conducted at three, six and nine months to examine acceptability and use. Framework method used for analysis.

Results Eight YP and two parents (on behalf of child) participated. 4/10 used the PHR; reasons included: (i) to help organise their care, (ii) feel more confident with communication, (iii) reduce the need to repeat details about condition(s)/medications, and (iv) manage health care when aspects of their lives were changing. PHR use depended on the level of need, desire for autonomy/self-management, and whether it brought benefits over how they currently managed their condition. Two additional contextual considerations which influenced PHR use were identified (i) YPs previous experiences in communication with HCPs, and (ii) the timing of the introduction of the PHR.

Conclusion PHRs may be useful for YP who wish to become more independent over management of their healthcare but should be targeted towards those who identify a need, and their usage supported by HCPs.

Funder Marie Curie.

22 **WHAT DO INFORMAL CARERS OF PEOPLE LIVING WITH BREATHLESSNESS IN ADVANCED DISEASE WANT TO LEARN ABOUT 'WHAT TO EXPECT IN THE FUTURE'?**

¹Sylvia Barnes, ²Gail Ewing, ¹Morag Farquhar. ¹University of East Anglia, UK; ²University of Cambridge, UK

10.1136/spcare-2019-mariecuriepalliativecare.22

Aim Breathlessness is distressing, disabling, and common in advanced disease. Informal carers (family/friends) can lack knowledge and confidence in caring, experiencing anxiety and uncertainty. The Learning about Breathlessness programme (LaB) addresses this.

LaB1 identified six topics carers want to learn about breathlessness.¹ LaB2 is co-developing (with carers, patients and clinicians) a prototype web-based educational intervention for carers on breathlessness. Content for five of the six topics was developed, but additional work was needed for the sixth topic, 'What to expect in the future', to ensure utility and sensitivity.

Method Two disease-specific focus groups and six interviews with bereaved carers of people with breathlessness due to