

Introduction The need for palliative care is increasing¹ and it is essential to look at how emerging technologies can improve care for palliative patients and their carers in the future.² With an increasing use of personal technology, many people are spending time creating their own online content.³ This online content is often described as a digital legacy, the digital information that is available about someone following their death.⁴ There is limited evidence around the experiences of digital legacy amongst palliative care healthcare professionals and the benefits of supporting patients in managing their digital legacy.

Aims This constructivist grounded theory study aims to identify palliative care healthcare professionals experiences of supporting palliative patients in managing digital legacy as part of advance care planning discussions.

Methods Semi-structured interviews were conducted with ten (n=10) palliative care healthcare professionals working in a hospice in the North West of England. Interviews were recorded and transcribed and data was analysed using NVIVO.

Results Four theoretical categories emerged from the data describing why palliative care healthcare professionals view digital legacy as an important topic. These four categories; 'accessing digital legacy', 'becoming part of advance care planning', 'impacting grief and bereavement' and 'raising awareness of digital legacy' were found to revolve around a core category 'understanding the impact of digital legacy'.

Conclusions The emerging theory 'understanding the impact of digital legacy' offers an insight into the knowledge and experiences of healthcare professionals working in a palliative care setting.

Further work is needed to explore palliative patients and their carers' views on digital legacy and how they can be supported to manage this better in the future.

Impact Digital legacy has the potential to impact many areas of palliative care, and this project highlights the importance of recognising that impact in order to improve care in the future.

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MORPHINE GAP IN CAMEROON: MORE ADMINISTRATIVE FACILITATION NEEDED TO REDUCE SUFFERING

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Introduction Many patients in Low- and middle-income countries lack access to the opioid medicines that the World Health Organization designates as essential for pain control. Disparities in opioid consumption are partly related to policies affecting opioid access. Pain associated with cancer can

significantly influence an individual's morbidity and quality of life. Therefore, Pain relief is fundamental to quality of life and palliative care.

Aims To evaluate the availability of oral Morphine in relation to pain control need in Cameroon and national opioids regulation policies.

Methods Analysis of opioid consumption data for Cameroon as published by the international narcotic control board (INCB), followed by a descriptive literature review of publicly available documents on pain control needs and opioid regulations for Cameroon using PubMed, Medline, Google Scholar, Google, Ministry of Public Health Website and National Institute of Statistics Cameroon.

Results The annual consumption of morphine in Cameroon has steadily increased from 0.07 mg/capita in 1985 to 0.35 mg/capita (7.6 kg) in 2012. About 55.3% of cancer and HIV related deaths are associated with moderate/severe pain. Almost all (98%) of patients dying of HIV or Cancer have untreated moderate/severe pain. An average annual import of 3.4 kg of Morphine was recorded between 20011 and 2013, while a minimum of about 183 Kg is required for HIV and cancer patients only. Importation of morphine is subject to signed authorization signed by the minister of public health.

Conclusions There is a huge unmet need for pain relief with oral morphine in Cameroon. Limited access is at least in part from unduly strict national narcotic drug policies and regulations. Continuous advocacy with the ministry of health is essential to reduce the suffering of many Cameroonians.

Impact Discussion on amended opioids regulatory policies

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'CHOICE' AND 'AUTONOMY' FOR OLDER PEOPLE LIVING WITH ADVANCED FRAILTY AND THEIR INFORMAL CARERS DURING HOSPITAL DISCHARGE

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Introduction There is a global theme of discharging ageing patients 'quicker and sicker,' with the average length of admission decreasing (Lilleheie et al, 2019). Hospital admissions can increase in the last 3 months before death, with most of those having three or more emergency admissions being over 70 years old (Public Health England, 2020). Previous studies looking at frailty, end-of-life and hospital discharge are few.

Aims To explore the experiences of those involved in the discharge from community hospital of an older person living with frailty who is nearing the end-of-life. This included the patient, their informal carer(s), community hospital staff and health and social care staff in the community.

Methods A constructivist grounded theory methodology was used, and semi-structured interviews were conducted with 57 participants.

Results It has been discussed internationally how older people living with frailty are a disadvantaged group (WHO, 2021). This study found informal carers further disadvantaged, particularly when overwhelmed by the power of the 'drive to discharge' and set adrift by lack of resources in the community. Choices made by patients are based on many different factors that the drive to discharge may not allow for or anticipate (Gott et al, 2004). Home may be the preferred

option for the patient but seem utterly overwhelming to the informal carer.

Conclusions The ‘drive to discharge’ causes a burden to the informal carer, which is exacerbated by a focus on patient-centeredness rather than the patient/carer intersection.

Impact This piece of work has significant importance for both older people living with frailty who are at the end of life but also their informal carers. It highlights causes of inequity and injustice during the discharge process at the end of life, and suggests how policy and practice could use relational ethics to improve outcomes and experiences through care planning and carer support.

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HEALTH-RELATED QUALITY OF LIFE IN ADULTS LIVING WITH EHLERS-DANLOS SYNDROME: A SYSTEMATIC REVIEW AND META-ANALYSIS INVOLVING 8251 PATIENTS

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Introduction Ehlers-Danlos Syndrome (EDS) is a serious chronic condition that leads to diminished quality of life and psychological problems. The current study systematically reviewed the existing literature on EDS patients' health-related quality of life (HRQoL) and evaluated the relationship between them.

Aims The purpose of this study is to perform a systematic review of the existing literature on health-related quality of life (HRQoL) in EDS patient populations and to corroborate the association among observed variables.

Methods Four electronic databases were used to identify papers on HRQOL in adults with EDS (Scopus, Medline (by Pubmed), Epistemonikos, and Web of Science). A random-effects meta-analysis was also performed on the 36-item Short Form Survey (SF-36) measure.

Results We contained 37 studies that fulfilled the inclusion criteria. According to the SF-36 meta-analysis, EDS patients and the general population had significant differences in all HRQoL components ($p < 0.01$). In EDS patients, the Physical Component Summary (35.34/100) was more seriously impacted than the Mental Component Summary (45.21/100) in these patients.

Conclusions Individuals with EDS have significantly lower HRQoL in all aspects compared to the general population,

with the physical component of wellbeing being the most pronounced disparity. Future research should look into the impact of different patient characteristics, evaluate the complications of EDS and their effects on wellbeing, and develop multiple intervention strategies to improve HRQoL.

Impact Due to the reduced HRQoL encountered by people with EDS, assessing QoL is critical for improving care for those suffering from this lifelong disorder.

The evidence can be used to improve treatment implementation, such as using a specific instrument based on patient experience, evaluating EDS complications, and creating different non-pharmacological strategies to ameliorate difficulties related to EDS.

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WALK AND TALK BEREAVEMENT SUPPORT: PILOTING AN INNOVATIVE SERVICE AT MARIE CURIE NORTHERN IRELAND

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Introduction At the advent of COVID-19 the bereavement support service in Belfast Hospice had to quickly adapt to new ways of working to ensure continued service provision, with counsellors transitioning to video-link platforms and telephone to facilitate client sessions.

However, counsellors reported challenges building a rapport with clients online, and had concerns that the client's grief was compounded by loneliness and social isolation.

In response, the Marie Curie walk and talk bereavement support project, in partnership with the National Trust, was proposed as an innovative solution. Taking traditional counselling sessions outdoors meant the counsellors could maintain adherence to COVID-19 guidance, while supporting the mental health and wellbeing of bereaved clients.

Furthermore, nature therapy has been shown to enhance both physical and mental health, reducing symptoms of depression. Whilst there are studies that demonstrate the benefit of nature therapy for mental health outcomes, research is limited in bereavement care.

Aims Supporting the mental health and wellbeing of bereaved clients.

Methods A pilot Walk and Talk bereavement therapy brings together the skilful, compassionate counselling work of Marie Curie staff and volunteers in beautiful, restorative National Trust spaces. We plan to conduct semi-structured interviews with service users to explore their experience of walk and talk therapy.

Results To date, the feedback received has been overwhelmingly positive, this is based on informal verbal feedback gathered by counsellors at the end of each session.

Conclusions Despite the physical distancing barriers faced during COVID-19, staff and volunteers were able to overcome these challenges through innovation, creativity, and flexibility, to provide person-centred, compassionate bereavement care and support

Impact Work is ongoing, but we hope to continue to develop the walk and talk bereavement service with the National Trust, to support the mental and physical health and wellbeing of people affected by dying, death and bereavement.