

Transforming Palliative Care

Oral presentations

Parallel session 1: Family carers: policy and practice

0-1 HOW DO FAMILY CARERS FEATURE IN END OF LIFE CARE POLICY? A SCOPING REVIEW OF NATIONAL GUIDELINES

¹Gail Ewing, ²Gunn Grande. ¹University of Cambridge, Cambridge, UK; ²University of Manchester, Manchester, UK

10.1136/bmjspcare-2018-hospiceabs.1

Background The ethos of end of life care (EOLC) embraces both carers and patients. For over a decade UK healthcare policy has acknowledged that carers' needs should be assessed and addressed in EOLC.

Aim To review national policy, guidelines and operational documents on carers and EOLC to examine the extent to which policy addresses carer assessment and support and its implementation in practice.

Methods Policy documents are not indexed by databases such as Medline preventing a conventional literature review. Instead a scoping review was conducted using searches of public body websites (e.g. Department of Health and NICE; provider organisations (e.g. National Council for Palliative Care, Hospice UK); charities (e.g. Carers UK, Carers Trust), personal resources (researcher libraries, personal contacts, serendipitous discovery) and 'snowballing' and reference checking. Included: publications 2004–2018, national guidance on EOLC delivery, or adult carers. Excluded: policy/guidance on children. Policy content was mapped to areas key to practice implementation for carers at individual and organisation levels.

Results Content mapping identified EOLC practice implementation issues for patients, rarely for carers. Conversely, generic carer strategy/guidance focused on carers, with little reference to EOLC. Key findings were: 1) Move from a distinct carer focus (their assessment/support) in early guidance to a joint patient/carers approach with corresponding loss of recognition of carers' separate situation; 2) Limiting carer assessment to statutory social-care assessments which do not address need for healthcare support; 3) Lack of detail on structures and processes required for organisational implementation of carer assessment and support.

Conclusions This scoping review has highlighted an absence of policy detail about carer identification, assessment and support in EOLC and the structures and processes required for its implementation in practice. These issues need to be fully addressed in order to support carers in their crucial role in EOLC.

0-2 ASSESSING THE BURDEN EXPERIENCED BY CAREGIVERS OF PATIENTS RECEIVING SPECIALIST PALLIATIVE CARE

Bridget Johnston. Trinity College Dublin, Dublin, Ireland

10.1136/bmjspcare-2018-hospiceabs.2

Background The important contribution made by caregivers has been recognised in the international literature. However, caregiving for someone with a life-limiting illness often

involves physical, emotional and other practical challenges. In order to support caregivers in their dual roles as care provider and care recipient, it is essential to understand the extent of their burden and the circumstances contributing to this.

Aim To assess caregiving burden among caregivers known to specialist palliative care teams, and identify whether clinical or demographic factors are associated with reported burden.

Methods Validated measures were administered during face-to-face interviews with caregivers in three regions of Ireland. The Zarit Burden Interview (ZBI) was used to assess caregiver burden, and financial impact associated with caregiving was measured using the Cost of Care Index. Participants were divided into low- and high-burden groups, using a previously established threshold of 24 for the ZBI score. Differences between regions were tested for statistical significance. Multiple linear regression investigated predictors of caregiver burden.

Results 69 caregivers were interviewed. The mean ZBI score was 26.8, and did not vary significantly between study sites ($p=0.215$). Overall, 51% of participants were considered heavily burdened. A significant proportion (40.6%) agreed that caring for their loved one was causing them to dip into savings, while almost one-quarter (24.6%) reported giving up necessities because of the costs associated with caregiving. Caregiver age ($p=0.01$), patients' psychosocial burden ($p=0.045$) and financial hardship ($p<0.001$) were significant predictors of caregiver burden.

Conclusion Understanding the difficulties experienced when caring for someone with a life-limiting illness allows for better supporting the caregiver. The findings of this study suggest that younger caregivers are particularly susceptible to feeling heavily burdened. Additionally, comprehensive support of caregivers in all circumstances might require adequate attention to financial protection and additional supports to address psychosocial burden.

0-3 SCOPING THE FINANCIAL SUPPORT FOR FAMILY CAREGIVERS AT END OF LIFE ACROSS SIX COUNTRIES

¹Bethany Taylor, ¹Clare Gardiner, ²Merryn Gott, ²Jackie Robinson. ¹University of Sheffield, Sheffield, UK; ²University of Auckland, Auckland, New Zealand

10.1136/bmjspcare-2018-hospiceabs.3

Background Informal caregivers of patients at the end of life can face significant financial burden. Some form of caregiver financial support is advised in most countries with developed healthcare systems. Whilst appropriate support can reduce the financial burden for informal caregivers and improve health and wellbeing, little is known about the scope of financial support for informal caregivers across countries with similarly developed healthcare systems.

Aim To identify and compare sources of financial support for informal caregivers of those at the end of life across six countries with similarly developed healthcare systems.

Methods A mapping exercise was undertaken in two phases. Phase one involved searches of grey literature and academic databases to identify sources of financial support in the UK, Ireland, New Zealand, Australia, USA and Canada. Phase two comprised a survey of experts across the six countries to confirm and extend the literature review findings, and

gain further insight into financial support. A total of 57 responses were received from experts including patients, family carers, academics, policy-makers and health care professionals.

Results Some form of financial support for caregivers was available in all six countries and included national and local support which was aimed at the carer or aimed at the patient and benefitted the carer. The type, extent and reach of financial support varied within and between the six countries and was administered by multiple agencies including healthcare providers, government and charities. Types of support included payments to cover prescription charges, transport costs, medical insurance fees, changes to employment and bereavement benefits.

Conclusion The findings highlight some novel examples of financial support available to family carers, alongside numerous gaps and inconsistencies, both within and between countries. In doing so, this study demonstrates the need for policy-makers, as well as palliative care providers, to learn from other countries' experiences.

Parallel session 2: Transforming palliative care: joint working and system-wide approaches

0-4 A DYING DISCREPANCY: THE ROLE OF THE LAW IN PALLIATIVE CARE PROVISION

Katherine Murdoch. *University of Bristol, Bristol, UK*

10.1136/bmjspcare-2018-hospiceabs.4

Background One hundred percent of people die, yet not everyone has a good death. Research and policy shows we understand what facilitates a good death. For example, specialist care will be available, symptoms will be managed and people will die in a place of their choosing. However, not everyone gets to die in their preferred place or even have access to adequate pain relief.

Aims (i) To assess, from a medico-legal and bioethical perspective the provision of palliative care funding in England. (ii) To assess the legal obligation of palliative care provision. (iii) To evaluate the role of new law in palliative care provision.

Methods January-March 2017: Assessment of literature, policy, law and practice. April-September: Evaluation of data to form and write an article on the topic of palliative care provision and the need for change in law.

Results There is an exponentially increasing demand for palliative care, (NHS England, 2014) but palliative care is not yet available to all of the current population. Trusts spend anywhere between £186/death to £6213/death, (Hughes-Hallett, Craft, Davies *et al.*, 2011) resulting in an extreme postcode lottery. Moreover, unlike many other parts of care, palliative care is largely provided by charities. As such, palliative care appears not to be a public funding priority and there appears to be a discrepancy in how palliative care is provided and valued.

Conclusion It is argued that the best way to ensure that everyone has equitable access to dying well and that good deaths are supported is to create a legal obligation. This is assessed by application of Human Rights Law and by enacting the Palliative Care Bill.

0-5 A JOINT COMMISSIONING APPROACH TO END OF LIFE CARE IN KIRKLEES

Sadaf Adnan, Michael Crowther. *Kirkwood Hospice, Huddersfield, UK*

10.1136/bmjspcare-2018-hospiceabs.5

Discussions with our local CCGs over the last three years have led to a change in our working relationship as part of the development of a Lead Commissioner model for end of life care. This forms a landmark achievement in establishing ourselves as leading end of life services in Kirklees.

This development provides us with the opportunities to:

- Work towards our vision to address unmet need in Kirklees
- Increase involvement in decision making around End of Life care
- Reach new people not currently accessing our services
- Protect existing NHS funding
- Receive commitment from CCGs to keep the development of end of life services at the forefront of their minds.

This will redress the traditional commissioner/provider relationship through:

- Sharing data – supporting and driving the assessment of needs as well as supporting a review of existing service provision in order to identify gaps. This will be the first time in Kirklees that data has been pooled to establish baselines for end of life care key performance indicators across the wider health and social system. System wide data being captured and reviewed jointly on a regular basis will not only improve understanding of overall demand but also help us evidence the impact of the care we provide.
- Agreeing a joint end of life commissioning plan – by establishing the overall system wide cost for end of life care and identifying a route to reinvesting savings, measures will be developed to better understand future demand. This plan will allow joined up approaches to key service development areas.
- Ensuring collaborative partnerships across health and social care – Kirkwood Hospice will take the lead on facilitating a provider alliance and scoping the development of a clinical network. Through alignment of contract monitoring measures there may be opportunity to impact on contract levers to ensure improved knowledge and understanding of end of life care.

0-6 WHY MISSING DATA MATTER-A GUIDE FOR PALLIATIVE CARE PRACTITIONERS

¹Jamilla Hussain, ²David Currow, ³Ian White, ⁴Martin Bland, ¹Miriam Johnson. ¹*Wolfson Palliative Care Research Centre, Hull, UK;* ²*IMPACCT, University of Technology, Sydney, Australia;* ³*UCL (University College London), London, UK;* ⁴*University of York, York, UK*

10.1136/bmjspcare-2018-hospiceabs.6

Evidence-based palliative care is essential to improving the value of palliative care clinical practice. In order to provide this, we not only need *more* research in palliative care but also, crucially, we need *better quality* research. Missing data (MD) present a particular challenge to clinical studies as they reduce the power, precision and generalisability of study findings. Importantly, they can also introduce bias.