

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

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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

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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

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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