

hospital was high quality, excepting notification of GP's. Few were referred to community palliative care post discharge, indicating needs may have been under recognised or unmet in the community. These results reflect challenges of accessing specialist palliative care in the aging frail population.

## REFERENCE

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OP-22

## MEASURING THE TRUE COST OF INFORMAL CANCER CAREGIVING: DEVELOPMENT OF A CO-DESIGNED ECONOMIC ASSESSMENT TOOL

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**Background** Recognised as the 'foundation of the palliative care workforce', informal caregivers disproportionately carry the burden of caring for patients with cancer, providing an estimated 75–90% of home-based care.<sup>1</sup> Current economic evaluations of health services and interventions are based on the benefits to the formal healthcare system, while the financial impact on informal caregivers is routinely overlooked. This lack of a societal approach precludes a more nuanced understanding of the drivers of burden experienced by caregivers and does not account for direct or indirect costs borne by caregivers, such as the impact on employment. To date, no standardised instrument exists to understand the economic impact of informal caregiving for cancer patients at the end-of-life.

### Aim

1. To co-design a questionnaire that comprehensively captures the resources incurred by caregivers for cancer patients at the end-of-life
2. To assess its feasibility, acceptability and face validity.

**Methods** This is a qualitative study conducted in three phases:

1. Semi-structured interviews conducted with caregivers to explore the depth and breadth of resources used in day-to-day life. Supported by economic theory, themes were grouped into direct and indirect costs and broader themes identified inductively according to the principles outlined by Braun and Clarke.<sup>2</sup>
2. Questionnaire design by a community advisory group (CAG) comprised of caregivers and community-based clinicians using the findings from phase one, previous literature and lived experience.
3. Questionnaire piloting and psychometric testing using cognitive-interviewing techniques to assess its feasibility, acceptability and face validity

**Results** For caregivers of someone with cancer who has accessed palliative care, direct cost categories include home environment, food, equipment, medications, transport, health-care, insurance and funeral and faith-based costs. Indirect cost categories include carer time, family and friend time, employment absenteeism and presenteeism, own health impacts, and

leisure or opportunity costs. These categories informed the final questionnaire content, which consists of eight domains with 36 questions that meaningfully capture the economic impact of informal caring for cancer patients at the end-of-life. The initial pilot results have found the tool to be feasible, acceptable and valid.

**Conclusions/Discussion** This tool has the potential to shape how we value informal caregivers by contributing data informed by a societal perspective to future economic evaluations for provision of care in the palliative and end-of-life phase.

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OP-23

## THEMATIC ANALYSIS OF THE EXPERIENCES OF HOME HOSPICE PROFESSIONALS WHEN COMMUNICATING WITH YOUNG CHILDREN OF TERMINALLY ILL PATIENTS

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**Background** Assisting young children when a parent faces a life-limiting illness presents significant challenges. Healthcare professionals play a crucial role in engaging them, and yet the impact of such interactions on the professionals themselves and their perceived ability to offer support remains unclear. The impact on home hospice professionals is even less understood, and yet they are more likely to interact with these children during their visits. They recognize the need to communicate with these children and address their needs, despite the delicacy of broaching the topic and potential challenges. Understanding the home hospice professionals' concerns is essential to enhance their capacity to provide effective support.

**Objectives** This study aimed to examine the experience of home hospice professionals when supporting the young children of terminally ill patients. We sought to understand the emotional and psychological impact of doing this work, and describe sources of strength and coping strategies.

**Methods** Semi-structured, in-depth interviews were conducted with 16 home hospice professionals who had supported patients with young children at home: 4 Doctors, 6 Nurses and 6 Psychosocial Support Professionals. The latter group consisted of 3 Medical Social Workers, 2 Art Therapists and 1 Spiritual Care Counsellor. Verbatim transcripts of recorded interviews were analyzed thematically.

**Results** Three themes emerged. First, the multidisciplinary team was a pillar of support, with members performing distinct roles. Art therapists and Medical Social Workers primarily attended to the children, with doctors and nurses tending more to the patient. Members supported each other, and more experienced colleagues provided supervision/advice. Collaboration with other institutions such as schools was also useful.