

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.

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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.¹ 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.²
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.

Secondly, understanding family dynamics and children's needs, including knowledge of how children grieve and process information, was important in order to support the child at home. Professionals advocated for the children's need to know what was occurring with their parent. However, time constraints and limited resources affected their ability to engage children. There was little formal training on communicating with children, with professionals largely drawing on prior experience or doing their own research.

Thirdly, professionals embraced their own vulnerability. They experienced countertransference, and most were intentional about self-care. While there was fear of making things worse for children, there was a sense of fulfillment and comfort in being of assistance.

Discussion Professionals showed awareness of the emotional toll, and vicarious post-traumatic growth was also evident in some. There was significant countertransference, mostly in for those who were themselves parents of young children. Parentified children who were caregivers causes significant distress to the Professionals.

Significance There is a need for better organizational support to manage emotional toll and time constraints. More specialized training and resources are required, as well as enhanced partnerships with external agencies to better support affected children. Findings can contribute to the development of an interdisciplinary project aiming to address these issues.

OP-24

EMBRACE: MEETING THE CHALLENGE OF LIVING WITH SERIOUS ILLNESS, A FEASIBILITY STUDY

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Background People with serious illness face multiple losses which necessitates a new way of living. Many experience a loss of meaning and purpose. There is a need for interventions to support people exploring opportunities for growth despite their changed circumstances.

Aim to develop and test the feasibility of an intervention that is based on the principles of posttraumatic growth and seeks to foster a stronger sense of meaning and purpose and that is relevant and appropriate to palliative care settings.

Methods Using participatory action research methodology, the intervention was designed in an iterative process with both health professionals and people with lived experience of a terminal illness. Further feedback from program participants and facilitators was then used to modify and refine the program before finalisation. The face to face group program was pilot tested over six weekly sessions each for two hours. Outcome measures include the Symptom Assessment Scale, FACIT-Sp, HADS and a qualitative interview. Ethics approval was obtained. Qualitative analysis was conducted using framework analysis.

Results Three major themes:

Engagement; Self-reflection and Empowerment.

Engagement

The theme of 'Engagement' describes how participants interact with others, both in taking part in the program and with family or other people during the course of their illness. Group interaction during the program demonstrated the care participants showed towards each other e.g. dealing with the

expression of emotion; trust was demonstrated by how participants allowed themselves to display emotion as they knew their fellow group members would understand their situation.

Self-reflection

The theme of 'Self-reflection' in response to the program offered participants an opportunity to listen to other participants' stories and consider their own situation. In particular, many commented on how, despite perceiving individual differences, they could learn from the similarities of their shared experiences. Many participants were open to learning more about how to manage differently while living with serious illness, however some participants felt this was not possible. Self-reflection and being open to learning allowed participants to consider alternative views about what was important in each individual's life and one's capacity to make changes to live life in a positive manner for the benefit of the individual, their family and friends.

Empowerment

The theme of 'Empowerment' describes the realisation that participants are able to manage their life differently in a way that still has meaning and purpose. Prioritising, making choices, and setting differently configured goals for oneself became ways of living with purpose and hope. Through self-reflection and discussion with others, many participants stated how they now felt they were better able to discuss and prepare for the future with close family and friends, with some stating a new found purpose and/or determination to benefit others while the participant is able.

Conclusions The Embrace program shows promise at addressing the widespread challenge of finding new sources of meaning and purpose for those living with serious illness.

OP-25

IMPROVING PARALLEL PLANNING IN TRISOMY 18 AND 13

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Background West Midlands Perinatal Palliative Care Service (WMPPCS) is the busiest such service in the United Kingdom with 62 referrals for the 12 months 2023 to 2024 to date. A large cohort of babies with Trisomy 18 and 13 are referred to this service. These conditions are associated with poor outcomes such that colloquially has been described as 'incompatible with life'. Increasingly services involved are recognising a variety of outcomes though, and questions about what interventions should be offered are being raised. Parallel planning varies and may or may not include offers of a doctor attending delivery, subspecialist review, access to respiratory support, access to Neonatal Intensive Care Units and surgical intervention. This balance between recognising potential to survive and need best possible care, and poor average survival makes care complex to navigate.

Objectives We reviewed the number of babies with a trisomy 18 or 13 diagnosis referred to the service and reviewed what service was provided, what interventions were undertaken and for those babies that died what their length of survival was. Using this information we hope to broaden understanding of possible outcomes and precedent clinical journeys to improve and provide consistency in parallel planning for these babies.