Editorial

Knowledge, attitudes and beliefs about paediatric palliative care

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Life-limiting and life-threatening conditions are respectively defined as conditions for which there is no reasonable hope of cure or for which curative treatment may be feasible but can fail (1). Paediatric palliative care is a holistic and child- and family-centred approach to care (1,2). It aims to support children and young people with life-limiting and life-threatening conditions and their families, through active and dynamic management of symptoms and concerns by multi-disciplinary care teams (1,2). Globally, it is estimated that over 21 million children and young people require support and would benefit from paediatric palliative care (3). Despite improvements to access and provision of paediatric palliative care services, particularly in higher-income countries, there are still significant barriers to access and integration globally (4-6). One significant barrier that remains, even when logistical, financial, and operational barriers are addressed is how palliative care is understood by health and social care professionals and families (7-9).

In this narrative review, Saad *et al.* (9) retrieved 60 articles that explored knowledge, attitudes and beliefs toward paediatric palliative care among healthcare professionals, parents and communities. The review highlights disparities in knowledge and understanding of both what paediatric palliative care is broadly and also what that means in terms of the approach to care. Lack of knowledge often created attitudinal barriers. For health and social care professionals this often related to reluctance to refer to paediatric palliative care teams due to personal attitudes and beliefs or concerns relating to the family's attitude and view of palliative care. The review found that parents lack of knowledge of palliative care was often linked to more negative perceptions and parents often view palliative care as intrinsically linked with end-of-life. Similarly, wider community knowledge and understanding of paediatric palliative care was also often limited even when there was awareness or familiarity with the concept. However, and importantly Saad *et al.* (9), found across multiple studies across professional, parent and community samples, when individuals are provided accurate information about paediatric palliative care, their attitudes towards it become more positive.

There is often significant misunderstanding between palliative care and end-of-life care, which have often been used inter-changeable (10). As per the International Children's Palliative Care Networks' definitions (11), children's palliative care aims to support children and young people and their families from diagnosis through all phases of illness (12), whereas end-of-life care generally focuses on providing care to those in the dying phase and into bereavement (12). This misunderstanding has also fed into the misconception from both health and social care professionals and families that referrals to palliative

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care services are synonymous with 'giving-up' (13,14). Early integration of palliative care has been shown to lead to improved outcomes of care including improved symptom management and quality of life (13,14). Addressing misconceptions and educating health and social care professionals and families as to the benefits that palliative care can provide for children and young people with life-limiting and life-threatening conditions may increase likelihood of referral to paediatric palliative care teams for the benefit of children and young people and their families (15).

Another key finding identified in this review was that even when health and social care professionals were knowledgeable and had positive attitudes towards palliative care, they were not always confident in delivering all aspects of palliative care (9). The World Health Organisation definition of palliative care consists of four domains of care: physical, emotional, social, and spiritual (16). Whilst most health and social care professionals feel confident in addressing physical symptoms, spiritual and existential concerns in particular have been seen to be difficult to discuss, in part due to clinicians lack of experience or confidence (9,17) but also due to discomfort related to discussing issues such as death and dying with children (18,19). This can contribute to the reluctance of health and social care professionals to refer families onto palliative care services due to the association of palliative care with death and dying (15).

However, findings from a multi-country qualitative study in Africa conducted by Namisango *et al.* (20) as well as a similar qualitative interview study in the UK conducted by Coombes *et al.* (17) both found that the symptoms and concerns that mattered most to children and young people and their families encompassed all four World Health Organisation domains of care (16). This further demonstrates the importance of providing health and social care professionals, and families accurate information about paediatric palliative care to increase positive attitudes and thus facilitate more timely referrals to these services to provide a holistic child- and family-centred care and to improve quality of life across the whole trajectory of the child's illness and better support families (1).

Saad *et al.* importantly acknowledge that as 82% of the studies included in their review are from high-income countries, with almost half being from the USA, as well as the search being restricted to English language articles (9) that there may be cultural differences that are important to consider that may not have been identified. Moreover, addressing knowledge and attitudinal barriers may also be easier to achieve in high-income countries compared to low and middle income countries where logistical and finical barriers such as staffing and material resources are more prominent and can sometimes take precedence over attitudinal barriers (4-6).

In conclusion, Saad *et al.* (9) highlight the importance of addressing misconceptions around paediatric palliative care and working to improve positive attitudes towards it from all key stakeholder perspectives including health and social care professionals, children and young people with life-limiting and life-threatening conditions, parents, and wider communities. By increasing knowledge and improving attitudes, barriers to accessing palliative care for children with life-limiting and life-threatening conditions may decrease and therefore improve care and outcomes for these children and families.

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