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Murray et al describe late palliative care as a missed opportunity to do better for patients, families and healthcare services (1). Their work has focused on adults, but there is also a need to do better for the growing number of children and young people (CYP) who could benefit from palliative care (2). Just as with adults, palliative care for CYP is often delayed, with referrals to specialist services occurring late in the course of illness, if at all (3).

The effective delivery of palliative care for CYP within resource constraints is the subject of ongoing debate (4). The need for clinicians to embed the principles of palliative care in their routine practice is pertinent; “palliative medicine is only going to have its greatest effect when everybody from that junior nurse or junior doctor has the skills to deliver that care to them in the way that’s appropriate for that child” (Dr A Thompson: <https://vimeo.com/170747606>).

Our current research is with CYP who are living with life-limiting and life-threatening conditions, and their families. The relevance of Murray et al’s concept of multi-dimensional wellbeing trajectories is highly evident in our interviews, with additional trajectories becoming clear for CYP. An education trajectory aligns closely with, but is distinct from, psychological and social trajectories. There is also an information and knowledge trajectory; describing when information is provided to CYP and families and how that contrasts with the knowledge they acquire as their condition and treatments progress (5).

Regarding the term “palliative care”, CYP who have received services from a children’s hospice report that they have never heard the term, perceive it negatively and don’t relate it to themselves. They prefer that it isn’t used. Previous research suggests similar responses from parents (6). These opinions warrant further consideration.

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