Transition to adult services of young people with palliative care needs is the crisis riding the wave of advances in paediatric medicine. The review by Doug et al has highlighted the extent of the crises we are facing, with a lack of standardised transition programmes, a poor evidence base to transition guidelines and insufficient outcome data to evaluate the different models. How, in palliative care, have we found ourselves in this position, with a long-anticipated patient population that has no clear destination and little means of getting there?

One of the difficulties must stem from the broad scope of paediatric palliative care, where early referral in the course of a life-threatening or life-limiting condition is the norm. Consequently, those transitioning to adult services encompass a diversity of diagnoses, disease groups and disease trajectories. One of the dilemmas facing paediatricians is not “should I transition my young adult patients” but “how and where do I transition them to”.

It is no surprise that published models of good practice, although limited, were mainly identified for condition-specific transition programmes, notably cystic fibrosis, cancer and congenital heart disease (CHD). Here, a single disease group, managed by disease-specific specialists in paediatrics, has a clearly identifiable disease-specific service in adult medicine. Of course, ‘palliative care’ also has an equivalent, clearly identified and developed specialty in adult medicine. Of course, ‘palliative care’ also has an equivalent, clearly identified and developed specialty in adult medicine. Of course, ‘palliative care’ also has an equivalent, clearly identified and developed specialty in adult medicine. Of course, ‘palliative care’ also has an equivalent, clearly identified and developed specialty in adult medicine. Of course, ‘palliative care’ also has an equivalent, clearly identified and developed specialty in adult medicine. 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Of course, ‘palliative care’ also has an equivalent, clearly identified and developed specialty in adult medic In blen care from terminal to one that includes long-term supportive care. Consequently, young adult graduates from paediatric palliative care do not ‘fit’ into existing adult palliative care programmes, generally more focused on patients with advanced progressive illness. This ‘poor fit’, however, is not unique to palliative care. In 2003 the Task Force on the Management of Grown Up Congenital Heart Disease of the European Society of Cardiology identified that “the ‘new population’ of patients with CHD no longer fits within traditional divisions of training and practice” and emphasised the need to re-integrate paediatric and adult cardiac services in order to provide smooth transition.

Doug et al were able to identify four transition models for CHD and while there remains controversy over the best model, the lack of evidence of similar planning between paediatric and adult palliative care services is disappointing.

It was disappointing, but not surprising, to see that high quality parent-provider relationships were strongly associated with addressing transition issues. This suggests that young people without strong parent advocates may be receiving a poorer quality of support for transition. Although acknowledging that the role of the family is crucial, it is essential that transition programmes are developed around the needs of the client group and are not parent-dependent.

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Individualised transition plans seem to be key. Even where young people have the same underlying condition, their transition needs will vary depending on family dynamics that are intrinsic to paediatrics.

A young man with Duchenne muscular dystrophy, for example, may be independently and emotionally a young adult in one family, but childlike and unwilling to be separated from his mother in another. How would you standardise place of care in hospital where admission to paediatric wards ends at 16 years and adult wards do not allow parents to sleep at the bedside?

Doug et al suggest a key worker should be involved in the transition process and we believe this could go some way to ensuring that transition is driven by the young person, alongside their parent. It is noted that peer-led transition models require further exploration, but this model may not be appropriate for young people with cognitive impairment or significant communication difficulties.

The lack of good quality transition data identified in this review highlights the urgent need for public health planners to collect the evidence and data needed to effectively plan the required service developments. While the focus of the study is predominantly healthcare, planning and evaluation of transition services must ensure common
processes between the varieties of services these young people require: health, social care, education and employment. For young adults to remain in paediatric services, to continue living with parents because there is no acceptable funded alternative and to have no meaningful daytime activities is unacceptable. The use of validated outcome measures is crucial, but may prove challenging owing to a lack of standardised service provision in paediatric and adult services and across different geographical areas and disease groups. Patient and family feedback data were significantly lacking from publications, yet are essential to improve quality and to build on good practice models.

There is at present a growing trend to reintroduce the general practitioner (GP) during transition to provide the generalist overview and to be able to refer back to adult specialist services. Doug et al observe that this primary care transition model has met considerable opposition because of a lack of integration between primary and specialist care. Perhaps, as paediatricians, we should be working harder to support the role of the GP during childhood—the one service that provides lifelong continuity in healthcare, regardless of age or diagnosis.

Competing interests None.

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REFERENCES