

A survey of Consultant led Paediatric Palliative Care Services in the UK: professional configuration, service and funding

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ABSTRACT

Objectives

To systematically gather information on the professional team members, services provided, funding sources and population served for all consultant-led specialist paediatric palliative care (SPPC) teams in the UK.

Methods

Two-part online survey.

Results

Survey 1: All seventeen medical leads from hospital or hospice based SPPC teams responded to the survey (100% response rate).

Only 6 services met the NICE guidance for minimum SPPC team.

All services reported providing symptom management, specialist nursing care, end-of-life planning and care, and supporting discharges and transfers to home or hospice for the child's final days-hours. Most services also provided care coordination (n=14), bereavement support (n=13), clinical psychology (n=10), and social work-welfare support (n=9). Thirteen had one or more posts partially or fully funded by a charity.

Survey 2: Nine finance leads provided detailed resource/funding information, finding a range of statutory and charity funding sources. Only one of the NHS based services fully funded by the NHS.

Conclusions

A third of services met the minimum criteria of professional team as defined by NICE. Most services relied on charity funding to fund part or all of one professional post and only one NHS based service received all its funding directly from the NHS.

What is already known on this topic

- NICE state that the minimum recommended professional team for specialised paediatric palliative care service.
- It includes a paediatric palliative medicine consultant, a nurse with expertise in paediatric palliative care, a pharmacist with expertise in specialist paediatric palliative care, and experts in child and family support with experience in end of life care.

What this study adds

- Only 6 of the 17 consultant-led Paediatric Palliative Care services in the UK met the minimum professional team members as recommended by NICE.
- Almost all services relied on charity funding for at least one of their professional posts.

How this study might affect research, practice or policy

- High-quality information about services is critical for national health service provision to respond to recent changes which mean that access to specialist palliative care is now a legal requirement.
- It is also important to understand make up and funding of teams to identify how and where improvements should be targeted and to prioritise.

INTRODUCTION

Receiving high quality palliative and end of life care is a human right, access to which is limited and highly varied in much of the UK [1]. There is evidence that specialised paediatric palliative care services (SPPC) can improve symptom control and quality of life for children and provide more choice in preferred place of care and family support [2].

The NICE guidance on 'End of life care for infants, children and young people with life-limiting conditions: planning and management' NG61 was published six years ago [3]. Most of the recommendations are based on low quality evidence. However, they do recommend a minimum professional team for a SPPC, of a paediatric palliative medicine consultant, a nurse with expertise in paediatric palliative care, a pharmacist with expertise in specialist paediatric palliative care, and experts in child and family support with experience in end of life care. There is no existing information on whether paediatric palliative care services in the UK are meeting these recommended professional configuration.

This paper reports one component of the ENHANCE study [4], which aims to increase understanding of care provision and examine different models of end-of-life care, including how this affects families at the centre of this care. It aimed, for the first time, to systematically gather information on the professional team members, services provided, funding sources and population served for all consultant-led specialist paediatric palliative care (SPPC) teams in the UK, and contrast this with NICE guidance.

METHODS

Study Design

A two-part online survey reported according to the CHERRIES statement [5].

Participants and recruitment

Survey 1: The medical leads of each of the UK's seventeen hospital or hospice-based consultant-led specialist paediatric palliative care teams were identified via the Association of Paediatric Palliative Medicine, and invited to participate via email. Up to two email reminders were sent. Data were collected from September to November 2021.

Survey 2: Respondents to survey 1 provided a contact for a business manager or finance lead to receive a second survey with detailed funding questions that the clinical leads were not expected to know. Data were collected between April and May 2022 and up to two email reminders were sent.

Questionnaires

Both questionnaires were designed to systematically capture data on the professionals involved, services provided, population served and funding arrangements using existing literature and NICE guidance.

Questions included the type of care provided, number of referrals in 2019 (or equivalent reporting period), members of the paediatric palliative care team (as per NICE recommendations), funding source of staff and broader service provision and population served.

Both surveys were hosted on the Qualtrics© platform.

Analyses

Descriptive statistics were applied to the data. A comparison between the responses to the survey and the recommendations from NICE about the professional configuration of a SPPC was also conducted.

Ethical Approval

Approved by the Department of Health Sciences Research Governance Committee, University of York (HSRGC/2020/418/G).

RESULTS

Seventeen clinical leads from hospital or hospice based SPPC teams responded to the survey (100% response rate). 10 of these services were fully based in NHS Trusts, the others were a mixture of hospice based or hospice/NHS based. Several consultants worked across more than one service. The services varied in size with the range of number of referrals in 2019 being from 40 to 241.

Staff

Figure 1 shows the percentage of services with each of the key professionals who were part of the consultant-led palliative care teams.

When assessing against the minimum requirements for a SPPC team as defined by NICE, only six (35%) services met these criteria in full. All services had medical consultants leads. Fourteen (N=82%) services had nurses specialist trained in palliative care. Among other members, chaplain/spiritual care staff was the most frequently reported (N=10, 59%), followed by family support worker (N=8, 47%) and pharmacists (N=7, 41%). Six (35%) teams included a clinical psychologist or social worker. Only two (12%) services reported having dedicated bereavement support staff.

Services provided

All services reported providing symptom management, specialist nursing care, end-of-life planning and care, and supporting discharges and transfers to home or hospice for the child's final days-hours. Most services also provided care coordination (N=14, 82%), bereavement support (N=13, 77%), psychological care (N=10, 59%), and social work-welfare support (N=9, 53%). Respite care was provided by three services (23.5%).

Source of referrals

All teams received referrals from neonatal and paediatric intensive care services, and all bar one team received referrals from maternity services. Most of the services also received referrals from children and teenage and young adult cancer services (N=15, 88% and N=14, 82%, respectively). In 2019, the main source of referral was paediatric intensive care (Median:19, Q1-Q3: 8, 31), followed by neonatal intensive care (Median:10, Q1-Q3: 5, 14), and children's cancer service (Median:10, Q1-Q3: 7, 15).

Funding

Eight (47%) teams had at least one post fully funded, and 13 (77%) at least one post funded partially or fully by a charity (multiple responses allowed). Four (23%) services reported no posts were funded by the charity sector.

Nine (53%) service leads responded to the second part of the survey (six NHS hospital and three hospice-based). Only one of the six NHS services reported receiving all their funding from the NHS. The other services received a mixture of central and local NHS funding (from clinical commissioning groups) and charity sector funding.

DISCUSSION

There are growing numbers of consultant-led paediatric palliative care teams in the UK but there are also rising numbers of children with palliative care needs [6]. Our analysis shows that only 35% of these consultant-led paediatric palliative care teams have the minimum professional configuration recommended in national clinical guidelines. The statutory funding of these services appears inequitable with more than three-quarters of services reliant on at least one professional post funded by charity funding and only one NHS team was fully funded by the NHS.

Access to specialist palliative care has recently been made a legal requirement in England following an amendment to the Health and Social Care Bill for England – now the Health and Care Act 2022 [7] and is the responsibility of the new Integrated Care Boards in England to deliver for all ages including babies, children and young people. As part of this expectation, SPPC teams should receive funding to have at least the minimum professional configuration recommended by NICE. Although 17 services were represented in this study, some of the tertiary level children's hospitals in the UK still do not have a consultant-led paediatric palliative care service.

Charitable organisations and funding have been a critical part of the hospice sector in the UK since the 1980s. The transparent, equitable and sustainable provision of funding in an area as important as end-of-life care in children and young people is vital to a functioning national health service. However, our analysis indicates this is not currently the case.

Strengths and limitations

This is the first comprehensive survey of all consultant-led paediatric palliative care services in the UK. We had a 100% response rate for the main survey but only just over half of the services provided detailed information for the second survey as they did not have ready access to the required funding information.

The survey did not capture information on nurse-led services which provide palliative care to children.

Hospice and NHS services have different aims, funding sources and governance structures and direct comparisons can be problematic. There are also key differences between the NHS funding and commissioning arrangements in the four nations of the UK.

Conclusions

Only a third of services met the minimum criteria of professional team members as defined by NICE. The funding source and amounts varied across services, 77% of services relied on charity funding to fund part or all of one professional post and only one NHS based service received all of its funding directly from the NHS. There is an opportunity for the newly formed Integrated Care Boards to use more transparent and equitable approaches to funding these services.

Contributorship Statement

LF and AB wrote the first draft of the manuscript. HW, SH, and JH also contributed to manuscript writing. Statistical Analysis: AB. Interpretation of findings: AB, SH, AP, BB, CV, GW, EM, GP, HW, RF, FM, JN, JH, RH, SO, GS, LF. Data collection and study management: BB, AP, AH, JH, LF. Planning and conceptualisation: BB, BP, GW, RF, CH, JN, RH, LF. Study supervision: LF and BB. All authors approved the submitted version of the manuscript.

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Conflict of Interest

None

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