

Referrals to a perinatal specialist palliative care consult service in Ireland, 2012–2015

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ABSTRACT

Objective To analyse the referral patterns of perinatal patients referred to a specialist palliative care service (SPCS), their demographics, diagnoses, duration of illness, place of death and symptom profile.

Design A retrospective chart review of all perinatal referrals over a 4-year period to the end of 2015.

Setting A consultant-led paediatric SPCS at Our Lady's Children's Hospital, Crumlin, Dublin, and the Coombe Women & Infants University Hospital, Dublin.

Results 83 perinatal referrals were received in a 4-year period. Chromosomal abnormalities accounted for 35% of diagnoses, congenital heart disease 25%, complex neurological abnormalities 11% and renal agenesis 4%. 22 referrals (26.5%) were made antenatally, with 61 (73.5%) postnatally. Of the postnatal referrals, 27 (44%) were asymptomatic on referral. An opioid medication was recommended (regularly or as required) in 46 cases. Symptom control was achieved without dose titration in 43 of these cases (93%). Of 47 deaths in this group referred postnatally, 22 of these (47%) died at home with support from community teams. Discharge home for best supportive care required complex interagency communication and cooperation.

Conclusions Perinatal palliative care requires effective multidisciplinary work, whether delivered in the inpatient setting or in the community. With appropriate support, end-of-life care can be delivered in the community.

INTRODUCTION

Background

Children's palliative care has evolved from the specialty of paediatrics rather than adult palliative care and is an active and total approach to care, embracing physical, emotional, social and spiritual elements.¹ It focuses on enhancing the quality of life for the child and providing support for the family. A life-limited condition is defined as any illness in a child where there is no reasonable hope of cure and from which the child or young adult will die.² Of childhood deaths due to life-limiting conditions, the majority occur within the first year of life, with most deaths occurring within the first 27 days.³ Offering parental choice in where end-of-life care is delivered should be a routine part of neonatal care.⁴ Despite this, 98% of all neonatal deaths in the UK occur in hospital settings, with few families spending time with their baby at home or at a children's hospice.⁵

Perinatal palliative care

Perinatal palliative care was defined by the British Association of Perinatal Medicine in 2010 as the

What is already known on this topic?

- ▶ Infants and neonates requiring palliative care have unique needs.
- ▶ Nearly all neonatal deaths in the UK occur in hospital settings.
- ▶ Parental choice should be offered on where end-of-life care is delivered.

What this study adds?

- ▶ Discharge home for best supportive care required complex interagency communication and cooperation.
- ▶ Effective symptom control was achieved without dose titration for most neonates for whom an opioid is recommended.

planning and provision of supportive care during life and end-of-life care for a fetus, newborn infant or infant and their family in the management of an appropriate candidate condition.⁶

Candidate conditions for perinatal palliative care can be considered in five broad categories⁶:

- ▶ category 1: an antenatal or postnatal diagnosis of a condition that is not compatible with long-term survival, for example, bilateral renal agenesis or anencephaly
- ▶ category 2: an antenatal or postnatal diagnosis of a condition that carries a high risk of significant morbidity or death, for example, severe bilateral hydronephrosis and impaired renal function
- ▶ category 3: babies born at the margins of viability, where intensive care has been deemed inappropriate
- ▶ category 4: postnatal clinical conditions with a high risk of severe impairment of quality of life and when the baby is receiving life support or may at some point require life support, for example, severe hypoxic ischaemic encephalopathy
- ▶ category 5: postnatal conditions that result in the baby experiencing 'unbearable suffering' in the course of their illness or treatment, for example, severe necrotising enterocolitis, where palliative care is in the baby's best interests.

Palliative care for the newborn is a developing area. The goals of care may be different for dying newborns, but they deserve the same high standard of care as those babies who go on to survive.⁷



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The Irish Health Service Executive (HSE) published a set of national standards for bereavement care following pregnancy loss and perinatal death in 2016.⁸ These require that each baby/family receives high-quality palliative and end-of-life care that is appropriate to his/her needs and to the wishes of his/her parents.

Particular challenges in perinatal palliative care

The neonatal intensive care unit environment can be challenging for professionals and families due to visiting restrictions, space limitations, staff availability and time restraints.^{9,10} Any decision on place of care must also take into account the health needs of the mother.

Irish legal context

Termination of pregnancy is legal in Ireland only when a pregnant woman's life is at risk.¹¹ Abortion is not legal in Ireland in cases of fatal fetal anomalies. At present there is a campaign to amend the provisions of the Irish Constitution which deal with abortion in such cases. This campaign has drawn particular public attention to the availability and provision of perinatal palliative care in Ireland.

Specialist paediatric palliative care service

A consultant-led paediatric specialist palliative care service (PSPCS) is available at Our Lady's Children's Hospital, Crumlin, Dublin (a tertiary paediatric hospital), also providing a service to the Coombe Women & Infants University Hospital, Dublin (a maternity hospital). The Coombe Women & Infants University Hospital is one of three maternity hospitals in Dublin City, each caring for over 8000 births per year. The PSPCS is composed of a full-time consultant paediatrician with a special interest in paediatric palliative medicine, with two consultant sessions from adult palliative medicine consultants and 1.5 whole-time equivalent clinical nurse specialists. The service accepts referrals from the antenatal period to age 18 years and provides a consult service only. The PSPCS does not take over the care of patients. As the service is the only one of its kind in the country, the team also provides telephone advice on a national basis (the population of Ireland was 4.76 million in 2016) to paediatric teams, adult community palliative care teams and general practitioners (GPs).

Aims

This retrospective study looked at the referral patterns of patients referred to the PSPCS over a 4-year period, their demographics, diagnoses, duration of illness, place of death and symptom profile.

METHODS

Study design

This is a retrospective chart review of all perinatal referrals over a 4-year period to the end of 2015.

Setting

The study was conducted at a tertiary children's hospital and a university maternity hospital in Ireland.

Participants

Participants included all referrals in the antenatal period together with all referrals in the first 6 weeks' postnatal.

Table 1 Perinatal referrals

Diagnosis	n	Percentage
Chromosomal abnormality	29	35
Trisomy 18	17	21
Trisomy 13	10	12
Other chromosomal abnormality	2	2
Congenital heart disease	21	25
Complex neurological abnormalities	9	11
Renal agenesis	3	4
Complications of extreme prematurity	3	4
Neoplastic	2	2
Other	16	19
Total	83	100

Study size

The study was composed of 83 referrals over a 4-year period to the service.

RESULTS

Referrals

Eighty-three perinatal referrals were received in a 4-year period (2012–2015). Of these referrals, 30 (36%) were for telephone advice and support only. The team received 309 paediatric palliative care referrals in total during this period, with perinatal referrals accounting for 83 (26.9%) of these. To put this in context, there were 65 904 births reported for Ireland in 2015, with 488 of these subsequently classified as perinatal deaths.¹² The national perinatal mortality rate for 2015 was 7.0 per 1000 births, and the stillbirth rate was 4.5 per 1000 births.¹²

Of the 83 perinatal referrals, 40 (48%) were female, 36 (43%) male, with the sex unknown in 7 cases (9%). Twenty-two referrals (26.5%) were made antenatally, with 61 (73.5%) in the postnatal period. Specialists in neonatology made 61% of referrals, with 22% coming from cardiologists, 9% from other palliative care professionals, 4% from neurologists, 2% from general paediatricians and 1% from oncologists.

Chromosomal abnormalities accounted for 35% of diagnoses on referral, with 25% of referrals attributable to congenital heart disease, 11% to complex neurological abnormalities and 4% due to renal agenesis. Complications of extreme prematurity (including hypoxic ischaemic encephalopathy and necrotising enterocolitis) also accounted for 4% of referrals. Just 2% related to a cancer diagnosis (table 1).

Antenatal referrals

Twenty-two referrals were made antenatally (table 2). Of these, 10 did not survive to delivery. Seven lived for a number of hours. Three lived for a number of days, with one surviving for weeks. One infant was still alive at the time of data collection. Of the 11 deaths in the postnatal period, 10 occurred in the hospital setting, with 1 death at home.

Postnatal referrals

Of the 61 postnatal referrals (table 3), 26 died in the hours or a short number of days after birth. Twenty-one lived for a number of weeks (less than 8 weeks) or short months (2–6 months), with 14 alive at the time of data collection (up to 4 years after referral). Of the 47 deaths, 22 of these (47%) took place at home with the help of community support. One death took place at a children's hospice.

Table 2 Antenatal referrals

Diagnosis	n	Intrauterine death	Lived hours	Lived days	Lived weeks	Place of death	Alive at data collection
Chromosomal	9	5	3		1		
Trisomy 18	8	5	3			Hospital (3)	
Trisomy 13	1				1	Home (1)	
Congenital heart disease	4	2		2		Hospital (2)	
Renal agenesis	3	1	2			Hospital (2)	
Other significant abnormality	6	2	2	1		Hospital (3)	1
Total	22	10	7	3	1		1

Postnatal referrals: symptoms on assessment

In 44% of postnatal referrals (table 4), patients were asymptomatic on referral and on initial assessment by the palliative care team. Twenty-three per cent were noted to have increased work of breathing, respiratory distress or apnoeic episodes. Pain or irritability was noted in 15% of referrals. Other symptoms included feeding problems, respiratory secretions or seizures.

Postnatal referrals: symptom control

This retrospective referral did not undertake a comprehensive review of the individual clinical assessments on each patient. Data were however collected on the symptom control medications prescribed regularly, or recommended on an 'as required' basis for each patient. Data were also collected on individual dose titrations. In many cases medications were recommended to be prescribed as required, in anticipation of potential symptoms, but were never administered.

Postnatal referrals: medications

Opioids and benzodiazepines were the medications most frequently recommended (in 75% and 72% of cases), with an anticholinergic recommended in 16% of patients. A non-steroidal anti-inflammatory was recommended for one patient only. This patient had a diagnosis of osteogenesis imperfecta with known fractures. Of the 46 patients for whom an opioid medication was recommended, no dose increase or titration was required in 43 cases. Of the three neonates who required dose increase, this increase was for musculoskeletal pain in each case. One had postoperative pain (cardiac surgery) and two had known fractures.

Discharge home for supportive care

Of the 61 neonatal referrals, 24 (39%) died in the acute hospital setting, while 22 (36%) died at home. Fourteen (23%) were alive at the time of data collection, and either discharged from

the community palliative care services or continuing to receive support at home. Discharge home for best supportive care required complex interagency communication and cooperation, involving six to nine separate care providers. These are listed in box 1. In Ireland, community palliative care services are provided by an adult specialist palliative care team who, with the patient's GP, coordinate the provision of services by these care providers. In the case of perinatal and paediatric patients, support from the PSPCS, based in the acute hospital, is available if necessary.

DISCUSSION

Palliative care in neonatology may involve a death in the intensive care unit or at home. The aims should be to ensure that there is a coordinated approach to family-centred care throughout the baby's short life, with clear and open communication and support to enable the family to build up and maintain access to an appropriate network of support, regardless of where they are cared for. A key finding of the 2005 report entitled 'A Palliative Care Needs Assessment for Children' by the Irish Hospice Foundation and the Irish Department of Health was that the preferred location of caring for a child with a life-limiting condition is the family home with the parents receiving adequate professional support.¹³

The number of perinatal deaths for Ireland in 2015 alone (488) suggests that the number of perinatal palliative care referrals over this 4-year period is low given that PSCS accepts referrals and gives telephone advice nationally, as well as the consult service it provides to the two Dublin hospitals it serves. It is expected that referral numbers should be higher based on the diagnoses and causes of perinatal death outlined in the 2015 National Perinatal Epidemiological Centre Annual Report.¹² Potential barriers to referral include a lack of understanding or knowledge of the role of perinatal palliative care, as well as the lack of a local and accessible service in most parts of the country.

Table 3 Postnatal referrals

Diagnosis	n	Lived hours (/days)	Lived (weeks)	Lived (months)	Alive	Died in hospital	Died at home	Died in hospice
Chromosomal abnormality	20	8	4	4	4	7	9	
Trisomy 18	9	2	4	1	2	3	4	
Trisomy 13	9	5		3	1	3	5	
Other	2	1			1	1		
Congenital heart disease	17	13	3	1		9	8	
Complex neurological	9	2	1	1	5	2	2	
Extreme prematurity	3	1	1		1	1	1	
Neoplastic	2	1		1		2		
Other	10	1	2	3	4	3	2	1
Total	61	26	11	10	14	24	22	1

Table 4 Postnatal referrals (n=61), symptoms on referral

Symptoms on referral	n	Percentage
None (including discharge planning or planning for compassionate extubation)	27	44
Respiratory distress/apnoea	14	23
Pain/irritability	9	15
Feeding difficulties	5	8
Secretions	4	6.5
Seizures	4	6.5

Discharge home for end-of-life care required complex multi-service care planning and communication. Despite this 47% of deaths in this study (from postnatal referrals) were facilitated in the home environment. This compares very favourably with international figures.

In 2013, Craig and Mancini⁵ concluded that choices of place of death are usually possible, although there may be practical or resource restraints that affect which choices are available or can be achieved. It is likely (they concluded) that the high proportion of hospital deaths currently reported reflects not that choice is unavailable, but that choice is not offered.

Parents are often concerned that symptom control may be difficult to attain. Speaking at the Children's Palliative Care Interdisciplinary Conference in Dublin on 22 April 2016 (as the parent of a baby born with the chromosomal abnormality tetrasomy 9p), Ms Tina Priestley described the greatest worry that parents in her situation have. She described the life and death of her 13-month-old son Bobby, and identified effective symptom control as being essential. This review did not look in detail at records of symptom assessment. This review of medication dose and titration however suggests that physical symptoms were well controlled with low doses of medications and without the need for dose titration in all but three cases.

Box 1 Care providers providing supportive care in the community in Ireland

- ▶ General practitioner (family doctor)
- ▶ Public health nurse
- ▶ Local paediatrician/paediatric department
- ▶ Local community palliative care team (adult)
- ▶ Children's outreach nurse for children with life-limiting conditions
- ▶ Jack and Jill Children's Foundation (nursing support and respite)
- ▶ Paediatric palliative care team (hospital-based, available for advice)
- ▶ Irish Cancer Society (provision of night nursing for terminal care)
- ▶ LauraLynn Children's Hospice (palliative care support/inpatient care)

Drawing on their experience in this field, and the results of this study, the authors suggest changes in provision of perinatal palliative care in Ireland. An increase in paediatric palliative care staffing levels is required to provide a safe, accessible and effective service nationally. A database for collecting baseline data on children with life-limiting conditions should be established and there should be enhanced education and training of all staff working with children with life-limiting conditions. Integrated care pathways for neonatal palliative care need to be developed, with enhanced discharge planning as an element. These suggestions are in line with the current Irish HSE National Clinical Programme for Paediatrics and Neonatology draft Model of Care for Paediatric Healthcare in Ireland.

Contributors All authors contributed equally to this paper.

Competing interests None declared.

Ethics approval Approval to undertake this retrospective review was obtained from the Chair of the Ethics Committee of Our Lady's Children's Hospital Crumlin, Dublin, Ireland.

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Data sharing statement There are no additional unpublished data from this study. The data can be accessed from the first named author on request.

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