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Clinical heterogeneity of adolescents referred to paediatric palliative care; a quantitative observational study

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Abstract

Objectives: Adolescents with life-limiting conditions are distinct from children or older adults in their palliative needs and developmental stage, yet, there is limited literature addressing this population. Our aim was to describe the characteristics of the adolescent population, aged 13–18, who have received specialist palliative care in the Republic of Ireland, from 2019 to 2022 inclusive.

Methods: This study examined medical records from the national paediatric palliative care centre and a radiation oncology network. These two centres hold medical records for all adolescents linked to paediatric specialist palliative care nationally.

Results: Of the 145 patients identified 58 (40.0 %) had cancer and 87 (60.0 %) a non-cancer diagnosis. Those with a non-cancer diagnosis were subdivided into those with severe neurological impairment (n=56, 38.6 %) and those without (n=31, 21.4 %). All groups had a high prevalence of physical symptoms. Just under half of those with cancer had psychological symptoms (n=26, 44.8 %). The majority of those with severe neurological impairment required medical devices/technology in the home, with 48 (85.7 %) requiring feeding devices and 33 (58.9 %) requiring respiratory support devices. Nearly a half of the adolescents had died at the time of the study (n=69, 47.6 %). Of these, the majority (n=44, 63.8 %) died at home and 9 (13.0 %) were referred less than one month before their death.

Conclusions: The high symptom burden of these young people highlights the need for early access to palliative care professionals with an appropriate skillset and access to quality, equitable psychological supports for this group.

Keywords: (MeSH) "palliative care"; adolescent health; observational study; quantitative evaluation

Introduction

Palliative care is an approach that aims to improve the quality of life of patients who are facing challenges associated with a life-limiting condition, as well as to support their families and caregivers [1]. Palliative care is offered to patients with a wide range of medical conditions, often with complex multimorbidity, across all age ranges. The importance and benefits of palliative care when introduced in the early stages of a potentially life-limiting condition are described in the literature [2–4]. Early introduction of such care has been shown to improve quality of life, symptom burden and healthcare service use [3, 5, 6]. Specialist palliative care services are those in which core activity is limited to the provision of palliative care. As these services are involved in the care of patients with more complex and demanding care needs they require a greater degree of training, staff and other resources [7].

The term "adolescence" is used to describe a critical period of development for which unmet health needs and disparities in access to appropriate healthcare are becoming increasingly recognised [8, 9]. There is variability in the terms and age criteria used for this group between organisations internationally. The World Health Organization defines "adolescents" as persons aged between 10 and 19 years, "youth" as between 15 and 24 years, and combines this into "young people" aged 10–24 years of age [10]. Sawyer et al. [11] proposes that the term "adolescence" should encompass the broader age definition of 10–24 years. Research on this group is challenging, not only due to the varying age definitions but

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also due to the current configuration of healthcare structures which divides the group into those accessing paediatric and adult healthcare services. Despite the need to explore the palliative care needs of broader age definition of "adolescents and young adults" (13–24 years in keeping with current practice of the adolescent and young adult cancer services in the Republic of Ireland [12]), this paper only focuses on those aged 13–18 who are still under specialist paediatric palliative care and the term(s) "adolescent/adolescence" will be used.

Adolescence is a period characterised by intense biological, psychological and social change, which impacts on behaviour, communication style and decision making [13]. A diagnosis of a life-limiting condition adds complexity to this already challenging period of growth and development. Medical advances are impacting on the prognosis of children with life-limiting conditions, with many now surviving into adulthood. This is partly due the use of medical devices that support organ function in life-limiting conditions. Some adolescents with a life-limiting conditions will require access to specialist palliative care services and require a service that encompasses particular skills, training and infrastructure to best serve their needs [14]. Further research is required to ascertain the palliative needs of this group and to identify the gaps in current knowledge and skills so as to best facilitate development of knowledge and services in the area. Literature to date suggests a need for an adapted approach to communication and decision making [15–17], a need to support normalcy [15, 18–20] and a need for consistency and continuity in the provision of healthcare [15, 16, 21] for adolescents with life-limiting conditions (both cancer and non-cancer conditions).

Much of the existing literature on palliative care for adolescents is focused on those with a cancer diagnosis [13]. Adolescents with non-cancer life-limiting condition have both overlapping and different requirements from a specialist palliative care service. They represent a group with complex, multidisciplinary needs and include those with congenital cardiac conditions, neuromuscular conditions and those who have severe neurological impairment. Severe neurological impairment describes "disorders of the central nervous system which arise in childhood, resulting in motor impairment, cognitive impairment and medical complexity, where much assistance is required with activities of daily living" and for which "the impairment is permanent but can be progressive or static" [22]. These adolescents are susceptible to pain and discomfort, gastrointestinal symptoms, respiratory symptoms, impaired sleep and neurological symptoms such as dystonia and autonomic dysfunction [23]. Physicians can find it challenging to identify pain and other symptoms in those who are non-verbal with severe neurological impairment [23].

Aims

Our aim was to describe the characteristics of the adolescent population, aged 13–18, who have received specialist palliative care in the Republic of Ireland, from 2019 to 2022 inclusive.

Methodology

Design

This retrospective, quantitative, observational study collected data from the paper and electronic records of patients known to specialist palliative care services in Children's Health Ireland and St Luke's Radiation Oncology Network from February to May 2023. These two centres encompass adolescents attending paediatric specialist palliative care nationally. Patients were included if they were aged 13–18 years and were reviewed by the specialist palliative care team between the years 2019 and 2022 inclusive. Data collected included demographic data, data on the diagnosis, age at diagnosis, gender, documented physical symptoms and psychological symptoms, outcome, duration of specialist palliative care involvement and medical technology/devices required by the adolescent at home to support care/organ function. Inconsistencies and incomplete entries into the medical record may have had an impact on the completeness of the data that were extracted.

Data collection

Data were managed in line with European legislation on data protection. The first twenty patient records were reviewed and utilised to form the initial categories for the data collection. Each symptom was recorded, with the results analysed and categorised into symptom groups (physical, psychological) and further subcategorised into organ systems as appropriate. The data from the rest of the records were collected and the results were analysed to condense/expand categories as required. In some cases, this necessitated extra categories to be added or for categories to be adjusted to ensure all data were accurately categorised. Regular meetings with the research team during the study aimed to reduce the risk of data collection and analysis bias by discussing methods, analysis and results. Ethical approval was granted by the research ethics committees in Children's Health Ireland (REC-252-23, 23/2/23) and St Luke's Radiation Oncology Network (28/2/23).

Analysis

Excel Version 16.74 was used for data management and data analysis. Once data from the two centres were collected, the data were merged for analysis. Adolescents who attended both centres were identified to avoid duplication of patients and data were collected from both sets of records to ensure comprehensive capture of data. The cases were divided into those with a cancer diagnosis and those with a non-cancer diagnosis. The adolescents with a non-cancer diagnosis were further sub-categorised into those whose condition caused severe neurological impairment and those that did not. Descriptive statistics were utilised to summarise and categorise the dataset. Where data were incomplete (n=3) cases were excluded from the relevant analysis. Due to the small sample size and rarity of some of the diagnoses, any diagnoses that could not be categorised into a number greater than 5 were described as “other” to protect anonymity.

Results

Primary diagnosis/condition causing a life-limiting condition

There were 145 adolescents in this study and of these 58 (40 %) had a primary life-limiting condition of a cancer diagnosis and 87 (60 %) a non-cancer diagnosis (Table 1).

Clinical characteristics of adolescents with a cancer diagnosis

Amongst adolescents with cancer (n=58, 40 %) there was a high prevalence of physical symptoms, with pain documented in 49 (84.5 %), gastroenterological symptoms in 43 (74.1 %), and fatigue/somnolence in 27 (46.5 %). Psychological symptoms were present in nearly a half of cases (n=26, 44.8 %). Data on the outcomes of these young people are displayed in Table 3. Most of the young people had died at the time of this study (n=38, 65.5 %). The majority of those that died, did so at home with support from community services (n=27, 71.0 %), with 9 (23.7 %) dying in the hospital setting and the remainder in an adult-focused hospice (n=2, 5.3 %). Nearly a third of those who died (n=12, 31.6 %) were referred to specialist palliative care services less than three months before they died, with 3 (7.9 %) referred less than two weeks before their death.

Table 1: Demographic data and diagnoses.

	All	Female	Male
Demographic data and diagnoses, n (%)			
All cases	145 (100 %)	65 (44.8 %)	80 (55.2 %)
Age at referral to specialist palliative care services			
</=13 years	41 (28.3 %)	20 (48.8 %)	21 (51.2 %)
>13 years	104 (71.7 %)	43 (41.3 %)	61 (58.7 %)
Primary diagnosis/condition causing life-limiting condition, n (%)			
Cancer	58 (40 %)	26 (44.8 %)	32 (55.2 %)
Solid tumour	53 (36.5 %)		
– Sarcoma	19 (13.1 %)		
– Glioma	19 (13.1 %)		
Haematological cancer	5 (3.4 %)		
Non-cancer	87 (60 %)	39 (44.8 %)	48 (55.2 %)
Non cancer with condition causing severe neurological impairment	56 (38.6 %)	25 (44.6 %)	31 (55.4 %)
– Cerebral palsy:	28 (19.3 %)		
– Single gene causes of severe neurological impairment:	10 (6.9 %)		
– Other:	18 (12.4 %)		
Other non-cancer	31 (21.4 %)	14 (45.2 %)	17 (54.8 %)
– Cardiology condition:	10 (6.9 %)		
– Neuromuscular condition:	9 (6.2 %)		
– Other:	12 (8.3 %)		

Clinical characteristics of adolescents with a non-cancer condition leading to severe neurological impairment

Of the total 145 adolescents included in this study, 80 (60.0 %) had a non-cancer condition, and of them, 56 (70.0 %) had a non-cancer condition leading to severe neurological impairment. For those with a non-cancer condition leading to severe neurological impairment, pain was documented in 35 (62.5 %) and the presence of irritability/agitation in 16 (28.6 %). The other two most prominent physical symptoms were neurological (n=46, 82.1 %) and gastrointestinal symptoms (n=43, 76.8 %). The most common comorbid conditions were seizure disorders (n=41, 73.2 %) and respiratory conditions (n=39, 69.6 %) as outlined in Table 2. Medical device/technology use in the home was particularly high for this group (Table 2). A large proportion of these adolescents (n=26, 46.4 %) had greater than four medical specialties involved in their care. Outcomes for this group are outlined in Table 3. Over a third had died at the time of this study (n=21, 37.5 %). The majority of those who died, did so at home (n=13, 61.9 %), 6 (28.6 %) died in the hospital setting and 1 (4.8 %) in a paediatric-focused hospice. The location of death for one was not documented. The adolescents who died within three months of their referral to specialist palliative care services (n=3, 14.3 %) were entirely made up of adolescents who were referred less than two weeks before their death.

Clinical characteristics of adolescents with other non-cancer conditions

Those cases without cancer or severe neurological impairment made up the final proportion of patients (n=31, 21.4 %). The two most common conditions in this group were congenital cardiac conditions and neuromuscular conditions. Pain (n=20, 64.5 %), gastrointestinal symptoms (n=20, 64.5 %) and respiratory symptoms (n=16, 51.6 %) were the most prevalent physical symptoms and over a third had psychological symptoms (n=11, 35.5 %). In this group, 13 (41.9 %) had greater that four medical specialties involved in their care. An equal number of these adolescents died at home (n=4, 40.0 %) and in the hospital setting (n=4, 40.0 %). One (10 %) died in a paeditric focused hospice and the location of death for one was not documented. One (10.0 %) was referred to specialist palliative services less than three months before their death.

Discussion

This study has shown the clinical heterogeneity of adolescents being referred to paediatric specialist palliative care services. The physical symptom burden was high amongst adolescents with both cancer and non-cancer conditions. Just under half of those with a cancer diagnosis had psychological symptoms documented. Over a third of adolescents in this study who had a non-cancer condition, without associated severe neurological impairment, had documented psychological symptoms. The documented psychological symptom burden was low in the adolescents with severe neurological impairment. This may be due to the

Table 2: Comorbidities, symptoms, medical device use and medical specialty involvement in adolescents with life limiting conditions known to specialist palliative care.

	Cancer diagnosis 58 (100 %)	**Non-cancer diagnosis with severe neurological impairment 56 (100 %)**	**Non cancer diagnosis without severe neurological impairment 31 (100 %)**
Comorbidities, n (%)			
Cognitive developmental delay:	5 (8.6 %)	56 (100 %)	9 (29.0 %)
Respiratory conditions: (recurrent lower respiratory tract infections/ chronic respiratory failure/obstructive sleep apnoea)	n<5	39 (69.6 %)	20 (64.5 %)
Sensory impairments (visual/hearing):	12 (20.7 %)	20 (35.7 %)	4 (12.9 %)
Seizure disorder:	15 (25.9 %)	41 (73.2 %)	2 (6.4 %)
Scoliosis:	n<5	28 (50.0 %)	12 (38.7 %)
Others			
– Autism spectrum disorder:	6 (10.3 %)	n<5	n<5
– Pubertal abnormalities: (delayed/ precocious):	7 (12.1 %)	n<5	n<5
– Other endocrinological conditions:	n<5	9 (16.1 %)	6 (19.3 %)
Symptoms, n (%)			
Pain:	49 (84.5 %)	35 (62.5 %)	20 (64.5 %)
Gastroenterological symptoms:	43 (74.1 %)	43 (76.8 %)	20 (64.5 %)
Neurological symptoms (seizures, dystonia, distressing altered sensation including itch, confusion):	20 (34.5 %)	46 (82.1 %)	5 (16.1 %)
Respiratory symptoms:	10 (17.2 %)	32 (57.1 %)	16 (51.6 %)
Fatigue/somnolence:	27 (46.5 %)	13 (23.2 %)	13 (41.9 %)
Poor/disturbed sleep:	13 (23.2 %)	13 (23.2 %)	n<5
Psychological symptoms:	26 (44.8 %)	n<5	11 (35.5 %)
Irritability/agitation:	6 (10.3 %)	16 (28.6 %)	n<5
Medical devices/technology at home, n (%)			
Mobility aids:	14 (24.1 %)	51 (91.1 %)	18 (58.1 %)
Enteral feeding devices:	n<5	48 (85.7 %)	11 (35.5 %)
Respiratory support devices:	7 (12.1 %)	33 (58.9 %)	19 (61.3 %)

Table 3: Outcome and mortality data.

	Cancer diagnosis 58 (100 %)	Non-cancer diagnosis with severe neurological impairment 56 (100 %)	Non cancer diagnosis without severe neurological impairment 31 (100 %)
Outcomes, n (%)			
Died:	38 (65.5 %)	21 (37.5 %)	10 (32.3 %)
Input is ongoing in paediatric services:	15 (25.8 %)	25 (44.6 %)	12 (38.7 %)
Care transferred to adult heatlhcare services:	n<5	6 (10.7 %)	8 (25.8 %)
Discharged from specialist palliative care service:	n<5	n<5	n<5

challenges in assessment of symptoms in non-verbal adolescents with severe neurological impairment, in particular, differentiating physical and psychological distress. Adolescents share core palliative care need domains with people of all ages, including physical, emotional, psychosocial and spiritual support [15–17, 20, 24]. Meeting spiritual needs is a core pillar of palliative care provision, however, there is often a lack of agreement on the conceptualisation of spirituality [25–27]. This can make it difficult to research and in clinical practice often results in a non-systematic and intuitive approach to patients' spiritual needs [25–27]. Spiritual concerns were not routinely documented in the clinical notes and therefore this data on this were not collected. This is a point for reflection on clinical practice and an area for future research. Symptom burden is a modifiable determinant of health related quality of life [28, 29] and standardization of palliative care assessments and interventions has the potential to improve quality of life [30, 31]. In an adult population, the palliative care needs, levels of anxiety and depression, and health related quality of life of patients with non-cancer conditions has been shown to be similar to those of patients with cancer [32]. The high proportion of those with non-cancer life-limiting conditions in this study, alongside the relatively sparse literature on this group, indicates a need for further research which characterises this group and explores their palliative care needs.

Good communication with the patient, family and health professionals remains crucial to good quality patient care [33]. Healthcare professionals need to be equipped with the communication skills to deliver person-centred care for adolescents with a life-limiting condition. Over a third of the adolescents in this study had severe neurological impairment. Members of this group may be non-verbal and require an adapted approach to communication, alongside a strategy to promote their involvement in care and decision making. Often the adolescent's parent/caregiver can assist in the decision making process but it is key to remember to involve the adolescents much as is possible, with the level of participation being tailored to their condition, preference and circumstance. A large number of medical specialties can be involved in the care of these adolescents. This necessitates streamlined communication and information transfer between professionals to enhance optimal care.

Some referrals to specialist palliative care for these adolescents occurred very close to their deaths, sometimes in their final weeks of life. In this study, 13 % (n=9) of those that died were referred less than 1 month before their death. Other studies have found that referral of adolescents to specialist palliative care services in the last month of life varied from 7 % [34] to 17 % [35].Whilst these results may seem favourable in their timeliness, when compared to studies of an older adult cohort [36], the adolescent and young adult group have been identified as a group that are vulnerable to psychosocial complexities, particularly in the context of a potentially life-limiting condition [37]. In practice, there is a need for a period to build a rapport with their healthcare providers, to nurture trusting relationships and open communication with healthcare providers [38]. Further research is required to explore how early referral to specialist palliative care may be supported and achieved for adolescents and young adults and their families, with an identified need.

A 2020 study by Fraser et al. which assessed trends in place of death for children with a life-limiting condition in England, demonstrated that only 27 % of young people between 16 and 20 years old died at home [39]. By comparison, the majority of the adolescents in our study died in the home setting. This may be due to the differences in the models of provision of palliative care and funding of healthcare systems [39]. A national study from England and Wales demonstrated that palliative care input was associated with more children and adolescents (under 16) dying outside of the hospital setting [40]. In the Republic of Ireland, planned end of life care for adolescents who wish to die at home, takes place with collaborative care between the general practitioner, public health nursing, community allied health professionals and community specialist palliative care services. This approach is reflective of the anticipated complexities (physical, psychosocial, spiritual/existential) that may arise at the end of life for this age group. For this reason (with only very rare exceptions), adolescents die with community specialist palliative care support in the home setting in the Republic of Ireland. The high proportion of adolescents who die in at home as opposed to other care settings, necessitates planning and appropriate resource allocation.

The use of medical devices/technology in the home (which is particularly high in those with severe neurological impairment) impacts on caring for these adolescents in the community. Advances in medical technologies and medical interventions such as artificial nutrition and respiratory support can impact on prognosis [41]. The use of these secondary supports has changed the norms of death and can pose ethical challenges when deciding about commencing or discontinuing such supports [42, 43]. Consideration needs to be given to the education and training of healthcare professionals in the use of these technologies in inpatient and community settings.

The effectiveness of provision of specialist palliative care to this population may be demonstrated through outcome measurement. It is hoped that the findings will facilitate a better understanding of the conditions and needs of this group and will inform service development and healthcare professional training in this area. The Palliative Care Outcomes Collaboration (PCOC) is an example of an initiative which aims to record and improve palliative outcomes in an adult population [44]. A better understanding of the characteristics and needs of this group may contribute to development and use of a multidimensional outcomes measures based on the particular palliative needs of adolescents with life limiting conditions [45].

Strengths and limitations

Strengths

This is the first study of this nature examining the adolescent population, referred to a national paediatric specialist palliative care service. It is comprehensive in its capturing of adolescents aged 13–18 years referred to paediatric specialist palliative care in the Republic of Ireland.

Limitations

For a retrospective review, the validity of the results depends on accurate medical records. Inconsistencies and incomplete entry into the medical record can affect the data that are extracted [46]. This paper only focused on adolescents referred to specialist palliative care and does not capture those with palliative care needs that could be managed by their primary medical teams nor those who may have required referral to specialist palliative care and were not referred. The barriers to referral to specialist palliative care were not explored (including individual, interpersonal, organisational, community and societal level barriers [47]). The recording of symptoms was not based on a standardised assessment but rather reflect the questions favoured by the physician carrying out the assessment on a given day. This paper examined the symptoms that were documented by the clinician and it is not known whether this was based on symptoms reported by the young person, family or ward staff. There is a risk of bias due to the fact that recorded symptoms are based on the assessment and documentation style of the individual clinician. Whist the number is estimated to be small, in the Republic of Ireland, young people who are aged 16 and above who are not already known to paediatric services, may be referred directly to adult services and will not have been captured in this study. In non-verbal young people with severe neurological impairment, pain and discomfort can manifest as irritability and/or distress [23]. The prevalence of pain may be underrepresented in cases where documented irritability/distress may have represented a pain behaviour. For this reason, the prevalence of pain in this group may be underrepresented. Accessing records from the psychology and medical social work services, may have enhanced the data on psychological needs, however, this was beyond the scope of this study.

Conclusions

To develop specialist palliative care services that cater to the needs of adolescents with life-limiting conditions, it is important to characterise the clinical characteristics and explore the palliative needs of this group. To date, our knowledge of this area has been limited, particularly for young people with non-cancer life-limiting conditions. This study demonstrates a high burden of physical and psychological symptoms in the adolescents in this study across both cancer and non-cancer groups. Some referrals to specialist palliative care for these adolescents occurred very close to their deaths which prompts reflection on how earlier referral to specialist palliative care services may facilitated. There is a need for professionals with an age and developmentally appropriate skill set, in order to provide services that understand and meet the needs of this group and can deliver coordinated services during this period of life, defined by multidomain transitions. Overall, this paper signals an opportunity to improve symptom management and quality of life for these adolescents and their families.

Implications for policy, services and future research

This work forms a platform for further work on community, hospital and hospice service gaps for this population. Further research is required to understand the unmet needs of those who could potentially benefit from specialist palliative care but who are not known to services.

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