Association for
Paediatric
Palliative
Medicine

Online Catalogue of Posters presented at the APPM Conference 16-17 November 2023 – Part 2

There are 33 posters in all. If you wish to contact the author, please email admin@appm.org.uk and you will be put in touch.

16

Can mediation avoid litigation in conflicts about medical treatment for children: an analysis of previous litigation in England & Wales

Dr Veronica Neefjes
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Can mediation avoid litigation in conflicts about medical treatment for children?

An analysis of previous litigation in England & Wales

Veronica Neefjes

Background

In the treatment of seriously ill children many medical treatment decisions must be made. Some of these decisions may lead to conflicts between parents and clinicians and some of these conflicts will lead to a court application. A disadvantage of court procedures is that they can be lengthy and expensive.

As a way to avoid court applications conflict resolution methods such as mediation have been proposed, either on a voluntary basis or compulsory.

However, evidence that mediation will prevent court applications is lacking.

Objectives

To investigate previous litigation for:

1. the reasons why parents disagree with clinicians

2. to estimate the number of cases which the use of mediation might have helped avoid.

Methods

Textual analysis of previous litigation in the courts of England & Wales that fulfilled the eligibility criteria.

Eligibility criteria:

1. Case heard between 1st January 1990 and 1st July 2022.

2. Initiated either by a NHS Trust or Local Authority

3. Topic of litigation is the medical treatment of an incompetent child

4. Court decided using the best interests standard

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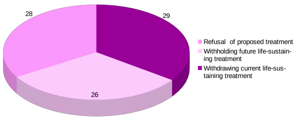
Results

Cases

83 cases were included. Cases were almost equally divided between parental refusal of proposed medical treatment and withholding/withdrawing life-sustaining treatment.



In 13 cases there was no underlying conflict. These cases reach the court because there is no person authorised to make this particular decision or the NHS Trust requested a declaration of lawfulness as the treatment proposal was deemed controversial.

Why parents disagree

1) Faith is a frequent reason for disagreement.

2) In cases in which withdrawal/withholding life-sustaining treatment is litigated parents of all major religions use a 'sanctity of life' argument. Non-religious parents use a secular 'sanctity of life' argument.

3) Important other areas of disagreement are factual issues, i.e. the child's health status or quality of life and the relationship with the clinical team, i.e. loss of trust.

4) Rarely, parents disagree based on non-acceptance of the diagnosis or views of society as a whole.

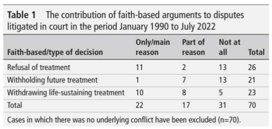


Table 1 The contribution of faith-based arguments to disputes litigated in court in the period January 1990 to July 2022

Faith-based/type of decision	Only/main reason	Part of reason	Not at all	Total
Refusal of treatment	11	2	13	26
Withholding future treatment	1	7	13	21
Withdrawing life-sustaining treatment	10	8	5	23
Total	22	17	31	70

Cases in which there was no underlying conflict have been excluded (n=70).

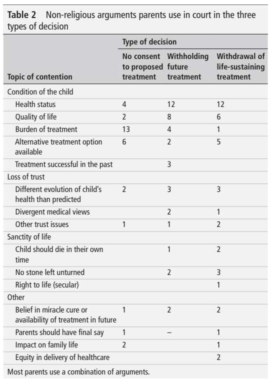


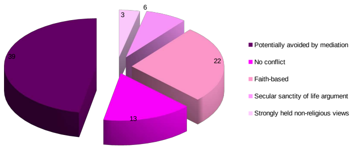
Table 2 Non-religious arguments parents use in court in the three types of decision

	Type of decision		
Topic of contention	No consent to proposed treatment	Withholding future treatment	Withdrawal of life-sustaining treatment
Condition of the child			
Health status	4	12	12
Quality of life	2	8	6
Burden of treatment	13	4	1
Alternative treatment option available	6	2	5
Treatment successful in the past		3	
Loss of trust			
Different evolution of child's health than predicted	2	3	3
Divergent medical views		2	1
Other trust issues	1	1	2
Sanctity of life			
Child should die in their own time		1	2
No stone left unturned		2	3
Right to life (secular)			1
Other			
Belief in miracle cure or availability of treatment in future	1	2	2
Parents should have final say	1	–	1
Impact on family life	2		1
Equity in delivery of healthcare			2

Most parents use a combination of arguments.

Would mediation avoid court applications?

Whether mediation can be successful depends on whether the parental position is negotiable.



Faith-based arguments and/or secular sanctity of life arguments and strongly held views incompatible with the diagnosis or decision making by authority figures were deemed non-negotiable. Mediation could have avoided a court application in 39/83 cases. This is likely to be an overestimation as most parents use several arguments and all must be resolved for mediation to succeed.

Key messages

1) The potential for mediation to avoid future litigation seems somewhat limited.

2) The data does not support compulsory mediation prior to a court application.

Full publication

Neefjes V. Can mediation avoid litigation in conflicts about medical treatment for children? An analysis of previous litigation in England and Wales. *Archives of Disease in Childhood* 2023;108:715-718 doi:10.1136/archdischild-2022-325033

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17

Caring for seriously ill children in paediatric hospices; are we keeping the children safe?

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University of Manchester

Caring for seriously ill children in children’s hospices

Are we keeping the children safe?

Veronica Neefjes

Background

Children with life-limiting conditions are living longer and have increasingly complex medical needs. Care in children’s hospices in England & Wales are based on a variety of models and differ greatly with regards to in house medical oversight.
In contrast to other paediatric specialist services, for example oncology and neonatology, palliative medicine does not have agreed levels of care relative to specialist knowledge available in the location of care. In addition, patient safety in children’s hospices is an under-researched area; a recent search in Pubmed found only 1 article on the subject.

Objective
To gain insight in concerns about patient safety in children’s hospices by:

1. comparing the number of expressed concerns to the Care Quality Commission (CQC) about children’s hospices relative to those in children’s hospitals in England.
2. quantifying the number of safeguarding concerns to responsible councils
3. evaluate the sector’s transparency by assessing their websites for an account of received complaints or concerns.

Methods

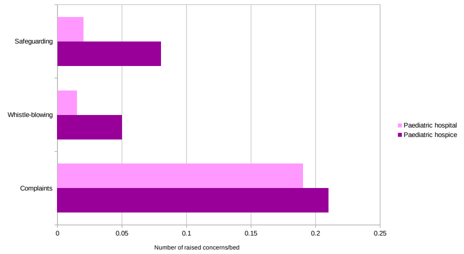
1. Freedom of Information requests about the number of concerns made to the CQC between 01-02-2018 and 01-02-2023 about English children’s hospices and hospitals.

2. Freedom of Information request to local councils about the number of concerns received about the children’s hospice in their area in the same time period.

3. Assessment of the children’s hospice’s websites for any account of received concerns about patient care in any year. Websites were searched with the terms: complaint, safeguarding and whistle-blowing. If no relevant documents were found an additional search for the most recent relevant reports, e.g. annual or quality account was performed and these documents were searched with the above search terms.

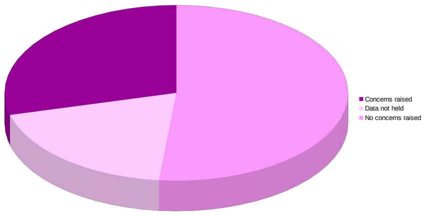
Results

Concerns raised with the CQC
In the 5 year period a total of 111 concerns were raised with the CQC about hospices caring for children averaging 2.5 per hospice. 67 complaints, 17 whistle-blowing events and 27 concerns about safeguarding were raised. All types of concerns were raised more frequently about children’s hospices compared to children’s hospitals when corrected for beds available as measure for activity.



Concerns raised with local councils
As safeguarding is primarily the responsibility of the local councils, 44 councils responsible for 45 hospices caring for children were asked about concerns raised in the same time period.

Of 31 councils that provided an answer 16 had received no concerns, 6 did not hold the requested data and 9 (30%) reported having received at least 1 concern, most often but not exclusively about safeguarding.



Transparency
In contrast to NHS Trusts, children’s hospices are charities and thus do not have a statutory duty to report raised concerns about their care to the public.
Of the 33 organisations running 45 hospices 17 did provide information about received concerns. However, the provided information was mostly limited to number of concerns received per year or number of upheld complaints per year. Only 1 organisation also provided which lessons were learned.

Definitions:
Whistle-blowing:
A concern about patient safety raised by a staff member.
Safeguarding concern:
A concern raised by anyone about abuse or neglect
Complaint: all other concerns raised about the care of a child

Key message

Based on the preliminary data patient safety and the quality of patient care in children’s hospices deserves more attention and should be a topic of research.

Discussion

The period here investigated includes the Covid pandemic in which hospices reduced their activity. The number of concerns raised may be less than in any other 5-year period.

Different factors and/or a combination thereof may explain the data.

First, the quality of patient care such as symptom control may be less than optimal certainly in light of the relatively high number of whistle-blowing concerns in hospices compared to those in children’s hospitals.

Second, the number of concerns raised with outside agencies may be the result in a lack of trust in the investigational procedures within the hospices. The lack of transparency about concerns raised may be a contributing factor in such a perception.

Whilst further research is required to clarify the contribution of each factor to the number of raised concerns, in order to maintain the high level of trust in the care delivered by children’s hospices, possible solutions could be:

1. Sector-wide agreed levels of care relative to the skills and knowledge of the staff.

2. Sector-wide agreement about what constitutes a reportable complaint and minimum requirements of reporting.

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War metaphors and medical treatment decision making in parental blogs about children with life-limiting diseases

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Who’s afraid of the war metaphor?

War metaphors and decision making in parental blogs about children with life-limiting diseases

Veronica Neefjes

Background

Metaphors aid understanding because it allows us to think of complex issues in terms of more simple and concrete information.

War metaphors are widely used in medicine.

Many authors[1,2] warn against the use of war metaphors because they fear that their use might lead to:

1) blaming the patient when they ‘lose the fight’

2) parents/patients insisting on continuing treatment when benefit is unlikely

Research questions:
1. which metaphors do parents of children with life-limiting conditions use?
2. does the use of war metaphors in this group of patients have the predicted negative effects?

Methods

Parental illness blogs are on line narratives written by parents about their ill child.

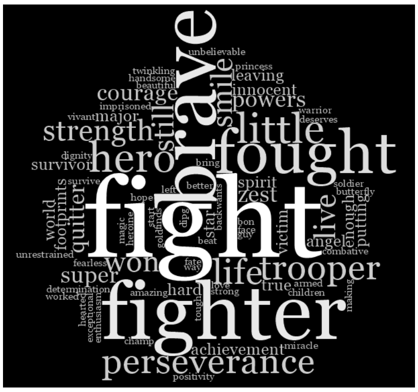
Publicly available blogs written by Dutch, German and English parents about children with a life-limiting illness were identified by a Google search.

15 blogs were analysed using Interpretative Phenomenological Analysis.

Results

The children suffered from incurable cancer (n=5), neuro-muscular (n=4) and neuro-degenerative (n=4) diseases, acquired brain injury (n=1) and 1 child remained undiagnosed. Blogs were maintained between 9 months and 5 years. Ten blogs were discontinued at the time of analysis, 7 because the child had died.

All parents use almost always war metaphors to describe their child as demonstrated in the word cloud.



Their child’s disease is also described in war metaphors, e.g. in terms of ‘monster’, ‘assassin’, ‘sniper’,

By using war metaphors parents place their child in an active role and identify the disease as a ‘thing’ to be fought on a daily basis.

Parents are proud of their child being a ‘fighter’ both before and after death. After death the child is understood as having ‘fought enough’ rather than as ‘having lost the fight’.

The familial situation is described in terms of three metaphors:
1. parents describe their ***vulnerability*** e.g. ‘walking on a cliff that can give way at any time’, ‘living under Damocles’ sword’
2. parents describe their life as a ***fight***
3. parents describe the ***time left available*** as a space that expands and constricts depending on the child’s health status and powerfully directs decision making. Especially when parents feel time is short their child’s comfort and filling the available time with good things becomes most important.

In 167 analysed medical treatment decisions parents balanced ‘fighting for their child’ against their child’s comfort and aimed for their child to live a ‘good life’.

- Throughout the child’s life parents either did not consent to or discontinued medical treatment that did not contribute to the child’s comfort.
- At the end of life parents agreed to limitations of life-sustaining treatment when they felt the treatment would cause their child suffering.

Conclusions

In this collection of 15 parental blogs written by West-European parents of children with life-limiting conditions it was found that::

Parents of children with a variety of life-limiting diseases almost always use war metaphors to describe their child and their child’s disease.

For their familial situation parents uses several metaphors describing their vulnerability, time left available and life as a struggle.

However:
- describing their child as a ‘fighter’ is a source of pride for parents both before and after death.

- for medical treatment decisions parents balance their fight on behalf of their child against their comfort especially when time is short.

The parental use of war metaphors in this group of patients does not have the expected negative effects of blaming the patient and continuing medical treatment when benefit is unlikely.
Use of the war metaphor is beneficial because
- it allows parents to express their pride in their child.
- It places the family and child in a active role in managing the child and their disease.

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References
1. Military Metaphors and Their Contribution to the Problems of Overdiagnosis and Overtreatment in the “War” Against Cancer. Malm H. The American Journal of Bioethics 2016 Vol. 16;10:p19
2. War and Peace in Cancer - The Words We Choose. Taubert M. https://www.huffingtonpost.co.uk/dr-mark-taubert/language-around-cancer_b_9758290.html

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19

Parental Ethical Decision Making and implications for Advance Care Planning: A Systematic Review and Secondary Analysis of qualitative literature from England & Wales, Germany and the Netherlands

Dr Veronica Neefjes
PhD Candidate
University of Manchester

Parental Ethical Decision Making and implications for Advance Care Planning:

A Systematic Review and Secondary Analysis of qualitative literature from England & Wales, Germany and the Netherlands

Veronica Neefjes

Background

Clinicians and parents are expected to make medical treatment decisions in the child's best interests. To reach their decisions clinicians typically apply a principled approach outlined by Beauchamp and Childress. How parents make ethical decisions is an under-researched area especially in Europe.

It is important to gain insight in the parental decision making process so as to be able to better support families and inform relevant policies.

A possible model for parental decision making is the Ethics of Care theory (EoC). Ethical decision making within this framework aims to benefit the caring relationship.

Objectives:

1) Investigate which *values* West-European parents use in medical treatment decision making

2) Investigate *how* parents use their values in decision making

3) Investigate how the parental decision making process fits with advanced care planning

Full publication:

Parental Ethical Decision Making and Implications for Advance Care Planning: A Systematic Review and Secondary Analysis of Qualitative Literature from England and Wales, Germany, and the Netherlands Journal of Palliative Medicine; DOI:10.1089/jpm.2022.0520

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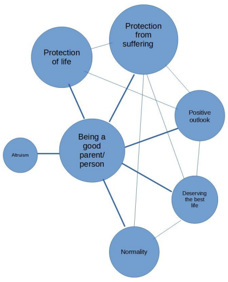
Results

43 papers were included representing the views of 880 parents about 731 children.



1) Dutch, German and English parents have the same six ethical values that are connected to each other and the overall goal of 'being a good parent/person'.

2) Parental values are *relational.* Five out of six values are in relation to As such parental decision making can understood in the context of the Ethics of Care (EoC) theory.

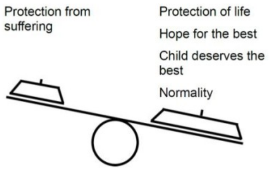
3) The EoC theory predicts that the overall aim of parental decision making is to nurture the caring relationship. What is right or wrong depends on the circumstances at the time of decision making.

4) An important aspect of advance decision making is that the circumstances at the time of implementation of the decision are unknown. EoC predicts that parents will be reluctant to make definitive decisions in advance

5) Re-analysis of 12 papers that explicitly discussed advanced care planning confirmed that parents tend to be hesitant to make decisions in advance for fear of the child 'missing out' on medical treatment. The ability to retract previous decisions at the time they would be implemented is essential for parents.

6) Combined the results indicate that early initiation of advance care planning, i.e. shortly after diagnosis does not fit well with the parental decision making process. It may be that despite best efforts parents will prefer to make definitive decisions closer to the time of implementation.

7) However, all parental values *except* protection from actual or expected suffering pull parents in the direction of continuing treatment.



When *parents* perceive their child is suffering or expect their child to suffer in future due to medical treatment, for example after a prolonged stay in PICU, offering advance care planning would be more appropriate.

8) Knowledge about the parental decision making process should be included in future policies.

Study limitations

This study represents the views of a large group of European parents. However as a secondary analysis the interpretation of the participant's views could not be checked with the participants themselves.

Key messages

1) The parental decision making process is consistent with the Ethics of Care framework.

2) Parental decisions aim to maintain the caring relationship and are dependent on the circumstances at the time

3) The parental decision making process seems inconsistent with advance care planning unless parents perceive the child to be suffering.

Methods

Systematic review and secondary analysis of qualitative research describing parental experiences caring for children with a life-limiting condition (LLC).

Eligibility criteria:

(1) the article reported on at least one medical treatment decision made by parents

(2) parental views on their child with LLC could be reliably separated from views of others

(3) the research was conducted in the Netherlands, Germany, or England and Wales

(4) published between 2010 and 2020.

Eight databases were searched: CINAHL-Plus, Medline, PsycINFO, ProQuest, Embase, Web of Science, DART-Europe, LIVIVO

Reflexive thematic analysis as described by Braun and Clarke was used for the secondary analysis.[1]

Reference:

1 Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77–101; doi: 10.1191/147808 8706qp063oa

20

The revision of the CYPACP through stakeholder engagement

Dr Helen Bennett
Director of Care
Alexander Devine Children's Hospice Care

Dr Ross Smith
Consultant in Paediatric Palliative Medicine
Leeds Teaching Hospitals NHS Trust/Martin House Children's Hospice

The revision of the CYPACP through stakeholder engagement

Helen Bennett and Ross Smith, Co Leads for the CYPACP

BACKGROUND

The Child and Young Person advance care plan (CYPACP) is a valuable resource for babies, children, young people and their families, used by a range of multi-disciplinary professionals. It is a core element of palliative care. Recommendations from a growing body of research informed the revision of the CYPACP.

AIM

To address research findings and engage with key stakeholders involved in CYP advance care planning. To collaborate ideas and improve the clarity, relevance and standardisation of the document.

RESULT

Two new versions

- Standard version
- Antenatal version

Both with and without ReSPECT

Name:	DOB:	NHS No:

Child and Young Person's Advance Care Plan

ID photo

QR code

FOR EMERGENCY MANAGEMENT TURN TO FINAL PAGES

Plans can begin antenatally (using ante-natal version of this document) and are suitable for infants, children and young people

Name (baby, infant, child or young person):			
Known as (if different):		**EDD** (if relevant):	
Address including postcode:		**DOB:**	
NHS no:			
		Gender (optional)	

ALLERGIES:

For Child/Young Person or Carers' Use – Who to call in emergency (eg 999 or 111, or Hospice, etc)

In emergency call:

Other situations:

See also Emergency Contacts on last page

This document is in accordance with NICE guideline NG61 and is a tool for discussing care preferences and communicating wishes. It is intended to enable clinicians and families to make good decisions together.

Not every page/section needs to be completed.

Date of Plan/Last review

Irrespective of the 'Date of plan' it is good practice to check this still reflects current decisions / views, and to regularly review the plan, especially if changes have occurred. However, an old / expired date does not necessarily negate this document.

For electronic copies of this form, information leaflets and guidance, see http://cypacp.uk/

ReSPECT http://cypacp.uk/ https://www.respectprocess.org.uk/

Version 5
Incorporating ReSPECT

Page 1 of 8

Out of hours support and emergency contacts can be found on the last page

KEY MESSAGES

The CYPACP is widely used by a range of professionals and is relevant to a diverse range of babies, children, young people and their families.

The CYPACP addresses goals of care, promotes sharing of information about treatment options and encourages conversations about wishes and values for life and death.

Key changes to the document emphasise the complex process of advance care planning, the breadth of paediatric palliative care and the importance of advance care planning conversations.

METHODOLOGY

- Review of existing ACP's
- Review of research recommendations
- Widespread consultation:
  - Authors of care plans
  - Users of care plans
  - Professions
  - Area's
- Focus groups gathering views and ideas
- Representatives from 'influencers' of policy/change
- Consensus approach

Profession

- **Consultant**
- **Speciality Doctors**
- **Training Doctors**
- **Specialist Nurses**
- **Nurses**
- **Psychology**

Area

- **Hospice**
- **Community**
- **Hospital (District & Tertiary)**
- **Emergency Services**

Authors

Antenatal / Neonatal

- **Midwife**
- **NICU**

Transition

- **Adult Palliative Care**
- **Transition**
- **GP**

Paediatric

- **Paediatric Palliative Care**
- **Community / Complex Paediatrics**
- **Specialists**

PICU
Neurodisability
Oncology

Neuro/ Renal/ Metabolic/ Endocrine..etc

Users

- **Emergency Departments**
- **Ambulance Services**

Influencers

- **Managerial**
- **APPM**
- **TfSL**
- **BAPM**
- **Resus UK**
- **PPI**
- **NICE**
- **RCPCH**
- **NHSE**
- **Research**

Regional / National Leads

FUTURE AIMS

To develop standardisation nationally, recognizing the complex web of care across boundaries and specialities for our population.

To ensure:

- A consistent journey for patient / family
- Easy recognition (and use) for professionals
- Access to standardised and central resources including guidance and education
- Improving influence on policy and courses (e.g. resuscitation courses)
- Informing standardised research

We believe we have developed a robust and thorough tool to aid and document these crucial discussions.

Helen Bennett, Director of Care, Alexander Devine Children's Hospice Service
Ross Smith, Consultant in Paediatric Palliative Care, Martin House Children's Hospice and Leeds Teaching Hospital NHS Trust

21

Pain assessment tools make me mad

Bev Mannion
Advanced Nurse Practitioner

Dr Catriona McKeating-Khan
Consultant Paediatrician/Hospice Doctor

Kirsty Tooley
Nurse

Meggan Kwan
Creative Therapist

Forget me Not Children's Hospice

forget me not children's hospice

"Pain assessment tools make me mad"

Learning lessons from the experience of supporting young people to develop their own pain tools.

Authors: Mannion, B.(ANP); McKeating, C. (Consultant Paediatric Palliative Care).
Contributors: Kwan, M. (Creative Therapy); Tooley, K (Nurse)

★ Background ★

Two young people with Severe Dystrophic Epidermolysis Bullosa (SRDEB) have been supported by the hospice for symptom management as part of the wider "pain" multidisciplinary team. SRDEB presents with both acute and chronic pain, includes daily painful interventions and requires a multidisciplinary/ multidimensional approach (Goldschmeider et al 2014). To note, neither of these young people have had consistent opportunities for regular psychological input due to availability and suitability of statutory services locally.

Causes of pain in SRDEB include:
Upper GI blisters/reflux/strictures
Emotional
Eye
Bathing/dressings
Joints/bones
Infections
Skin/wound
Colitis
Itch
Constipation

MDT in pain management includes:
Physiotherapist
Regional Pain Team
Eye specialists
EB Specialist Team
Psychology (ideally!)
Hospice team: Doctors /ANP/nurse/therapists

A number of different validated pain tools are available at the hospice. Both young people hated them all! Despite recommendation (Goldschmeider et al 2014), no EB specific pain assessment tools are available.

What the young people told us...

My pain is never 0. I never have no pain.

The pain tools make me mad.

The tools do not relate to how I actually feel.

They wanted more "good days"......

"I want to bounce on the trampoline with my dog"

The team including a Creative therapist/ Nurse/Clinical support worker/Doctor/Advanced Nurse Practitioner who worked to identify how an individualised tool may be helpful ....

Chronic Illness Pain Scale

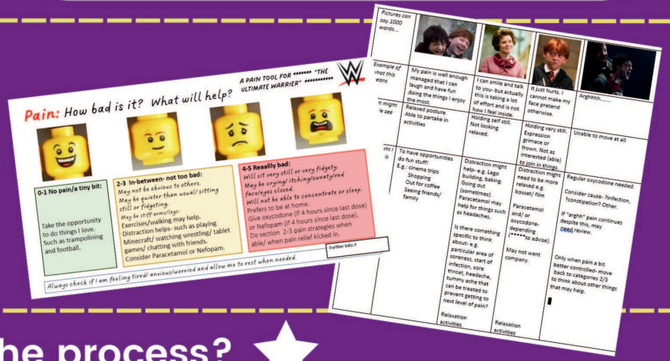
0-3: No pain! VERY rare. Like some kind of magical unicorn.

4-6: This is how we feel every day. This is our "normal". Because of this we are really good at hiding it. We can even ignore the pain, which might cause us to overextend ourselves.

7-10: This is when our pain is "heightened" above the usual. Here the pain may be apparent to others but still easily hidden with a smile. This level of pain interferes with tasts but we can work through it.

11-13: This is when pain is more widespread. It is apparent to others. We are probably quiet, set back, and moody. At this point we are having a hard time concentrating.

14+: This pain is UNBEARABLY overwhelming. We will not want to move. We will be in tears. This is our breaking point.



A PAIN TOOL FOR ******* "THE ULTIMATE WARRIER" **********

Pain: How bad is it? What will help?

0-1 No pain/a tiny bit:
Take the opportunity to do things I love. Such as trampolining and football.

2-3 In-between- not too bad:
May not be obvious to others.
May be quieter than usual/ sitting still or fidgeting.
May be stiff arms/legs-
Exercises/walking may help.
Distraction helps- such as playing Minecraft/ watching wrestling/ tablet games/ chatting with friends.
Consider Paracetamol or Nefopam.

4-5 Reaallly bad:
Will sit very still or very fidgety.
May be crying/ itching/sweaty/red face/eyes closed.
Will not be able to concentrate or sleep.
Prefers to be at home.
Give oxycodone (if 4 hours since last dose) or Nefopam (if 4 hours since last dose).
Do section 2-3 pain strategies when able/ when pain relief kicked in.

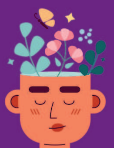
Further info: F

Always check if I am feeling tired/ anxious/worried and allow me to rest when needed.

Pictures can say 1000 words....				
Example of what this eans	My pain is well enough managed that I can laugh and have fun doing the things I enjoy the most.	I can smile and talk to you- but actually this is taking a lot of effort and is not how I feel inside.	It just hurts. I cannot make my face pretend otherwise.	Arghhhh........
t might e see	Relaxed posture. Able to partake in activities	Holding self still. Not looking relaxed.	Holding very still. Expression grimace or frown. Not as interested (able) to join in things.	Unable to move at all
ht I is	To have opportunities do fun stuff! E.g.: cinema trips Shopping Out for coffee Seeing friends/ family	Distraction might help- e.g. Lego building, baking. Going out (sometimes). Paracetamol may help for things such as headaches. Is there something specific to think about- e.g. particular area of soreness, start of infection, sore throat, headache, tummy ache that can be treated to prevent getting to next level of pain? Relaxation activities.	Distraction might need to be more relaxed e.g. boxset/ film Paracetamol and/ or oxycodone- depending (*****to advise). May not want company. Relaxation activities	Regular oxycodone needed. Consider cause- ?infection, ?constipation? Other. If "arghh" pain continues despite this, may need review. Only when pain a bit better controlled- move back to categories 2/3 to think about other things that may help.

★ What did we learn from the process? ★

- Assessment tools that start at "0 "may cause distress for people who have never experienced 'no pain' in their life.
- Assisting the development of individualised pain tools enabled young people to have their own voice heard/ reflected in the tools they use on a day-to-day basis.
- Finding pictures that reflected the feelings experienced on a day-to-day basis helped communication across different settings for a more consistent approach to both assessing and managing pain.
- The process of developing these individualised tools explored/identified holistic strategies (mostly non-pharmacological) which reduced frequency of pharmaceutical intervention.



- The process of developing these tools prompted conversations that explored:
  - How the pain may look to others
  - Differentiating between general 'feelings' of pain/distress vs. locality and intensity of 'injury' related pain.
- Opportunities:
  - Voice of Child/Young Person being heard.
  - Multidisciplinary team working.
  - The power of creative/play therapy should not be underestimated.
- Challenges:
  - Lack of early and consistent psychology input apparent.
  - No formal evaluation of outcomes.
  - Limited replicability.

Despite there being a variety of standardised pain assessment tools for use in children's palliative care to aid quantification/description of pain felt (Jassal, 2022) these do not always meet the needs of children with chronic pain.

Individualised pain assessment tools may be helpful to ensure the voice of the child is heard/reflected and to provide a more consistent approach.

The process in these case studies evolved informally and therefore capturing views/reflections and outcomes in a more formal way would be recommended.

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Special acknowledgments/thanks to the 2 awesome young people who have kindly agreed to let us share their work.

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Developing a Patient Pictorial Symptom Management plan for use in Paediatric Oncology Palliative Care

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Developing a Patient Pictorial Symptom Management plan for use in Paediatric Oncology Palliative Care

Chennells, V. Paediatric Oncology and Palliative Care Clinical Nurse Specialist
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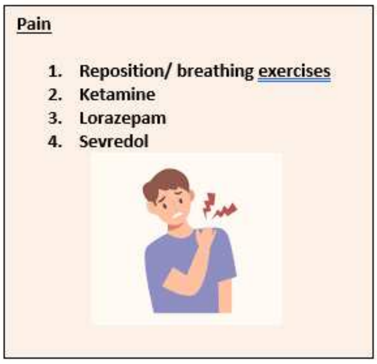
Background and Objectives: In Paediatric Oncology Palliative care, we rely on children and their parents to administer medication with varying dosing and complexities. Within my NHS Trust we provide a written symptom management plan (SMP) to support children in the last months, days, and hours of life. This aims to cover all anticipated symptoms improving the quality of life for patients as their disease progresses. These however can be difficult for children and their parents to interpret particularly if they struggle to read/understand English or if English is their second language.

Visual tools for communicating health-related information can improve comprehension, satisfaction with information, self-management, and provider-patient engagement (1). NHS England promote using a range of resources to make health care resources accessible to all (2). When reviewing literature there are pictorial communication tools in many health care resources, however these are not widely used in our service in Paediatric Palliative care.

Aims: The aim of the project was to develop a pictorial SMP for patients and their families to provide them with an easy to interpret resource to administer symptom relief. This was created due to feedback from family members that SMPs were complex and difficult to follow especially when their child may be experiencing distressing symptoms.



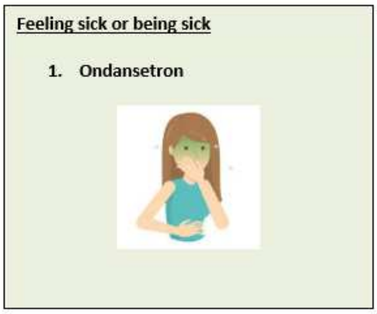
Pain

1. **Reposition/ breathing exercises**
2. **Ketamine**
3. **Lorazepam**
4. **Sevredol**

Feeling worried or anxious

1. **Breathing exercises**
2. **Lorazepam**
3. **Buccal midazolam**

Results: A protype of a patient pictorial SMP was developed and trialled for two patients. Informal feedback was collected and both families found it easy to use as a quick reference guide for their child. They felt this helped them to know which medications to give in a straightforward way.



Feeling sick or being sick

1. **Ondansetron**

Breathlessness

1. **Breathing exercises**
2. **Fan on face**
3. **Sevredol**
4. **Lorazepam**

Conclusions: Further development and trial use of the pictorial symptom management is required. A survey and audit will be developed to review the use of a pictorial SMP, following which it will be implemented it to practice for all patients as a quality improvement project.

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23

Determinants of suffering in Paediatric Palliative Care

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WHAT ARE THE DETERMINANTS OF SUFFERING IN PAEDIATRIC PALLIATIVE CARE?

AN INTEGRATIVE REVIEW

LUCY PARKER & ANNE-SOPHIE DARLINGTON

University of Southampton

NHS Solent NHS Trust

BACKGROUND

For children receiving paediatric palliative care (PPC), significant suffering from physical and psychosocial symptoms continue to be reported, which is distressing and harmful to children, parents and clinicians.

AIM

The aim of this work was to understand how suffering is experienced by children, families and clinicians, as well as any factors which impact reports of suffering.

RESULTS

PAIN DYSPNOEA AND FATIGUE WERE MOST FREQUENTLY ASSOCIATED WITH CHILD SUFFERING

SUFFERING HAS BEEN ASSESSED BY PROXY AND MAY NOT CAPTURE THE CHILD'S EXPERIENCE ACCURATELY

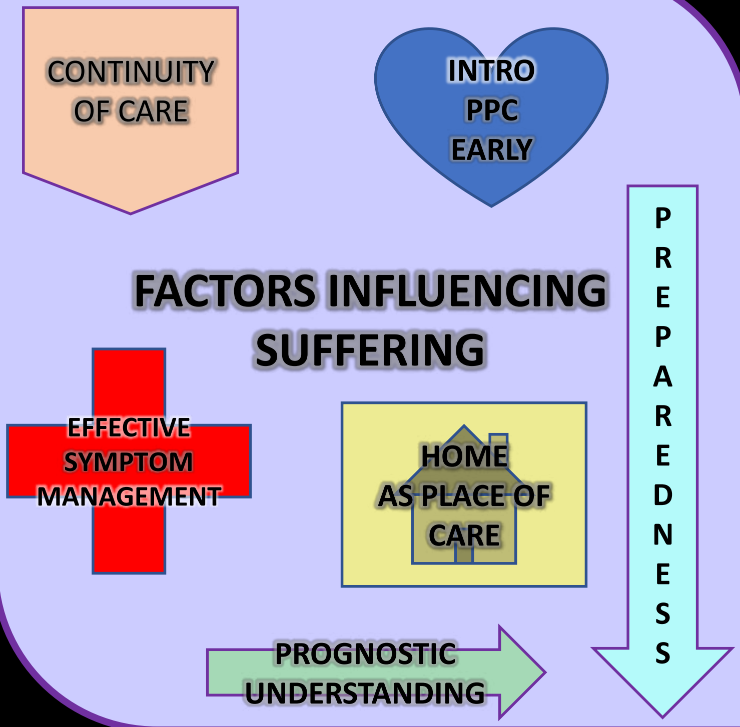
MULTIPLE STUDIES FOUND PARENTS WERE WILLING TO ACCEPT SIGNIFICANT CHILD SUFFERING IN HOPE OF THEIR CHILD'S SURVIVAL

METHODS

An integrative review was undertaken to enable the inclusion of all literature with relevance to the topic, combining diverse methodologies.

Inclusion: children with oncology/non-oncology diagnosis and with a focus on suffering or perceived suffering of children.
Exclusion: Adult and neonatal population, sudden/unexpected deaths and articles focusing solely on suffering or perceived suffering of caregivers.

Data extracted: use of validated instrument, key findings, symptoms associated with suffering and factors influencing suffering.



FACTORS INFLUENCING SUFFERING

CONTINUITY OF CARE

INTRO PPC EARLY

PREPAREDNESS

EFFECTIVE SYMPTOM MANAGEMENT

HOME AS PLACE OF CARE

PROGNOSTIC UNDERSTANDING

DISCUSSION

- A combined symptom assessment and validated suffering scale would ensure direct patient report alongside proxy reports which could assist with reducing actual and perceived suffering.
- Goals of care and a focus on quality of life are essential to avoid regret related to suffering in pursuit of increased chances of survival.
- Further research into more effective symptom management of dyspnoea and fatigue is required and would likely benefit from utilising prospective study designs.

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Healthcare Professionals’ Attitudes, Knowledge, Meaning and Understanding of Paediatric Palliative Medicine (PPM) within the Paediatric Intensive Care Unit (PICU): A Summative Content Analysis in a Tertiary Children’s Hospital in Scotland “an in vitro study”

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Healthcare Professionals’ Attitudes, Knowledge, Understanding and Meaning of Paediatric Palliative Medicine (PPM) within the Paediatric Intensive Care Unit (PICU): A Summative Content Analysis in a Tertiary Children’s Hospital in Scotland

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FOR MORE INFORMATION ON THE STUDY CONTACT DR. SATYAJIT RAY, BUBURAY@HOTMAIL.COM

BACKGROUND & AIMS

PPM is a holistic approach to care for children and families. Services providing PPM are growing and developing worldwide[1 2]. However, there is significant disparity in service provision[1 3] In Scotland, the Paediatric Supportive and Palliative Care Team (PSPCT) at the Royal Hospital for Children in Glasgow was established in 2019. However, there is still no clear integrated role within PICU at present, prompting further investigation[4].

Aims:

1) To understand the meaning, knowledge and understanding of the PPM working within the PICU environment
2) To identify potential barriers and facilitators to providing this care within an integrated model

METHODS

Participants and Methodology:
Advanced nurse practitioners, nursing staff (band-7s) and Consultants were asked to fill in an online survey containing five open-ended and five closed questions

The data was studied then analysed by two coders using summative content analysis[5 6] using NVivo. Codes were later developed to form categories and subcategories.

RESULTS

(N=16) out of (N=32) healthcare professionals took part in the study.
Two categories were found:

1) *The role of palliative care*

Two Subcategories: Collaborative working; Family-centred care

2) *Experiences of providing palliative care*

Three subcategories: Education and collaboration; Stigma associated with palliative care; Resources impacting palliative care

CONCLUSIONS

This study shows that PICU professionals have a good understanding of the concepts of PPM and view it as an essential part of PICU work. Barriers related to resources and misperceptions of palliative care can be overcome through improved education[7], funding and staff retention, but this would require buy-in from policymakers. The perspective from our relatively small sample increases generalisability to growing teams across the country.

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Category: The role of palliative care

“Collaborative” (D/ANP2), “Integrated” (N1), “Compassionate” (D/ANP10), & viewed as assisting “child and family to decide how to get the most out of the time they might have” (D/ANP8).

Category: Experiences of providing palliative care

“How can you ask a cardiologist to give a balanced approach to single ventricle pathway when they will only manage one side of the pathway?” (D/ANP6)

Category: Experiences of providing palliative care

“Lack of understanding from patients and parents” [barriers] (D/ANP10)

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25

Do Children and Young People with Life-limiting Conditions Receive Timely Palliative Care Input and Advance Care Planning?

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Do Children and Young People with Life-limiting Conditions Receive Timely Palliative Care Input and Advance Care Planning?

James Parry-Reece, Sarina Jassal, Archana Soman & Ramesh Kumar.

Introduction

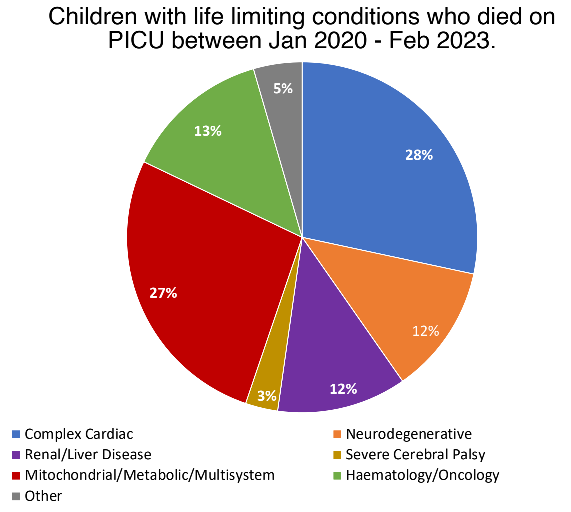
Early integration of paediatric palliative care (PPC) and advance care planning (ACP) are believed to improve outcomes and experience for children and young people (CYP) with life-limiting conditions (LLC) and their families and are therefore widely recommended. ACP not only facilitates individualized, objective and considered decision-making for possible serious eventualities balancing the benefits and burdens of various interventions, but also ensures that CYP's and their families' voices are heard and documented, and their values, priorities, and goals influence such decisions.[1,2.]

Aims

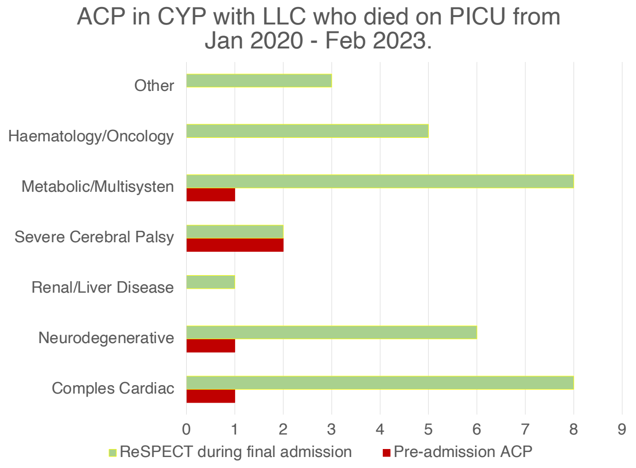
To assess the prevalence of ACP in CYP with LLC who die on the paediatric intensive care unit (PICU).

Method

We retrospectively audited data on CYP who had died on PICU at Leeds General Infirmary between January 2020 and February 2023. We included only CYP who had a known LLC and excluded for children aged 28 days or less at the time of death.



Children with life limiting conditions who died on PICU between Jan 2020 - Feb 2023.



ACP in CYP with LLC who died on PICU from Jan 2020 - Feb 2023.

Results

Sixty-seven children met our inclusion and exclusion criteria. Of these, only 5 had an ACP in place prior to their final admission to PICU, and 1 other had a pre-admission ReSPECT form in place. 33/67 children received a ReSPECT form in the days or hours preceding their death, during their final stay. 9/67 children had PPC input prior to admission and 22/67 had PPC input during admission. 26/67 (38%) children were White/Caucasian, 28/67 (42%) were other ethnic groups and 13/67 (19%) the ethnicity was unknown. Of those who had ACP prior to admission 3/9 (33%) were White/Caucasian, 5/9 (56%) were other ethnic groups and 1/9 (11%) the ethnicity was unknown.

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Discussion & Conclusion

End-of-life care discussions are well documented whilst CYP are in our PICU. However, it appears that CYP with known LLC do not often receive specialist palliative care input and the opportunity to formulate advance care plans before a life-threatening crisis.

Children from ethnic groups other than White/Caucasian make up 14.5% of the population of Yorkshire and the Humber but accounted for 42% of the children who died with a LLC in our regional PICU.[3] We did not find that White/Caucasian children were able to access pre-admission PPC more easily than other ethnic groups.

Greater understanding of the barriers to accessing PPC and/or ACP amongst various subgroups of CYP with LLC is required and only then can appropriate recommendations be made.

We have identified that complex cardiac patients make up a significant proportion of our audit population and hope to present the data at the paediatric cardiology audit meeting to help identify how we can improve access to PPC.

Our data will also be presented at the Children's Hospital End of Life Care Steering Group.

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Development of the "Managing Diabetes Mellitus in Paediatric Palliative Care" Guideline

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Glycaemic Control in Gut Failure at End of Life

Authors: **Dr Christine Mott** (1,2), **Dr Yifan Liang** (1), **Dr Erin Sharwood** (3), **Assoc Prof Anthony Herbert** (3)
1. Birmingham Women's & Children's NHS Hospital Foundation Trust, 2. Acorns Children's Hospices, Birmingham, 3. Children's Health Queensland, Australia

Objectives: In managing a complex paediatric palliative care (PPC) case in the West Midlands, the challenges of comorbid diabetes management at end of life were noted. This case inspired a search for paediatric diabetes management at end-of-life guidelines, particularly looking for guidance around management where a continuous insulin pump or Percutaneous Endoscopic Gastrostomy (PEG) were being used as in our index case.

Results: We found no guidelines specific to the paediatric context or focusing on use of a continuous insulin pump. We reviewed multiple recommended adult-based guidelines and only one mentioned PEG access. Adult-based guidelines reviewed relied on consensus and experience, with very limited evidence base on which to develop recommendations. Colleague groups approached (Australian and New Zealand Society of Palliative Medicine Paediatric Special Interest Group and the Association of Paediatric Palliative Medicine Consultant Group UK) were not aware of any additional paediatric guidelines and mentioned how uncommonly they managing comorbid diabetes at end of life, so were supportive of development of a guideline. We brought together a working group from relevant organisations in Australia, New Zealand and the UK to develop a guideline, based on concepts from adult-based guidelines. We addressed paediatric gaps, seeking consensus of experience from endocrinology and palliative care stakeholders, and present our progress to date.

Guideline progress: The guideline is currently under review by the Australian and New Zealand Society of Paediatric Endocrinology and Diabetes, and we would like to thank Trend Diabetes for their support in the content and in assisting with future graphic design of the guideline. We then plan to formally ask for endorsement from Australian and New Zealand Society of Palliative Medicine, the Association of Paediatric Palliative Medicine (UK) and Paediatric Palliative Care Australia and New Zealand.

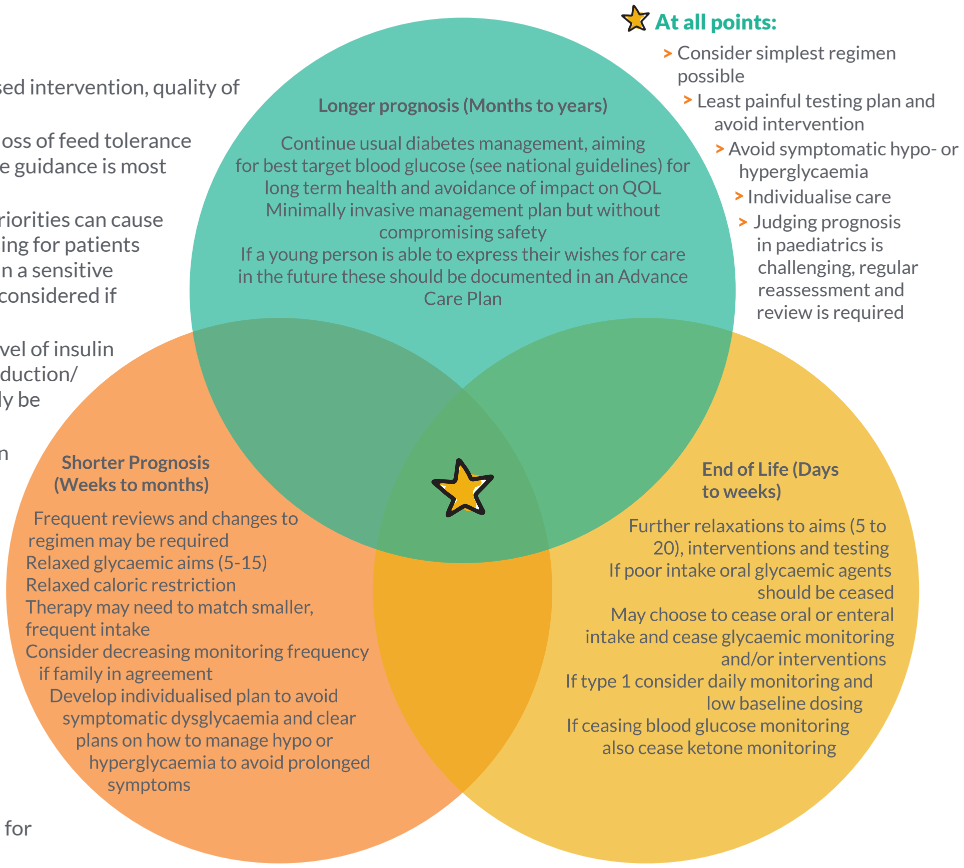
Conclusion: Managing diabetes is an uncommon situation in PPC, so a guideline would assist in providing consistency in approach and confidence in management. A guideline entitled "Managing Diabetes Mellitus in Paediatric Palliative Care" has been written. Further research is critical to develop best practice and optimize the experiences of patients like our case and their families.

Key guideline points:

> Goals of care are symptom avoidance, minimised intervention, quality of life and respect for patient and family choices.
> Loss of oral intake (where no feeding tube) or loss of feed tolerance indicates shorter timeframes and so end-of-life guidance is most appropriate.
> Discontinuation of therapies and changes in priorities can cause confusion in management and may be distressing for patients and families, so this should be communicated in a sensitive manner and additional psychosocial supports considered if needed.
> Patients with Type 1 diabetes always have a level of insulin requirement, however with type 2 diabetes reduction/cessation of oral and insulin therapies will likely be tolerated
> The developed guideline will provide details on specific glucose management
> We recommend collaborative care with the child or young person's endocrinologist, treating team, dietician and palliative care services to provide best individualised clinical care
> Place of care should not be influenced by diabetes management requirements

We would like to thank the family of Lucy Watson for allowing us to acknowledge her memory here as the inspiration for this project.

Additional thanks to: Sue Langley, EACH Librarian for literature search support



☆ **At all points:**

> Consider simplest regimen possible
> Least painful testing plan and avoid intervention
> Avoid symptomatic hypo- or hyperglycaemia
> Individualise care
> Judging prognosis in paediatrics is challenging, regular reassessment and review is required

Longer prognosis (Months to years)

Continue usual diabetes management, aiming for best target blood glucose (see national guidelines) for long term health and avoidance of impact on QOL
Minimally invasive management plan but without compromising safety
If a young person is able to express their wishes for care in the future these should be documented in an Advance Care Plan

Shorter Prognosis (Weeks to months)

Frequent reviews and changes to regimen may be required
Relaxed glycaemic aims (5-15)
Relaxed caloric restriction
Therapy may need to match smaller, frequent intake
Consider decreasing monitoring frequency if family in agreement
Develop individualised plan to avoid symptomatic dysglycaemia and clear plans on how to manage hypo or hyperglycaemia to avoid prolonged symptoms

End of Life (Days to weeks)

Further relaxations to aims (5 to 20), interventions and testing
If poor intake oral glycaemic agents should be ceased
May choose to cease oral or enteral intake and cease glycaemic monitoring and/or interventions
If type 1 consider daily monitoring and low baseline dosing
If ceasing blood glucose monitoring also cease ketone monitoring

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Clinical heterogenicity of adolescent and young adult patients with a life-limiting illness referred to paediatric palliative care services in Ireland

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Clinical Heterogeneity of Adolescent and Young Adult (AYA) Patients with a Life-Limiting Illness Referred to Paediatric Specialist Palliative Care Services in Ireland.

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Background

There is a recognition of the need to provide adapted palliative care services to cater to the needs of adolescents and young adults (AYA) with life-limiting/life-threatening illnesses (1-3). There are few studies providing information to inform the development of such services.

Aims

To examine the demographic information of AYA who have received paediatric specialist palliative care in Ireland, and to map the heterogeneity of clinical conditions, symptoms, service utilisation, medical technological support utilisation and disease outcomes in this population.

Methods

This retrospective review examined data from AYA, reviewed by the paediatric specialist palliative care teams in Children's Health Ireland (CHI) and St Luke's Radiation Oncology Network (SLRON), following their 13th birthday, from 2019-2022 (inclusive). Ethics approval was granted from CHI and SLRON.

Settings/Participants

Patients were identified from records which are collected to submit to the National Palliative Care Office in the Health Service Executive (HSE).

Results

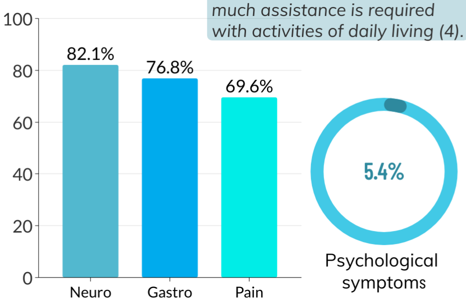
145 Total number of cases

AYA with non-malignant conditions with SNI (n=56)

38.6%

SNI describes a group of 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 (4).

Symptoms:

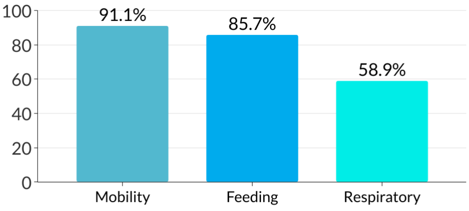


For those that died (n=21):

61.9% (n=13) died at home

14.3% (n=3) were referred to specialist palliative care <3 months before their death

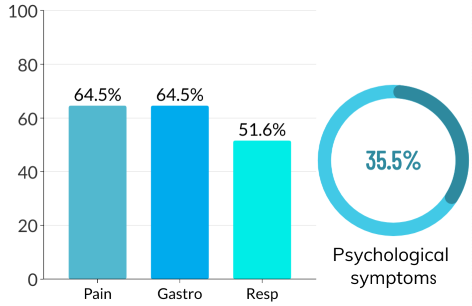
Medical Technology in the Home:



AYA with non-malignant conditions without SNI (n=31)

21.4%

Symptoms:



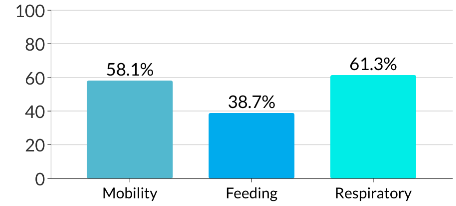
For those that died (n=10):

40% (n=4) died in **hospital**

40% (n=4) died at **home.**

10% (n=1) were referred to specialist palliative care <3 months before their death.

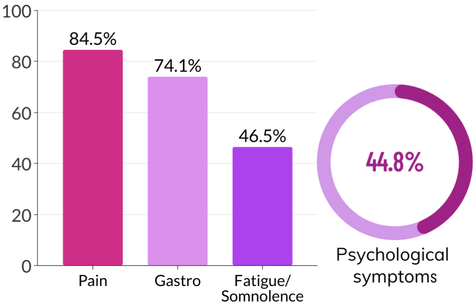
Medical Technology in the Home:



AYA with malignant conditions n=(58)

40%

Symptoms:

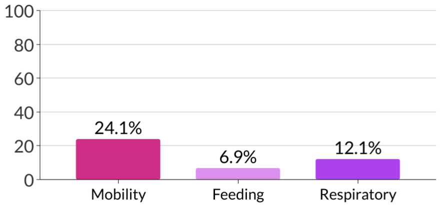


For those that died (n=38):

71% (n=27) died at **home.**

31.6% (n=12) referred to specialist palliative care <3 months before their death

Medical Technology in the Home:



Conclusions

The high symptom burden and relatively late referral of some AYA to SPC, highlights the need for early referral to palliative care professionals with an appropriate skillset and access to adequate, equitable psychological supports for this group. Utilisation of medical devices/technology in the home adds complexity to end-of-life decision making and indicates the need for professionals who are educated in their use, in the community setting.

Funding

The Royal City of Dublin Hospital Trust

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28

Advanced Care Planning in Adolescents and Young Adults (AYA) with Life-Limiting or Potentially Life-Threatening Illness, Guidelines and Frameworks for Practice: A Scoping Review.

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Advanced Care Planning in Adolescents and Young Adults (AYA) with Life-Limiting or Potentially Life-Threatening Illness, Guidelines and Frameworks for Practice: A Scoping Review.

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Background

Advance care planning (ACP) discussions are crucial in the management and support of individuals living with life-limiting/life-threatening conditions. Engaging young people in discussions about ACP, dying, and end-of-life care are increasingly recognised as an essential part of standard of care (1). Despite increased understanding of the importance of engaging adolescents and young adults (AYA) in ACP discussions, few studies have examined best practices for ACP discussions with AYA with life-limiting/life-threatening conditions.

Aim

To identify core components of current guidelines, frameworks, and tools to facilitate ACP discussions with AYA with life-limiting/life-threatening conditions and their families.

Design

This scoping review was conducted according to the Joanna Briggs Institute approach to the conduct of scoping reviews (2). An extensive literature search from the inception of five databases [Cochrane Central Register of Controlled Trials (CENTRAL), Cochrane Database of Systematic Reviews, PsycInfo, PubMed, and Scopus] until January 23, 2023, was carried out.

Results

The search yielded 2976 papers, of which 9 met the inclusion criteria. Five main themes were identified:

(i) utilisation of standardised documents and protocols;

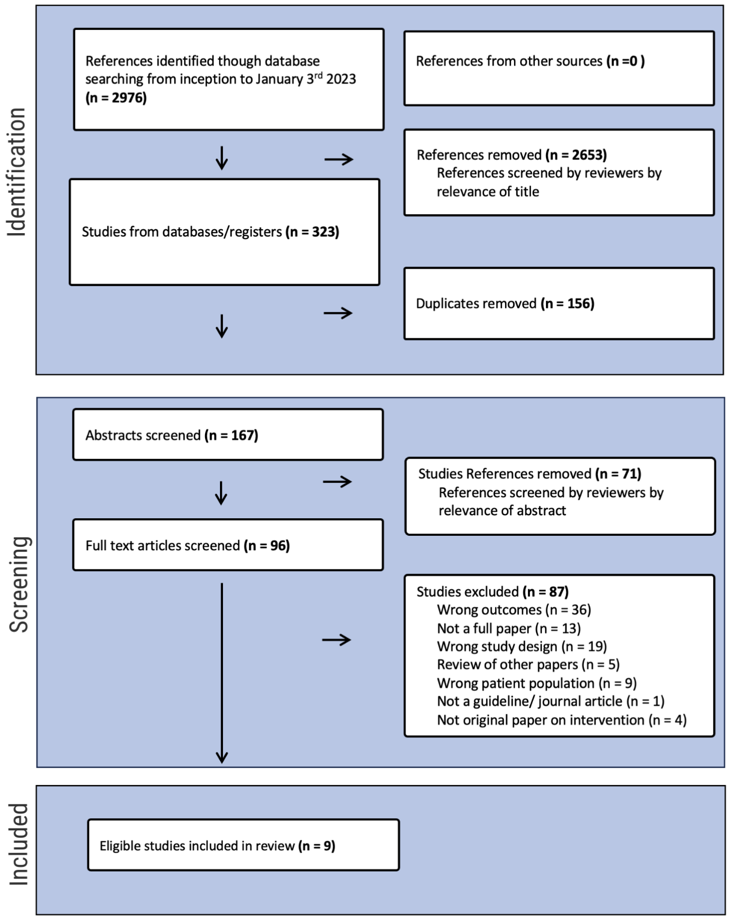
(ii) shared decision-making between the AYA, their families, and the healthcare team;

(iii) the importance of open and honest communication with AYAs during ACP discussions;

(iv) individualisation and flexibility in the ACP process;

(v) timing of ACP initiation and discussions.

Prisma Flow Chart



Identification

References identified though database searching from inception to January 3rd 2023 **(n = 2976)**

References from other sources **(n =0)**

References removed **(n = 2653)**
References screened by reviewers by relevance of title

Studies from databases/registers **(n = 323)**

Duplicates removed **(n = 156)**

Screening

Abstracts screened **(n = 167)**

Studies References removed **(n = 71)**
References screened by reviewers by relevance of abstract

Full text articles screened **(n = 96)**

Studies excluded **(n = 87)**
Wrong outcomes (n = 36)
Not a full paper (n = 13)
Wrong study design (n = 19)
Review of other papers (n = 5)
Wrong patient population (n = 9)
Not a guideline/ journal article (n = 1)
Not original paper on intervention (n = 4)

Included

Eligible studies included in review **(n = 9)**

Conclusion

AYAs with life-limiting/life-threatening conditions have unique needs and challenges as compared to other patient populations. Our findings highlight the importance of engaging AYAs in ACP discussions, and the importance of considering their unique needs when initiating and framing these discussions. These key components of ACP discussions with AYA can be used by healthcare professionals to inform and enhance ACP discussions. Further research is needed to test the effectiveness of these guidelines and frameworks in improving end-of-life care for AYAs and to explore experiences with ACP discussions from the perspective of AYA patients themselves and their families.

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29

Key strategies for recruiting children and young people with life-limiting or life-threatening conditions and their families to participate in research

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Key strategies for recruiting children and young people with life-limiting or life-threatening conditions and their families to participate in research

Daney Harðardóttir[1], Debbie Braybrook[1], Hannah Scott[1], Lucy Coombes[1,2], Inez Gaczkowska[1], Lorna Fraser[1], Richard Harding[1] on behalf of C-POS.

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Background

Children and young people (CYP) with life-limiting or life-threatening conditions (LLLTCs) and their families are traditionally considered a vulnerable population and their participation in research is consequently perceived as high-risk.[1] It is important for all stakeholders to support this population to participate in research about them so they can benefit from robust research-based practice.

Aim

To identify key strategies to successfully recruit and include CYP with LLLTCs and their families in research.

Methods

Learnings from the Children's Palliative care Outcome Scale (C-POS) project, a mixed-methods, multi-phase research project involving CYP with LLLTCs and their families, including qualitative interviews[2], a Delphi survey[3], cognitive interviews[4], and an observational study. Table 1 demonstrates recruitment numbers for the different phases of the project.

Table 1. recruitment numbers for the different phases of the C-POS project

Participant Type	Qualitative Interviews	Delphi Survey	Cognitive Interviews	Observational Survey*	Overall Project Total
CYP with LLLTCs 5-17 years	26	Not recruited	12	48	86
Parents/Carers	40	23	36	161	260
Siblings > 5 years	13	Not recruited	Not recruited	Not recruited	13

*NOTE Recruitment to the observational survey is still ongoing these numbers reflect recruitment as of 13th November 2023

Results and Recommendations

Key strategies for successful recruitment of CYP with LLLTCs and their families to research have been identified:

1. Early collaboration. Involving clinical experts and patient and public involvement members in early stages of study planning ensures realistic and manageable study processes and fosters good relationships built on collaboration and trust.
2. Setting realistic timelines. Administration and study set-up is time consuming and can often consume valuable time originally allotted to recruitment. Research teams should account for this in study planning.
3. Equal access to research. Offering all CYP with LLLTCs and families the opportunity to decide for themselves whether to participate in research studies. This reduces potential gatekeeping issues and allows for more diverse representation of CYP with LLLTCs and families in research.
4. Active communication and reflection. Providing recruiting health and social care professionals with frequent progress updates and support at all stages. Additionally, facilitating regular collective reflection on recruitment successes and failures in ongoing research to allow for re-evaluation of approaches where needed.

Utilising these strategies will contribute to robust future work. Continuing to include CYP with LLLTCs and their families in research will enable us to better understand their needs and experiences, leading to better care.

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C-POS is funded by the European Research Council's Horizon 2020 programme [Grant ID: 772635] and supported by the National Institute for Health Research Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust.

Cicely Saunders International
Better care at the end of life

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30

Deep breath- Tracheostomies in a tertiary hospital paediatric palliative care caseload, retrospective audit

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Yasmin Djouadi
??

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Deep breath- Tracheostomy prevalence in a tertiary hospital paediatric palliative care caseload

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Background

The Evelina Paediatric Palliative Care (PPC) team is a tertiary palliative care team covering a large geographical area across south east London and south east England.

Reflecting on the high number of local MDT/ethics panel discussions around tracheostomy with PPC involvement in the last 6 months, we undertook a retrospective review of prevalence of patients under the Evelina PPC team with tracheostomies (+/-ventilatory support) over the last 9 years.

National level work has identified a doubling of LTV paediatric patients in the UK between 2008 and 2018 (1). Our hypothesis was that local prevalence of patients with tracheostomies known to paediatric palliative care has increased dramatically across a comparable time frame also, potentially to an even greater extent.

Having a long-term tracheostomy is a significant marker of medical complexity, impacting on the child, family and carers, care package and hospital care use.

Aim

We hoped that better understanding the demand for the service in this area could be a starting point, within our team and other teams involved in care of these patients, to explore factors behind any increase in palliative tracheostomy insertion, and support service design in view of anticipated future demand.

Methods

The Evelina PPC master database of referred and accepted cases was filtered to identify cases active on the caseload at four discrete dates evenly covering the last 9 years in the service:

April 2023, April 2020, April 2017, April 2014

As coding for tracheostomy varies across the trusts involved, and many patients have the majority of their notes held within their local DGH system, Evelina electronic notes were then searched manually through the letters/problem list function to ascertain which patients had a tracheostomy at each time point.

The total Evelina PPC caseload has substantially increased in total number over this time period, therefore this data was also gathered for comparison.

Each CYP who had a tracheostomy at the April 2023 and April 2020 time points then had further review of their electronic notes and original PPC referral forms to ascertain:

-main diagnosis

-place of care at time of referral to PPC

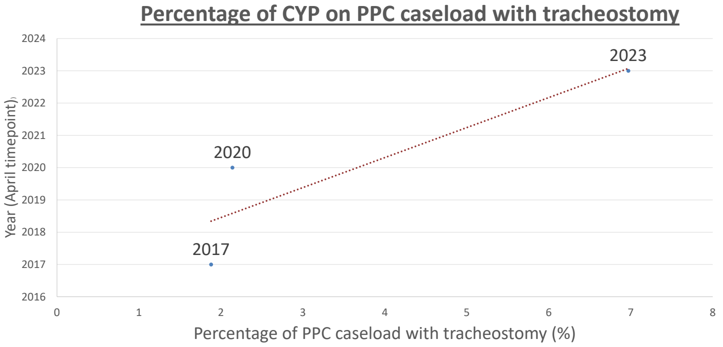
-whether the CYP had an advanced care plan or symptom management plan.

Results

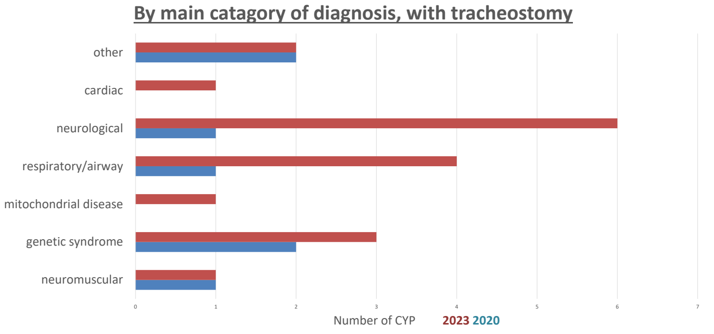
Total caseload numbers increased significantly, particularly at the start of the timeframe as the PPC service was established. Between 2020 and 2023 a drive to increase discharges from the active caseload accounted primarily for falling total caseload numbers with annual referrals continuing to increase. The same three CYP were on the caseload with tracheostomy in 2014 and 2017. Between 2017 and 2020 number of CYP with tracheostomy more than doubled, and between 2020 and 2023 nearly trebled. The table and chart below shows absolute numbers and expressed as a percentage of total caseload by year.

Year (mid-April timepoint)	2023	2020	2017	2014
Total PPC caseload number	258	327	159	67
Number of CYP with tracheostomy on caseload	18	7	3	3
% of caseload with tracheostomy	6.9	2.1	1.8	4.4

Percentage of CYP on PPC caseload with tracheostomy



By main catagory of diagnosis, with tracheostomy



2020 data		
Those with tracheostomy with ACP	3/7	42%
Those with tracheostomy with SMP	2/7	28%

2023 data		
Those with tracheostomy with ACP	4/18	22%
Those with tracheostomy with SMP	4/18	22%

Discussion

The technology to insert and manage long-term tracheostomy is not new, yet prevalence of CYP with tracheostomy in our PPC caseload has increased during the last decade, and particularly dramatically within the last 4 years. These CYP span a wide variety of main diagnoses, and the majority at the timepoints studied did not have an advanced care plan or symptom management plan in place.
On a local level we believe this work stands as a springboard for further discussions with the MDT involved around tracheostomy insertion and management. We are not aware of any other published data from the UK around trends in PPC cohort tracheostomy numbers. If our data reflects national or even international trends then this raises wider interesting and important ethical questions, with marked social and financial consequences.

- Has the eligible population increased? Ie is this a reflection of medical complexity increasing? Were these children with tracheostomy just not referred to PPC before, or are there markedly more children with tracheostomy in the community now?
- Has the definition of eligibility changed? Ie has societal and medical expectation and judgement on best interest decisions with high-level life-support in the community shifted?
- If it has not, how can we account for the change in prevalence? Is there a robust, equitable, ethical MDT framework for considering best interests in long term tracheostomy? Whose responsibility is this to instigate and manage?
- What are the financial and societal implications of this largely 'hidden' cohort of CYP with very high needs being managed in hospital and in community? Are services adequate for need now; and for projected need into the future?

Conclusion

This single-site prevalence data over the last decade reflects a significant increase in clinical complexity of this cohort of CYP, with a rapidly rising trend in PPC cohort patients having long-term tracheostomy.

Beyond the impact on the PPC team, this has wide-reaching implications for the broader health system in local hospital settings and the community, social care system and affected families within society.

We pose questions on where the role of the PPC lies in decisions regarding tracheostomy insertion, and how as a health system we better monitor and adapt to this changing trend in patient cohort going forwards, to deliver the best outcomes for this vulnerable, high needs group of CYP and families.

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31

Transforming Care for Children with Medical Complexity and Life Limiting Conditions: Developing a Virtual Ward and Embedding Family Wellbeing

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Informing Transformation of Care for Children with Complex and Palliative Medical Needs: A Service Evaluation of Acute Care Use

NHS England

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With special thanks to the parents who contributed and shared their lived experience

Background

- The population of children and young people (CYP) living with medical complexity and life limiting illness is increasing, mainly due to advances in medicine, technology and therapies leading to improved survival rates[1].
- These CYP require care from multiple providers and have unmet needs due to gaps and fragmentation in service provision[1,2].
- They have high healthcare utilisation[1,3,4] with some studies suggesting medically complex patients account for up to a third of all healthcare expenditure in paediatrics[5].
- The population of CYP with medical complexity and life limiting conditions in Bradford is disproportionately high[3,6,7].
- Of particular concern in Bradford, an area of significant health inequality, is that the burden of care placed on family caregivers carries greater risk of worsening health inequalities[8].

Purpose

As part of the Bradford, District and Craven Health and Care Partnership our shared vision is to keep children and young people Happy, Healthy at Home. Acute paediatric pathways, children with complex needs and disability, and paediatric palliative care are highlighted within priority work streams within our place. A service evaluation was conducted to assess the acute healthcare usage of children with medical complexity and life limiting conditions to inform a strategy to transform care.

Method

Small casenote audit (n=20) of hospital admission information: presentation, intervention, barriers to discharge. Opportunistic sample identified from Palliative Ward Round or Complex Inpatient MDT.

Family caregiver interviews exploring lived experience of urgent care and suggestions for improvement (n=5)

Electronic Patient Record data analysis of acute healthcare use of a large sample of community patients under the care of the Child Development Centre (CDC) (n=3196)

Complex/palliative bed occupancy audit for paediatric inpatient unit. All patient notes accessed at six separate times Jan-Mar '23 (n=156). Complex patients identified subjectively using Cohen's definition of medical complexity (2011) and palliative patients identified from existing caseload.

Results

- On average, 29% of inpatient paediatric beds were occupied daily by medically complex/palliative CYP (Jan-Mar '23)
- Most complex CYP are in hospital with respiratory infection/virus (85% of sample)
- 50% of a sample of 20 hospital admissions could have been stepped down sooner if additional support was available in the community, saving 24 bed days from 10 admissions.
- Large numbers of CDC CYP access acute services frequently (see Table 1)
- >6 urgent care assessments within ED or Children's Clinical decision Area per day on average sought by CDC patients last year

CDC Patient Acute Hospital Usage by year	19/20	20/21	21/22	22/23
ED Attendances (no. of patients)	1416 (887)	878 (624)	1608 (1005)	1515 (904)
Inpatient Admissions (no. of patients)	1155 (560)	655 (350)	1090 (497)	1047 (496)
Admit source ED	386	255	384	323
Admit Source Direct Access	483	291	521	523
LOS <72 hours (0 day)	922 (509)	506 (269)	830 (468)	796 (447)
LOS > 7 days	92	52	111	110
CYP > 7 admissions	27	12	28	26

Table 1: data extracted from the Electronic Patient Record System for Urgent Care Use of CYP under the care of a Neurodisability Consultant in CDC

- Parents want to be supported to keep their children at home as much as possible by a team who know them
- Hospital admissions impact on social, psychological and emotional wellbeing of the whole family

Recommendations/Opportunities

Develop a high quality, sustainable, urgent care pathway for life limited and complex CYP
Clinical leadership from a specialist multidisciplinary team
Collaboration with key stakeholders
Complex and Palliative Paediatric Virtual ward within Virtual Royal Infirmary
Rapid response community care to support admission avoidance
High quality step down acute care
Strengthen existing relationships with local teams and children's hospices
Partnership with VCS Alliance
Address psychosocial support gaps
Reduction of health inequalities
Continuity across the whole journey
Reduction in carbon footprint
Workforce transformation

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32

Improving the documentation and tracking of paediatric Advance Care Planning in the patients' database and in the Electronic Patient Record in a UK District General Hospital

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Professor Fiona Rawlinson
Postgraduate Course Director
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IMPROVING THE DOCUMENTATION AND TRACKING OF PAEDIATRIC ADVANCE CARE PLANNING IN PATIENTS' DATABASE AND IN THE ELECTRONIC PATIENT RECORD IN A UK DISTRICT GENERAL HOSPITAL

E Harterink-Rojas[1], J Frost[2], J Roberts[3]
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2. Paediatrics Palliative care Lead
3. Community and palliative care lead nurse

Background:

The Paediatric Palliative Care (PPC) patient list was updated and the ACPs were reviewed. Many ACPs were incomplete or out of date. Some ACPs from patients who were either transitioned or passed away were still in the folder. I was also prompted to do this project after a complex patient who had an ACP presented to ED with status epilepticus in 3 different nightshifts, but the ACP was not found on EPR.

Aims:

- Create an alert on EPR for patients who have a paediatric ACP.
- All patients who are part of PPC to have a completed and in-date ACP. All
- ACPs to be scanned to EPR and distributed to all concerned.
- Modify the PPC patient's database according to the team needs.

Abbreviations:
ACP Advance Care Plan, PPC Paediatric Palliative care, ED Emergency Department, EPR Electronic Patient Record, QIP. Quality improvement project

Methods:

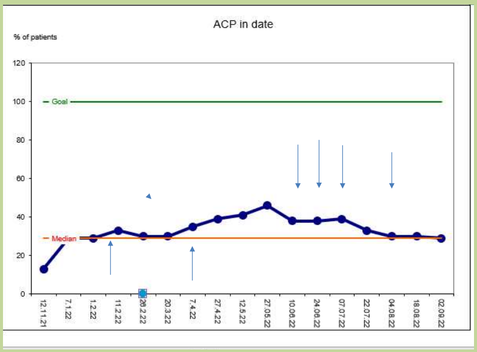
PDSA cycles were implemented throughout 10-months.
The database was modified.
Data of the new added columns, the percentage of patients with an in-date, out of date and in progress ACPs were collected every 2 weeks during this period.
Summary of the interventions in table 1.

Interventions	Date implemented
To the database	
• ACP in patient's folder	June 2021
• ACP yes/no	June 2021
• When the last ACP was done	September 2021
• When the ACP needs reviewing	September 2021
• When a patient has changed colour of life	September 2021
• Electronic Records Alert	12th November 2021
• Tap for recording ACP distribution	11th February 2022
• Name of the CNN involved in the care of the patient	18th August 2022
• Reminding on CNN's calendar yes/no	18th August 2022
To the process	
• Creation of the ACP Alert on the electronic records	12th November 2021
• Tray of drawers for the office	January 2022
• Change of review dates according to colours of life	7th April 2022
• CNN's calendar message to remind them when the ACP needs reviewing	4th August 2022
To the health care providers	
• Education for CNN's	28th January 2022

Table 1

Date	Number of patients known to PPC	% of ptes having an ACP	% of ptes having an ACPin date	% of ptes having a not in date ACP	% of patients with no ACP	No of ptes with an ACP in progress	% of ptes having an Alert on EPR	% of ACP uploaded to EPR	% ptes having recorded distribution	% of ACPs in the folder
12/11/2021	23	47% (11)	13% (3)	35% (8)	43% (10)	9% (2)	13% (3)	13% (3)	0	69% (16)
07/01/2022	24	58% (14)	29% (7)	29% (7)	33% (8)	8% (2)	29% (7)	29% (7)	13% (3)	
01/02/2022	24	58% (14)	29% (7)	29% (7)	33% (8)	8% (2)	29% (7)	29% (7)	25% (6)	10
11/02/2022	24	63% (15)	33% (8)	29% (7)	33% (8)	4% (1)	33% (8)	33% (8)	29% (7)	11
26/02/2022	23	61% (14)	30% (7)	30% (7)	30% (7)	9% (2)	30% (7)	30% (7)	30% (7)	13
20/03/2022	23	61% (14)	30% (7)	30% (7)	30% (7)	9% (2)	30% (7)	30% (7)	30% (7)	14
07/04/2022	24	63% (15)	33% (8)	29% (7)	29% (7)	8% (2)	33% (8)	33% (8)	30% (7)	14
27/04/2022	25	68% (17)	40% (10)	28% (7)	28% (7)	4% (1)	36% (9)	36% (9)	32% (8)	16
12/05/2022	24	67% (16)	42% (10)	25% (6)	29% (7)	4% (1)	42% (10)	42% (10)	33% (8)	16
27/05/2022	24	71% (17)	46% (11)	25% (6)	29% (7)	0	46% (11)	46% (11)	38% (9)	17
10/06/2022	24	71% (17)	38% (9)	33% (8)	29% (7)	0	46% (11)	46% (11)	46% (11)	18
24/06/2022	24	71% (17)	38% (9)	33% (8)	29% (7)	0	46% (11)	46% (11)	46% (11)	17
07/07/2022	23	70% (16)	39% (9)	30% (7)	30% (7)	0	48% (11)	48% (11)	48% (11)	17
22/07/2022	24	67% (16)	33% (8)	29% (7)	33% (8)	4% (1)	46% (11)	46% (11)	46% (11)	17
04/08/2022	23	65% (15)	30% (7)	25% (6)	30% (7)	13% (3)	43% (10)	43 % (10)	43% (10)	15
18/08/2022	23	65% (15)	30% (7)	22% (5)	30% (7)	17% (4)	43% (10)	43% (10)	43% (10)	15
02/09/2022	24	63% (15)	29% (7)	21% (5)	33% (8)	17% (4)	42% (10)	42% (10)	42% (10)	15

Excel table from data collection.

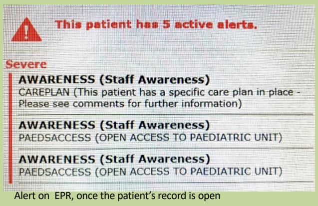


ACP YES/NO	ACP ALERT ON EPR YES/NO	ACP Review Date	ACP in Folder	Latest Update Date
Yes	No		01/09/2016	02/10/2020
Yes	yes	03/02/2023	19/04/2022	19/04/2022
No				02/10/2020
No				
No	No			
Yes	Yes	12/05/2023	19/05/2022	16/06/2022
No			only summary 22/05/17	22/05/2017
No				
Yes	Yes	29/04/2022	19/04/2021	19/04/2021
Yes	Yes	23/12/2022	23/12/2021	16/06/2022
Yes	No	25/04/2020	25/04/2019	25/04/2019
Yes	No	01/11/2020	01/11/2019	02/10/2020
Yes	Yes	01/12/2022	25/11/2021	25/11/2021
Yes	Yes	24/02/2022	24/02/2020	24/02/2020
No				
Yes	Yes	19/04/2023	19/04/2022	19/04/2022
Yes	Yes	11/11/2022	11/11/2021	11/11/2021
Yes	Yes	08/07/2022	08/07/2021	08/07/2021
yes	yes	13/05/2023	19/05/2023	13//05/2022

Database modifications

Year	Name	Hopsital Numbe	Date ACP Done	Location/Status	Parents	Carers	Julias House	Naomi House	Lily's Place
2019			02/01/2019				04/06/2019	04/06/2019	
2021			18/03/2021				21/05/2021		
2021			19/05/2021				19/05/2021		
2021			15/11/2021				09/12/2021 dorset.juliashouse@nhs.net	09/12/2021 wat.nhjpcareadmin@nhs.net	
2021			25/11/2021				10/12/2021 dorset.juliashouse@nhs.net		10/12/2021 info@diverseabilities.org.uk
2021			09/12/2021				23/12/2021	23/12/2021	
2022			11/11/2021				07/02/2022		
2022			06/01/2022				22/03/2022		
2022									
2022			03/02/2022				19/04/2022		

ACP distribution and tracking



This patient has 5 active alerts.

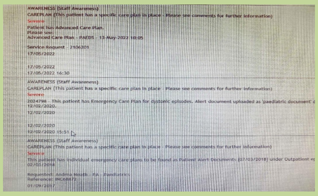
Severe

AWARENESS (Staff Awareness)
CAREPLAN (This patient has a specific care plan in place - Please see comments for further information)

AWARENESS (Staff Awareness)
PAEDSACCESS (OPEN ACCESS TO PAEDIATRIC UNIT)

AWARENESS (Staff Awareness)
PAEDSACCESS (OPEN ACCESS TO PAEDIATRIC UNIT)

Alert on EPR, once the patient's record is open



AWARENESS (Staff Awareness)
CAREPLAN (This patient has a specific care plan in place - Please see comments for further information)
Severe
Patient has Advanced Care Plan.
Please see:
Advanced Care Plan - PAEDS - 13-May-2022 10:05

Service Request - 2106201
17/05/2022

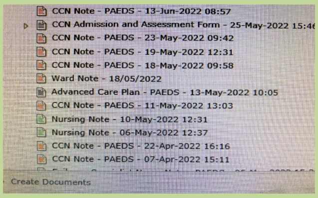
17/05/2022
17/05/2022 16:30

AWARENESS (Staff Awareness)
CAREPLAN (This patient has a specific care plan in place - Please see comments for further information)
Severe
2024798 - This patient has Emergency Care Plan for dystonic episodes. Alert document uploaded as 'paediatric document'
12/02/2020.
12/02/2020

12/02/2020
12/02/2020 15:51

AWARENESS (Staff Awareness)
CAREPLAN (This patient has a specific care plan in place - Please see comments for further information)
Severe
This patient has individual emergency care plans to be found as Patient Alert Documents (07/03/2018) under Outpatient
02/03/2018

Requested: [illegible] - PA - Paediatrics
Reference: INC68872
01/09/2017



CCN Note - PAEDS - 13-Jun-2022 08:57
CCN Admission and Assessment Form - 25-May-2022 15:46
CCN Note - PAEDS - 23-May-2022 09:42
CCN Note - PAEDS - 19-May-2022 12:31
CCN Note - PAEDS - 18-May-2022 09:58
Ward Note - 18/05/2022
Advanced Care Plan - PAEDS - 13-May-2022 10:05
CCN Note - PAEDS - 11-May-2022 13:03
Nursing Note - 10-May-2022 12:31
Nursing Note - 06-May-2022 12:37
CCN Note - PAEDS - 22-Apr-2022 16:16
CCN Note - PAEDS - 07-Apr-2022 15:11
Create Documents

Advance care plan on the tree

Run Chart

1. 1st arrow correlates to the CNN's talk, after which a marginal improvement is observed.
2. 2nd arrow corresponds to meeting with the PPC lead, when the ACP review and update date was modified. Between the 20th of March until the 27th of May there was an upwards showing that there was a gradual improvement.
3. The 3rd, and 4th arrows percentage of patients who have had the ACPs done in 2021, that needed a review.
4. The 5th arrow corresponds to 3 new referrals, a busy time with an EoL case and staff shortening.

Results:

- The adjustments of the database were implemented. It records the patient information of the referrals to the PPC team.
- The number of in-date ACPs improved by 16%.
- 16% of patients had the ACPs in progress.
- 21% had an out-of-date ACP
- 33% still have no ACP.
- 46% of patients have and alarm, have had the ACP scanned to EPR and have had the ACP distributed.

Conclusions:

Evidence regarding documentation of paediatric ACP on EPR is scarce. Teamwork and leadership are very important to achieve the aim of improving the standards of care we provide to our patients. It was also demonstrated all the challenges involved in managing change, which is possible despite happening at slow pace. Although the improvement seems small in numbers, the process was established, and it is the base to continue to work on increasing the percentage of in-date ACPs.

Acknowledgements: Dr Fiona Rawlinson for all her guidance, advice, encouragement and patience during these months of supervision.

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The Final Journeys: Paediatric Setting Workshops

Dr Alice Anderson
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Irish Hospice Foundation

Final Journeys - Paediatric Settings

The Final Journeys – Paediatric Settings workshop aims to improve end-of-life care by promoting a culture of awareness and personal empowerment for staff.

The workshop focusses on exploring the elements that supports a culture of good end-of-life care within the hospital environment; delivering a child, young person and family-centred care approach.

Key Learning Outcomes

- Describe some elements which support a culture of good end-of-life care in your paediatric setting
- Deliver a child, young person & family-centred approach to end-of-life care
- Use effective communication skills during end-of-life care
- Provide supportive care to families after death
- Look after yourself by exploring self-care practices

It is a one-day education workshop and is relevant for all hospital staff. It encourages a collaborative and collective approach to the provision of compassionate, empathic, and supportive culture of care for child, young people, their families, and staff. The workshop creates a reflective, safe space where staff can think about how end-of-life care is provided in their hospital.

The workshops explore some features of communication which include our own confidence and comfort in communicating with children, young people and their families at end of life; the barriers or challenges to good communication; what words and language would be helpful and useful; demonstration of empathy; responding to difficult questions within the remit of the role such as 'Am in dying'.

Poor communication is often cited as an issue in complaints about end-of-life care and developing communication skills in a supportive way for all hospital staff (clinical and non-clinical) is an important channel for cultural change.

There are a number of key points which are emphasised during training:

- It can be difficult to interpret what is going on for someone – good communication can bridge the gap and support mutual understanding
- Every child, young person and family is unique, there is 'no one size fits all' for how we communicate together
- Even with many years' experience there may be situation and encounters that catch us off guard
- Developing good communication is an ongoing process

For more information visit: www.hospicefoundation.ie

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