

© 2022. This manuscript version is made available under the CC-BY-NC-ND 4.0 license:
<http://creativecommons.org/licenses/by-nc-nd/4.0/>

COVID-19: impact on pediatric palliative care

Corresponding author: Hannah May Scott, Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, Bessemer Rd, London SE5 9RS, hannah.m.scott@kcl.ac.uk Co-authors:

Lucy Coombes, Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, London, UK; Royal Marsden NHS Foundation Trust, London, UK

Debbie Braybrook, Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, London, UK

Anna Roach, Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, London, UK; University College London, London, UK.

Daney Harðardóttir, Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, London, UK

Katherine Bristowe, Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, London, UK

Clare Ellis-Smith, Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, London, UK

Irene Higginson, Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, London, UK

Wei Gao, Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, London, UK

Myra Bluebond-Langner, University College London, Louis Dundas Centre for Children's Palliative Care, London, UK; Rutgers University, New Jersey, USA.

Bobbie Farsides, Brighton and Sussex Medical School, University of Sussex, Brighton, UK

Fliiss EM Murtagh, Wolfson Palliative Care Research Centre, Hull York Medical School, University of Hull, Hull, UK

Lorna K Fraser, Martin House Research Centre, Department of Health Sciences, University of York, York, UK

Richard Harding, Florence Nightingale Faculty of Nursing Midwifery and Palliative Care, Cicely Saunders Institute, King's College London, London, UK

On behalf of C-POS

Word count: 2455

Tables: 1

References: 6

Abstract

Context Children and young people (CYP) with life-limiting or life-threatening conditions (LLTTC) and their families are potentially vulnerable during COVID-19 lockdowns due to pre-existing high clinical support needs and social participation limitations.

Objectives To explore the impact of the COVID-19 pandemic and lockdowns on this population.

Methods Sub-analysis of an emergent COVID-19 related theme from a larger semi-structured interview study investigating priority paediatric palliative care outcomes. 106 UK-wide purposively sampled CYP with LLTTC, parent/carers, siblings, health professionals and commissioners.

Results COVID-19 was raised by participants in 12/44 interviews conducted after the UK's first confirmed COVID-19 case. Key themes included loss of vital social support, disruption to services important to families, and additional psychological distress.

Conclusions Continued delivery of child- and family-centred palliative care requires innovative assessment and delivery of psycho-social support. Disruptions within treatment and care providers may compound support needs, requiring co-ordination for families facing multi-agency delays.

Key Words

Pediatrics; Palliative care; COVID-19

Key Message

Children, young people and their families experienced loss of vital sources of social support, disruption to services important to families, and additional psychological distress during the pandemic. Thus child- and family-centred palliative care requires the delivery of additional psychosocial support, engagement in decision-making, and co-ordination for families facing multi-agency delays.

INTRODUCTION

Children and young people (CYP) living with life-limiting and life-threatening conditions (LLTTC) have many symptoms and concerns that span health and social care domains¹. Social connectedness and retaining a degree of normalcy is vital for their quality of life¹. In the context of the COVID-19 global pandemic CYP with LLTTC and their families in the UK were required to isolate indefinitely, from 29th March 2020 onwards with no certainty of when restrictions would be lifted due to their 'extremely clinically vulnerable' health status²⁻⁴. The primary aim of the qualitative interview phase of the Children's Palliative Care Outcome Scale (C-POS) study was to identify which child- and family-centred outcomes are most important to CYP with LLTTC and their families. In subsequent phases we develop and test items to measure core outcomes for this population, as part of a cross-national programme to advance

the science of measurement in paediatric palliative care. The theme of COVID-19 related issues emerged in interviews conducted after the UK's first confirmed COVID-19 case providing a unique opportunity to explore the impact of the pandemic on this population. This brief report describes how the COVID-19 pandemic and lockdown measures impacted CYP with LLLTC and their families.

METHODS

Recruitment and sampling

Health and social care professionals (HSPCs) and CYP, parents/carers and siblings, identified by their palliative care teams were recruited from six hospitals and three children's hospices within the UK. Commissioners of UK pediatric palliative care services were recruited via a national children's palliative care non-governmental organisation and HSPCs recommendations. Inclusion criteria: CYP 5-17 years with any LLLTC; parents/carers with a CYP <18 with any LLLTC; siblings 5-17 years of CYP <18 with any LLLTC; any HSCP with >6 months experience caring for CYP <18 with any LLLTC; commissioners responsible for commissioning UK pediatric palliative care services.

Exclusion criteria: CYP unable to communicate any views or wishes; speaks a language not supported by the NHS Trust translation service; currently enrolled in another study; deemed clinically unable to give consent/assent. Parents/carers and siblings: deemed clinically unable to give consent/assent or speaks a language not supported by the NHS Trust translation service.

CYP and their families were purposively sampled to ensure a wide range of ages and LLLTC.

Ethical approval

Granted by the Bloomsbury research ethics committee (HRA:19/LO/0033).

Data collection

106 semi-structured interviews were undertaken by LC, DB, and AR from March 2019 to September 2020 as part of the larger C-POS study to identify the symptoms and concerns most important to CYP with LLLTC and their families across physical, emotional, social, and spiritual domains of care. 44 interviews (N=16 CYP, 18 parents/carers, four siblings, six commissioners) were conducted after the first UK cases of COVID-19 were confirmed by the Chief Medical Officer on 31st January 2020. All interviews with HSPCs were conducted in 2019. Whilst most were conducted face-to-face before the pandemic, later interviews were remote (telephone or video) following UK lockdown measures introduced in March 2020. Interviews were audio recorded, transcribed verbatim and pseudonymised.

Analysis

Transcripts were coded by LC, DB, AR, DH, and HS in NVivo (Version 12). Inductive thematic coding used the 5-step process of Framework Analysis: familiarisation, constructing a thematic framework, indexing and sorting, charting, and mapping/interpretation.

RESULTS

Participant characteristics

COVID-19 related issues, although not directly asked about, were reported in 12 interviews. Of the 12 participants who mentioned COVID-related issues, 2/7 parent/carer interviews were between initial outbreak of COVID-19 and the start of the first UK lockdown on 23rd March 2020; 3/3 CYP, 5/7 parent/carer, and 2/2 commissioner interviews were conducted after this date but during the early

pandemic. To protect anonymity of CYP with rare LLLTC, International Classification of Diseases-10 (ICD-10) chapter headings have been used in lieu of precise diagnosis (see Table 1).

<i>Table 1 Demographic details of participants</i>		N or median (range)
Children and Young People (n=3)		
Age (yrs)		14 (10-17)
Gender	<i>Female:Male</i>	2:1
Diagnosis	<i>Cancer</i>	2
	<i>Neurological</i>	1
Parent/carers (n=7)		
Age (yrs)		53 (21-65)
Gender	<i>Female:Male</i>	3:4
Relationship to child	<i>Father</i>	4
	<i>Mother</i>	2
	<i>Sibling Caregiver</i>	1
Diagnosis of child	<i>Cancer</i>	4
	<i>Congenital</i>	2
	<i>Neurological</i>	1
Age of child with LLLTC (years)		15 (0-17)
Commissioners (n=2)		
Gender	<i>Female:Male</i>	2:0
Geographical location	<i>Yorkshire and Humber</i>	2

Findings

Three main themes were identified that describe the additional impacts experienced by CYP with LLLTC and their families: loss of vital sources of social support, disruption to services important to families, and additional psychological distress.

Loss of vital sources of social support

CYP with LLLTC described their sadness at losing their already limited social contact.

“I love meeting up with like my best friend [...] but obviously it’s getting more difficult with everything that’s going on” - CYP, aged 14, living with cancer diagnosis [ICD-10] (August 2020)

School closures had a significant impact, further isolating CYP from their friends and unsurprisingly, like other children surveyed, CYP with LLLTC also described a loss of normalcy with limited social contact⁵.

“I felt different when I was in school, it felt like I was...I was getting to norm...back to normal [...] and then we had to stop” - CYP, aged 17, living with cancer diagnosis [ICD-10] (June 2020)

For parents and carers and family members, this loss extended to vital sources of care and support from extended family and friends.

“But I think it’s been difficult with COVID as well...like not being in touch with friends so much” - Parent/carer of CYP aged 17, living with cancer diagnosis [ICD-10] (June 2020)

“I think the main thing for me is for COVID to go away and then we get more families come round and help support us you know [...] so I think as soon as COVID is gone umm we’ll probably get a bit more family support” - Parent/carer of CYP aged 11 months, living with cancer diagnosis [ICD-10] (July 2020)

Parents and carers described the exhaustion they experienced, and the increased burden of care due to the sudden loss of their support network.

“I’m actually the main carer now, so I’m literally everything to be honest with you [...] but sometimes I don’t think I can do all of it by myself! It’s a bit draining and exhausting... being responsible for all of it” - Parent/carer of CYP aged 17, living with cancer diagnosis [ICD-10] (June 2020)

Disruption to services important to families

Alongside the loss of social support, CYP and their families described disruptions to essential health and social care services.

“Things were slowed down a bit because of the whole COVID thing of er erm we he couldn’t go into the it was either the GP surgery or the local [local hospital]” - Parent/carer of CYP aged 11 months, living with cancer diagnosis [ICD-10] (July 2020)

These included missed chemotherapy sessions, lack of access to specialist services, and reduced face to face appointments with many appointments instead being conducted virtually.

"In May he started the chemotherapy, which was oral chemotherapy, and the consultant said it would be for a year. So that just finished in April this year but he should have, it should have been in May, we missed the 12th one because of COVID" - Parent/carer of CYP aged 17, living with cancer diagnosis [ICD-10] (June 2020)

"Well due to the current situation it's been hard to see my consultant, so it's had...I haven't seen him in a long time...erm I've seen him in hospital, but I haven't seen him recently [...] we were going to have video calls with him [...] 'Cause it's was more safer" - CYP, aged 17, living with cancer diagnosis [ICD-10] (June 2020)

In addition, vital modifications to the home were delayed, and respite provision reduced or cancelled.

"prior to COVID, they have to, they will be doing adaptations to the bathroom. At the moment we have a bath and he needs a shower facility, so we're waiting for that to happen as well" - Parent/carer of CYP aged 17, living with cancer diagnosis [ICD-10] (June 2020)

"So at the moment, we're just waiting. There was a delay 'cause of COVID, 'cause there's quite a lot of adaptations that need to be found to the foster parents house" – Commissioner (September 2020)

"During COVID [Hospices have] not been able to provide the same amount of respite" – Commissioner (September 2020)

This resulted in additional strain to the home care situation for CYP and families, further compounded by their loss of informal social support networks.

Additional psychological distress

CYP and their families expressed concerns about the psychological impact of COVID-19, with many parents and carers noting the negative impact on their mental health due to the loss of support networks and the additional burden of care due to COVID-19.

"this is a lot for you know mine and [wife's] mental health this is a lot more difficult now erm back when COVID, childcare, care for [child], trying to work [...] I don't think we could do this for an extended period of time [...] I don't think we would umm be able to cope with it" - Parent/carer of CYP aged 11 months, living with cancer diagnosis [ICD-10] (July 2020)

CYP and families were worried about COVID-19 generally, and this was often intensified for those CYP who were immunocompromised or living with conditions that increased their vulnerability.

"There can be times when, whilst lockdown has been up here, so sometimes I worry about things" - CYP, aged 17, living with cancer diagnosis [ICD-10] (June 2020)

"I mean very topically we're slightly concerned about the coronavirus thing, because he's immunocompromised and there's...it's changing every day, there's not much

*information.” - Parent/carer of CYP aged 8, living with congenital diagnosis [ICD-10]
(March 2020)*

A lack of clear communication from schools also increased anxiety for parents and carers, particularly from specialist education provision where there were different rules in relation to school opening.

“so there’s no information really about...because are special schools a bit different to normal schools in that the kids there are a bit more sick [...] the gravity of it is slightly greater and the unpredictability is greater” - Parent/carer of CYP aged 8, living with congenital diagnosis [ICD-10] (March 2020)

DISCUSSION

CYP with LLLTC and their families have faced additional challenges during the COVID-19 pandemic compared to before the pandemic. These challenges are related to changes in service provision, cancellation of appointments, delays in necessary home adaptations, and loss of both respite and inhome carers, each increasing the burden of care on other family members. For many families, this was compounded by the loss of friend and family support networks, which together had a negative psychological impact on their wellbeing. Many families were worried about COVID-19, but evidence suggests that CYP with ‘extremely clinically vulnerable’ health status and their families have particular concerns due to CYP being immunocompromised and at greater risk of poorer outcomes²⁻⁴.

Health services have faced significant challenges as a result of the pandemic⁶, and the impacts for CYP with LLLTC and their families have been wide ranging. Delays or cancellation of services that are important to families, alongside loss of informal sources of support, have left families feeling isolated. The increased use of telehealth and online consultations has brought opportunity and challenge^{3 6}. HSCPs should communicate clearly with families if treatment plans need to change, provide up-to-date information about the impact of COVID-19 on treatment and services, and engage CYP and their families in decision-making processes.

Families also need additional support due to the reduction in respite, home care, and family support, which have led to increased burden of care on families⁴. Where possible, respite providers should consider novel ways in which they can continue to support families, such as through telehealth programmes³. The additional burden of care, coupled with isolation, requires timely psychological support by existing teams known to the family.

However, a key limitation of this analysis was the absence of non-English speaking participants in the study meaning issues arising as a result of language barriers were unable to be explored.

CONCLUSIONS

This brief report has revealed the ways in which the COVID-19 pandemic and subsequent response has impacted the lives of CYP with LLLTC and their families. The analysis has highlighted the wide ranging and long-lasting impact on family life of social isolation, increased family burden of caring, and disruption and delays to important health and social care provision. The psychological impact of the uncertainty about the pandemic and the future, and loss of support networks on the mental wellbeing of CYP and their families is also evident.

Going forwards, CYP and their families must be informed of the potential impact of the COVID-19 pandemic for them specifically. CYP and their families should also be actively engaged in decision making if treatment plans change. Service providers should carefully review their responses to the pandemic to ensure they are able to continue to assess and support family psychosocial needs.

Disclosure/Conflict of Interest

No conflicts of interest declared

Principal Investigator: Richard Harding. This article reflects only the author's views and the European Research Council is not liable for any use that may be made of the information contained therein.

Professor Fliss Murtagh is a UK National Institute for Health Research (NIHR) Senior Investigator. The views expressed in this article are those of the author(s) and not necessarily those of the NIHR, or the Department of Health and Social Care.

Professor Myra Bluebond-Langner's post is supported by funding from The True Colours Trust. All research at Great Ormond Street Hospital NHS Foundation Trust is made possible by the NIHR Great Ormond Street Hospital Biomedical Research Centre.

The C-POS study is supported by the NIHR Applied Research Collaboration South London (NIHR ARC South London) at King's College Hospital NHS Foundation Trust. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Acknowledgments

We thank the European Research Council for the financial support needed to undertake this study. The Children's Palliative care Outcome Scale (C-POS) Study Steering Group members are: AnnaKarenia Anderson, Lydia Bates, Rachel Burman, Lizzie Chambers, Alan Craft, Finella Craig, Aislinn Delaney, Julia Downing, Sara Fovargue, Ann Goldman, Jane Green, Ping Guo, Julie Hall-Carmichael, Michelle Hills, Mevhibe Hocaoglu, Gill Hughes, Joanna Laddie, Angela Logun, Steve Marshall, Linda Maynard, Andrina McCormack, Renee McCulloch, Eve Namisango, Cheryl Norman, Susan Picton, Pat Sartori.

Contributors

RH conceived the project and provided supervision throughout alongside IH, GW, MB-L, BF, FM, LF, CE-S and KB. LC, DB and AR did the data collection and LC, DB, AR, DH and HS performed initial analysis. HS performed further analysis and prepared the manuscript for submission.

Funding

This work was supported by the European Research Council's Horizon 2020 programme [Grant ID: 772635].

Patient consent for publication

Permission given for anonymised direct quotes to be used in the report, publications and presentations

Data availability statement

No data are available. Not applicable.

REFERENCES

1. Namisango E, Bristowe K, Allsop MJ, et al. Symptoms and Concerns Among Children and Young People with Life-Limiting and Life-Threatening Conditions: A Systematic Review Highlighting Meaningful Health Outcomes. *The Patient - Patient-Centered Outcomes Research* 2019;12(1):15-55. doi: 10.1007/s40271-018-0333-5
2. Williams N, Radia T, Harman K, et al. COVID-19 Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection in children and adolescents: a systematic review of critically unwell children and the association with underlying comorbidities. *European Journal of Pediatrics* 2021;180(3):689-97. doi: 10.1007/s00431-020-03801-6
3. Ellis K, Lindley LC. A Virtual Children's Hospice in Response to COVID-19: The Scottish Experience. *Journal of Pain and Symptom Management* 2020;60(2):e40-e43. doi: 10.1016/j.jpainsymman.2020.05.011
4. Lunt C. No end in sight: The Impact of the Pandemic on Disabled Children, their Parents and Siblings 2021.
5. Loades ME, Chatburn E, Higson-Sweeney N, et al. Rapid Systematic Review: The Impact of Social Isolation and Loneliness on the Mental Health of Children and Adolescents in the Context of COVID-19. *Journal of the American Academy of Child & Adolescent Psychiatry* 2020;59(11):1218-39.e3. doi: 10.1016/j.jaac.2020.05.009
6. McNeil MJ, Kaye EC, Vedaraju Y, et al. Global Experiences of Pediatric Palliative Care Teams During the First 6 Months of the SARS-CoV-2 Pandemic. *Journal of Pain and Symptom Management* 2021 doi: 10.1016/j.jpainsymman.2021.03.016