The Martin House RESEARCH CENTRE

In partnership with

UNIVERSITY of York

The Martin House Research Centre

THE FIRST FIVE YEARS: 2017 TO 2021

RESEARCH AT YORK

CREATIVITY

CULTURE & COMMUNICATION

ENVIRONMENTAL SUSTAINABILITY & RESILIENCE

HEALTH & WELLBEING

JUSTICE & EQUALITY

RISK, EVIDENCE & DECISION MAKING

TECHNOLOGIES FOR THE FUTURE

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Introduction

The Martin House Research Centre is a partnership between Martin House Children's Hospice, the University of York (Department of Health Sciences and the Social Policy Research Unit) and the University of Leeds. It undertakes research concerning the care and support of children and young people with life-limiting conditions or medical complexity, their families and staff who care for and support this population. It is a multi-disciplinary centre, with expertise in a range of research designs and methods. The Centre is holistic in its scope, recognising that the care and support needs of children and families span clinical/medical, social, emotional, parenting/caring, spiritual, financial and practical domains.

Vision

The Martin House Research Centre will be a resource that, via a model of collaboration with families, professionals and academics in other institutions, undertakes and enables high quality applied research of national and international significance.

This report highlights some of our work over the first five years of the Centre and is grouped by our six research themes.

Martin House Children's Hospice

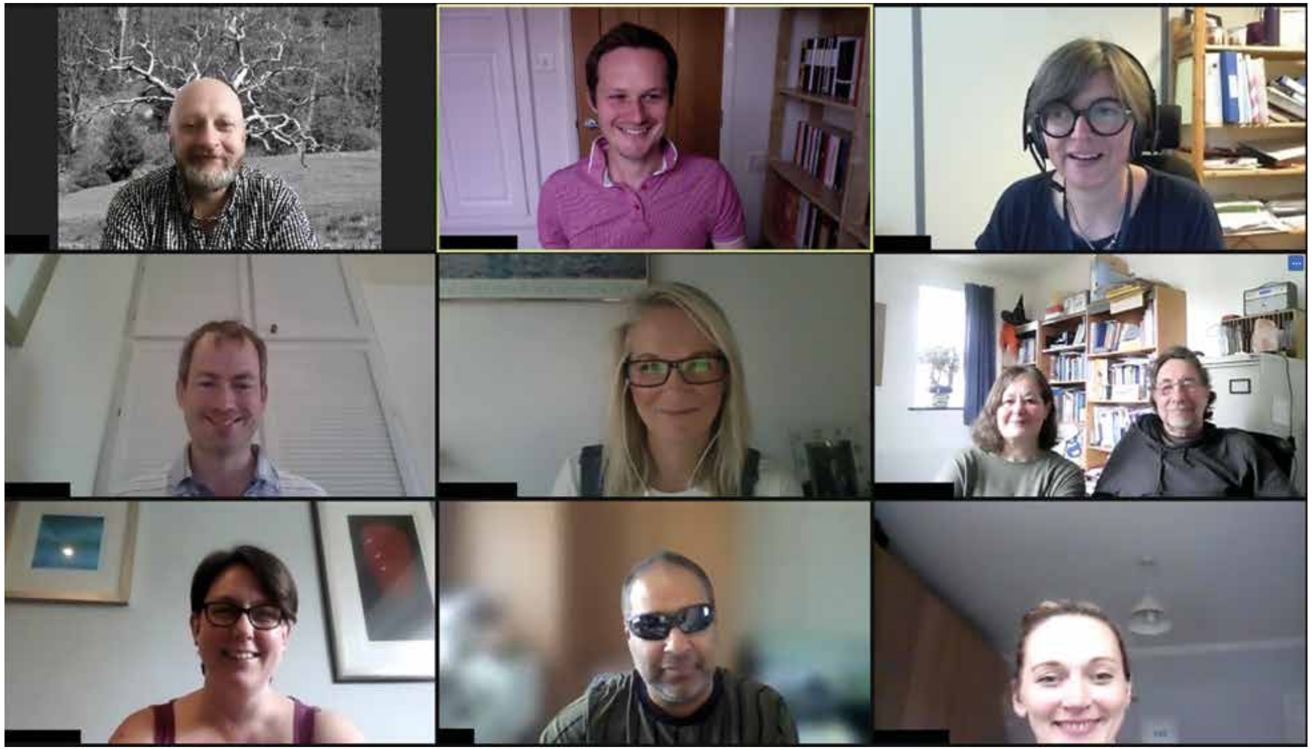
Patient and public involvement

The Centre is committed to working in such a way that all our research is informed by children and young people, their families and others who support them. To do this, we work in partnership with young people, parents, other family members and relevant organisations to enhance the quality, relevance and impact of the research that we undertake. We now have more than 40 parents and young people involved in our research studies and governance processes.

Our young people and parent contributions to our recent conference were rated very highly by the delegates and can be seen here:-

Link to conference videos

https://www.youtube.com/playlist?list=PLrNjdTIP91QH_qPEv5I_Sqge1qOABo0Ev



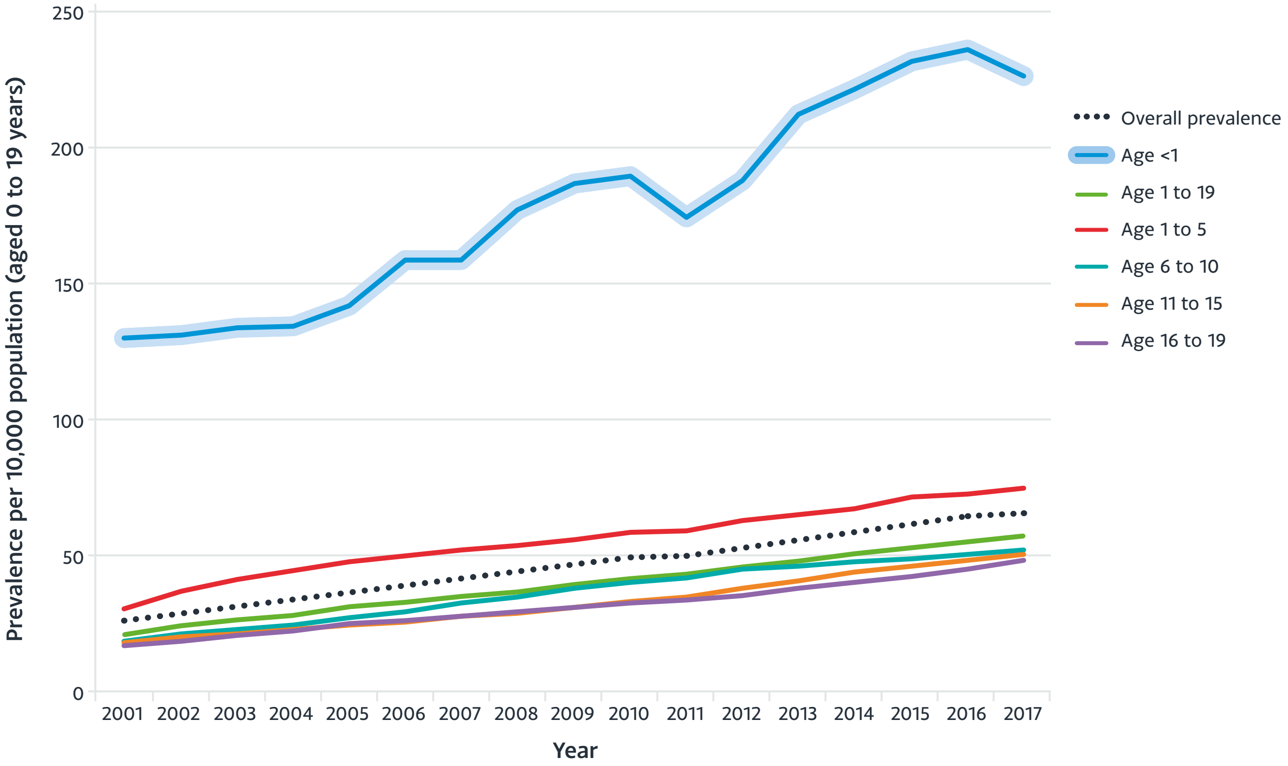
Virtual Family Advisory Board Meeting (2021)

> “Being part of the Family Advisory Board for the MHRC is one of my favourite bits of Patient and Public Involvement because I feel like we are listened to, that changes are made to research because of our input, and our expertise as carers is recognised and valued.”
>
> **Sarah, bereaved mum.**

Theme 1: Service planning, organisation and delivery

About this theme

The way services are organised and delivered, including access to services which are needed, can significantly affect the quality of care and the extent to which children and young people's needs are met. Studies within this theme range from work on primary care through to specialist palliative care, and also include work on transition between services.



Prevalence of life-limiting conditions (with 95% confidence intervals in lighter shading) by age 2001/2 to 2017/18
Graph from Make Every Child Count Study

CASE STUDY 1

Make Every Child Count

The number of children and young people aged 0 to 19 years with a life-limiting condition increased between 2002 and 2018, which may, in part, be due to young people living longer. In 2002, there were 31,000 children and young people, which means that 27 out of every 10,000 children and young people in the UK had a life-limiting condition. In 2017, this had increased to 87,000 children and young people, or 66 per 10,000 in the population. This number is expected to continue to rise to around 116,000 in 2030, indicating an increased need for children's palliative care services in all parts of the UK. These data are being used by NHS England to inform commissioning of paediatric palliative care services including children's hospices.

Link to published papers

https://doi.org/10.1177%2F0269216320975308

https://www.york.ac.uk/media/healthsciences/documents/research/public-health/mhrc/Prevalence%20reportFinal.pdf

CASE STUDY 2

The Role of GPs in Caring for Children and Young People with Life-Limiting Conditions

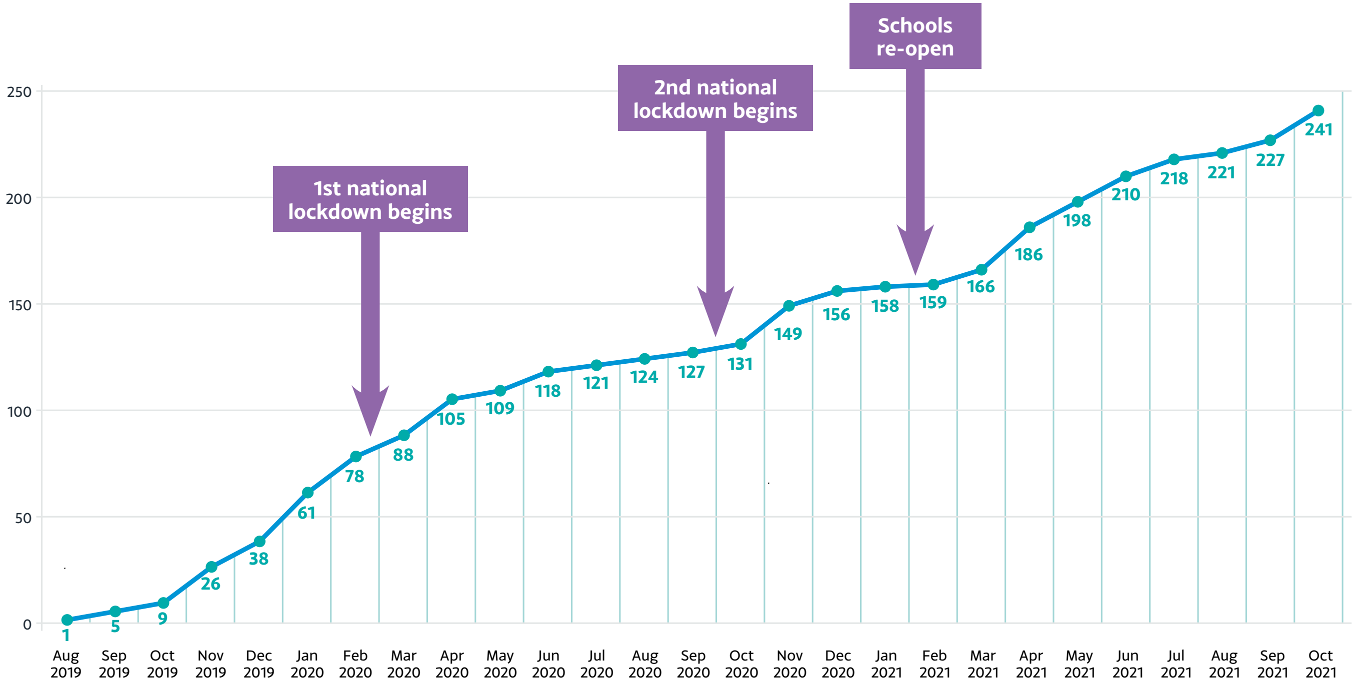
This study examined GP and hospital attendances in children and young people with life-limiting conditions, using data collected from GP practices and hospitals in England. We found that children and young people who saw a GP less regularly had more emergency admissions to hospital and more A&E visits than those having more regular GP contact. We also looked at continuity of care, and found that children who saw the same GP more often were also less likely to attend A&E departments.

At a time when general practice services are becoming increasingly fragmented, this research is an important reminder of the value of continuity of care between GPs and their patients. There is scope for improvement in communication, including sharing electronic records between paediatricians and GPs, and for truly integrated care in the community for children and young people with life-limiting conditions.

Theme 2: Clinical care

About this theme

Children and young people with medically complex or life-limiting conditions have a number of issues with their health which require careful management to ensure their symptoms are managed effectively and they are as comfortable as possible. Studies within this theme are interventions implemented and managed by the clinical team.



PARTICIPANT RECRUITMENT TO THE 'YOUR TUBE' STUDY
Recruitment to the 'Your Tube' Study began in August 2019 and was on-going through the pandemic. The use of verbal and electronic consent forms allowed recruitment to continue despite the disruption to services. Recruitment ended in October 2021 with 241 families consenting to take part. The study has an 18 month follow-up period, which will finish in May 2023.

CASE STUDY 3

The Role of Different Diets in Children who are Gastrostomy Fed 'Your Tube'

There are increasing numbers of children and young people who require having all, or part, of their nutritional intake via gastrostomy (a tube that allows a person to be fed directly into their stomach). The recommended feeds for children via gastrostomy is commercially produced formula. However, there is a growing interest in feeding children blended foods instead, or using a combination of formula feeds and home-blended meals. Currently there is little evidence about the safety and benefits of these different diets. In the first part of this study the parents, young people and professionals helped us decide what to measure in part two of the study. The key findings were:

- Sleep is a key outcome for children and parents.
- Gastrointestinal symptoms and physical health were regarded as outcomes most likely to be affected by type of diet.
- Well-being and participation were identified as key secondary outcomes.

Link to published papers

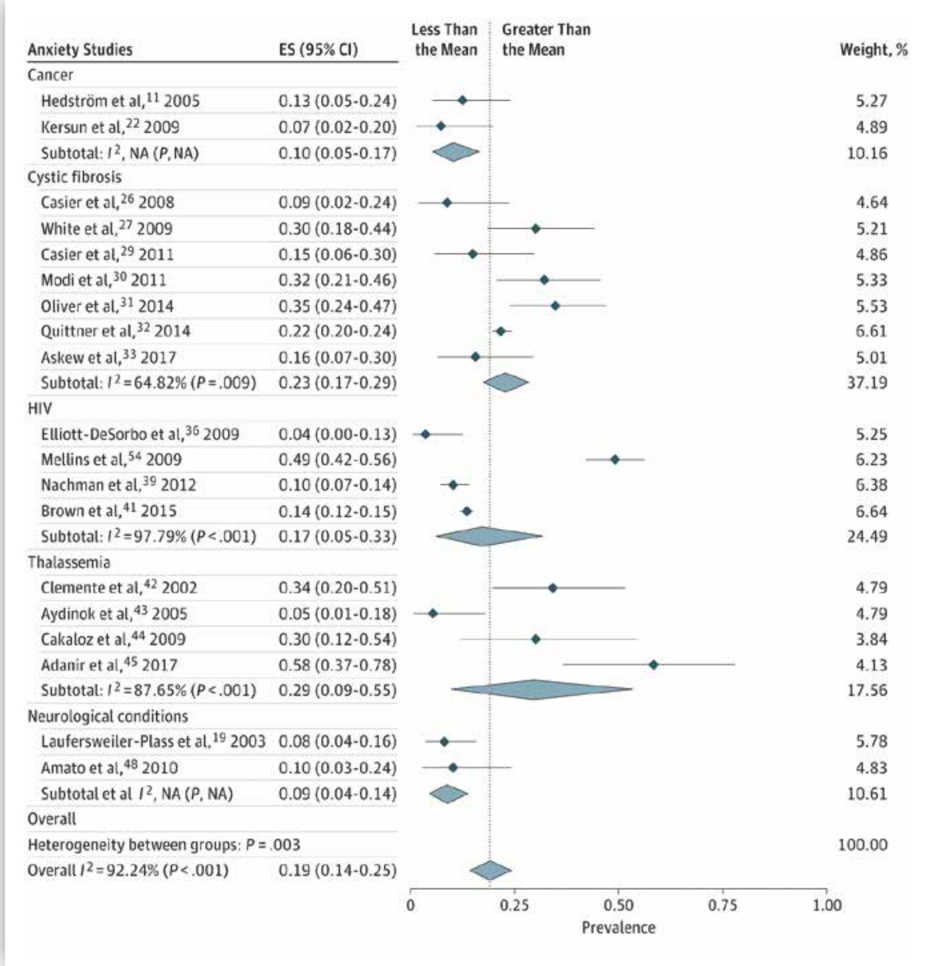
https://doi.org/10.1111/dmcn.14868

http://dx.doi.org/10.1136/bmjopen-2019-033831

Theme 3: Emotional health and wellbeing

About this theme

There are a number of reasons why having a life-limiting condition may affect a child or young person's mental health or emotional well-being. For a number of our studies children/young people's emotional well-being is among a number of outcomes we are investigating.



Anxiety Studies	ES (95% CI)	Weight, %
Cancer		
Hedström et al,[11] 2005	0.13 (0.05-0.24)	5.27
Kersun et al,[22] 2009	0.07 (0.02-0.20)	4.89
Subtotal: I^2, NA (*P*, NA)	0.10 (0.05-0.17)	10.16
Cystic fibrosis		
Casier et al,[26] 2008	0.09 (0.02-0.24)	4.64
White et al,[27] 2009	0.30 (0.18-0.44)	5.21
Casier et al,[29] 2011	0.15 (0.06-0.30)	4.86
Modi et al,[30] 2011	0.32 (0.21-0.46)	5.33
Oliver et al,[31] 2014	0.35 (0.24-0.47)	5.53
Quittner et al,[32] 2014	0.22 (0.20-0.24)	6.61
Askew et al,[33] 2017	0.16 (0.07-0.30)	5.01
Subtotal: I^2 = 64.82% (P = .009)	0.23 (0.17-0.29)	37.19
HIV		
Elliott-DeSorbo et al,[36] 2009	0.04 (0.00-0.13)	5.25
Mellins et al,[54] 2009	0.49 (0.42-0.56)	6.23
Nachman et al,[39] 2012	0.10 (0.07-0.14)	6.38
Brown et al,[41] 2015	0.14 (0.12-0.15)	6.64
Subtotal: I^2 = 97.79% (P < .001)	0.17 (0.05-0.33)	24.49
Thalassemia		
Clemente et al,[42] 2002	0.34 (0.20-0.51)	4.79
Aydinok et al,[43] 2005	0.05 (0.01-0.18)	4.79
Cakaloz et al,[44] 2009	0.30 (0.12-0.54)	3.84
Adanir et al,[45] 2017	0.58 (0.37-0.78)	4.13
Subtotal: I^2 = 87.65% (P < .001)	0.29 (0.09-0.55)	17.56
Neurological conditions		
Laufersweiler-Plass et al,[19] 2003	0.08 (0.04-0.16)	5.78
Amato et al,[48] 2010	0.10 (0.03-0.24)	4.83
Subtotal et al I^2, NA (P, NA)	0.09 (0.04-0.14)	10.61
Overall		
Heterogeneity between groups: P = .003		100.00
Overall I^2 = 92.24% (P < .001)	0.19 (0.14-0.25)	

Forest plot of pooled anxiety prevalence, grouped by life-limiting condition diagnostic group forest plot of 19 studies included in the meta-analysis of anxiety prevalence. The pooled anxiety prevalence from the meta-analysis was 19.1% (95% CI, 14.1%-24.6%). ES indicates effect size (prevalence).

CASE STUDY 4

Anxiety and Depression among Children, Adolescents, and Young Adults with Life-Limiting Conditions

Children, adolescents, and young adults with life-limiting conditions experience various challenges that may make them more vulnerable to mental health problems, such as anxiety and depression. However, the prevalence of anxiety and depression among this population appears to be unknown. In this systematic review and meta-analysis, the pooled prevalence of anxiety in 19 studies was 19.1%, with significant differences in prevalence according to the type of assessment tool used; in a meta-analysis of 36 studies, depression prevalence was 14.3% and was associated with increasing age.

The high prevalence of anxiety and depression in children, adolescents, and young adults with life-limiting conditions highlights the need for improved services to address their psychological needs.

Link to published paper

http://jamanetwork.com/article.aspx?doi=10.1001/jamapediatrics.2019.1712

Theme 4: Bereavement

About this theme

Work under this theme concerns the experience of bereavement care and support that is provided to bereaved parents, both prior to and after the death of their child.

CASE STUDY 5

Current Evidence about Bereavement Support for Parents

Only eight research studies have been published in this topic since 1980, nearly all of which were conducted in the USA and in young babies. These studies used very different interventions, which were poorly described. They also measured lots of different outcomes including parental grief, mental and physical health, social functioning, and religious beliefs. Only three of these studies reported a finding that suggests parents might benefit from a bereavement support intervention. However, there were significant concerns about the quality of study methods and the outcomes used to assess effectiveness. This means that current research cannot tell us whether bereavement interventions are helpful to parents or not.

Link to published paper

http://dx.doi.org/10.1136/bmjspcare-2019-001823

CASE STUDY 6

Early Days

The death of a child is a distressing experience. Evidence on the benefits and value to parents of spending time with their child following their death, means this is integrated into routine care. Importantly, parents report that they want to spend time with their dead child. However, whilst many parents are given the opportunity to do this, it is typically limited to a few hours, to prevent deterioration. In the UK, all children's hospices offer parents the use of cooling facilities to extend this period of time.

In this study, we surveyed children's hospices about their provision and practices regarding cooling facilities. We also spoke to bereaved parents who had used them. We found that provision, usage, and access to cooling facilities is varied. In particular, there were differences in the amount of time families were able, and wanted, to use them. Parents believed that using a cooling facility enabled them to begin to engage with their grief. Use of cooling facilities may influence bereavement outcomes in the longer term.

Whilst parents differed in how they used cooling facilities, all believed it had positively impacted their experiences of the early days of bereavement and ongoing grief. Our findings support the practice of offering bereaved parents the opportunity to use a cooling facility. We need further research to explore whether place of use impacts experiences and outcomes. We also need to understand why some parents choose not to use a cooling facility, and impacts of cooling facility use on parents' bereavement outcomes in the longer term.

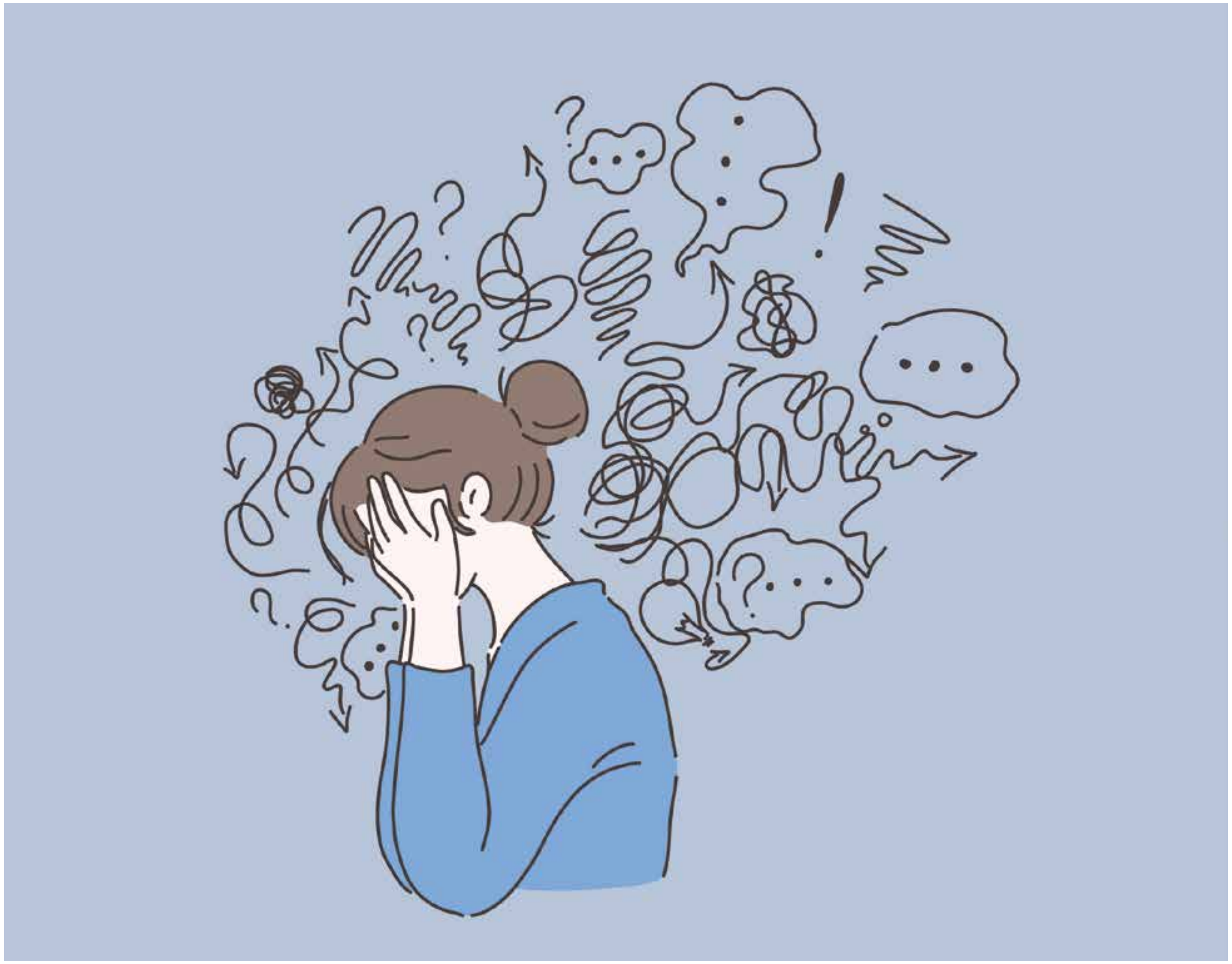
Link to published paper

https://journals.sagepub.com/doi/pdf/10.1177/0269216320984335

Theme 5: Parents and families

About this theme

The studies within this theme concern parents and other family members. They include work on emotional and physical well-being, and the experiences of having a child with medical complexity or a life-limiting condition.



CASE STUDY 7

The Experiences of Fathers of Children with a Life-Limiting Condition

This study examined evidence from 30 published studies about the experiences of fathers of children with a life-limiting condition. Studies highlight fathers' experiences of uncertainty throughout their child's illness and working fathers' difficulties in balancing their roles at work and home. Findings also tell us about problems experienced by fathers in discussing their emotions, seeking support, and forming relationships with healthcare professionals as well as feeling side-lined in their child's care. They described the life-changing nature of their child's diagnosis, affecting all aspects of their lives, from everyday activities to their relationships, spirituality, values, and ambitions.

Link to published paper

http://dx.doi.org/10.1136/bmjspcare-2021-003019

CASE STUDY 8

Mothers' Health and Wellbeing

Many children in the UK live with medical conditions that may shorten their life, which is often referred to as a life-limiting condition. Mothers of these children commonly end up coordinating and providing their child's healthcare for 24 hours a day, seven days a week.

Using data for 35,000 mothers, we found the rates of common physical and mental health conditions were higher in mothers of children with a life-limiting condition when compared to mothers whose children had other long-term conditions, e.g. asthma, or no long-term conditions. For example, depression was 20 per cent higher and heart disease was 75 per cent higher when compared with mothers of children with no long-term conditions.

Further research is required to understand how best to support these mothers, and healthcare providers should consider providing preventative and treatment services.

Link to published paper

http://dx.doi.org/10.1136/archdischild-2020-320655

Theme 6: Workforce

About this theme

The focus of this theme is the implications of working in settings where children and young people are at end of life or receiving palliative care in terms of implications for, and impacts on, the staff involved.

Martin House Hospice staff (2018)

CASE STUDY 9

Working Together to Deliver Children's Palliative Care across a Region

Managed clinical networks – formalised groups of health staff and organisations who work together – have been recommended as a solution to the inequity in access to paediatric palliative care. This study showed that having a paid member of staff who coordinates the network, enthusiastic individuals who lead the network, and clear ways for staff to get involved, were all factors that helped the network to become established and share best practices. However, key barriers made it difficult for the network to assess and improve children's palliative care across the region. These included limited funding, difficulty sharing information, and the lack of standards and evidence for children's palliative care.

Link to published paper

https://doi.org/10.1186/s12904-021-00712-7

CASE STUDY 10

Informing Staff Support Interventions and Practices in Children's Hospices (SWICH)

The children's hospice sector has become increasingly concerned about levels of work-related stress among its staff. This stems from increasing evidence that staff wellbeing is associated with the quality, cost and safety of patient care, and an acknowledgment of the important role of those working in children's hospices.

This study aimed to increase understanding about the work-related stressors and rewards experienced by children's hospice care staff, and to identify the staff support systems and organisational practices that offer the most potential to enhance wellbeing at work.

A national survey found hospice staff respondents had an average burnout score of 32.5 (n=500), which is lower than the average score of 45.7 amongst a sample of NHS staff during Covid-19. Thirty-four percent of respondents (n=418) had felt unwell as a result of stress in the last 12 months.

Further data analysis for the study will explore how these outcomes relate to the work-related stressors and rewards of working in a children's hospice, and what staff support systems and organisational practices have an impact on psychological wellbeing.

Link to published abstract

http://dx.doi.org/10.1136/spcare-2021-Hospice.204

COVID-19 pandemic

The pandemic was an extremely worrying time for families of children with a life-limiting condition and the healthcare staff that look after them. The Centre team were involved in a number of collaborative COVID related studies.

CASE STUDY 11

Identifying those Children and Young People at most Risk of Serious Illness from COVID 19

COVID-19 infection is usually mild and asymptomatic in children, but we know some children have required admission to hospital with COVID-19. In order to guide families, clinicians and policy makers about future shielding policies, school attendance and vaccine prioritisation we assessed which children and young people were at risk of severe illness with COVID-19.

In England, 5830 children were admitted to hospital with COVID-19 and 251 went to PICU in the first year of the pandemic. Those from non-white ethnic groups and chronic conditions were more likely to go to intensive care. 61 children died after having a positive COVID-19 test; 25 of these children were deemed as having died from COVID-19 by clinical experts; 15 of these 25 children had a life-limiting condition and 13 had a complex neurodisability.

Children at highest risk from COVID-19 are those known to be at risk from any winter virus or other illness e.g. those with complex disabilities and other health conditions, but even in those groups, risk remains low.

Link to published paper

https://doi.org/10.1038/s41591-021-01578-1

Organisations:

UCL Great Ormond St. Institute of Child Health, RCPCH, NHS England, University of Bristol, PHE, Imperial College London, University of Liverpool

CASE STUDY 12

Rapid Evaluation of the COVID-19 Pandemic Response in Palliative and End of Life Care: National Delivery, Workforce and Symptom Management (CovPall)

This multinational survey of palliative care providers demonstrated that shortages were common. 48% of services reported shortages of Personal Protective Equipment (PPE), 40% staff shortages, 24% medicines shortages, 14% shortages of other equipment. These shortages were more likely in charity funded organisations than in the public sector.

Organisations:

Lead Kings College London, Hull York Medical School, University of Lancaster

Link to published paper

https://doi.org/10.1016/j.jpainsymman.2021.01.138

Capacity building

Building capacity within the children's palliative care sector and academia is a key aim of the Martin House Research Centre team. The Centre team has grown to include 13 researchers, PhD students and support staff. The Centre team contribute to teaching on modules for undergraduate nursing and medical students.

CASE STUDY 13

Vicky Kammin

Vicky is a Music Therapist with more than 20 years' experience working in children's hospices and started her part-time PhD with the Centre in October 2020.

Children and young people with life-limiting conditions and their families face significant challenges in their lives. Music therapy is reported to help improve their quality of life and wellbeing by offering an alternative means of emotional expression, supporting relationships and creating memories. However, there is little evidence about the specific benefits of music therapy for children with life-limiting conditions or understanding about how and when music therapy should be used in children's palliative care.

Her research aims to develop evidence about the potential benefits of music therapy in children's palliative care and increase understanding about how music therapy should be delivered for children with life-limiting conditions.

CASE STUDY 14

Stuart Jarvis

Stuart is a research fellow in the final year of his PhD funded by the NIHR Academy. His PhD question is one that has been raised by our parents – Transitioning from paediatric to adult healthcare with a life limiting condition; does this lead to increased healthcare usage, cost and worse patient outcomes?

His review of published literature highlights that the evidence for changes in healthcare use at the transition is mixed and conflicting, although there appears to be evidence for an increase in Emergency Department visits and a reduction in access to physiotherapy post-transition. He has also developed a method to more accurately identify if children are in paediatric or adult healthcare services using routine hospital data.

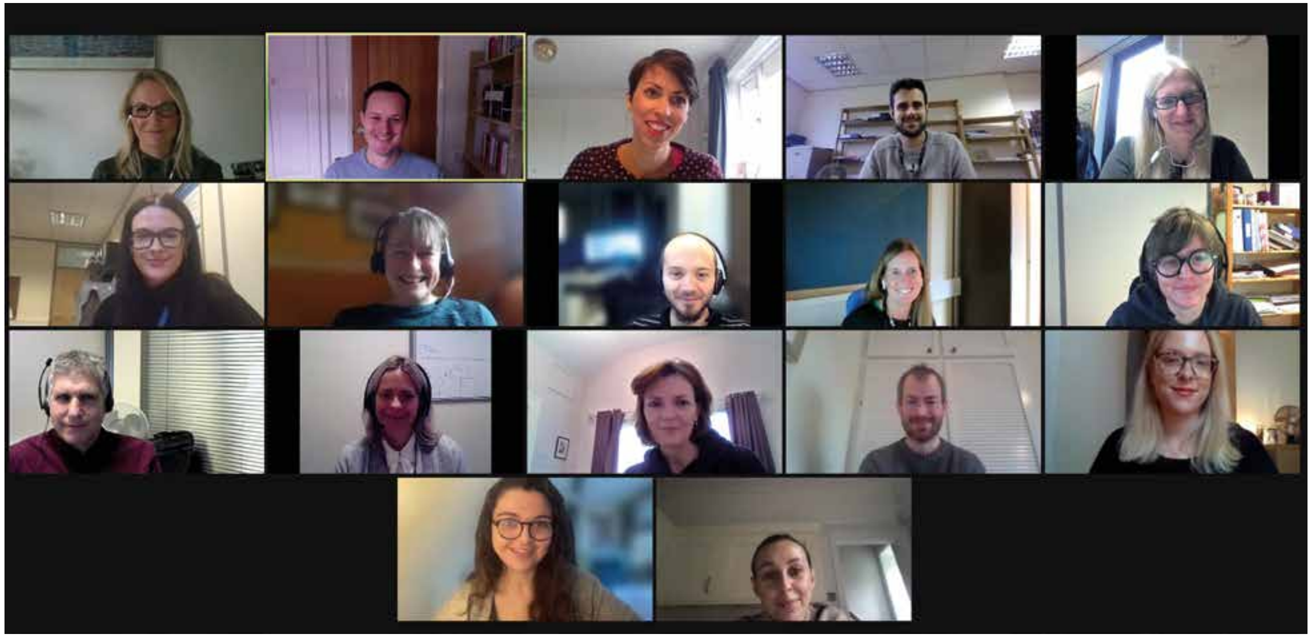
Link to published papers

https://doi.org/10.1038/s41390-021-01396-8

https://doi.org/10.23889/ijpds.v6i1.1685

Collaborative working

As well as leading many research studies, the Centre team are working with other academic and clinical colleagues on a number of other research studies both in the UK and internationally.



Virtual MHRC Team Meeting (October 2021)

CASE STUDY 15

Children's Palliative Care Outcome Scale (C-POS)

Developing a measure to assess outcomes for children and young people requiring palliative care is an international research priority. The purpose of this study is to develop and validate a person-centred outcome measure for children, young people and their families affected by life-limiting and life-threatening conditions. This novel study will draw together a unique multidisciplinary collaboration and seek to engage children within the research process, rather than relying on proxy data. Currently children and young people are often neglected in the research process and this study hopes to change this.

Lead

Professor Richard Harding, Cicely Saunders Institute, Kings College London

Link to published paper

https://doi.org/10.1007/s11136-021-02814-4

Future directions

Clinical Research

The management of distressing symptoms is a critical component of effective high-quality care for CYP with palliative care needs. Whilst standard randomised controlled trials may be possible for some symptom related research in paediatric palliative care, it may be that for some research questions alternative approaches such as more pragmatic trials or augmentation of study data with routinely collected data sources will be required.

National/International

Continuing to grow our national and international collaborations will be a key focus of the next years of the MHRC. We have just been awarded the following national NIHR partnerships award to help us achieve this:-

Developing the UK Collaborative
Paediatric Palliative cAre
Research (CoPPAR) Network

What are we aiming to achieve?

We are aiming to develop a network of academics, clinical teams (e.g. children's hospices or NHS palliative care teams) that will work together to share experiences and expertise to improve their confidence in undertaking and participating in research studies – the CoPPAR network. This network will be a single point of information, held on the Together for Short Lives website (national charity for PPC), and accessible to parents, clinicians and academics so they can find out about current and new research studies and how to get involved.

How will we achieve this?

We will work with the seven partner organisations to understand what educational needs they have and will run a series of webinars to share experiences of undertaking research in voluntary sector and NHS settings e.g. how to involve children and parents in research studies. These webinars will be accessible for all 63 children's palliative care services in the UK. The academics will also provide mentorship to any clinical staff who would like to have formal research training.

We will also work with these partners to develop applications for future research studies that are driven by their experience and needs as front line staff and with input from our PPI partners. These grants are likely to be on topics such as collecting child centred outcomes and management of distressing symptoms in palliative and end of life care in children.

Funders

Martin House Children's Hospice

True Colours Trust

Together for Short Lives

NIHR Academy

NIHR HTA

NIHR HSDR

Welsh Government

NHS England

Children's Hospitals Alliance

Make A Wish Foundation

Thank you

Team members (current)

Michelle Scaife, Centre Administrator
Dr Stuart Jarvis, Research Fellow
Dr Julia Hackett, Research Fellow
Dr Andrew Papworth, Research Fellow
Mark O'Neill, Study Co-ordinator
Victoria Fisher, Research Trainee
Andrew Haynes, Study Support Officer
Dr Andre Bedendo, Research Fellow
Laura Barrett, Research Fellow
Dr Suzanne Mukherjee, Research Fellow
Dr Natalie Richardson, Research Fellow
Diana Fields, Research Fellow
Emma McClorie, Research Fellow
Nicola O'Donnell, PhD Student

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Dr Jo Taylor, Lecturer
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Dr Tom Ainscough, Research Fellow
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Professor Neil Lunt (University of York)

Partnership Committee Members (previous)

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Our thanks to all the children, families and professionals who have participated in our studies.

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