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Parent and professional experiences of 24/7 paediatric end-of-life care: shining a light on inequity

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Background



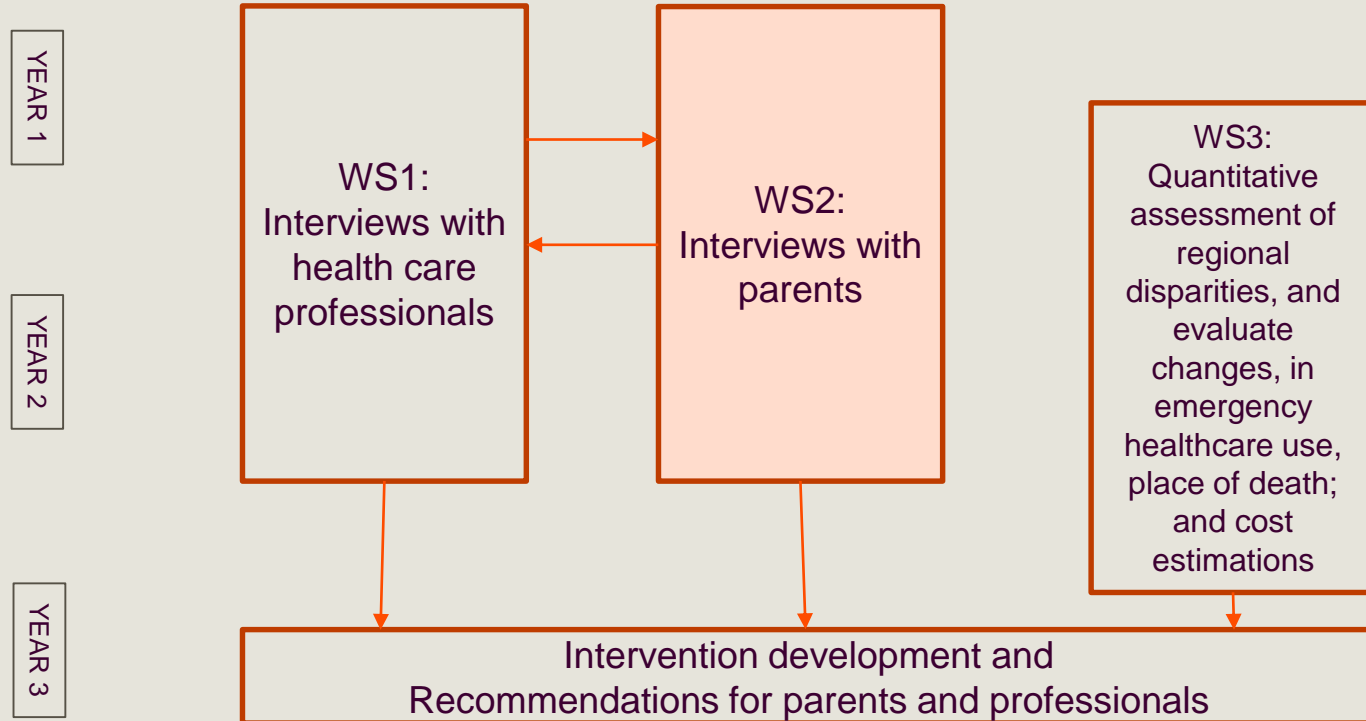
- Need for 24/7 End-of-life (EoL) care for children recognised in palliative care service specifications and NHS Ambitions of Palliative and End-of-Life Care
- Understanding that parents need support when things go wrong, can't wait for 'opening hours'
- Currently wide variation in how children's palliative care is provided both geographically and by diagnosis

Research aim



To develop a complex intervention to help the delivery of, and access to, 24/7 paediatric end-of-life care in the North-East and Yorkshire region, by assessing parent and professional experiences and needs, and patterns of care at end-of-life and outcomes in other regions where interventions have been developed

Study design



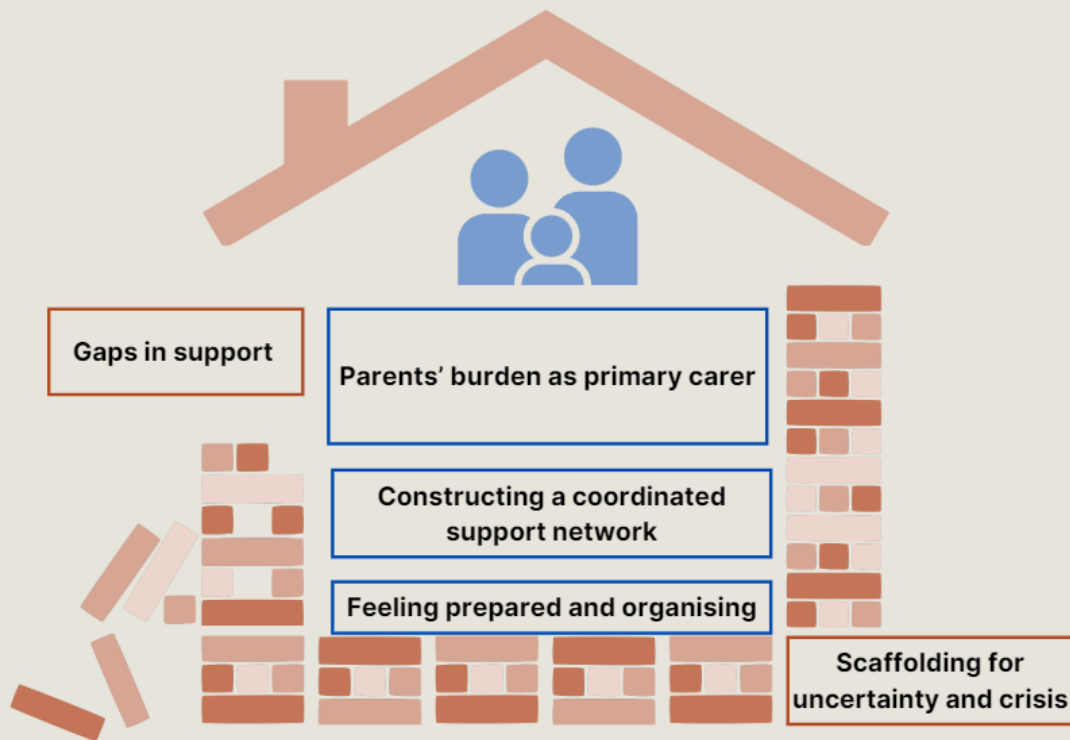
WS2 Methods

- **Design:** Qualitative study
- **Setting:** 4 ICBs in North-East and Yorkshire
- **Participants:** 26 parents: 14 parents of children receiving end-of-life care, 12 bereaved parents
- **Recruitment:** Identified through NHS sites, hospices, social media.
- **Data collection:** In-depth interviews
- **Data analysis:** Thematic Analysis

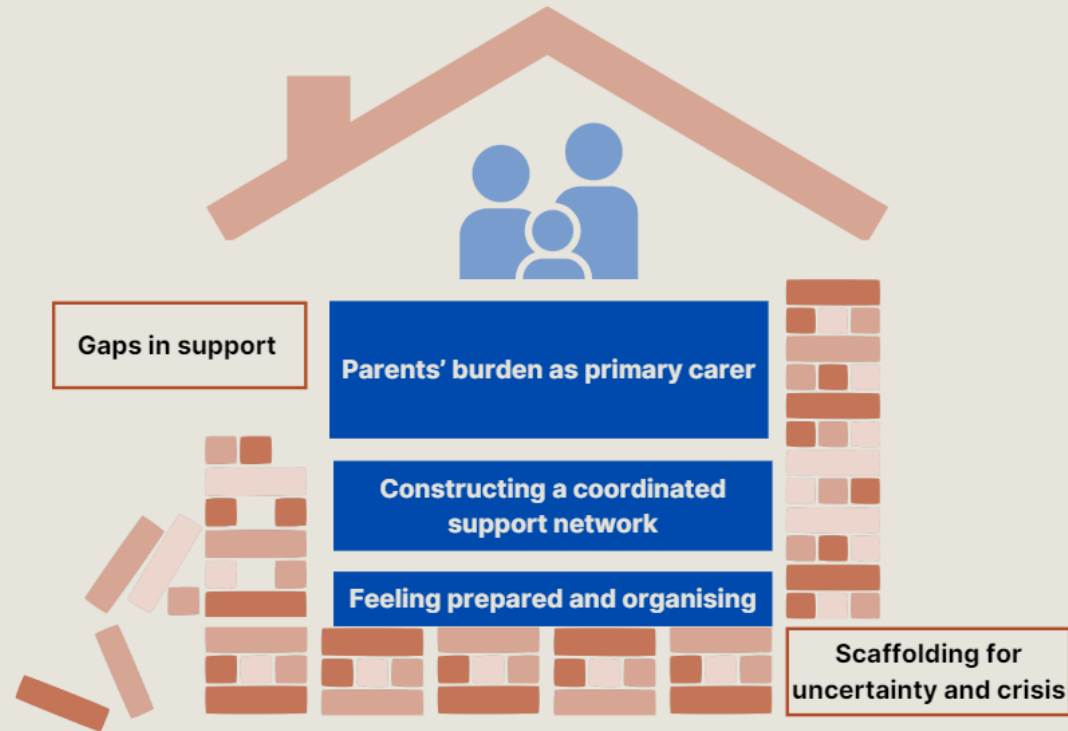
Interviews with parents of 26 children

	Cancer	Other diagnosis	Total
Died	5	7	12
Receiving care	0	14	14
Total	5	21	26

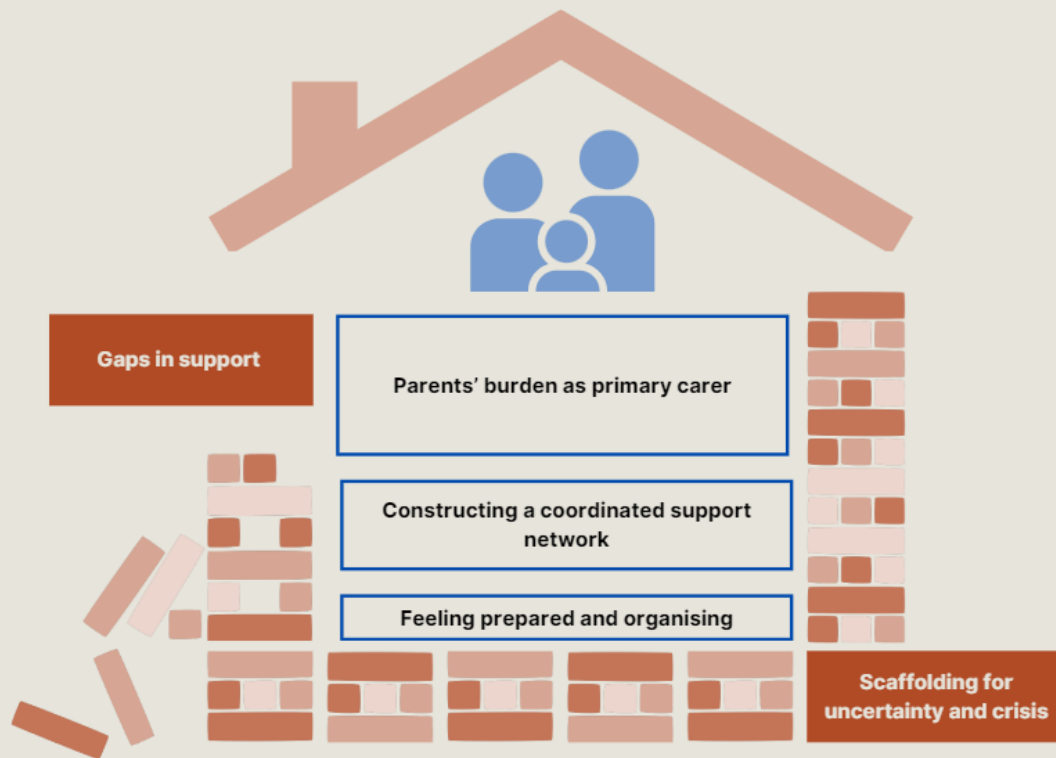
Themes



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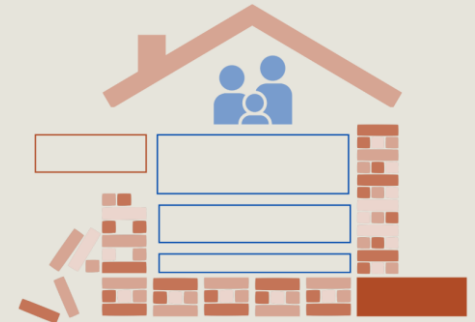
Scaffolding for uncertainty and crisis

Confidence from seamless support

*Yeah, yeah. Once we got [Hospice X], they're amazing. They are amazing [..]
Because like I rung them at 3am, 4am, 5am, like you said, just to talk it through,
they're amazing. Yeah, they listen and we could ring 24 hours a day, seven days a
week, that's what we needed. We needed that, and we utilised that a lot. (08-34)*

*It was more someone who knew [child] inside out, who knew us as a family inside
out and if I needed her at two o'clock in the morning, she'd be there (11-15)*

*And on the days where she didn't visit, she'd text me in the morning to say, um, do
I want her to come, do I want her to look over [child]. Um, so that happened for
about a week which was really reassuring and really supportive. (03-22)*



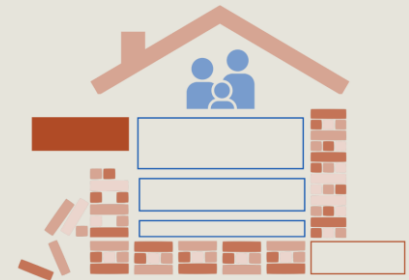
Gaps and unmet needs

Abandoned and scared

I think with anything, the support you need is on a nighttime. I think during the day everything else seems okay, you know? You've got daylight, you've got shops open, you've got the hospitals open. On a nighttime everything just feels like you're alone and it's just you and the poorly person. and on weekends you feel alone because there's not that service there, erm, and I think that that's hard. (02-35)

..but we needed their help, and we were scared. Like we were really scared Yeah, it's like a trauma, like what we had to do. We should have at least had help to do it. Like we were all petrified. (08-34)

it's a little bit of a panic for us as well cos we're like, oh God, we've gotta get it done before they go off for weekend or oh God, we gotta get it done before they go off at night. (03-24)



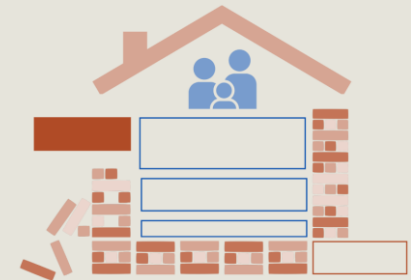
Gaps and unmet needs

Navigating limited support

Yes, I'd a lot of open access even to the point where because I was becoming that worried, it would be, right, bring her in (11-15)

They [the nurses] were absolutely petrified. And we had it said on more than one occasion that them nurses aren't there to look after children like (child) when they're dying. (08-34)

but I never wanted her to die in hospital. That wasn't what we wanted, 'cos she hated the hospital. [...] And because of how ill she was, the palliative team in [town x] advised us that we wouldn't be able to care for her at home, the amount of medication that she was having, and the doses changing every day through the night. There's nobody in [town x] to come and administer them medications at two in the morning. (08-34)



Conclusion



- Parents carry the weight of caregiving and value a core team that knows them and their child well and that is available to contact directly for advice and support as and when needed
- Variation in regional provision has led to real inequity of access and experiences.
- Examples of good practice show that it is possible for services to support parents to confidently care for their child at the end of life.

**Thank you to the parents for
sharing their experiences**