

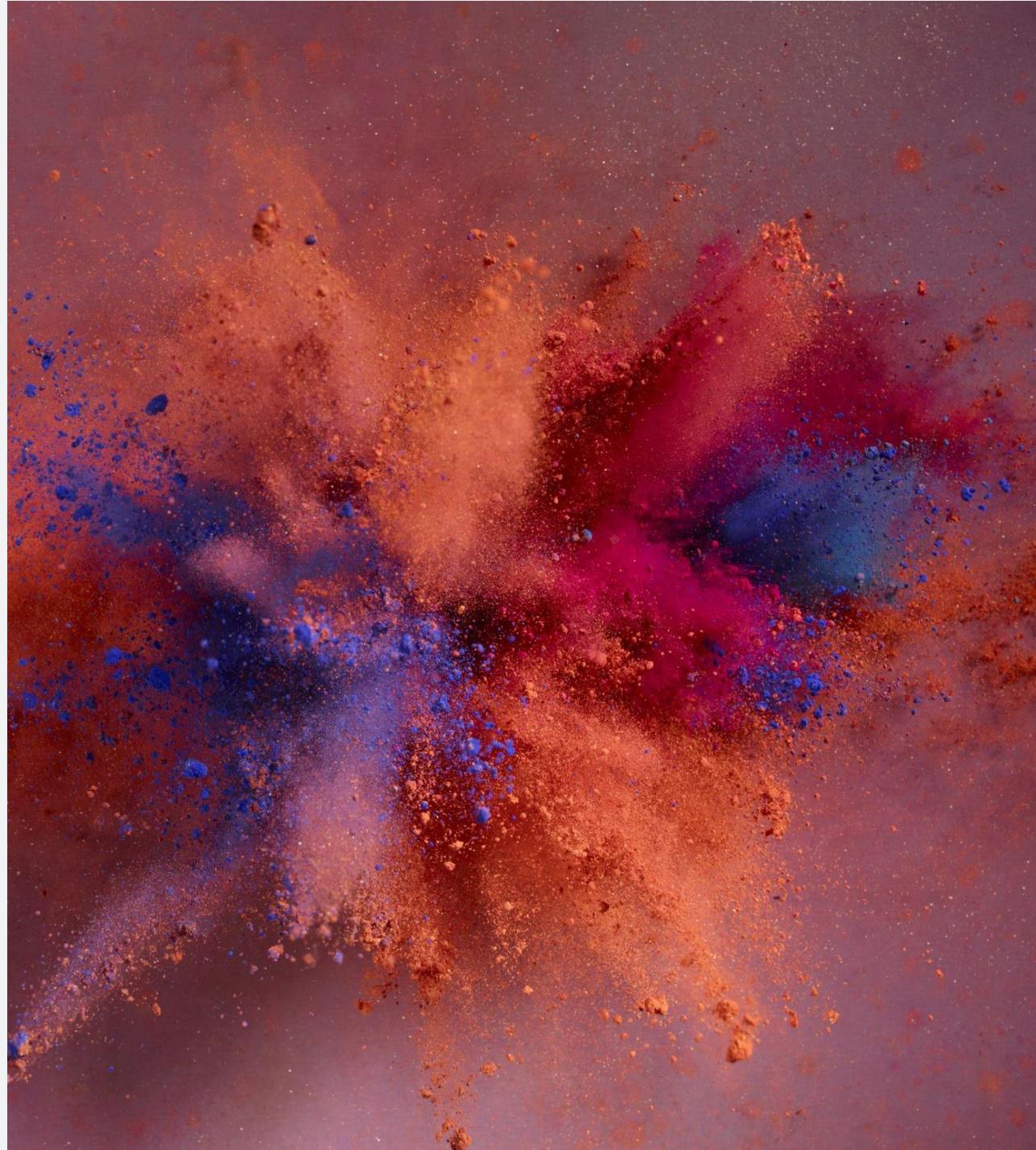


Healthcare Professionals' Experiences of Endings in Paediatric Cancer Treatment: An Interpretative Phenomenological Analysis (IPA)

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End of Treatment research background

In clinical work in a paediatric oncology setting, patients, families and staff describe finishing treatment as a complex and emotional experience, with mixed beliefs about how to mark this.

Rituals such as the End of Treatment Bell have become popular and widespread, without any research into how this is experienced in a paediatric setting.

Consultation with the Paediatric Oncology Special Interest Group in 2019 confirmed this was an important subject to investigate (thank you!)



End of Treatment project

Explore the experiences of children, parents and staff in relation to finishing treatment.

Qualitative method adopted due to lack of existing research in the area.

Three projects under one umbrella:

Child: 7 children aged 8-11

Parents: 11 parents

Staff: 7 staff members



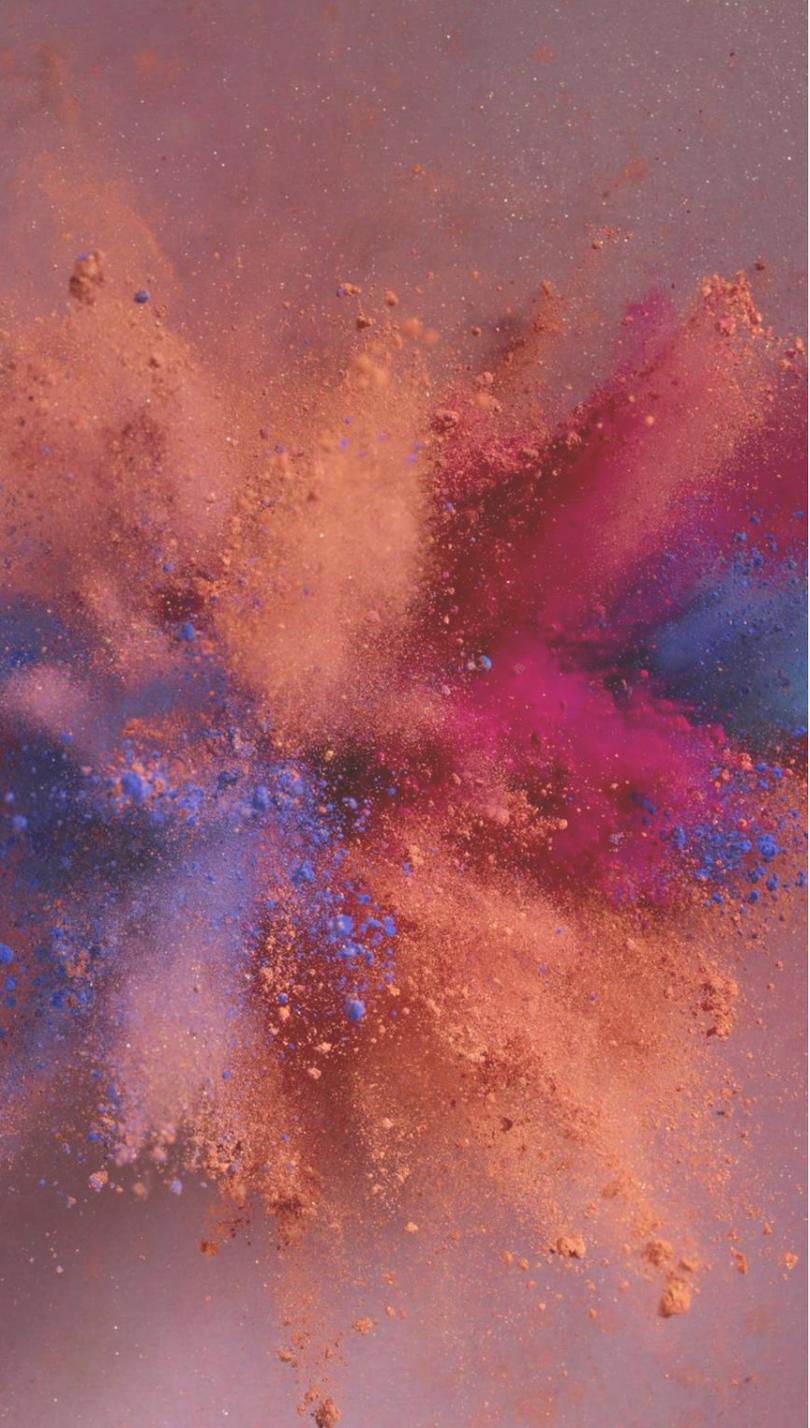
Aim

To present an overview of the study undertaken with **healthcare professionals** (HCPs) working in a single tertiary **paediatric cancer treatment centre** about their **experiences** providing care to children with cancer around the **end-of-treatment (EOT) phase**.



Study Background & Aims

- The point of **ending active treatment** is a period of **disruption and heightened stress** for children with cancer and their families.
- The **involvement of HCPs** in the identification and management of difficulties during this phase appears **crucial**.
- At EOT children and their families are invited to ring the **cancer bell**; a **ritual** that is intended to mark that children have now completed cancer treatment and are transitioning into survivorship.
- **No previous published research** has explored HCPs' experiences of providing care during the EOT phase nor have their perspectives on the use and meaning of the end-of-treatment bell been sought.



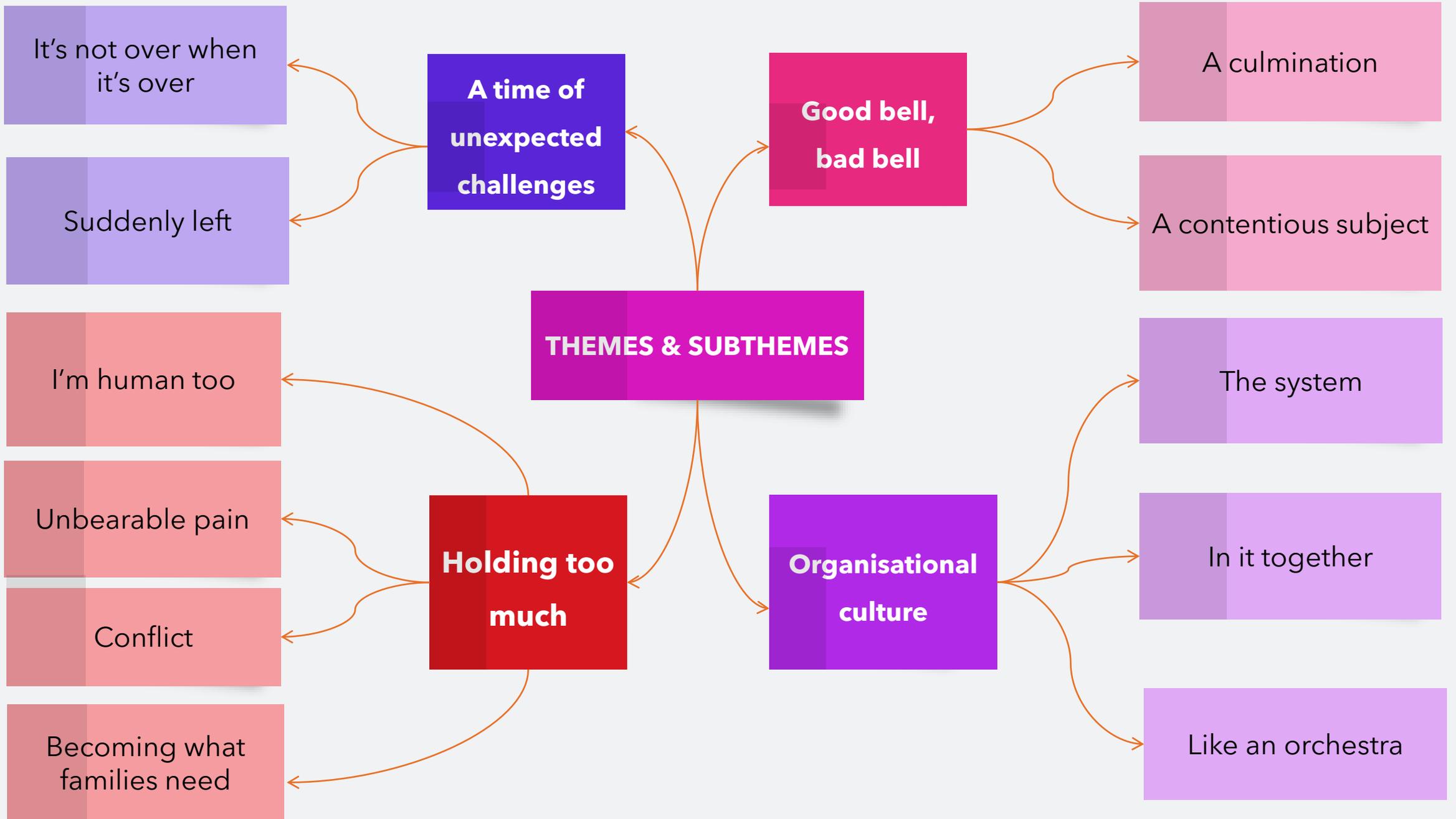
Study Impact

- **Systematic review** conducted prior to the study being conducted.
- Initial review aim was to **focus specifically on endings** in paediatric cancer treatment and how any strategies used to mark endings are experienced by HCPs.
- Search revealed **no qualitative papers** focusing on HCPs' experiences in relation to endings and/or ending rituals.
- Researching the perspectives of HCPs may provide **insights into the unmet needs of children and their families during EOT** and can help inform **best practices** following treatment completion. Moreover, such research may provide insights into **possible challenges faced by** HCPs and inform **staff support initiatives**.



Methods

- Qualitative study design using **Interpretative Phenomenological Analysis** (IPA) as the method of data analysis.
- **One-to-one semi-structured** interviews via Zoom
- Purposive sampling
- Single site research
- Ethical approval received from HRA; Bloomsbury REC (ref: 20/PR/0295).
- **Seven interviews** conducted between April 2021 and June 2021.
- Mean interview time: 1 hour
- All interviews were transcribed by the researcher.





A time of unexpected
challenges

Suddenly left

"For parents it can seem quite abrupt. Because one day the child is on treatment and being seen quite regularly and with more intense monitoring and the next day the child just stops treatment. There's no weaning [...]. And some of the parents undergo this, kind of, almost withdrawal syndrome of suddenly finding themselves having to go back to a semblance of normality, which they'd forgotten?" (P2)

"Families will say "Gosh, this is really difficult" umm.. For many different reasons but usually the reasons that are given around are umm "We're gonna miss you", [...], What are we gonna do without you there anymore?", "[...] "We're on chemotherapy and it makes us feel safe [...], now you're stopping the treatment and what's gonna happen? Will it come back?". Those massive anxieties around stopping treatment. [...] The parents will often often, often express fears about how are they gonna cope when their support network's gone? How are they gonna go back to normal life? How are they gonna get through the scan anxiety?" (P4)

It's not over when it's over

"It probably never ends, does it? You know, it.. It's.. I mean for me.. Well.. Is.. Is.. Then, sort of, that next five years off-treatment mark. When we say "Actually, this is never coming back now". [...] That's where I stop, in theory, where I stop looking after those patients and refer them onto another team. Umm.. But for them that's not the end because, you know, they will continue to.. To long-term follow up and, you know, to be seen sort of life-long.." (P3)

"I don't know if I really have a definite ending? And obviously the only.. The only definite ending for me is, when sadly, when that, umm, the child umm.. Dies. So, that is the only really definite ending because I don't see an end of active treatment as an end? Because I know that what lies ahead for this child and family [...]" (P6)



Good bell, bad bell

A culmination

"It's just, like a culmination of everything, you know? It's all finished and it's all gone and they.. And the.. The poem, it's all about, you know "My treatment's done, and I'm on my way and I'm gonna go off now and I don't need to come back here anymore" type thing and umm, it's just.. It is. You know, it's just.. It's positive." (P7)

"And I think it's a good thing. I think it's an important, uh.. For the parents, an emotional uh.. Milestone, which they would.. They would like to mark? Much like an anniversary or a birthday? And some parents continue to mark that as an anniversary subsequently. So, just as celebrating a birthday gives us pleasure, uh.. Or an anniversary of some sort. Celebrating the end of treatment on a certain date.. No matter that it may be arbitrary, umm, is still an important milestone that I think parents get a lot of comfort from marking that." (P2)

A contentious subject (part 1)

"So, it's become a really kind of.. Umm.. Mixed feelings about the bell because umm.. It's hard because they do it on the ward and you'll have a family nearby where their child is dying and hear what goes on because it's not thick walls.. So, in one minute you've got a dying child in that bed and the next minute you have another family cheering and clapping and celebrating their child's finished cancer treatment. You know, the emotional impact on those parents, I think, must be really hard. 'Cause you know - you're hearing that and yet your child.. Your child's gonna die. Your child's never gonna get that experience of ringing that bell. [...] And don't.. Don't get me wrong. They're lovely ceremonies, they're lovely. [...] But in the back of my mind I'm thinking "Well, what about the families that'll never gonna get to do this?" and "What about the families that will never get to experience going home and getting back on with their lives?". (P4)

A contentious subject (part 2)

"I remember a.. Patient on [name of ward] who, umm.. Who.. Who passed away on [name of ward]. And he had a type of leukemia and he never got to ring the bell. And he was an inpatient for quite a long time? And so both him and his mum and family had witnessed people ring the bell for a long time. [...] Mum was finding (it) very difficult that there was no more treatment left to try. And he sadly passed away on the ward. And.. You know, that noise of - I don't know if you've personally heard it - but the, umm.. When fam.. When.. Particularly mums.. The noise of grief.. That.. Just, kind of, raw grief. Is just so.. The kind of inner.. Ahh.. It's just the most horrendous noise. But she ran out of the room after he died and she just hung onto this bell and was just ringing it and ringing it and ringing it. And everyone was just, kind of, coming out of their rooms to see if somebody's ringing the bell and there's this grief-stricken woman.. Was just ringing this bell in quite a, kind of, mad.. It was just.. It was just horrific to watch really. And be part of.. You just think.. I just think.. I don't know how much that bell has had to play a part in.. In all of this.. Or, you know, how much that's, kind of, really got (to) her that he was never able to do it or she was signifying that he'd left this kind of wo.. I don't know what the purpose was but it was.. It was quite harrowing." (P6)



Holding too much

I'm human too

"But if the child dies, that.. That.. And it is again I think for me it's like a grieving process actually because.. You know, we're only human and often I'll think to myself "God, I'm really gonna miss that child, I'm really gonna miss that mum, I'm really gonna miss that family", you know, and it is.. I think as a health professional you still go through a slight grieving process. If the child dies. Or even if a child then finishes treatment and doesn't really contact you very much. You still miss them.. You still think about them." (P4)

"All I'm trying to say is.. We all get quite attached to the patients and the families and we build good relationships with them. So, often by the.. You know, by the end of treatment it's quite.. It's a mixture of emotions really.. I think for us and the families, particularly the parents, because you build up.. There's such a relationship an then they.. They obviously go along and they.. They only really get seen every so often for follow-ups and outpatients and things. So.. But it's.. It's.. It's positive ultimately." (P7)

Unbearable pain

"I went and saw her, sort of, around 20 minutes after he died. [...] There was lots of whaling and, you know, how upset she was with us that we'd never done the second transplant and.. That she should have left.. She should have left and taken him to [abroad] and that she should have done this and that and.. You know we.. We didn't do the best for him.. So, I, sort of.. I was just like.. I'm really sorry you know.. I was really sorry that we couldn't get that.. I'm really sorry we couldn't do that for him.. You know, he was lying there beside her.. dead. Um.. While she's sort of laying on the bed whaling. So, so it was really really (laughs).. Difficult." (P3)

"[...] I find funerals really hard. I do go to some and again I think in my head "What makes me pick that family's funeral to go to over that family's funeral?".. It's hard. That's really, really hard. Umm.. I go to less certainly as I've got older, I try and go to less. Because they are so incredibly difficult! Emotionally they kill me for a few days afterwards. Emotional.. Uh, I find it really really.. Really tricky funerals. But sometimes if the parents say "Look, I'd really want you to come to the funeral, you're a really important part of her life" or whatever they're gonna say then umm.. I do go." (P4)

Becoming what families need

"You know, I often say to my guys, or you know, and to myself, "I'm the one who needs to be different going from bed to bed". You know, as I go from different patients I need to, sort of, be, you know, I need to be, different for what that patient needs. Because, sort of, information needs will be different. There's a basic level of information that you've got to get over, umm.. But, you know, the degree of that information will be different for each family and it's for me to be able to read that and.. And.. You know.. And work with, you know, what you've got in front of you. "

(P3)

"You know, some of it is real emotional intelligence from that staff member about realising that actually that, yeah, this is the way to go with this family and actually, d'you know what, now is not the right time we'll shut this down, or we'll retry it or try a different avenue but, umm.. I guess then that's kind of experience really about knowing when is the right time to persist with something and when it's a different time. And that's like anything with, you know.. Anything within healthcare is emotional intelligence. You know, if you've got that then you're kind of halfway there and if you haven't then it's very difficult to learn (laughs)." (P6)

Conflict

"And what happens in those situations is that.. Inevitably the focus.. How hard you try is distracted by this.. Battle.. Ongoing battle with the family. And that can be quite time, energy and emotionally consuming. Which, therefore, you have to constantly remind yourself that you have to try and separate those two things. Is that the child's welfare should remain the paramount focus and you need to separate that from the difficult conversations that you are having with the family. [...] Umm. And it isn't always successful. Because often you get pressured into doing things that are not in the child's best interests for the sake of satisfying the parents." (P2)

"And I really hope as well that that might improve some of the equity. Because actually some of the feedback, umm, that we've had from families is that if we meet some children early on in treatment, they can get a very good service form us because we know them regularly, their medical team then know that we're involved, we get asked to see routinely. And then there are some families who we don't get to see at all. And so, when we get to end of treatment days some parents we know very, very well and other parents we haven't. And actually, their children's treatment hasn't been that dissimilar, but we don't know about them. [...]. And so, there isn't often a huge amount of equity. [...] I just feel a little bit uneasy at times how we know about some children and we don't know about them all." (P6)



Organisational culture

The system

"You know, these children were very well supported on treatment and then they've got a five-year gap and then they're going into long-term follow-up clinic and they are just a mess! And the families, have, you know, the community services have stopped, these children are in inappropriate schools with not the right, umm, educational healthcare plan in place, umm.. So, I think we need to change our model of.. Of working. Particularly because cancer treatment is changing. Well, it's changing now as we're speaking, but it has changed significantly over the last 5-10 years. More and more children are surviving with different, umm, presentations, umm, and we need to change our model of working to adapt with that."

(P6)

In it together

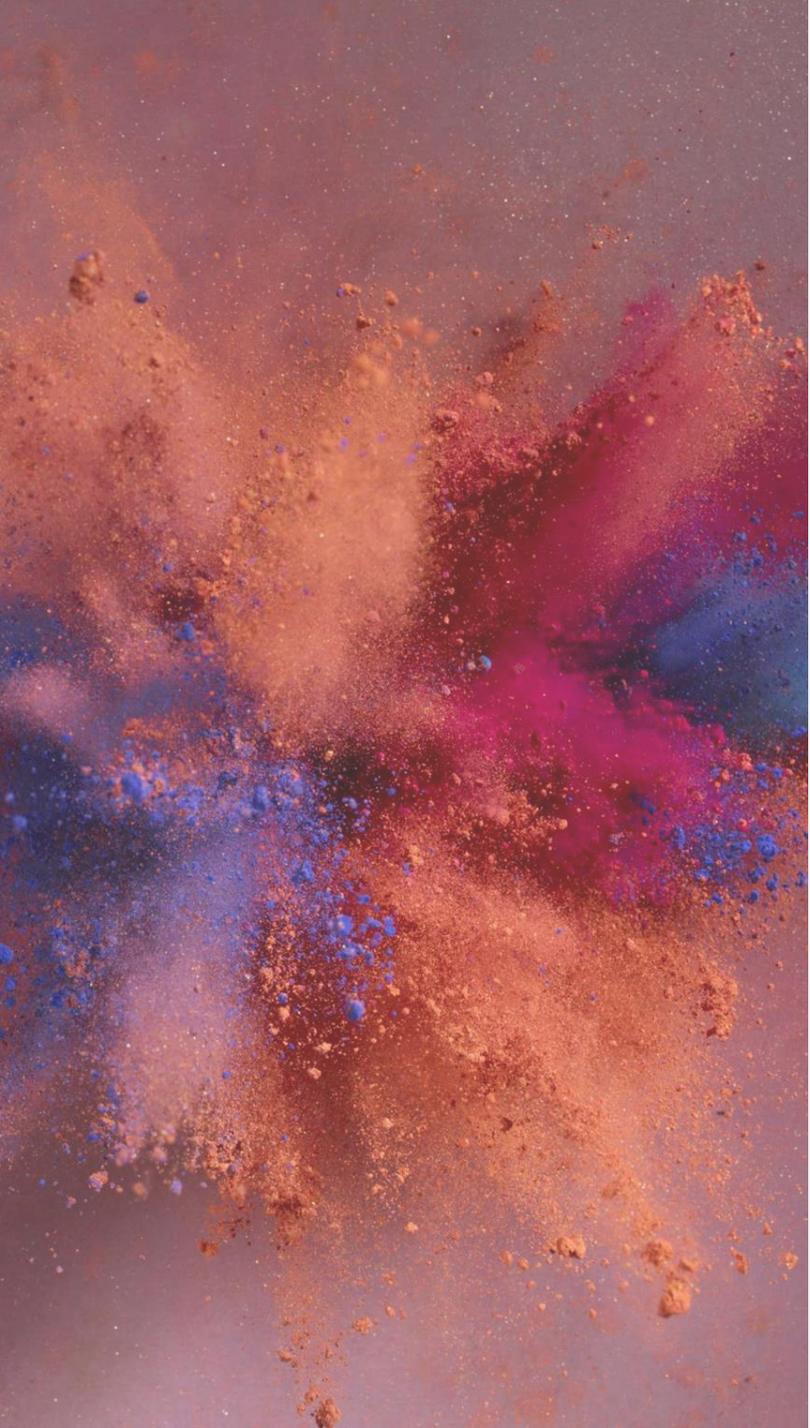
"Ah - colleague.. Colleague support is massive and actually, you know.. Big part of how you do these jobs is working within a team of amazing colleagues as well. And they do.. They get you through.. They get you through some situations. Because it.. Like.. It helps with the emotional burden I think. Talking to other people. And talking to colleagues that understand and it.. It does help." (P4)

"And obviously the starting point there is the multidisciplinary, multi-professional, team agreeing that we have reached the end of the road. That's the first step. And then once there is consensus around that and that any treatment is futile and potentially will do more harm than good, then that uh.. That information is given to the parents. Even if it's just me having the conversation, usually though it's always me and someone else, it's given as a team decision rather than my decision." (P2)

Like an orchestra

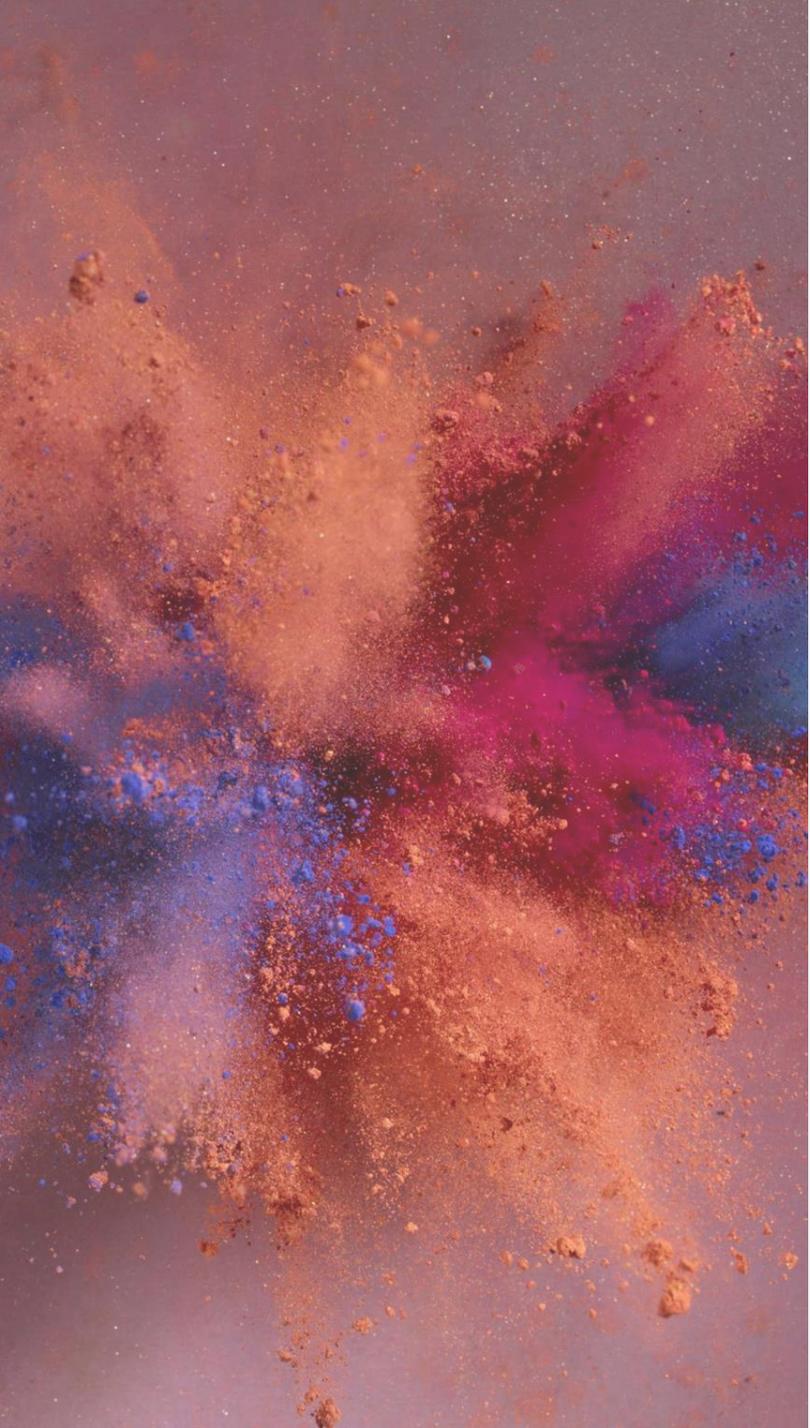
"Some families will say that finishing is as scary as starting, you know, so that support they need is, you know, is almost just as much as what they needed at the start. Umm.. You know.. And I will often just say to families "You just need to be really kind to yourself" and, you know, "Be kind to each other and don't expect .. you know, you will feel worried.. You will.. You know, at times.. You will feel worried and that's.. that's absolutely okay". Just.. And "Don't be surprised if you have a little crumble as you finish treatment." (P3)

"We can do quite simple things. Like it might just be giving a wheelchair to someone who's got really deconditioned and can't get to the playground but actually, whilst it's a really simple thing, it can be really empowering, umm, as well. So, I sort of, like we've got these little things that you can tick off quickly, like I say, whether it's a wheelchair or maybe helping somebody in and out of the bath or the toilet, right through to kind of ongoing, weekly developmental support." (P5)



Discussion

- End of active treatment was perceived as an important **milestone** but **not really the end**.
- The end signifies the start of a new phase during which families struggle to establish a **“new normal”**.
- HCPs’ narratives conveyed a sense of **endlessness**.
- Dynamic interplay between the **relational**, the **personal** and the **professional**.
- **How do HCPs themselves navigate the EOT phase?**
 - *A felt sense that staff always ought to be thinking and prioritising their patients.*
 - *Inability to separate their experiences from the experiences of patients/families.*



Discussion

- Endings **abrupt** for HCPs too.
- Important to think about ways to support HCPs process and cope with **work-related losses** and **professional grief**.

Your views/thoughts?

- **Acknowledging** and normalising that endings can be emotionally challenging for staff.
- Important to **validate** staff's losses and grief responses in the professional setting.
- Staff **hesitant** to discuss the more emotional and relational aspects of providing care or express vulnerability.

Why might HCPs hold back from discussing these aspects?

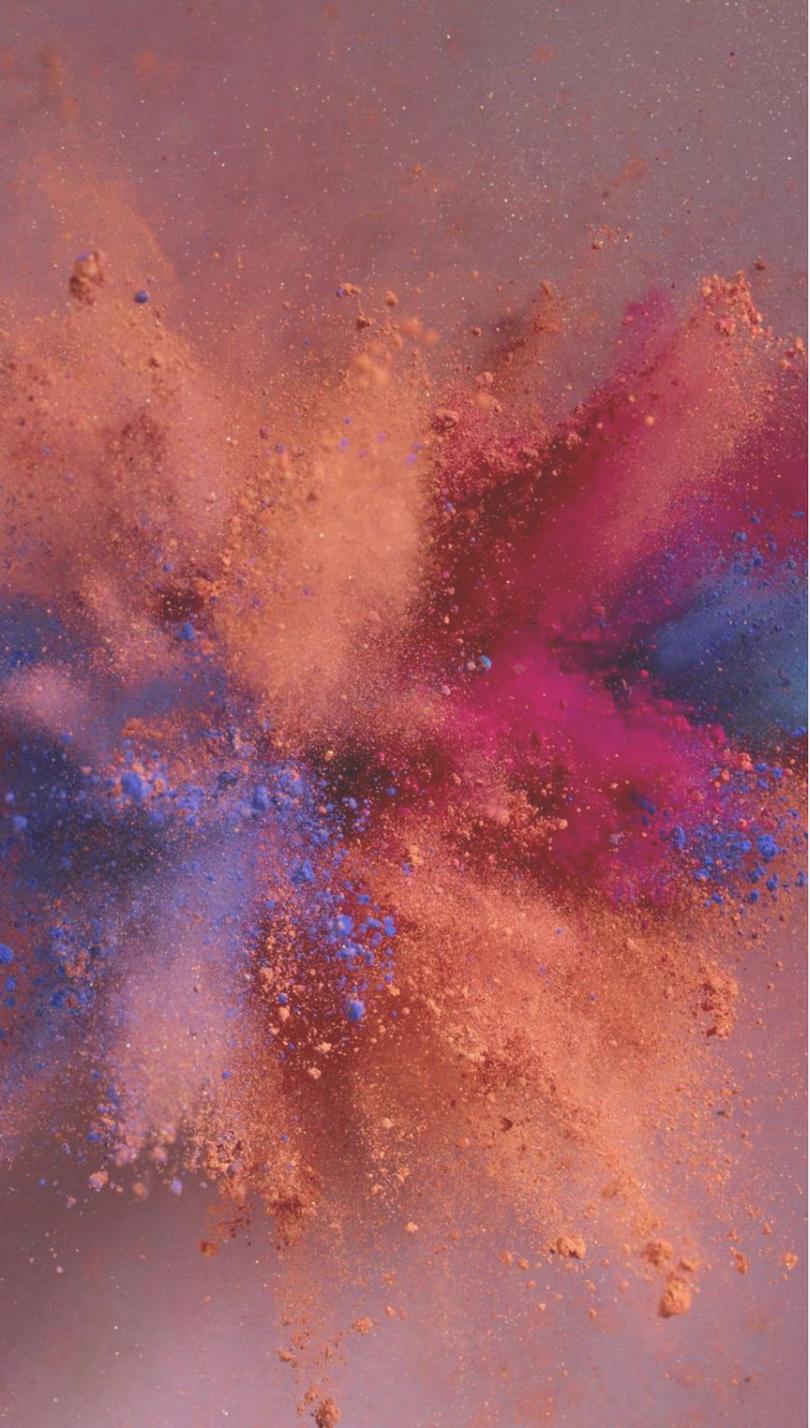


Discussion

Why does it matter that staff feel able to reflect and discuss their own emotional experiences?

- Important to acknowledge that HCPs need support to navigate and safely explore the **relational complexities** within this setting.
- Not doing so might carry a **risk** → maladaptive coping strategies → greater risk for emotional exhaustion, burnout, compassion fatigue.
- Important in terms of patient safety: higher risk for medical errors, poorer quality care, higher intention to leave the profession.

How can HCPs provide high-quality, compassionate care without sacrificing their own wellbeing?



Discussion – The Bell

- HCPs' narratives in their majority conveyed a sense that this ritualised activity evokes **conflicting emotions** for them.
- A way for families to **mark** this important milestone. Represents a moment of joy on the ward.
- These ceremonies were described as moving by HCPs as well.
- Importance of rituals and **symbolic objects** – a representation of the relationship. An opportunity for HCPs to bid families farewell?
- Bell ringings: a public statement for achieving curative treatment – **insensitive** for other children and families on the ward?
- Associated with **moral distress** for some HCPs.



Discussion – The Bell

Some things to think about:

- What might we need to reconsider in relation to bell ringings?
- Should anything change in terms of how staff are informed about the bell ringings?
- Should staff be given the option to attend or not?



Thank you for listening!
Any questions?