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"It's like being chained up" - The oral mucositis experiences of children and young people with cancer, their parents, and healthcare professionals: a qualitative study.

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What is already known on this topic

Oral mucositis affects children's quality of life during cancer treatment and their treatment outcomes. Mucositis prevention is of importance to children and their families, as well as healthcare services. Validated paediatric reported outcome measures have predominantly been formed from nominal group technique with clinical experts prior to validation with children and families, without capturing first hand experiences through qualitative interviews with children and young people.

What this study adds

This study adds to the limited literature in this area and represents the first qualitative exploration in the United Kingdom. This study triangulates the experiences of children, their parents, and the healthcare professionals involved in their care to identify commonality and contrast in these experiences. It demonstrates the complexity of these nuanced experiences psychologically and physically for these groups, whilst highlighting the challenges in management of severe mucositis for families and healthcare services. Additionally, it highlights the cross-cutting impact of mucositis on children's oral health which has not previously been described.

How this study might affect research, practice, or policy

This study highlights the complex, negative impact of mucositis on families and healthcare services. Additionally, it highlights the lack of available viable options for children and young people to prevent and treat mucositis. The themes generated in this study highlight additional outcomes of importance to children that are not currently included in paediatric outcome measures widely utilised in clinical practice. These outcomes may supplement existing outcome measures, and when considering child quality of life during cancer treatment. Additionally, it highlights the challenges faced by families and the dental team in maintaining oral health during episodes of mucositis, and the need to establish oral health behaviours and preventive care from the outset of cancer treatment. This research reinforces the morbidity of oral mucositis and its impact on curative treatment schedules and treatment experiences; supportive care research focusing on implementation of effective mucositis treatments is required, with a stronger emphasis on the impact of such cancer treatment side effects and their influence on patient safety and quality of life.

ABSTRACT

OBJECTIVE To explore the experiences of children and young people (CYP) with cancer, their parents, and healthcare professionals (HCPs) involved in their care of oral mucositis **DESIGN** A qualitative study was conducted. CYP with experience of mucositis were purposively sampled, aiming for diversity in age, sex, and cancer diagnosis. HCPs were purposively sampled aiming for diversity in professional role, and years of experience. Semi-structured interviews with CYP and their parents and focus groups with HCPs were conducted. Interviews were audio recorded and professionally transcribed. Anonymised transcripts underwent reflexive thematic analysis using an inductive essentialist approach. Codes were discussed and constant comparisons made to increase validity. Recruitment occurred alongside analysis until no new codes were identified. **RESULTS** Twenty-seven participants were interviewed (eight CYP, ten parents, nine HCPs). CYP had diverse cancer diagnoses and were aged between 8-15 years. HCPs had diverse professional roles across medicine, dentistry, nursing, dental nursing, and play therapy with a mean of 7.4 years of experience in their individual role. Four themes were generated: (1) mucositis as a multi-faceted, negative emotive experience; (2) being taken away from “normality”; (3) complex biopsychosocial impact on eating; (4) management of mucositis presents additional strain. Within these themes, multiple sub-themes were generated and cross-cutting challenges in maintaining oral health were identified. **CONCLUSION** Oral mucositis presents a significant challenge to CYP, families and HCPs during cancer treatment functionally, psychologically, and socially, with an adverse impact on treatment experiences. Prevention of oral mucositis is a priority to these groups within supportive cancer care.

INTRODUCTION

Oral mucositis affects up to 8 in 10 children and young people (CYP) during their cancer treatment.[1] Where mucositis is severe, and ulceration occurs, CYP can experience significant pain.[2,3] Additionally, these lesions present an opportunistic infection risk in this immunocompromised population.[4,5] Oral mucositis can affect CYP's ability to eat,[6] and can result in inpatient admissions for parenteral nutrition and pain-relief in severe disease.[7] These impacts have been found to reduce quality-of-life for CYP. Mucositis is significant to CYP and families, with 10% of parents ranking mucositis prevention as most important out of ten listed cancer treatment side effects,[8] and proven negative impact on CYP quality-of-life.[6] Additionally, severe mucositis can result in delayed delivery of scheduled curative chemotherapy resulting in treatment deintensification, increasing the risk of curative treatment failure.[9] Mucositis management also impacts healthcare services, with severe disease commonly necessitating administration of additional medications, parenteral nutrition, oral care protocols, and additional diagnostic tests.[10,11]

The Children's International Mucositis Evaluation Scale (ChIMES) is a paediatric patient-reported outcome measure (PROM) validated for children over eight years old.[12] Its domains consider pain, function and appearance.[13,14] However, there is limited existing qualitative research exploring children's lived mucositis experiences and how these align with such outcome measures.

This study aims to explore the mucositis experiences of children and young people, their parents, and the healthcare professionals providing care in the United Kingdom.

METHODS

A qualitative study was conducted and reported in line with the consolidated criteria for reporting qualitative studies (COREQ).[15] Interviews were part of a wider project that also explored acceptability of photobiomodulation, these findings are beyond the scope of this paper and will be reported separately. Ethical approval was obtained from the National Health Service Health Research Authority (ID316813).

Setting and sampling

The Leeds Teaching Hospitals Trust (LTHT) includes the Leeds Children's Hospital and Leeds Dental Institute. The Leeds Children's Hospital is one of 20 Principal Treatment Centres for children's cancer in the U.K.[16]

CYP aged 6-15 years old with experience of mucositis, and their parents, were purposively sampled for diversity in: age, sex, and cancer diagnosis. Families were recruited through direct clinical care and the family support networks of a regional charity (Candlelighters children's cancer charity).

Healthcare professionals (HCPs) involved in the clinical care of CYP with cancer were purposively sampled for diversity in professional role and clinical experience. HCPs were approached by email through existing relationships, and snowball sampling.

Recruitment occurred alongside data collection and analysis. Upon the repetition of codes and no new sub-themes being generated, recruitment closed. Participants received a £20 voucher as recognition for their time and contribution.

Data collection

Topic guides were developed following literature review, and discussion with Patient and Public Involvement (PPI) groups. These were iterative and responsive to emerging findings. Topic guides consisted of two distinct sections: experiences of mucositis as reported in the present study (Supplementary Table 1), and the acceptability of photobiomodulation (reported elsewhere).

Supplementary Table 1. Topic guide for semi-structured interviews

Question	Probes
Families: What was it like to have oral mucositis HCPs: What is it like to manage children with oral mucositis	- What do you remember about it? - What was the worst thing? - What treatments did you receive / do you deliver?
What outcomes are important at the time	- Duration - Severity - Oral intake - Curative treatment delays - Analgesia - Oral hygiene
Families: What impact did that have on your life or cancer treatment? HCPs: What impact does this have on your job and the service?	- Hospitalisation - Nutrition - Pain - Curative treatment delays

Semi-structured interviews with CYP and parent dyads were conducted by two researchers (CH&BP; female and male). A dyad approach was utilised to explore shared experiences and a distress protocol adopted in case of sensitive issues arising.

For HCPs, a combination of focus groups and semi-structured interviews were conducted. Focus groups were utilised to explore team experiences; semi-structured interviews were conducted to reduce hierarchical impact and to accommodate participant availability. Focus groups were conducted in the same manner as semi-structured interviews but allowed for participants to respond to each other's thoughts and ideas.

Focus groups and interviews were conducted in a non-clinical environment at LTHT, the regional charity's family support centre, or online via virtual conferencing based on participant preference.

Researchers were known to participants by virtue of their clinical professional role or when children had previously been involved in research. Demographic and clinical history data were collected from families, and details of professional experience were collected from HCPs. Interviews were audio recorded and field notes taken, which were referred to during analysis.

Data analysis

Audio recordings were professionally transcribed and de-identified. Data pertaining to mucositis experiences were analysed, on an individual participant level, inductively using a reflexive thematic analysis at a semantic level (essentialist approach). Following familiarisation with audio recordings and correction of transcripts, one researcher (CH) coded the data and developed initial themes. Initial themes were then reviewed across all groups. Finally, discussions with experienced qualitative researchers (AC+KG-B), enabled the themes to be sense-checked, defined, and refined. No repeat interviews occurred. Member-checking was not completed to avoid transformation of data, but discussion of preliminary results occurred with PPI representatives.

RESULTS

A total of 27 participants were interviewed: eight CYP, ten parents, and nine HCPs (Table 1). All children had experienced severe oral mucositis.

Following initial expression of interest, three families and four HCPs did not meet inclusion or sampling criteria and seven parents and four HCPs failed to respond to further communication.

Table 1 Characteristics of participants

Children and young people (n=8)		
Demographics	Sex (M:F)	6:2
	Median age (years, [range])	12 [8-15]
Cancer diagnosis[+]	Non-Hodgkin's lymphoma (n=)	3
	Acute lymphoblastic leukaemia (n=)	2
	Anaplastic large cell lymphoma (n=)	1
	Acute myeloid leukaemia (n=)	1
	Osteosarcoma (n=)	1
	Hodgkin's lymphoma (n=)	1
Treatment modality[+]	Chemotherapy (n=)	9
	Haematopoietic stem cell transplant (n=)	5
	Proton beam therapy (n=)	1
	Immunotherapy (n=)	1
Parents (n=10) [±]		
Demographics	Sex (M:F)	2:8
	Median age (years, [range])*	45 [35-55]
Healthcare professionals (n=9)		
Demographics	Sex (M:F)	2:7

Professional role	Senior Paediatric Oncology Nurse (n=1)	Focus group 1
	Paediatric Dental Nurse (n=1)	Focus group 1
	Paediatric Dentistry Specialty Trainee (n=1)	Focus group 1
	Paediatric Dental Therapist (n=1)	Focus group 1
	Paediatric Dentistry Consultant (n=1)	Focus group 1
	Play Therapist (n=1)	Semi-structured interview
	Paediatric Haematology & Oncology Advanced Clinical Practitioner (n=1)	Focus group 2
	Paediatric Medicine Specialty Trainee (n=1)	Focus group 2
	Paediatric Oncology Consultant (n=1)	Semi-structured interview
Experience in professional role	Mean experience (years, [range])	7.4 [3-15]

(+) Cancer diagnosis and treatment modality for eight children and young people interviewed, and the child of an interviewed parent who did not meet age inclusion criteria. Some children received more than one treatment modality
(±) Ten parent participants: seven dyads with children, one triad with child, one parent whose child did not meet inclusion criteria due to age
(*) Three parents declined to disclose age

Data were collected between April-December 2023. Mean interview duration was 61 minutes for families and 52 minutes for HCPs.

Four themes, with multiple sub-themes, were generated. Across the dataset, a cross cutting theme of challenges in maintaining oral health was identified.

(1) Mucositis as a multi-faceted, negative emotive experience

Emotions identified were diverse and nuanced, associated with both physical and psychological impacts. This theme was generated predominantly from data from families.

Table 2. Summary of Theme 1, constituent subthemes, and representative quotes. (*) Indicates a subtheme identified within a cross-cutting themes of oral health.

(1) Mucositis as a multi-faceted, negative emotive experience	
Subthemes	**Sub-themes**
(1a) Fear, anxiety and distress	*"Yeah, like it scared me like, it was just horrendous. But they did say it was quite a severe, you know, [CYP3] had quite a severe case of it"* ***Parent 3 (Parent of 8-year-old male with relapsed disease)*** ***"****I think it's scary, isn't it? I think you could go ahead and show them a load of pictures of this is what it could look like, but then that's also quite scary, isn't it, you wouldn't want to… I don't know."* **Senior Paediatric Oncology Nurse**

	"And although [CYP4] couldn't see it, one day when he went into the toilet, he wanted to brush his teeth and he saw his tongue, that upset him. That's when he [could] really see what is the state of his tongue, he had really white things around his tongue. That was quite sensitive." ***Parent 4 (Parent of 14-year-old male)***
(1b) Parental guilt	*"Obviously you would like your child to receive the necessary treatment to rid them of cancer, so you're in between a rock and a hard place because as a parent you want that, so to get rid of it. But on the other side I know good nutrition helps promote healing and wellness. And him not being able to get that initially and that social aspect of him, and him being in pain, and not being able to swallow, et cetera, that's hard as well. You're caught between the two. You know, you want them to be well and you want them to have the treatment, but you don't want them to have the side-effects that go with it"* ***Parent 7 (Parent of 15-year-old male)*** ***"****I think it's more the emotional effect that it has, and already, I don't know erm, you go through that whole cycle of like, [CYP9] used to blame but then need, she, they need you more, but then they're blaming you and I think that, erm, it's the emotional upset I think of giving more things"* ***Parent 9 (Parent of 11-year-old female)*** *"But I think I pushed... I mean, again, I felt guilty because I pushed you to try one [a mouthwash] and you just got really angry at me because it hurt so much, so … no. Yeah, I remember that because I felt so bad. But no, yeah. But no, it was—no, nothing was done."* ***Parent 7 (Parent of 15-year-old male)***
(1c) Impact of pain and its management	*"The pain that you see your child in, I think that's worse than the cancer is, the mucositis and stuff."* ***Parent 1 (Parent of 13-year-old female)*** *"I'd say it's the pain really, because the eating just tube feed it, TPN [Total Parenteral Nutrition], you know it's a very short period of they've got that much going after having that much medicine anyway, you know what's one more, what's one more pump up there. But the pain although it can be managed it still is painful and I think that's the worst thing I think that's the worst memory for the kids is being in pain. They won't be able to remember that they didn't eat for 2 months, but they will be able to remember [the pain] […] Yeah, I would say it's the pain that would be the worst."* ***Parent 5 (Parent of 3-year-old male)*** "Another big thing was yawning. Yeah, because I think, I couldn't open my mouth. Yeah, because I think, I couldn't open my mouth. Yeah, I had to like try to keep my mouth closed, like not open nor closed and it was so difficult. And if I forgot, if I opened it too far it would be agony, yeah, I'm screaming. Yeah." CYP7 ***(15-year-old male)***
(1d) Negative experiences of toothbrushing*	*"[Brushing my teeth was] Hard. It was brutal, because the mint in the toothpaste was so bitter against my entire mouth. It felt stinging. It was literally so brutal to hurt, and it was really hurt. And just slightly touching them made – it made it start. And like having anything brushed against it was really hard"* ***CYP1 (13-year-old female)*** *"I think I was scared [to brush his teeth] because it just looked so bad. I wouldn't have like just, I don't think I'd attempted to put owt in his mouth, you know, apart from well, they did give us the Gelclair (barrier gel) stuff"* ***Parent 3 (Parent of 8-year-old male with relapsed disease)*** *"Yeah, I couldn't brush my teeth at all. We tried the mouthwash, didn't we?"* ***CYP7 (15-year-old male)*** *"That didn't happen [tolerating mouthwash]"* ***Parent 7*** *"No, not a chance. I think we got this soft toothbrush, didn't we? And we did do that every now*

	and then. Towards the end [of cancer treatment], we did." […] "Yeah, yeah, but at the start no chance." ***CYP7*** *"But at the beginning after his [chemotherapy], not a chance." Parent 7 "Nothing was going in the mouth."* ***CYP7***
(1e) Severity is unimagined	*"It was just all coming away, you know. Like, because obviously I were expecting ulcers and stuff, but it were more than I expected. When they said you were going to have a sore mouth, I couldn't imagine it was going to be as bad as it actually was"* ***Parent 3 (Parent of 8-year-old male with relapsed disease)*** *"Yeah. And it's easy to say like you get ulcers in your mouth, but it's not just like – we 've all had an ulcer at some point, haven't we, and they're really uncomfortable, but nothing on the scale of what I would imagine mucositis is like."* ***Paediatric Dental Therapist*** *"I'd be like, give me anything. Anything. Like, this is why we were really like, I made sure we're every, you know, like we were doing this mouth stuff in Newcastle, because I did not want, that [mucositis] was the one thing I didn't want to happen. Like I didn't want it to happen again and I would have done anything to stop it, you know, like to stop it happening again"* ***Parent 3 (Parent of 8-year-old male with relapsed disease)***

Several families described anxiety, fear, and distress over the visible extent and severity of mucositis. Some parents experienced complex feelings of blame and guilt in consenting to aggressive curative treatments for their children, and when witnessing their child in pain after encouraging use of topical treatments.

Pain was the most frequently reported negative experience and many participants felt that this was the worst aspect. Participants linked pain with severity, and many CYP required patient-controlled analgesia (PCAS) during severe episodes. However, contrasting data were identified, with some parents finding pain to be easier to manage than other functional aspects such as eating.

Within this theme, negative oral health experiences were identified, with families experiencing feelings of sickness, pain, and fear around oral care. Families reported making adaptations, such as changing toothpastes or using mouthwashes, with many CYP avoiding toothbrushing.

Families found severe mucositis to be incomprehensible without previous experience; previous experience served as a motivator in mucositis prevention. HCPs experienced challenges in explaining severity without increasing families' fear and anxiety.

(2) Being taken away from "normality"

"Normality" was a diverse concept, and removal from this was attributed to multiple aspects contributing to the overall experience and feeling of being "chained up". This theme was developed predominantly from data from families.

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226 **Table 3.** Summary of Theme 2, constituent subthemes, and representative quotes. (*)
227 Indicates a subtheme identified within a cross-cutting themes of oral health.

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(2) Being taken way from "normality"	
Subthemes	**Sub-themes**
(2a) Prevented from being at home	*"I mean, yeah, patient wise it's pain and the removal from their normality, because if they could manage their mucositis at home through whatever means, that does preserve a lot of normality for that kid to not have to come into hospital for prolonged periods of time."* ***Specialty Trainee in Paediatric Medicine*** *"So, yeah, and on several occasions, he had a small dog, it's little Teddy. So, yeah, he used to drool on him and we had to send it back home to get it washed. So, he used to miss that. So, even though there are little things for us, for him it was quite important being in the hospital. And that was part of his home he wanted to have with him. So, he missed that."* ***Parent 4 (Parent of 14-year-old male)*** ***"****Yeah, I think because the impact of mucositis is huge to the in-patient stay: it can prolong it, it can you know affect every aspect of their life, playing and eating and just generally, how they're feeling."* ***Play Therapist*** *"You know, we can sometimes think, oh, everyone would rather be at home but actually, I think there is sometimes that security when they're undergoing these intensive blocks. Some families yeah, I think it's very family dependent as well."* ***Paediatric Oncology Consultant***
(2b) Not being able to communicate	*"It's really, like I said, it's [mucositis] like being chained up right? Because your mouth is how you talk, how you communicate and how you eat."* ***CYP1 (13-year-old female)*** *"That is the most difficult thing to go through, where you can't speak and you're salivating. For a teenager, it's difficult, isn't it? Because they want to communicate always or speak to friends, family, and then you can't that really brings them down."* ***Parent 4 (Parent of 14-year-old male)*** *"Another thing I didn't mention is I couldn't talk either, so I had to write it down a piece of paper.[…] Yeah. I write stuff on a book and just show them."* ***CYP7 (15-year-old male)*** ***"****That was very—I don't know about you but it came across to me you were very frustrated with that."* ***Parent 7 "****Mm-hmm. Yeah."* ***CYP7 "****We had many a frustrated moment when he was trying to write things down. Yeah. Correct me if I'm wrong, from what you were articulating or trying to, there was a lot of frustration would you say?"* ***Parent 7 "****Yeah, not being able to talk, just... Something that you do all the time. You go to talk and you physically can't because how painful it is. And it just didn't feel right having to write it down"* ***CYP7***
(2c) Consequences on oral health*	***"****We knew that when he was eating, he was basically eating rubbish that he liked and that was good calorie-wise but not good for sugar. So, I was acutely aware. I didn't want him to come out of all of this and then have a load of cavities."* ***Parent 8 (Parent of 11-year-old)*** *"You know we still struggle now with his teeth [after treatment], we still have to do quite a lot of forcing with it and like positive reinforcement […] I think you know it was really painful, really sore, really unpleasant. And it was having to have his teeth brushed and it's for 4 or 5 months. It's always been a really negative thing brushing*

	your teeth, it's not been just a regular thing you do before you bed […] he can't remember that previously, what he remembers now is how painful it is and I think that's like a memory that stuck" ***Parent 5 (Parent of 3-year-old male)*** *"I think there's a bit of a risk as well and particularly if that's the first or one of the first encounters that the child have with the dental team, like it reinforces sort of a negative like dental anxiety and should they need dental in the future that can really be more difficult as well because as [Consultant in Paediatric Dentistry] says, it's [mucositis] such as really difficult thing to treat and treat painlessly without causing distress to the child, it would be better if that could be avoided"* ***Paediatric Dentistry Specialty Trainee***

The impact on CYP's ability to communicate was identified by all participant groups. One participant described this as "losing freedom", with CYP utilising additional communication aids such as hand signals and writing.

Many families reported that mucositis had prevented them from being at home, which was predominantly seen as an adverse outcome. However, for some, the hospital was perceived as a safer environment during severe episodes.

"I don't think when it were like how it was the first time [severe], we wouldn't have wanted to be at home with it like that" ***Parent 3 (Parent of 8-year-old male)***

A subtheme of consequences on oral health was identified, with CYP experiencing removal from their dietary norms with necessitated enteral or parenteral feeding, increased dietary sugar intake, and disruption to oral hygiene routines. Dental professionals were sympathetic to the relative lower priority of oral health during cancer treatment but expressed concerns around perceived links between mucositis experience and dental anxiety. Families reported ongoing challenges with toothbrushing beyond completion of cancer treatment, due to negative and painful experiences during episodes of mucositis.

(3) Complex biopsychosocial impact on eating

Eating and swallowing represented a complex phenomenon, with multiple generated subthemes. This theme was developed from data across all participant groups.

Table 4. Summary of Theme 3, constituent subthemes, and representative quotes. (*) Indicates a subtheme identified within a cross-cutting themes of oral health.

(3) Complex biopsychosocial impact on eating	
Subthemes	**Sub-themes**

(3a) Pain and loss of function	***"****It [The worst thing] was probably not being able to eat because inside, I was hungry. But it couldn't, it was too painful to eat. So, that was probably the worst thing about it […]I'm still really hungry."* ***CYP8 (11-year-old male)*** *"I think [the difficulty eating] was the worst thing as well, [CYP1] ate a jacket potato and the doctor walked in and all of her tongue fell right off onto the jacket potato and [there was] blood everywhere. So it was a right struggle for anyone there"* ***Parent 1 (Parent of 13-year-old female)*** *"Erm, I just wanted foooood, and erm, yeah"* ***CYP9 (11-year-old female) "****Did you feel hungry?"* ***Parent 9 "****No, I just wanted to chew on something […]Like I wasn't hungry, but I wanna chew on something."* ***CYP9***
(3b) Difficulty managing nutrition*	*"Some points where it's soothed enough for them to be able to consume some food because I think when they're on treatment, they're losing weight rapidly and that's always a massive concern. And when they've got the tube in you constantly, every gram that's coming off, you're worrying about them being strong enough to fight."* ***Parent 9 (Parent of 11-year-old female)*** ***"****They wanted the tube in, the feeding tube, because she couldn't swallow, she couldn't eat, she couldn't anything, and she couldn't drink water. So she was literally hooked [to Patient Controlled Analgesia], when you are putting that in, and literally pressing the button like that and was eating, like, you could see the pain in her face. And she was literally forcing herself so they wouldn't put that tube down with it though."* ***Parent 1 (Parent of 13-year-old female)*** ***"****But nutrition is also particularly challenging because even if they're a basic mild mucositis and they're at home, they're still not going to eat and drink. So, you know, that stops them, because if they don't want to eat and drink, they're going to lose weight, so, they don't have a much calorie intake. And that has a knock-on effect kind of generally for them."* ***Advanced Clinical Practitioner*** **"**There are also additional challenges with children such as maintaining weight and it sometimes can be a bit complex about what we would advise sort of in terms of diet and sugar-containing drinks and food versus them being able to maintain a healthy weight during their treatment. So, yeah, amongst all of that, issues obviously with dental treatment and treating dental disease." **Paediatric Dentistry Registrar**
(3c) Disruption of social norms around eating	*"It's, it's a natural instinct to think as a parent to feed, and when you can't feed physically, you know, feed them yourself. You're worrying about what they're actually getting and, and just…"* ***Parent 9 "****Mushed up food in a bag."* ***CYP9 (11-year-old female)*** *"[…] Yeah, because I think, when you've got a child that's unwell anyway, giving them food is something, that you, is contentment for you because when they can't eat, when they've been vomiting and then you know you can make something for them that, you know that they really love. But then when they can't, even erm, have that because they just can't bear it. It's... emotionally, I don't know what the right is. It's a really stressful time, it's, you know. […] Yeah. It just adds to all that, anxiety and stress even for her. Yeah, it's something else that's been taken away from them."* ***Parent 9*** *"I'm a feeder, so me not being able to provide that for him and encourage him to do, because I know he needs that good nutrition to be able to fight the next one, if that makes sense."* ***Parent 7 (Parent of 15-year-old male)***

	"*It's you know like routine really revolve around food, because I know that his mum used to have to try and you know like, every time we are going for treatment, and you know before treatment he couldn't eat and everything, so food was always very important for him.*" ***Parent 6*** *"It was eat, sleep and then the same thing every day."* ***CYP6 (15-year-old male)***

Functional difficulty was experienced due to pain and mucosal trauma. Physical eating processes, such as chewing and taste, were also important to CYP with many disliking alternative puréed "baby foods". Some CYP experienced a lack of satiety from enteral and parenteral nutrition.

Inability to swallow resulted in excessive drooling for many participants, and for some this affected sleep quality. For many, the inability to swallow saliva was more distressing than the inability to eat orally.

"*I think the constant like saliva in my mouth and not being able to swallow [was the worst thing], because eating wise, I have like my PEG tube, so, I still get like nutrients and stuff in. But not being able to speak and constantly having saliva in my mouth was quite annoying."* ***CYP4 (14-year-old male)***

Participants groups had different experiences of nutrition. CYP generally disliked enteral and parenteral nutrition, particularly nasogastric tubes. HCPs and parents experienced worry around maintenance of nutrition to avoid adverse outcomes; impacts on oral health were identified in this subtheme, with dental professionals experiencing conflict between their 'low sugar' dietary advice and nutritionists' advice aiming to maintain weight during cancer treatment.

Families experienced disruption to the social norms around eating. This encompassed loss of routine and mealtimes but also the social role of "feeder", a role that multiple parents felt would have brought them comfort during their child's cancer treatment.

(4) Management of mucositis presents additional strain

This theme was developed from all participant groups representing different perspectives and aspects of strain.

Table 5. Summary of Theme 4, constituent subthemes, and representative quotes. (*) Indicates a subtheme identified within a cross-cutting themes of oral health.

(4) Management of mucositis presents additional strain	
Subthemes	**Sub-themes**

(4a) Severe mucositis impacts cancer treatment experiences.	*"So, in the first time he had it, [CYP8] was still coping with the rest of his life within hospital. On the second time, he was very unwell. And that contributed to the majority of the symptoms."* ***Parent 8 (Parent of 11-year-old male)*** ***"****Yeah, just and kind of changing, rather than experiential outcomes in terms of actually changing physical, you know, event free survival, you know, all of those kind of things. And how quickly you can get on to the next block of chemotherapy and all of those bits and bobs."* ***Paediatric Oncology Consultant*** ***"****The more severe the mucositis, the more effects it's going to have to the patient. So, you know, they're more at risk of gram-negative infections from their gut, so, therefore they're going to get temperatures, so, then they're going to be on antibiotics, then they're at risk of sepsis"* ***Advanced Clinical Practitioner*** *"And it affects such a high proportion of patients undergoing chemotherapy, that it can have really significant burden on their care when they're going through a really obviously stressful and difficult time and treatment, that it's just additional burden on them and the family, that if there's a potential treatment to avoid that, it can only be a good thing." Paediatric Dentistry Specialty Trainee*
(3b) Difficulty managing nutrition*	*"For us [it's] managing nutrition as well because that would involve then having an NG [nasogastric] tube, maybe TPN [Total Parenteral Nutrition], so that then has an effect on everything else. […] Well, I think it's more workload because then you've got to juggle the nutrition around and you've got to feed them, but then that often makes them feel sick and if they've got mucositis in the mouth, they've often got gut issues as well so then it's hard to then put a lot of feed in them. So then we have fluid balance issues, we'll probably need diuretics then to manage that, so everything kind of has a bit of knock-on effect."* ***Senior Paediatric Oncology Nurse*** ***"****Certainly, from a medical ward round perspective, if they're a sick patient with mucositis, that can take you a fair bit longer, I think, on your daily clinical assessment, because obviously you've got to factor in TPN, PCAS or NCAS, you know, temperatures, whatever else, bloods. So, they can be quite time consuming when they're unwell, I think. I think they're a basic mucositis and they're not too bad. They're probably fairly quick and easily manageable."* ***Advanced Clinical Practitioner*** ***"****A normal day to day job, it impacts massively because if they're in pain, they may be in bed. They may be not able to access the playroom like they would normally be able to – impacts us *hugely*. And the flipside of that is that obviously we're then going to start with the more specialised area of our role so then we would be helping prepare them and discuss procedures and things like that. So, it impacts the normalisation of play because they aren't able to do the things that they would normal, they'll be able to do. However, then, we kind of ramp up the specialist side."* ***Play Therapist***
(4c) Perceived lack of effective options*	*"He probably had more pain relief but he wouldn't use any of the, you know the topical things like the mouthwash and things like that. He just, he wouldn't entertain anything like that would you?"* ***Parent 2a*** *"Never want mouthwash!"* ***CYP2 (8-year-old male)*** *"[…] You wouldn't use any of them. Even I used them to show you that they were okay, and you still wouldn't use them"* ***Parent 2b*** ***"****It's [other treatments] also focused on treatment rather than prevention. So I'm not really aware of many options to help prevent the oral mucositis, there's obviously things like holding ice cubes in the mouth but practically with younger children it's basically impossible."* ***Paediatric Dentistry Specialty Trainee***

	"The challenge with Difflam is the taste, as we've already alluded to, is the taste can really put people off and the feeling of it on the back of the throat. Yet, weirdly, the Difflam is probably more effective than the Gelclair. Because the Difflam will get down the back of the throat, whereas the Gelclair will only go as far as the cheeks and the bit that was washed around and spat out. Yeah. My personal experience, I'd say they're both good Gelclair works very well as a preventative, I think in mucositis. It's not the best once they've actually got mucositis because it just stings too much and they don't, they won't have it." ***Advanced Clinical Practitioner (ACP)*** *"Yeah, once there's the breakdown and the ulceration, it's kind of past –"* ***Specialty Trainee in Paediatric Medicine*** *"It's past that point."* ***ACP*** *"- past, and Gelclair its purpose is to help protect and preserve the barrier, as it were. But if the barrier is gone, then like [ACP] says, if it's more stingy or more uncomfortable."* ***Specialty Trainee in Paediatric Medicine*** *"They're not going to let you near, are they? But the spray is a little bit better from that perspective, I think, because it - - Difflam spray is much better because it doesn't taste very nice, but it works."* ***ACP*** *"Yeah, you're supposed to—no, you're supposed to put it [Gelclair] in your mouth, like that with it. But again you wouldn't entertain that either."* ***Parent 7*** *"Nothing. Anything you tried just made it 10 times worse. It was just best to leave it, wasn't it, yeah."* ***CYP7 (15-year-old male)***

Families perceived severe mucositis to have had adverse effects on CYP's cancer treatment, with reported: treatment delays, hospital admissions, secondary infections, and overall increased burden. Many CYP experienced multiple episodes of severe mucositis with little respite; families and HCPs perceived the degree of pain, extent, and duration of mucositis to be important factors in determining severity.

HCPs felt severe mucositis led to compounding burden on services, with the costs of hospital admission and utilisation of inpatient beds highlighted along with increased strain on daily care schedules with administration of nutrition and analgesia. Dental professionals experienced challenges in delivering any required dental treatment for CYP with severe mucositis, with implications on child oral health.

CYP disliked the taste and sensation of topical treatments such as gels and mouthwashes, with subsequent treatment refusal. All groups felt that this was particularly challenging for younger children.

"The [numbing] spray didn't work. It just covered it. It just covered it and made food taste horrible. The cream made food taste horrible." ***CYP1 (13-year-old female)***

HCPs expressed that oral cryotherapy, a preventative measure recommended for use during short infusions, was often not tolerated by CYP. Some participants valued topical treatments in mucositis prevention but found that following onset of ulceration, CYP would experience pain and stinging sensations on application and "wouldn't let them near". The perceived lack of viable preventative options, and challenges with topical treatments, were identified as challenges in maintaining oral health by all groups.

DISCUSSION

The current study has generated novel themes and diverse sub-themes from a rich dataset. It highlights removal from normality, unimagined severity, and a perceived lack of available treatment options. Additionally, it draws on HCP and parental perspectives to triangulate experiences, highlighting the compounding strain in providing care for CYP with severe mucositis, and complex parental experiences including feelings of guilt. Cross-cutting challenges to oral health were identified across all generated themes, highlighting the need to prioritise establishing preventative oral health behaviours and dental assessment at the outset of cancer treatment, prior to developing mucositis, to reduce negative long term impacts on oral health.

Despite oral mucositis being one of the most common side effects of chemotherapy in paediatric populations, there is limited existing qualitative research. Experiences of chemotherapy side effects has been explored in a Brazilian population of caregivers, with findings of parental concern around secondary infection risk with oral ulceration.[17] A study focusing on the mucositis experiences of CYP and parents in Hong Kong generated five key themes of: symptoms experienced, negative emotional outcomes, the dilemma of eating, challenges in oral care, and healthcare needs.[18] CYP reported similar experiences of pain, emotional distress, and difficulties with communication, sleep, oral care, and oral intake. “The dilemma of eating” centred primarily around parental concerns in maintaining nutrition, and children experiencing lack of satiety. A further study exploring the dietary consequences of mucositis and nausea found that CYP valued eating orally during cancer treatment, and that pain from mucositis reduced intake.[19] In contrast, the current study found the relationship between oral mucositis and eating to be complex and biopsychosocial, and not limited to pain and mucosal trauma. CYP missed physical aspects of eating, such as taste and chewing, and experienced excessive drooling. Additionally, families experienced disruption of the social norms around eating orally, with loss of the parental identity as “feeders”, and the structure of mealtimes. Additionally, it highlights concerns around long term impacts of oral mucositis on diet and nutrition, toothbrushing, and receiving dental care.

ChIMES is widely utilised as a PROM in international clinical care; ChIMES was developed from systematic review of existing measures and expert consensus opinion, prior to content validation with 40 CYP and 34 parents in Canada.[13,14] Nearly half of these participants (47%,n=35) had not previously experienced mucositis. The current study highlights additional outcomes of importance to participants with experience of severe mucositis, such as difficulty communicating, oral health impacts, and strain on families and services, which supports refinement of measures in capturing CYP experiences.

The strength of this study is its ethical and methodological rigor. Triangulation of participants and use of constant comparisons increases validity, and sense-checking supports reliability.[20] A diverse sample in all criteria was achieved allowing for consideration of a range of perspectives across and within participant groups. However, the sample consisted of families with experience of severe mucositis, rather than milder disease, which influences the experiences explored in this study. Additionally, time from last mucositis event amongst families ranged from days to years, which may result in recall bias. However, this does not

negate the credibility of these experiences, and these groups did not generate contrasting data.

Conducting interviews with CYP with their parents increased richness of data, with parents prompting CYP to elaborate on experiences, complementing encouragement from researchers.[21] This is particularly evident in our data derived from interviews with younger children, enabling them to participate key data to this study. Similarly, HCPs in focus groups generated group discussions, stimulated debate, and allowed exploration of shared team experiences.[22] Families were familiar with one interviewer (BP) through their clinical care team. On reflection, this provided a supportive environment for child participants to disclose their experiences to a familiar adult. However, it may have also influenced their responses where families wished to avoid reporting treatment side effects directly to their care teams. The lead researcher (CH) conducted all interviews and primary analysis. Her background is a specialist Paediatric Dentist with an interest in oral health during cancer treatment. This perspective likely influenced the degree that oral health was discussed by participants during interviews. Finalising of themes with experienced qualitative researchers with backgrounds in psychology occurred to help mitigate against this influence.

CONCLUSION

Oral mucositis presents significant strain functionally, psychologically, and socially during cancer treatment, and negatively affects treatment experiences and healthcare services. CYP experience challenges in maintaining oral health, and struggle to tolerate available treatments for mucositis management. This current study therefore highlights the importance of mucositis prevention as a supportive care priority, not only to improve patient experiences, but also to reduce the subsequent impacts on curative cancer treatment and oral health during cancer treatment. Additionally, it highlights outcomes of importance to these groups in mucositis prevention and management, supporting refinement of outcome measures and further research in this area.

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