



## RESEARCH ARTICLE OPEN ACCESS

# 'All I Had to Do Was Open My Mouth Wide'—A Qualitative Exploration of the Acceptability of Photobiomodulation for Oral Mucositis Management in Paediatric Supportive Care

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## ABSTRACT

**Background:** Oral mucositis (OM) presents a common and debilitating side effect of chemotherapy for children and young people (CYP). Photobiomodulation is recommended for OM prevention in international guidance; however, the acceptability of photobiomodulation in paediatric cancer care is uncertain. This study explores this acceptability with CYP, their parents, and healthcare professionals (HCPs).

**Methods:** Semi-structured interviews with CYP/parent dyads and focus groups with HCPs were audio-recorded and professionally transcribed. Framework analysis was completed utilising the Theoretical Framework of Acceptability (TFA) using an initial deductive approach for theoretical rigour. Over-arching themes within and between constructs and participant groups were developed. Recruitment occurred alongside analysis until there was repetition of data and an absence of novel codes.

**Results:** Twenty-seven participants were interviewed. CYP were aged 8–15 years old; HCPs had diverse professional roles within paediatric oncology and dentistry. Over half of families and three quarters of HCPs had previous photobiomodulation experience. Data were coded for all seven TFA constructs. Four themes, consisting of multiple subthemes, were developed from 42 distinct codes: (i) positive attitudes towards photobiomodulation; (ii) importance of child-centredness and autonomy; (iii) lack of understanding of photobiomodulation treatment; (iv) perceived additional burden to healthcare teams.

**Conclusion:** Photobiomodulation for OM prevention is acceptable to CYP, their parents, and HCPs during cancer treatment. Exploration of the theoretical facets of this acceptability supports adaptation of services to overcome highlighted challenges to

**Abbreviations:** COREQ, Consolidated Criteria for Reporting Qualitative Studies; CYP, children and young people; HCPs, healthcare professionals; HSCT, haematopoietic stem cell transplant; LCH, Leeds Children's Hospital; LED, light-emitting diode; LTHT, Leeds Teaching Hospitals Trust; OM, oral mucositis; PPI, patient and public involvement; TFA, Theoretical Framework of Acceptability; UK, United Kingdom.

**Meeting abstracts:** Previously presented at the national level (British Society of Oral and Dental Research National Conference, September 2024), but no abstract was published.

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## 1 | Introduction

Oral mucositis is a significant and common side effect of chemotherapy, affecting more than half of children [1]. Children and young people (CYP) are more likely to experience mucositis when compared to adults, due to the rapid division and proliferation of their epithelial cells [2]. Incidence and severity of oral mucositis are influenced by chemotherapy regimen [1]; up to 99% of people receiving conditioning chemotherapy prior to haematopoietic stem cell transplant (HSCT) experience oral mucositis, with a higher proportion of severe disease in this population [3]. Additionally, several chemotherapy drugs utilised in paediatric cancer care, such as alkylating agents, anthracyclines and methotrexate, have a highly stomatotoxic effect [4].

As well as being highly prevalent, severe oral mucositis impacts a child's quality of life. CYP may struggle to eat and drink, swallow, communicate and sleep [5]. Previous qualitative research demonstrates a sense of removal from CYP's 'normality' and an increased strain on healthcare services [6]. Although encompassed within supportive care, oral mucositis impacts curative care; ulcerative disease presents a secondary infection risk, and CYP often require hospital admission for intravenous nutrition and pain relief, which can delay scheduled curative treatments [2, 7].

Photobiomodulation describes the application of low-power visible red or near-infrared wavelengths onto tissues to stimulate cell proliferation and healing [8]. Photobiomodulation can be delivered using low-level laser or light-emitting diodes (LEDs) during chemotherapy to counteract the stomatotoxic effects on the oral epithelium. It has been found to reduce severe mucositis incidence in CYP by approximately a half in two meta-analyses [9, 10]. Prophylactic intra-oral photobiomodulation is recommended in international guidance for CYP receiving HSCT, or for those at high risk of developing mucositis [11, 12]. Despite these recommendations, our previous research identified that photobiomodulation is not widely used in routine paediatric cancer care in the United Kingdom (UK) [13]. Barriers identified in this study, and highlighted in paediatric guidance, included uncertainties around the acceptability of photobiomodulation to CYP [11, 13].

The acceptability of an intervention to patients and healthcare providers is critical, as it influences its implementation, adoption, fidelity and overall effectiveness in clinical practice [14]. Adoption into clinical practice requires acceptance from healthcare professionals (HCPs) in intervention delivery prior to acceptance by parents and CYP themselves. Acceptability is commonly reported in studies by proxy of behaviours (e.g., trial dropouts, treatment refusals), rather than exploration of affect (feelings) and cognition (perception). The Theoretical Framework of Acceptability (TFA) was therefore developed following a systematic review of the literature to theorise and define seven distinct constructs

of acceptability [15]. Exploring acceptability through this lens enables understanding of why interventions are accepted and supports their adaptation and adoption. The present study aimed to explore the acceptability of photobiomodulation with children and young people, their parents and healthcare professionals involved in their care, utilising the TFA.

## 2 | METHODS

### 2.1 | Study Design

A realist qualitative study was conducted and reported in line with the Consolidated Criteria for Reporting Qualitative Studies (COREQ) [16]. Interview schedules additionally pertained to the mucositis experiences of these groups; these findings are beyond the scope of this paper and are reported elsewhere [6].

Ethical approval was obtained from the NHS Health Research Authority (22/SC/0456). Patient and public involvement (PPI) was incorporated throughout the study at stages of research design, ethics application, data analysis and co-creation of research outputs.

### 2.2 | Setting

The study was conducted at the NHS Leeds Teaching Hospitals Trust (LHT), UK. LHT includes the Leeds Dental Institute, where consultant-led specialist paediatric dentistry services are delivered, and the Leeds Children's Hospital (LCH). LCH is one of 20 Principal Treatment Centres for paediatric oncology [17], and one of 16 paediatric HSCT centres in the UK [18]. An LED photobiomodulation system had recently been implemented at LCH for CYP receiving inpatient chemotherapy, who were at high risk of developing oral mucositis.

Candlelighters Children's Cancer Charity (Registered Charity Number 1045077) provides support for CYP and their families from the point of cancer diagnosis across Yorkshire and the Humber.

### 2.3 | Participants and Sampling

Sampling criteria for all groups were selected according to theoretical influence on acceptability. CYP and their parents were recruited in combination through direct clinical care and the family support network of Candlelighters. Inclusion criteria included: CYP aged 6–15 years old with experience of chemotherapy and English language comprehension. Purposive sampling occurred, aiming for diversity in age, sex, cancer diagnosis and photobiomodulation experience. CYP without photobiomodulation experience were included to explore changes in acceptability with exposure to the intervention. Where parents expressed interest in

taking part in qualitative interviews, but their child did not meet the minimum age inclusion criteria, they were invited to complete research interviews as a proxy for their child and to share their own experiences. This approach enabled inclusion of perspectives on younger children, whilst ensuring that participants could meaningfully engage with TFA-based interviews.

HCPs involved in paediatric cancer care were purposively sampled for diversity in professional role, professional experience and experience in delivering photobiomodulation. HCPs were recruited by email through existing relationships and snowball sampling.

Recruitment occurred alongside data collection and analysis until no new codes were identified. Participants received a £20 voucher as recognition for their time and contribution.

## 2.4 | Data Collection

Topic guides were developed following a literature review, consideration of the TFA [15], and discussion with PPI groups. Topic guides were iterative and responsive to emerging findings. Where families did not have direct experience of a photobiomodulation system, this was explained in a standardised way with supporting clinical photographs.

Semi-structured interviews were conducted in CYP/parent dyads by two researchers (Claudia Heggie and Bob Phillips). Claudia Heggie is a female clinical academic in paediatric dentistry, and Bob Phillips is a male senior clinical academic in paediatric oncology. Both researchers work within the clinical care team at LTHT. A dyad approach was utilised to explore shared experiences from differing perspectives and to provide parental support. A distress protocol was developed in the event of sensitive issues arising.

Data collection for HCPs consisted of focus groups and semi-structured interviews completed by up to two researchers (Claudia Heggie and Bob Phillips). The collection method and presence of Bob Phillips (as a senior clinician) were decided by the need to reduce hierarchical influence and participant availability.

Data collection occurred in a non-clinical environment at LTHT, Candlelighters family support centre, or online through virtual conferencing, depending on participant preference. Demographic data pertaining to sampling characteristics were collected. Interviews were audio-recorded, and field notes taken during interviews were referred to during analysis.

## 2.5 | Data Analysis

Descriptive statistics of demographic data were carried out. Audio-recordings were professionally transcribed and assigned a code number. Data analysis followed a framework approach, utilising the TFA [15].

The lead researcher (Claudia Heggie) completed initial analysis following familiarisation with audio-recordings and correction of transcripts. Data were deductively coded to the theoretical constructs of the TFA at each participant level. Following this,

codes were developed within constructs by comparing data within and between participant groups. Inductive development of overarching themes and subthemes then occurred through comparison of codes across constructs. Codes, subthemes, and themes were refined through discussion with experienced qualitative researchers (Amrit Chauhan and Kara A. Gray-Burrows) for sense-checking. No repeat interviews or member-checking occurred to avoid the transformation of data. Preliminary findings were discussed with PPI representatives to aid interpretation.

## 3 | RESULTS

Twenty-seven participants were interviewed between April and December 2023. Mean interview duration for families was 61 minutes, and 52 minutes for HCPs. This included data relating to mucositis experiences, which is reported elsewhere [6].

Nine families were interviewed: seven CYP/parent dyads, one CYP/parent triad, and one parent whose 3-year-old child did not meet the age inclusion criteria for interview. CYP were aged between 8 and 15 years old with experience of six distinct cancer diagnoses. Five of the nine families had received photobiomodulation (Table 1).

HCPs had diverse professional roles within paediatric oncology and paediatric dentistry, with a range of clinical and photobiomodulation delivery experience (Table 1). Data were coded to all seven TFA constructs, with 42 distinct codes generated (Table 2). Inductive development of subthemes and themes from the codes generated four overarching themes, each containing data from multiple theoretical constructs.

### 3.1 | Theme 1: Positive Attitudes Towards Photobiomodulation

A theme of positive attitudes towards photobiomodulation was developed from 12 codes across six theoretical constructs (Table 3). Codes relating to positive affective attitudes, low opportunity cost, and ethicality were most frequently attributed to this theme. No codes relating to the construct of self-efficacy contributed to this theme.

#### (1a) Value of having an intervention to prevent mucositis

Participants felt excitement and relief at having a preventive treatment available and were generally willing to try any treatment that might reduce mucositis for CYP. The purpose of photobiomodulation was well understood and perceived to be effective, but participants felt that this was difficult to determine without direct comparators.

‘For me, that’s quite a difficult one to answer [effectiveness] because I don’t know how he would have been without it. I don’t know how long that... so it’s difficult

**TABLE 1** | Demographics and photobiomodulation experience of participants.

<b>Children and young people (<i>n</i> = 8)</b>	
<b>Demographics</b>	
Sex (M:F)	6:2
Median age, years [range]	12 [8–15]
<b>Cancer diagnosis<sup>a</sup></b>	
Non-Hodgkin's lymphoma	<i>n</i> = 3
Acute lymphoblastic leukaemia	<i>n</i> = 2
Anaplastic large cell lymphoma	<i>n</i> = 1
Acute myeloid leukaemia	<i>n</i> = 1
Osteosarcoma	<i>n</i> = 1
Hodgkin's lymphoma	<i>n</i> = 1
<b>Treatment modality<sup>a</sup></b>	
Chemotherapy	<i>n</i> = 9
Haematopoietic stem cell transplant	<i>n</i> = 5
Proton beam therapy	<i>n</i> = 1
Immunotherapy	<i>n</i> = 1
<b>Photobiomodulation experience</b>	
Proportion of CYP with experience of photobiomodulation	50% ( <i>n</i> = 4)
<b>Parents (<i>n</i> = 10)</b>	
<b>Demographics</b>	
Sex (M:F)	2:8
Median age, years [range] <sup>b</sup>	45 [35–55]
<b>Photobiomodulation experience</b>	
Proportion of parents whose children had received photobiomodulation	60% ( <i>n</i> = 6)
<b>Healthcare professionals (<i>n</i> = 9)</b>	
<b>Demographics</b>	
Sex (M:F)	2:7
<b>Focus group composition by professional role</b>	
Senior paediatric oncology nurse ( <i>n</i> = 1)	Focus group 1
Paediatric dental nurse ( <i>n</i> = 1)	Focus group 1
Paediatric dentistry specialty trainee ( <i>n</i> = 1)	Focus group 1
Paediatric dental therapist ( <i>n</i> = 1)	Focus group 1
Paediatric dentistry consultant ( <i>n</i> = 1)	Focus group 1
Play therapist ( <i>n</i> = 1)	Semi-structured interview
Paediatric haematology and oncology advanced clinical practitioner ( <i>n</i> = 1)	Focus group 2
Paediatric medicine specialty trainee ( <i>n</i> = 1)	Focus group 2
Paediatric oncology consultant ( <i>n</i> = 1)	Semi-structured interview

(Continues)

**TABLE 1** | (Continued)

<b>Children and young people (<i>n</i> = 8)</b>	
<b>Experience in professional role</b>	
Mean experience, years [range]	7.4 [3–15]
<b>Experience of photobiomodulation delivery</b>	
Observed delivery only	22% ( <i>n</i> = 2)
Delivered on less than 5 occasions	33% ( <i>n</i> = 3)
Delivered on 5–10 occasions	0% ( <i>n</i> = 0)
Delivered on more than 10 occasions	44% ( <i>n</i> = 4)

<sup>a</sup>Cancer diagnosis and treatment modality of children in the nine interviewed families. Many children received more than one treatment modality.<sup>b</sup>Three parents declined to disclose age.

to see the benefit of it. But you know, knowing that he wouldn't take anything else, anything is better than nothing in my opinion' **Parent 2a (parent of 8-year-old male with photobiomodulation experience)**

Where families had experience of chemotherapy with and without photobiomodulation, they perceived photobiomodulation to have been effective in reducing their mucositis compared to no, or irregular, treatment. Families reported actively requesting photobiomodulation treatment, demonstrating its acceptability.

### (1b) Perceived low opportunity cost and risk

Photobiomodulation was perceived to be low in opportunity cost. This is related to the intervention characteristics of portability and flexibility of timing of delivery, which did not require scheduling or transport across the hospital, and the continued availability of other interventions (e.g., mouthwashes). Families generally perceived there to be minimal opportunity cost during inpatient stays, but that this would increase should children be treated as outpatients.

'We were there, we weren't... we couldn't escape, same four walls. He wouldn't accept any other treatment, so we're... it was a case of anything to try and help make it better quicker' **Parent 2b (parent of 8-year-old male with photobiomodulation experience)**

Families had a desire to avoid systemic drugs with potential side effects and perceived photobiomodulation to be low risk. One focus group generated contrasting data, relating to the unknown theoretical long-term risks.

'I guess my only concern with it is, like anything that affects something at a cellular level, are there going to be long-term side effects, long-term changes that are really not good? But you don't know that when you start using something, do you?' **Advanced clinical practitioner**

**TABLE 2** | Number of constructs generated within each theoretical construct of the Theoretical Framework of Acceptability adapted and contextualised from Sekhon et al. (2017).

Theoretical construct	Contextual construct definition	Codes generated within construct (n)
Affective attitude	How an individual feels about photobiomodulation	8
Burden	The perceived amount of effort that is required to participate in photobiomodulation	8
Ethicality	The extent to which photobiomodulation has a good fit with the individual's value system	5
Opportunity costs	The extent to which benefits, profits or values must be given up to engage with photobiomodulation	4
Perceived effectiveness	The extent to which photobiomodulation is likely to achieve its purpose	6
Self-efficacy	The individual's confidence that they (and others) can perform the behaviours required to participate in photobiomodulation	6

**(1c) Opportunity for healthcare teams and services**

This subtheme encompassed HCPs' attitudes that photobiomodulation presents an opportunity for a positive clinical encounter, personal skills development, inter-disciplinary collaborations, and organisationally for the Trust.

'So I think from a dental point of view, we have a bit of a reputation of not being one of people's favourite professionals, and so to have a positive impact on patients and have a reasonably positive experience is nice'. **Paediatric dental therapist**

**(2b) Empowering families in service design**

Families valued the opportunity to 'participate' by engaging in self-delivery. Parents felt empowered by the optionality of photobiomodulation and felt that this was less dictated than curative cancer treatments.

All participants valued patient-reported outcome measures in monitoring treatment effects and eliciting the child's voice; however, there was no consensus on how frequently these should be collected. Families receiving inpatient treatment highlighted that daily completion would be acceptable 'because there wasn't a lot else [for us] to do'.

**3.2 | Theme 2: Importance of Child-Centredness and Autonomy**

The theme of importance of child-centredness and autonomy was developed from 13 codes across five theoretical constructs (Table 4). Codes within this theme most frequently related to both positive and initially negative affective attitudes, and opportunities to support child self-efficacy.

**(2a) Child-friendly characteristics of photobiomodulation**

Participants perceived photobiomodulation to have child-friendly characteristics of being intriguing, novel, non-invasive, and pain-free. This was linked to perceived low-burden characteristics of the LED system: being quick, and simple to deliver and receive. Portability and the ability to deliver bedside supported child-centredness.

Participants felt that photobiomodulation was easy to receive in comparison to topical treatments such as mouthwashes and gels. LED systems were favoured over low-level laser systems due to the ability to self-deliver, flexibility of delivery and short treatment time.

**(2c) Supporting children to receive photobiomodulation**

This subtheme encompassed challenges with photobiomodulation delivery and opportunities to overcome these challenges. This is related to initial perceptions of photobiomodulation as intimidating, scary, or painful, particularly for participants without prior photobiomodulation experience, and negative connotations with the word 'laser'.

Universally, intra-oral treatment was perceived as the least acceptable facet of the intervention by all participants. This was more challenging when oral mucositis was present and was related to the LED intra-oral probe size, termed 'the lollipop', with no paediatric version currently available.

Participants valued the flexibility and sense of control within the treatment; this included provision of choices (e.g., glasses, order of treatment sites) and the use of child-friendly incentives and preparatory aids to support self-efficacy. Families valued the ability to treat themselves with LED systems; however, when receiving treatment from others, established relationships with the staff delivering the treatment and availability and continuity of care supported acceptability. As a result, ward staff were perceived as best placed to deliver photobiomodulation compared



**TABLE 3** | Summary of Theme 1, constituent subthemes and representative quotes.

Theme	Subthemes	Representative quotes
(1) Positive attitudes towards photobiomodulation	(1a) Value of having an intervention to prevent mucositis	<p>'It's [other interventions] 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. And as we've discussed already, it's so difficult to treat children with that condition, and therefore, a prevention sort of based approach is better than trying to just treat it probably when it happens' <b><i>Paediatric dentistry specialty trainee (experience of delivery of photobiomodulation)</i></b></p> <p>'It was a bit of respite, wasn't it? To the pain and stuff. I think in my personal opinion, if you didn't have the light treatment, I think that you would have to have a food tube [NGT] because I don't think you'd be able to eat or drink' <b><i>Parent 1 (parent of 13-year-old female with photobiomodulation experience)</i></b></p> <p>'I think just that peace of mind of like knowing that in the long run with the [photobiomodulation]—yeah, It's going to help and it's going to get us out a bit quicker, isn't it? Which it did I think yeah' <b><i>CYP4 (14-year-old male with photobiomodulation experience)</i></b></p> <p>'Well, it's good that it's available full stop because it's not available everywhere. So, that is a real privilege to have it. And we believe it's helped [CYP8] so that's a real positive' <b><i>Parent 8 (parent of 11-year-old with photobiomodulation experience)</i></b></p>
	(1b) Perceived low opportunity cost and risk	<p>'It got wheeled in and it was quite simple and like I said non-invasive and he'd just sit there. So, it wasn't as if it was something we were putting down his line and he didn't know his body would react to it or we didn't we had to go to another part of the hospital and it was getting him a porter or putting him in a wheelchair and taking him out it was just brought to us and it was perfect for that' <b><i>Parent 5 (parent of 3-year-old male with photobiomodulation experience)</i></b></p> <p>'I don't think there's a lot else to lose out on, because what I would probably do is like, even though you're having that [photobiomodulation], I would still probably, you know, [...], not do it instead of the mouthwash and the other stuff, do it as a whole. So that everything, you're doing everything together to make, you know, to prevent. So it's not replacing any, it's not replacing, like, the mouthwashes to do as well as, isn't it' <b><i>Parent 3 (parent of 8-year-old without previous photobiomodulation experience)</i></b></p> <p>'And because it's quite a portable device, the only impact I could see if we had like an activity going on or an entertainer coming in or something like that that would maybe pull the child away from what's going on. However, my understanding at the minute is that that could be prolonged for an hour and done after you know. It's not, "You're booked in at MRI at 2 o'clock and you have to go"' <b><i>Play therapist (experience of observation of photobiomodulation delivery)</i></b></p>
	(1c) Opportunity for healthcare teams and services <sup>a</sup>	<p>'It is an additional skill. It depends how savvy you want, it is an additional skill. And there is an argument that for anyone, be it a nurse, junior doctor, a nurse practitioner, it's something you can say that you do on a daily basis, which you are trained in that someone else may not be. So, it is I think' <b><i>Advanced clinical practitioner (experience of delivery of photobiomodulation)</i></b></p> <p>'We all learned a little bit more about how oncology treatments are completed, and there's building up a rapport with the staff that are over there, and the parents, because if we were doing it over the 5 days, Monday to Friday, between us all who were doing it, we got to see that patient for the week, and that was really nice actually. I mean it's nice to meet the new staff and go, "Oh yes, I remember you, blah, blah, blah," and talk about the patient, how were they doing today. So all of that was a good thing about it' <b><i>Paediatric dentistry consultant (experience of delivery of photobiomodulation)</i></b></p> <p>'Well, I guess that this isn't available in every hospital. We're always wanting to be that specialist place aren't we that delivers specialist high quality care. I think anything that we can do to offer like an extra branch of specialist high quality care has got to be a great thing for [the hospital] in the whole' <b><i>Play therapist (experience of observation of delivery photobiomodulation)</i></b></p>

<sup>a</sup>Indicates a subtheme generated from predominantly healthcare professionals' data.

TABLE 4 | Summary of Theme 2, constituent subthemes and representative quotes.

Theme	Subthemes	Representative quotes
(2) Importance of child-centredness and autonomy	(2a) Child-friendly characteristics of photobiomodulation	<p>'My first thought was this is actually great. You know it's got sunglasses. It's got sunglasses. It's got really, that we could—it's got a really, how can I put it? Like a child-friendly approachable way that we could approach that child and say you know [3-year-old child] for instance. They loved wearing the sunglasses. You know it seems something that could easily be explained and easy for a child to understand. [...] When I was watching it being done, there was lots of things that they were great' <b>Play therapist</b></p> <p>'I think it's like something, I think it was kind of, like, good in a way of like, because with the mouthwashes, I still have to have it. Like I have to use it and like swill in my mouth and stuff. But with the photobiomodulation, it's kind of like, it's not like—' <b>CYP4 (14-year-old male with photobiomodulation experience)</b> 'Less effort: <b>Parent 4</b> 'yeah, less effort. Thank you. It's kind of like less effort for me to use and then I don't have to like-' <b>CYP4</b> 'Especially because of the gagging thing, yeah, you would prefer this any day' <b>Parent 4</b></p> <p>'I think it was quite cool how you could see the light through my mouth because... Because when the lollipop [intra-oral probe] went through my cheeks. But I couldn't see it, obviously, but I thought it was quite cool.' <b>CYP8 (11-year-old male with photobiomodulation experience)</b></p> <p>'Honestly, it's not invasive you know compared to some of the other stuff, needles stuck in you and things like that so you know this would be something. It doesn't really seem too difficult does it to you know take...' <b>Parent 6</b> 'It won't make you cry' <b>CYP6 (15-year-old male without photobiomodulation experience)</b></p> <p>'So like with the red-light therapy he liked to pick which side he went for first whether it's left or his right cheek and then even holding the lollipop and doing the countdown and I think it's just them taking control and making it a lot less scary, you know if they're doing it to themselves it's, you know, it's just that bit easier for them' <b>Parent 5 (parent of 3-year-old male with photobiomodulation experience)</b></p> <p>'I think if the child can do it, I think initially—yeah, I think they should be allowed to do it. Obviously if they're not comfortable doing it but they prefer their mum or dad to do it, then I think that again would give the parents a little bit of control back as well because you're handing over control of your child to somebody and I think... this is coming from a big control freak, but you're handing over your child's life in someone else's hands because you can't do the things that the nurses are doing and the doctors are doing. So I think giving the parent this opportunity to help and to have a little bit of control, and be part of it, I think that would be quite boost—confidence boosting and help the parents feel part of what's going on' <b>Parent 7 (parent of 15-year-old male without photobiomodulation experience)</b></p> <p>'They're the ones receiving the treatment. Getting feedback from the patient and the parent, as well as our feedback is important, but actually, really, it's their feedback that we should be paying more attention to' <b>Paediatric dentistry consultant</b></p>
	(2b) Empowering families in service design	

(Continues)

TABLE 4 | (Continued)

Theme	Subthemes	Representative quotes
	(2c) Supporting children to receive photobiomodulation	<p>'It might be scary for little kids. Do you know what I mean? Because it's like they have no experience so it might be like quite intimidating for them when they see it first [...]. Like it's, I haven't really had it first-hand but it's like it's a machine that goes to your mouth and it probably is, might be very scary for kids that are quite young. Whereas like, other stuff like mouthwash and all that could be less intimidating to them. And it's like, not as in your face if you know what I mean' <b>CYP6 (15-year-old male without experience of photobiomodulation)</b></p> <p>'Showing that it's okay to have and you shouldn't be scared. [...]. It is okay to have because it causes no pain, only warm' <b>CYP3 (8-year-old male without photobiomodulation experience)</b></p> <p>'[Holding it myself helped] a little, because I could control how far' <b>CYP4 (14-year-old male with photobiomodulation experience)</b>. 'How far it, the mouth one, I would prefer the child do it themselves because they know how far they can push it. If a third person does it, you know, you can do it a little too much, and then yeah. So, [CYP4] preferred to do it himself'</p> <p><b>Parent 4</b></p> <p>'I do think, for smaller kids mainly, it's a bit big like the lollipop for putting in your mouth. [...]. Because even in my mouth, it's quite big' <b>CYP8 (11-year-old male with photobiomodulation experience)</b>. 'It's massive. It doesn't fit in your mouth' <b>Parent 8</b> ' [...]. It would be a lot better if it was smaller so you could actually put it inside and nobody really sees the light' <b>CYP8</b></p> <p>'But for me, using the word laser is a scary, you know to say it's a laser, so it definitely would be something that we would need to know a little bit more about, probably be a bit more blasé about the other one [LED]. But this is a bit, seems a bit scary doesn't it? Taking you into the other room, having special training, zapping that spot you know like particular spots and stuff'</p> <p><b>Parent 6 (parent of 15-year-old without photobiomodulation experience)</b></p> <p>'As long as it was somebody who we, well, I wouldn't even say familiar, on the ward more than anything. If he just knew it was happening every day I don't think he would have bothered who was delivering it. And especially for [CYP5] the fact that he took control of doing it, you know somebody was just there to pass it to him and press the button he did the therapy himself almost' <b>Parent 5 (parent of 3-year-old with photobiomodulation experience)</b></p>



to visiting dental teams. When these supportive measures were taken, intra-oral photobiomodulation was well tolerated by CYP.

‘All I had to do was open my mouth wide’ **CYP2 (8-year-old male with photobiomodulation experience)**

### 3.3 | Theme 3: Lack of Understanding of Photobiomodulation Treatment

This theme was developed from seven codes across three theoretical constructs (Table 5). Data predominantly related to challenges with intervention coherence and the influence of perceived effectiveness on acceptability.

#### (3a) Difficult to understand the mechanism and effect

Data from all participant groups were coded to this subtheme for both those with and without direct experience of the photobiomodulation. This was related to: complexity and indirectness of the mechanism of effect, and difficulty understanding risk.

‘Probably my first initial thoughts were along the voodoo line, if I’m honest’ **Advanced clinical practitioner**

There was individual variation in desire to understand the treatment mechanism with variable influence on acceptability; most participants expressed that they did not necessarily need to fully understand the mechanism, provided photobiomodulation had a positive effect, whilst others wanted more information. Participants highlighted the value of age-appropriate information resources to support coherence.

‘I would probably say no [to having photobiomodulation], because I haven’t seen it before. I wouldn’t know what it does’ **CYP3 (8-year-old male without photobiomodulation experience)**

Limited intervention coherence resulted in reported variation in case selection and protocols for delivery; HCPs highlighted concerns around equity of availability due to this variation in practice.

#### (3b) Social influence of knowledgeable healthcare professionals

Families placed trust in their healthcare teams’ recommendations, which supported photobiomodulation acceptability.

‘I just thought if it’s offered, give it a go, and I trusted everybody on the ward and, you know, so why not

give it a shot?’ **Parent 5 (parent of 3-year-old with photobiomodulation experience)**

The social influence within healthcare teams was also important, with the knowledge and attitudes of senior clinicians influencing treatment acceptability and perceived effectiveness.

### 3.4 | Theme 4: Perceived Additional Burden to Healthcare Teams

The theme of perceived additional burden to healthcare teams was developed from 10 codes across five theoretical constructs (Table 6). Data within this theme predominantly related to relative burden and healthcare professionals’ perceived self-efficacy of themselves and others.

#### (4a) Balancing priority and burden of interventions

Photobiomodulation was identified as presenting an additional task in inpatient cancer care schedules. Participants reported that photobiomodulation was often placed at ‘the bottom of the priority list’ compared to other interventions. The opportunity cost of HCPs’ time taken from other tasks was highlighted, within already ‘stretched’ and ‘understaffed’ services. However, participants recognised that effective mucositis prevention would reduce overall service burden.

In contrast, families perceived photobiomodulation to be an integrated part of their cancer care and expressed a desire for consistency in its delivery, which they perceived to influence treatment effectiveness. All participant groups felt that the availability of trained staff would decrease the burden and improve service delivery.

#### (4b) Simple treatment within a complex wider context

LED photobiomodulation treatment was perceived to be simple and deliverable by ‘anybody’, resulting in uncertainty over who was best placed to deliver treatment. Some participants felt that a dedicated, trained team should deliver photobiomodulation to increase ownership of the task, whereas others felt that widening training to all staff groups would improve consistency in delivery.

Overall, participants perceived the treatment to be easy for CYP to receive.

‘I think it’s been very acceptable to the children generally. I think you rarely get someone who says, it didn’t really work for me very rarely, and they don’t really want it. Most of the time, I think the parents or the children will say to you, won’t they, “Am I having my lights today?” Which says it all, I think’. **Advanced clinical practitioner**

**TABLE 5** | Summary of Theme 3, constituent subthemes and representative quotes.

Theme	Subthemes	Representative quotes
(3) Lack of understanding of photo-biomodulation treatment	(3a) Difficult to understand mechanism and effect	<p>'I don't really understand how the laser works. But I understand, just obviously I was half out of it with pain. But it was to help get rid of it. Instead of like taking something, just removing it by giving it something towards the actual ulcers' <b>CYP1 (13-year-old female with photobiomodulation experience)</b></p> <p>I think it explaining in a bit more detail as to how it's going to contribute towards the mucositis and how it's going to help your child I think would be worthwhile before the child and the parent going into this process, I think. I think that would be helpful because like I said, I never knew what that was. There was a mention of photobiomodulation but what is it? We don't know. So, it will help with mucositis. Okay, but, you know, is it a tablet? What is it?' <b>Parent 4 (parent of 14-year-old with photobiomodulation experience)</b></p> <p>'And so, my introduction was, you know, infamous [consultant paediatric oncologist] introduction, where he kind of briefly explained that, you know, we'd zap people's mouths whilst they're in hospital for mucositis. And I remember us having a conversation about me saying, "Why did people think that was a good idea?" You know, "How on earth did we stumble across this?" And "How on earth can a bit of red light possibly help with mucositis?"' <b>Paediatric oncology consultant</b></p> <p>'They wonder, proper science behind how it works and stuff. And then it's really hard to describe it to like a parent or a child. So, it gets confusing. So, again, having that like visual video to watch can really help with like understanding' <b>Parent 4 (parent of 14-year-old with photobiomodulation experience)</b></p> <p>'I just think that one thing which would be really helpful in the wards is just having it clear as to who, you know, it feels at the moment, it's a bit vague as to who, for how long do you get it when you get your mucositis? And because no one's clear, I think that also influences it getting dropped. So, that would be the thing for me, as consultant on call would be the most helpful thing' <b>Paediatric oncology consultant</b></p>
	(3b) Social influence of knowledgeable healthcare professionals	<p>'One of the transplant nurses, before I went into my transplant, they recommended that we go with the photobiomodulation if we were asked' <b>CYP4</b> 'They said if the suggestion comes, you'll have to take it in. That it's a new thing' <b>Parent 4</b> 'Yeah, they definitely recommended it, so' <b>CYP4 (14-year-old male with photobiomodulation experience)</b></p> <p>'From a parent's point of view, I don't think it would make a difference [if I knew how it worked]. If it would stop the hurting or the pain then we'd probably be, just at the word of the staff really' <b>Parent 6 (parent of 15-year-old male without photobiomodulation experience)</b></p> <p>'So, I have to say, working again with [paediatric oncology consultant], he is very much an evidence-based man. So, I take what he says seriously, and if he says something wacky, if someone else had said it to me and I would have met it, perhaps with a bit more scepticism. And I thought, if he's asking me to do something, there probably is a good reason for doing this and there probably is some evidence behind it. So, I was more receptive to it than perhaps if someone else had told me' <b>Paediatric oncology consultant</b></p>

The wider operating procedures, including transportation, cross-infection protocols and documentation, were seen as a burden. HCPs perceived the additional training and laser safety requirements necessitated by low-level laser systems as presenting an additional barrier.

#### 4 | Discussion

The present study demonstrates the acceptability of photobiomodulation in the context of paediatric care, addressing a key area of uncertainty. Inclusion of HCPs and parents, in addition to children and young people, allowed exploration of the facets

of, and barriers to, acceptability from these different perspectives. This aids the adaptability of the intervention to support wider adoption into standard paediatric cancer and HSCT care.

The existing literature in this area focuses on acceptance behaviours. Infant children under 1 year old have been compliant with intra-oral low-level laser systems [19]. However, delivery of photobiomodulation in this study often occurred whilst infants were sleeping and with reduced treatment times compared to older children. Similarly, a feasibility study exploring the acceptance of extra-oral LED photobiomodulation reported only six complete treatment refusals out of 355 attempted administrations in a sample of 13 participants aged 4–21 years old [20].

TABLE 6 | Summary of Theme 4, constituent subthemes and representative quotes.

Theme	Subthemes	Representative quotes
(4) Perceived additional burden to healthcare teams	(4a) Balancing priority and burden of interventions	<p>'You can go and you're asking permission to come and do <i>something else</i>,<sup>a</sup> you know, when some boys and girls don't know they're poorly at certain stages, do they, so I think it's just gauging all that on top of trying to encourage them to have that therapy as well' <b><i>Paediatric dental nurse</i></b></p> <p>'From my perspective, I think, you know, this was part of the transplant and it was important that he had it. Yeah' <b><i>Parent 4 (parent of 14-year-old male with photobiomodulation experience)</i></b></p> <p>'I think from a parental point of view because [CYP8] won't necessarily think about this, although he might say, "When is the treatment coming?" For us, it was more about, when will this be fitted into the day, will this be fitted into the day, can someone do this today so [...] So, that in itself is a slight barrier and slightly stressful as a parent. Because you want them to be the best version of themselves and that [photobiomodulation] helps and you want them to have it' <b><i>Parent 8 (parent of 11-year-old male with photobiomodulation experience)</i></b></p> <p>'I don't actually think it's because people think it doesn't work. I think it's just, you know, drugs <i>have</i><sup>a</sup> to be changed, discharges <i>have</i><sup>a</sup> to be done before they can get home, scans <i>have</i><sup>a</sup> to be requested. But there's not that same kind of accountability that if the PBM [photobiomodulation] isn't done it's, "Oh, well, we didn't have time." So, it's one of those jobs. If it doesn't get done, at the end of the day, no one's really going to come back to them and chase them up' <b><i>Paediatric oncology consultant</i></b></p> <p>'The staff obviously come around. They give you chemo, they do your obs [observations], they sort your TPN [total parenteral nutrition] out, they do your PCAS [patient controlled analgesia]. But if you think about some of those things, that—what would that do that would prevent hopefully, a couple of those things occurring anyway. So—and if some children can hold it themselves [...] So that would entail basically, lessen the burden for staff to sit there for the 10 minutes while—or 10–15 minutes while it's delivered? [...] In the grand scheme of things... and if a parent can help, I think it would <i>lessen</i><sup>a</sup> the burden of staff, of having to be there and do the light therapy, if the parent is happy to sit there with their child which I'm sure they would be. So yeah, I think it'd be less of a burden than if the child develops horrendous mucositis like [CYP7] did' <b><i>Parent 7 (parent of 15-year-old male without photobiomodulation experience)</i></b></p>
	(4b) Simple treatment within a complex wider context <sup>a</sup>	<p>'Yeah. It's an easy thing to deliver. Physical skill is easy to deliver. It's not invasive, doesn't seem to hurt the child in any way. And it's the being able to actually do it... You know, [the environment] is the challenge' <b><i>Advanced clinical practitioner</i></b></p> <p>'I think it's quite a junior team over the wards at the minute, and I think they're already struggling, staffing and things. So I think just to keep that to a smaller group so it doesn't get missed, it can be all passed on and it's not just, oh, anyone will do it so it'll be done today kind of thing. I think, yeah' <b><i>Senior paediatric oncology nurse</i></b></p> <p>Just getting I suppose going back to it getting more people kind of into that mindset that they can do it too [...] I mean from a nursing belief that this is a medical job, or not a nursing role, it's something that has to be done by a medic or a nurse practitioner, which it doesn't. And I think that's something that's still holding it back. May not be the case but certainly my experience' <b><i>Advanced clinical practitioner</i></b></p> <p>'My experience with laser [system] as a research project previously... So in my experience with that, much more training, required understanding obviously of settings around you, the cleaning process, so that were different in that we use the [cleaning] system, much longer to clean, logbooks, infection prevention, bits and pieces. A little bit more intense with that though because with the [cleaning] system, you have to have... you have to keep a log of that and dates and signatures and everything that goes with it. So in terms of easier to use, I would definitely go and say the light [LED]. [...] I think it's very onerous. I think it's really intense. And it's understanding, like nurses understanding reflective surfaces, everybody has to have safety goggles, you know, and the cleaning process, we cannot... The protocols alone' <b><i>Paediatric dental nurse</i></b></p> <p>'But equally, I think sometimes it's the process of going from one patient to the next and it's the cleaning it from the next patient and cleaning it before the next one. And then you turn up in the side room and they're asleep or they don't want it at the moment. So, then you go find the next one who might not be at the bedside. So, some of the logistics around it is time-consuming. And there is the element that [advanced clinical practitioner in focus group] said about how it kind of feels in a way that when you stood there for that minute, or however many minutes you're with the kid, you kind of feel like it's time you could be doing something else. Because they can, they are holding it themselves, they are capable of doing it themselves. And although, it's only 2 minutes or 5 minutes, add up the five kids on the ward who need it. That's 10 or like 20 minutes where you could do all the discharge letters for the kids. So, again, it's not down to like a disrespect for PBM [photobiomodulation] itself. It's just that there are elements of it that allow you to think about the other jobs you should be doing' <b><i>Paediatric medicine trainee</i></b></p>

<sup>a</sup>Indicates a subtheme generated from predominantly healthcare professionals' data.

However, photobiomodulation was delivered partially in nearly 9% of the total administrations. This study population was small with a median age of 15 years, potentially representing a more cooperative subset of the paediatric population. Although these studies provide behavioural indications of acceptability, they do not explore the perceptions of the intervention or how to improve acceptability.

The present study represents a methodologically robust, theory-driven analysis of these under-explored facets of acceptability with a diverse population. Deductive framework analysis ensured consideration of theoretical acceptability constructs, whilst inductive generation of themes supported comparison across constructs and between groups. The results highlight the key intervention components contributing to overall acceptability, such as the perceived child-centredness, autonomy, low risk and opportunity cost, and positive professional opportunities. Additionally, it identifies barriers to acceptability and treatment delivery from both patient and healthcare provider perspectives, in relation to intervention coherence and relative burden. These findings inform the development of information resources and adaptation of services to address these barriers to further support acceptability.

Acceptability of an intervention is likely to change with exposure, and photobiomodulation treatment will be novel to all children at a certain point in time [15]; inclusion of CYP and parents without previous experience allowed exploration of acceptability across this continuum. Similarly, inclusion of HCPs with different levels of direct clinical experience allowed comparison within and between these groups. Participants with experience of photobiomodulation in this study had predominantly exclusive experience with LED systems, with low-level laser systems described and demonstrated with photographs, which may influence the perceived acceptability of each system. However, this was mitigated by the inclusion of participants without direct experience of either system. Further research could be conducted to explore the acceptability of low-level laser systems among individuals with direct experience and compare this to the present population. Additionally, comparison could be made between CYP receiving photobiomodulation for different clinical indications.

Children and young people interviewed in this study were aged between 8 and 15 years, with a minimum age of 6 years established for inclusion. Children below this age were felt to be unlikely to be able to draw on temporally distant experiences of photobiomodulation, or to interpret and respond to topic guide questions; this minimum age was additionally influenced by the potentially upsetting nature of the interview content and complexity of the topic [21]. Nonetheless, the inclusion of younger children is crucial, particularly given that approximately 45% of childhood cancers occur in children aged 0–4 years in the United Kingdom [22], and so challenges remain in reflecting the experiences of these younger children in qualitative research in paediatric oncology and haematology. To address this, parents and healthcare professionals served as proxies for younger children in the present study, describing their experiences of observing photobiomodulation delivery to infant children and their perceptions and behavioural indications of child acceptability. This approach ensured that the perspec-

tives of younger children were meaningfully represented, while maintaining methodological rigour and ethical standards. Future research should prioritise the development and application of age-appropriate, creative methods such as drawing or modelling, to support direct participation of younger children and capture their lived experience [21].

An adaptable questionnaire has been developed by the authors of the Theoretical Framework of Acceptability, which presents a cost-effective and efficient method to explore photobiomodulation acceptability across a wider population [14]. Qualitative interviews in the present study allowed exploration of *why* participants found photobiomodulation acceptable within each construct and supported theoretical depth. However, a questionnaire could be considered to determine acceptability across wider populations or as part of future clinical trials in this area.

Consideration was given to the influence of the researchers conducting the interviews and focus groups on the participants in this study. The researchers (Claudia Heggie and Bob Phillips) were known to participant groups due to their role within the clinical care team, or through previous involvement of families in PPI groups. Both researchers conducted interviews with CYP and parents to provide familiarity and support in the elicitation of experiences, and with consideration of paediatric safeguarding. For HCP data collection, Bob Phillips did not conduct interviews where hierarchical influence may affect data collection. Within their clinical job roles, Claudia Heggie and Bob Phillips had led the local implementation of photobiomodulation at LTHT. This may have resulted in response bias from participants, should they not wish to share negative experiences. This was mitigated through the inclusion of families with no knowledge of the researchers' roles in its implementation, and the use of focus groups to draw on team experiences and to reduce interviewer influence.

## 5 | Conclusion

Photobiomodulation for the prevention of oral mucositis was found to be acceptable to children and young people, their parents and healthcare professionals involved in paediatric cancer care. Qualitative exploration of the multiple facets of acceptability from these different perspectives supports understanding of how to support children and young people to receive photobiomodulation treatment. Additionally, it provides insight into barriers to acceptability, allowing adaptation of services and development of resources to support wider adoption to improve access to this supportive care treatment and improve child quality-of-life during cancer treatment.

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## Disclosure

The views expressed in this publication are those of the authors and not necessarily those of the NIHR, the NHS, or the Department of Health and Social Care.



## Conflicts of Interest

The authors declare no conflicts of interest.

## Data Availability Statement

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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