

Patient experiences of dentofacial adverse effects after proton therapy: A qualitative study

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DETOFACIAL - PBT (DENtofacial TOxicity: Facilitating Advancement in paediatric Cancer toxicity reporting And Liaison in Proton Beam Therapy)



BACKGROUND

At the point of cancer diagnosis, patients' and their guardians', if applicable, principal focus is on survival.^[1] However, with childhood head and neck (HN) cancer survival rates increasing^[2], focus is shifting towards the management of treatment-related late adverse effects (AE). Proton beam therapy (PBT), a type of radiotherapy, offers a theoretical reduction in AE in childhood HN cancer patients.^[3] The development of the teeth and jaws in this population, however, presents many unanswered questions.^[4]

To understand both the presence and implications of AE to dentofacial development, the perspectives of HN childhood cancer survivors (CCS) and/or their families was explored. The voices of individuals with lived experiences of having and supporting a loved one with this diagnosis and treatment are fundamental in prioritising and designing research.

METHODS

DENOFACIAL-PBT is a multi-site, multi-stage, mixed-methods study examining AE to dentofacial development following PBT in UK HN-CCS.^[5] In stage 1, virtual semi-structured qualitative interviews were conducted.

RQ: What are the perspectives of HN-CCS on the impact of PBT on dentofacial development?

Recruitment posters were displayed in three large hospitals in Manchester. Due to the geographical spread of the eligible population, convenience sampling targeting key clinical areas was selected. Ten interviews were conducted by the chief investigator (EF-T). Interviews were transcribed verbatim, and reflexive thematic analysis was performed.^[6] Transcripts were manually coded and grouped into themes and sub-themes.

RESULTS



Data was garnered from **10** participant interviews lasting between 20 - 70 minutes with HN-CCS [age at treatment range: 2.8 - 15 years] both independently and alongside parents, and with parents on their own.

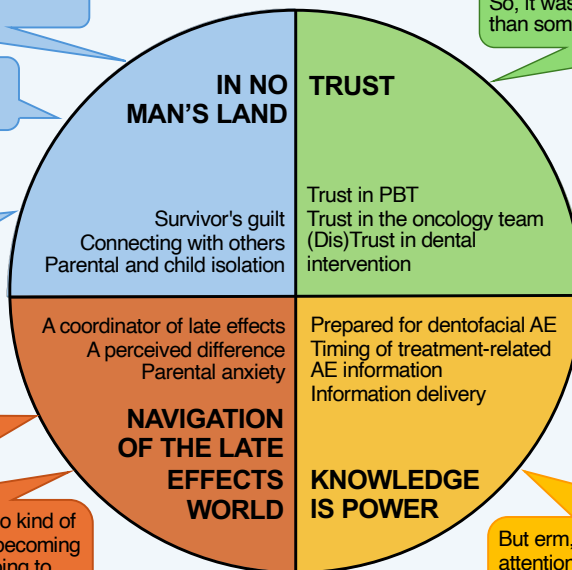
I think that once you finish treatment, the help kind of stops. (Tom)

Because it's so rare, nobody else understands. (Jonathan)

It's constantly there and it's horrible. But because he's doing so well, you feel guilty for feeling that. (Kate)

She says that sometimes her friends make fun of her. Because her face is slightly smaller in some ways and bigger in others. (James)

When we weren't noticing it, it was easier to kind of move on and not think about it. But as it's becoming more obvious, it's a reminder each day. Going to high school is my big fear. He is safe where he is now in his little primary school. (Kate)



I was told that it would be much better and much safer. So, it was more like something to look up to rather than something to be scared of. (Kerry)

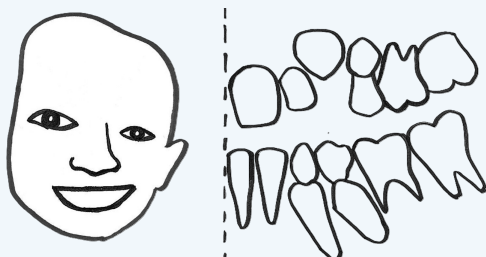
Is it right that he is the person I have to go to for my radiation questions? I don't know. You know he's trying to save kids' lives and here I am on about, you know, about her wobbly teeth. (Felicity)

Given her age, I thought that everything would be much better than other therapy, so yeah, I can say that I had my hopes up. So yeah, maybe just be clear with it. Just say what the truth is to the parents. We can handle it. (Adam)

But erm, sometimes I'm like, 'should I have paid more attention to late effects?'. It's not available at the time and it's still the best treatment available, but I just wish I was more aware of late effects. (Felicity)

IMPLICATIONS

- Highlighted priorities and challenges facing both patients/guardians and clinicians.
- Striking the balance between imposing fear and supporting a patient and/or their guardian in being fully informed is key.
- HN-CCS want to be involved in the conversation and are seeking support networks.
- Not all HN-CCS are proactive in seeking direct dental support.
- Adult HN-CCS with dentofacial AE can present numerous restorative challenges.
- Collaborative working with oncology teams to develop knowledge and support survivorship care of this cohort is recommended.
- Patient advisory group developed to support co-production in stages 2 and 3 of the DETOFACIAL-PBT study.



A participant's drawings: An interpretation of their dental and facial treatment-related adverse effects.

REFERENCES



Scan me!