


RESEARCH ARTICLE

Experiences of families post treatment for childhood brain tumours during medical clinic consultations regarding health-related quality of life, unmet needs and communication barriers: A qualitative exploration

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Funding information

The Brain Tumour Charity, Grant/Award Number: GN-000366

Abstract

Background: Many studies highlight poor health-related quality of life (HRQoL) in children treated for brain tumours and their parents. However, little is known about the extent to which their informational, healthcare and communication needs regarding HRQoL are met during medical outpatient consultations.

Aim: To explore the experiences of families regarding communication with physicians about HRQoL issues during consultations after treatment for childhood brain tumours.

Methods: Interviews were conducted with 18 families of children and adolescents aged 8–17 years after completion of brain tumour treatment. Participants had completed treatment within the last 5 years and were receiving regular outpatient follow-up care. Thematic analysis was undertaken using the Framework Method.

Results: Five main themes were identified: (i) unmet emotional and mental health needs; (ii) double protection; (iii) unmet information needs; (iv) communication barriers within consultations; and (v) finding a new normal.

Conclusion: There was a need to improve communication between clinicians and these families, improve information provision, and overcome barriers to conversing with children within these outpatient consultations. Children and their parents should be supported to voice their current needs and concerns regarding their HRQoL. These findings will inform further development of the UK version of the 'KLIK' patient- and parent-reported outcome (PROM) portal.

Abbreviations: HRQoL, health-related quality of life; PROMOTE study, Patient Reported Outcome Measures Online To Enhance Communication and HRQoL after childhood brain tumour study; PROMs, patient-reported outcome measures.

Kim S. Bull and Shelly Stubbley are joint first authors.

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KEYWORDS

brain tumour, children and adolescents, doctor–patient communication, health-related quality of life, patient experiences, qualitative interviews

1 | INTRODUCTION

Brain tumours and the treatments used to combat them can result in brain injury, leading to adverse outcomes with impaired health-related quality of life (HRQoL).^{1–9} A Swedish population-based cohort study of adult survivors of childhood brain tumour reported that one or more of vision, hearing, speech, dexterity, ambulation, cognition, emotion and pain were impaired in the majority, with problems tending to worsen over time.^{2,10} Specific risks include neurocognitive dysfunction, seizures, sensory and motor deficits, endocrinopathies and psychosocial difficulties.^{2,11–14} Memory deficits, social isolation, impaired daily functioning and fatigue are common,¹⁵ and may negatively affect educational achievement, employability^{16,17} and social interactions.^{3–9,15–21} The lifetime impact of these disabilities for the individual and their wider families is very high.

Unmet needs of survivors and caregivers have a negative impact on HRQoL and include anxiety, uncertainty about the future and depression.^{19,22} Caregivers and survivors have expressed a need for information about financial support, state benefits and survivor fertility¹⁰ and for support with reintegration into daily life, including school.²³ Parents of childhood cancer survivors have reported that good communication with physicians made them feel acknowledged and comforted, and gave them greater trust in the responsible physician.²⁴

Although better communication during outpatient healthcare consultations may allow early identification and treatment of adverse outcomes and lead to subsequent improved adjustment and HRQoL,^{25,26} a scoping search of the literature found no studies specific to children treated for brain tumours that addressed their communication about HRQoL issues with parents and physicians during scheduled medical outpatient consultations. Patient-reported outcome measures (PROMs) are now widely used in clinical trials and increasingly used in daily adult oncological care to improve communication and screen for problems.^{27–29} The KLIK PROM portal is one potential tool that could be used to improve paediatric outpatient consultations.³⁰ Within this portal, paediatric patients (≥ 8 years) and/or their parents and adult patients are asked to complete PROMs regarding HRQoL, symptoms and/or psychosocial functioning online at home prior to the outpatient consultation. The answers are converted into an electronic PROfile that contains a broad range of feedback options tailored to each specific PROM. The clinician discusses the KLIK ePROfile during the outpatient consultation with patients and/or parents in order to monitor well-being over time, detect problems at an early stage, and provide tailored advice and interventions.

The context of the present study was the PROMOTE study (Patient Reported Outcome Measures Online To Enhance Communication and

HRQoL after childhood brain tumour)³¹ in which we combined different methods of enquiry to develop and test the feasibility of using the KLIK PROM portal³² in a UK National Health System (NHS) clinical outpatient setting. We aimed, in the study reported here, to explore the experiences of families regarding HRQoL issues, unmet needs, and barriers to communicating with physicians during consultations after treatment for childhood brain tumours to inform the subsequent development of the United Kingdom version of this portal.

2 | METHODS

The present study used a qualitative semi-structured interview design to gather patient and parent views to meet the aims of the research.

2.1 | Ethics approval

Ethics approval was granted by South Central Hampshire A Research Ethics Committee as part of the PROMOTE study (Reference 16/SC/0633). Informed consent or assent for participation and publication was obtained.

2.2 | Participants

Participants included parents and their children aged 8–17 years who had completed treatment for a brain tumour within the last 5 years and returning for regular follow-up outpatient care at a UK Children's Cancer Principal Treatment Centres in the United Kingdom. Three centres participated to increase diversity of experiences and views. We expected to achieve saturation of themes with 18 or fewer families, and therefore planned to include that number. Saturation in qualitative research is a complex issue^{33,34} and this was a pragmatic decision, based on previous studies, to balance the need to achieve saturation against the burden on families and treatment centres.

2.3 | Materials

Semi-structured interview topic guides, one for children and one for parents (Appendix S1), were developed to capture information to meet the aims of the research, while allowing participants free expression to talk about their experiences. The topic guides were refined during the first five interviews to include additional prompts.

2.4 | Recruitment and data collection procedure

Potential participants were first contacted about the study by their neuro-oncology treating physician. Written face-to-face consent was provided to the researchers. All interviews took place either in the family home or at their treatment centre, according to family preference, and children aged at least 8 years chose whether to be interviewed on their own or with a parent present. Interviews were conducted and audio-recorded by Kim S. Bull, Anita Freeman and Shelly Stublely.

Following a broad question about HRQoL, participants provided personal accounts of the impact of diagnosis and treatment on the child's HRQoL prompted by pre-determined lines of enquiry about HRQoL, communication barriers and needs, and family emotional needs. Interviews were transcribed and checked by the research team.

2.5 | Analysis

A combined deductive and inductive approach was used to analyse the data thematically, using the Framework Method to manage and organise the themes.³⁵ This method allows one to identify, describe and interpret patterns within and across interviews for themes specific to the phenomenon of interest. Child and parent data were analysed separately in a four-stage process: (i) transcription and familiarisation with the data; (ii) initial coding and development of a coding framework; (iii) further in-depth coding, analysis and reliability checks; and (iv) interpretation of the themes.

Anita Freeman and Shelly Stublely independently coded parent and child interviews. The framework of themes that emerged was mapped onto the lines of enquiry. Anita Freeman and Shelly Stublely then jointly reviewed and agreed on the codes and checked the reliability of their coding by independently recoding two transcripts against the identified themes. This process identified a 97.8% agreement between the two researchers' codings. Christina Lioffi was available to arbitrate on any disagreements, but no arbitration or extended discussions were necessary as, having read all the transcripts and codes, Christina Lioffi was in full agreement with Anita Freeman and Shelly Stublely. Finally, Anita Freeman and Shelly Stublely reviewed the completed framework matrices together with the notes on their own interpretations and impressions that they had formed throughout the process. They then jointly identified subthemes derived from the codes, and classified these under main themes.

The study's methodological rigour was considered by Anita Freeman and Shelly Stublely in relation to: continued reflexivity and engagement with material; transparency and coherence of the process; commitment to engagement with the topic of HRQoL; and confidence in the completeness of the data collection, analysis and grounding of theme descriptions in examples from the data.³⁶ Data saturation was deemed to have been reached when no new themes emerged from the data.³⁴

3 | RESULTS

Of 34 families invited, 18 participated, including 10 female and eight male brain tumour survivors ages 7–17 years (Table 1). Their socio-economic and ethnic backgrounds were diverse (Table 1). Three of 32 interviews included in the analysis were conducted with child and parents together (205, 210, 211), three with both parents together (101, 109, 201), 12 with one parent alone (102, 103, 105, 111, 202, 203, 301, 303, 304, 305, 306, 307), and 14 with the child alone (101, 102, 103, 105, 109, 111, 201, 202, 203, 303, 304, 305, 306, 307). Two were not audio-recorded and so detailed notes were taken during the interview: in one case, the child felt uncomfortable with her voice (205) and, in the other case, the mother felt uncomfortable with her accent (210). The codes derived from the data are presented in Table 2, and the subthemes derived from these codes and the resultant five main inter-related and sometimes overlapping themes are presented in Table 3.

3.1 | Main themes

Five main themes were identified: (i) unmet emotional and mental health needs; (ii) double protection; (iii) unmet information needs of families; (iv) communication barriers within consultations; and (v) finding a new normal. Illustrative interview content relating to the first four of these themes is the focus of this report. It is summarised hereunder and illustrated in Table 3. The fifth theme, 'finding a new normal' relates to the experiences of participants regarding their HRQoL itself following discharge from hospital when their HRQoL concerns shift from hospital life and medical procedures to the return to normality. This provides important context for the issues that were salient to the lives of our participants, but is not the focus of the present report and illustrative interview content relating to this theme is provided in Appendix SII.

3.1.1 | Unmet emotional and mental health needs

Children: Children felt their emotional well-being had decreased. They wanted to know if they were normal and whether they would have been the same if they had not had the brain tumour, perhaps suggesting a need for the child to receive some support in exploring their own experiences and understanding of the effects of their brain tumour (Table 3, row 1). They talked about anxieties related to uncertainty about their future, whether they would manage at school, whether their memory would improve, and wondered whether they would be able, for example, to learn to drive or to be able to have children in the future (Table 3, row 1).

Parents: Most parents felt that their family's mental health and emotional well-being had paramount importance for a good HRQoL but, like the children, felt that these had decreased since their child's illness. They vocalised a need to come to terms with what had happened

TABLE 1 Demographic characteristics of families who were interviewed.

Family ID	Participants	Ethnicity	Parent marital status ^a	Number of children in family	Parent education ^a	Parent work situation ^a	Child's age at consent	Child's gender	Tumour diagnosis
101	Father, mother, child	White	Married	1	University (father)	Father F/T, Mother not employed	14	Male	Germinoma
102	Mother, child	White	Married	2	University	P/T	11	Male	Pilocytic astrocytoma
103	Father, child	White	Married	3	University	F/T	16	Female	Craniopharyngioma
105	Mother, child	White	Married	4	University	P/T	12	Female	Craniopharyngioma
109	Father, mother, child	White	Married	2	University (both)	Father F/T, Mother P/T	13	Male	Medulloblastoma
111	Mother, child	White	Married	2	College	P/T	15	Male	Low-grade glioma
201	Father, mother, child	White	Married	6	University (mother)	Father F/T, Mother P/T	12	Female	Tuberous sclerosis-related benign tumour
202	Mother, child	White	Married	5	School	Mother F/T	13	Male	Pilocytic astrocytoma
203	Mother, child	White	Divorced	2	School	Mother F/T	17	Male	Germinoma
205	Mother, child	White	Married	1	College	Not employed	17	Female	Pilocytic astrocytoma
210	Father, mother, child	Black	Married	2	School (mother)	Both F/T	8	Female	Pilocytic astrocytoma
211	Father, mother, child	Asian, White	Married	2	University (mother)	Father F/T, Mother P/T	13	Female	Germinoma
301	Mother	Asian	Married	3	College	Not employed	7	Female	Pilocytic astrocytoma
303	Mother, child	White	Married	3	University	Not employed	12	Female	Suprasellar tumour
304	Mother, child	White	Separated	3	School	P/T	10	Female	Pilocytic astrocytoma
305	Mother, child	White	Married	3	University	Not employed	11	Male	Medulloblastoma
306	Mother, child	White	Separated	1	School	Not employed	8	Female	Medulloblastoma
307	Mother, child	Asian	Married	3	School	Not employed	11	Male	High-grade glioma

Abbreviations: F/T, full time; P/T, part time.

^aParent demographic information relates to the parent(s) who participated in the interviews.

to their child and recalled traumatic stories about their child's diagnosis, illness and treatment. These recollections often related to late or missed opportunities for diagnosis. Some parents were aware that they had unmet emotional, psychological or mental health needs, and acknowledged their own needs for counselling and support since their child's diagnosis and the difficulty in obtaining this (Table 3, row 1).

Parents talked about their fears of fast and unpredictable deterioration of symptoms or, in one case, fear of the child collapsing, which left the family wondering whether they could leave their child to shower alone. Parents explained how they felt the need to balance these fears for their child's health with the need to support independence and autonomy. Living and coping with uncertainty regarding health,

symptoms, late effects and future health was experienced as distressing and anxiety-provoking by children and their parents, affecting emotional well-being. One mother expressed concern about her child's mental health, having found him searching on the Internet about his diagnosis and the risks of relapse (Table 3, row 1).

3.1.2 | Double protection

This unexpected theme arose regarding communication within families, particularly with respect to concerns relating to the child's future health.

TABLE 2 Coding framework—Initial codes, organised and mapped onto the three predefined lines of enquiry explored in the interviews.

Health-related quality of life	
Children	Parents
Challenges with school and learning (settling in, missing school, support, cognitive difficulties) Maintaining and rebuilding friendships and activities (being sociable, active, able to compete, developing new skills and activities, being treated the same as before, being able to go on holiday/day trips) Changed relationships with family Adjusting to changes in me after my brain tumour: Physical change and fatigue-restrictions and adaptations, feeling tired, reduced strength Concerns over hunger and weight Having autonomy/control over what happens to me	Adverse changes to daily life and adapting to a new normality Managing the impact on other family members Fewer holidays/days out Adapting to new role of parent expert/child health advocate (managing health, fitness and nutrition, weight, exercise, lifestyle and growth, energy, fatigue and physical limitations) Family needing increased support from others, e.g., wider family Housing and finance difficulties Supporting independence and autonomy, helping child to adapt Managing cognitive impact and cognitive problems Ensuring right school support and enjoying school Striving for happiness, enjoyment of life, good mental health and lessening emotional impact
Communication barriers and needs	
'What am I able or allowed to do?' A lack of tailored advice about child's return to school and daily activities Talking to the doctor—wanting to speak for themselves/wanting to speak to doctor alone vs. happy for parents to talk Need to understand more about cognitive functioning and memory Need for help to communicate about health anxiety and worries about the future Cognitive functioning and memory as a barrier to communication (sometimes get a big burst of information and then forget it) Wanting to put it all behind them (suppressing what happened) Verbal communication limitations The need to present themselves to others as being OK when they were not Fear of relapse as a barrier to honest communication Some issues are not seen as relevant to discuss with the doctor Child finds it difficult to raise issues due to anxiety, shyness, being secretive	Requires more information about talking to their child about their illness Requires treatment plans in advance The need to be able to monitor and track changes in child's health status Would like more information on tumour types and cognitive impact Needs more clarity on who to contact about different issues Needs help in understanding (e.g., What is 'normal'? What is brain tumour related? What is due to being a teenager?) How to talk to child about fertility issues
Emotional needs	
Help with regulating emotions (frustration and anger) Rediscovering their identity and sense of self Coming to terms with and understanding what has happened to them Exploring am I normal, am I different? Adjusting to a different life trajectory Emotional difficulties related to cancer Anxiety about health Support with moving on and future plans (uncertainty)	Guidance on supporting the child emotionally, e.g., child feeling different/bullying Coming to terms with what has happened to their child Overcoming trauma Counselling for mental health and psychological needs Help managing own and child's anxiety about child's health (uncertain future and the need to keep my child safe) Fear of others being cruel

Children: Children felt the need to show others they were OK, and this sometimes led them to keeping things to themselves. Many of the children did not want to reveal their feelings and worries regarding their health to their parents and, for these reasons, parents and children were not always frank with each other (Table 3, row 2). Children also talked about hiding their symptoms; some parents seemed to be aware of this whilst others did not (Table 3, row 2). This sometimes indicated misalignment between the parent's and child's perceptions

of the other, but could also indicate 'alignment' in the sense that the narratives of both child and parent provided examples of the 'double protection' theme.

Parents: Parents felt unsure about how to encourage their child to share experiences with them. Parents did not want to upset or scare their child, and felt it important to protect their child from their own fears and worries (Table 3, row 2). One mother described how her son hid any physical symptoms from her and was reluctant to tell her

TABLE 3 Main themes and subthemes derived from initial coding of child and parent interviews.

Main themes	Subthemes	Examples of theme from child	Examples of theme from parent
(i) Unmet emotional and mental health needs	Decreased emotional well-being (both) Processing and managing the emotional and mental impact of illness on themselves and rest of family (both) Uncertainty about the future of the child and fears for their health (both) How to cope with worries (child)	'... I've become more mature than, like my brother and sister, like a mini adult. Do all children become like that when they have cancer, or not?' (Child 303) 'How my life is going to turn out?... I'm just thinking that I can't achieve as much as I used to be able to... I just think how...? What's going to happen when I go out of school'. (Child 109)	'I really needed help not long afterwards, erm... when everything had sort of settled down and then it all sort of came back... speaking to a lot of the other dads... they felt the same and they felt that they couldn't talk to anybody' (Father 103) 'Yeah you kind of adapt to it, the uncertainty's not very good because you just don't know time spans, what it's gonna be like, you know... whether she'll have a shortened life or whether she will have a reasonably normal life, age wise, 'cause if any of these things flare up, the potential side effects of these drugs, or any of these tumours, if it goes horribly wrong then it can be terminal very quickly so it's, there's that aspect of uncertainty that's quite, not very easy to handle...'. (Father 201) 'I do worry about him sometimes, his mental state of mind, because I found things once that he'd been Googling, "Will my brain tumour kill me?" and things like that, and that really upset me'. (Mother 202) '... hmmm, well I don't really feel we need any support at the moment, well there is obviously the growth and that, and we have an idea on that, and well, we are hoping we'll spend a bit of time on that, and we are hoping it won't be a lot of appointments or time in hospital. Well, I think actually in a way it is nice to distance ourselves a bit actually I think...'. (Mother 305)
(ii) Double protection needs	The need to show others s/he is okay (child) The need to keep things to her/himself (child) Uncertain how to encourage child to share experiences (parent) Being unable to trust her/his memory (child) Feeling need to be present (in consultations) to help child remember what they want to ask Protecting parents/child from her/his fears and worries (both)	'Uhhmmmm for these 5 years I'm sort of worried I might get cancer, I'll have it, catch cancer again'. (Child 101) (cf Mother 101) 'I hurt a lot yeah, I mean I was throbbing in the head and it's just distracting, and it is annoying when you are in pain. When I first came out of hospital, I would definitely tell anyone if I was hurt but a few weeks or months after I kind of just wanted to keep it to myself and shut up... yeah, because everyone was doing so much, and you didn't want to complain about it still hurting and stuff'. (Child 102)	'... he doesn't feel worried about the future at all and is bullet proof. He's beaten cancer, which is fantastic. That's how I want him to feel. He's unaware of anything else that might happen in the future and that's the way I want it to stay for now...'. (Mother 101) (cf Child 101) 'Sometimes, really, he doesn't want to worry me, y' know what I mean? Like I say about the headaches... y' know... he'll go like that, and I'll say, "what's the matter?" and he'll say, "Oh I've got a headache y' know" but he wouldn't actually tell me straight away, y' know, I have to encourage him to not, not tell me. I have to say, "I need to know these things," y' know'. (Mother 203) '... there are some things that I don't want him to know about. As in, he knows everything about his treatment, but, and we've said to him right from the word go, that we would be honest with him and we have been as much as possible, but it's the next stage, because it's still unknown, and because it's unknown, I don't want to worry him with any of that...'. (Mother 101)

(Continues)

TABLE 3 (Continued)

Main themes	Subthemes	Examples of theme from child	Examples of theme from parent
(iii) Unmet information needs of families	<p>Wanting to know what s/he can do (e.g., returning to sports) (child)</p> <p>Space to share issues without parent/s vs. happy for parents to speak for her/him</p> <p>Contact information for relevant physicians or services or advice (parent)</p> <p>Knowledge on speaking to child regarding their condition (parent)</p>	<p>'So would you like to talk to your Doctor about your memory?' (Interviewer)</p> <p>'That is what I have been saying but no one's really answered me. I said to her... she explained it in, basically saying, your, your brain's been cut off or stuff like that, but she didn't give me any ways of getting round it'. (Child 109)</p> <p>'Would you like to talk to your doctor on your own?' (Interviewer) 'Yes'.</p> <p>'...and has that ever happened?' (Interviewer)</p> <p>'No, no, normally either me and mum, me and dad, or me and mum and dad, we all go in together, it is never really just me'. (Child 303)</p> <p>'I think it's good that my parents hear everything as well because in fact that I would like them to hear stuff that I would probably forget'. (Child 102)</p> <p>'...said I was allowed to play, after being told at hospital I wasn't, then I was, then I wasn't, they've confirmed that I am allowed to play rugby now which is absolutely brilliant!' (Child 102)</p>	<p>'I don't think I know where the correct conduit would be. I don't know what appointment I'd... cause (child) sees, she sees (physician) for endocrine erm... she sees the eye people down in (hospital), there's a chap called (physician) that we saw last time, even though I couldn't remember what he actually, what his thing is... oh no I think he's neuro, so I think maybe that might be the opportunity, erm, to say...'</p> <p>(Father 103)</p> <p>'A lot of people say it's his age, but I don't think it is his age 'cause I think the tasks that I give him aren't exactly strenuous or hard to do, you know, I do try and say, right, you use your own initiative and think what needs to be done. Yeah, he's just not got that, y'know'. (Mother 203)</p> <p>'... it is quite difficult to know whether it is just 'cause of this, so it is hard to know'. (Mother 101)</p> <p>teenage boy or whether it is just 'cause of this, so it is hard to know'. (Mother 101)</p>
(iv) Communication barriers within consultations	<p>Not getting the answer to question or question misunderstood (both)</p> <p>Unable to recall question in hospital setting (child)</p> <p>Shy or not wanting to speak (child)</p> <p>Belief that certain subjects (i.e., non-medical) are not relevant (parent)</p> <p>Fear of the answers (parent)</p> <p>Good relationship with a physician, who knows them well (both)</p>	<p>'Would you like to talk to the doctor on your own?' (Interviewer)</p> <p>'I would like to try that... Erm my parents usually talk because y' know whenever I'm going into the assessment my mind just goes blank'. (Child 109)</p> <p>'Oh, erm yeah and sometimes I'm like err, I have pain or something and I forget to tell the details... and the doctors always want details'. (Child 307)</p>	<p>'I don't want to bother anybody with something that isn't related to this so I probably would let things get worse before I call'. (Mother 101)</p> <p>'Well, they were listening 'cause we've brought it up every time we've had an appointment, but we think it's just been misinterpreted... I dunno, as I said, I dunno if we just haven't put it across properly'. (Mother 211)</p> <p>'Well, we did bring it up last time because it had got to, like... a head, with me, and I was, like, I don't really know what else to do... so when we went there, it was, she would never bring it up, she would never bring any of this up, and um she is embarrassed by her feelings, and like, so when they said, is everything alright? And she was like "yeah," and I was like, "Well she thinks she's going to die!" and they were like "why?" and she went into it'. (Mother 304)</p> <p>'I think the only thing I can think is, that since he's been ill, about the future, that we're trying to protect him from maybe, but most things we're quite happy to share with him'. (Father 101)</p> <p>'So (the oncologist) always provides an opportunity to discuss school and she always asks and there always has been that opportunity'. (Father 109)</p> <p>'Yeah, well the doctor and everyone at the hospital have been brilliant in terms of giving us time and giving us appropriate review dates and follow-up'. (Father 304)</p>
(v) Finding a new normal	See Appendix S11		

about them (Table 3, row 2). Another mother had tried to get her son to engage in discussions about his worries and had sought the help of a counsellor, but he had not engaged in psychological treatment. In another interview, the parent said that the child worried, but the child declined to talk about it when asked directly by the interviewer.

3.1.3 | Unmet information needs of families

Children: For the affected children, information and advice or guidance on coping with their worries about their health and their future were important requirements. In several cases, children were keen to get back to their old lives and expressed similar information needs related to their own concerns about how far to push themselves physically (e.g., in sporting activities), whether their cancer would return, changes in their memory function, attention, other cognitive abilities and academic abilities (Table 3, row 3).

Communication barriers within the family led some children to express a strong preference for speaking to their treating physician alone to obtain information (Table 3, row 3). Some were vocal about their need to explore issues about which they preferred that their parents not know they were concerned, such as their cancer recurring, their ability to have children, or the impact that their illness might have had on their cognitive function in general and specifically their memory. Other children were happy for their parents to 'speak for them' as they felt that they were not able to communicate adequately or remember things themselves (Table 3, row 3).

Children experienced a deficit of advice regarding what they were and were not allowed to do or what was safe for them to do and what might cause them physical discomfort or injury. For example, returning to playing rugby, going to the gym or cycling (Table 3, row 3).

Parents: It was unclear to some families whom they should contact about different issues after treatment. Parents needed more contact information for relevant physicians, services and people who could offer advice and practical guidance on topics such as managing their child's weight, diet, nutrition and psychological needs, or how to talk to their child about their diagnosis, health and recovery (Table 3, row 3).

Parents felt there was a lack of information regarding the expected trajectory of recovery over time. They also needed information about how to cope with their own emotional well-being, uncertainty about how far to push their child, and anxiety regarding their child's health. Information about tumour types and cognitive impacts, receiving treatment plans in advance, and being able to monitor or track change over time were all seen as useful. For example, some parents felt they would like to be aware of timelines for starting growth hormone. Some parents felt confused and wanted more clarity on whether they should be concerned about aspects of their child's behaviour; whether their child's health or behaviour was 'normal' for a child or for a teenager or, on the other hand, related to their brain tumour (Table 3, row 3).

3.1.4 | Communication barriers/facilitators within consultations

The focus of the narratives of families was on the difficulties they had experienced. During the interviews, it was clear families wanted to communicate about HRQoL and were positive about doing so using web-based questionnaires, yet it was evident that some of them faced barriers to being able to express themselves in the consulting room and to raising issues with which they required support.

Children: The need for parents and children to keep things from each other (double protection) was sometimes counteracted by the child requiring the support of their parents within the consultation to help them remember the issues they wanted to communicate about. Parents felt the need to be present to help the child remember important questions they wanted to ask, and children required their parents to repeat or remember for them answers that the physicians gave. For some families, this meant that there was a consensus that parents should be present and involved in the discussions (Table 3, row 4).

The children described how they might forget the details of something and that the physicians always needed the details or that it might take a while for them to recall information (Table 3, row 4).

Parents: Parents had experienced having their questions being misunderstood, avoided asking questions due to a fear of the answer, and were unsure in some instances whether it was relevant or appropriate to raise concerns about issues such as school or behavioural problems.

Being reluctant to raise anything 'non-medical' was also a reason parents gave for not raising HRQoL issues in consultation. One issue that arose was a reluctance on the part of the families to 'bother' the physician with issues that they did not deem relevant. For example, several of the families felt that it was not relevant or appropriate to discuss bullying at school with the physician. Sometimes, this was couched in terms of gratitude that the hospital had saved their child's life and they did not want to then complain about a late effect or an issue at school (Table 3, row 4). Some parents raised issues but did not get the answers they needed. One mother described how they kept trying to ask about a symptom their daughter had, but were unable to communicate effectively (Table 3, row 4).

More commonly though, we identified an emotional barrier to effective communication in the sense that participants were reluctant to, or not able to, raise an issue that was anxiety-inducing. They wanted to communicate about, for example, fertility issues but anxiety got in the way of raising the issue. Being in the hospital environment affected the ability of some parents to think straight and remember what they wanted to talk about or find the words to express themselves. Participants described feeling overwhelmed during the consultation and consequent impairment of their ability to communicate well. Some children became shy during the consultation and found it difficult to speak (Table 3, row 4). In addition to these matters that might prevent certain topics from being raised, there was also a perceived need for the parents to protect their child from hearing about things that they may not wish them to know, such as their future prognosis or fertility, and

so important issues were not always raised by parents and discussed (Table 3, row 4).

The relationship between the physician and the families had an influence on communication, with some families describing close connections with their physicians and the ability to ask them anything. Knowing that a physician understood their family's journey in relation to their illness and recovery was valuable to families in helping them to feel comfortable and understood (Table 3, row 4).

4 | DISCUSSION

Five main themes were identified in these interviews of children receiving outpatient care following treatment for a brain tumour: unmet emotional and mental health needs; double protection; unmet information needs; communication barriers within consultations; and finding a new normal. We conducted separate interviews of child and parent in such a way as to allow the interviewee the opportunity to present their narrative account. Neither interview was constructed to shed light specifically on the extent to which the narratives of the child and parent on these five themes were aligned with each other: that alignment would be difficult to assess, particularly given the varied developmental stages and cognitive difficulties of the children. Parent and child have different perspectives and their accounts are complementary.

'Double protection' within families inevitably affected communications during consultations where issues were not raised due to parents wanting to keep things from their child and children not wanting to reveal their feelings and worries to their parents. Family members' attempts to protect each other may therefore be creating a barrier to communicating openly regarding their worries and emotional needs. The need for both children and parents to keep information from each other provides a new insight into families' experience of communicating HRQoL issues and a potential barrier to communication both between family members and also between the family and the physician. 'Double pretence' has previously been identified in children of this age in the specific context of palliative care³⁷ and prognostic disclosure.³⁸ Here, we identify its role in providing 'double protection' in the survivorship period.

The finding in the present study of anxiety, uncertainty about the future, feeling down or depressed and of unmet need for concrete information about lifestyle, fertility, physical consequences of childhood cancer, the post-treatment period and the long-term future have also been reported by others.^{10,19,39-41} Increased number of unmet needs and failure to overcome barriers to communication have been associated with poorer quality of life in previous reports.^{10,42}

During our interviews in the present study, challenges in communicating with brain tumour survivors were noted, with some children appearing almost non-verbal, partly due to the established impact of tumour and treatment on cognitive and speech abilities or language problems,^{43,44} and partly due to the underlying anxiety or depression, particularly in those children who were especially avoidant or ineffective communicators.⁴⁵ These difficulties could be recognised earlier using proxy- and self-report questionnaires,^{46,47} and the latter could

be particularly valuable to adolescents who may not want to discuss psychosocial issues in a clinical interview.^{46,47}

The families in the present study said they would be happy to report to physicians using such a platform but did not elaborate due to having no experience of using an online PROMs portal. An on-line PROMs platform, designed for use by children with medical conditions and their parents to report on and monitor the HRQoL of a child with a medical condition, may therefore be a facilitator of communication by providing survivors and caregivers with the opportunity to report HRQoL issues and needs. This would be particularly useful for those children treated for brain tumours who are experiencing memory and/or speech problems.

KLIK⁴⁸ is an example of such a platform that can be adapted for children with visual or literacy and language needs. It is designed to enable children and adolescents to use PROMs to share their report of their HRQoL, with clinicians in advance of consultations and may encourage families to discuss issues together at that time. The development of the UK version of the portal was informed by the present study, and provides separate logins for children and parents. This offers confidentiality, if required, and should help to circumvent the 'double protection' barrier to communication with care providers. KLIK could also facilitate the provision of information and proper tailored support where there are currently gaps. These short-term benefits are easily achieved using parent- and child-report (and possibly teacher-report) PROMs. When undertaken on-line, the information is digitally recorded and can readily be tracked over time.^{48,49} The long-term benefits of monitoring HRQoL this way in these children are yet to be explored.

The present study's finding that communication of survivors was hindered by a lack of opportunity to speak to their physician alone and without their parents was noted in a previous report,³⁹ and suggests that offering adolescents the opportunity to have time on their own with physicians would facilitate communication. The need to address the broader communication challenges faced by these patients is central. These challenges manifest in various environments, including the difficulties encountered during medical consultations explored in the present study. Seeing patients on their own is one aspect; implementing more structured consultations and introducing KLIK, which provides focus and structure, is another. Additionally, there is a need for the development and evaluation of developmentally informed social communication training interventions. These should be tailored for survivors of childhood brain tumours, as was done with programmes developed for adults with traumatic brain injury and their communication partners.^{50,51}

The 8-17 years age range of participating children and the inclusion of three different treatment centres are strengths of the study and make our findings likely to be generalisable to children's cancer principle treatment centres across the United Kingdom. Of the families approached to take part in this study, just over half participated in the interviews and their experiences of outpatient consultations may differ from those of the non-participants. Reasons for non-participation were not collected. Furthermore, 80% of participants were White and only English-speaking families were approached. These are limitations of the study.

In summary, we found a need to improve information provision, better address communication needs, and overcome barriers to conversing within consultations with children following treatment for a brain tumour. Information and communication methods that address the diverse needs of this patient group need to capture what is uniquely important to that child and family at that point in time, and to provide the child with the confidence to know that they can and should voice their HRQoL needs and concerns.

ACKNOWLEDGEMENTS

We thank the Brain Tumour Charity for funding this research (Grant GN-000366), and the families and physicians for sharing with us their experiences of paediatric neuro-oncology outpatient consultations. We also thank paediatric oncologists Dr Christine Dahl and Dr Ramya Ramanujachar and parent advisors Dr Hazel Everitt and Mr Andy Newman for their valuable contributions as members of the PROMOTE study steering group.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Bull KS, Stubble S, Freeman A, et al. Experiences of families post treatment for childhood brain tumours during medical clinic consultations regarding health-related quality of life, unmet needs and communication barriers: A qualitative exploration. *Pediatr Blood Cancer*. 2024;e31253. <https://doi.org/10.1002/pbc.31253>