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Impact of the SARS-CoV-2/COVID-19 pandemic on the patient journeys of those with a newly diagnosed paediatric brain tumour in the UK - a qualitative study

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IMPACT OF THE SARS-COV-2/COVID-19 PANDEMIC ON THE PATIENT JOURNEYS OF THOSE WITH A NEWLY-DIAGNOSED PAEDIATRIC BRAIN TUMOUR IN THE UK - A QUALITATIVE STUDY

ABSTRACT

Objectives: To explore the impact of the SARS-CoV-2/COVID-19 pandemic on the diagnosis, management, and patient journey for children and young people with a newly diagnosed brain tumour in the UK.

Design: Exploratory qualitative study focused on patient journeys from multiple perspectives, conducted as part of a wider mixed-methods study.

Setting: Three paediatric oncology tertiary centres in the UK.

Participants: 10 children and young people with brain tumours (n=6 female, n=4 male), 20 caregivers (n=16 female, n=4 male), and 16 stakeholders (specialist nurses, consultant neurosurgeons and oncologists, and representatives from brain tumour charities) were interviewed between January 2022-June 2023.

Results: The paper incorporates multiple perspectives, including those of children and young people, parents/caregivers, clinical staff, and charity representatives to explore the patient journey. Five themes describe the journey for new paediatric brain tumour patients during the pandemic, focusing on: (1) challenges getting into the healthcare system; (2) managing as a family during restrictions imposed by the pandemic; (3) complexities of building a cohesive and supportive healthcare team; (4) difficulties caregivers experienced in accessing practical and emotional support in hospital; (5) ongoing difficulties experienced by families in the community.

Conclusions: Findings from this study offer practical insights from children, parents/caregivers and relevant stakeholders to improve the healthcare system during future disruptions. Overall, this study not only sheds light on the challenges faced by families during the pandemic but also provides suggestions for improving healthcare services to ensure a more comprehensive and effective response in times of crisis.

STRENGTHS AND LIMITATIONS

- We collected rich data that incorporates multiple perspectives, including those of children and young people, caregivers, clinical staff, and charities from different regions of the UK.
- A limitation is that participants were self-selecting and we were unable to recruit any bereaved families.
- The retrospective nature of the study posed challenges, particularly for children and young people recalling experiences.

IMPACT OF THE COVID-19 PANDEMIC ON THE PATIENT JOURNEYS OF THOSE WITH A NEWLY-DIAGNOSED PAEDIATRIC BRAIN TUMOUR IN THE UK - A QUALITATIVE STUDY

BACKGROUND

The global SARS-CoV-2/COVID-19 pandemic, declared by the World Health Organisation on 11 March 2020, presented a significant challenge to the provision of healthcare services. In the UK, as other countries, this impacted on the diagnosis and treatment of non-COVID-19 conditions. Evidence suggests that children and young people were less acutely affected by COVID-19 in terms of morbidity and mortality, but that their lives were disrupted in other ways, including access to routine healthcare services. Evidence suggests that there were changing patterns of use as services were impacted by the measures put in place to mitigate the spread of infection.[1–4]

This paper investigates the impact of the pandemic on one non-COVID-19 condition: paediatric brain tumours, the commonest childhood solid tumour. Every year around 500 children and young people are newly diagnosed with a brain tumour in the UK.[5] Mortality rates vary according to tumour type, but are generally high, with a five-year survival rate of 66% overall for all types of brain tumour in Europe.[6] Around 60% of patients are left with some form of lifelong neurological disability.[7] Delays in diagnosis can make treatment more complex and increase the likelihood of tumour progression, death or disability, as well as impacting relationships between families and healthcare teams.[8]

Diagnosis is often difficult, as symptoms and signs are often non-specific. Initial symptoms are often picked up in optometry, primary care, emergency departments or in nurseries and schools, with research suggesting that in around 40% of cases, initial detection of paediatric brain tumours occurs in optometry.[7] Care for paediatric brain tumours is complex, and treatment and rehabilitation require strong interdisciplinary and inter-agency collaboration across hospital and community-based health, education, and social care services. [8] Recent research into family experiences of paediatric brain tumours has concluded that the psychosocial needs of children, young people and families need to be prioritised.[9,10] There is some emerging evidence that the relationships between families and healthcare staff were disrupted during the pandemic [11] and that the experience of being hospitalised with a condition (such as a brain tumour) that necessitates careful infection prevention measures is isolating.[12]

As part of a wider study exploring the diagnosis, management, clinical outcomes, and patient/carer experiences of receiving treatment for a paediatric brain tumour during the pandemic, we sought to answer the research question: *What is the impact of the COVID-19 pandemic on the diagnosis, management, and patient journey for children and young people with a newly diagnosed brain tumour in the UK?* By exploring the impact of the pandemic on the patient journey of those diagnosed with a paediatric brain tumour at the time, the paper presents internationally relevant lessons about how healthcare services may need to prioritise maintaining particular services to prevent delays in diagnosis of childhood cancers and ensure better outcomes for children and young people.

METHODS

Interviews were used to collect detailed qualitative data about experiences of children and young people, parents/caregivers, clinical staff working in hospitals and representatives of paediatric brain tumour charities at three paediatric oncology centres in the UK. The qualitative approach allowed us to explore participants' understanding of their experiences of tumour diagnosis, treatment and care. This was contrasted with quantitative data on clinical outcomes collected as part of the wider mixed methods study, presented elsewhere. Analysis was conducted using a six-phase reflexive thematic analysis.[13] We adopted a broadly realist epistemological stance.[14] By including multiple participant groups, who were based in different hospitals, and having multiple experienced researchers working on a detailed analysis process, we were able to triangulate our findings to ensure they were robust and rigorous.[15] As researchers, we recognise that meaning is constructed through dialogue and that our values, interests, and assumptions shaped the research questions and analytical process.

Recruitment and participants

We recruited participants from three tertiary centres treating paediatric brain tumour patients. There were two groups of participants: children and young people and their caregivers, and key stakeholders (clinical and allied health professional staff, charities), who provided insights into how treatment and care services may have been disrupted during the pandemic.

We identified eligible patient and caregiver participants through hospital databases. Potential participants were approached if they were diagnosed in the study period and the 12 months prior to the pandemic (i.e. 1st March 2019 to 28th February 2021). Caregivers were provided with information about the study by post or by a clinician known to them, and invited to contact the research team if they wished to participate themselves and/or were happy for their child to participate. We approached bereaved families as well as those with surviving children. Families that declined to participate gave various reasons, including a reluctance to revisit traumatic experiences, other commitments, dissatisfaction with existing services, and significant life events affecting their family. All bereaved families declined to participate. Clinical and charity staff were recruited through their organisations, provided with information via email or in team meetings, and were asked to contact the research team if they were able to participate.

We estimated our sample size by referring to similar qualitative studies, and then assessed the adequacy of our sample size during the data collection process, guided by the information power framework.[16] Overall, according to the information power framework, our sample size was sufficient for developing new insights in line with the study's objectives.

Data Collection

The research team consisted of two research active clinicians (IJ, RI), one health psychology researcher (KA), one clinical psychologist (RC) and one medical sociologist (LB). Both interviewers (KA and RC) had extensive experience of working within NHS services, but were independent of the clinical services from which participants were recruited. Interviews with stakeholders were conducted between January 2022 and February 2023 by KA. Interviews with caregivers and children were conducted between May 2022 and June 2023 by KA and RC. Interviews took place 24-44 months after initial diagnosis.

For children, young people and parents/caregivers, we conducted semi-structured interviews, based on an interview schedule (Supplementary file 1). These typically lasted around one hour and were conducted in person or online, depending on participants preferences. In interviews with children and young people, for whom recalling treatment experiences was challenging, tools such as Talking Mats and children's creative work (e.g. art, photos) were used to facilitate the interview process.[17] As a team, we were conscious that interviews might be challenging for participants in terms of recalling traumatic experiences. This was mitigated by the involvement of a clinical psychologist and clarity that consent could be withdrawn at any stage.

For stakeholders who had been working with paediatric brain tumour patients during the study period, including clinical staff working in the paediatric neuro-oncology departments of each treating centre, and representatives of paediatric brain tumour charities, we conducted semi-structured interviews, again based around an interview schedule (Supplementary file 2). These interviews typically lasted 30-60 minutes, and were conducted online. All interviews were recorded using a digital voice recorder, and transcribed using the online Happy Scribe transcription service.

Patient and Public Involvement

Prior to the research study, we conducted a patient and public involvement co-design event with children and families. This event included presentations from the research team and a group discussion. We incorporated feedback into the design in terms of: (a) adopting a flexible and inclusive approach to data collection (e.g. inviting children to contribute written submissions,

drawing, or other media as an alternative to interviews) to enable all children to participate; (b) broadening the scope of the interviews to include the patient journey from initial awareness to longer term adjustment.

Ethical approvals

Ethical approval was provided by the NHS Health and Research Authority in December 2021 (IRAS:295305 HRA: 21/PR/1571). Written informed consent was given by parents for all children participating, and informed assent was also given by children and young people aged 11-16. For all other participants (e.g. key stakeholders and parents), written informed consent was also given.
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Data analysis

We completed a six-phase reflexive thematic analysis, following Braun and Clarke's (2022) framework.[13] First, we immersed ourselves in the data by re-listening to interviews to ensure accurate transcripts, and creating case summaries. Second, KA and RC coded the interview transcripts and then collated interview extracts. Through team discussion, including LB, we generated ideas about parallel experiences for stakeholders and families. Conducting a second round of coding developed more abstract codes, making the large dataset more manageable. RC then generated preliminary themes via mind maps, reflective writing, reading, consultation with experts possessing relevant professional and/or lived experience, and regular discussion sessions with LB.

During this phase we refined and defined these themes. This approach enabled us to explore various ways of interpreting the data, structuring themes and to consider perspectives that may have been missing from the data - for example those of parents who were bereaved, or stakeholders who had left their service. We refined and structured the analysis around the concept of 'patient journeys' and aimed to acknowledge the complexities of the family, services, and wider systems around the child.

RESULTS

The paper explores the patient journey from multiple perspectives, including the experiences of children, their family, those delivering healthcare services, and charities that supported families at the time. Five themes describe the journey for new paediatric brain tumour patients during the pandemic (figure 1). First, we describe 'getting into the system', the challenges caregivers encountered in reaching a diagnosis, and how this was impacted by lack of access to 'non-essential' services at the time of the pandemic. Second, we explore 'managing as a fragmented family unit', the impact of restrictions during the pandemic, particularly the impact of the 'one parent' rule. Third, we examine 'establishing an integrated team around the child,' or how stakeholders' attempts to create a cohesive and supportive team around the family were compromised by challenges to services. Fourth, we highlight 'getting through this,' addressing difficulties caregivers experienced in accessing practical and emotional support in hospital and how this was impacted by decisions about what services were seen as essential and which were not. Fifth, we address 'supporting the new normal', considering the ongoing difficulties experienced by families in the community.

Participant characteristics

Interview participants were families and key stakeholders based in three tertiary centres, and representatives from national charities. We spoke to 20 caregivers (n=16 female, n=4 male) and 10 children (n=6 female, n=4 male; age range: 5-14 years old at time of interview). These spanned 18 different family/household units. Age at diagnosis ranged from four months to 13 years (mean = 7 years) and diagnoses included low grade glioma, ependymoma, craniopharyngioma and choroid plexus carcinomas.

The sixteen stakeholders working within paediatric neuro-oncology included six specialist nurses, six consultants (neurosurgeons, oncologists), one allied health professional, and three representatives from brain tumour charities.

Getting into the system

Many families described a prolonged journey from initial awareness to diagnosis, typically encountering multiple attempts by healthcare professionals to reassure and normalise symptoms.

> *We get delayed diagnosis all the time with brain tumours, because the symptoms are not very specific. So it might be headaches or vomiting or if it's visual impairment that's difficult to pick up at the best of times. (Specialist Nurse #4)*

This delay was not unique to the pandemic, but the 'lockdown' period introduced additional challenges for concerned parents. Public health messages emphasising the importance of protecting the healthcare system led to reluctance to seek help. Seeing a GP face-to-face was more difficult and remote consultations relied on clear caregiver reporting to ensure that 'red flags' were noted.

> *I think just by the nature of the pandemic, just as a society, everybody did not want to utilise the NHS unless they absolutely had to. […] You have to weigh up whether it is worth [it]… if somebody is ill enough to take them in. (Caregiver #1)*

> *A lot of them were telephone consultations. They wouldn't actually see us because of COVID. […] If you explain stuff over the phone, they're just agreeing with you. They're just taking your point of view. (Caregiver #17)*

Children were also not being seen in other settings such as nursery, school or social situations, making it harder for caregivers to evaluate their concerns.

> *I think we had a couple of delayed presentations just because they had no idea that their child was different to anyone else. And it wasn't until they became quite sick, because that was then picked up when they brought the child to A&E. (Specialist Nurse #5)*

Although some felt that getting onto a treatment pathway during the pandemic was the key challenge, as noted by this specialist nurse, many parents/caregivers emphasised that treatment was compromised throughout the whole patient journey.

Managing as a fragmented family unit

The national infection control restrictions, which only allowed one primary caregiver to attend hospital with their child, posed significant challenges for families, including siblings and grandparents. Caregivers commented that coming to terms with the diagnosis, managing treatment, collaborating with healthcare teams, and supporting each other required togetherness, which was often not possible.

> *COVID just made it more difficult because it was harder to see people. […] You were in on your own a lot of the time, because some of the time me and [partner] swapped, so we didn't really communicate much. […] When [daughter] came out of theatre, I wasn't allowed to go and see her, because I wasn't the designated parent. And it is heartbreaking, absolutely heartbreaking, to not be able to go and see that your child is okay. (Caregiver #15)*

> *We found that the biggest overriding challenge was that many hospitals only allowed one parent carer to accompany a child, which meant that many children and their parents felt isolated from their own family as well. (Charity #3)*

Although appreciating the need to manage risks of infection from COVID-19, families and stakeholders felt that the rules were too rigid. Rules were also applied inconsistently, sometimes differing between families, wards and hospitals and it was unclear to outsiders why exceptions were made, leading to resentment. On a practical note, opportunities for caregivers to eat, drink, rest, and speak to friends and family were severely restricted as they often felt unable to leave the

bedside. This was compounded by a lack of access to communal spaces in hospital, and limited activities for children and young people.

For [husband], the whole thing was just awful. […] nobody really explained anything to him […] he was just left a lot of the time on his own. There was just very little support and that's what I think made it really hard for him. […] sometimes they would bring [child's] food and then forget about him - because he couldn't leave the room to get his food. (Caregiver #15)

Establishing relationships and communicating with healthcare teams was challenging because of mask wearing and maintaining social distancing. Comprehending and retaining complex and emotional information without wider support was difficult, and it was harder to involve those outside the room because of technical issues (e.g. poor wi-fi/ mobile phone signal coverage).

You're not in the right frame of mind to ask those questions because […] them saying 'it's a tumour' and you're [saying to yourself] 'right'. Then you've got oncology coming to see you […] There's a lot of different emotions you go through, to be honest, which really wasn't helped by the fact that you can't all be together as a family. (Caregiver # 13)

Without access to their own practical and emotional support systems, caregivers were conscious of placing additional pressure on depleted healthcare teams.

Establishing an integrated team around the child

Healthcare workers also experienced significant challenges, including managing uncertainty and confusion, dealing with an increased workload, a sense of guilt and anxiety about assuming unfamiliar roles, and the social isolation inherent in their role during the pandemic.

We don't want to let our families down. So we were all working extra hours to make sure that things weren't getting missed and that things were getting done as they should be. None of us wanted the patients and the families to suffer because we were being pulled right, left and centre. (Nurse Specialist #1)

On top of these challenges, it was clear that communication and collaboration within and between teams suffered, impacting on families. Caregivers often received conflicting information, finding out about issues accidentally, referred to as '*news that leaked out'* by one parent, or found themselves communicating key information between healthcare professionals. Investigations or treatments were frequently postponed as key people or resources were not available. Clinical services and charities that were deemed 'non-essential' by healthcare authorities became less visible, impacting on relationships that would usually be built with families in hospital. This was difficult for all involved.

I had to tell them that it was an incurable brain tumour whilst they were on the COVID ward and that was really difficult because you know you cannot see the family's faces, they cannot see you and you are telling them that their child is dying. (Consultant #2)

[Families] said they would have liked a conversation with someone at the point of diagnosis to understand their situation, their needs, their goals and the support needs of those that are important to them. (Charity #3)

While online interactions had some benefits, such as reduced travel time and exposure risk, and easier access to specialists, most participants felt that the quality of interactions had suffered, especially for children and young people.

Getting through this: the importance of support

Managing hospital alone took a toll on primary caregiver mental health. Caregivers felt they had to 'stay strong' for their child, but were often traumatised by their own experiences.

A few people said to me we managed it really well. I really didn't want to scream and say 'I didn't have any other choice!' I tried my best to navigate it for [child] and the rest of my family. (Caregiver #1)

I couldn't get to hospital without having panic attacks […] Now I struggle to drive to there. I struggle to be outside. (Caregiver #11)

Restrictions prevented many caregivers from accessing the support they felt they needed from family, friends, and peers, in person or remotely. A lack of privacy was a key issue for many in feeling comfortable to access any kind of support.

Being able to just see somebody who could support me privately would have been awesome […] I just think the rules made it exceptionally difficult […] how could I pour out my heart about how I was feeling when there was no distance between myself and my [child]? […] you don't have that safe space to be able to let yourself go.(Caregiver #8)

Caregivers were grateful for the compassionate actions of healthcare staff, with many highlighting the significance of the sense of camaraderie built during a difficult and isolating phase of their journey. For children, many of whom found treatment traumatic, the relationships established during treatment and a supportive and calm environment played a pivotal role.

It was kind of all right because we got to bond a lot […] I knew everyone else was kind of worried, but […] I got a lot of time to myself to think about things, do things I enjoy. (Child #2)

Whenever we were bored, we decided to open our curtains up to each other […] he was a lovely boy. And dad has still got his number on his phone in case anyone wants to phone him and say hello to him, remember how good the memories were. (Child #10)

Caregivers often found it necessary to 'break the rules' as the risks to their mental health outweighed the perceived risks of infection.

Sometimes you felt really naughty. I remember at the end of [child]'s treatment, [child] started having seizures and one of the mums came in and I know a nurse had told her to step back and she's like, 'no, I'm giving her a hug' and came in and gave me a hug. And you really need that because you're all just stood there and no one's comforting you. (Caregiver #14)

Overall, a huge frustration for caregivers during the pandemic was how they were prevented from accessing their own support systems.

Supporting the new normal

Returning home after treatment was an important landmark for families. However, during the pandemic, many caregivers experienced an enduring sense of isolation and continued to lack appropriate guidance.

We were so underprepared when we left. We were just given, like a pamphlet, basically. And I look back now and I just think, how on earth were we ever allowed to be sent home with no support? […] It was very difficult, very lonely, very isolating. (Caregiver #20)

The transition to community-based services, which form an integral part of the usual support after discharge was disrupted by restrictions on home visits, a shift to remote appointments, and cancelled outpatient appointments. Temporary closures of 'non-essential' services left many families feeling the absence of a 'safety net'. Remote consultations were rarely experienced as reassuring.

Knowing that normally [a doctor] would have come out [to see the child] and said, 'yeah, that rash is normal, they get that.' [...] Or 'maybe we should check this'. That would have put our minds at rest. (Caregiver #12)

Families struggled to access community-based services, particularly where they had not established relationships with those services whilst in hospital. Navigating complex health and social care systems was experienced as time consuming and frustrating.

It is easy enough to find out about services, but it is harder to know what you should be asking for, what is reasonable, what makes sense for your child – you need the support of someone with experience of brain tumours. (Caregiver #2)

Healthcare professionals commented on the impact of the pandemic on outcomes, in terms of delayed recognition and emergency admissions, and ongoing support for families, in terms of experiences of treatment, and impact on family resilience and mental health. These affected the establishment of a stable 'new normal' as disruption was ongoing.

I think one of the big problems we did have was the follow-up appointments, so I think we've had a couple of children that had come to be seen and then because of COVID it didn't get followed up and then they presented later on that were actually really quite poorly […]. I think the outpatient suffered a lot more than the inpatient. (Specialist Nurse #5)

Caregivers were appreciative of strong multidisciplinary and inter-agency coordination, of having an experienced key worker such as a specialist nurse or clinician, and of proactive guidance and support at key transitions. A specialist multi-disciplinary team working across hospital and community operated in one of the study sites, and most caregivers commented that their involvement had been critical in 'adjusting to the new normal.'

DISCUSSION

The findings presented in this paper, taken from the qualitative arm of a mixed-methods study, explore the impact of the SARS-CoV-2/COVID-19 pandemic on the diagnosis, management, and patient journey for children and young people with a newly-diagnosed brain tumour in the UK. The findings highlight the considerable challenges encountered by families and healthcare professionals, which could have had an impact on outcomes. While some issues identified are common to significant diagnoses at any time, the additional challenges of the pandemic on healthcare provision amplified these impacts on families.

Delayed recognition of brain tumours emerged as a clinically and emotionally significant issue, resulting from delayed help-seeking, difficulties in accessing healthcare services, and the limitations of remote consultations. Families experienced ongoing challenges after gaining access to treatment, largely as a result of caregivers having to manage hospital time alone. Stakeholders struggled to establish a cohesive and supportive team around the family due to restrictions on their usual practice. Caregivers strived to ensure their child felt safe in hospital, which was challenging when they themselves felt depleted and unable to access the support they needed from family, friends, peers and services. The transition from hospital to home setting accentuated feelings of anxiety and vulnerability, as families found themselves alone and without support. In particular, differences between usual care and care during this time were noted. Children and young people are usually supported after discharge by specialist neuro-rehabilitation teams or allied health professionals. Typically at discharge, children and young people have access to a keyworker from the neuro-rehab team or an allied health professional who liaises with community therapy teams. Disruption to community services during the pandemic meant that it was often not possible form these links, leaving families more isolated. While the pandemic exposed weaknesses in the healthcare system, it also underscored the resilience and adaptability of healthcare professionals and families.

Strengths of this study are that by incorporating multiple perspectives, including those of children and young people, caregivers, clinical staff, and charities from different regions of the UK, this study provides a comprehensive understanding of the ongoing challenges linked to the pandemic response. The feedback we received about the interview process was that, despite remembering traumatic memories, it had been cathartic, and participants were keen that their experiences and insights benefit others. Stakeholders' perspectives were valuable, in that they were able to compare healthcare provision before and during the pandemic in a way that most families were not. Limitations include that participants were self-selecting and that we were unable to recruit any bereaved families, whose perspective may have been particularly valuable in understanding challenges around late presentation and any relationship to increased risk of mortality. Our reflections on reasons for refusal to participate may be useful to consider for future studies to understand why data is potentially difficult to collect with these groups. As interviews were conducted after the restrictions associated with the pandemic had ended, the retrospective nature of the study posed challenges, particularly for children and young people, in terms of their ability and motivation to recall their experiences.

The findings of this study are consistent with previous research on experiences of the impact of childhood cancer for families,[9,18,19] and also align with emergent research on how the pandemic disrupted healthcare.[20–23] Evidence suggests that the severity of impact of COVID-19 infections on

paediatric patients with brain tumours was predominately low [24–26], meaning that the main impact on children was in their experience of delayed diagnosis and experiences of disrupted care. What this study adds are specific insights into the roles of wider services in the delivery of specialist tertiary care. The findings are also likely to be applicable to other complex medical conditions that require a coordinated approach. Reassessing what is considered 'essential' service provision may strengthen healthcare collaboration around the child and family. In particular, the role of services like charities in providing support and information were challenged by the delineation of services as essential and non-essential. Our findings suggest that enabling families to access their usual support networks and systems, including peer support, is crucial even in times of severe disruption.

These insights are also relevant to current circumstances, as many of the difficulties encountered by families and stakeholders reflect longstanding challenges in healthcare. Building system capacity and effective public health messaging to prompt timely help-seeking are also emphasised. Future research should continue to engage with children and young people directly, as their voices are often unheard in clinical research, yet understanding their perspective is vital to improving service provision.

Findings from this study offer practical insights from families and stakeholders to improve the healthcare system during future disruptions. Overall, this study not only sheds light on the challenges faced by families during the pandemic but also identifies recommendations for improving healthcare services to ensure a more comprehensive and effective response in times of crisis.

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Contribution statement
KA - Study Co-ordinator, study design and materials, data collection and analysis, reviewed and revised draft
RC – Data collection and analysis, writing of manuscript first draft
LB - Co-Investigator, supervised data collection and analysis, reviewed and revised draft
GAAB - Co-Investigator, design and conception of research,
JPK - Recruitment/local set up
DCM - Co-Investigator, design and conception of research, recruitment/local set up
RI – Co-Investigator, design and conception of research, reviewed and revised draft
IJ - Principal Investigator, design and conception of research, reviewed and revised draft. IJ is the guarantor.

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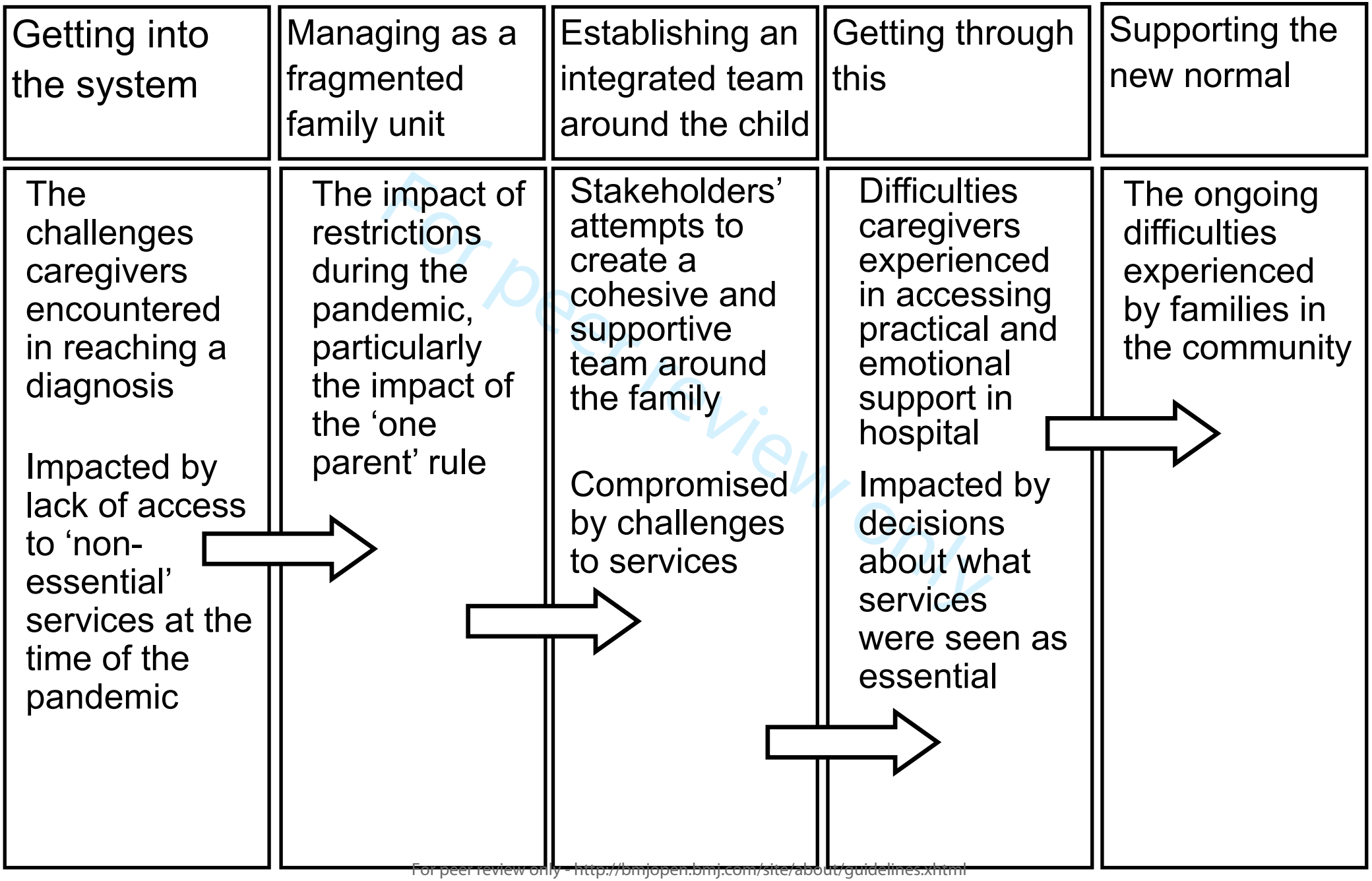
Figure legend

Figure 1: summary of themes from data analysis



Supplementary file 1: Interview Schedule for children and young people and parents

Interview Guide - Parents

Opening
- Introductions / thank you for participating
- Explain purpose of the research
- Overview of interview (areas covered, time, method, recording, breaks)
- Confidentiality
- Consent / sign form / any questions?

1. Before they became unwell, how would you describe your child?

(personality, interests and activities, family, friendships and other important relationships, school, health, what was going on in their life at the time, mood)

2. How did you become aware of the brain tumour (events leading to diagnosis)?

(If we were in a room with participant we could be drawing out a timeline as they speak)

Areas we could prompt if participants do not mention them:

- symptoms pre-diagnosis
- attempts to get help (e.g. GP, optician, A&E, school)
- when and where and by whom the tumour was diagnosed
- your reaction to the diagnosis (thoughts, feelings, behaviours)
- anything you remember as being particularly helpful or unhelpful at the time? (communication with experts, charities, internet forums and sites, friends and family etc)
- prior knowledge / experience of brain tumours / cancer

3. What happened after the tumour was diagnosed?

Areas we could prompt on if participants do not mention them:

- Treatment (neurosurgery, chemotherapy, radiotherapy, etc)
- Timelines (in-patient, out-patient, follow ups etc)

4. As a parent / family, what were your experiences of diagnosis and treatment?

- What was it like for you finding about the tumour?
- thoughts, feelings, behaviours - you and your family

- What was it like for you and your family getting treatment for the tumour?
- Day to day experiences of being in hospital, receiving treatment, attending appointments
- Particular challenges
- Adjustments that you had to make as a family / practicalities
- How you managed / how the family managed (emotion focussed / action focussed etc)
- How did the pandemic affect things for you whilst your child was getting treatment?

- What did you and your family find particularly helpful or unhelpful during this time? (particularly thinking about the pandemic)

- Practicalities e.g. work, staying at hospital, financial support,
- Support from the hospital system - doctors, nurses, play specialists, healthcare professionals, others at hospital

- Support from other patients and people in the hospital
- Support from charities / brain tumour networks / school etc

5. Reflecting on your experiences, what could others learn from them (especially considering future service disruptions)?

- what were the things that services did well, what were the things that they could do differently?

- advice, information, support, practicalities

- what advice would you give to other families who are about to start treatment for a tumour?

6. Debrief

- How was it talking about these things? How are you feeling now?
- Is there anything you want to ask or comment on about the interview?
- Outline what will happen next (e.g. continuing interviews, dissemination plan, etc)
- Are you happy to be contacted with updates on the project?

Supplementary file 2: Interview Schedule for stakeholders

Structured interview guide for stakeholders
(Clinical staff, patients groups & non-commercial third sector)

1. Can you please tell me about your role in this organisation and how long you have been working on this role?

2. What was your day to day routine before the pandemic as part of this role in terms of supporting service user/patients?

3. Looking at the pandemic situation, can you tell me how it has affected your ability to perform this role?

4. How your services were disrupted during the pandemic?

5. How you think this disturbance might have affected your service users/patients?

6. What other issues (from your point of view) have been caused by the pandemic?

7. Looking at the areas (in your services) affected by the pandemic and any lessons learnt, what needs to be in place during future periods of disruption?

8. Who you think can play a vital role to implement these recommendations and how?

9. Is there anything else you would like to add/clarify?

10. How did you find this experience of reflection?

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	1/ 1-3
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	1/ 4-31
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	2/ 37-74
Purpose or research question - Purpose of the study and specific objectives or questions	2/ 67-70
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	2-3/75-87
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	3/ 111-114
Context - Setting/site and salient contextual factors; rationale**	3/90-94
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	3/95-108
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	4/143-146
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	4/110- 133

Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	4/119 -133 plus supplementary materials
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	4/181-190
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	4/132-133
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	4/148-164
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	3/82-87

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	4/165-178
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	5/192-343

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	7/344-398
Limitations - Trustworthiness and limitations of findings	7/362-374

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Title page
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Title page

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

IMPACT OF THE SARS-COV-2/COVID-19 PANDEMIC ON THE PATIENT JOURNEYS OF THOSE WITH A NEWLY-DIAGNOSED PAEDIATRIC BRAIN TUMOUR IN THE UK - A QUALITATIVE STUDY

ABSTRACT

Objectives: To explore the impact of the SARS-CoV-2/COVID-19 pandemic on the diagnosis, management, and patient journey for children and young people with a newly diagnosed brain tumour in the UK.

Design: Exploratory qualitative study focused on patient journeys from multiple perspectives, conducted as part of a wider mixed-methods study.

Setting: Three paediatric oncology tertiary centres in the UK.

Participants: 10 children and young people with brain tumours (n=6 female, n=4 male), 20 caregivers (n=16 female, n=4 male), and 16 stakeholders (specialist nurses, consultant neurosurgeons and oncologists, and representatives from brain tumour charities) were interviewed between January 2022-June 2023.

Results: The paper incorporates multiple perspectives, including those of children and young people, parents/caregivers, clinical staff, and charity representatives to explore the patient journey. Five themes describe the journey for new paediatric brain tumour patients during the pandemic, focusing on: (1) challenges getting into the healthcare system; (2) managing as a family during restrictions imposed by the pandemic; (3) complexities of building a cohesive and supportive healthcare team; (4) difficulties caregivers experienced in accessing practical and emotional support in hospital; (5) ongoing difficulties experienced by families in the community.

Conclusions: Findings from this study offer practical insights from children, parents/caregivers and relevant stakeholders to improve the healthcare system during future disruptions. Overall, this study not only sheds light on the challenges faced by families during the pandemic but also provides suggestions for improving healthcare services to ensure a more comprehensive and effective response in times of crisis.

STRENGTHS AND LIMITATIONS

- We collected rich data that incorporates multiple perspectives, including those of children and young people, caregivers, clinical staff, and charities from different regions of the UK.
- A limitation is that participants were self-selecting and we were unable to recruit any bereaved families.
- The retrospective nature of the study posed challenges, particularly for children and young people recalling experiences.

IMPACT OF THE COVID-19 PANDEMIC ON THE PATIENT JOURNEYS OF THOSE WITH A NEWLY-DIAGNOSED PAEDIATRIC BRAIN TUMOUR IN THE UK - A QUALITATIVE STUDY

BACKGROUND

The global SARS-CoV-2/COVID-19 pandemic, declared by the World Health Organisation on 11 March 2020, presented a significant challenge to the provision of healthcare services. In the UK, as other countries, this impacted on the diagnosis and treatment of non-COVID-19 conditions. Evidence suggests that children and young people were less acutely affected by COVID-19 in terms of morbidity and mortality, but that their lives were disrupted in other ways, including access to routine healthcare services. Evidence suggests that there were changing patterns of use as services were impacted by the measures put in place to mitigate the spread of infection.[1–4]

This paper investigates the impact of the pandemic on one non-COVID-19 condition: paediatric brain tumours, the commonest childhood solid tumour. Every year around 500 children and young people are newly diagnosed with a brain tumour in the UK.[5] Mortality rates vary according to tumour type, but are generally high, with a five-year survival rate of 66% overall for all types of brain tumour in Europe.[6] Around 60% of patients are left with some form of lifelong neurological disability.[7] Delays in diagnosis can make treatment more complex and increase the likelihood of tumour progression, death or disability, as well as impacting relationships between families and healthcare teams.[8]

Diagnosis is often difficult, as symptoms and signs are often non-specific. Initial symptoms are often picked up in optometry, primary care, emergency departments or in nurseries and schools, with research suggesting that in around 40% of cases, initial detection of paediatric brain tumours occurs in optometry.[7] Care for paediatric brain tumours is complex, and treatment and rehabilitation require strong interdisciplinary and inter-agency collaboration across hospital and community-based health, education, and social care services. [8] Recent research into family experiences of paediatric brain tumours has concluded that the psychosocial needs of children, young people and families need to be prioritised.[9,10] There is some emerging evidence that the relationships between families and healthcare staff were disrupted during the pandemic [11] and that the experience of being hospitalised with a condition (such as a brain tumour) that necessitates careful infection prevention measures is isolating.[12]

As part of a wider study exploring the diagnosis, management, clinical outcomes, and patient/carer experiences of receiving treatment for a paediatric brain tumour during the pandemic, we sought to answer the research question: *What is the impact of the COVID-19 pandemic on the diagnosis, management, and patient journey for children and young people with a newly diagnosed brain tumour in the UK?* By exploring the impact of the pandemic on the patient journey of those diagnosed with a paediatric brain tumour at the time, the paper presents internationally relevant lessons about how healthcare services may need to prioritise maintaining particular services to prevent delays in diagnosis of childhood cancers and ensure better outcomes for children and young people.

METHODS

Interviews were used to collect detailed qualitative data about experiences of children and young people, parents/caregivers, clinical staff working in hospitals and representatives of paediatric brain tumour charities at three paediatric oncology centres in the UK. The qualitative approach allowed us to explore participants' understanding of their experiences of tumour diagnosis, treatment and care. This was contrasted with quantitative data on clinical outcomes collected as part of the wider mixed methods study, presented elsewhere. Analysis was conducted using a six-phase reflexive thematic analysis.[13] We adopted a broadly realist epistemological stance.[14] By including multiple participant groups, who were based in different hospitals, and having multiple experienced researchers working on a detailed analysis process, we were able to triangulate our findings to ensure they were robust and rigorous.[15] As researchers, we recognise that meaning is constructed through dialogue and that our values, interests, and assumptions shaped the research questions and analytical process.

Recruitment and participants

We recruited participants from three tertiary centres treating paediatric brain tumour patients. There were two groups of participants: children and young people and their caregivers, and key stakeholders (clinical and allied health professional staff, charities), who provided insights into how treatment and care services may have been disrupted during the pandemic.

We identified eligible patient and caregiver participants through hospital databases. Potential participants were approached if they were diagnosed in the study period and the 12 months prior to the pandemic (i.e. 1st March 2019 to 28th February 2021). Caregivers were provided with information about the study by post or by a clinician known to them, and invited to contact the research team if they wished to participate themselves and/or were happy for their child to participate. We approached bereaved families as well as those with surviving children. Families that declined to participate gave various reasons, including a reluctance to revisit traumatic experiences, other commitments, dissatisfaction with existing services, and significant life events affecting their family. All bereaved families declined to participate. Clinical and charity staff were recruited through their organisations, provided with information via email or in team meetings, and were asked to contact the research team if they were able to participate.

We estimated our sample size by referring to similar qualitative studies, and then assessed the adequacy of our sample size during the data collection process, guided by the information power framework.[16] Overall, according to the information power framework, our sample size was sufficient for developing new insights in line with the study's objectives.

Data Collection

The research team consisted of two research active clinicians (IJ, RI), one health psychology researcher (KA), one clinical psychologist (RC) and one medical sociologist (LB). Both interviewers (KA and RC) had extensive experience of working within NHS services, but were independent of the clinical services from which participants were recruited. Interviews with stakeholders were conducted between January 2022 and February 2023 by KA. Interviews with caregivers and children were conducted between May 2022 and June 2023 by KA and RC. Interviews took place 24-44 months after initial diagnosis.

For children, young people and parents/caregivers, we conducted semi-structured interviews, based on an interview schedule (Supplementary file 1). These typically lasted around one hour and were conducted in person or online, depending on participants preferences. In interviews with children and young people, for whom recalling treatment experiences was challenging, tools such as Talking Mats and children's creative work (e.g. art, photos) were used to facilitate the interview process.[17] As a team, we were conscious that interviews might be challenging for participants in terms of recalling traumatic experiences. This was mitigated by the involvement of a clinical psychologist and clarity that consent could be withdrawn at any stage.

For stakeholders who had been working with paediatric brain tumour patients during the study period, including clinical staff working in the paediatric neuro-oncology departments of each treating centre, and representatives of paediatric brain tumour charities, we conducted semi-structured interviews, again based around an interview schedule (Supplementary file 2). These interviews typically lasted 30-60 minutes, and were conducted online. All interviews were recorded using a digital voice recorder, and transcribed using the online Happy Scribe transcription service.

Patient and Public Involvement

Prior to the research study, we conducted a patient and public involvement co-design event with children and families. This event included presentations from the research team and a group discussion. We incorporated feedback into the design in terms of: (a) adopting a flexible and inclusive approach to data collection (e.g. inviting children to contribute written submissions,

drawing, or other media as an alternative to interviews) to enable all children to participate; (b) broadening the scope of the interviews to include the patient journey from initial awareness to longer term adjustment.

Ethical approvals

Ethical approval was provided by the NHS Health and Research Authority in December 2021 (IRAS:295305 HRA: 21/PR/1571). Written i~~I~~nformed consent was given by parents for all children participating, and informed assent was also given by children and young people aged 11-16. For all other participants (e.g. key stakeholders and parents), written informed consent was also given. ~~or assent (as appropriate for age) was received from all participants~~.

Data analysis

We completed a six-phase reflexive thematic analysis, following Braun and Clarke's (2022) framework.[13] First, we immersed ourselves in the data by re-listening to interviews to ensure accurate transcripts, and creating case summaries. Second, KA and RC coded the interview transcripts and then collated interview extracts. Through team discussion, including LB, we generated ideas about parallel experiences for stakeholders and families. Conducting a second round of coding developed more abstract codes, making the large dataset more manageable. RC then generated preliminary themes via mind maps, reflective writing, reading, consultation with experts possessing relevant professional and/or lived experience, and regular discussion sessions with LB.

During this phase we refined and defined these themes. This approach enabled us to explore various ways of interpreting the data, structuring themes and to consider perspectives that may have been missing from the data - for example those of parents who were bereaved, or stakeholders who had left their service. We refined and structured the analysis around the concept of 'patient journeys' and aimed to acknowledge the complexities of the family, services, and wider systems around the child.

RESULTS

The paper explores the patient journey from multiple perspectives, including the experiences of children, their family, those delivering healthcare services, and charities that supported families at the time. Five themes describe the journey for new paediatric brain tumour patients during the pandemic (figure 1). First, we describe 'getting into the system', the challenges caregivers encountered in reaching a diagnosis, and how this was impacted by lack of access to 'non-essential' services at the time of the pandemic. Second, we explore 'managing as a fragmented family unit', the impact of restrictions during the pandemic, particularly the impact of the 'one parent' rule. Third, we examine 'establishing an integrated team around the child,' or how stakeholders' attempts to create a cohesive and supportive team around the family were compromised by challenges to services. Fourth, we highlight 'getting through this,' addressing difficulties caregivers experienced in accessing practical and emotional support in hospital and how this was impacted by decisions about what services were seen as essential and which were not. Fifth, we address 'supporting the new normal', considering the ongoing difficulties experienced by families in the community.

Participant characteristics

Interview participants were families and key stakeholders based in three tertiary centres, and representatives from national charities. We spoke to 20 caregivers (n=16 female, n=4 male) and 10 children (n=6 female, n=4 male; age range: 5-14 years old at time of interview). These spanned 18 different family/household units. Age at diagnosis ranged from four months to 13 years (mean = 7 years) and diagnoses included low grade glioma, ependymoma, craniopharyngioma and choroid plexus carcinomas.

The sixteen stakeholders working within paediatric neuro-oncology included six specialist nurses, six consultants (neurosurgeons, oncologists), one allied health professional, and three representatives from brain tumour charities.

Getting into the system

Many families described a prolonged journey from initial awareness to diagnosis, typically encountering multiple attempts by healthcare professionals to reassure and normalise symptoms.

We get delayed diagnosis all the time with brain tumours, because the symptoms are not very specific. So it might be headaches or vomiting or if it's visual impairment that's difficult to pick up at the best of times. (Specialist Nurse #4)

This delay was not unique to the pandemic, but the 'lockdown' period introduced additional challenges for concerned parents. Public health messages emphasising the importance of protecting the healthcare system led to reluctance to seek help. Seeing a GP face-to-face was more difficult and remote consultations relied on clear caregiver reporting to ensure that 'red flags' were noted.

I think just by the nature of the pandemic, just as a society, everybody did not want to utilise the NHS unless they absolutely had to. […] You have to weigh up whether it is worth [it]… if somebody is ill enough to take them in. (Caregiver #1)

A lot of them were telephone consultations. They wouldn't actually see us because of COVID. […] If you explain stuff over the phone, they're just agreeing with you. They're just taking your point of view. (Caregiver #17)

Children were also not being seen in other settings such as nursery, school or social situations, making it harder for caregivers to evaluate their concerns.

I think we had a couple of delayed presentations just because they had no idea that their child was different to anyone else. And it wasn't until they became quite sick, because that was then picked up when they brought the child to A&E. (Specialist Nurse #5)

Although some felt that getting onto a treatment pathway during the pandemic was the key challenge, as noted by this specialist nurse, many parents/caregivers emphasised that treatment was compromised throughout the whole patient journey.

Managing as a fragmented family unit

The national infection control restrictions, which only allowed one primary caregiver to attend hospital with their child, posed significant challenges for families, including siblings and grandparents. Caregivers commented that coming to terms with the diagnosis, managing treatment, collaborating with healthcare teams, and supporting each other required togetherness, which was often not possible.

COVID just made it more difficult because it was harder to see people. […] You were in on your own a lot of the time, because some of the time me and [partner] swapped, so we didn't really communicate much. […] When [daughter] came out of theatre, I wasn't allowed to go and see her, because I wasn't the designated parent. And it is heartbreaking, absolutely heartbreaking, to not be able to go and see that your child is okay. (Caregiver #15)

We found that the biggest overriding challenge was that many hospitals only allowed one parent carer to accompany a child, which meant that many children and their parents felt isolated from their own family as well. (Charity #3)

Although appreciating the need to manage risks of infection from COVID-19, families and stakeholders felt that the rules were too rigid. Rules were also applied inconsistently, sometimes differing between families, wards and hospitals and it was unclear to outsiders why exceptions were made, leading to resentment. On a practical note, opportunities for caregivers to eat, drink, rest, and speak to friends and family were severely restricted as they often felt unable to leave the

bedside. This was compounded by a lack of access to communal spaces in hospital, and limited activities for children and young people.

For [husband], the whole thing was just awful. […] nobody really explained anything to him […] he was just left a lot of the time on his own. There was just very little support and that's what I think made it really hard for him. […] sometimes they would bring [child's] food and then forget about him - because he couldn't leave the room to get his food. (Caregiver #15)

Establishing relationships and communicating with healthcare teams was challenging because of mask wearing and maintaining social distancing. Comprehending and retaining complex and emotional information without wider support was difficult, and it was harder to involve those outside the room because of technical issues (e.g. poor wi-fi/ mobile phone signal coverage).

You're not in the right frame of mind to ask those questions because […] them saying 'it's a tumour' and you're [saying to yourself] 'right'. Then you've got oncology coming to see you […] There's a lot of different emotions you go through, to be honest, which really wasn't helped by the fact that you can't all be together as a family. (Caregiver # 13)

Without access to their own practical and emotional support systems, caregivers were conscious of placing additional pressure on depleted healthcare teams.

Establishing an integrated team around the child

Healthcare workers also experienced significant challenges, including managing uncertainty and confusion, dealing with an increased workload, a sense of guilt and anxiety about assuming unfamiliar roles, and the social isolation inherent in their role during the pandemic.

We don't want to let our families down. So we were all working extra hours to make sure that things weren't getting missed and that things were getting done as they should be. None of us wanted the patients and the families to suffer because we were being pulled right, left and centre. (Nurse Specialist #1)

On top of these challenges, it was clear that communication and collaboration within and between teams suffered, impacting on families. Caregivers often received conflicting information, finding out about issues accidentally, referred to as '*news that leaked out'* by one parent, or found themselves communicating key information between healthcare professionals. Investigations or treatments were frequently postponed as key people or resources were not available. Clinical services and charities that were deemed 'non-essential' by healthcare authorities became less visible, impacting on relationships that would usually be built with families in hospital. This was difficult for all involved.

I had to tell them that it was an incurable brain tumour whilst they were on the COVID ward and that was really difficult because you know you cannot see the family's faces, they cannot see you and you are telling them that their child is dying. (Consultant #2)

[Families] said they would have liked a conversation with someone at the point of diagnosis to understand their situation, their needs, their goals and the support needs of those that are important to them. (Charity #3)

While online interactions had some benefits, such as reduced travel time and exposure risk, and easier access to specialists, most participants felt that the quality of interactions had suffered, especially for children and young people.

Getting through this: the importance of support

Managing hospital alone took a toll on primary caregiver mental health. Caregivers felt they had to 'stay strong' for their child, but were often traumatised by their own experiences.

A few people said to me we managed it really well. I really didn't want to scream and say 'I didn't have any other choice!' I tried my best to navigate it for [child] and the rest of my family. (Caregiver #1)

I couldn't get to hospital without having panic attacks […] Now I struggle to drive to there. I struggle to be outside. (Caregiver #11)

Restrictions prevented many caregivers from accessing the support they felt they needed from family, friends, and peers, in person or remotely. A lack of privacy was a key issue for many in feeling comfortable to access any kind of support.

Being able to just see somebody who could support me privately would have been awesome […] I just think the rules made it exceptionally difficult […] how could I pour out my heart about how I was feeling when there was no distance between myself and my [child]? […] you don't have that safe space to be able to let yourself go.(Caregiver #8)

Caregivers were grateful for the compassionate actions of healthcare staff, with many highlighting the significance of the sense of camaraderie built during a difficult and isolating phase of their journey. For children, many of whom found treatment traumatic, the relationships established during treatment and a supportive and calm environment played a pivotal role.

It was kind of all right because we got to bond a lot […] I knew everyone else was kind of worried, but […] I got a lot of time to myself to think about things, do things I enjoy. (Child #2)

Whenever we were bored, we decided to open our curtains up to each other […] he was a lovely boy. And dad has still got his number on his phone in case anyone wants to phone him and say hello to him, remember how good the memories were. (Child #10)

Caregivers often found it necessary to 'break the rules' as the risks to their mental health outweighed the perceived risks of infection.

Sometimes you felt really naughty. I remember at the end of [child]'s treatment, [child] started having seizures and one of the mums came in and I know a nurse had told her to step back and she's like, 'no, I'm giving her a hug' and came in and gave me a hug. And you really need that because you're all just stood there and no one's comforting you. (Caregiver #14)

Overall, a huge frustration for caregivers during the pandemic was how they were prevented from accessing their own support systems.

Supporting the new normal

Returning home after treatment was an important landmark for families. However, during the pandemic, many caregivers experienced an enduring sense of isolation and continued to lack appropriate guidance.

We were so underprepared when we left. We were just given, like a pamphlet, basically. And I look back now and I just think, how on earth were we ever allowed to be sent home with no support? […] It was very difficult, very lonely, very isolating. (Caregiver #20)

The transition to community-based services, which form an integral part of the usual support after discharge was disrupted by restrictions on home visits, a shift to remote appointments, and cancelled outpatient appointments. Temporary closures of 'non-essential' services left many families feeling the absence of a 'safety net'. Remote consultations were rarely experienced as reassuring.

Knowing that normally [a doctor] would have come out [to see the child] and said, 'yeah, that rash is normal, they get that.' [...] Or 'maybe we should check this'. That would have put our minds at rest. (Caregiver #12)

Families struggled to access community-based services, particularly where they had not established relationships with those services whilst in hospital. Navigating complex health and social care systems was experienced as time consuming and frustrating.

It is easy enough to find out about services, but it is harder to know what you should be asking for, what is reasonable, what makes sense for your child – you need the support of someone with experience of brain tumours. (Caregiver #2)

Healthcare professionals commented on the impact of the pandemic on outcomes, in terms of delayed recognition and ~~,~~ emergency admissions, and ongoing support for families, in terms of experiences of treatment, and impact on family resilience and mental health. These affected the establishment of a stable 'new normal' as disruption was ongoing.

I think one of the big problems we did have was the follow-up appointments, so I think we've had a couple of children that had come to be seen and then because of COVID it didn't get followed up and then they presented later on that were actually really quite poorly […]. I think the outpatient suffered a lot more than the inpatient. (Specialist Nurse #5)

Caregivers were appreciative of strong multidisciplinary and inter-agency coordination, of having an experienced key worker such as a specialist nurse or clinician, and of proactive guidance and support at key transitions. A specialist multi-disciplinary team working across hospital and community operated in one of the study sites, and most caregivers commented that their involvement had been critical in 'adjusting to the new normal.'

DISCUSSION

The findings presented in this paper, taken from the qualitative arm of a mixed-methods study, explore the impact of the SARS-CoV-2/COVID-19 pandemic on the diagnosis, management, and patient journey for children and young people with a newly-diagnosed brain tumour in the UK. The findings highlight the considerable challenges encountered by families and healthcare professionals, which could have had an impact on outcomes. While some issues identified are common to significant diagnoses at any time, the additional challenges of the pandemic on healthcare provision amplified these impacts on families.

Delayed recognition of brain tumours emerged as a clinically and emotionally significant issue, resulting from delayed help-seeking, difficulties in accessing healthcare services, and the limitations of remote consultations. Families experienced ongoing challenges after gaining access to treatment, largely as a result of caregivers having to manage hospital time alone. Stakeholders struggled to establish a cohesive and supportive team around the family due to restrictions on their usual practice. Caregivers strived to ensure their child felt safe in hospital, which was challenging when they themselves felt depleted and unable to access the support they needed from family, friends, peers and services. The transition from hospital to home setting accentuated feelings of anxiety and vulnerability, as families found themselves alone and without support. In particular, differences between usual care and care during this time were noted. Children and young people are usually supported after discharge by specialist neuro-rehabilitation teams or allied health professionals. Typically at discharge, children and young people have access to a keyworker from the neuro-rehab team or an allied health professional who liaises with community therapy teams. Disruption to community services during the pandemic meant that it was often not possible form these links, leaving families more isolated. While the pandemic exposed weaknesses in the healthcare system, it also underscored the resilience and adaptability of healthcare professionals and families.

Strengths of this study are that by incorporating multiple perspectives, including those of children and young people, caregivers, clinical staff, and charities from different regions of the UK, this study provides a comprehensive understanding of the ongoing challenges linked to the pandemic response. The feedback we received about the interview process was that, despite remembering traumatic memories, it had been cathartic, and participants were keen that their experiences and insights benefit others. Stakeholders' perspectives were valuable, in that they were able to compare healthcare provision before and during the pandemic in a way that most families were not. ~~Weaknesses~~ Limitations include that participants were self-selecting and that we were unable to recruit any bereaved families, whose perspective may have been particularly valuable in understanding challenges around late presentation and any relationship to increased risk of mortality. Our reflections on reasons for refusal to participate may be useful to consider for future studies to understand why data is potentially difficult to collect with these groups. As interviews were conducted after the restrictions associated with the pandemic had ended, the retrospective nature of the study posed challenges, particularly for children and young people, in terms of their ability and motivation to recall their experiences.

The findings of this study are consistent with previous research on experiences of the impact of childhood cancer for families,[9,18,19] and also align with emergent research on how the pandemic disrupted healthcare.[20–23] Evidence suggests that the severity of impact of COVID-19 infections on

paediatric patients with brain tumours was predominately low [24–26], meaning that the main impact on children was in their experience of delayed diagnosis and experiences of disrupted care. What this study adds are specific insights into the roles of wider services in the delivery of specialist tertiary care. The findings are also likely to be applicable to other complex medical conditions that require a coordinated approach. Reassessing what is considered 'essential' service provision may strengthen healthcare collaboration around the child and family. In particular, the role of services like charities in providing support and information were challenged by the delineation of services as essential and non-essential. Our findings suggest that enabling families to access their usual support networks and systems, including peer support, is crucial even in times of severe disruption.

These insights are also relevant to current circumstances, as many of the difficulties encountered by families and stakeholders reflect longstanding challenges in healthcare. Building system capacity and effective public health messaging to prompt timely help-seeking are also emphasised. Future research should continue to engage with children and young people directly, as their voices are often unheard in clinical research, yet understanding their perspective is vital to improving service provision.

Findings from this study offer practical insights from families and stakeholders to improve the healthcare system during future disruptions. Overall, this study not only sheds light on the challenges faced by families during the pandemic but also identifies recommendations for improving healthcare services to ensure a more comprehensive and effective response in times of crisis.

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Contribution statement
KA - Study Co-ordinator, study design and materials, data collection and analysis, reviewed and revised draft
RC – Data collection and analysis, writing of manuscript first draft
LB - Co-Investigator, supervised data collection and analysis, reviewed and revised draft
GAAB - Co-Investigator, design and conception of research,
JPK - Recruitment/local set up
DCM - Co-Investigator, design and conception of research, recruitment/local set up
RI – Co-Investigator, design and conception of research, reviewed and revised draft
IJ - Principal Investigator, design and conception of research, reviewed and revised draft. IJ is the guarantor.

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Figure legend

Figure 1: summary of themes from data analysis

Please include a 'Strengths and limitations of this study' section after the abstract. This section should contain up to five short bullet points, no longer than one sentence each, that relate specifically to the methods. The novelty, aims, results or expected impact of the study should not be summarised here. This will be published as a summary box after the abstract in the final published article.	A strengths and limitations section has been added. • "We collected rich data that incorporates multiple perspectives, including those of children and young people, caregivers, clinical staff, and charities from different regions of the UK. • A limitation is that participants were self-selecting and we were unable to recruit any bereaved families. • The retrospective nature of the study posed challenges, particularly for children and young people recalling experiences."
- In your ethics statement please clarify at what ages participants provided consent or assent and whether parental consent was obtained.	This has been clarified in the ethical approval section – "Written informed consent was given by parents for all children participating, and informed assent was also given by children and young people aged 11-16. For all other participants (e.g. key stakeholders and parents), written informed consent was also given."
Overall this is an excellent paper, suitable for publication. If you are making edits you might consider the following, especially in regard to the Discussion section.	Thank you for this feedback. We have revised in line with these suggestions.
Methods Good use of positioning statement with regards to impact on research.	Thank you for this feedback.
Recruitment- Interesting to see the refusal reasons, thank you for including those. Is there opportunity to help these inform future recruitment in the space, for example in articulating that families experiences with the service, whether positive or negative, are useful insights to gather? Or if this was in the recruitment information this would be useful to record here. Was there emotional support offered to participants? What stage in bereavement were families who were invited?	We have added a few sentences to speak to these points in the discussion section, with a view to inform future recruitment. In the recruitment section, we have clarified that potential participants were approached if they were diagnosed in the study period and the 12 months prior to the pandemic (i.e. 1st March 2019 to 28th February 2021). This included all outcomes for CYP, including parents who were bereaved.

The importance of support This is a really powerful section, the picture of a nurse trying to deny the mum a hug from her friend is such an exemplar of the issues raised.	Thank you for this feedback – we appreciate your comments on this example.
Supporting the new normal More information on the usual support available after discharge would be helpful. What is reported here seems quite usual for many areas.	We have added more information on support available after discharge. This is highlighted in this section, and then clarified in the discussion.
P8- 'Healthcare professionals commented on...' - This seems like it should be a new section rather than under the 'new normal' heading.	We have clarified so that it is more linked to the previous section, showing how healthcare practitioners also recognised the challenges in establishing a new normal for families.
Discussion More comparison to usual issues faced by families would be useful here, with reference to the literature. Fragmentation of the family unit and difficulty re-integrating after discharge are quite usual- how does this cohort differ?	We have added a short section to highlight how this compared with usual issues faced by families in terms of care provided to support re-integration.
Reviewer: 2	
Comments to the Author: Kalsoom et al present value insight on the impact of the COVID-19 pandemic on patient with CNS tumors and their journey to be diagnosed. The authors should be congratulated on this valuable work.	Thank you for these kind words.
Major comment	
- A figure that connect the different themes would be valuable to connect the themes that resulted from the qualitative analyses	A figure has been added.
- The Discussion needs to be expanded a bit more to contextualize the data. How this is different form other pediatric cancers or how this relates to the pre-pandemic state?	Given the word limits, we have added a sentence to clarify - “While some issues identified are common to significant diagnoses at any time, the additional challenges of the pandemic on healthcare provision amplified these impacts on families.”
Minor comments: - I believe some key references are missing in the description of pediatric oncology services during the pandemic (PMID 34454651, PMID 33675698), and specifically for children with CNS tumors (PMID	Thank you for this comment – we have added these references in to the introduction (reference 4) and discussion (24-26) for context.

34415031, PMID 37194498). These will allow to connect the clinical context more robustly,	
- Study limitations should be expanded upon. The strengths are mentioned, but not the converse.	Limitations have been clarified.