

# No wrong decisions in an all-wrong situation. A qualitative study on the lived experiences of families of children with diffuse intrinsic pontine glioma

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## Abstract

**Background:** Diffuse intrinsic pontine glioma (DIPG) is a rare, but lethal pediatric brain tumor with a median survival of less than 1 year. Existing treatment may prolong life and control symptoms, but may cause toxicity and side effects. In order to improve child- and family-centered care, we aimed to better understand the treatment decision-making experiences of parents, as studies on this topic are currently lacking.

**Procedure:** The data for this study came from 24 semistructured interviews with parents whose children were diagnosed with DIPG in two children's hospitals in Switzerland and died between 2000 and 2016. Analysis of the dataset was done using reflexive thematic analysis.

**Results:** For most parents, the decision for or against treatment was relatively straightforward given the fatality of the tumor and the absence of treatment protocols. Most of them had no regrets about their decision for or against treatment. The most distressing factor for them was observing their child's gradual loss of independence and informing them about the inescapability of death. To counter this powerlessness, many parents opted for complementary or alternative medicine in order to "do something." Many parents reported psychological problems in the aftermath of their child's death and coping strategies between mothers and fathers often differed.

**Conclusion:** The challenges of DIPG are unique and explain why parental and shared decision-making is different in DIPG compared to other cancer diagnoses. Considering that treatment decisions shape parents' grief trajectory, clinicians should reassure parents by framing treatment decisions in terms of family's deeply held values and goals.

**Abbreviations:** CAM, complementary and alternative medicine; DIPG, diffuse intrinsic pontine glioma; RT, focal radiotherapy.

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## KEYWORDS

coping strategies, death, decision-making, DIPG, lived experiences, regret

## 1 | INTRODUCTION

Diffuse intrinsic pontine glioma (DIPG) is a cancer that originates in the brainstem, which controls many vital functions (e.g., breathing, blood pressure, and heart rate) as well as nerves. It is a rare, but lethal pediatric tumor with a median survival of less than 1 year.<sup>1</sup> The tumor is characterized by a highly diffuse and invasive growth process. Problems with walking, coordination, swallowing, and speech are common symptoms among patients. DIPG is usually diagnosed based on clinical symptoms and MRI,<sup>2</sup> but in the last 5 years and within the scope of recent preclinical trials, biopsies have (re)gained importance.<sup>3–5</sup> Due to its sensitive location and undefined borders, the tumor is nonresectable. The standard treatment for DIPG is focal radiotherapy (RT) commonly delivered over 6 weeks. Studies have shown that with RT, overall survival increases by around 3–6 months, but the main goal of treatment is to control symptoms and support quality of life. In some patients, re-irradiation is used at the time of disease progression.<sup>6</sup> Still, RT can only temporarily control the tumor's growth. Curative treatment is currently non-existing.<sup>7–9</sup>

Studies show that compared to other cancers, parental caregivers of children with brain cancer face higher levels of distress due to changes in the child's cognitive development and personality.<sup>10–13</sup> As a result of neurologic deterioration or cancer treatment, the child might lose the ability to express its needs, emotions, and desires and this loss of communication might cause anger and frustration to both parents and children.<sup>14</sup> This may explain why families living with a brain cancer diagnosis often report living under a constant cloud of uncertainty.<sup>15</sup> Although the challenges of childhood brain tumor are unique and require special attention, a critical knowledge gap exists regarding the psycho-social support needs of such families from the point of diagnosis, throughout the illness trajectory, survivorship, death, and bereavement.<sup>15</sup>

Even less is known about the lived experiences of families who are confronted with a diagnosis of DIPG. Unique about DIP is that families find themselves in a situation that is grim from the start insofar they are confronted with treatment decisions that do not have the goal of cure, but only potentially prolong children's lives. Moreover, compared to other cancer diagnoses parent–clinician relationships are less firmly established due children's short life expectancy, and the fact that parents often forego treatment and care for their children at home. This unique situation raises important questions for healthcare professionals on how to best support parents in making treatment decisions and to help them cope throughout the grieving process.

Although essential, existing research on DIPG has almost exclusively focused on the mechanisms of tumorigenesis in order to develop new targeted therapies. Hence, the aim of the present study was to gain a better understanding of how parents experience the treatment decision-making process when their child is diagnosed with DIPG. For

this purpose, we conducted semistructured interviews with parental caregivers in Switzerland whose child died from DIPG (1–15 years ago) with a focus on their values, hopes, and decision-making experiences. The ultimate objective was to provide recommendations to health-care staff to improve communication with families and offer support according to their needs.

## 2 | METHODS

The data for this study came from 24 semistructured interviews with parents who lost their child to DIPG between January 2000 and December 2016. Participants were eligible if their child was cared for in Switzerland. No restriction was placed on participant's nationality or partnership status. Participants were able to speak either German or English. The qualitative study was approved by the Ethics Review Board at the Institute of Biomedical Ethics and History of Medicine, University of Zurich. The data were stored in accordance with the General Data Protection Regulation (GDPR) on a secure university server and was only accessible to the research team. The participants' names were not linked with their data and all identifying information was removed before using the data.

Eligible parents were identified with the help of the databases of two University children's hospitals in Switzerland (with an average of 75 diagnoses/year and three deaths). Due to the relatively long timespan (16 years) not all current addresses of the families could be found. Of the 35 eligible couples, 20 families were contacted per letter by an experienced oncologist and informed about the study purpose (contact details of others went missing or could not be contacted probably because of address change). If families showed interest in participating, they received a second letter with further information and an informed consent form. Eventually, 25 parents (of 14 children) agreed to participate. In a next step, these families were contacted by phone or email to schedule an appointment at a time and place of their convenience. Before the start of the actual interview, the overall purpose of the study was explained once more and remaining questions were addressed. Written informed consent was obtained from all participants before the start of the interview.

A semistructured interview guide was developed by an ethicist, two psychologists, and an oncologist who care for children with DIPG. To verify the adequacy of the interview guide, two pilot interviews were conducted, which resulted in some minor adjustments. The first part of the interview was conducted in the presence of both parental caregivers and focused on the family situation at the time of diagnosis and on the general disease course. The second part of the interview, which was discussed with each parent separately, revolved around decision-making and its impact on all persons involved. Of the 14 consenting couples, three interviews were conducted only with the mother.

**TABLE 1** Participant characteristics

#	Age of child at diagnosis (years)	Treatment decision	Biopsy	Survival time
1	2	No treatment	No	8 months
2	7	Radiotherapy	No	1 month
3	10	Radio- and chemotherapy	No	16 months
4	7	Radio- and chemotherapy <sup>a</sup>	No	8 months
5	1	No treatment	No	1 month
6	7	Radio- and chemotherapy	Yes	10 months
7	4	No treatment	No	Unknown
8	6	No treatment	Yes	21 months
9	4	Radiotherapy	No	5 months
10	5	No treatment	No	7 months
11	7	No treatment	No	2 months
12	6	No treatment	No	3 month
13	3	No treatment	No	1 month
14	5	No treatment	No	Unknown

<sup>a</sup>Chemotherapy was discontinued after less than 1 month.

The study was carried out between May 2017 and October 2018. Interviews lasted between 90 and 120 minutes, took place in the families' homes, and were conducted by two female master students in psychology with the support of an experienced nurse practitioner and a psychologist. Once the two pilot interviews were completed, both students received constructive feedback from their supervisors to guarantee data quality. One interview was carried out by an experienced nurse upon request of the mother.

The interviews were tape-recorded and transcribed ad verbatim. After accuracy check, the transcripts were transferred into the qualitative analysis software MAXQDA<sup>16</sup> to support with data management. Analysis of the dataset was done using reflexive thematic analysis.<sup>17,18</sup> After data familiarization through reading and transcription, initial (inductive) coding was done (based on a close line-by-line analysis) jointly by EDC, JS, and MF. After examining the codes, potential themes were identified. After agreeing upon a coding tree, the first author (EDC) then coded the remaining transcripts. Themes were further refined by checking them against the dataset and the scope and focus of each theme was determined with the support of JS and MF. When needed, subthemes were added and similar ones were combined. In the last step of the analysis, clear definitions and names for each theme were generated. Data saturation was monitored by starting data analysis in parallel to data collection. No new themes were found after the 14th interview.

### 3 | RESULTS

For the study, 24 interviews were completed, 10 sets (mother and father separately), three interviews with one parent (mother), and one interview with both parents contemporarily. One interview was con-

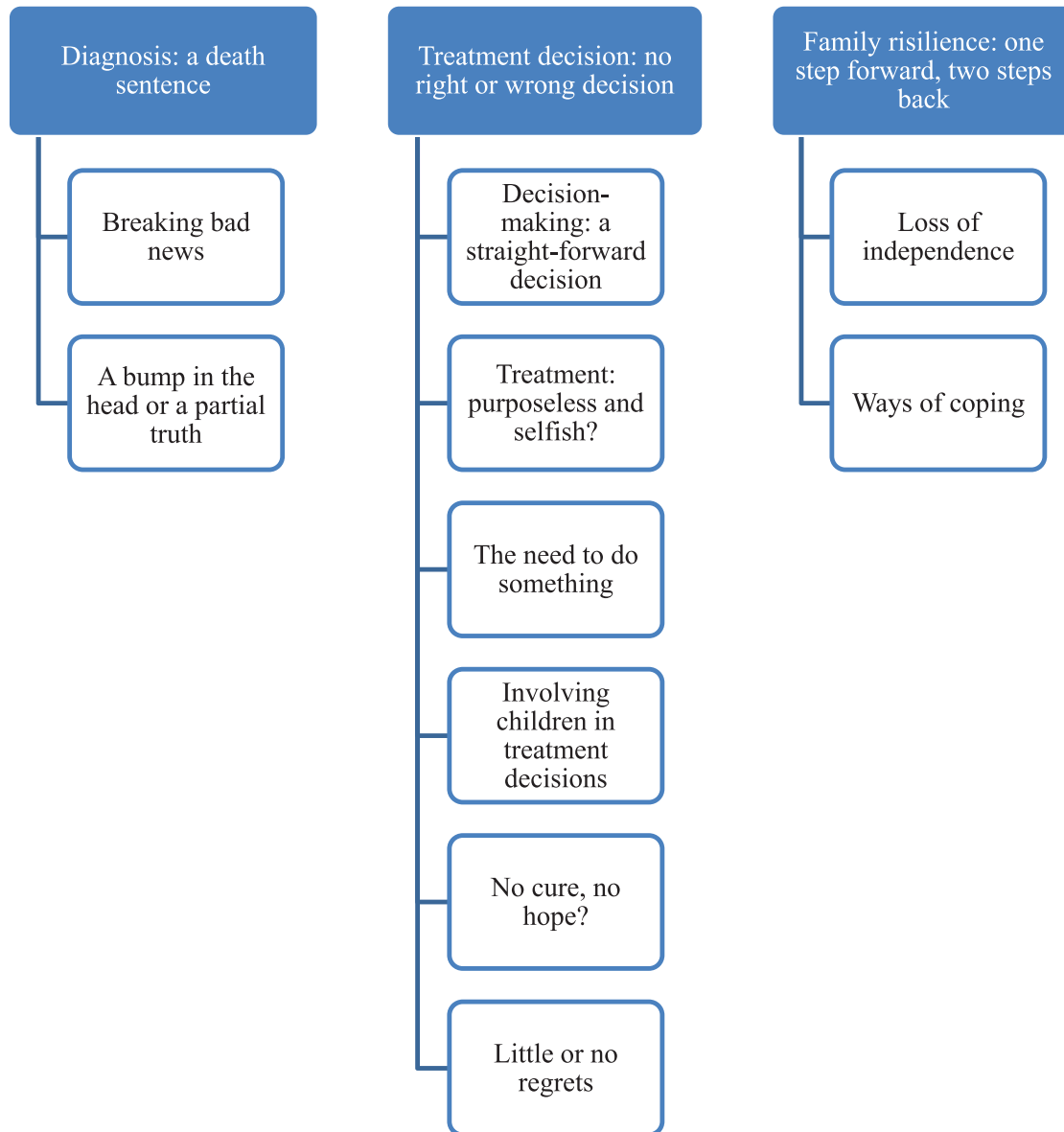
ducted in English, all the other ones in German. The average time between the death of the child and the time of the interview was 7 years (range 1–15 years). The children were on average 5 years old at the time of death, with the youngest child being 1 and the oldest one 10. The mean survival time was 6 months (range 1–21 months). Nine children received no therapy. Radiation therapy alone was used in two cases. Three children received both radio- and chemotherapy. The patients who did receive treatment were on average 7 years, patients without treatment 4 years old (Table 1). All children received outpatient treatment. None of the patients was involved in a clinical trial.

Analysis of the interviews resulted in the following three themes (and various subthemes) (Figure 1): (a) diagnosis, a death sentence; (b) treatment decision: no right or wrong answer; (c) family resilience: one step forward, two steps back. Representative and anonymized quotes were taken from each interview. The quotes were translated into English.

#### 3.1 | Diagnosis: A death sentence

##### 3.1.1 | Breaking bad news: Who is the bogeyman in the room?

The communication of DIPG was for all parents an extremely difficult moment, but their experience of how the diagnosis was communicated varied. Some parents had a very humane experience, for others the process was too short and too blunt, still others thought that it was good that the doctors were so straightforward. Although parents were well aware that it was not the doctor's fault that their child was ill, the mere fact of them delivering this terrible message turned them



**FIGURE 1** Overview of themes

into a kind of bogeyman. Other parental caregivers admired the physicians' capacity of being able to communicate such a diagnosis at all (Table 2.1).

### 3.1.2 | A bump in the head or a partial truth

Almost all parents tried to involve their child in diagnosis communication, taking into account the child's age and physical condition. Some caregivers talked about a bump in the head, or made a cross on the child's head to show them what was hurting them. In some cases, parents used the word (brain) cancer. None of the parents felt able to tell their child that they would die. It was psychologically very hard for them to inform the child that there was nothing they could do. In a few cases, they felt "pushed" by healthcare providers to tell the "truth."

According to the parents, their children somehow intuitively knew that they would die, although almost none of them directly asked (Table 2.2).

## 3.2 | Treatment decision: No right or wrong answer

### 3.2.1 | Decision-making: A straightforward process

Most parents emphasized that they were the main decision makers and that physicians or other family members had no leading influence in their decision to treat or not to treat. The fact that there were no curative treatment options, felt for many parents, retrospectively, almost as a relief in the sense that they did not need to take a decision as there was no "real" decision to make. Although it was emotionally challenging to know that there were no curable options, many families reported

**TABLE 2** Diagnosis, a death sentence

<p>2.1 Breaking bad news: Who is the bogeyman in the room?</p>	<p>That was very, very human, he took her in his arms, he took us in his arms, and I knew when he came to get us ... (...) then he said "I just took a few more colleagues with me," then I thought "oh," for me, in my head there was "oh this will be a strong treatment" and she will have to repeat the school year, somehow like that or can't start school anymore, that was my thought. When he sat then, he told us and then it was clear. I appreciated that very much, no that was good. (mother 11)</p> <p>What really bothered me in the whole process is how the diagnosis was delivered. So the way they told us was really pretty blunt, and hard. Because I mean ... sure, you have to tell the truth but I don't think you have the right to say... she'll die (...) So we've really got "Your child is going to die." There's no hope, there's nothing that can heal her. I found that pretty blunt, so that really got to me. (mother 4)</p> <p>[Name of the physician] was the bearer of bad news, so he was just the "bad" person. That's probably psychological, that played a role. The first conversation where you get the diagnosis didn't go so well. (mother 1)</p> <p>This person tells you something and you just have the feeling, now I have to wake up, this is a stupid dream (...) So actually he brings you a horror story ... bad news and he can't help it, but he just brings it (...) he knows it from the medical side, but he also has to be able to stand up and say "look, it is like that." Well, that takes a lot of courage (...) I gave him a lot of credit for that; that he didn't get lost in wording. That is certainly a competence that not everyone has in this situation, but I think that is very important, isn't it? (father 7)</p>
<p>2.2 A bump in the head or a partial truth</p>	<p>She couldn't talk anymore, she was lying in bed (...), then I told her: "Little mouse (Mäuslein) would you like to know what you have?" And then she rolled her eyes and I tried to explain it to her (...). I painted a circle on her head and told her that there was a bump in her head (...) I told her she has to imagine it like a tower at the airport. There are people and they say that the plane may take off (...) but in the tower there is this bump and it gets bigger and bigger and presses and then the people can no longer say you may take off now or you can land or you may now move your legs. I simply told her that with the radiation we will try to get the bump smaller so that she can move her leg again and talk again. (mother 4)</p> <p>We didn't tell her she was going to die. We did not tell her that. We simply told her she had a brain tumor and that it is difficult to cure. And then she also said "Am I going to die from this?" and then we didn't say "Yes" but just said "everybody has to die some time" (...) She realized that it's possible and that she was getting worse and worse. (mother 3)</p> <p>I also wonder what's the point. What would have been the point of trying to explain to her (...) "you still have a month or 2 years to live." Time is not rational for such a child at this age anyway (...) they live in the moment, so if there is anything concrete to say yes: why this might be the case now, but other than that, I don't think it would help. (father 7)</p> <p>Some psychologist (...) said that we have to tell her [that she is going to die] and we have to educate her. "Have you told her yet?" but I think you're not allowed to tell somebody and you can't do that; you're not a God, you can't say "you're terminally ill" or "you're going to die" (...) that's something I think you just can't say to a child and for us it was good like this "you have a tumor in your head" and "you have cancer" and "we have to see what we do now." (mother 4)</p>

that the treatment decision in itself was "clear" and straightforward (Table 3.1).

### 3.2.2 | Treatment: Purposeless and selfish?

Among the nine families who opted against treatment, most believed treatment would only prolong the child's suffering and that it would be selfish to ask the child to support treatment just to spend more time with the family. Some of the parents compared treatment to a form of

torture or violation. Of the five families that did opt for treatment, only one parent was outspokenly negative and associated treatment with poison due to severe side effects (Table 3.2).

### 3.2.3 | The need to do something

Many parents expressed the need "to do something" or to have at least the feeling that they were "doing something." This desire manifested itself in two different ways: some families, especially if the

**TABLE 3** Treatment decision, no right or wrong answer**3.1 Decision-making: A straightforward process**

I thought "you know what, it's actually good, we didn't have any alternatives" (...) actually it was good, you couldn't do anything. So rather nothing at all, as something and then in the end having a severely handicapped child that dies anyway. (mother 12)

I always say, Jane died twice, on Y (day of diagnosis) and on Z (day of death). The decision-making process has been relatively, how should I say, clear, of course not easy, but clear, because we knew the outcome is fatal, there is no survival. And from that point of view, it was almost, how shall I put it, almost easy. Not easy, but clear, that's how it was. (father 11)

Yes, I have to say, yes it [the treatment decision] was certainly not easy but not difficult either. It's difficult to explain because it was easy, it wasn't so difficult to decide, but it was painful. (mother 13)

Despite the terrible situation (...) maybe retrospectively it was beneficial, it felt good to hear that we, that we don't have to, how should I put it, wrestle for a decision. (mother 5)

The physician really poured clear wine (...) it's been difficult for me, but still, now I am contradicting myself, on the one hand it was clear, on the other hand (...) nobody said "yes, but still try that" or, we've had good experiences with that (...) nowhere was such a possibility left open. (mother 7)

**3.2 Treatment: Purposeless and selfish?**

I think it's the kind of tumor (...) it's terminal (...) I also asked if with this therapy or with (...) another therapy how long it could be, if he had said 10 years or maybe only 3 years, then (...) but I think there have been very few cases (...) normally also with therapy I believe survival time is about 8 months (...) it has been so clear for us (...) to delay it more, would have been more for us as parents, but for the child it would have been just, torture (...) with the radiation he would need a general anesthetic, because he had to be very quiet. (mother 5)

We really felt like this is some kind of poison (...) at some point it was clear to both of us, we are not doing it. We really had the feeling that it was a way of violating the child. (mother 1)

For us, it was clear that we (...) just accompany him until he dies and give him a bit of quality of life. For us, therapy was out of the question. What good does it do to have a child, where perhaps, I do not know, you give him radiotherapy and he feels ill for 4, 5, 6, or 7 months and has nothing left to live and then dies anyway. So yes, that would be a bit selfish, my husband and I shared the same opinion. (mother 12)

If you're sick, (...), you have to be treated (...) you need some treatment, (...) maybe the chemotherapy or the radiation helped (...) to extend time (...) you understand what I mean? It didn't have any good outcome in the long run (...) whenever she came home, she was exhausted (...) she vomited (...) there was nothing human left in her. (...) Just like a dead walking girl. Just alive, just for the sake of living (...) injecting some poison does not help. (father 4)

**3.3 Traditional and alternative treatments****(a) Traditional treatments**

It was immediately clear to us that we had to do something (...) that has actually always been clear, that was never a question. So we actually decided it already at the diagnosis. We told ourselves that we just wanted to do everything that was possible. We thought that this was reasonable for her. She was not so small anymore, was she? (mother 3)

So actually already from the reaction before the biopsy, one could conclude that it would go the wrong way. So between doing everything or nothing ... Well, you can't tell your kid that you're doing nothing. Because the child wants to try to see if it's going to be okay. (father 3)

So actually, very realistic (...) it makes me wonder if there are people who don't do treatment, if it's 2 months instead of 8 or a year (...) I always wondered, who would do it? For me, for the survivors, the other months are very important. (...) Who really says I'm not doing it? That wouldn't work for me (...) then the question afterwards is, how do I tell the child? Doing nothing was out of the question for both of us. Maybe when the child is 2 and does not speak yet (...) it depends on how much the child can still tolerate in therapy (...) but if you receive radiation, every week, that helps the child a little bit, if you try to do something. (father 6)

**(b) Alternative treatments**

You somehow need to have trust, (...) the healer we had, I think she did us (...) good, because you had the feeling that you were doing something (...) retrospectively I cannot really say whether I believed that she was healing Marie, but she did our family a lot of good. So it has also been a kind of psychological care and also somehow the feeling that you do something that might be useful, that certainly didn't hurt. (mother 1)

Well so you just have to have something; if you get such hard news then you just try to find another way or another straw. But in the end, it's more for yourself, so that you have the feeling you're doing something after all, although you know you can't do anything. (father 7)

We tried it once, laying on of hands, or whatever. We figured it wouldn't probably do any good, but if it did, there's no harm in that. They warned us about it (...) But because it was a colleague, I thought one could try it. It is not realistic but there are also things, phenomena, which cannot be explained (...) We thought it would be of no use. But just tried it. Three hours weren't that expensive. (mother 6)

Pongglioma is not curable. Period. All I cared about was how this period of time would be for my daughter. How much she has to suffer. (...) We were of course harassed by some people who then proposed alternatives. (...) I told my wife, she was even more desperate than I, as a mother (...) I always insisted that she would discuss it with Dr. X (name of physician) (...) of course there are also people who are afraid to talk to their doctor (...) There is a lot of money involved in here, you know. (father 9)

**3.4 Involving children in treatment decision**

(Continues)

**TABLE 3** (Continued)**3.1 Decision-making: A straightforward process**

We didn't actually talk to her about treatment options because we simply, well, we didn't know how she would deal with it. How can she picture something like this? (...) we probably could have told her but we did not know what to tell her (...) we treat you and then you die (...) That was incredibly difficult. I realized that with time this child noticed that, she noticed it somehow and we didn't have to talk about it at all. (...) It was simply unnecessary (...) she reacted like a grown-up person and I found that incredible. (father 11)

We actually said that we would do radiation and chemo and then she always said "It doesn't help anyway" (...) with chemo she said very clearly "I'm not taking that anymore" and we accepted that (...) she was extremely afraid to go into the radiotherapy machine (...) so it really took a lot of strength from all of us, from the whole family and friends we came along every time and we motivated her to get in there (...) she always said (...) "I'm only taking this for you," so for her it was clear that this would not help (...) she felt that she was dying, that she would leave and yes she only took this for us, for me and for daddy.

**3.5 No cure, no hope?**

Yes of course I hoped he would heal, but primarily it was about accompaniment. It was clear to me that he would die. So, we tried laying on of hands, because as I said, we had nothing to lose. Miracles do happen. I am convinced of that (...) but being able to accompany him is already a miracle in itself, in retrospect. But no, percentage-wise, I hoped for 100% in a cure while I knew that it was actually 0%. (mother 14)

Healing was ruled out from the start (...) they said 6–9 months, I think 12 max., but more likely 6–9 months (...). We hoped that Sophie could walk again, talk again, we wanted to travel with her (voice trembles). My husband had lost his job, he was home anyway I am a housewife, we had time and we wanted to go with Sophie on great holidays ... yes, our hope was that we have our sunshine (mother cries) still a little bit longer with us in good health. (mother 9)

We believe in eternity and for me it's ok that Mia is with my father and I know that he loves me and that he loves Mia (...) for me she is really at home now, she doesn't have to suffer anymore, she doesn't cry, she is not ill, she is free again, and now waits until mummy and daddy come (...) She plays a lot and is in paradise. (mother 13)

**3.6 Little or no progress**

No, I wouldn't do anything different, it was as good as it was (...) it's still right in retrospect, because otherwise I would have a bad conscience, but what I wished for was that she wouldn't have to die in hospital but she was so bad and, and I think, it was good because they could give her a little bit of oxygen and yes somehow it was good for us too that we had a little bit of the staff there (...) for the medical care. (mother 5)

The question is always, do we do another cycle (...) at some point you notice it's getting worse and worse (...). You always ask yourself, what if we hadn't done anything, but the end is exactly the same. (...) I think I would do it again (...) the extra few months, the extra 6 months, I think it's been valuable. For the child, yes, I think so, but also for myself and for the family. (father 6)

Do we really have the right to decide about another living being? So that's what I asked myself. I mean, we adults simply decide about a child, but we don't even listen to the opinion of the child (...). Sure, I mean today I think sometimes I should have tried it differently (...) maybe she would have had 3 or 4 years longer, but in what condition? Would she still have had her friends? Would she still have been the same person? (...) But when I think back to the way her light shone on me, I have to say that I did the right thing. (mother 8)

You know, the 4 remaining months we had, there was no walking in the park for Sophie... It was bad (starts to cry) terrible... I sometimes think I would rather have an end with horror than a horror without end and I don't know if I would agree to that again (...) I would probably do it again, probably because the hope is so big that you can still do something... But I was of course hoping that Sophie would be in good health and but that was not what happened (...) but probably I would do it again (...) you always hope. (mother 9)

children were a bit older, opted for radiotherapy (sometimes combined with chemotherapy); others sought for some kind of complementary or alternative medicine (like, e.g., bio-resonance, laying on of hands, meditation, spiritual healing, etc.). Some parents decided to try both. Parents who opted for traditional treatment often did so because they did not want to give their children the impression that they were giving up on them. This was especially the case when children were older because they have a better understanding of what is happening.

Parents who tried alternative treatments often reported that although they knew these treatments would not heal the child, they are nevertheless harmless so families had nothing to lose by trying. Others were really upset when people approached them about these complementary practices because they felt as if those persons were taking advantage of their despair to make money. One father believed that parents should address the topic with the medical staff, but feared that many of them would feel uncomfortable doing so (Table 3.3).

**3.2.4 | Involving children in treatment decisions**

Most parents did not explicitly communicate the treatment decision to their children. In their eyes, it was both impossible to tell the child that they would not be treated as to inform them that they would be treated but die anyway. Although parents usually took the lead in the decision-making process, they nevertheless involved the (older) child, for example by letting them choose to continue therapy or not. Various parents also insisted that there was no real need to share the treatment decision with the child as they somehow intuitively knew that there was no cure (Table 3.4).

**3.2.5 | No cure, no hope?**

For none of the families, the decision about treatment was motivated by "therapeutic misconception." Although none of the parental

caregivers, with the exception of one, explicitly talked about palliation or palliative care during the interviews, all parents seemed to be aware that the tumor was fatal and that radio- and chemotherapy could only extend the time of survival. Still, that does not mean that they were not hopeful. Some families (both those who opted for treatment and those who did not) hoped for a miracle, others to maintain quality of life, to reduce suffering, or to have some more time with their children or hoped to meet them in afterlife (Table 3.5).

### 3.2.6 | Little or no regrets

Retrospectively, almost none of the families regretted the treatment decisions they had made. The responsibility of taking a decision for someone else fell hard on parents, but they were convinced to have handled in their child's best interest. Only two caregivers were doubtful about the rightfulness of their decision (although their respective partners were not) because their children had suffered a lot of side effects (Table 3.6).

## 3.3 | Family resilience: One step forward, two steps back!

### 3.3.1 | Loss of independence

The psychological burden for families was huge, both during the illness course and when the child died. One of the most distressing things for parents was to see their child gradually lose all the cognitive and physical abilities they had acquired in the past. The loss of independence was also frustrating for the children and could lead to aggressive outbursts. Parents often felt unprepared to deal with this behavioral change and some of them felt guilty about the way they had dealt with this change. These feelings of guilt often affected their resilience following their child's death (Table 4.1).

### 3.3.2 | Ways of coping

For many parents, it was comforting to know that they had been able to spend extra quality time with their children, and that they had been able to say goodbye. Some of them found support in their faith, others in family or friends, or in the generosity of employers and colleagues. Still, in the aftermath of their child's death, the majority of parental caregivers reported psychological problems. Couples also often dealt with the loss in very different ways and this often put a lot of pressure on the family as a unit. The need to talk about what happened in fact was more outspoken in mothers than in fathers. Women were also more likely to attend parental support groups and to relive happy memories (e.g., by watching photo albums). Some parents were hopeful about the future, but others found it difficult to build up a new life (Table 4.2).

## 4 | DISCUSSION

In line with other studies, we observed that the time of diagnosis is a very distressing experience for families as their everyday life gets suddenly interrupted.<sup>19–23</sup> The main difference with most other cancer diagnoses, however, is that in the case of DIPG, the diagnosis is also a death sentence. This means that whereas other families can live in-between the promise of cure and disease progression,<sup>23,24</sup> parents of children diagnosed with DIPG cannot ward off the certainty of their child's imminent death. This inevitability, together with their child's loss of independence, was for all parents one of the most upsetting aspects of DIPG.

One of the most surprising findings of our study was that for almost all parents, the decision to pursue therapies that may prolong life—though risk toxicities and side effects—was perceived as a straightforward and easy process. They also reported that they felt in charge of that decision. The fact that parents assume decisional priority when treatment outcome is poor and decisions affect quality of life has been testified by other studies.<sup>25</sup> Still, in the case of relapse and disease progression, parents are often confronted with various treatment options that render the decision-making process long and stressful.<sup>26</sup> For many of the families that we interviewed, there was not a real decision to make as they could not choose between two or more treatment options that would potentially save their child's life. As shown by other studies,<sup>27,28</sup> parents often perceive decision-making in pediatric oncology as a kind of “choiceless choice.” However, this feeling is usually associated with the likelihood of cure and physicians' guiding role in choosing the best medical choice. In these potentially curative cases, the feeling of having no choice is mitigated by parents' trust in physicians' medical expertise. However, the parents in our sample could not rely on those professional recommendations for best treatment as no such curative treatment is currently in place. That does not mean, however, that professional teams cannot support parents in making decisions that best align with their values and needs.

Almost none of our participants reported regret about their choice for or against cancer treatment. This finding is inconsistent with other studies that show that regret is a common phenomenon among parents whose child died of cancer.<sup>29,30</sup> Parents might blame themselves of not having recognized the symptoms earlier, of not having chosen the best oncologist, of not having tried everything to save their child, for not having stopped curative treatment earlier,<sup>29</sup> or for not having pursued more or different types of treatment.<sup>29</sup> This discrepancy can be explained by the fact that unlike other parents,<sup>31</sup> our participants were well aware of the fact that there was no realistic chance for cure. This awareness might have enabled them to make a decision in line with their personal values and beliefs. Still, in another study<sup>32</sup> with a similar study population as ours—bereaved parents of incurable pediatric cancer patients—families who had opted for chemotherapy for their own children seemed to feel remorse for their decision as they would not recommend treatment to other families. A possible explanation for this discrepancy with our findings is that most children in our sample who received treatment, received radiotherapy and only a few of them also (mild) chemotherapy. Thus, they might have suffered



**TABLE 4** Family resilience: One step forward, two steps back!**4.1 Loss of independence**

Every step Marie had made during the first 2 years, slowly disappeared again (...) the situation itself is very stressful (...) the child had actually gained independence, now it loses it again in a short time. So it is not in the sense that the child is in much pain (...) just the whole psychological situation, knowing that the child is going to die. (father 1)

When we walked across the street, I gave her my hand, the right hand to be exact, then I felt that she had less strength. ... the symptoms increased (...) it went very quickly (...) the one thing after the other ... And then we hoped that it would go quickly, for her and for us. For her for sure, but I think for us probably too. (mother 11)

It is really sad to see, it is, is really very, very bad, (...) when Maria started to stumble, to walk diagonally, I sometimes grabbed her by the arm and said "walk normally," I was really angry, not at her, but at the tumor (...) it is difficult to accept that it is going downhill, I didn't want to admit it (...) I was actually angry at myself, (...) at some point you just have to accept it, at some point she just couldn't walk anymore, she just crawled (...) it is so creepy, you have to look at her like this. (mother 8)

Suddenly he couldn't lift his arm very well anymore and then he really had to start eating and then suddenly the food and drink ran out of his mouth again and he couldn't do it anymore and he realized everything and he was so independent before. In the first moments, he compensated with aggression and often took it out on me (...) He started hitting me and so I told him very clearly that I could not accept that. (mother 2)

What was very difficult is that Sophie had a hard time, her behavior changed with the cortisone, (...) in the beginning when she could still move, she got angry and she scratched and hit (...) at some point I couldn't bear it anymore and then I said—I am so ashamed about that [mother is crying]—I said, "Sophie, if you don't stop hurting yourself then I tell the nurse to tie you to the bed" and then, she was so helpless and desperate. (mother 9)

**4.2 Ways of coping****(a) Saying goodbye**

We also took time at work, they gave us, we took sick leave, so with the agreement of the employer, and also colleagues, they said no, you have to take your time, you have to take it and, they were really good, that was good. (mother 11)

Retrospectively I have the feeling that it was a good time, (...) we were able to do nice things and say goodbye. So that's what I always have when I hear about an accident or something like that, I always think about the fact that I was allowed to say goodbye and I was able to lie next to my child and be there when he had to go. (father 7)

I think I would do it again. The extra time was great. We went on holiday for a long time and just consciously enjoyed the moment, without saying, "I'm working now, I don't have time to play," just to say: "okay, let's play now." To no longer postpone things. (...) It was actually, stupidly said, a wonderful time. (mother 6)

**(b) Psychological problems**

Afterwards, it is naturally, especially me I have a lot of health problems now, sleeping problems and so. (...) It is a burden after (...) she died in this room, it happened in here and you have to be able to deal with that afterwards. (mother 7)

It [support group] helped me a lot personally, my husband, he didn't want anything to do with it, it helps me a lot to talk, I can talk about Sophie all day long, my husband not at all, zero (...) and when we have a nice evening two or three times a month and talk about Sophie that's a lot. You know I watch videos of Sophie on my iPad, every night before I go to bed or I look at photos, I've made photo books and now I'm going to write a diary (...) a few weeks ago the press reported that chemotherapy in combination with methadone, a German doctor discovered that cancer cells can be destroyed (...) I would have tried everything (...) maybe they could have saved our daughter. I cannot get it out of my head. (mother 9)

I have now noticed there is a difference between how women and men deal with it (...) the men don't talk about it at all. Or they are like, like nothing has happened, or they avoid it a little bit, or they are incredibly afraid to talk about something (...) Sometimes I had suicidal thoughts (...) in the beginning I thought, "what is this? this is not my life here" (...) but now it is somehow gone (...) it's a tightrope walk, you can fall on the other side, with addictive drugs, whatever and maybe some men have more trouble with that. (father 11)

For our marriage, in the beginning, I thought sometimes, when this is all over then we fall apart again, because as a woman just behaved completely different (...) also afterwards, she goes to such a mother group (...) they all tell the same story, men repress it and the women swallow it, badly put. (father 9)

less from treatment compared to the children in the study of Mack and colleagues.<sup>32</sup> That does not mean that the parents in our sample had no other forms of regret. Some felt sorry for being unable to properly deal with the changes in their child's cognitive development and personality, for treating them unfairly, or for lacking patience. Two parents, who had opted for treatment, did feel sorrow for the pain they had put their children through. As unresolved regret negatively impacts the grieving process, healthcare professionals should reassure parents that they did everything within their power to help their child.

Although the decision to treat or not to treat had no impact on the final disease outcome, the great majority of parents expressed the need

"to do something." This desire could take two different forms: some parents opted for radio- and chemotherapy, others looked for complementary and alternative medicine (CAM), and some decided for both. CAM refers to healthcare practices (e.g., dietary and nutritional supplements, homeopathy, spiritual treatments, acupuncture, meditation, reflexology, animal assisted, and music therapy) that are not part of traditional medicine but are increasingly *combined* with conventional medical treatments to counter side effects, manage symptoms, and improve patients' quality of life. For this reason, the term alternative is often replaced by the term integrative.<sup>33</sup> CAM is an integral part of child and adolescent healthcare in Switzerland and is increasingly used

in pediatric oncology.<sup>34–37</sup> Still, overall family doctors seem to be more familiar with CAM than pediatric oncologists who report the use but do give the treatment themselves.<sup>37</sup> The majority of pediatric oncology patients in Switzerland in fact receives CAM from non-medical practitioners or from their parents. This finding is supported by our data and raises important questions about potential risks and abuse if CAM is not prescribed and applied by a CAM-qualified physician. Most parents in our study were positive about CAM, or believed it could do no harm. A few warned about potential fraud and, in line with other studies,<sup>35</sup> expressed the need to receive reliable and nonjudgmental information about it from the treating physician.

Most children who received radio- and/or chemotherapy were older compared to those who did not. This raises the important question of whether and why parents' need "to do something" might increase with the age of the child. Parents often reported that they decided to go for therapy to push back against the impression that they surrendered themselves to the tumor. Failing to go for therapy was perceived as if they were saying to their children that they were giving up on them. This shows that parents need more guidance on how to communicate with and listen to their children when approaching end of life. Children certainly have the right to be involved in decisions regarding their own health,<sup>38</sup> including end-of-life decisions, and many of them do want to be fully informed if their disease progresses.<sup>39</sup> Still shared decision-making (SDM) in the case of DIPG might need to take a different pace given that the illness is terminal from the start and does not give parents and children the time to gradually adapt to the progression of the disease.<sup>40</sup> From this perspective, the SDM experience of parents with a child diagnosed with DIPG might be more similar to that of parents of children with other fatal conditions such as Tay Sachs, Gaucher disease, Krabbe disease, Pompe disease, and even of infants in neonatal intensive care (we thank an anonymous reviewer for this valuable insight). In each of these cases, in fact, the diagnosis is grim from the start; life expectancy is generally short, and therefore a long-term parent–clinician relationship might be missing. Although relatively rare, existing research on SDM in these other fields may inform SDM in the case of DIPG.<sup>41</sup> The healthcare team can lift some weight off parents' shoulders by framing treatment decisions in terms of family's deeply held values and goals (e.g., spend quality time together, protection from suffering, buy time). For this purpose, it is important that they actively listen to families and try to discern their hopes, fears, goals, and values, for example, by paying attention to parents' explicit heuristics (i.e., patterns of language like aphorisms, mantras, or maxims, like e.g., "we will do everything in our power").<sup>42,43</sup> For some families, it might be important to experience the treatment to be able to get a real-life understanding of its impact. However, physicians have to remind families that the decision to start treatment does not imply that they need to continue it if it is no longer in line with their goal of care.<sup>142</sup> Within this regard, it could be interesting to introduce a shared decision horizon that allows families to recalibrate their decisions and expectations.<sup>44</sup> Likewise, the healthcare team should reassure parents that the decision to forego treatment is not the equivalent of "doing nothing." Raising awareness about palliative care as actively taking charge of the child, might make parents feeling less pressured to do "something."

Within this regard, it is quite striking that only one parent explicitly talked about palliative care. Why did none of the other families do so? Among the general Swiss population, the knowledge gap regarding palliative care is still great compared to other countries like the United Kingdom,<sup>45</sup> despite palliative care being an evidence-based standard of care in pediatric oncology.<sup>46</sup> Studies further show that despite high-quality healthcare in Switzerland, important barriers to the timely implementation of pediatric palliative care (PPC) continue to persist and that late and non-referrals are still common in the pediatric oncology setting.<sup>47,48</sup> Swiss PPC providers themselves lament the absence of a well-established, nationwide bridging (inpatient/outpatient) care system that complements familial caregiving at home.<sup>47</sup> Still, in line with other countries, PPC is receiving more and more support from within the Swiss pediatric oncology community itself.

Finally, various studies highlight that parents whose children died from cancer are vulnerable to prolonged grief, depression, stress, and insomnia and need more long-term bereavement support.<sup>49–51</sup> Also, the parents in our sample reported difficulties in dealing with their child's death. Furthermore, in line with previous studies,<sup>52,53</sup> there seemed to be important gender differences in coping strategies between mothers and fathers, especially after the child's death. Mothers often sought opportunities to recall memories, whereas fathers adopted a kind of discreet silence. These different ways of coping might negatively affect relationships. Parents of children who died from DIPG need more bereavement support to deal mutually with their shared loss.

## 4.1 | Strengths and limitations

The study provides unique insight into how families perceive the decision-making process when their child is diagnosed with DIPG and can inform future research to improve SDM in DIPG and other child fatal conditions. Still, it has some important limitations. First, it was a retrospective study; this means that we needed to rely on parents' capacity to recall past events and there is the possibility of a recall bias. It would be extremely valuable to explore parental experiences during the child's illness course, but this would mean interviewing them during a very vulnerable time. Second, our findings are not generalizable to other contexts abroad, as they are based upon a qualitative sample with a relatively small and homogeneous participant group (Swiss nationality and German speaking) and within a specific healthcare setting. This lack of diversity does not allow us to apply our findings to parents with different cultural backgrounds.

## 5 | CONCLUSION

The challenges of DIPG are unique (i.e., lethal from the start; short life expectancy, absence of long-term parent–clinician relationship) and explain why parental and SDM are different in DIPG compared to other cancer diagnoses. To counter the powerlessness coming from the inevitable disease course, many parents opted for CAM to "do

something.” Considering that treatment decisions shape parents’ grief trajectory in the future, clinicians should reassure parents by framing treatment decisions in terms of family’s deeply held values and goals. Palliative care seemed for most parents not a known resource. Our findings suggest therefore that oncology teams should start the conversation about palliative care from the time of diagnosis. For this purpose, palliative care guidelines for DIPG patients should be further developed and bridging care should become a priority in the Swiss oncology setting.

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## CONFLICT OF INTEREST

The authors have no conflicts of interest to disclose.

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