ONCOLOGY: RESEARCH ARTICLE

Pediatric Blood & Cancer

SIOP SOCIÉTÉ INTERNATIONALE D'ONCOLOGIE PÉDIATRIQUE / INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY

aspho The American Society of Pediatric Hematology/Oncology

WILEY

Parents' responses to prognostic disclosure at diagnosis of a child with a high-risk brain tumor: Analysis of clinician-parent interactions and implications for clinical practice

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[Corrections added on 3rd December, 2020 after first online publication: Funding information has been added to the Acknowledgement section].

Funding information
True Colour's Trust; NH, KV, EH, JR,GB and DH's

Abstract

Background: Previous studies have found that parents of children with cancer desire more prognostic information than is often given even when prognosis is poor. We explored in audio-recorded consultations the kinds of information they seek.

Methods: Ethnographic study including observation and audio recording of consultations at diagnosis. Consultations were transcribed and analyzed using an interactionist perspective including tools drawn from conversation and discourse analysis.

Results: Enrolled 21 parents and 12 clinicians in 13 cases of children diagnosed with a high-risk brain tumor (HRBT) over 20 months at a tertiary pediatric oncology center. Clinicians presented prognostic information in all cases. Through their questions, parents revealed what further information they desired. Clinicians made clear that no one could be absolutely certain what the future held for an individual child. Explicit communication about prognosis did not satisfy parents' desire for information about their own child. Parents tried to personalize prognostic information and to apply it to their own situation. Parents moved beyond prognostic information presented and drew conclusions, which could change over time. Parents who were present in the same consultations could form different views of their child's prognosis.

Abbreviations: ATRT, atypical teratoid rhabdoid tumor; DIPG, diffuse intrinsic pontine glioma; HRBT, high-risk brain tumor; MDT, multidisciplinary team meeting; UK, United Kingdom

Conclusion: Population level prognostic information left parents uncertain about their child's future. The need parents revealed was not for more such information but rather how to use the information given and how to apply it to their child in the face of such uncertainty. Further research is needed on how best to help parents deal with uncertainty and make prognostic information actionable.

KEYWORDS

cancer, communication, parent, pediatric, prognosis, prospective studies, uncertainty

1 | INTRODUCTION

Prognostic information about seriously ill children is challenging for clinicians to reveal[1] and painful for parents to receive.[1,2] Yet it is something that many argue is necessary from diagnosis forward for parents to make decisions about care and treatment for their children.[2,3] In interview and survey studies, parents report a desire for additional prognostic information.[1,4]

In order to determine what prognostic information parents were actually given and what further information they sought, we observed and audio-recorded consultations between clinicians and parents at diagnosis of their child. Analysis was directed to the content of what was said as well as the sequences of participants' statements including the responses of clinicians to parents' questions.

This is the first study to use verbatim transcripts of consultations to investigate prognostic disclosure to parents of children newly diagnosed with high-risk brain tumors (HRBT).

2 | METHODS

The data presented in this article are drawn from a larger prospective, ethnographic study of decision making for children diagnosed with HRBT at a tertiary pediatric oncology center in the United Kingdom (UK). All patients discussed at the weekly specialist neuro-oncology multidisciplinary team meeting (MDT) with diagnosis of high-grade glioma, diffuse intrinsic pontine glioma (DIPG), atypical teratoid rhabdoid tumor (ATRT), or high-risk embryonal tumor (previously high-risk CNS primitive neuroectodermal tumor) were eligible for the study.

3 | DATA ANALYSIS

3.1 | Analytic approach

Analysis was conducted from an interactionist perspective,[5] and used analytic concepts drawn from conversation analysis[6–8] and discourse analysis.[9] Analysis was confined to what was said and done in the consultation.

3.1.1 | Analysis

Consultations were observed, audio-recorded, and transcribed verbatim with nonverbal behaviors and contextual detail incorporated from embedded observers' handwritten observational notes.

Analysis was an iterative process, which began with a priori codes drawn from the literature for elements of prognosis including: Survival/Length of Life, Disease Recurrence, Cure/Curability, and Dying/Death.[1,10] Four researchers (Myra Bluebond-Langner, Richard W. Langner, Katherine Vincent, Nicolas Hall) analyzed patterns, structures, and actions grounded within the interactions using new inductively generated codes together with additional codes drawn from the literature. The final coding scheme is detailed in Figure 1.

Constant comparison was performed throughout the analytic pathway, and coding queries were run through NVivo 11 (QSR International qualitative data analysis software).

3.2 | Ethics

Per UK research guidance, data collection methods and procedures were reviewed by the Patient and Public Involvement Group for this project. All were found to be necessary and acceptable.

Advice and support were sought and received from UK Health Research Authority Confidential Advisory Group. The study was approved by the Bloomsbury Research Ethics Committee and the Research and Development departments at both sites.

4 | RESULTS

During 20 months of data collection, newly diagnosed patients and families were identified as eligible for the study at MDT. Eligible families were approached about participation sequentially until ethnographer capacity limited new enrolments. At that point, newly diagnosed cases were approached only if ethnographer resources could accommodate an additional case at the time of diagnosis. Sixteen families were approached and 13 families completed written consent to participate in the study and were followed from diagnosis forward (see Table 1 for patient, family, and household characteristics). Assent was sought

Coding Category	Codes	Type/Source	Description
1.Elements of Prognostic Information	Survival/Length of Life	A priori/Literature: Mack et al 2006, 2007	Any utterance that explicitly mentions life expectancy, survival length of life including how long child/children would/could live, survive
	Cure/Curability	A priori/Literature: Mack et al 2006, 2007	Any utterance with explicit mention of the word cure, curability/curable, incurable
	Dying/Death	A priori/Literature: Mack et al 2006, 2007	Any utterance about death or dying including words death, dying, deceased, died, passed away
	Disease Recurrence	A priori/Literature: Mack et al 2006, 2007	Any utterance about disease recurrence, progression, spread, metastases
2.Statistics and Frequencies	Statistic	Common usage	Population based statistic of cure or survival
	Natural frequency	Literature: Gigerenzer (2011)	Statistic given in the form of, e.g., 10 out of 100
	Qualification of statistic	Inductive	Any utterance mentioning replicability, up to date, or other expression implying statistic may not be accurate, e.g., a caveat
3. Non-Numeric Outcomes	Possible and most Likely	Inductive	Any scenario presented as being most likely to occur using expressions many, most, the majority, often, usually
	Possible but unlikely	Inductive	Any scenario presented as being less likely to occur using words such as few, a couple, some are an exception/exceptional, one of the ones
	Hoped for	Inductive	Any utterance characterizing outcome as hoped for, wished, preferred
	Unfortunate	Inductive	Any utterance characterizing outcome as dispreferred, unwanted
4.Features of Discourse	Framing	Literature: Tversky & Kahneman (1973)	Any utterance in which outcome is presented in terms of survival, living on the one hand or dying on the other
	Good and bad news exits	Literature: Maynard (1997)	Ending a section of the consultation with an item of "good "or "bad news"
	Proximal pairings	Literature: Leydon(2008)	Any utterance in which good news and bad news are delivered in proximity
5.Parents' responses to clinicians	Continuers	Literature: Lehtinen (2005)	Words, interjections, or gestures acknowledging what the clinician has said which allow the clinician to proceed
	Reformulations	Literature: Lehtinen (2005)	Restatement of clinicians' presentation in own words
	Questions	Literature: Lehtinen (2005)	Any question asked by a parent about prognosis
	Personalisation	Inductive	Any question or statement made by parent about the outcome for their child
6.Clinicians' response to parents' questions	Every child different/not possible to say	Inductive	Statement to the effect that population based statistics cannot be used to determine the outcome for a specific child
7. Parental Response to prognostic presentation	(Existential) Dichotomisation	Inductive	Any utterance recognizing that their child faces two mutually exclusive existential outcomes
	Existential Uncertainty	Inductive	Any utterance about not *knowing* what their child's future will be
	Recipes, Heuristics	Literature: Renjilian et al (2013), Parsons and Atkinson (2008)	Expressions used to resolve uncertainty, to make sense of the world, ease the process of assessing values or making a judgment about a course of action

FIGURE 1   Coding scheme

from children and young people as appropriate for their age and condition.

All of the 40 consultations occurring between diagnosis and initiation of treatment were analyzed. No consultations were missed. The number of consultations per case ranged from one to five (mean 3.1). Consultations were led or co-led by 12 different clinicians (see Table 1 for clinician characteristics).

Twenty-four consultations were attended by one parent, 16 by both. Additional family or friends were present at 11 consultations. Though children and young people were present during some consultations, only one adolescent made a statement about prognosis.

4.1 | Prognostic talk in the consultation

The occurrence of talk about prognosis, by either clinician or parent, was identified using four codes mentioned above. Discussion of Survival/Length of Life occurred in all 13 cases, Disease Recurrence in 11 cases, Cure/Curability in 10 cases, and Dying/Death in seven cases. Prognosis codes appeared in all 13 cases; at the first consultation in 11 cases and by the second consultation in the remaining two cases. All four codes occurred in four cases; three codes featured in seven cases; two codes in the remaining two cases. Prognosis was raised first by a clinician in eight cases, and by a parent or family member in five cases.

The four elements of prognosis talk were frequently intertwined as in Figure 2.

4.2 | Clinicians' presentation of prognostic information

We found that clinicians presented prognosis using population-based statistics, descriptive formulations, or a combination of both.

4.2.1 | Prognosis in statistics and numbers

In seven cases, a statistic was given, in terms of population-based statistics or natural frequencies[11] (eg, 10 out of a 100). Both survival and mortality frames[12] were used to present prognostic statistics, sometimes both in immediate succession, (Figure 2, lines 11-14). The subject of the statistic varied, sometimes referring to survival at 1, 2, 3, or 5 years, at other times to cure, or to something less definite, as in "less than five patients who are doing, you know, much better."

Statistics were qualified in various ways using, for example, words and phrases such as "probably," "sort of," or "around about" (Figure 3, examples 1 and 2).

Statistics were also qualified by their presentation in conjunction with additional information. For example, in the dialogue in Figure 2 at lines 9-11, the clinician qualifies the statistic they are about to give at lines 13-14 saying that it applies to an outdated treatment modality. In other cases, clinicians quoted statistics from the treatment protocols they planned to use, allowing that figures from previous studies might not be replicated (Figure 3, examples 3 and 4).

	Elements of Prognosis
	Survival/Length of Life
	Disease Recurrence
	Cure/Curability
	Dying/Death

Commentary:

01	Clinician 6:	So that's where we are.
02	Mother:	What are the, what are the, like, is it statistics? What –
03	Clinician 6:	Yeah –
04	Mother:	- what –
05	Clinician 6:	- the prognosis?
06	Mother:	- what, what are – what's the likelihood of her recover –
07	Clinician 6:	Okay.
08	Mother:	- like, living?
09	Clinician 6:	So historically – and the reason I'm saying historically is that the
10		treatment that we're using now is relatively new so obviously we're
11		hoping it's better. But historically the treatment for children under the
12		age of 3 with ATRT was – the survival rate at 3 years, which we take as
13		a surrogate, was only about 15 or 20 percent, which meant that 80
14		percent of children probably died from their tumour at that time. The
15		early results with the type of chemotherapy – this more aggressive
16		chemotherapy has been better in that – but it's only – we've only really
17		got the results over the past 2 years or so. So it seems that we're –
18		we've made progress but of course what we're – what might happen is
19		that those children might relapse at a later stage. So although, you
20		know, they're actually doing better, that their tumour could come back.
21		So I have to say at the moment we would have to say that there's still
22		more of a chance that ultimately [child's name] could die of this tumour
23		than perhaps be cured, but our cure rates have improved. So we are
24		treating her – or I'm proposing, if you agree, to treat her with curative
25		intent. So the idea is to tr – to cure her –
26	Mother:	<Mother starts to cry and one of the nurses hugs her>

Commentary notes:
- Mother pivots back to prognosis with a question about survival
- Caveat precedes presentation of statistic
- Statistic is framed in terms of both survival and death
- "Possible and most likely" formulation is paired with the "possible but unlikely" formulation

FIGURE 2 Clinician's response to parent's questions about the child's prognosis (Clinician 6; Case 11: 16 months old, atypical teratoid rhabdoid tumor)

4.2.2 | Prognosis in descriptive categories

Clinicians also discussed the prognosis of children in dichotomous descriptive terms. Such talk dichotomized future outcomes. The inductive codes "possible and most likely," and "possible but unlikely," or in an alternative phrasing, "what happens to most children," and "what happens to some children" (Figure 3, examples 5, 6 and 7, 8, respectively) were developed to identify such segments in the consultations. Both formulations appeared together in four cases. The outcome for "most children" formulation appeared in six cases, and the outcome for "some children" formulation appeared in eight cases.

A second set of dichotomous categories sometimes used by clinicians in conjunction with the outcome for the most and the outcome for some was the "hoped for" outcome and the "unfortunate" outcome.

We observed no pattern to the order in which prose formulations were used when they co-occurred in clinicians' utterances. The relatively good outcome[13] was paired[14] as both antecedent and consequent to the relative bad outcome with equal frequency. For example, in Figure 2 (at lines 21-22), the "most likely" outcome ("more of a chance that ultimately [child's name] could die of this tumor") is immediately followed by the more favorable if less likely formulation that she could "perhaps be cured" (line 23).

TABLE 1 Patient, parent, household, and clinician characteristics

Patient characteristics		n = 13
Gender	Female	7
	Male	6
Age at diagnosis (years)	Median	4.8
	Range	0.9-15.7
Diagnosis	ATRT[a]	3
	DIPG[b]	2
	High-grade glioma	2
	High-risk medulloblastoma	6
Individual parent characteristics	n = 21	
Gender	Female	11
	Male	10
Coupled parent characteristics	n = 13	
Marital status	Married	11
	Other	2
English speaking	Yes	12
	No	1
Household characteristics	n = 13	
Religion	Buddhist	1
	Christian - other	2
	Muslim	6
	Not religious[c]	2
	Roman Catholic	1
	Unknown	1
Languages other than	Albanian	1
English known to be	Arabic	1
spoken in the household	Bangladeshi	1
	Mandarin	1
	Polish	1
	Somali	3
	Sylheti	1
Clinician characteristics	n = 12	
Gender	Female	7
	Male	5
Role	Consultant	10
	Registrar	2
Specialty	Oncology	10
	Neurosurgery	1
	Genetics	1

[a]Atypical teratoid rhabdoid tumor.
[b]Diffuse intrinsic pontine glioma.
[c]As stated by family.

4.3 | Parents' responses

4.3.1 | Parents' comprehension

In nine cases, parents made substantive responses[15] (ie, more than a conversational acknowledgment or continuer) to the prognostic information presented by the clinician. In the remaining four cases, parents responded during the clinician's explanations with verbal and nonverbal acknowledgments, which allowed the clinician to continue with their presentation.

Parents' responses reflected appropriate processing of the complex information they had just received by asking a concise question or making a point designed to establish that they had understood correctly. For example, at their initial consultation, the father of one child diagnosed with DIPG condensed over 50 lines of clinician dialogue—encompassing diagnosis, causation, treatment options and their efficacy, and whether the tumor is cancerous or not—into the salient point:

> "Radiotherapy, that is [you're] saying, after a period of time it [the tumor] actually comes back again?"

Parents also demonstrated understanding by reformulating points made by the clinician in their own words. For example, a mother recapitulated the clinician's reservation that the treatment protocol they would use to treat her daughter's ATRT was new and perhaps not curative, when she said:

> "No, because it hasn't been going long enough, you don't know if they, if they're cured because you're waiting to see."

4.3.2 | Parents' drive to personalize

In the majority of substantive responses parents sought to apply prognostic information to their own situation and formulate an individualized prognosis for their child.

Parents designed questions that moved from a disease population to one more closely related to their own situation. For example, the father of one child who had received published information from an American study asked:

> "How many [children treated on the protocol] in the UK?" (Case 13, Father)

Other parents sought information from a specific context, such as the specialist hospital where their child was to be treated:

> "Even at this hospital, it's never been cured?" (Case 1, Father)

Statistics with qualifiers

1. *"…the survival rates are probably somewhere between 30 and 50 percent."*

   (Clinician 12; Case 14: 15 months old, ATRT)

2. *"…we are talking sort of below 30 percent are the chances of surviving."*

   (Clinician 12; Case 5: 11 months old, ATRT)

3. *"I just think that sometimes this [published statistics of treatment protocol] might be a bit overoptimistic."*

   (Clinician 12; Case 4: 5 years old, high-risk medulloblastoma)

4. *"…we don't yet know whether we're going to replicate that [published statistics of treatment protocol]."*

   (Clinician 2; Case 13: 9 years old, high-risk medulloblastoma)

Prognosis dichotomized – "possible and most likely"

5. *"Most children do actually die from this tumor."*

   (Clinician 6; Case 1: 6 years old, DIPG)

6. *"Lots of children die from this disease."*

   (Clinician 12; Case 14: 15 months old, ATRT)

Prognosis dichotomized – "possible but unlikely"

7. *"And there are some children who've had – including at our own hospital – who've had very similar tumors, who've had chemotherapy and are alive several years later."*

   (Clinician 6; Case 12: 2 years old, high-grade glioma)

8. *"Now there is a chance that she can be cured, but that's not a huge percentage."*

   (Clinician 3; Case 9: 15 years old, high-risk medulloblastoma)

FIGURE 3 Examples of clinicians' use of statistics and prose in discussing prognosis with parents

Parents also asked clinicians about their personal experience treating children with the same diagnosis as their child:

> "I don't know if I want to ask the question, but how many survived out of your seven [the seven children you treated]?" (Case 11, Father)

Most parents explicitly asked what the outcome would be for their child (Figure 4, tiles 1, 3, 5; Figure 5, statement 6).

For some parents asking for a statistic and asking about the outcome for their child were posed sequentially as formulations of the same question. For example,

> *Mother*: What are the, what are-there's like is it statistics?
>
> *Clinician*: The prognosis.
>
> *Mother*: What, what are-what's the likelihood of her recover-her living? (Clinician 6, Case 11)

4.3.3 | Clinicians' response: uncertainty

Clinicians frequently responded to parents' questions by invoking the uncertainty of individual-level predictions (Figure 4, tiles 2, 4, and 6). They frequently cautioned that each child is a unique individual; further, prognosis would be contingent upon the response to treatment:

> "So I think everyone's very, very different and we will need to see what kind of response she has to the radio-therapy." (Clinician 4, Case 1)
>
> "It's, it's quite difficult because it depends on whether or not he responds to the chemotherapy." (Clinician 6, Case 12)

Clinicians acknowledged that they simply did not know what the outcome would be:

> "Well I think we have to be a little bit guarded about that because the honest answer is we don't know." (Clinician 5, Case 7)

The message to parents, implicitly and explicitly, was to wait and see. As one clinician put it

> "I think that's all that we can do." (Clinician 4, Case 1)

4.3.4 | Parents' persistence

Some parents persisted in their search for personalized information. In Figure 4 for example, the mother's pursuit of a personalized prognosis is evident. She responds to the clinicians' statements of uncertainty by reformulating the same question about her son's chance of survival on three separate occasions over three consecutive consultations led by two different clinicians. Each iteration of her question is met with the same response from the clinicians:

> "it's difficult" to predict."

4.4 | Parents' application of the clinician's message

In case 1, three findings emerged about parental response to clinicians' prognostic disclosure. First, the parents exhibited the use of what has been termed explicit heuristics or recipes[16,17] (Figure 5, consultation 3). These were used to resolve their uncertainty about their child's future as either "buying time" (mother) or as "after if it all goes well…it could be something very, very good" (father).

Second, the sum of prognostic disclosure did not lead to a single unique application of it to that child, concerning that child's future (Figure 5, consultation 3). Two parents present throughout the diagnostic consultations applied the same information from the clinician differently.

Third, a parent's application changed over time. In this same case while the parents were aligned in the first two consultations, both envisioning the "most likely," "unfortunate," outcome that their daughter's condition is incurable (Figure 5; statements 1-4), by the third consultation they were no longer aligned; the mother's interpretation having remained unchanged during the three consultations. In Figure 5, we see the father's interpretation evolve over 3 days. He moves from a view of his daughter's condition as incurable, to a view that the outcome is not necessarily predictable (Figure 5, statement 5), to a formulation of the unlikely outcome that his daughter could be the exception (Figure 5, statement 7).

5 | DISCUSSION

The goal of this study was to observe in situ what prognostic information was actually given to parents, how it was presented, and parents' voiced responses to the information presented, particularly what else parents wanted to know about their child's prognosis at the time of diagnosis.

We found clinicians' behavior in line with guidance[18] to communicate directly and honestly with parents. Parents of children with HRBTs were told that the majority of children with such tumors do not survive. At the same time, highly unlikely outcomes were not dismissed as impossible or as unrealistic. Clinicians expressly stated that the odds,
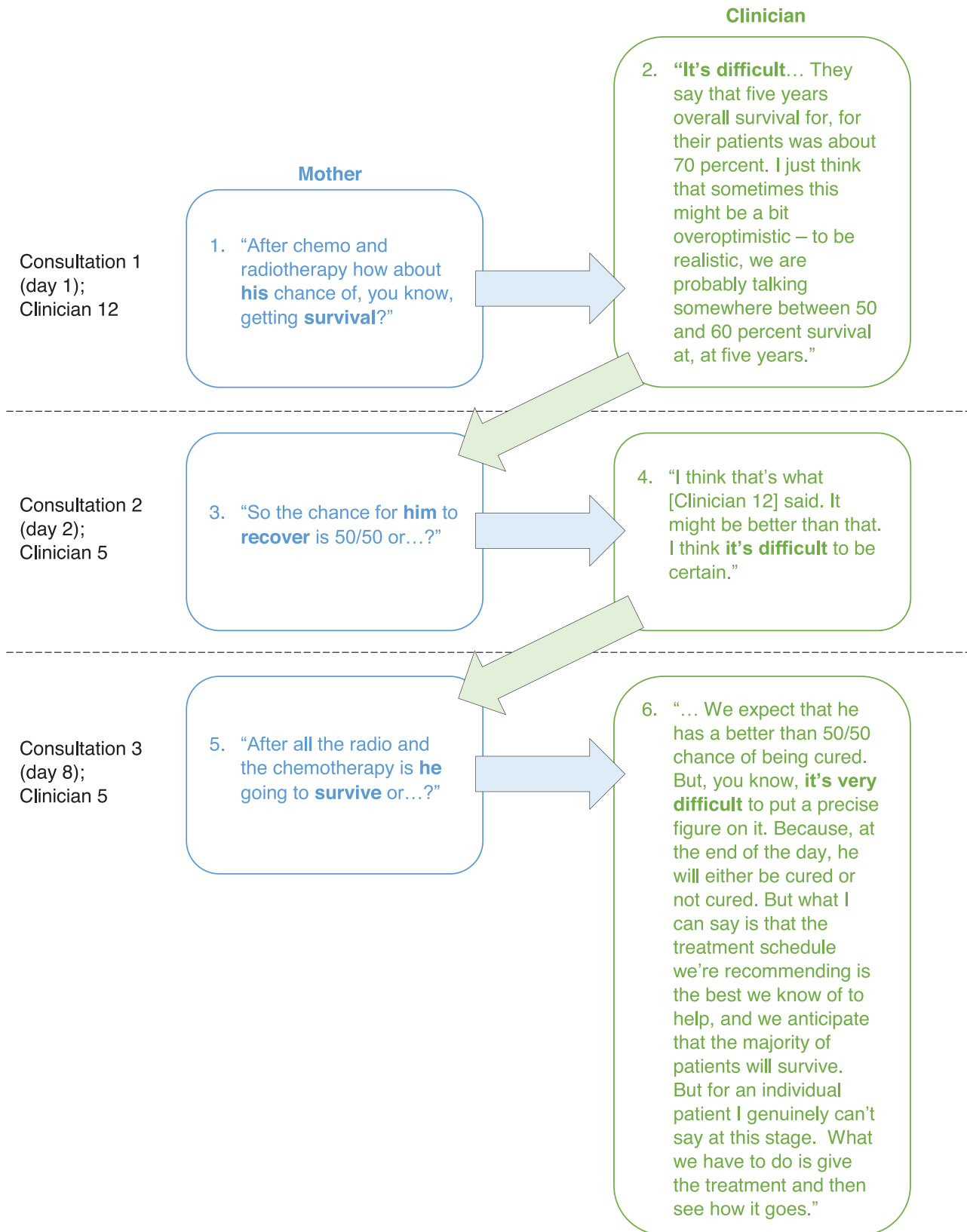
Clinician

Mother

Consultation 1
(day 1);
Clinician 12

1. "After chemo and radiotherapy how about **his** chance of, you know, getting **survival**?"

2. "**It's difficult**… They say that five years overall survival for, for their patients was about 70 percent. I just think that sometimes this might be a bit overoptimistic – to be realistic, we are probably talking somewhere between 50 and 60 percent survival at, at five years."

Consultation 2
(day 2);
Clinician 5

3. "So the chance for **him** to **recover** is 50/50 or…?"

4. "I think that's what [Clinician 12] said. It might be better than that. I think **it's difficult** to be certain."

Consultation 3
(day 8);
Clinician 5

5. "After all the radio and the chemotherapy is **he** going to **survive** or…?"

6. "… We expect that he has a better than 50/50 chance of being cured. But, you know, **it's very difficult** to put a precise figure on it. Because, at the end of the day, he will either be cured or not cured. But what I can say is that the treatment schedule we're recommending is the best we know of to help, and we anticipate that the majority of patients will survive. But for an individual patient I genuinely can't say at this stage. What we have to do is give the treatment and then see how it goes."

FIGURE 4   Common pattern in discussion of prognosis: Parents asking for more patient-specific information, clinician responding with more general statement of prognosis (Clinician 12 and Clinician 5; Case 4: 5 years old, high-risk medulloblastoma)
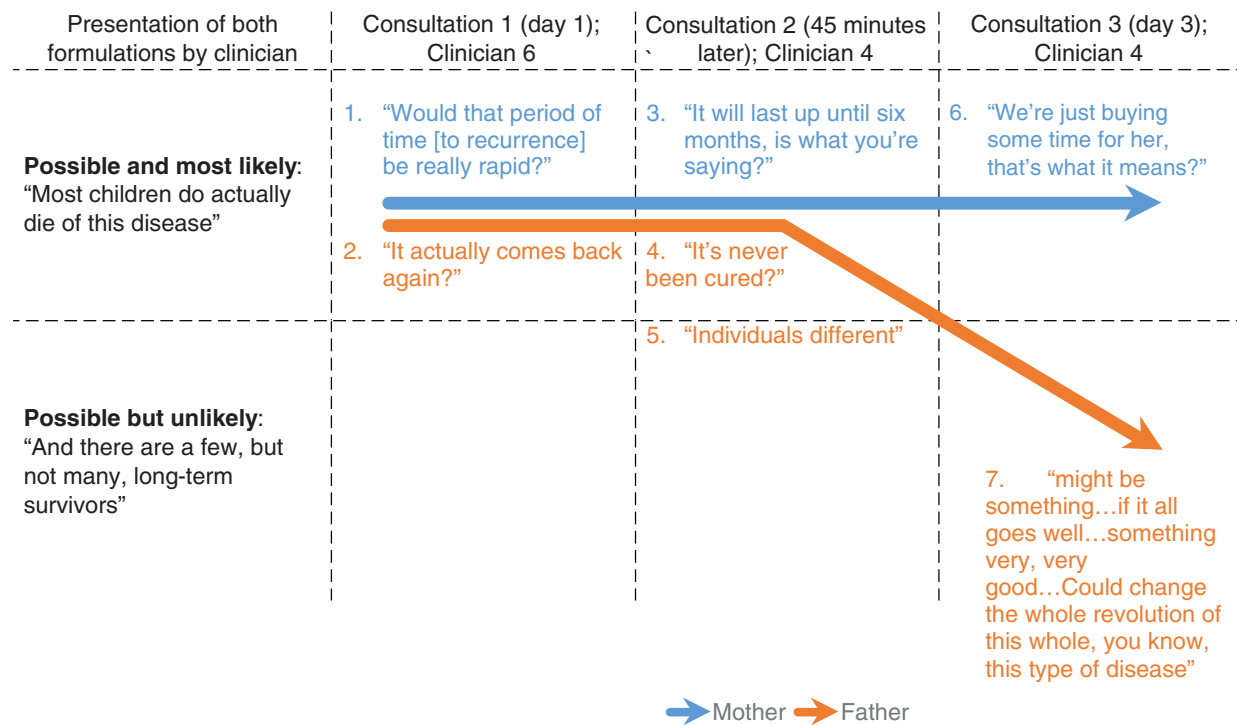
Presentation of both formulations by clinician	Consultation 1 (day 1); Clinician 6	Consultation 2 (45 minutes later); Clinician 4	Consultation 3 (day 3); Clinician 4
Possible and most likely: "Most children do actually die of this disease"	1. "Would that period of time [to recurrence] be really rapid?"	3. "It will last up until six months, is what you're saying?"	6. "We're just buying some time for her, that's what it means?"
	2. "It actually comes back again?"	4. "It's never been cured?"	
		5. "Individuals different"	
Possible but unlikely: "And there are a few, but not many, long-term survivors"			7. "might be something…if it all goes well…something very, very good…Could change the whole revolution of this whole, you know, this type of disease"

→ Mother → Father

FIGURE 5 Differences in parents' responses when presented with the same formulations of the prognosis (Clinician 6 and Clinician 4; Case 1: 6 years old, diffuse intrinsic pontine glioma)

however low, were not zero. Clinicians provided statistics in more than half the cases, but also usually qualified these statistics. None of the clinicians prioritized statistical understanding. They just as often used descriptive categories in talking about the child's prognosis.

The receipt of a poor prognosis diagnosis puts parents in the position of having to redefine their child's and family's future.[19,20] Our findings suggest that prognostic information, including population-level statistics, was not by itself sufficient for parents to use to accomplish this. We observed parents in the consultations moving beyond the information given them to construct a personally meaningful and actionable account.

Through their questions about prognosis, parents searched for personalized information rather than population-based information. They asked about outcomes in the hospital where their child was being treated, about the outcomes of past patients of the treating clinician, and about what was going to happen to their child.

Parents used a binary framework to frame prognostic information. Would their child survive or die? Would it be 0% or 100% for them? Here the numbers are metaphors for something nonnumeric and existential.

Parents focused on a unique, unrepeatable event. Their question was one for which no probabilistic or frequency data about similar events were relevant. As a result, they were left with an unresolvable uncertainty.

The case in Figure 5 illustrates two parents dealing with uncertainty about their child's outcome. They each came to different resolutions between the most likely outcome, that their child would die, and the unlikely though possible outcome, that their child would survive. They

used terse characterizations of the situation: "just buying time" and "a revolution."

Past research in other cancer populations and in other diseases has found parallels to what we observed in these parents of children with HRBTs. Renjilian et al[16] found that parents of children with life-threatening illnesses faced "an irreducible amount of uncertainty."[16(e567)] In such a situation, parents used "explicit heuristics"[16] in the form of aphorisms, mantras, or rules of thumb. These heuristics are distinct from the implicit heuristics of behavioral psychologists[12] in that their goal is not to estimate probability but to "help parents to make sense of the world, ease the process of assessing values and [cast] judgment about a course of action."[16(e567)]

Such heuristics were used by parents to frame the problem, and to imagine and commit to courses of action. In Figure 5, we see such heuristics being deployed. The mother sums up her child's condition and treatment as "just buying time." The father embraces the possible but unlikely trajectory and rests the child's future in the hands of progress in treatment. Each of these is what Renjilian et al[16] describe as an explicit heuristic.

The response of parents of children with HRBTs also parallels what has been found in studies of parents receiving genetic counseling. Recipients of statistics about carrier and reproductive risks translated this information into binary descriptive categories and found themselves in a state of uncertainty about the outcome for their child. They personalized statistical information and made it usable by developing "recipes," which made information actionable rather than paralyzing.[17]

Given the question that parents want to answer, their uncertainty could not be resolved by more robust knowledge or understanding of

the probability or frequency of similar events. Renjilian et al[16] suggest that the heuristics parents elect to use may be linked to what they perceive as required by their role as a parent. The situation in which parents find themselves at diagnosis is that of defining their identity as the parent of a child with cancer. We suggest that parents' interpretation of prognostic information may be part of establishing their changed identity and that of their child. Prognostic interpretation is thus an act that engages parents as both social and moral actors.

It is essential that these parental acts be better understood, because it may be that in transforming statistical information into descriptive, binary categories and personalizing the clinician's prognostic information and making it actionable,[16,17] we may have arrived at an empirically developed account of parents' prognostic understanding, which stands between the clinician's communication and parent's subsequent decisions about their child's care and treatment.

While the sample is small, it is consistent with prevalence and expected referral patterns as well as representative of the HRBT population in the UK where each year approximately 100 children are diagnosed with HRBT. The 16 patients identified by the MDT represent roughly 10% of the total number of newly diagnosed HRBT patients in the UK during the 20-month period. The religious and linguistic diversity of the sample reflects the wider population of patients diagnosed with HRBT in the UK and their families. The sample included parental dyads and was gender balanced: fathers and mothers were recruited and participated.[21]

A primary role of qualitative research is to uncover process, rather than to generate statistically significant findings about populations.[22,23] A number of factors contribute to the quality of the analysis presented here. The data have been collected using what Kaye et al[24] have termed a gold-standard methodology for the investigation of clinician communication. The method of real-time recording eliminates issues of recall bias and insures the accuracy of our accounts of what participants said and did.

Established theories[19,20] and previous research in pediatric cancer and other areas support our analysis of parents' response to prognostic information in that these responses derive from fundamental patterns of response to serious illness. These theories and findings add credibility to our finding that parents facing an irresolvable existential uncertainty about their child's future may resolve this situation through explicit heuristics or recipes that parents employ to define a future for themselves and their child and to repair the disruption of diagnosis of a poor prognosis illness.

Further research is needed to extend these findings to other pediatric cancer and serious illness populations. This would include a search for negative and deviant cases[25] in which for example, in an effort to come to terms with their uncertainty about prognosis, the parent sought more population-based statistics. Through the discovery of such cases we would learn of limits to or conditions which might be placed on the findings presented here.

The aspects of parents' appreciation of prognostic information, which this study has pointed up have implications for the important question of what constitutes optimal clinician communication about prognosis with parents and how to achieve it. There is a critical element of parents' response to prognostic information, which does not fit within the straightforward model of the delivery and uptake of a message of factual information. This additional element is not simply the parents' emotional reaction to prognostic information. It adds social and ethical dimensions as well.

From a clinical perspective, the study also demonstrates the importance of listening to parents' formulations and applications of the information they receive. Recipient's form interpretations of what is said regardless of the clarity of the "message." This independent dimension of the communication process needs further attention in communication research. An exclusive focus on the clinician's use of language and nonverbal gestures in solving perceived shortcomings in clinician-parent communication addresses only one side of the process.

Evidence of parental interpretation and realization can be found within the consultation itself. Learning to recognize these parental contributions is vitally important.[26] Clinicians can on the basis of this understanding better detect parents' specific needs and goals, and engage parents accordingly.

Clinician communication training must therefore address ways of sensitively eliciting parents' points of view. Direct questions may not be the most effective way of helping parents to display their understanding,[27,28] especially at diagnosis. Further research is needed to provide clinicians with resources to facilitate parents' expressing their understanding of their child's condition and prognosis, and what further information they seek.

This study also points up that parents of children with poor prognoses experience fundamental uncertainty at diagnosis. Managing uncertainty, Snaman et al[29] wrote, is an essential part of patient-centered care. Families would benefit from research into how this intractable uncertainty affects daily life and into how adverse effects can be mitigated.

In summary, what is needed to improve clinician-parent communication lies not just in furthering the parent's understanding of the clinician, but in developing the clinician's understanding of the parent as well.

CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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