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Uncertainty, responsibility, and reassurance in paediatric palliative care: A conversation analytic study of telephone conversations between parents and clinicians

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ABSTRACT

Background: Families play a vital role in the day-to-day medical care of children with life-limiting conditions. Navigating their child's symptoms, treatments, and the possibility of sudden deteriorations, presents myriad challenges and can be distressing for the family. Paediatric palliative care can provide crucial support for families who are typically responsible for many aspects of their child's care. **Aim:** To understand how paediatric palliative care clinicians use reassurance to support families through the uncertainties associated with caring for their children. **Methods:** One hundred routine telephone conversations between parents and clinicians of a paediatric palliative care service were recorded and analysed using Conversation Analytic methods. **Findings:** When parents report uncertainty about a specific care task, imply a causal link between this care task and an adverse outcome for their child, and a moral responsibility for the outcome, clinicians respond with reassurance. Clinicians produce reassurance through refuting parents' accounts and providing an explanation to reframe the potential adverse outcome as independent of parent actions. Parents often agree with the clinicians' reframings and demonstrate being reassured. **Discussion:** Specialist paediatric palliative care clinicians routinely foreground support for family members through reassurance. **Conclusions:** This study demonstrates how family-centred care can be accomplished in clinical practice.

KEYWORDS

Conversation analysis, morality, paediatric palliative care, parents, reassurance, responsibility, uncertainty

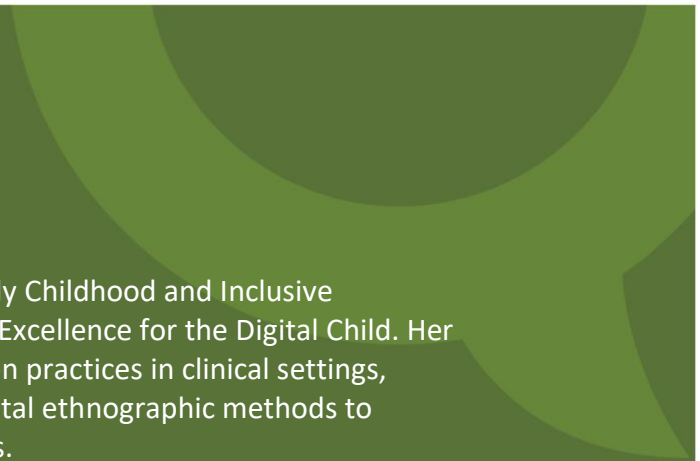
BIOGRAPHIES

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Introduction

When parents learn that their child has a life-limiting diagnosis, it is often the beginning of a campaign for the family. This campaign has a largely unknown trajectory and an indeterminable length. Parents are often the primary carers of these children, and their child's variable condition and changing care requirements can produce uncertainty for parents while they manage certain tasks at home. For many families attending to their child's complex care, paediatric palliative care services provide crucial support. This article examines communication between parents and paediatric palliative care clinicians over the telephone to understand how clinicians use reassurance to support parents who report being confronted with uncertainty.

Literature Review

Effective communication is a vital element in the provision of high-quality end-of-life and palliative support care (Betcher, 2010; Ngo-Metzger, August, Srinivasan, Liao, & Meyskens, 2008). Clinician communication helps patients and families navigate the uncertainty of the illness trajectory and associated day-to-day care tasks. While adult and child palliative care can be similar, there are also many differences (Goldman, 1998; Groh, Feddersen, Führer, & Borasio, 2014). For instance, families of children referred to palliative care are often the primary care providers and choose to care for their child in the home (Hynson & Sawyer, 2001). Additionally, children often have diagnoses with longer and more unpredictable illness trajectories (Bradford et al., 2014; Feudtner et al., 2011). A family's responsibility for their child's changing care requirements can contribute to their uncertainty while managing their child's care.

Uncertainty is an intrinsic part of navigating a life-threatening or life-limiting diagnosis for patients and their families, and clinicians manage the uncertainty that exists in these highly sensitive settings as routine practice. Conversation analytic research shows how interactants can manage sources of uncertainty in conversations (Anderson, Stone, Low, & Bloch, 2020a, 2020b; Cortez, Maynard, & Campbell, 2019; Lutfey & Maynard, 1998; Pino & Parry, 2019; Plastina & Del Vecchio, 2014). For instance, in response to prognostic uncertainty in adult palliative care, clinicians use categorical time references such as 'days', rather than absolute time references such as 'two hours' (Raymond & White, 2017), to deliver prognostic estimates to patients' families (Anderson et al., 2020a). While accommodating this prognostic uncertainty, clinicians may also provide assurances to patients' families about the patient's comfort in their final days (Anderson et al., 2020b).

The prevalence of uncertainty in paediatric palliative care is reflected in clinical guidelines for communicating with patients and families (Bradford et al., 2020). These guidelines address the importance of attending to families' emotions during consultations (Fineberg, Kawashima, & Asch, 2011; Hudson, Quinn, O'Hanlon, & Aranda, 2008), including providing reassurance when delivering bad news (Hudson, Quinn, O'Hanlon, & Aranda, 2015) and following deteriorations in a child's condition (Bradford et al., 2014). A family's uncertainty, however, is not restricted to these matters. Uncertainty can be in relation to the day-to-day tasks

necessary for a child's ongoing care and can become observable when parents' talk relates to their responsibility of establishing their child's consistent wellness, even when maintaining wellness over time is impossible due to the child's condition. Talk of responsibility, especially if it is implied that there has been a potential breach of this responsibility, can bring morality into focus within a conversation (Bergmann, 1998).

The study of morality has been a focus across a range of disciplines, including in psychology and sociology. Common approaches to investigating and understanding morality tend to share three broad features (Cromdal & Tholander, 2012). First, instruments such as surveys or interviews often are used to study morality retrospectively, which overlooks how morality is understood and created by interactants during actual instances of talk. Second, morality is often conceptualised as part of an individual's capacity or character, which negates how interactants construct and maintain systems of morality, or moral orders, within their social interactions. Third, investigations into morality are often framed from a pre-theorised position, such as a duty-based ethical theory (Cromdal & Tholander, 2012). An alternative to these common approaches to understanding morality is exemplified in fields such as conversation analysis. A conversation analytic approach seeks to understand morality by examining how interactants orient to the moral orders underway in their social interactions with each other. This approach shows that moral orders are accomplished and maintained through interactants' engaging in *practices* that create the moral order locally (Danby & Emmison, 2014).

Research on the moral and ethical dimensions of caring for dying children tends to focus on clinicians (Af Sandeberg et al., 2020; Dryden-Palmer, Meyer, Farrell, & Parshuram, 2018; Prentice, Janvier, Gillam, & Davis, 2016). Less attention has been given to parents' attributions of their moral responsibilities, how these may affect their emotional wellbeing, and how these attributions are managed in conversation. Parents, though, do identify the moral burden of difficult aspects of care, such as in relation to strict infection control policies in paediatric intensive care (Evans, Jonas, & Lantos, 2020) and the withdrawal of life-prolonging measures (Fournier, Belghiti, Brunet, & Spranzi, 2017). In relation to day-to-day care, parents in paediatric palliative care report having 'full ownership of responsibility' for their child's care tasks, that then impacts their emotional wellbeing (Collins et al., 2016). There is little known research, however, about how morality and uncertainty are managed in everyday paediatric encounters between parents and their child's healthcare team.

The World Health Organization describes psychosocial support for families as an integral part of paediatric palliative care (World Health Organization, 2014). The scant research in this area, however, has yet to explore how parents may express morality and uncertainty in conversations with clinicians or how clinicians manage their responses to support parents. The current study aims to address this by focusing on instances where clinicians appear to be reassuring parents. This study examines how parents create contexts of uncertainty that make clinicians' attempts to reassure a possibly relevant next action, how clinicians accomplish their attempts to reassure parents, and how parents respond by possibly displaying 'being reassured'.

Methods

At a children's hospital in Australia, clinicians from a paediatric palliative care service audio recorded conversations between themselves and consenting parent participants on the service's 24-hour telephone number. The service's 24-hour number connects referred families to a specialist paediatric palliative care clinician any time of the day or night. All paediatric palliative care clinicians were eligible for participation. Families who were actively engaged with the service were eligible to participate, were sent an information sheet, and asked at the time of telephone contact to participate. Potential participants were excluded if clinicians deemed a family too vulnerable to participate. The children's hospital Human Research Ethics Committee provided ethical clearance for this study (approval reference: HREC/2018/QCHQ/43757).

Recordings were analysed using conversation analysis. Conversation analysis uses recordings of naturally occurring conversations to explain how specific interactional practices are used in particular contexts to accomplish recognisable actions (Heritage, 2011). Conversation analytic research includes conventions for transcribing vocal conduct, including tempo, pitch changes, and silences (Hepburn & Bolden, 2013; Jefferson, 2004). See Appendix A for transcription conventions used within this article.

Results

This article comes from a broader analysis of instances of apparent reassurance provided by clinicians to parents in paediatric palliative care. Over a five-month period, nine paediatric palliative care clinicians recorded 100 telephone calls to and from 34 consenting parents. In twenty-five calls there appeared to be one or more instances in which clinicians attempted to reassure parents. The forthcoming analyses focus specifically on instances of reassurance provided in response to parental expressions of uncertainty about specific care tasks.

A range of apparent reassurance sequences were identified within the calls. The one type considered here demonstrates that parents' expressions of uncertainty about a specific care task, along with an orientation to moral responsibility about the outcome of this task, made clinicians' attempts to reassure a possibly relevant next action. Uncertainty is often understood as an epistemic matter of claiming not to know something sufficiently or at all (Beach & Metzger, 1997; Lerner, Bolden, Hepburn, & Mandelbaum, 2012). It was found that parents may also express uncertainty as it relates to affect (e.g., not knowing how to feel), and to the normative orders of moral responsibility (e.g., that the parents' actions may be accounted for as 'right' or 'wrong'). Parents' uncertainty, therefore, may be expressed as epistemic, affective, or moral, and could be a combination of these. Clinicians' responses to parents' uncertainty about a specific care task were examined to consider whether and how they might be attempting to reassure parents. These actions are summarised in Table 1. Due to the length and complexity of these cases, two fragments are presented as exemplars of the five instances that were identified within the data that included these key actions.

Clinicians never explicitly expressed that they were delivering reassurance (e.g., “I can reassure you that...”). The status of the clinicians’ actions as an attempt to reassure nonetheless seemed *apparent* to the interactants. There are two key ways in which this seemed apparent. First, attempts to reassure seemed apparent by virtue of the consistency of the contexts in which reassurance became a possibly relevant action. In this article, we focused on parental expressions of uncertainty as one such context. Second, the consistently supportive nature of the focal action as a response made its reassuring nature apparent. The instances considered in this article, therefore, are referred to as ‘apparent’ reassurance until parents display ‘being reassured’. When parents’ conduct changed in response to clinicians’ apparent attempts to reassure, such as changing from uncertain to certain language, reduced displays of affect, and displays of gratitude, it was considered a display of ‘being reassured’.

Table 1: Sequence of Parental Uncertainty and Clinicians’ Apparent Reassurance

<p>1→ The parent produces a turn, or turns, that: (a) indicate their uncertainty about a specific care task, and (b) attribute a causal relationship between the care task and a potential, or actual, adverse outcome for their child. The order in which the uncertainty and the causal relationship is expressed is interchangeable. Whichever is produced second incorporates the parent’s orientation to the moral order of responsibility.</p> <p>2→ The clinician refutes the parent’s responsibility for a potential or actual adverse outcome.</p> <p>3→ The clinician provides an alternative account suggesting an alternate cause for the adverse outcome.</p> <p>4→ The clinician reframes some aspect of the care task and proffers an explanation using a declarative statement. (e.g., “whenever you introduce the catheter you are gonna make it [bleed]”)</p> <p>5→ The parent produces a potential indication of agreement or acceptance, followed by a potential indication of reassurance.</p>

Fragment 1, below, is an instance that includes the key actions described in Table 1. It comes from a telephone call that took place after a child has been admitted to hospital due to a deterioration in their condition. Although in hospital, a parent can still administer the child’s ‘as required’ medications as they would at home, although all prescription medications must be signed out by a nurse. ‘As required’ medications are written into a child’s care plan for when symptoms are temporarily unmanaged by the child’s regular, ‘background’, medications. This may happen more often during deteriorations in a child’s condition, as this child had just experienced. The parent called the service to discuss the child’s overall increase in need of symptom management and get updates on changes to the child’s treatment plan:

Fragment 1, PPC190506_1007, 4:29-5:29

1 PAR Sometimes it's ha:rd for us too ta- (0.2) to want to
 2 gi:ve, 'cause a- >yesterday there were a few times where
 3 1a→ I **Really felt that he needed the Midaz and (.) the**
 4 1a→ **hydro morph toge[ther:]**
 5 DOC [Y e :]ah.
 6 PAR 1a→ **That sca:red 'me.'**
 7 (0.4)
 8 PAR U:hm. I didn't wan' to,
 .
 . ((5 lines omitted. Overlapping talk))
 .
 14 DOC .hhh HU:hm:. tchk y'know if you think he needs both
 15 of those together, that's okay? u:hm.
 16 PAR Yea.
 17 DOC And duhm[: m :] [tchk]
 18 PAR 1b→ [**>I just don't] want to< cause [him to] stop**
 19 1b→ **brea:thi:ng, b[ut]** but I guess 'it's just' (' ['])
 20 DOC 2→ [**NO.**] [Well,]
 21 (0.2)
 22 DOC Well <I think, I think, >I I I< I don't think uhm, (0.4)
 23 like I don't think yO:u'll be the o:ne causing hi:m to
 24 stop breathi:ng o:r, or the nursi:ng sta:ff who gives
 25 that medication,=I think .hhhh you know it'll be::,(0.8)
 26 3→ **it'll be:, his: you know u::hm, °.pa° ((lip smack))**
 27 3→ **(0.6) it'll be::, his: little body:, >sort of< u::hm.**
 28 3→ **saying that he's had enough, and his bre:athing cent:re**
 29 [sort of,]
 30 PAR [Ye:ah.]
 31 DOC Yeah so, .hhhh
 32 PAR Ye:a:h.
 33 DOC 4→ **And I guess, we're wantin' tah (0.2) make sh- make sure**
 34 4→ **that that he:'s (.) comfortable at the moment, so::**
 35 4→ **it ↑Is a bit of a balance,** [Jus'] yeah. but [uhm,] Yeah.
 36 PAR [Yep.] [Yep.]
 37 PAR 5→ **'Yep' I agree.**
 38 DOC [Yeah]
 39 PAR 5→ **[We've] got to do it.**
 40 (.)
 41 PAR [I guess] he, needs it.
 42 DOC [Ye:ah.]
 43 (0.2)
 44 PAR Okay.
 45 DOC Yeah.
 46 PAR 5→ **All ri:ght. thanks.**

The extract begins with the parent expressing uncertainty about a specific care task (see action 1a in Table 1), that of simultaneously giving her child two medications: hydromorphone and midazolam (lines 3, 4 & 6). The uncertainty displayed here differs from how uncertainty has been previously considered in conversation analytic literature, which is largely in terms of epistemics (Beach & Metzger, 1997; Lerner et al., 2012; Maynard & Frankel, 2003). Here, the parent displays uncertainty affectively. She reports two differing perspectives about giving her child the two medications simultaneously (lines 3, 4 & 6). The first perspective is that her son needs the medications to manage his symptoms (lines 3-4). This perspective is strengthened using an intensifier 'really' (line 3). Her second perspective is that the prospect of delivering the two medications together 'scared' her (line 6). The parent thus displays intense and differing perspectives, with at least one of these having an affective dimension ("That scared me", line 6). Explaining these differing perspectives accomplishes a display of uncertainty

about the care task. The clinician's next response sanctions the care task and displays confidence in the parent's ability to decide (lines 14-15). The parent continues, however, indicating she has not been reassured by the clinician's sanctioning.

The parent's next turn accomplishes multiple actions (lines 18-19). First, she attributes a causal relationship between the care task and a potential adverse outcome for the child (see 1b in Table 1). Second, she expresses an assumption that administering the medications together may cause her child to stop breathingⁱ (lines 18-19). Although the inference is that the medications may cause an adverse outcome, the parent nevertheless designs her utterance so that *she* is positioned as the agent of the respiratory cessation rather than the medication, "I just don't want to cause him to stop breathing" (emphasis added, lines 18-19). The morality of caring is made visible because the parent articulates the possibility that she may personally cause her child's death.

Directly following the moral ascription of responsibility (Jayyusi, 1984), the clinician immediately refutes the parent's utterance by issuing a firm "NO", which overlaps the parent's turn [lines 20] (see action 2 in Table 1). The clinician's quick response is louder than the surrounding talk and is hearably refuting the parent's proposed moral responsibility. The timing of the clinician's turn and its volume makes the response hearably more direct, or urgent, than the surrounding talk. The clinician's turn could be heard as work to 'seize the floor' (Sacks, 1995). After the clinician's turn, the parent lowers her volume then abandons her turn (line 19), leaving the clinician to speak.

The clinician's ensuing talk supports his refutation of the parent's projected responsibility ascription and her candidate outcome. First, he provides a negative assessment of the parent's position as agent: "I don't think you'll be the one causing him to stop breathing" (lines 23-24). Next, he begins an account to support his refutation, which is the third key action in the focal sequence (see action 3 in Table 1). The clinician refers to the child's body as an alternative cause for when the child stops breathing: "it'll be his little body sort of saying that he's had enough" (lines 27-28). Presenting the child's body as the cause of the child's death absolves those providing care as the cause of this outcome. The clinician thus supports his refutation of the parent's claim by providing an alternate account and absolving the parent. The parent accepts this explanation (lines 30 & 32), and the clinician moves next to attempt and reassure her about the care task itself.

The clinician's first turn ("we're wanting to make sure he is comfortable at the moment", lines 33-34) works to reframe the care task in relation to the morality of a caring parent, from a task that was perceived as a possible risk to one that could be beneficial to the child's comfort (see action 4 in Table 1). Symptom management is a primary goal of paediatric palliative care (Bradford et al., 2014; Ekberg et al., 2019; World Health Organization, 2019). Referring to the child's need for comfort highlights this goal, and the clinician's use of "we're" (line 33) recruits the parent as united with the clinician in working toward this goal. The parent's fear had been potential 'overmedication' (see lines 18-19), but the clinician's reframing transforms the medicating care task to something necessary to achieve a primary goal of care.

The clinician continues their attempt to reassure by employing a declarative statement (see action 4 in Table 1) and using the concept of 'finding a balance' (lines 34-35). Balance phrases seem to work like an idiomatic expression, insofar as they are characterised by a universal, indisputable, quality (Antaki, 2007; Drew & Holt, 1988). The clinician's balance statement, "it is a bit of a balance", refers to the child's comfort from the previous turn (line 33-35).

Achieving a child's comfort, or the relief of suffering, appeals to the overarching priority within palliative care (World Health Organization, 2019), making the claim difficult to dispute. In addition to the clinician's appeal to the child's comfort, the clinician's balance phrase appeals to the jointly framed experience of managing the child's comfort day-to-day, which can sometimes take many adjustments because of the child's delicate and variable condition. Appealing to a jointly framed experience of finding a balance in the child's care taps into the significance of this concept and invites an agreement from the parent. An agreement from the parent could make the closure of this sequence a relevant possibility (Schegloff, 2007).

The parent's next action is agreement with the clinician's claim about finding a balance (see action 5 in Table 1; lines 36-37). She first agrees in overlap with the clinician (line 36). She next explicitly agrees with the clinician about keeping the child comfortable (line 37), and then uses language that expresses more certainty about the previously uncertain medicating care task: "we've got to do it" (line 39). Reassurance is further demonstrated by the parent's move towards a possible closing of the sequence. First, she transitions with an "evaluative" (Schegloff, 2007): "We've got to do it. I guess he needs it" (lines 39 & 41). Next, she produces a sequence-closing third ('okay', line 44), which is a possibly final utterance confirming a mutual agreement (Schegloff, 2007). Following this, the parent thanks the clinician (line 46). The clinician collaborates in the closing, agreeing twice (lines 42 & 45). The parent's willingness to close the sequence with an expression of gratitude after expressing her certainty is further indication of her being reassured by the clinician's sequence of actions.

Overall, the sequence progresses from a display of parental uncertainty to interactional indicators of reassurance about the care she is providing to her child. The parent made reassurance a possibly relevant next action through three core actions: (1) indicating uncertainty about a specific care task; (2) linking an adverse outcome with the performance of the care task; and (3) ascribing responsibility to herself for the adverse outcome. The clinician responded with what could be understood as an attempt to reassure the parent. The clinician did this by: (1) refuting the parent's ascription of responsibility; (2) providing an alternate account for the potential adverse outcome; (3) reframing the care task as necessary and providing an explanation using a declarative statement, which projects agreement from the parent. The parental actions indicating reassurance included: (1) a shift from uncertain to more certain language about the care task; (2) moving to a possible closure of the sequence; and (3) thanking the clinician.

Fragment 2 is a second example of a clinician who attempts to provide reassurance in response to a parent's uncertainty about a specific care task. This fragment exhibits the same general organisation observed within Fragment 1, although there are some differences to the previous excerpt. First, the two parental actions (see actions 1a & 1b in Table 1) are in the opposite order from those observed in the previous fragment. Irrespective of order, these parental actions nonetheless make apparent reassurance by the clinician a possibly relevant next action. These parental actions are thus interchangeable with one another, but still precede the sequence of clinician actions. Second, instead of the parent's uncertainty being about a possible future action, the parent in the following fragment called *after* the care task and a possible adverse consequence occurred. Despite these differences, the clinician works to reassure the parent using similar actions as seen in Fragment 1. The clinician produces apparent reassurance using the actions described in Table 1: (2) refuting the parent's proposed responsibility; (3) accounting for this refutation by providing an alternate cause for

the adverse outcome; and (4) reframing the conduct and using a declarative statement, which makes agreement a relevant next action from the parent.

In the following fragment, the parent has called the service in the middle of the afternoon. The fragment begins shortly after initial enquiries about the reason-for-call:

Fragment 2, PPC190215_1512, 0:14-0:48

1 PAR 1b→ A::hm. I just did a suction up the no:se for him;
 2 and it- a::nd, (0.2) Um got a whole heap of of muck
 3 1b→ out, .hhh but then I made it blee::d.
 4 NUR Oh, [okay.]
 5 PAR 1a→ [I- ehha:] .hhhh I haven't
 6 1a→ [done] anything wro:ng have [I:†]
 7 NUR 2→ [Yeah.] [No:,] no:, no.
 8 3→ that's just, (0.4) and especially if he's
 9 3→ had oxy[g e n .]
 10 PAR [It's jus'] all irri[t a t e d ?]
 11 NUR 3→ [It's going through]
 12 3→ his no:[s e] as well, a::nd u::m. #it-#
 13 PAR [Yeah.]
 14 PAR Ye[ah.]
 15 NUR 3/4→ [Can ma]ke it very dry.=so whenever you do
 16 4→ intro[duce,] (0.4) the: cath[eter] you are gunna=
 17 PAR [Yeah.] [yeh.]
 18 NUR 4→ =make It=is it, (0.4) yeah, [is it] pou:ri:ng, out=
 19 PAR [Okay.]
 20 NUR =or is it jus' (.) som[ething's (not norm-)]
 21 PAR [N o: : it's n o t.]
 .
 . ((10 lines omitted - Parent describes blood))
 .
 32 NUR 4→ Which is gun[na hap]pen un[fortune]ately.
 33 PAR [Yeah.] [y e p.]
 34 PAR 5→ [Y e p o k a y. .h h] He's o::ff the Oxygen=
 35 NUR [Yeah you c'n try to heal it]
 36 PAR 5→ =[no:w,]=he's he holding his SATS=
 37 NUR [Okay.]
 38 PAR 5→ =and not working ha:rd.=He's doing rea:lly we:ll.

The fragment opens with the parent's account of events that lead to the call: a report of a care task, and an account of its outcomes. The parent introduces the care task of suctioning the child's nasal secretions (line 1), expanding her turn to explain a positive outcome of this task (line 2) to perhaps to delay the forthcoming 'bad news'. A feature of bad news is that it can be obscured in some way within an interaction (Maynard, 2003). In this case, ostensibly 'bad news' is obscured by reporting a positive outcome first. After reporting this success, the parent reports a negative consequence: that she made her son's nose bleed (line 3; see action 1b in Table 1).

Following the parent's report of the nosebleed, she then explicitly expresses uncertainty (see action 1a in Table 1) and, in the process, orients to the responsibility of her caring and lack of knowledge about how to do so competently. The parent's uncertainty is made explicit through a claim of insufficient knowledge (Beach & Metzger, 1997). She defers to the clinician's expertise with the question: "I haven't done anything wrong have I" (lines 5-6). This makes her caring relevant, through a request for an assessment (Danby & Emmison, 2014). Through the design of her talk, the parent morally implicates herself in causing an adverse outcome to

the child during a care task: “but then / made it bleed” (emphasis added, line 3). The parent additionally orients to the potential moral implications of her action with the word “wrong” in her question (line 6). Although the parent is asking the clinician to pass judgement on her conduct, the design of the parent’s question appears to anticipate moral absolution. This is because negatively valenced questions, such as “I haven’t done anything wrong have I?”, project disconfirmation as the preferred response (Raymond, 2003).

The clinician aligns with the polarity of the parent’s question and immediately refutes any wrongdoing (see action 2 in Table 1). The clinician’s response is delivered quickly, and in overlap with the end of the parent’s tag question (line 6). The clinician’s multiple repeats (“no no no”, line 7) begin almost immediately after the parent states the word “wrong”. The purpose of multiple repeats produced under a single intonation contour, such as this one, is to stop a line of action that is in the course of being implemented by another party (Stivers, 2004). The clinician thus halts the current activity being pursued by the parent, which questions the moral responsibility of her actions.

The clinician’s next utterance includes an account in support of her refutation of the parent’s ascribed responsibility for the adverse outcome. The clinician does this by offering an alternative cause for the adverse outcome (see action 3 in Table 1): “that’s just, and especially if he’s had oxygen” (lines 8-9). It seems the clinician was going to refer to the child’s nosebleed in a minimising way (“that’s just”) before reformatting her turn to include an intensified formulation (“especially if he’s had oxygen”). Reformatting the turn to use the word, “especially”, is hearably the clinician taking a stance that the oxygen would have a definite bearing on the outcome of the child’s nosebleed. The clinician continues with an account of the drying effect that oxygen flow would have on the child’s nasal passage (lines 11-12 & 15), confirming a line of reasoning already produced by the parent (line 10). Using the child’s oxygen requirement to account for his bleeding diverts the perception of ‘fault’ from the parent by providing an alternate cause for the child’s nosebleed. Now that the clinician has accounted for her refutation of the parent’s ascribed moral responsibility with an alternative reason for the nosebleed, she provides a summarising explanation.

The clinician’s next action is delivering an explanation of her account by using a declarative statement which makes agreement from the parent a possibly relevant next action (see action 4 in Table 1). The clinician asserts, “whenever you introduce the catheter you are gunna make it” (lines 15-16 & 18). Although the statement is left incomplete, the clinician’s use of the intensifiers, “*whenever*” and “*going to*”, displays her certainty of the suction catheter causing a nosebleed anytime it is inserted under these circumstances. The clinician’s certain explanation reframes the cause of the bleed as related to the child’s oxygen flow. The parent would not be at fault for causing the bleed if anytime a catheter is introduced a bleed was *going to* occur. This is instead treated as an unfortunate outcome of performing a suctioning care task on a child who also requires oxygen flow. The clinician then suspends the apparent reassurance sequence to check on the child’s nosebleed (lines 18-20).

Following discussion of the child’s nosebleed (omitted from the transcript), the clinician resumes the reassurance sequence. The clinician provides another certain explanation, characterising the bleed as inevitable and “unfortunate” (line 32). Thus, the clinician resumes the sequence by again making it clear that oxygen flow is the cause of the child’s nosebleed.

The parent’s next turns indicate her agreement with the clinician and displays her reassurance (see action 5 in Table 1; lines 34 & 38). The parent accepts the clinician’s claims about oxygen

and catheters as the cause of the nosebleed, using the term 'okay' which claims acceptance. The 'okay' (line 34) also acts as a sequence-closing third (Schegloff, 2007). The parent further indicates the resolution of her uncertainty by providing an update on the child, which includes a positive assessment of his condition post-nosebleed (lines 34, 36 & 38). She reports that the child is currently off the oxygen flow. This decision is consequential as it reduces the child's risk of future bleeds, however, it could also place the child at risk of losing his blood oxygen saturations, which is the reason he requires the oxygen. The parent, displaying vigilance to the implications of the oxygen removal, reports that his blood oxygen saturations ('SATS', line 36) are stable and the child is not challenged in his breathing. The parent then provides a summary reporting that the child is "doing really well" (line 38). Reporting that the child is first stable, then upgrading to 'really well', is a positive assessment and indicates an affective shift from the uncertainty displayed at the beginning of the call. This positive assessment indicates that her uncertainty has been reduced, thereby reassuring her about the care she is providing to her child.

Here again, the sequence moved from a parent's display of uncertainty to indicators of being reassured. The parent created a context in which reassurance by the clinician was a possibly relevant next action. She did so through three core actions: (1) linking an adverse outcome with her performance of a care task; (2) indicating her uncertainty surrounding that care task; and (3) orienting to responsibility for the adverse outcome. The clinician's response could be understood as apparent reassurance accomplished by: (1) refuting the parent's moral responsibility; (2) providing an alternate account for the adverse outcome; (3) reframing and explaining the outcome using a declarative statement which can facilitate agreement from the parent. Parental actions indicating reassurance included: (1) accepting the clinician's reframed explanation; (2) shifting from uncertain to certain language concerning the state of her child; and (3) positively assessing her child. These actions indicate an alignment with the clinician's reassurance and a shift from considering the negative moral implications of her conduct to a positive assessment of the state of her child.

In Fragment 2, the adverse outcome for the child had already transpired, so there is opportunity to understand how the parent's uncertainty was treated as a priority over the child's nosebleed. In contrast, in Fragment 1 the adverse outcome was a future possibility, so there were only two central problems to which the clinician needed to attend: (1) the parent's uncertainty of the effect of the care task; and (2) her implied moral responsibility. In Fragment 2, however, there were three central problems for the clinician: (1) the parent's uncertainty; (2) the parent's implied moral accountability; and (3) the child's actual nosebleed. Fragment 2 is consistent with an understanding that what is treated as a priority by interactants will precede over other less-urgent matters (Schegloff, 1986). In Fragment 2, the clinician treated the parent's uncertainty and moral responsibility as the interactional priority. The manner in which the nosebleed itself was attended to, established this as a secondary concern. In particular, the clinician only enquired about the volume of blood loss after parental uncertainty had been largely addressed. What this fragment shows is that emotional matters, such as reassuring parents, can take precedence over other matters. This fragment highlights a high level of parent-oriented care associated with the calls to the service.

Discussion

This article is the first systematic study of how reassurance is made relevant, produced, and responded to within interactions between clinicians and families about the care of children with life-limiting conditions. This study found that when parents called the paediatric palliative care service, clinicians may manage parents' accounts of uncertainty about specific tasks using a series of practices that could be understood as attempts to provide reassurance. During some calls to the service, parents reported uncertainty about specific care tasks to imply potential, or actual, adverse outcomes of these tasks for their child. They also indicated their agency in these adverse outcomes and, by extension, oriented to the moral order that ascribed the parent as having responsibility for the care of their child. Their implied breach of the moral order of caring was made relevant when parents spoke about their care in a way that implicitly or explicitly sought clinicians to 'pass judgement'. Clinicians' ensuing talk recurrently provided alternate accounts and used declarative statements that absolved the parents of responsibility for a potential or actual adverse outcome. Clinicians' transition to declarative statements in their explanation projected parental agreement as a relevant next action. Within the collection of cases analysed for this study, parents often agreed or accepted the clinicians' accounts and moral order reframing which suggested they were reassured. In paediatric palliative care, parents experience moral distress in decisions made around their child's death (Evans et al., 2020; Fournier et al., 2017). The present analysis is the first to underscore the fundamental moral work done by parents relating to the everyday care of their child, and how this morality is demonstrated within parent-clinician interactions. Consistent with previous research showing that interactants actively monitor the moral order of a conversation (Stivers, Mondada, & Steensig, 2011), parents and clinicians in the current study oriented to the moral implications associated with uncertainty about specific care tasks.

Morality underscores all social interaction, but it is only through particular actions that interactants make it observable (Bergmann, 1998). In the calls examined here, parents made moral orders observable through ascriptions of responsibility for an adverse outcome. Parents of very sick children report feeling great responsibility for their child's experiences, and 'full ownership of responsibility' for their child's care tasks (Carnevale, 2007; Collins et al., 2016). In the calls examined in this article, parents oriented to a moral order of responsibility and care by treating themselves as the agent of a possible, or actual, adverse outcome of a care task. In the current analysis, parents expressed their responsibility to a particular recipient, a clinician specialising in the provision of paediatric palliative care. These clinicians used their expertise to attempt to reassure parents' uncertainty and absolve parents' ascribed responsibility.

The World Health Organisation's definition of paediatric palliative care is holistic, including the treatment of physical, psychosocial and spiritual pain for the patient and their family (World Health Organization, 2019). A responsibility of a clinician is to care for a child using their training and expertise, and an extension of caring for the child is a responsibility to care for parents (Jones, Contro, & Koch, 2014). One way this is accomplished in paediatric palliative care, as demonstrated in this article, is by providing reassurance. There are related ways of caring for patients' families found in adult palliative care. For instance, in adult hospice care clinicians may follow prognostic claims to family members about end of life approaching with assurances about what the clinicians can do to ensure a patient's comfort (Anderson et al., 2020b). Both assurances of what can be done and reassurance about what is already being

done are instances in which holistic care is accomplished, encompassing both a patient and their family.

Attending to the family of a patient takes time, and this article has shown that clinicians from this specialist paediatric palliative care service do not evade or devalue the emotional care that the parents of referred children require. Understanding precisely how specialist clinicians care for the changing needs of children, while also caring for parents' myriad practical, moral, and emotional needs, affords insights into how clinicians provide reassurance in a challenging clinical context. Understanding what makes reassurance relevant, as well as the specific actions that constitute apparent reassurance, can develop a deeper understanding of what reassurance is, how it works, and how it can be effectively used in diverse settings.

Conclusions

Parents of children referred to the paediatric palliative care service face tremendous uncertainty while performing the myriad tasks they undertake each day to manage their child's complex condition. Uncertainty about these tasks can be a barrier to parents' emotional wellbeing, and parents report instances of uncertainty about care tasks in their interactions with clinicians. In response, clinicians may target parents' emotional wellbeing as an interactional priority. This article demonstrates that clinicians will sometimes provide an alternate account when parents assume moral responsibility for an adverse outcome of a care task. Clinicians may also reframe some element of the care task and use a declarative statement about an underlying priority of care to provide moral absolution and garner alignment from the parent. Parents routinely respond to these actions with indications they have been reassured. This analysis shows how expert clinicians communicate carefully and sensitively with parents, as they work together to provide the best possible care for dying children.

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Endnotes

¹This assumption is likely because both medications (lines 3-4) have side effects of respiratory depression (Montravers, Dureuil, Molliex, & Desmots, 1994; Pattinson, 2008). It is a common misperception that appropriate palliative doses of opioid analgesia can cause unconsciousness and even respiratory cessation (Berger & Vadivelu, 2013; Grant, Ugalde, Mancuso, Vafiadis, & Philip, 2017).

Appendix A

Supplementary Material: Transcription Conventions

Temporal dimensions

Wo[rd]	Square brackets mark speaker overlap, with left square brackets indicating overlap onset and right square brackets indicating overlap offset.
[Wo]rd	
Word=word	An equals sign indicates absence of discernable silence between two utterances or actions, which can occur within a single person's turn or between the turns of two people.
Word (0.4) word	A number within parentheses refers to silence, which is measured to the nearest tenth of a second and can occur either as a pause within a current speaker's turn or a gap between two speaker's turns.
Word (.) word	A period within parentheses indicates a micropause of less than two-tenths of a second.

Verbal conduct

Word.	A period indicates falling intonation at the end of a unit of talk.
Word,	A comma indicates slightly rising intonation.
Word¿	An inverted question mark indicates moderately rising intonation.
Word?	A question mark indicates rising intonation.
<u>Word</u>	Underlining indicates emphasis being placed on the underlined sounds.
Wo:::rd	Colons indicates the stretching of the immediately preceding sound, with multiple colons representing prolonged stretching.
Wo::rd	Underlining followed by one or more colons indicates a shift in pitch during the pronunciation of a sound, with rising pitch on the underlined component followed by falling pitched on the colon component that is not underlined.
Wo:rd	An underlined colon indicates the converse of the above, with rising pitch on the underlined colon component.
↑Word↑	Upward arrows mark a sharp increased pitch shift, which begins in the syllable following the arrow. An utterance encased with upward arrows indicates that the talk is produced at a higher pitch than surrounding talk.
WORD	Upper case indicates talk produced at a louder volume than surrounding utterances by the same speaker.
°Word°	Words encased in degree signs indicate utterances produced at a lower volume than surrounding talk.
>Word<	Words encased with greater-than followed by less than symbols indicate talk produced at a faster pace than surrounding talk.
Wor-	A hyphen indicates an abrupt termination in the pronunciation of the preceding sound.
.hhh	A period followed by the letter 'h' indicates audible inhalation, with more letters indicating longer inhalation.
(word)	Words encased within single parentheses indicate an utterance that was unclear to the transcriptionist. Unfilled space within the

parentheses indicates that it was not possible to identify a possible hearing of an utterance.



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