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Discussing death: Making end of life implicit or explicit in paediatric palliative care consultations

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ABSTRACT

Objective: To consider whether and how family members and clinicians discuss end of life during paediatric palliative care consultations.
Methods: Nine naturally occurring paediatric palliative care consultations were video recorded and analysed using conversation analytic methods.
Analysis: Focusing on three consultations in which end of life was treated as a certain outcome, analysis explored ways in which end of life was made either implicit or explicit within these consultations. Our analysis suggests that end of life was made explicit when: 1) ancillary to the current focus of discussion, 2) in relation to someone else's child, or 3) specifically relevant to the local context of the discussion. More commonly, in all other instances in the data, end of life was made implicit during discussions relating to this matter.
Conclusion: This preliminary research indicates that the local context of a conversation can influence how end of life is mentioned and discussed.
Practice implications: Clinicians often are encouraged to promote honest and 'open' discussions about end of life. Our findings show that it is not necessary to explicitly mention end of life in order to discuss it.
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1. Introduction

In the suburbs of an Australian city, a doctor and nurse from a paediatric palliative care service are visiting a family for the second time in a week. Sitting with the family in the backyard, they discuss a nine-year-old boy who is inside the house. Half an hour into their conversation, and shown in Table 1, the boy's future becomes their focus.

Here and elsewhere, the parties to this conversation seem to be discussing the end of the boy's life. However, neither 'death,' 'dying,' nor a euphemistic version of these terms, were used in the preceding moments. The last explicit reference to end of life was three and a half minutes earlier (see Table 7 below). Nevertheless, each party to this interaction appears to understand that the mother has referred to her son's end of life. By considering conversations such as this, our goal is to understand the ways that people discuss dying and death without necessarily using such terms. Throughout this article, we use the term 'end of life' to encompass the range of ways that people discuss these existential states.

Over recent decades, sustained debates have focused on whether contemporary societies – at least in the West – are 'death-denying' or treat death as taboo [1–9]. These debates include universal claims applied to entire societies to limited claims about individuals, groups, or circumstances. Some researchers, usually sociologists, argue that such claims are typically simplistic and reductionist [1–7]. Other researchers, often writing with a clinical perspective, focus on the denial of death as a tangible obstacle to effective care [4]. Such research informs clinical guidelines. For example, clinicians are encouraged to speak

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Table 1
C9/31:46-31:57.

```
01 MUM:   [>But I< s:til]l don't think it's long.
02        (.)
03 DOC:   Ye:ah no I'd- uhm you kno:w,=yeah >I have to agree< with you,=[>that's a<] (.) very .hhhhh
04 AUN:                                                                  [   M  m   ]
05 MUM:   (°We're- (.) talking-°)
06 NUR:   Tr:us:' your o:wn: ins:[tincts I] [th:in]k,
07 DOC:                          [ M m m .]
08 AUN:                                    [ Mmm.]
```

'openly' about the end of life, and are suggested to do so with practices such as avoiding euphemisms and, wherever possible, using the words 'death' and 'dying' [10,11]. This ongoing debate therefore has important implications for clinical practice.

A major gap in the debate about the interpersonal dimensions of death denial and death as taboo is that little of the cited research involves detailed analysis of naturally occurring social interaction, either in everyday or clinical settings. Given that interactions with others is a fundamental dimension of human society [12], and is central to clinical practice [13,14], social interaction provides an important domain for exploring how people discuss the end of life. Fortunately, the special section of *Patient Education & Counseling* that this article contributes to indicates that a body of evidence is emerging that fulfils this aim.

Studies of naturally occurring social interactions highlight that end of life can, but need not necessarily [15:174–175], be discussed 'delicately' [16] or 'cautiously' [17]. Moreover, because these discussions are the collaborative outcome of contributions from two or more parties, 'cautiousness' can vary between conversations [17]. One relevant factor appears to be whether a dying or deceased person is represented as a consequential figure. People appear to discuss end of life differently when the dying or deceased person is represented as significant to one or more of the parties to a conversation [18,19]. When discussed in clinical settings, where consequential figures are usually present, existing research shows that discussions about end of life typically are implicit rather than explicit [17,20–23]. In these contexts, end of life tends to be discussed implicitly, using practices such as pronouns or euphemisms, expressing concern, or referring to people in general rather than a specific person [23]. Most of this existing research, however, focuses on adult patients, consultations that involve attempts to deliver a life-limiting diagnosis, and practices that are used by clinicians. This article offers a different perspective by: 1) considering practices that are employed by healthcare users as well as clinicians, 2) investigating consultations concerning child patients, and 3) focusing on practices that occur sometime following diagnosis of a life-limiting condition.

2. Methods

A total of nine consultations involving eight families were video recorded within a single paediatric palliative care service. Consultations were conducted in a variety of settings: inpatient, outpatient, telehealth, and home visits. The same paediatric palliative care specialist was involved in each consultation. Some consultations involved additional medical, nursing, and allied health professionals.

The Children's Health Queensland Hospital and Health Service Human Research Ethics Committee provided ethical clearance (approval reference: HREC/14/QRCH/363). Each participant provided their informed consent to participate; parents consented for their children. All participants authorised publication of transcripts of the video recordings made for this study. Pseudonyms are employed where this has been requested by participants. The names of all non-participants who were referred to by name in the consultations were replaced with pseudonyms.

Conversation analytic methods were employed for this study. This approach included established conventions for transcribing vocal [24] and, where it was determined to be potentially relevant, embodied conduct [25]. Appendix A provides a list of the transcription symbols. Further study details have been reported elsewhere [22].

The current study focuses on the ways that healthcare users and clinicians make end of life either explicit or implicit within a conversation. For many instances, although not all, our analysis builds on existing conversation analytic research that has investigated how people design reference within social interaction. Reference enables participants to establish or maintain particular ontological categories [26] – in this case, existential states such as dying and death. Typically, however, such references are not the primary focus of subsequent contributions to an interaction [27], which precludes the use of the common conversation analytic method of examining responses to understand how participants make sense of the focal phenomenon. Instead, we adopt the conversation analytic methods of: 1) exploring ways in which participants make end of life either explicit or implicit, and 2) the local context of an interaction in which end of life is made explicit or implicit [28].

3. Analysis

Our analysis focuses on a subset of three consultations where end of life is treated as a certain outcome. The child patient was not physically present in these three consultations. Across these three focal consultations, there were thirteen instances where a family member (n = 11) or clinician (n = 2) appeared to make end of life implicit. In addition, there were seven instances where a family member (n = 4) or clinician (n = 3) made end of life explicit, using either a variant of 'death' or 'dying' or an apparent euphemism for one of these terms (e.g. "when he passes"). Our analysis suggests that end of life was not made explicit unless: 1) ancillary to the current focus of discussion, 2) used in relation to someone else's child, or 3) specifically relevant to the local context of the discussion.

3.1. Making end of life implicit

In this section we focus in instances in which end of life is made implicit rather than explicit within a consultation. The implicit practices that we consider reflect a principle of circumspection, which involves the systematic avoidance of explicit reference [29], in this case to end of life. Given that the majority of instances involved a family member making end of life implicit, we focus on these here. Table 2 presents the first instance. It comes from a consultation involving a mother and the paediatric palliative care doctor. Although the mother does begin by making end of life explicit (line 1), she does so in relation to someone else's child. Moreover, the design of her reference to this other child does not depict this person as a consequential figure [18,19]; she does not, for instance, identify her referent by name. Across this fragment,

Table 2
C6/2015-05-13/32:52-33:48.

```
01 MUM:   =°the littl-° (.) the youn:g la:dy opposite died [didn't she]
02 DOC:                                                    [  Y↑eah.↑ ]
03        ΔYeah.=
   mum:   Δraises hands to place tissue over nose--->
04 MUM:   =An:d, .hh (.) Δpwhhh! >you know,< (.) ~thΔAt's ha:rd~ Δtoo
                    -->Δblows then wipes nose-----Δ,,,,,,,,,,,,Δ
05        be[caus:e] (.) he:r parents:: (0.6) .hhh °you kno[w,°]
06 DOC:     [ Yeah.]                                     [  Y]ea[h .  ]
07 MUM:                                                        [ (°it] would°) just (.) hope,
08        <like they s[:aid you're t]o:ld >so many< ti:mes, this- (.) >this is< probably it.=This is
09 DOC:               [  Y e a h .  ]
10 MUM:   probably i:t.=She got to eighteen: and then[:]
11 DOC:                                            [Y]eah.
12 MUM:   it really was:=>and I could< see them: s:aying, .h ↓oh I better go and do: this,↓ cos
13        we're gonna be home soon,=>and we're going-<.hh (.) and I thought that's ri:ght, you
14        go[t-]
15 DOC:     [ Y]ea[h. ]
16 MUM:           [you] ca:n't s:ay (0.8) you know even I cud see that she was f:ailing:,
17 DOC:   Yeah.=
18 MUM:   =and I didn't know 'er medically,=but I >could j[us'< under]sta:nd that you weren't even
19 DOC:                                                  [ Y e a h. ]
20 MUM:   putting any food in: but (.)
21 DOC:   Yea[h.]
22 MUM:      [ a]ny l:iquid,
23        (0.2)
24 DOC:   Yeah.
25 MUM:   °you were,° (.) .mph an:d (0.4) >but her< dad was: jus' carrying on:, an:' [>I got to<]
26 DOC:                                                                            [ Y e a h. ]
27 MUM:   phone ↓so and so because gotta sort that out.=And >we gotta-<↓ meaning: to ↑for l:if:e,↑
28        to carry on.=
29 DOC:   =Yeah.=
30 MUM:   =>And I thought,< I bet that is what we do:, becau[se]
31 DOC:                                                  [ Y]eah.
32 MUM:   you've told us: a f:ew times:, Lizzy, >you know,< (.) this is it,
33        (0.2)
34 DOC:   Mm[m. ]
35 MUM:     [>So] when it< finally does come I think I:'ll probably think ↓o:h here >we go again.<↓
36        Hopefully this is:- cos you don't [want to] accept- (.) (that.)
37 DOC:                                    [ Yeah. ]
```

this reference to 'the young lady opposite' is only time that end of life is referred to explicitly. Through this explicit reference, the mother invokes a type of 'state category' [30:V1:57–59] that can be used to categorise people. Along with other types of state categories, such as being 'well' or 'unwell', the state of someone being at end of life can be made relevant and maintained across a spate of interaction. By maintaining this state category, the mother is able to subsequently discuss her own child's end of life without explicitly referring to this outcome.

In this fragment, the mother maintains the relevance of the category 'end of life' through the use of a series of pronominal references using the word 'it' [26,30,31]. The initial use of these references, at lines 8, 10, and 12, refers to the end of life of 'the young lady opposite.' The same pronouns are used again, sometime later (at lines 32 and 35), in reference to the mother's child Lizzy (see lines 30–36). Because there was no reference to another event in the intervening period – or, for that matter, any other domains of referents [26] that could be referred to using this pronoun (e.g. an object) – the most recent reference that these pronouns could refer to is the state category 'end of life' [30].

There are additional practices in this fragment that help connect the initial reference to the past death of 'the young lady opposite' and the future death of Lizzy. For instance, the modified repetition of the phrase 'you're told so many times' (lines 8) as 'you've told us a few times' (line 32) and 'this is probably it' (line 8) as 'this is it' (line 32) depict the two families as facing the same scenario in relation to the state category 'end of life'. These repetitions help specify which initial reference the pronouns refer to [30:V1:722–723]. Because the scenario is the same, an explicit reference to end of life on the second occasion is not necessary. Thus, by maintaining the state category 'end of life', the mother is able to refer to her daughter's end of life without explicitly referring to this existential outcome.

The fragment in Table 3 illustrates another way of making end of life implicit within a consultation. There is no specific reference to end of life at any point in this fragment or the immediately preceding discussion. Nevertheless, this existential state is made implicit through listing activities that can occur across the end of life period. Prior to the beginning of this fragment, the mother and father have been obtaining a professional opinion about their child's prognosis from his neurologist[1]. Although the neurologist explicitly referred to end of life during the preceding discussion, this was over three minutes earlier and was in relation to death as a universal possibility for people who experience seizures rather than a certain outcome for this specific child. Having apparently received the neurologist's professional opinion to her satisfaction, the mother explicitly closes down this prior activity with her

[1] A paediatric palliative care specialist is present, but does not speak, during this fragment.

Table 3
C8/2015-07-16/11:30-11:57.

```
01 MUM:   =Okay.
02        (0.3)
03 MUM:   So,
04 SIB:   E:a[:  :  :  y  :  : - y  i  :  h - y i : h  ]-ya:h=
05 MUM:      [pretty much our dec:isions have been that]
06 MUM:   =that we: don't want any: (0.3)
07 DAD:   N:o resus at this [s:ta:ge.]
08 MUM:                     [No:  re:]sus::, (.) no: in:vasive >sort of< tu:bes down the [throat o]r
09 NEU:                                                                                  [Y e a h.]
10 MUM:   a:nything li:ke tha:t, .hhh we'd like wa:rd ca:re, (.)
11 NEU:   Right.=
12 MUM:   =U:[: h m : ,  ]
13 DAD:      [And pref:er]ably a cha:nce to take him home.
14 NEU:   Y[eah.]
15 MUM:    [ Yea]h. Yeah.
16        (.)
17 MUM:   U:hm, we do: want to do: (.) u:hm some tissue dona:tion if possible¿
18 NEU:   °Sure.°=
19 MUM:   =And we a:lso want to donate his brain: ((continues))
```

utterance at line 1 [32,33]. She lists the family's preferences for their child's care, using 'so' (line 3) to indicate that what follows[2] is an upshot of the preceding discussion [34]. It is in this context that end of life is made implicit through the mother's and father's talk.

The mother provides details of her care preferences across two lists. Consistent with the usual design of lists [35], each of these lists is organised into three parts. The mother's first list contains resuscitation (line 8; first mentioned by the father at line 7), invasive intubation (line 8), and a generalised list completer ("or anything like that", lines 8 and 10). This first list therefore indicates actions that the family do not wish to be undertaken. The mother's second list (lines 10–19), which is interposed by the father's contribution at line 13, indicates that ward care (line 10), tissue donation (line 17), and brain donation (line 19) are activities that the family would like to occur.

Listing provides a device for inductively identifying a particular class that may not be made relevant by any individual item on that list [36,37]. In this case, the combined contents of these lists contain activities that relate to the state category 'end of life'. Although the items on the first list and the initial item on the second list (ward care) could occur during life-threatening circumstances from which recovery is possible, what follows indicates that the mother is not describing this circumstance. From line 17 onwards, she lists activities that can only occur towards, and following, her child's end of life. The mother's lists thus makes end of life implicit without this existential state needing to be explicitly mentioned.

Many of the instances in which end of life is made implicit are more allusive than those considered above. The fragment in Table 4 is one such instance. This interaction involves the child's mother, his maternal grandmother, his maternal aunt, and a family friend, along with a doctor and nurse from the paediatric palliative care service. The fragment occurs in the context of a broader discussion about the uncertainty of a child's condition. Although the full discussion of this matter is too long to present here, lines 1–18 indicate a focus on deterioration. It is in this context that the child's mother makes end of life implicit without explicitly referring to this existential state. The focal utterance, in lines 39 and 41, is part of an extended telling by the mother that contrasts a past physical process ('last time he went blue', line 19) with what will happen in the future (lines 19–47). When verbally describing this future process " . . . as signs of him getting closer and closer" (lines 39 and 41) and using a hand gesture to indicate the same, the mother does not specifically indicate what will happen to her child at the culmination of this process.

The local context provides resources for understanding the meaning of the mother's focal utterance at lines 39 and 41 [18]. The mother's extended telling (lines 19–47) is a description of a physical process that is contrasted with what happened 'last time'. The omitted object of the mother's utterance at lines 39 and 41, then, must be a physical state rather than some other domain of reference (e.g. a place, time, person, thing, etc.) [26]. Given that her child clearly survived what happened 'last time', the mother's use of a contrastive implies that he will be getting 'closer and closer' to an alternative outcome. Although more allusive than the previous instances, this appears to be an occasion where the mother makes her child's end of life implicit without explicitly referring to this outcome.

The instances considered above highlight some of the diverse ways in which family members design their talk to make end of life implicit. Although there are instances in which end of life *is* made explicit, the analysis we report in the next section indicates that these tend to occur in specific contexts.

3.2. Making end of life explicit

There were instances in our three focal consultations where family members and clinicians explicitly referred to end of life, using either a variant of the words 'dying' or 'death' or an apparent euphemism for these terms. We have already reported one instance above, in Table 2, where a mother explicitly refers to end of life but does so in relation to someone else's rather than her own child. Here we consider other contexts in which end of life is made explicit. Although this occurred in all three of our focal consultations, four of the seven instances occurred in a single consultation, considered above in Tables 1 and 4. The instances we consider below all come from this particular consultation.

The first instance is presented in Table 5. The fragment begins with the doctor thanking everyone for their meeting (line 1). Given that appreciations such as this can make closing the conversation a relevant next activity, they afford an opportunity for another party to mention something that has not been previously discussed [38].

[2] The mother's utterance following this upshot marker is produced in overlap with babbling by her infant daughter, who is a sibling of the child patient. The patient is not present.

Table 4
C9/2015-11-13/30:04-30:58.

```
01 DOC:   =.hh Ye::ah no:,=I: mean I->you get a< s:ens:e that (.) u:hm:, tch .hhh there is this
02        dete:ri'a:tion going on[:,]
03 AUN?:                          [ M]m[m,]
04 MUM:                                [ O]:[h definat'l]y,=
05 DOC:                                     [U : h m : ,]
06 MUM?:  =#°Ye-ah°#=
07 DOC:   =An:d u:hm:, (.) tch .hh >but< yeah it's jus' really ha:rd to kno::w >you know< so- ↑we↑
08        jus:' don't have a (.) crystal ba:ll [unfortunatel]y.=>But< u:hm:, ye:ah.=And we: will
09 MU/AU?:                                        [ M  m  m  , ]
10 DOC:   do: a:ll >we can to make sure he doesn't have< .hhh pa:in:,
11        o[:r      u:hm:     distress:.=Yeah.   ]
12 MUM:    [Yeah that's my main: thing I don't wa]nt 'im °in:°
13        ye:[a h . ]
14 GRA:      [>You d][on't want (any)[o n e   )<] in pa:i[n do ya, ]=
15 DOC:              [   Y e a h .  ]
16 MUM:                              [But won't-]        [  U[:hm:,]=
17 DOC:                                                     [Yeah.]=
18 AUN:   =°No:.°=
19 MUM:   =Isla-Ma:y expla:ined to me is it's- (.) like la:st ti:me he went <bl:ue,>=>that he<
20        [pro'ly >won't go] blu- he'd< mo:re go: (.)
21 NUR:   [   ( Y e a h )  ]
22 MUM:   Δpa:le, [po:rcelain]:: da[:rk [under th]eΔ e::yes[:,]
23 DOC:           [ M m h m .]     [ M m[ h m .  ]         [ M]m]m,=
24 NUR:                              [Y e : h.]         [Yep.]
   mum:   Δwipes hand several times over face------Δsweeping hand motion moving towards table--->
25 MUM:   =And the bre:athin:g, and >↑th[ere↑ might< even b]e: a gap of three: minutes:, >and then
26 DOC:                              [   Y  e  a  h  .  ]
27 MUM:   he might< take a[::]
28 DOC:                  [Ye]ah.=
29 NUR?:  =[M m m.]
30 MUM:   =[a: ga:]s:p.Δ=[And then:,]=
31 NUR:                [°Y e a h.°]=
   mum:            -->Δ
32 DOC:   =Yeah.
33        Δ(0.2)
   mum:   Δ.....-->
34 MUM:   ΔAn:' it's mo:re about=
       -->Δwiping face--->
35 DOC:   =.niff!
36        (.)
37 MUM:   he'll go more <pa::le,>=Δ
                              -->Δ
38 DOC:   =Yeah.
39 MUM:   ΔA[s   s::i:Δgns   of    ]
40 AUN:     [(°And he'll kind of°) ] hmmm.
   mum:   Δ..........Δstepping hand across table--->
41 MUM:   h[im getti]ng closer and closer? [A:nd  that  he]:Δ
42 DOC:    [  M m . ]                      [Yeah >I< mean:]
   mum:                                                 -->Δ
43 DOC:   Δye[a h .   ]
44 MUM:      [And Δ>co]s his< e:ar was going a bit- (.) white_ (0.2) porcelain:,=
          Δ.......Δstroking ear--->
45 DOC:   =Mmhm.=
46 MUM:   =an' stuff:. U::hm:, Δ(0.4)Δ Cla:ra n:oticed, but then::, he still manages to tu:rn
                           -->Δ,,,,,Δ
47        aroun[d.]
```

The mother does this, reminding the doctor about participating in a research project (line 8).[3] In the course of this activity, it becomes relevant to refer to her child's end of life. In listing the materials that the research team would like (lines 17–25), the mother refers to a lumbar puncture. Given this procedure can be conducted on either living or deceased patients, she explicitly refers to death to specify when the procedure should occur.

Although the mother makes her child's future death explicit, she designs the turn in which this occurs in a way that displays its delicacy. First, her reference to death is delayed by her elongated pronunciation of 'then', followed by her glottal stop ('°e-°' in the transcript), and then by the preface 'that other thing is' (line 21). Second, through embodied actions of closing her eyes and shaking her head (line 21), the mother appears to withdraw momentarily from the interaction. Finally, when she refers to her child's end of life, she does so using a euphemism ('passes', line 21), rather than a literal reference to death. Delays, embodied actions, and euphemisms are all recognised practices that can be used for delicately designing utterances [16,17,23]. This delicate design may be suited

[3] Although this research participation is something that they have apparently discussed before, our inspection of the recording indicates that this was not within the current conversation.

Table 5
C9/2015-11-13/53:59-54:40.

```
01 DOC:   .tlu u::hm, (.) ye:ah >so thank you< fo:r um yeah jus' for .hh [touching   ba:s]e
02 GRA:                                                                  [No that's okay.]
03 DOC:   and u:hm .hhh
04 GRA:   It a:ll helps you out,=
05 DOC:   =Ye:ah no [th:ank   you.   Yeah.   Yeah.   Yeah.   ]
06 AUN:             [(We're all            Yeah) if it helps:]
07        (0.2)
08 MUM:   An' >as I said< I s:- fo:rwarded that email from the re:search people in Ame:rica,
09 DOC:   Ye::ah [no if you f:orward that on to me an' Da:n,] and if it's info- if- you- with your
10 MUM:          [(that- that                  information)]
11 DOC:   perm:ission, if it's information that's not ha:rd to provide, ye[:ah so-]
12 MUM:                                                                  [Y e : :]ah,
13        ye-eah.=[>And I-<] I've gotta sign a con[:sen ]t fo:rm, and >then [I said< I]:'d
14 DOC:           [ °Yeh°  ]                     [Yeah.]                   [ Y e a h.]
15 MUM:   fo:rward (.)
16 DOC:   Yeah.=
17 MUM:   =he:r d[eta]ils to you [gU::Ys]:, (0.2) and then it's about medical reco::rds:, u:hm a
18 AUN:          [Mm ]
19 DOC:                          [ Yeah.]
20 MUM:   blood tes:t, (0.4) >I said well I've< (.) pretty sure there's one that went to Am:erica
21        I'm not shu::re, (0.4) an' then∆:: °e-°∆ that other thing is when he pa:sses, [u:hm, ] (.)
22 DOC:                                                                                 [Ye:ah.]
   mum:                                  ∆----┬---∆
                                              └> closes eyes, shakes head slightly
23 DOC:   .mphh
24        (.)
25 MUM:   can:: they do a l:umbar punc[tu:re,] an:' if so what's the ti:mefra::me,
26 DOC:                               [.niff!]
```

to a context where explicit reference to death is important for the intelligibility of an utterance (in this case, understanding whether a procedure should be conducted before or after death).

A similar instance to the one in Table 5 can be observed in Table 6. Whereas the fragment in Table 5 involved a family member explicitly referring to end of life, the fragment in Table 6 involves a clinician doing the same. The fragment commences with the mother asking the nurse to provide her opinion about her child's condition in relation to a serious deterioration that he experienced in July (line 4). This creates a context in which it may be pertinent for the nurse to refer to end of life. Although a response from the nurse is conditionally relevant [39], she responds in a way that displays the delicacy of her response.

First, she delays her response by almost two seconds (line 7), and then by cutting off her turn midway through the production of her third lexeme to restart her turn (line 8). Second, she punctuates part of her response with laughter (lines 8–10). Delays and laughter are both recognised practices that can be used for delicately designing utterances [16,17,23,40–43]. Moreover, the nurse also provides a considerably hedged perspective on the child's prognosis. The first part of her response claims that it is not possible to provide a clear prognosis (lines 8 and 10), before continuing to explaining the nature of uncertainty about the timeframe of the child's disease trajectory (line 10 and lines 17–18). In explaining her uncertainty, the nurse explicitly refers to end of life as a possibility, using the description 'won't be here' (line 17) as

Table 6
C9/2015-11-13/26:54-27:22.

```
01        (0.8)
02 MUM:   So ho:w's he looking¿
03        (0.3)
04 MUM:   >I [ know  (he's)  looking< ] peaceful,=but [in re]lation to:: (0.3) compa:red to July::,
05 NUR:      [>Actually he looks goo-<]              [ M m ]
06 MUM:   an::d (.) a:nd the f:uture¿
07        (1.8)
08 NUR:   Look I:'m e- (.) as fa:r as I:'m concerned <William> does every£t(h)h↑ing [h(h)is own]
09 DOC:                                                                          [>heh  heh<]
10 NUR:   w(h)ay.=I(h)t's like <Will[iam's way.>£=And one minute you think] he['s:] .hhhh=
11 AUN:                             [ < I :    k n o : : w >    i t ' s : ]
12 DOC:                                                                  [Mm ]
13 GRA:   =That's it [William's  wa]↑:y,=
14 NUR:              [(>You'd be-<)]
15 NUR:   =Wi:[lliam's   wa:y, ]
16 AUN:       [It's William's w]a↑:[y, ]
17 NUR:                            [Wil]liam won't be he:re tomo:rrow, o:r in a few ho:urs, but
18        (.) ↑here he i:s:.↑=You kno[w it's really] (0.3) °ha::rd isn't it.°
19 AUN?:                           [ M  m  m  ,  ]
20 MUM:   >°Especially when he was< la:ughing yesterday.°
```

a euphemism for death. By conducting herself in this way, the nurse manages the delicate task of referring to end of life as part of providing the prognosis that was warranted by the mother's question across lines 2-6. The analysis of the fragments in Tables 5 and 6 thus indicates that if making end of life explicit is specifically relevant within the local context of a discussion, the turn containing this reference can be designed to display the delicacy of this undertaking.

Unlike the two previous fragments, in the fragment presented in Table 7 the mother makes end of life explicit but does not does not appear to do so in a way that treats this as delicate. A crucial difference, however, is that in this fragment end of life is made explicit at a point where this is ancillary to the explicit focus of discussion. It occurs during the course of a laughable telling [44]. Within her telling, the mother represents her reported conduct as laughable, smiling and punctuating her talk with laughter (e.g. at lines 12–13), and it is treated as such by others (e.g. at line 14). When summarising her telling, the mother explicitly indicates that her child is dying (line 38). At this point in the conversation, dying is made explicit as part of a laughable telling, and is treated by the other parties as such (e.g. at line 45). The child's end of life does not, here at least, become a specific focus of the conversation.

The fragments examined in this section highlight that there are circumstances in which end of life is made explicit. Moreover, the local context of these circumstances appears to influence the way in which end of life is made explicit. If end of life is ancillary to the current focus of discussion (as in Table 7) or used in relation to someone else's child (as in Table 2), it is made explicit without any apparent display of hesitation. However, if there are local reasons that warrant making end of life explicit and this matter is pertinent to the current discussion (as in Tables 5 and 6), this is designed in ways that display the delicacy of this undertaking. In the data available for the current study, instances in which end of life was made explicit were restricted to these types of contexts.

4. Discussion and conclusion

4.1. Discussion

This study contributes to a small but growing body of evidence from naturally occurring clinical interaction that finds discussions about end of life typically are implicit rather than explicit [17,20–23]. Our study has found that end of life can be made either implicit or explicit within paediatric palliative care consultations, while observing that it is more common for this existential state to be made implicit. Although based on a small number of cases, detailed analysis indicates that end of life is made implicit or explicit in different contexts. End of life may be made explicit in relation to someone else's child (e.g. Table 2) or if this matter is ancillary to the current focus of discussion (e.g. Table 7). In these circumstances, end of life tends to be made explicit without hesitation. However, end of life also can be made explicit during discussions that more closely focused on this matter as a tangible outcome for the family's child (e.g. Tables 5 and 6). This occurred when there were local reasons that warranted explicitly referring to end of life in relation to a family's child. In these contexts, participants constructed turns in which end of life was made explicit in ways that displayed their delicacy. Outside of these specific contexts, it was typical for end of life to be made implicit by both family members and clinicians.

Our reported analysis identifies a series of ways in which discussions about end of life can be progressed without making end of life explicit. First, a family member can compare their personal situation to someone else's experience of a child dying

Table 7
C9/2015-11-13/27:55-28:25.

```
01 MUM:   [He e:ven smi:led th]is mo:rning:. °Cos°
02 AUN:   ↑YE[: a : h . ↑   ]
03 MUM:      [we >couldn't g]et into< his mouth:=
.
.    ((3 seconds omitted))
.
12 MUM:   =To do the: the sucti- ∆you hear it in that .h∆ so I £h:old his n(h)hose
                                 ∆touches top of sternum∆
13        [f:or a lhittle bit.£]=
14 AUN:   [ Heh  heh  heh  heh ]=
.
.    ((4 seconds omitted))
.
28 MUM:   =But you see he still won't <mouth b[reathe> bu]t when I l:et go he >s:ort of<
29 DOC:                                      [  M m m . ]
30 MUM:   releas[:es his]: his
31 DOC:         [>Mmhm< ]
32 DOC:   Mmhm.=
33 MUM:   =clenching,=[and I:] duck in[:¿]
34 AUN?:              [M m m ]
35 DOC:                              [Mm]h m .  ]
36 GRA:                              [°>he heh<°]
37 AUN?:  Mmm,=
38 MUM:   =A:h I'm like >y'know< ∆o:nly a mother can do this: [to a dying ch]i:ld.]
                                 ∆clicks finger
39 AUN?:                                                    [h[e  heh  hah]  heh] ha[h   h a h    ]
40 DOC:                                                       [Yu- ye:ah. ]
41 MUM:                                                                          [>And he eve-<]
42        he actu'lly grinn:ed at that [(°and [it's l]ike°)]
43 DOC:                               [  Y e [a h , ]
44 NUR?:                                     [ e h  ] heh ] heh hoh hoh [hoh hoh °hoh°]=
45 AUN?:                                                                [ °So funny,° ]=
46 DOC:   =£So his teeth are still very cle:an.£
```

(e.g. Table 2), and thereby make their own child's death relevant. Second, they can list things that are clearly associated with end of life or could only happen following death (e.g. Table 3). Third, they can contrast their current situation with an alternative that involves the child's survival (e.g. Table 4), to imply that the current situation is different from the alternative.

This study brings a new perspective to ongoing debates regarding the denial of death or death as taboo [1–9]. We report evidence that there are particular contexts in which end of life is made explicit and show how these differ from contexts in which end of life is made implicit. Our findings are consistent with previous research on the design of reference, which shows how the selection of one referential practice over alternatives can be used to adopt a particular stance towards a referent [29,45,46]. Consistent with the principle for circumspection [29], making end of life implicit can therefore be a means of displaying a particular stance towards a person's end of life. Existing research suggests that the extent to which a dying or deceased person is represented as a consequential figure for one or more of the parties to an interaction can be related to how people discuss end of life [18,19]. Our research extends this finding. We show that unless there is a reason warranting otherwise, people routinely design their talk in ways that avoid making end of life explicit during discussions that specifically focus on this outcome in relation to a consequential figure. If this is the case, it seems appropriate to understand instances in which end of life is made implicit as sophisticated use of language in relation to a topic that, in most circumstances, is likely to be a sensitive one.

4.2. Conclusion

Although based on a small number of instances, our analysis is an important demonstration that there may be important reasons that account for why end of life is made implicit rather than explicit during conversations that relate to this matter. Given calls for discussions about end of life to be honest and 'open' [4,10], our finding that people can discuss end of life without making this existential state explicit has important implications. In particular, end of life may not need to be made explicit in order to have an 'open' discussion about it.

4.3. Practice implications

Evidence suggests that many people in many circumstances do not explicitly discuss end of life. Clinicians are often encouraged to promote honest and 'open' discussions with patients and their families about this topic. By exploring instances from real-world paediatric palliative care consultations, this study shows that it is not necessary for end of life to be made explicit in order to clearly discuss this outcome. This finding suggests that there is no necessary reason for clinicians to challenge patients and their families when they appear to be discussing end of life implicitly. Rather, it may be more appropriate for clinicians to monitor ways that patients and families might be referring to end of life and, where possible, contribute to the discussion using similar expressions [47]. If all parties to a conversation can be clear about the focus of their discussion, even if that discussion does not explicitly refer to end of life, honest and 'open' discussions about this matter are possible.

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Appendix A. Transcription conventions

Participant labels	
`DOC:`	Labels in upper case indicate lines that transcribe vocal conduct.
`doc:`	Labels in lower case indicate lines that transcribe embodied conduct. If such a label is absent, this means that the embodied action belongs to the speaker of the immediately above line in the transcript.
Temporal dimensions	
`Wo[ rd]` `[Wo] rd`	Square brackets mark speaker overlap, with left square brackets indicating overlap onset and right square brackets indicating overlap offset.
`Word=word`	An equals sign indicates absence of discernible 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.
Vocal 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.
`Word`	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↓`	Downward arrows mark a sharp decreased pitch shift, which begins in the syllable following the arrow. An utterance encased with downward arrows indicates that the talk is produced at a lower pitch than surrounding talk.
`°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.
`<Word>`	Words encased with less-than followed by greater-than symbols indicate talk produced at a slower pace than surrounding talk.
`Wor-`	A hyphen indicates an abrupt termination in the pronunciation of the preceding sound.
`£Word£`	Pound signs encase utterances produced with smile voice.
`Eh heh hoh hah`	These are different ways of transcribing laughter tokens throughout the transcripts.
`W(h)ord`	The letter 'h' enclosed within parentheses indicates plosive laughter particles that punctuate a speaker's talk.
`Whord`	The letter 'h' enclosed without parentheses indicates breathy laughter that punctuate a speaker's talk.
`~Word~`	Tilde signs encase utterances produced with tremulous voice.
`.hhh`	A period followed by the letter 'h' indicates audible mouth inhalation, with more letters indicating longer inhalation.
`.niff!`	A period followed by these symbols indicates audible nasal inhalation.
`.mph`	A period followed by these symbols indicates audible lip smacking.
`pwhhh!`	These symbols indicate nose blowing.
`(Word)`	Words encased within single parentheses indicate an utterance that was unclear to the transcriptionist.
Embodied conduct	
`Δ Δ`	Triangles encase descriptions of embodied actions of a particular participant.

+ +	Plus signs are used to encase descriptions of embodied actions of another participant, if the embodied actions of multiple participants are transcribed within a single fragment.
Δ– –>	An arrow indicates an action continues across subsequent lines,
– –>Δ	until a corresponding arrow is reached.
. . . .	Periods indicate the preparation of an action.
– –	Dashes indicate the maintenance of an action.
, , , ,	Commas indicate the retraction of an action.

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